



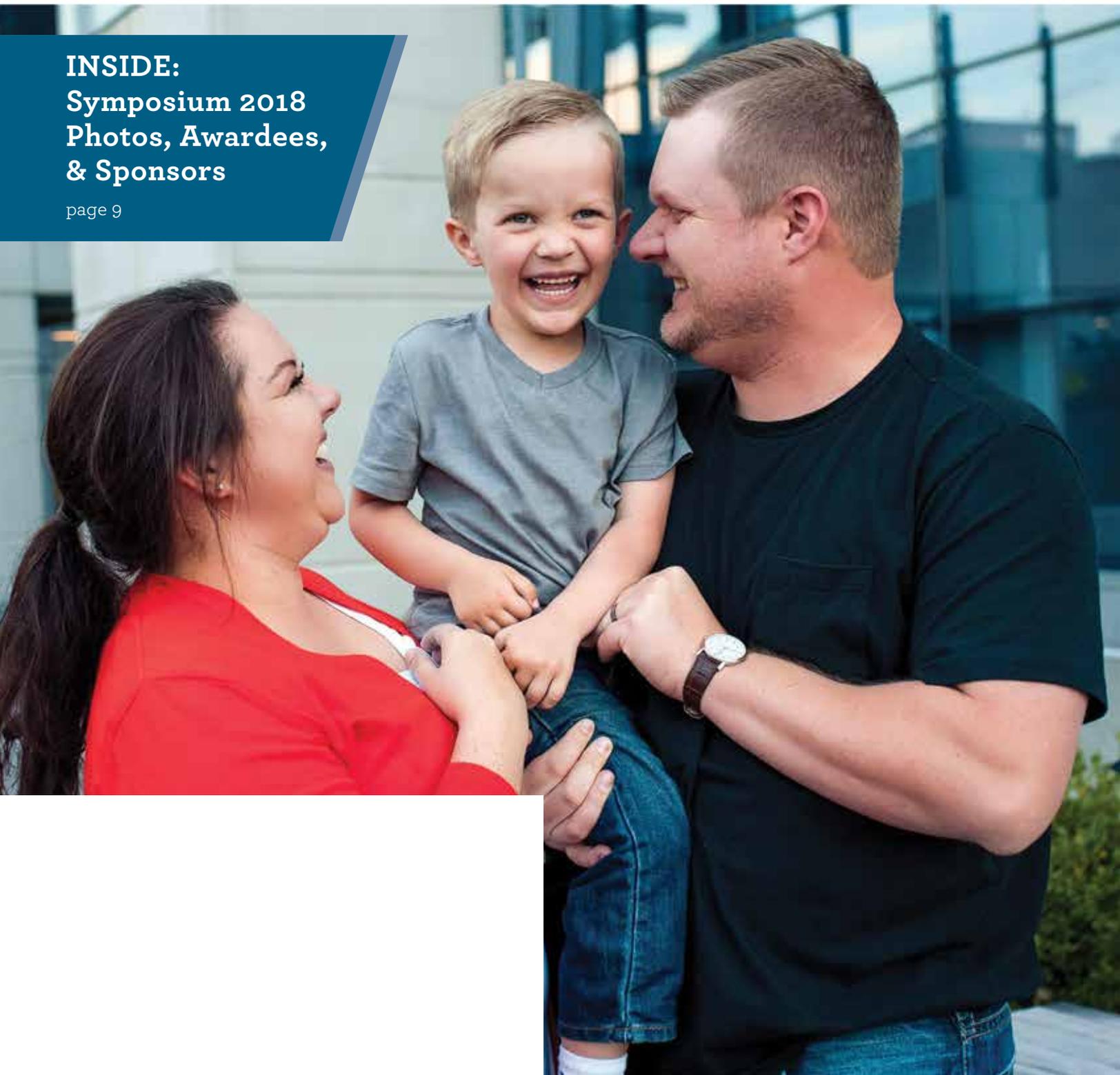
# DATELINE

F E D E R A T I O N

Issue 56 | Volume 18 | Spring 2018

**INSIDE:**  
**Symposium 2018**  
**Photos, Awardees,**  
**& Sponsors**

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# PROJECT CALLS

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

**YOU ARE NOT  
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,

**Project CALLS is for you!**



**To contact us about your insurance issue, please call (202) 836-2530, email [projectCALLS@hemophiliafed.org](mailto:projectCALLS@hemophiliafed.org), or visit [www.ProjectCALLS.org](http://www.ProjectCALLS.org)**



Assisting, educating, and advocating for the bleeding disorders community since 1994.

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**Dear Reader,**

**W**hen I attended Symposium for the first time more than 12 years ago it was in the capacity of a representative on the board of directors. My local Member Organization was looking for someone to fill the seat on the board and I saw it as a good opportunity to immerse myself within the community. I had little knowledge of the specifics of HFA's work and felt like I knew precious little about hemophilia as well. My son Nicholas was just a few years old and my husband and I were still trying to navigate our lives with a child with severe hemophilia. With no family history of bleeding disorders we had a lot of learning to do. At that time Nicholas had already endured several joint and soft tissue bleeds, had a port placed, and was on prophylaxis. It was a whirlwind of a Symposium, and a trip that redefined the next chapter in my family's story.

As you enjoy this latest issue of *Dateline*, my role as the chair on the board of directors has come to an end. After four terms of serving in this capacity, two questions continue to whirl around in my mind: how did this happen and where did the time go? I'm not sure I know the answer to either, but I can say that it's been a tremendous blessing. I'm thrilled to see a group of passionate and dedicated individuals has been voted on to the board's executive committee, with Josh Hemann as chair.

I've had the privilege of witnessing tremendous growth and evolution at HFA over the last decade as my family, too, has gone through its own metamorphosis. We've transitioned from port to peripheral infusions and are gently moving Nicholas towards self-infusing. He's been going to sports practices by himself and has even attended some sleepovers with friends. Ah, teenagers! Through each of these milestones or transitions, we've had a village of people supporting and championing us. Whether it's reading the latest post on HFA's blog from a mom, talking with a dad going through a similar situation, or Nicholas looking to an older Blood Brother for suggestions — we haven't been alone.

