



DATELINE

F E D E R A T I O N

Issue 53 | Volume 17 | Summer 2017

SYMPOSIUM 2017

PHOTOS AND AWARD
RECIPIENTS

pg. 14



PROJECT CALLS

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

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JUST A NUMBER;
you are part of a community
THAT CARES!**

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

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

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

If you or a member of your family have been:

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

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To contact us about your insurance issue, please call (202) 836-2530, email projectCALLS@hemophiliafed.org, or visit www.ProjectCALLS.org



Assisting and advocating for the bleeding disorders community since 1994.

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Dear Community Members,

To those who joined us in Providence, RI for our annual Symposium, thank you. It was wonderful to see you and be a part of this special event. Providence was an amazing host city and the New England Hemophilia Association, a fantastic host chapter. From the “Hope Ignites” signs which were displayed throughout the city, to the Mayor joining us for the awards luncheon and presenting a proclamation declaring the month of March Bleeding Disorders Month, the city welcomed and embraced HFA, and our community’s presence in their city.

As the days progressed, Symposium somehow just got better and better, leading up to a final night event that did not disappoint. The WaterFire event was a mind-blowing way to wrap up all the events and sessions that took place at Symposium. It was truly breathtaking to see the rivers winding through downtown Providence and take in the mesmerizing serpentine line of floating wood-fired braziers burning brightly. On top of that, the banks of the river were adorned by the state banners of our Member Organizations. It was a wonderful time to reflect on the days we spent together learning about up-and-coming treatments, new research, advocacy and policy issues, as well as honoring and remembering the contributions that made an impact on our community.

The awards luncheon was particularly touching this year because of the number of honors conferred posthumously. Over the past twelve months, our community lost several dynamic figures. It’s easy for me to get weighed down by the sadness

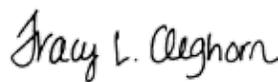
of those losses. I know I am not alone in wanting to remember those we honored and what they did for our community. But, setting aside our natural sorrow at their passing, I think the best way to honor their memory is to carry on the mission that meant so much to them. We need to continue the fight.

Corey Dubin, John Reed, Ellis Sulser and Star Tyree were all remarkable examples of advocates at work. While each had his or her own unique approach to advocating, the goal was the same. Yes, they may no longer be here, but they continue to lead us by their example. Our unity and hard work as a community is needed now, perhaps more than ever. My challenge to each of you is to honor their memory and continue the good fight.

Are you, or do you know, a young adult looking to become more active within the community? Our inaugural Young Adult Advocacy Summit is taking place this fall, and is just the ticket for young adults interested in getting more involved. Details and information can be found on page 7. Don’t miss the Symposium overview on pages 14-17, full of photos from the event, and Martha Boria’s story about Sangre Latina, HFA’s Spanish-language program, on page 20.

For those of who were unable to make it to this year’s Symposium, we hope you’ll join us in next year in Cleveland, OH. We are so excited about being in Cleveland and know that 2018 will be just as amazing as 2017!

Warm regards,



Tracy Cleghorn
Board Chair



Connect with us on social media for daily posts and updates about what’s happening at HFA.



Gears for Good

By Emily Bobolz, Staff

Photos by Michael DeGrandpre, Staff



Registration is now open for the 2017 Gears for Good season, which begins with a two-day ride in Avon, CT from June 24-25. The National Ride will take place from September 22-24 with a course from the Eastern Panhandle of West Virginia to Washington, DC, and the one-day Northern Ohio ride will happen on October 14.

Gears for Good charity bicycle rides are a fun and high-energy fundraiser for HFA's Helping Hands program. "We are thrilled to participate as a family in every single New England Gears for Good ride," said Arvid Badics of Massachusetts. "Each one has been a great experience in its own way, and we love the supportive, fun atmosphere—all in support of a tremendous cause."

Here's how it works: upon registering on the website, each rider is asked to create a fundraising goal. HFA provides an intuitive fundraising platform in which the rider can design a personal

fundraising page to share with family, friends, and coworkers who might be interested in pledging support. Riders can choose to raise the funds in a variety of ways, like hosting an event or party to get people engaged, or using social media.

Those interested in riding can register for any, or all, of the three rides at www.gearsforgood.org. Participation is not limited to physically riding the course, however. We also offer a virtual-rider option in which you can fundraise for the ride and take part, all from the comfort of your own home. Early registration allows riders, actual or virtual, more time to reach their fundraising goals, so register today!

The Good in Gears for Good

One hundred percent of funds raised by riders directly benefits Helping Hands, a program HFA runs to provide emergency assistance to those in the bleeding disorders community who

"Each one has been a great experience in its own way, and we love the supportive, fun atmosphere—all in support of a tremendous cause."



find themselves in unexpected financial distress and in need of assistance.

“Helping Hands is a fantastic program. As a former HFA board member, I’ve heard many stories of how Helping Hands has made a difference,” said Tommy Russomano of New Jersey, who participated in the Connecticut ride. “The opportunity to support this worthwhile cause AND have a blast riding with a great group was an easy decision.”

New features for 2017

To make it easier for Gears for Good riders to participate in the Connecticut ride this year, there is now a one-day option. Riders can choose to ride one day with a minimum fundraising goal of only \$100. The Connecticut ride is a 70-mile total ride along the scenic Farmington Heritage and Farmington River Trails. With the new one-day option, riders can choose the 40-mile Saturday leg or the 30-mile Sunday leg. Of course, the full, two-day option for the Connecticut ride is also still available. “I was a little skeptical when I saw the number of miles that we would have to commit to,” said Jacqueline Moore of Massachusetts. “But I found I really enjoyed the experience and I plan to participate from now on.” Daniel Leonard of Massachusetts convinced his hesitant wife, Lorena, to participate in one of the rides, for their seventh wedding anniversary. The two normally spend their anniversary weekend off on their own, but they found they enjoyed the ride experience together, despite Lorena’s initial reluctance. “It was clear to me that doing something to help individuals with hemophilia, in whatever

small way I could, was the right choice and is the right choice every time,” she said. “It was a win-win no matter what because I got to do something meaningful with my husband during our anniversary.”

The National Ride in September is a 156-mile ride along the Chesapeake & Ohio Canal from eastern West Virginia to Washington, DC. The Northern Ohio ride in October comprises 50 miles along the Erie and Ohio Canal Towpath from Independence to Akron.

This year, consider becoming a rider and/or supporting riders in your community. The success of the ride and riders is essential to the success of our Helping Hands program, so **register today!** It’s fun with a purpose! ■ ■



Announcing HFA's Inaugural Young Adult Advocacy Summit: Fall 2017

By Sarah Shinkman, Staff

Since 2014, HFA has offered programming tailored to young adults, providing education and social support for those living with bleeding disorders. We're excited to announce the Young Adult Advocacy Summit, a national event taking place this fall at HFA's national headquarters in Washington, DC. HFA will bring together young adults, ages 18 through 30, from multiple patient communities, including bleeding disorders, for the three-day advocacy summit. Participants will develop advocacy, coalition-building, and leadership skills through interactive training with experts in policy, advocacy, and communications.