No matter which measurement you use, HFA has grown. With 48 Member Organizations currently in partnership, the scale and reach of the great work we're doing spans from coast to coast. The Blood Brotherhood program continues to grow while other groups of individuals are receiving attention and services like never before through programs targeting dads, moms, families, and caregivers. Spanish-language content is reaching an underserved group of individuals, and people living with vWD or rare bleeding disorders have access to unparalleled programming and resources. Our policy and advocacy work has moved beyond just federal issues as we also work with Member Organizations to tackle state-level concerns across the country. The Gears for Good fundraising bike ride has grown to be one of our signature events, and just this year, HFA was selected as a charity partner for the Marine Corps Marathon in Washington, DC. We've even launched our own research department with initiatives that are at the forefront of patient-centered research.

Despite the growth, not everything has changed: I still don't enjoy public speaking! And, HFA continues to be the leading voice and advocate for people living with bleeding disorders in this country. You, the community, have always been, and will always be, this organization's focus, drive, and motivation.

Perhaps without even knowing it, you've done so much for me and my family. I will be forever grateful to have had this experience. It's been my absolute pleasure. I look forward to seeing you at Symposium next year in San Diego, CA as HFA celebrates 25 years!

*Gratefully,*

*Tracy L. Cleghorn*

**Tracy Cleghorn**  
Past President



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



# Run the Marine Corps Marathon with HFA's Team Resilience

**SUNDAY, OCT. 28, 2018**

HFA is an official charity partner of the 2018 Marine Corps Marathon and has your entry spot in this sold-out, exclusive race. Run on HFA's Team Resilience while raising funds for the Helping Hands program, providing financial relief to community members in crisis.

**Race Registration Fee: \$175**  
**Minimum Fundraising Amount: \$500**

Recognized for impeccable organization on a scenic course managed by the US Marines in Arlington, VA and the nation's capital, the Marine Corps Marathon is one of the largest marathons in the US and the world. Known as 'the best marathon for beginners,' the MCM is the largest marathon in the world that doesn't offer prize money, earning its nickname, "The People's Marathon."



**Less than 25 spots remain — register today!**

To sign up to run the MCM with Team Resilience follow these three steps:

1. Visit [www.hemophiliafed.org](http://www.hemophiliafed.org) register with HFA, and pay the registration fee.
2. Receive an email from HFA containing an access code.
3. Visit the Marine Corps Marathon website, follow the prompts, and enter your access code.



Launched in 2018, Team Resilience is HFA's endurance fundraising team, participating in various athletic and competitive events across the country to raise awareness about bleeding disorders and funds for Helping Hands, a financial relief program for families in crisis. Have a suggestion about an event we should attend? Contact us at [HFAdev@hemophiliafed.org](mailto:HFAdev@hemophiliafed.org).



# “How Do I Participate in PCOR & CER as a Community Member?”

## Lessons Learned from HFA & PCORI Webinar Collaboration

By Julie Lesch, MPA and Krista Woodward, MPH, MSW,  
of the Patient-Centered Outcomes Research Institute (PCORI)

**A**nn-Grete Tan, who has a son with hemophilia, remembers simply checking a box at her son’s clinical visits giving her consent to share his data and medical information for research purposes. But she never heard whether her son’s information contributed to any specific discoveries or whether it helped advance the science and treatment of hemophilia.

This experience rings true for so many patients. Patient and stakeholder engagement in clinical research has long been a hard-fought battle. Until recently, most patients had only participated as “subjects” being studied. They had seldom been given the opportunity to meaningfully engage in the planning, conduct, or dissemination of a research project.

However, research institutions like the Patient-Centered Outcomes Research Institute (PCORI) have recognized that patients and stakeholders have experiential expertise that should be used to inform clinical research. PCORI is working to ensure that research is done differently and that patients are involved at every step of the process.

A recent HFA webinar led by Tan and Julie Kennedy Lesch, a PCORI Engagement Officer, highlighted the power of stakeholder engagement in clinical research, particularly for individuals with bleeding disorders. Their presentation spoke to the valuable role patients and caregivers can play as study partners, and provided examples of successful engagement activities and outcomes.

This webinar was the second in a series for the Patient-centered Research for Innovation, Development, and Education (PRIDE) project. PRIDE is an initiative funded through the PCORI Eugene Washington Engagement Awards program that aims to foster communities prepared to advance patient-centered outcomes research (PCOR) and train individuals to participate in

comparative effectiveness research (CER). CER tests the effectiveness of two or more different treatments or inventions to learn what works best and for whom.

Patient and stakeholder engagement is the crux of PCORI, an independent research funder authorized by Congress in 2010. PCORI funds CER that engages patients and other stakeholders throughout the research process. PCOR does the same thing as CER, but intentionally asks patients and other stakeholders what features or outcomes are most important to them and involves them throughout the research process. PCORI aims to increase the amount of patient centeredness and meaningful engagement in health research, which will ultimately improve the speed, uptake and usefulness of clinical findings for all communities.

PCORI believes that patient and stakeholder engagement must occur throughout a research project, including the planning, conducting, and dissemination phases. PCORI has observed that patient and stakeholder engagement has significant influence and impact on the overall outcomes of research projects across therapeutic areas, populations and intervention types.

In PCORI’s view, engagement can take many forms, but always leads to the intentional and meaningful involvement of patients and stakeholders given their experiential expertise. The intensity of patient engagement can range from consulting to directing a research project’s trajectory. Projects such as PRIDE are important for training patients and stakeholders about how they can be actively engaged and share their perspectives with researchers and clinicians.

In the webinar, Lesch spotlighted specific examples of successful engagement from the PCORI research portfolio. One example included patient input in the enrollment script used

to recruit research participants from hard-to-reach populations. Patients weighed in on the language to make it more understandable to people of all reading levels. Because of the patient engagement in the planning process, there was a significant and quantifiable increase in the project recruitment rate. This example alluded to general activities and practices that lead to successful and sustainable engagement, including creating a safe space for sharing, ensuring materials are lay accessible and equalizing the playing field between researchers and stakeholders.

PCORI and other funders recognize that conducting meaningful patient and stakeholder engagement comes with challenges, such as consensus building and buy-in from diverse communities. Many patients struggle through the growing pains of integrating their perspective in the planning, conduct and dissemination of research. These challenges may delay project milestones. In response, PCORI and other organizations have developed tools and resources to help researchers better initiate and sustain stakeholder partnerships in their work. One example is the PCORI Engagement Rubric, which provides guidance on facilitating and maintaining engagement throughout the course of a research project.

PCORI is applying the principles and traditions of community involvement observed in parallel fields, such as community development, political activism and civic engagement. Researchers eagerly seek innovation in the field to more quickly determine effective interventions and treatments for end users.

In respect to the HFA community, PCORI is funding research around bleeding and blood disorders as well as pain management. Visit [pcori.org](http://pcori.org) to learn more about PCORI's research portfolio and future funding opportunities.

The demand for patient and stakeholder perspectives will only continue to grow. Anyone can get involved in research and help the research culture continue to shift toward patient and caregiver centeredness. HFA Pride Project will continue to educate and equip the bleeding disorder community to become more active in PCOR to ensure that research is relevant, useful and valuable.

*Research reported in this article was partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (4349-HFA). The views, statements, and opinions in this article are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee. ■■*



**Your dreams. Our dedication.**

For over 60 years we have been inspired by people like you. We continue to work as tirelessly as we did in the very beginning, with unwavering focus on our ultimate goal: **a life full of dreams and free of bleeds.**

**Shire**

[bleedingdisorders.com](http://bleedingdisorders.com)

Alex  
Hemophilia A  
Massachusetts

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# Now What? Maintaining Momentum after HFA's Young Adult Advocacy Summit

By Catherine Anderson, Introduction by Sarah Shinkman

**HFA** hosted our inaugural Young Adult Advocacy Summit this past October. Fifteen young adults with bleeding disorders from across the country participated in the four-day event in Washington, DC and received training on state and federal policy, advocacy, coalition building, communications, and health insurance. One of the participants, Catherine Anderson, shares more on her experience and its lasting impact.

Living with a rare condition means that I often have to act as the expert on my condition. As I deal with everyone from curious strangers to overwhelmed physicians, it is important to me to know what is happening in my body and be able to explain this to others. However, I have often found myself trailing off into a long description of the many ways my life is affected, when the listener was anticipating a simple explanation.

As therapeutic as it can be to speak openly about my condition, I have been embarrassed by my tendency to overshare. Even worse, I fear being seen as a chronic complainer.

During the Young Adult Advocacy Summit, I was encouraged to develop an “elevator speech”—a concise personal statement about my life with a bleeding disorder. By workshoping my speech with groupmates, I was able to focus on the big picture of my life, rather than naming the many details. Hearing the stories of my peers also helped me to realize how I can use my voice to speak for our community as a whole.

We put our speeches to the test by meeting with members of Congress and their staff. Before and during those meetings, we tried to keep a few affirmations in mind. First: we are stronger in numbers. Having my blood brothers and sisters beside me made me more confident because I knew that I was not alone in my experience. In addition, during these meetings, we speak not only for ourselves, but amplify the voice of the entire bleeding disorders community. By sharing my story, I bear witness for ev-

ery person who has ever been disabled by their unmanageable menstrual bleeding. Last but not least, legislative officials have an obligation to work for the wellbeing of their constituents. If anyone should be intimidated during those meetings, it's them! The Young Adult Advocacy Summit empowered me to shift my message from one of feeling like a victim to one of agency and use that to advocate for a better life for our community.



Part of the reason the Summit was so transformative for me was that it focused on people in my age group. As young adults, we were mostly concerned about the same things: avoiding bleeds, finding meaningful work, establishing relationships, furthering education, and how the current discussion of access to health-care will impact our lives. I feel liberated having a group of peers

who already understand this central element of my life.

I am reassured knowing that I am not alone in my chronic joint pain or my worries about the future. My successes feel all the more bright for being able to share them with a community of young people who know that sometimes even taking a walk can be a struggle. Though our stories are not identical, being part of a team of like-minded (and -bodied) individuals has energized me, and I know that we have each other to lean on as we continue to fight for a better life. ■■

# Rockin' and Rollin' at Symposium

## HFA's Largest Event Brings Community Together

**M**ore than 1,000 community members from 43 states, the District of Columbia, and Puerto Rico traveled to Cleveland, to attend HFA's annual educational Symposium. Held at the Hilton Cleveland Downtown Hotel from April 26 - 29, the conference boasted a range of educational sessions covering a variety of topics from policy issues and legislation at the local and federal levels to patient-centered research initiatives, from engaging with insurance companies to pain management. Tracks of sessions were offered with content geared toward the needs and interests of community members with different bleeding disorders including hemophilia, vWD, inhibitors, and rare bleeding disorders. A Spanish-language track was also available for community members who preferred or required Spanish-language content. As in previous years, programming for children and teens was a core part of Symposium, with

age-specific activities keeping kids engaged and learning while having fun.

The Exhibit Hall provided community members with an opportunity to visit more than 50 booths and meet with product manufacturers, specialty pharmacies, companies researching new products and therapies, and local and national nonprofit organizations.



Festivities culminated with a final night event at the Rock & Roll Hall of Fame. Aptly titled, Together We Rock, the event's venue provided an opportunity for the

community to see memorabilia from music icons such as Elvis, Prince, Carole King, Elton John, Etta James, Michael Jackson, Madonna, and the queen of soul, Aretha Franklin. Attendees enjoyed delicious Cleveland fare and rocked out to Ohio's premier cover band 56 Daze. ■■



## SYMPOSIUM 2019

**Add it to your calendar now, because you won't want to miss out on next year's Symposium! Hosted in San Diego, CA from April 4-6, this event will recognize 25 years of HFA serving the bleeding disorders community. Visit our website and subscribe to our emails to be one of the first to know when registration opens. [www.hemophiliafed.org](http://www.hemophiliafed.org)**

# OUR SPONSORS

It is with the support of our sponsors that we are able to host Symposium. Without it, we couldn't host the largest community-centered educational event for people living with bleeding disorders, where hundreds come together to share information, learn about new advancements, and build a network of support. We thank the following companies for their generous support:

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Kedrion Biopharma  
uniQure



I feel so blessed to have received a scholarship to attend. I was able to make connections, get additional information and an education on new topics.