Activities will include:

- Intensive advocacy training on how larger policy issues affect the patient community at large, including people with bleeding disorders
- Intensive communications training about how the stories of the bleeding disorders community fit in the broader patient narrative
- Coalition-building training
- State and local advocacy training
- Sharing stories and challenges with other young adults living with chronic disorders
- Building networks across multiple patient advocacy groups to benefit activism at the local level
- Congressional Hill meetings to practice skills

HFA has the capacity for 15-20 young adults with diagnosed bleeding disorders and other chronic disorders to attend the Young Adult Advocacy Summit. Registration will close once we reach capacity. All travel, lodging and programming fees will be covered for the selected participants.

Want to attend?

Register on HFA's website, www.hemophiliafed.org/programs/youngadults. Be sure to follow HFA on Facebook, Twitter, and Instagram for news and updates. For more information, contact Sarah Shinkman, Advocacy and Outreach Manager, at s.shinkman@hemophiliafed.org.



TIME AFTER TIME

How to Respond to Microaggressions

By Justin Levesque, Care Access Working Group (CAWG)

Bleeding disorders are genetic. Why would you choose to have second kid and risk another diagnosis?

But FVII deficiency isn't even that bad right?

Only men can have hemophilia. I'm not prescribing you factor.

Maybe if you were more compliant, you wouldn't have so many bleeds.

Imagine you're the mom of a daughter with hemophilia, you've just changed doctors, and your first appointment is coming up soon. You've heard good things about your new doctor, but, still, you painstakingly prepare by gathering your medical documents and printing off pages and pages to prove that women and girls can have hemophilia, just in case.

Or, you've been going to events at your local hemophilia chapter. You're especially interested in the educational sessions, but it seems like they are always talking about hemophilia A or B, and you have vWD. Does this chapter take vWD seriously? You're hesitant to speak up and share your story, just in case.

As members of the bleeding disorder community, we've all had experiences like these. They illustrate the daily trials and tribulations that consistently punctuate the life of someone with a chronic condition. And, while each of these moments on its own appears manageable on the surface, we know how they can accumulate and become a burden emotionally. We know they can shape our view of the world and of ourselves, each instance an unmistakable reminder that your experience is different, **YOU** are different.

These small slights or twinges, collected over time, amount to what people are calling now a microaggression. Microaggressions are technically defined as brief, everyday exchanges regarded as an instance of indirect, subtle, or unintentional discrimination against members of a marginalized group. From the uninformed ER doctor who wonders how long you've had a bleeding disorder, misinformed about people being born with a bleeding disorder, to the stranger in the grocery store staring at your child's bruised shins, this type of interaction is common among community members.

Though we may not immediately recognize it, these events can impact us greatly over time. It's also important to remember that interactions like these can occur *within* the bleeding disorders community. We are not immune from perpetrating casual, but ultimately hurtful, oversights of our own. For instance, a friend who only infuses once a week might say, "Maybe if you were more compliant, you wouldn't have so many bleeds." But this friend has never had an inhibitor. He doesn't understand your personal challenges and how his words and assumptions might sting.

In an effort to help you manage microaggressions that you may experience, consider the following tips:

1. Remain calm and take a deep breath.

Before assuming someone's intent and reacting right away, find a way to pause the conversation and clarify the statement. If it's the first time you've been in this situation with this individual, you should ask them to repeat what they said. That will give them the opportunity to restate more clearly, or even realize that they were being hurtful without knowing. Responding with anger will only work against you.

2. Don't go to the extreme.

Taking extreme stances either as a victim or a tough person will ultimately hurt you. By seeing yourself as a victim, you are, in a way, helping the aggressor disempower you. Toughing it out and moving past it, we create the illusion of strength without having processed the effects of the microaggression properly.

3. Focus on the event, not the person.

By directing the conversation to the behavior, event, or comment, you will decrease the likelihood of a defensive response.

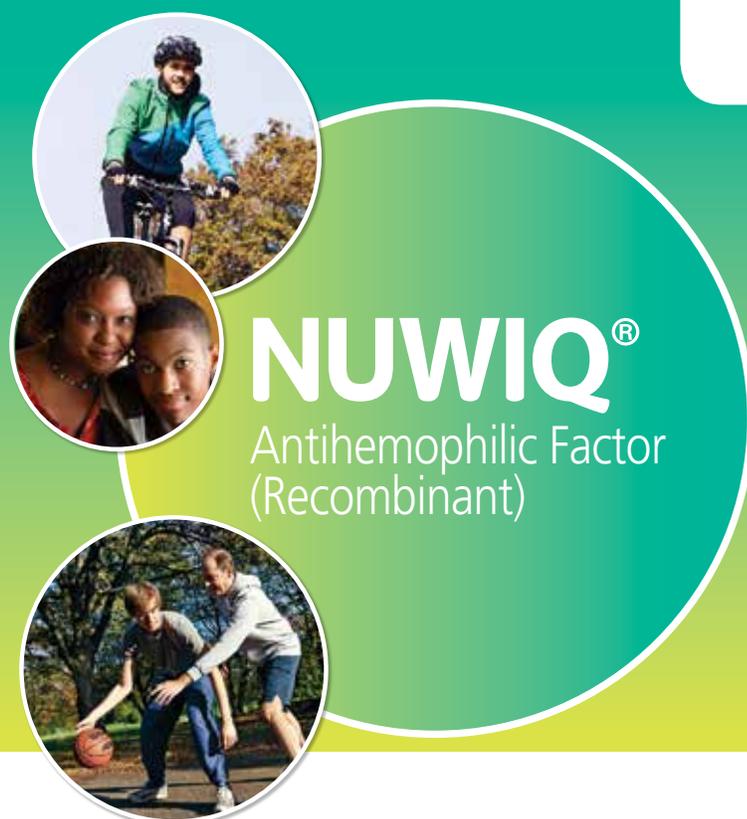
4. Be clear about the different elements of a microaggression.

Who said or did what? Who was in the room? Were others complicit in their silence or agreement? What is the relationship between you and the sender? Was this the first time or is this an ongoing issue? Having a clear understanding of the factors that surround the microaggression helps you evaluate your next steps strategically, rather than emotionally.

5. Develop your own way to handle microaggressions.

Thinking there is a cookie-cutter approach will sabotage your efforts from the beginning. Follow these suggested steps, consider thoughts from other resources, and customize them to your fit your own situation.

HFA's Care Access Working Group (CAWG) serves the bleeding disorders community with a focus on rural communities and those who have difficulty accessing quality care. If you have questions or ideas about inclusive language, please contact cawg@hemophiliafed.org. ■■



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Food and Drug Administration Recall Procedures

By Deema Tarazi, JD, Staff

It is important to pay attention when a product is recalled, but with all the different sources of information, and the different types of recalls, it can also be confusing! The Food and Drug Administration (FDA) follows several different recall procedures, outlined in its Regulatory Process Manual.

First, what is a recall? A recall is an action taken by a manufacturer to remove a product from the market. A recall may be voluntary by the manufacturer. Or a recall may be initiated by a request from the FDA, or by an FDA order pursuant to its authority under federal statute, also known as a mandatory recall.