  
**Thank you for offering a track on rare bleeding disorders. Please keep up the awareness!**



# AWARDS

Each year at the Symposium awards luncheon, HFA recognizes a number of individuals who have had a positive impact on the community. This year, nine awards were presented to 12 individuals for their contributions.

## ▼ Pictured below:

Left to right: Manuel Lopez Serrano, Liliana Gomez, Anthony Llanes Rodriguez, Martha Boria Negron, Barry Haarde's sister, Emily Cobb, Gwenn Welsch, Barry Haarde's nephew Patrick Vepieri, Emily Bisson, Chris Seistrup, Connie Montgomery, Shai Mann Robinson, Cynthia Chavez with Southern California, Tom Knoerzer with Get Out and Go Tours, and Southern California Executive Director Michelle Kim.

## It Takes a Village — Connie Montgomery

*For an individual who goes above and beyond in uniting community and has demonstrated a unique ability to connect members of a newly diagnosed family with those who have experience living with a bleeding disorder to foster relationships.*

Connie has abundant professional experience as a business owner, occupational therapist, writer, national and international motivational speaker, and member of the bleeding disorders community. She continues her path of excellence as she wholeheartedly commits to addressing the needs of the community. She is passionate about speaking about bleeding disorders.

As a seasoned and recognized volunteer of national and local organizations, she uses her life experiences to contribute in new and meaningful ways. As a member of the Hemophilia of South Carolina Advocacy Coalition and Ambassador Program, her latest topics for engagements have been on welcoming and utilizing diversity in professional programs.

She has also developed the Patchwork Quilt Series, a national program focusing on diversity and the importance of working together in the bleeding disorders community.

Connie brings her uniqueness to the table by engaging everyone in fun and challenging conversations and programming that allow you to see how people with varying perspectives can come together like the fabric of a woven patchwork quilt. ■■



## Leaders of the Future — Shai Mann Robinson

*For exemplary service, leadership, and integrity by a teen or young adult under the age of 21 who demonstrates courage and promise.*



Shai is a 15-year-old young man with severe hemophilia from Massachusetts. Aside from being exceptionally thoughtful and creative, he has proven himself to be an engaged teen-member of this community.

In his work to innovate the way young people understand what's happening with their bleeding disorder, he created a stop-motion-animation video using Legos® to help ease the fears of children about getting an MRI. He is currently using human-centered design techniques to study challenges and create an app focused at young adults regarding their prophylaxis adherence.

Last summer he attended an advocacy summit hosted by HFA in DC to advocate for the bleeding disorders community and demonstrated superb abilities at the meeting. During his trip, Shai filmed his experience and created a mini-documentary to illustrate the message that anyone can be an advocate.

Shai has been a part of the New England Hemophilia Association's (NEHA) teen adventure club, a leadership development group, where he and peers instruct a Bleeding Disorders 101 Class for international staff who work at the camp. He regularly speaks to other teens on his advocacy efforts and recently assisted Patrick Lynch with a *Stop the Bleeding* educational session. Shai shines a light on the importance of awareness and independence.

■ ■

## Ron Niederman Humanitarian Award — Emily Bisson

*For extraordinary and inspirational service to the national or international community via one's professional work or volunteer service, honoring Ron Niederman, a champion in the fight to make the country's blood supply safe.*



Emily goes above and beyond with her dedication to the community: she cares for everyone with whom she works.

Wherever she is, whatever she is doing, Emily puts 100% into her engagement and critical thinking about solutions for her patients. She works at Yale School of Medicine, serves on several local and national steering committees, and is a regular speaker at NEHA events. Her commitment to volunteerism extends far beyond her role as an advanced registered nurse practitioner (ARNP): she has been a participant at the National Association of County and City Health Officials conference, National Hemophilia Foundation events, Connecticut Hemophilia Society events, and NEHA's Family Camp.

It's at Family Camp where her passion for the outdoors fuses with her love of working with teens and young adults. With this group, Emily emphasizes the importance of being able to learn to infuse anywhere. Under her guidance, these young people have infused in the woods, on a moving bus, and most notably and recently, in canoes, floating on Lake Winnepesaukee in New Hampshire!

Like Ron, Emily always helps those in need with compassion and a commitment to making life better for those in the bleeding disorders community. ■ ■

## **Teach, Empower, Advocate Award** — Gwenn Welsch

*For outstanding national or global support and advocacy for women's bleeding disorders issues.*



For decades, Gwenn has tirelessly volunteered for the bleeding disorders community in north/central California. Her expertise in organizational event planning contributed to various feats: from silent auctions to negotiating hotel space for Family Education Day, she has done it all!

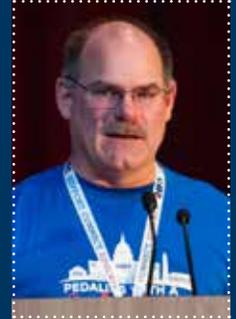
As a continuing medical education specialist at University of California, Davis Medical Center, she uses her professional experience and connections with a commitment to good health all around.

Gwenn is passionate about improving health within the community. She has helped connect women with resources, developed educational programs to address new concerns of an aging population, and promoted health and wellness thereby ensuring educational programs are built upon each other progressively.

Consistently giving in so many ways, Gwenn has positively impacted the lives of many through her generosity of time, dedication, and personal resources. ■■

## **Michael Davon Community Service** — Tom Knoerzer

*For extraordinary service to the community via one's national or global volunteerism and charitable giving. Named in honor of Michael Davon, who was integral to the inception of HFA, a man of extraordinary vision and compassion, and strengthened HFA with his philanthropy.*



Tom has been a passionate supporter of HFA from the moment he connected with us more than five years ago to host the Gears for Good ride, a 156-mile bike ride from West Virginia to DC to benefit the Helping Hands program. He works hard to provide riders with an amazing experience and is focused on making the fundraising initiative successful. Each year he works to solicit food donations and discounted rooms for the riders on the trip to minimize cost and lower our fees, increasing our fundraising profit.

Over the years, Tom has surprised HFA with an end-of-year donation to show his support. Yearly, he joins as an official Member and proudly wears his HFA t-shirt when out and about.

Beyond his superb talents and generous contributions, Tom's other gift is his amazing heart. He actively supports HFA in his personal online communications, soliciting donations and riders from his own networks. He's developed deep friendships with many bleeding disorders community riders and inspires members of the team to keep riding and stay true to supporting HFA's mission. After just a quick glance at his Facebook pages, you'd bet he was a person with a bleeding disorder!

Tom is extraordinary to many, yet he doesn't look for kudos or praise — he just does what he feels is right. Tom has adopted HFA and our community into his heart. ■■



## Terry Lamb Health and Wellness — Chris Seistrup

*For exceptional commitment to supporting HFA in its national efforts to encourage health, nutrition, and wellness behaviors in the community. Named in honor of Terry Lamb, a respected leader who passionately encouraged an active lifestyle to reduce and prevent bleeding episodes.*



When we think about physical fitness for people living with hemophilia, endurance cycling hasn't always been the first thing that comes to mind. But for Chris, it was the logical next step in his quest to push the boundaries set by his hemophilia.

Last year, with nothing more than a few bags strapped to a bicycle, he started the 1,900-mile journey from California to Vancouver, British Columbia. He took an arduous route with no car following to provide comforts, companionship, or support. His efforts were made in the name of HFA's Helping Hands program with a goal of raising money to support our initiative. In just 13 days and 9 hours, Chris raised \$5,500.

This wasn't his first long-distance ride but one of several as his perspective on the challenges of living with hemophilia broadened over the years. In 2015, while preparing for his first 100-mile ride, his grandfather, who also had hemophilia, had been in an accident and experienced severe bruising and blood loss. It was a scary time for the entire family as his grandfather's health quickly declined due to many complications including internal bleeding and co-morbidity issues. Watching his grandfather cope with the challenges of aging while having hemophilia was a thought-provoking experience.

That insight, added to his natural impulse to help others, prompted him to start planning his 1,900-mile fundraising excursion. We celebrate and champion Chris's commitment to family, the community, and good health. ■■

## Member Organization Spotlight — Hemophilia Foundation of Southern California, accepted by Michelle Kim, Executive Director

*Recognizing a Member Organization with a true passion for service to their community, honoring an organization that has created an environment that engages members, continually promotes education, and consistently encourages self-advocacy.*



This organization has revitalized itself in recent years under the strong and committed leadership of a bright and fearless woman, Michelle Kim. The group has grown by 300% in attendance and engaged its membership with a plethora of new programs that meet the needs of its diverse and special community. Hosting an Educational Symposium in partnership with its four local hemophilia treatment centers to train parents on education rights, recruiting subject experts in education law to its board, and energizing its teens with a Teen Leadership Summit, this group is meeting the needs of families. ■■



 **Volunteers of the Year** — Manuel Lopez Serrano, Liliana Gomez, Martha Boria Negrón, and Anthony Llanes Rodríguez

*Selected by HFA staff in recognition of tremendous national spirit and remarkable volunteerism with HFA for the bleeding disorders community.*



Four gracious and dedicated souls who give without expecting a return are recipients of the award. Each exemplifies a national spirit for volunteerism and each has been dedicated to working with HFA to support families faced with disasters. Making multiple trips to Puerto Rico following the September hurricanes, the awardees gave time and financial contributions, and continue to provide endless hours of calls, texts, and online support to families on the island and those transitioning now to living on the mainland. Days and days have been spent going door to door, over damaged roads at personal risk, bringing supplies and support to families, truly teaching us all what it means to be a national community family.

Manny dropped everything when we called and asked him to travel to Puerto Rico. Lily has traveled back and forth to the island more than six times to check on families and even hosted her own gift drive for Christmas. Anthony has been on the ground in Puerto Rico despite being personally impacted by the storm: always humble and gracious, never mentioning that he didn't have water at home yet himself while spending countless hours for weeks helping others. Martha is an asset to HFA, working with our Spanish-speaking community members. She jumped right on board to help with the disaster relief in Puerto Rico with no hesitation and brought an immense amount of the passion along with her.

While this recent disaster has spotlighted their service to our community, these individuals are always committed, often behind the scenes, to supporting our most vulnerable families. ■ ■





**I loved Representative Howse's energy and enthusiasm during her session.**



## **Charles Stanley Hamilton Legacy — Barry Haarde, in memoriam**

*For extraordinary lifetime service that encompasses national volunteerism, professionalism and leadership. Named in honor of Charles, whose work directly contributed to HFA's existence and impact within the community. Son of the late Dr. Charles Hamilton, a pediatrician and physician surveyor for The Joint Commission, and husband of Jan Hamilton, one of the HFA's founders and a long-time executive director, it was Charles's hemophilia which led to his greatest legacy.*



When he first encountered HFA less than 10 years ago, Barry shared that he hadn't had any idea how many of his generation were still around. He told us many times that the Blood Brotherhood program got him involved in the community where he found his true passion after a knee replacement: cycling.

Barry didn't cross the United States on a bicycle just once, he did it five times, raising more than \$250,000 for Save One Life, an organization providing aid for people living with bleeding disorders in developing countries. He was an early supporter of and rider with our Gears for Good ride, and his friendships within Blood Brotherhood were deep and fulfilling.

Laurie Kelley, a community member, summarized many of our feelings after Barry's passing: "I was shaken to my core when I learned yesterday that my dear friend Barry Haarde had passed. It was surreal; how could this giant of a man—in stature, in compassion, in physical prowess, in notoriety, be gone? How? He was so loved by so many. Hundreds of people around the world looked up to him and were inspired by him. I became a cyclist because of Barry, and rode the last 50 miles with him on his first cross-country tour."

But life was the hardest endurance ride of all. Despite all he suffered and overcame, he passed all-too-early at the age of 52. He loved lighthouses and jazz, and adored his mother and family.