Here are the different recall classifications.¹

CLASS OF RECALLS	
Class I	There is a reasonable probability that the use of, or exposure to, a violative product will cause serious adverse health consequences or death.
Class II	Use of, or exposure to, a violative product may cause temporary or medically-reversible adverse health consequences, or the probability of serious adverse health consequences is remote.
Class III	Use of, or exposure to, a violative product is not likely cause adverse health consequences.
Market withdrawal	When a product has a minor violation that would not be subject to FDA legal action.
Medical device safety alert	When a medical device may present an unreasonable risk of substantial harm. In some cases, these situations may also be considered recalls.

Voluntary Recall: Initiation of a Recall by a Manufacturer

A manufacturer may decide to **voluntarily initiate** a recall at any time to fulfill their responsibility to protect the public health from products that present a risk of injury or gross deception, or are otherwise defective.² If a recall is manufacturer-initiated, the FDA reviews the information provided by the manufacturer, conducts a health hazard evaluation, classifies the recall, and then advises the manufacturer in writing of the assigned recall classification.³ The FDA then places notice of the recall in the weekly FDA Enforcement Report. Almost all recalls implemented in the US are begun on a voluntary basis by the manufacturer.⁴

If a manufacturer has **voluntarily initiated** a recall, it is their responsibility to promptly notify each of its direct accounts. If the recall extends beyond the direct accounts, then the direct accounts should be instructed by the recalling manufacturer to contact sub-accounts that may have received the product.⁵

Once the sub-accounts are informed about the recall, the sub-accounts must promptly follow the recall strategy that was previously put in place for that account.

FDA Requested Recall

In urgent situations, the FDA may request a recall.⁶ The request is directed to the manufacturer that has primary responsibility for making or marketing the product. These recalls fall most often into the Class I category. Before the FDA formally requests such a recall, the agency has usually collected evidence sufficient to support legal action.

The Associate Commissioner for Regulatory Affairs approves all recall requests from the FDA. After an Alert is submitted, the recall is recommended to the Recall Enterprise System (RES).⁷ The RES is an electronic data system used by the FDA to submit, update, classify, and terminate recalls.⁸ The manufacturer is then notified via letter specifying the violations and health hazards involved, and recommending a recall strategy to ensure an effective recall of the product.⁹

FDA Mandated Recalls

Under very limited circumstances, federal statute authorizes the FDA to order a **mandatory recall** of a product.¹⁰ Subjects of mandatory recalls can include: devices, biological products, human tissue intended for transplantation, infant formula, tobacco products, and food.¹¹ The FDA also has discretion to order a mandatory recall if it finds that a human cell, tissue, or cellular or tissue-based product, is a source of dangerous infection to humans, or does not adequately protect against the transmission of communicable disease.¹²

Each FDA mandated recall follows specific timelines and procedures depending on the circumstances.¹³ For example, each recall is initiated with a written order that states the violation, the product, lot and serial numbers to be recalled, and the timeline for the recall. Each recall is unique and requires its own strategy developed by the Center Recall Unit (CRU).¹⁴ The CRU will consider how far the recall should extend, whether the public needs to be warned and if so, in what geographical area, and the appropriate assessment level for recall effectiveness.¹⁵

The Recall Differences

The major difference between voluntary, requested, and mandatory recalls is who initiates the process. With voluntary recalls, the manufacturer of the product initiates the recall and it is the manufacturer's responsibility to contact the direct accounts about the recall. Requested recalls are initiated by the

FDA and deal specifically with Class I recalls that can have a catastrophic effect on those who take/use the product. Based on the gravity of the situation, the FDA will issue a public warning. The FDA mandatory recalls are narrowly restricted by the statute and the FDA will only authorize a manufacturer recall if it fits within the parameters of the statute.

To read more about FDA recalls, please visit the FDA's Regulatory Process Manual found online.

1 <http://www.fda.gov/Safety/Recalls/ucm165546.htm>

2 <http://www.fda.gov/downloads/ICECI/ComplianceManuals/RegulatoryProceduresManual/UCM074312.pdf>; <http://www.fda.gov/MedicalDevices/DeviceRegulationandGuidance/PostmarketRequirements/RecallsCorrectionsAndRemovals/>.

3 <http://www.fda.gov/MedicalDevices/DeviceRegulationandGuidance/PostmarketRequirements/RecallsCorrectionsAndRemovals/#3>

4 <http://www.fda.gov/downloads/ICECI/ComplianceManuals/RegulatoryProceduresManual/UCM074312.pdf>

5 http://www.fdalawblog.net/fda_law_blog_hyman_phelps/2014/08/who-can-recall-what-fdas-mandatory-recall-authority-is-a-us-district-court-could-not.html

6 Id.; 7 Id.; 8 Id.; 9 Id.; 10 Id.; 11 Id.

12 http://www.fdalawblog.net/fda_law_blog_hyman_phelps/2014/08/who-can-recall-what-fdas-mandatory-recall-authority-is-a-us-district-court-could-not.html

13 Id.; 14 Id.; 15 Id.

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Helping Others

By Brandon Young

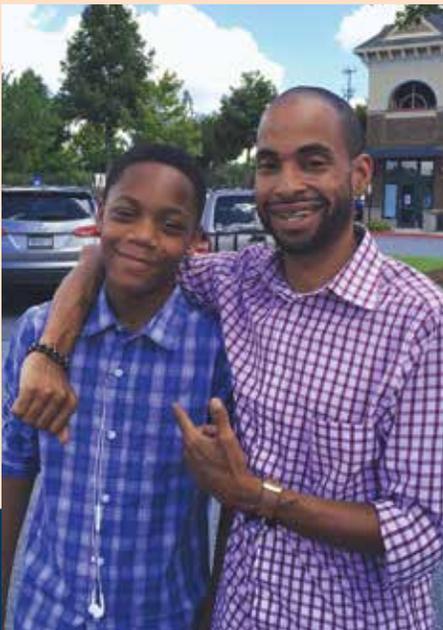
I was diagnosed with hemophilia at the age of two. The bruise in the middle of my forehead rapidly became a knot that grew larger and darker as the days went on. This was the start of my life with hemophilia. I spent many nights in the hospital because at that time not many doctors really knew much about hemophilia. One doctor even cut the bruise on my forehead, thinking to drain it, but he found that the bleeding would not stop. Fortunately for me, I grew up amid a loving family and strong faith community. My grandmother was particularly influential and for that I am especially grateful. Early on, I met a young doctor named Buchanan who was able to provide my grandmother and me some much-needed clarity about hemophilia, helping us lay the groundwork for the rest of my life.

As most people know, HIV and hepatitis C were ravaging the bleeding disorders community back in the 1980s. It was difficult for me, as a child, to understand

what was happening, still less making sense of it all, but I do know that, at Children's Hospital in Dallas, TX, I felt cared for and cared about. I made some great friends there and have nothing but good memories.