Barry, a private person with a shy demeanor and a sometimes-solitary nature, hid his suffering. His ability then to galvanize our community the way he did was an act of bravery. ■■



**HFA did a wonderful job putting this together! I cannot wait for San Diego!**





**HFA made the presentations fun to be a part of from the beginning. I feel informed and empowered.**



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*Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 60 years.*

**Stay empowered by the possibilities.**

**References:** 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. 2. Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure and stability. *Haemophilia*. 2010;16(suppl 3):7-12. 3. King MW. Introduction to blood coagulation. <http://themedicalbiochemistrypage.org/blood-coagulation.php>. Last modified January 2, 2017. Accessed November 21, 2016.

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I really enjoyed being able to talk with other families and make new connections. I loved that my children made new friends who they now text with.

**IXINITY**<sup>®</sup>  
coagulation factor IX  
(recombinant)

**Discover more  
about IXINITY**<sup>®</sup>

Visit [IXINITY.com](http://IXINITY.com)

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If I attended just one meeting a year, this would be my choice. I can't say it enough, this is a family-friendly experience for and relationship building. I so enjoy catching up with old friends and making new.



 It's always great to see members of the community speak honestly and publicly about their hemophilia, hopes, fears, challenges, and personal victories. It's empowering and a moment of growth. I appreciate their honesty and vulnerability.





Meeting other people and learning about their situations is always the best part of attending. Not everyone's bleeding disorder experience is the same and it is truly humbling to be surrounded by others who are going through it as well.

## In hemophilia B TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®

**17%** Factor IX (FIX) levels sustained after 7 days with a single 40 IU/kg dose in adults with ≤2% factor levels\*



Clayton, 34 years old, is a pilot who hikes and camps in his spare time. Clayton lives with hemophilia B.

\*In two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebinyn® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years. Image of hemophilia B patient shown is for illustrative purposes only.

### INDICATIONS AND USAGE

#### What is Rebinyn® Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for routine prophylaxis or for immune tolerance therapy.

### IMPORTANT SAFETY INFORMATION

#### What is the most important information I need to know about Rebinyn®?

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center. Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

#### Who should not use Rebinyn®?

Do not use Rebinyn® if you:

- are allergic to Factor IX or any of the other ingredients of Rebinyn®.
- are allergic to hamster proteins.

#### What should I tell my health care provider before using Rebinyn®?

Tell your health care provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

#### How should I use Rebinyn®?

- Rebinyn® is given as an infusion into the vein.

#### • Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.

- Do not stop using Rebinyn® without consulting your healthcare provider.

#### What are the possible side effects of Rebinyn®?

- Common side effects include swelling, pain, rash or redness at the location of the infusion, and itching.
- Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction: hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- Tell your healthcare provider about any side effect that bothers you or that does not go away.

- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

#### Please see Brief Summary of Prescribing Information on the following page.

Rebinyn® is a prescription medication.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**NOW AVAILABLE**

Learn more at [rebinyn.com](http://rebinyn.com)



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**rebinyn®**  
Coagulation Factor IX  
(Recombinant), GlycoPEGylated

# rebinyn®

## Coagulation Factor IX (Recombinant), GlycoPEGylated

### Brief Summary Information about: REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated

#### Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit [www.novo-pi.com/REBINYN.pdf](http://www.novo-pi.com/REBINYN.pdf) to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

### Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN® after reading this information, ask your healthcare provider.

#### What is the most important information I need to know about REBINYN®?

#### Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing REBINYN® so that your treatment will work best for you.

#### What is REBINYN®?

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

REBINYN® is used to treat and control bleeding in people with hemophilia B.

Your healthcare provider may give you REBINYN® when you have surgery.

REBINYN® is not used for routine prophylaxis or for immune tolerance therapy.

#### Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

#### What should I tell my healthcare provider before I use REBINYN®?

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor IX.

#### How should I use REBINYN®?

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to

infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

#### Call your healthcare provider right away if your bleeding does not stop after taking REBINYN®.

If your bleeding is not adequately controlled, it could be due to the development of Factor IX inhibitors. This should be checked by your healthcare provider. You might need a higher dose of REBINYN® or even a different product to control bleeding. Do not increase the total dose of REBINYN® to control your bleeding without consulting your healthcare provider.

#### Use in children

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

#### If you forget to use REBINYN®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

#### If you stop using REBINYN®

Do not stop using REBINYN® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

#### What if I take too much REBINYN®?

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

#### What are the possible side effects of REBINYN®?

##### Common Side Effects Include:

- swelling, pain, rash or redness at the location of infusion
- itching

##### Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor IX products. **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

Animals given repeat doses of REBINYN® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

These are not all of the possible side effects from REBINYN®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

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

#### What are the REBINYN® dosage strengths?

REBINYN® comes in three different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The three different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial

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

#### How should I store REBINYN®?

**Prior to Reconstitution** (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

#### After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

#### What else should I know about REBINYN® and hemophilia B?

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

#### More detailed information is available upon request.

Available by prescription only.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 11/2017

REBINYN® is a trademark of Novo Nordisk A/S.

For Patent Information, refer to: <http://novonordisk-us.com/patients/products/product-patents.html>

Manufactured by:  
Novo Nordisk A/S  
Novo Allé, DK-2880 Bagsværd, Denmark

For information about REBINYN® contact:  
Novo Nordisk Inc.  
800 Scudders Mill Road  
Plainsboro, NJ 08536, USA

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USA17BIO03951 12/2017



# TEACH Immersion Educates and Inspires Attendees

By Carrie Koenig

In October 2017, HFA was honored to host our inaugural English TEACH Immersion in Washington, DC. TEACH (Together we Empower, Advocate, and Collaborate for Hemophilia and other Bleeding Disorders) offered 24 men and women from the bleeding disorders community three days of educational programming and advocacy training. The training was designed to educate participants about bleeding disorder history, HFA's ongoing advocacy efforts, the legislative process, and current policies affecting the bleeding disorders community. Our goal was to create strong, informed advocates within the bleeding disorders community and provide them with the tools to continue their advocacy work at home.