A few years after my initial diagnosis, I was introduced to a concept that was new to me and my family: summer camp. It was at camp that I started to understand I was not alone, that others were sharing my journey. Here, in this special and protected environment, we could just be kids and participate in activities that were not possible outside the safety of the camp setting. One of the main lessons I learned was the importance of helping others. I saw my counselors, people who were not affected by hemophilia themselves, come to camp to help those who were. Their compassion and support touched me then, and still moves me today. It was through these good people that I learned the art of giving. My experiences at camp were so profound for me, I can easily say that camp is one of the most important things a child with hemophilia will ever experience.

As a young child, I might not have been allowed to play all the traditional sports in school, but I was introduced to the outdoors and the sport of fishing. Fishing brought so many things to my life, like an appreciation for environmental conservation, teamwork, and even alternative ways of getting physical exercise. Fishing has really helped my joints stay loose, mitigating the internal bleeding that can happen over the years. I've made it a priority to share my love of fishing with my bleeding disorders community. The relationships that fishing together can offer is one of the most beautiful things in life. We already share the bond of hemophilia, and that bond is strengthened by sharing, and enjoyed, activity. I founded a nonprofit organization called Cruz's Fishermen to help people of all ages and backgrounds hone their fishing skills, especially within the hemophilia community. Our mission is to "enrich the dreams of the





youth and to empower them with the right tools to catch their dreams.” We teach leadership skills, concern for others, and sharing life’s experiences. We demonstrate with our lives that dreams are worth pursuing, and that hemophilia will not slow us down.

It sometimes surprises me that, even though I have hemophilia, I can directly and constructively impact others and my community all at once. It’s tremendously fulfilling to me that I can share something I love that can then become someone else’s favorite pastime, and all while bringing awareness of hemophilia to the public.

Sharing how I live a full life with hemophilia is how I give back to my community. The more you impact others, the stronger your community becomes. If I had one message to share, it would be that we are all in this world together and everyone deserves a helping hand. ■■

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SYMPOSIUM 2017

Photos by Gina Sierra

More than 1,100 people gathered in Providence, RI to take part in our annual Symposium, a family-friendly conference offered to the bleeding disorders community. From April 6 through 9, we held more than 50 educational sessions for parents, men, women, teens, children, and stakeholders on a range of topics including navigating insurance issues, pain management, clinical trials, and the future of research.





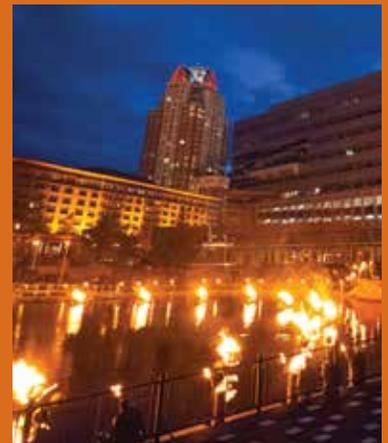
ANNUAL AWARDS CEREMONY

Each year, HFA recognizes volunteers who have made a significant contribution to the organization and the bleeding disorders community by presenting awards at Symposium. Nominations are gathered from across the country through HFA's board and 44 member organizations. And the winners were:

- Michael Davon Community Service Award: **Kelly Ambrosio**
- Member Organization Spotlight Award: **Hemophilia Alliance of Maine**
- It Takes A Village Award: **Darcy Zwier**
- Volunteer of the Year: **Star Tyree** (*posthumously*)
- Chairman's Award: **Corey Dubin** (*posthumously*)
- Charles Stanley Hamilton Legacy Award: **John Reed** (*posthumously*)
- Leader of the Future Award: **Rose Bender**
- Terry Lamb Health & Wellness Award: **Kim Philo**
- Ron Niederman Humanitarian Award: **Ellis Sulser** (*posthumously*)

FINAL NIGHT EVENT & WATERFIRE CEREMONY

A WaterFire Ceremony recognizing HFA Member Organizations took place outside during the final night event. This Providence tradition was a beautiful and symbolic ending to Symposium 2017. Waterfire is a nonprofit arts organization whose mission is to inspire Providence and its visitors by revitalizing the urban experience, fostering community engagement and creatively transforming the city by presenting WaterFire for all to enjoy. During this beautiful, ceremonial lighting of bonfires at the tidal basin, all Symposium attendees and the public had the opportunity to feel the hope ignited by the bleeding disorders community while in our host city of Providence.



SYMPOSIUM 2018

We're headed to Cleveland, OH for Symposium 2018! Save the dates, we'll be hosting the bleeding disorders community in the Great Lakes region from April 26 - 29, 2018!

Thank you!

We'd like to extend a heartfelt thanks to all of our volunteers and board members who contributed their time and energy to make Symposium a success!





OUR SPONSORS

Our sponsors are dedicated to improving the lives of people with bleeding disorders and we thank them for their generous support of this year's Symposium. Thank you!

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Symposium Participants Get Active

By Meredith Clarke, Staff

It is important for people with a bleeding disorder to find a form of physical activity that they enjoy doing. Through regular exercise, muscles remain flexible and strong. Physical activity helps people maintain a healthy weight which minimizes stress on the joints. Exercise has even proven to reduce the number of bleeds a person may experience.

HFA is committed to education and awareness of health and wellness practices. At this year's Symposium, HFA's FitFactor program hosted fitness and nutrition experts from all over the US to lead workshops for attendees. In the Wellness Lounge, a holistic nutritionist gave cooking demonstrations of healthy recipes and offered tips for eating well and maintaining a healthy weight. To kick off each day at Symposium, participants worked to get their heart rates up by joining one of the many fitness sessions led by certified instructors. Sessions included:

Martial Arts

Brothers Anthony and Michael Pezzillo, both chief instructors at Mastery Martial Arts, led martial arts classes for adults and children alike. Participants learned basic martial arts techniques and how the disciplines taught can help you become stronger mentally, physically, emotionally, and socially. Confidence, self-control, self-respect and respect for others are a few of the benefits of the sport that Michael and Anthony demonstrated. The physical benefits are significant - from flexibility and muscle-building to balance and coordination. Martial arts can also aid in the treatment of high blood pressure, arthritis, depression, heart disease and many other illnesses.

Yoga

Yoga instructor Corey Pierce led participants in morning and moonlight yoga classes. Participants stretched and strengthened their bodies, and relaxed their minds in one of our most popular fitness sessions. Many in the bleeding disorders community favor yoga over other types of exercise. Corey explained that it helps strengthen joints and muscles, leading to fewer bleeds, and it gives the practitioner the tools to cope more effectively with pain, through mindful breathing and mental focus. Yoga can simultaneously help one discover one's limits, and expand beyond them.



Zumba

Symposium participants got their bodies moving in Zumba fitness classes every morning. Wanda McLendon, a certified Zumba instructor, cranked up the music and led everyone through 45 minutes of an intense dance workout. If you've never tried it, you should! "Exercise is fun," Wanda says, "Zumba uses music to energize. When you hear the music, it makes you move. And when you move, you are burning calories." Wanda reported that even people who claim they don't like dancing, can't help but move to the music.

Morning Walk/Total Body Workout

Many participants had a refreshing start to their day by joining Michael Zolotnitsky, a physical therapist, and Rich Pezzillo, Executive Director of New England Hemophilia Association, on a morning walk around Providence. The group walked about a mile and a half, taking in the sights and learning the historical and cultural background of the city, provided by Rich, a Providence native. At each stop, Michael Zolotnitsky led everyone through a different strength-building exercise, pointing out the location and needs of the target muscle group. Michael also led a total body workout session, which focused on using resistance bands and other exercises you can do at home. Michael encourages everyone to do some sort of strength training, even if it's done while sitting down. "If it hurts," he says, "modify it. The stronger we build our muscles around the joints, the less chance we have of bleeding episodes."



Cooking Demonstrations/Nutrition

Holistic Nutritionist, Jenny Helman, gave cooking demonstrations each day in the Wellness Lounge, offering samples, recipes of healthy snacks, and tips for eating well. These recipes required only a handful of ingredients, so participants could see how simple and easy healthy recipes can be. Recipes included a dessert (German Chocolate Cake Bites) and a protein-packed Colorful Bean Dip. Jenny also offered nutrition classes in the children's program, focusing on the importance of a balanced plate, the food groups, and what those different food groups do for our bodies, particularly in the all-important absorption of iron. Jenny explained that we should not only eat from all food groups, but we should diversify the foods within those groups so that we get all the nutrients we need, all while keeping our palates happy and our senses engaged.

Mix up your daily routine by trying a new fitness activity, like Zumba, yoga or martial arts. Not only is it important to work different muscle groups to keep your body at its strongest and most flexible, but you may also find a new favorite workout! Along with getting regular exercise, HFA encourages maintaining a healthy diet. Experiment with recipes to get your daily nutrients in new and different ways. HFA's Fit-Factor website pages are full of ideas to help you get started or maintain a healthy lifestyle. Fire up your fitness program today and don't forget to join us for next year's symposium in Cleveland for more in-person nutrition tips and innovative, energizing fitness classes. See you there! ■■

GERMAN CHOCOLATE CAKE BITES

Makes 10 "bites"

Ingredients:

- 1/2 C raw pecans
- 2 T unsweetened, shredded coconut
- 1/2 C (about 6-7) fresh Medjool dates, pitted
- 2 T raw cacao (not cocoa powder)

Instructions:

1. Place pecans and coconut into high-speed blender or food processor.
2. Process on high until ingredients have a flour-like consistency.
3. Add the remaining ingredients to the blender/food processor and blend on medium high until ingredients are fully incorporated.
4. Dump mixture into bowl. Scoop a tablespoon of the mixture in your hands and roll to form a ball. Repeat until all mixture is used.
5. Store in a sealed container in the refrigerator for up to 5 days (if they can last that long!).

Source: Murray, Michael, ND, 2005 The Encyclopedia of Healing Foods, Atria Books, New York, NY

COLORFUL BEAN DIP

Makes 12 servings

Ingredients:

- 1 can black beans, drained and rinsed
- 1 can pinto beans, drained and rinsed
- 1 C frozen corn, thawed
- 4 green onions, chopped
- 2 C tomatoes, chopped
- 1 red pepper, seeded and chopped
- 1 jalapeño pepper (optional), seeded and chopped
- 1 bunch cilantro, finely chopped
- 1 C Italian salad dressing

Instructions:

Combine beans with corn. Stir in all remaining vegetables with bean and corn mixture. Add Italian salad dressing and mix well. Chill for at least 30 minutes prior to serving. Serve with tortilla chips or cut veggies.

The Sangre Latina Program Ignites Hope!

By Martha Boria, Staff

We are pleased that for the second consecutive year, Symposium offered sessions held entirely in Spanish for our Hispanic community. Again, it was a great opportunity for families affected by bleeding disorders who prefer or require Spanish-language educational materials to learn about their conditions, hear about the latest research, and connect with other people who are in similar medical situations.

The sessions and educational materials were developed particularly for the Spanish-speaking community and incorporated not only language but cultural elements and interests in the design. One participant voiced their appreciation this way, “We feel the closeness of everyone, because we can all express ourselves in Spanish and we understand each other.” It was wonderful to see how grateful and engaged the families were, especially enjoying the fun and appealing way in which the relevant themes were presented. This year’s programs clarified for everyone HFA’s commitment to the Hispanic community and demonstrated the positive impact of the Sangre Latina Program on each family.

This Symposium track offered several presenters, including Felix Garcia who broke the ice with dynamic momentum. Each participant had the opportunity to share a bit about themselves and meet others in a series of questions and answers. The participants quickly became comfortable sharing their concerns, talking about their families, and revealing their personal situations without feeling judged. This open format engendered not only feelings of compassion for others but an openness when it came to seeking answers to their own circumstances.

After a brief overview of HFA’s programs and services, the educational sessions related to the Symposium theme of “Hope Ignites” began. Session topics included “Fostering Independence in Youth,” designed to help parents identify the benefits of encouraging independence in children and adolescents, as well as “Social Media Ignites,” to coach parents on the importance of helping their children manage a healthy social media presence. One father commented, “I must be more alert and know the dangers of social networks.”

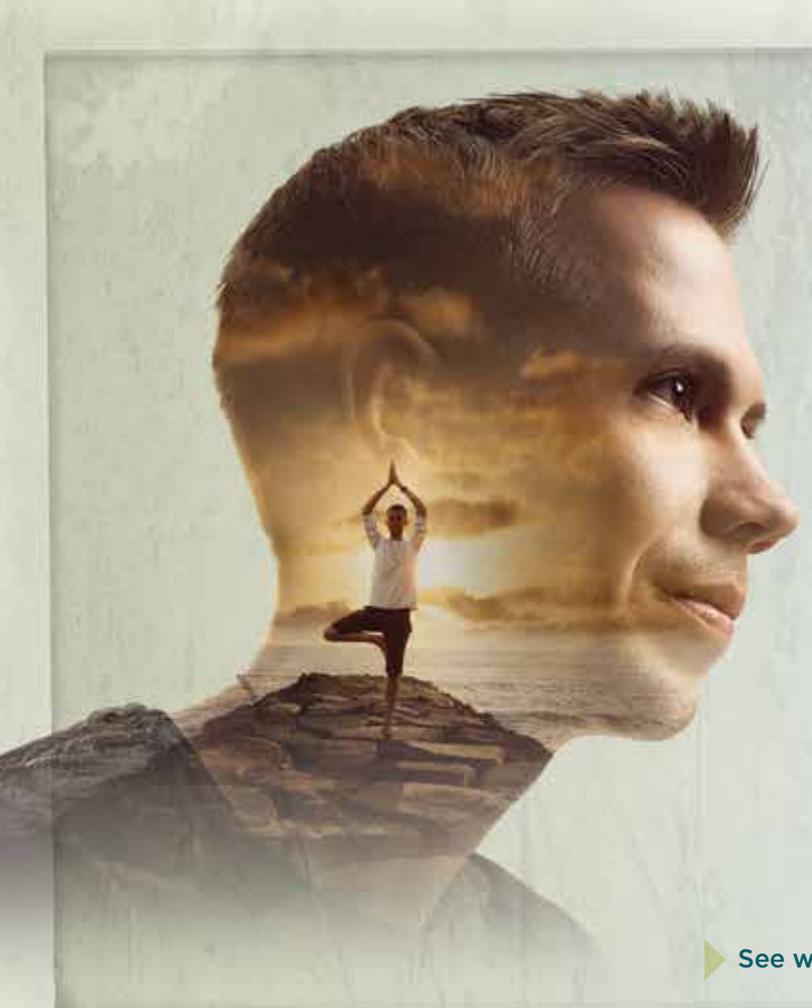
The day continued with “Only for Women - Women, You Have the Right” presented by Martha Boria, Program Coordinator of HFA. This session showed participants how to take control of their health, bodies, and minds for a healthy lifestyle and to understand their rights when requesting services. “Just for Men