The intimate size of the group of attendees provided time and opportunity for participants to connect and develop relationships, build a network of peers and fellow advocates, and, for many, create lifelong friendships. Attendees received detailed information on our community's unique and intricate history and HFA's journey to become a national patient advocacy organization. Additional activities included an overview of the Foundation of Women & Girls with Blood Disorders, educational sessions on proper nutrition, new approaches to pain management, patient-centered research, and of course, advocacy. An entire day was focused on personal and political advocacy, including an update on state and federal policies affecting the community. Attendees applied their newly learned advocacy skills in a meeting on Capitol Hill; we even squeezed in some time for a tour of the Capitol building. ■■



Because of overwhelmingly positive feedback, HFA will be hosting English and Spanish TEACH Immersions again.

Upcoming dates include:

- August 11-14 (English TEACH)
- November 3-6 (Spanish TEACH)

Contact [info@hemophiliafed.org](mailto:info@hemophiliafed.org) for more information or to register.

Attendees of HFA's TEACH Immersion pose for a photo outside of the US Capitol. After educational sessions and trainings on policy and advocacy efforts to benefit the bleeding disorders community, a visit to the Capitol was fitting.

Crystal Hoernlein takes notes during a meeting on Capitol Hill, one of the components of HFA's TEACH Immersion. After several training sessions, attendees took part in meetings with congressman to test their advocacy skills.

Attendees of HFA's TEACH Immersion posing for a photo with Matthew Fuentes of Senator Chuck Schumer's office, first row, fourth on the right. This hands-on experience meeting with a Senator's office was the culmination of the advocacy training attendees received at the immersion.

Attendees of HFA's TEACH Immersion make introductions during a welcome session, October 2017, Washington, DC. These 24 individuals were kicking off a multiday training, so getting acquainted with one another and HFA's policy and advocacy efforts was instrumental in the immersion's success.

Matthew Fuentes, from Senator Chuck Schumer's office, pictured center right, meets with HFA's immersion attendees on Capitol Hill.

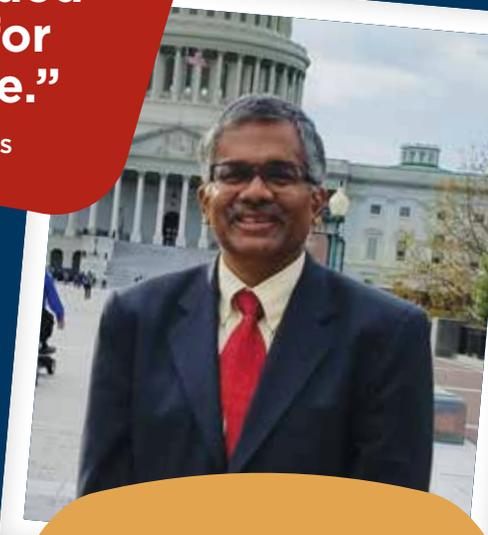
**"I hope that our voices can be heard."**

~Lindsay, New York



**"I am here to get continued support for healthcare."**

~Murali, Illinois



**"I am here in hopes of becoming a better advocate for myself and my son."**

~Crystal, North Carolina

**"I hope to gain knowledge to take home to educate others in El Paso about bleeding disorders."**

~Socorro, Texas

**"I am here to advocate for my three-year-old son and to keep my father's history alive"**

~Nichelle, Illinois



# Now Approved

**A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS**

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®.

We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

## **WHAT IS HEMLIBRA?**

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

## **WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?**

**HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use.**

**HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**



#### HOW SHOULD I USE HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

#### WHAT ARE THE OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

**The most common side effects of HEMLIBRA include:** redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or [www.fda.gov/medwatch](http://www.fda.gov/medwatch). You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

**Medication Guide Brief Summary**  
**HEMLIBRA® (hem-lee-bruh)**  
**(emicizumab-kxwh)**  
**injection, for subcutaneous use**

**WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?**

**HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

See “**What are the possible side effects of HEMLIBRA?**” for more information about side effects.

**WHAT IS HEMLIBRA?**

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

- Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.
- HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

**BEFORE USING HEMLIBRA, TELL YOUR HEALTHCARE PROVIDER ABOUT ALL OF YOUR MEDICAL CONDITIONS, INCLUDING IF YOU:**

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

**Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.**

**HOW SHOULD I USE HEMLIBRA?**

**See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.

- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

**WHAT ARE THE POSSIBLE SIDE EFFECTS OF HEMLIBRA?**

- See “**What is the most important information I should know about HEMLIBRA?**”

**The most common side effects of HEMLIBRA include:**

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

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

**HOW SHOULD I STORE HEMLIBRA?**

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than 7 days at 86°F (30°C) or below.
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

**Keep HEMLIBRA and all medicines out of the reach of children.**

**GENERAL INFORMATION ABOUT THE SAFE AND EFFECTIVE USE OF HEMLIBRA.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

**WHAT ARE THE INGREDIENTS IN HEMLIBRA?**

**Active ingredient:** emicizumab

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,  
1 DNA Way, South San Francisco, CA 94080-4990  
U.S. License No. 1048

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For more information, go to [www.HEMLIBRA.com](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.  
This Medication Guide has been approved by the U.S. Food and Drug Administration  
Issued: 11/2017



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**Genentech**  
A Member of the Roche Group

# Gears for Good Fundraising Bike Ride

SEPTEMBER 21-23, 2018

WEST VIRGINIA TO WASHINGTON, D.C.

**Ride the C&O Canal Trail from Paw Paw, WV to our nation's capital while raising funds for HFA!**

Gears for Good is not a race, it's a ride and so much more. It's camaraderie, friendship, a passion to help others, inspiration, determination, and pure enjoyment. Part cycling, part endurance: an experience you will never forget.

Whether you are an experienced cyclist or a novice rider, Gears for Good celebrates the dedication to health and wellness for those who work hard to achieve beyond their disorder. With each pedal stroke, you help others in the bleeding disorder community experiencing a financial crisis breathe a little easier tomorrow.