– Dad, You Light Up My Life!” was presented by Dave Robinson, PhD, LMFT, director of the Marriage and Family Therapy Program at Utah State University and served to inspire parents to be active in raising their children. The Rap Session closed out the track with families hearing the stories of empowerment of some of our heroic community members, bringing tears to the eyes of many, and energizing and empowering everyone in the room. Participants shared the common determination that, despite adversity and the difficulty of having a rare or chronic condition, we do not let that conquer us.



HFA’s commitment to the Hispanic community and their educational growth serves as the motivation behind our efforts to offer the best tools available to achieve a healthier, happier and more knowledgeable community. See you in Cleveland in 2018! ■■



Just B Yourself

Switching to IXINITY was the best decision I ever made with my doctor. Sometimes, I don't feel like someone with hemophilia.

—James has hemophilia B and uses IXINITY

▶ See why James switched to IXINITY at JustBIXperiences.com

This information is based on James' experience. Different patients may have different results. Talk to your doctor about whether IXINITY[®] may be right for you.

INDICATIONS AND IMPORTANT SAFETY INFORMATION

What is IXINITY[®]?

IXINITY [coagulation factor IX (recombinant)] is a medicine used to replace clotting factor (factor IX) that is missing in adults and children at least 12 years of age with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents clotting. Your healthcare provider may give you IXINITY to control and prevent bleeding episodes or when you have surgery.

IXINITY is not indicated for induction of immune tolerance in patients with hemophilia B.

IMPORTANT SAFETY INFORMATION for IXINITY[®]

- You should not use IXINITY if you are allergic to hamsters or any ingredients in IXINITY.
- You should tell your healthcare provider if you have or have had medical problems, take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies, have any allergies, including allergies to hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.
- You can experience an allergic reaction to IXINITY. Contact your healthcare provider or get emergency treatment right away if you develop a rash or hives, itching, tightness of the throat, chest pain, or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

- Your body may form inhibitors to IXINITY. An inhibitor is part of the body's defense system. If you develop inhibitors, it may prevent IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to IXINITY.
- If you have risk factors for developing blood clots, the use of IXINITY may increase the risk of abnormal blood clots.
- Call your healthcare provider right away about any side effects that bother you or do not go away, or if your bleeding does not stop after taking IXINITY.
- The most common side effect that was reported with IXINITY during clinical trials was headache.
- These are not all the side effects possible with IXINITY. You can ask your healthcare provider for information that is written for healthcare professionals.

You are encouraged to report side effects of prescription drugs to the Food and Drug Administration. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see accompanying brief summary of Prescribing Information on next page.



IXINITY® [coagulation factor IX (recombinant)]

Brief Summary for the Patient

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.IXINITY.com.

Please read this Patient Information carefully before using IXINITY. This brief summary does not take the place of talking with your healthcare provider, and it does not include all of the important information about IXINITY.

What is IXINITY?

IXINITY is a medicine used to replace clotting factor (factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents clotting. Your healthcare provider may give you IXINITY when you have surgery.

IXINITY is not indicated for induction of immune tolerance in patients with hemophilia B.

Who should not use IXINITY?

You should not use IXINITY if you:

- Are allergic to hamsters
- Are allergic to any ingredients in IXINITY

Tell your healthcare provider if you are pregnant or breastfeeding because IXINITY may not be right for you.

What should I tell my healthcare provider before using IXINITY?

You should tell your healthcare provider if you:

- Have or have had any medical problems
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies
- Have any allergies, including allergies to hamsters
- Are breastfeeding. It is not known if IXINITY passes into your milk and if it can harm your baby
- Are pregnant or planning to become pregnant. It is not known if IXINITY may harm your baby
- Have been told that you have inhibitors to factor IX (because IXINITY may not work for you)

How should I infuse IXINITY?

IXINITY is given directly into the bloodstream. IXINITY should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their IXINITY by themselves or with the help of a family member.

See the step-by-step instructions for infusing in the complete patient labeling.

Your healthcare provider will tell you how much IXINITY to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting IXINITY to be sure that your blood level of factor IX is high enough to stop the bleeding. Call your healthcare provider right away if your bleeding does not stop after taking IXINITY.

What are the possible side effects of IXINITY?

Allergic reactions may occur with IXINITY. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms:

- Rash
- Hives
- Itching
- Tightness of the throat
- Chest pain or tightness
- Difficulty breathing

- Lightheadedness
- Dizziness
- Nausea
- Fainting

Tell your healthcare provider about any side effect that bothers you or does not go away.

The most common side effect of IXINITY in clinical trials was headache.

These are not all of the possible side effects of IXINITY. You can ask your healthcare provider for information that is written for healthcare professionals.

Call your healthcare provider for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

How should I store IXINITY?

250 IU strength only; store at 2 to 8°C (36 to 46°F). Do not freeze.

500, 1000, 1500, 2000 and 3000 IU strengths; store at 2 to 25°C (36 to 77°F). Do not freeze.

Do not use IXINITY after the expiration date printed on the label. Throw away any unused IXINITY and diluents after it reaches this date.

Reconstituted product (after mixing dry product with Sterile Water for Injection) must be used within 3 hours and cannot be stored or refrigerated. Discard any IXINITY left in the vial at the end of your infusion.

After reconstitution of the lyophilized powder, all dosage strengths should yield a clear, colorless solution without visible particles. Discard if visible particulate matter or discoloration is observed.

What else should I know about IXINITY?

Your body may form inhibitors to factor IX. An inhibitor is part of the body's immune system. If you form inhibitors, it may stop IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests to check for the development of inhibitors to factor IX. Consult your doctor promptly if bleeding is not controlled with IXINITY as expected.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use IXINITY for a condition for which it is not prescribed. Do not share IXINITY with other people, even if they have the same symptoms as you.

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.



Manufactured by:
Aptevo BioTherapeutics LLC
Berwyn PA, 19312
U.S. License No. 2054

Part No: 1000973_1
CM-FIX-0078

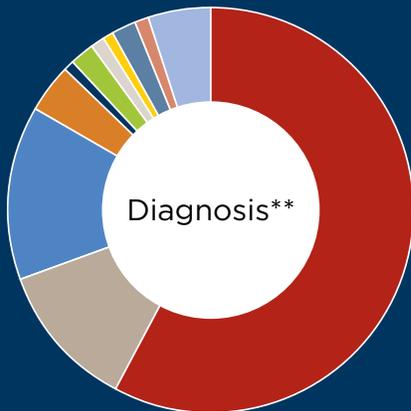
PROJECT CALLS

Creating Alternatives to Limiting and Lacking Services

Project CALLS is 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.

This data is used to advocate for change on a national, state and local level with both legislators, regulators and private payers.

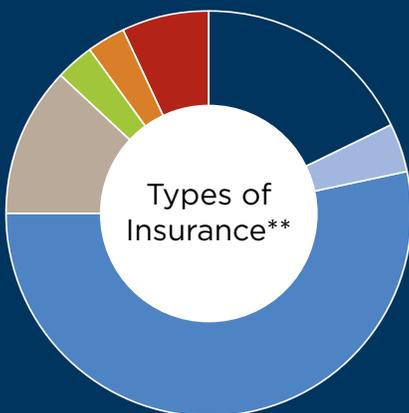
For more information about Project CALLS, visit www.hemophiliafed.org/advocacy



■ Hemophilia A	59	■ Factor X	1
■ Hemophilia B	12	■ Factor XI	1
■ von Willebrand	14	■ Platelet Disorder	2
■ Factor I	4	■ Other	1
■ Factor II	1	■ Inhibitor	5
■ Factor V	2		



■ Denied Coverage	15	■ Prior Authorization*	16
■ Exception	8	■ Out-of-Network	10
■ Pharmacy Mandate	18	■ Financial Hardship	9
■ Step Therapy*	6	■ Other	18



■ Medicaid	18
■ Medicare	4
■ Commercial/Private	54
■ Marketplace	12
■ State Sponsored	3
■ Military TRICARE/VA/Champ VA	3
■ I don't know	7



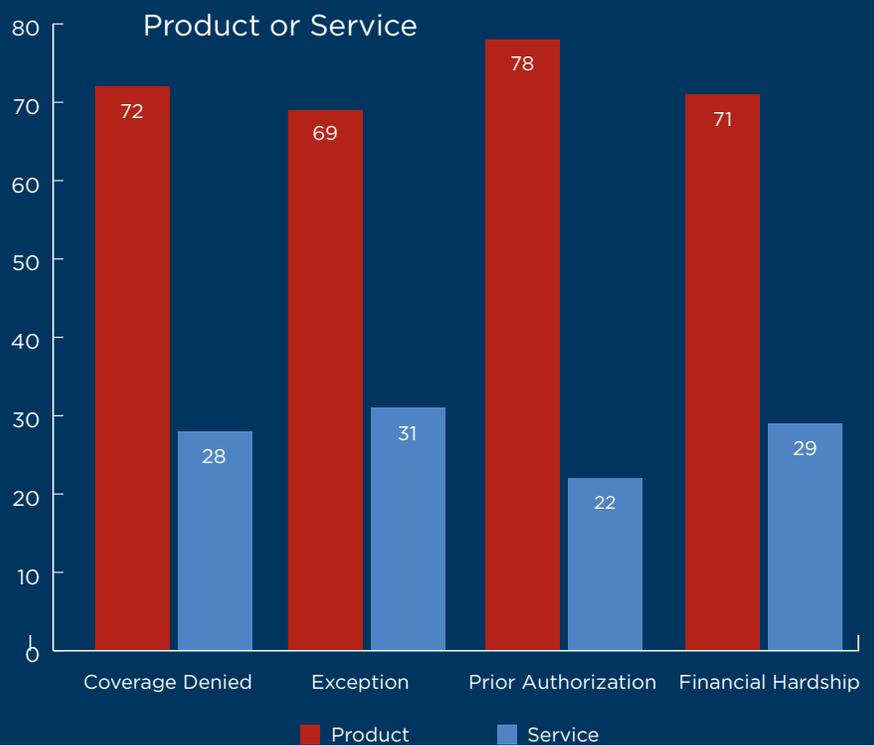
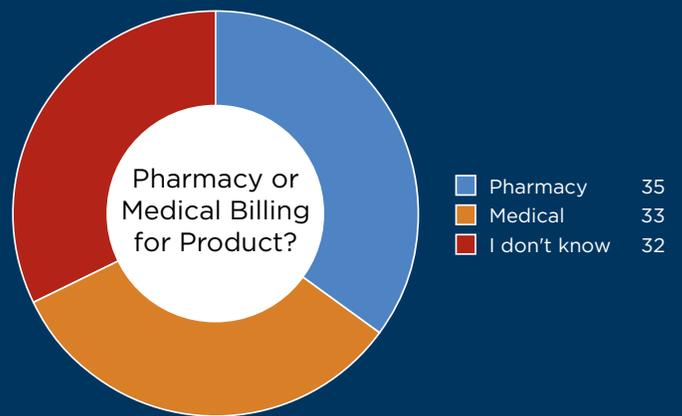
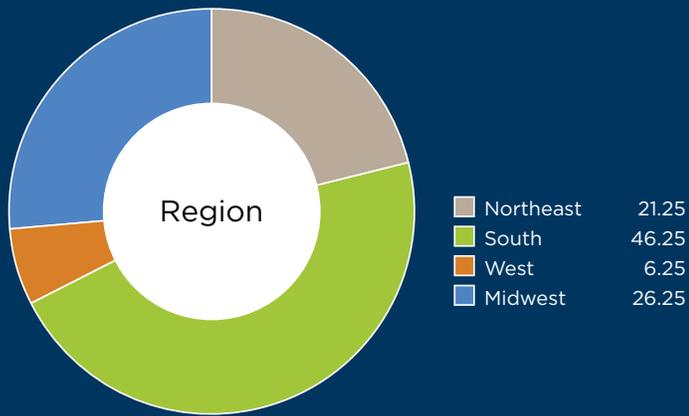
■ Yes	58
■ No	25
■ I don't know	17

* all reports not for bleeding disorders treatments

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

PROJECT CALLS

Creating Alternatives to Limiting and Lacking Services



Nothing Will Inhibit Building Our Knowledge

By Greg Hogan

Have you ever walked into a large room full of strangers and felt like such an outsider that you were desperate to maintain the lowest profile possible? You concentrate on keeping your head down, not making eye contact, quietly shuffling through the furniture and people. Ultimately you choose a seat as far back as possible from the speaker or presentation. With luck, no one will notice you or realize your status as a newbie or an interloper.

In 2016, my wife and I attended our first Symposium in Las Vegas where this scenario played out. At least it started to play out, but within the first five minutes we realized we were not outliers *or* among strangers. We were with families who were going through the same struggles we were, or they had weathered those struggles and were there to share their victories. Once our nervousness of being in an unfamiliar group wore off, we found that this group quickly felt like family and our experience in the session was exceptional. We very much looked forward to attending the inhibitor track at this year's HFA Symposium in Providence, and it did not disappoint. It was an informative, enlightening, and inspiring day.

This year, much like last, a panel of four individuals from the inhibitor community answered questions from the attendees and provided insight into their challenges and their successes. These panels are valuable opportunities, in an informal and laid-back setting, to gain perspective and understand the similarities and differences in the journeys we all experience. You get the real story, and real answers, from someone who has walked the walk. There are no case study results, no clinical trial parameters, no textbook answers—just a fellow human being's truth. Coincidentally, one of the panelists was undergoing the same medical treatment as our young son. Despite the age

gap between the two, this gentleman offered insight into what our son, who is not old enough to communicate effectively with us, was going through. It was immensely beneficial to be able to ask questions and get answers that can only come from someone who has been there himself. After the panel discussion, the panelist approached us and generously invited us to ask more detailed questions. It was priceless information from a qualified source.



“This wonderful community is a precious resource and it allows us to put things into perspective in a way that we never could have if we were going it alone.”

Hemophilia is still so very new for us. We had no family history of it, and although we have three boys, the first two showed no signs of hemophilia. It wasn't even on our radar. With our third son, we have lived through a seemingly-unending fusillade of issues: major head injuries, ports breaking and needing replacement, extremely high inhibitor levels, and two and a half years

of immune tolerance with daily infusions. While the curveballs keep coming our way, we now have a community to turn to, one in which we can reach out with questions and have someone listen to our concerns. This wonderful community is a precious resource and it allows us to put things into perspective in a way that we never could have if we were going it alone.

Finding and attending Symposium has been an enormous blessing for our family. We're already anticipating next year's event! ■■



Health and Fitness: Does One Size Fit All?

By Ruth Mulvany, PT, DPT, MS



One thing I've learned in my more than 30 years of helping people with bleeding disorders manage their health is that when it comes to exercise, there is no "one size fits all." Even a specific exercise program designed for a particular individual can change with each new bleed they experience, and then change again with their gradual recovery from that bleed. Exercise guidelines also transform with age, co-morbidities, hormones, clotting factor, severity, inhibitors and myriad other things that might come into play. Any physical therapist with an understanding of the unique needs of people with bleeding disorders would find it a challenging, even impossible, task to give helpful information that applied to all people with bleeding disorders.

If my many years of experience have taught me anything, it's that women, with or without bleeding disorders, tend to put their own health and well-being last on the priority list while scrambling to fulfill their multiple roles and responsibilities within a family. For women in the bleeding disorders community, the first step toward a healthy life involves accepting the following:

- 1. YOU ARE WORTH IT.** Your health is just as important as any other priority. Yes, when you or someone in your family has a chronic health condition, everything is harder, but few things are impossible. And you ARE worth the extra effort!
- 2. ANYONE CAN EXERCISE.** Regardless of your current weight, physical condition, time constraints, and the barriers you face, you can exercise.
- 3. YOU CAN INCORPORATE HEALTHY LIVING INTO YOUR LIFE.** List the barriers that keep you from mental, physical and spiritual health and then address each obstacle, one by one, including time, accessibility, desire, pain, depression, fatigue and joint issues. You can do this!
- 4. YOU'RE NOT ALONE.** Help is out there. People and resources to help you accomplish your goals are available.

Though men with bleeding disorders may have somewhat different issues, adopting this positive approach is an important first step in becoming healthier.

Another important thing I've learned is that a talk or presentation (or, even, *Dateline* article) may inspire, motivate and challenge an individual to pursue health and fitness, but it is only a jumping-off point. People need more information to develop their own strategies for managing their challenges and developing healthy lifestyles. To be sure, there is no lack of advice or enticements in the realm of health, fitness, and weight loss and pain management. One can get mired in the hundreds of thousands of advertisements, fad diets, and aggressive exercise programs, all developed to get your attention and, most especially, your money. Beware of unsubstantiated claims that sound too good, promise too much, or use anecdotal evidence ("It worked for my cousin!") to "prove" their merit. Take the time to make a considered, and researched, choice when it comes to your health. Be a wise consumer.

With that in mind, one of the most helpful things I can do is provide a list of resources for individuals to find reliable information. Remember, knowledge is power! Many foundations, associations and organizations have excellent resources that anyone interested in improving his or her life can access. The alphabetical list below can get you started. Please note that these sites end in dot-gov, dot-org, and dot-edu. There are no dot-com sites and therefore no one is trying to sell you anything. Explore these sites and search for information that pertains to you. These resources are your starting place to find information that can guide you and your family. Remember that there is no "one size fits all" prescription for health and fitness! Always speak with your HTC or primary care specialists who know you as an individual for the final steps in developing your plan for a healthy life. Good luck!

American Academy of Orthopedic Surgeons

www.aaos.org

Look up different disorders, injuries, treatments and surgeries.

American Academy of Pediatrics

www.apa.org

Arthritis Foundation

www.arthritis.org

Amazing resource on exercise, pain management, living with arthritis and more. Check out the tools and resources, especially exercise and fitness tools and mobile apps.

Centers for Disease Control, Bleeding Disorders

www.cdc.gov

Department of Health and Human Services

www.dhhs.gov

Important information for the health of the whole family, and www.womenshealth.gov for women's health specifically. Check out Bleeding Disorders, Fitness and Nutrition, and A-to-Z Health Topics.

Foundation for Women and Girls with Bleeding Disorders

www.fwgbd.org

A great site developed by some of the leaders in bleeding disorders. Definitely worth a look.

Hemophilia Federation of America

www.hemophiliafed.org

Check out the wide range of resources and opportunities. Look through the site for valuable, user-friendly advice and information. For women, check out the "Blood Sisterhood" pages.

National Academy of Medicine

www.nam.edu

What do you want to know about medical conditions? Check here. Researched and reliable.

National Hemophilia Foundation

www.hemophilia.org

Check out the resources, research, educational material, interest groups and more. A great organization for people with bleeding disorders.

National Institute on Aging: National Institute of Health

www.nia.nih.org

For anyone getting older, this is a valuable resource that addresses many relevant topics and helps us live longer, more independent lives.

National Institutes of Health

www.nlm.nih.gov

The NIH offers reliable, researched, top-level information on hundreds of health matters. Go to the search bar and type in your topic. For weight control and diet, check out www.nlm.nih.gov/medlineplus/weightcontrol

PUBMED

www.ncbi.nlm.nih.gov/pubmed

A great place to find scientific research, articles and publications. Follow the tutorial to guide you through how to conduct searches.

World Foundation for Hemophilia

www.wfh.org

A must-see site at an organization supported by experts and consumers from around the globe. Check out "Guidelines for Managing Hemophilia" and get the free pdf, *Exercise with Hemophilia*. ■ ■



Meet Bioverativ: putting patients first

A new company dedicated to the hemophilia community and building upon Biogen's legacy of science and innovation

Bioverativ has a singular purpose: striving for progress when and where people need it most

The pioneering hemophilia treatments provided by Biogen are now available to you through Bioverativ with a continued focus on quality, safety, manufacturing, and product accessibility.

Many of those who worked to advance treatments at Biogen are continuing their scientific pursuits at Bioverativ. Our dedicated team of Community Relations (CoRe) Managers will continue with Bioverativ to create lasting relationships with the hemophilia community using their decades of experience and understanding. Together, we are deeply committed to developing meaningful therapies for people with hemophilia and their caregivers.

We challenge the status quo at every step. Bioverativ is passionate about making a substantial impact in the lives of people with hemophilia and other rare blood disorders.

**Visit Bioverativ.com for more about us
and our mission**



–The Bioverativ Community Relations (CoRe) Managers