## HOW IT WORKS:

-  Meet in Washington, D.C. on September 21 and take chartered transportation to the starting point in West Virginia.
-  Bike and helmet rentals are available. Personal equipment can be used.
-  You'll ride at your own pace to each day's destination. Day 1: 30 miles; Day 2 & 3: 60 miles.
-  Throughout the ride, hotel accommodations, meals, rest stops along the bike route to keep you going, bike maintenance, and medical assistance are provided by HFA.
-  Culminating in Washington, D.C., you'll enjoy a celebratory dinner with riders and supporters.

100% of the contributions raised by all individual donors provide families in need with immediate financial assistance for expenses like housing, utilities, transportation, and medically-necessary goods. Gears for Good has a minimum fundraising requirement of \$1,000 per rider.

**REGISTER TODAY AT [www.gearsforgood.org](http://www.gearsforgood.org)**





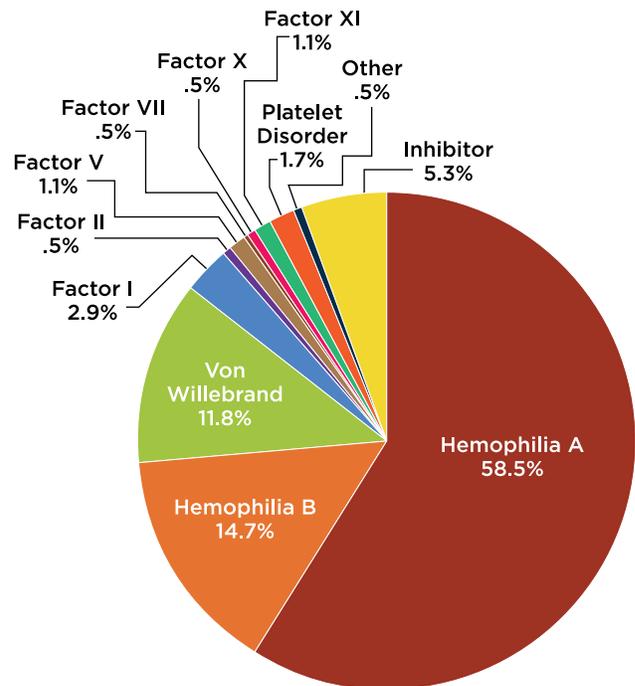
# Project CALLS Report

## Creating Alternatives to Limiting and Lacking Services

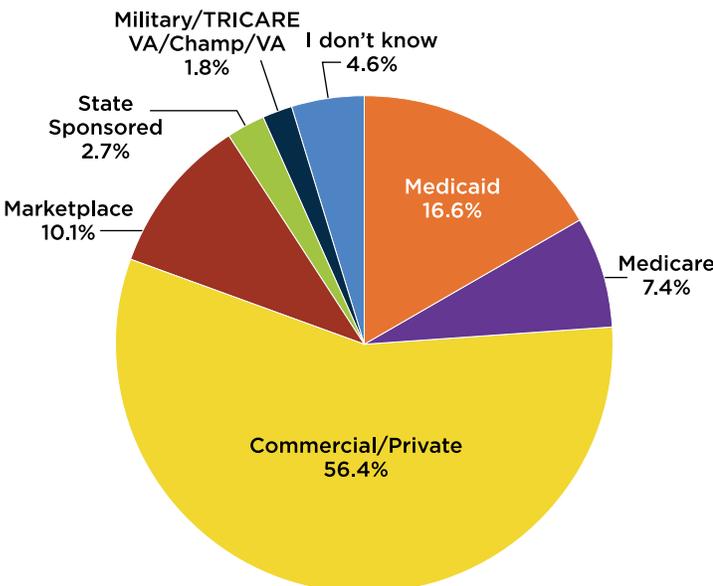
In the summer of 2015, Hemophilia Federation of America (HFA) launched Project CALLS, an initiative designed to collect data and personal stories about how changes in insurance company policies are impacting the care of those with bleeding disorders. After the results of the first iteration of the Project CALLS survey were reported, HFA learned that the community was having more issues with their insurance than first imagined. Questions were added to significantly expand the data sets being collected and HFA launched an updated survey, Project CALLS 2.0. With this, data about network adequacy, deductibles, premiums, balance billing, prior authorization, and specialty pharmacies was gathered.

Since the launch of Project CALLS, more than 150 members of the bleeding disorders community have completed surveys, helping HFA create a more accurate picture of the types of insurance issues encountered by the bleeding disorders community. The following report reflects Project Calls data updated as of winter 2018. ■■

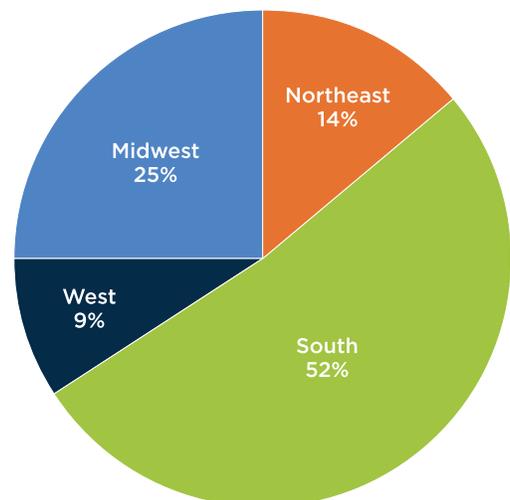
### Diagnosis\*\*



### Types of Insurance\*\*

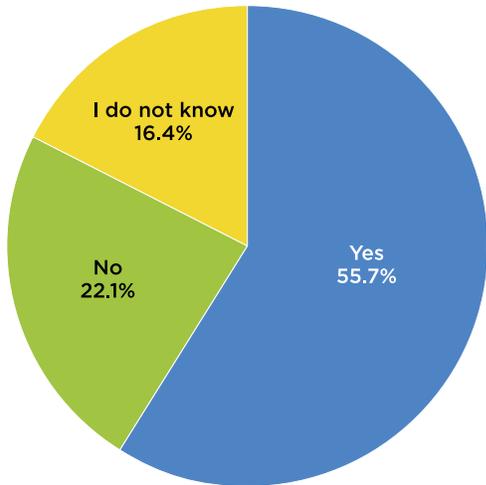


### Region

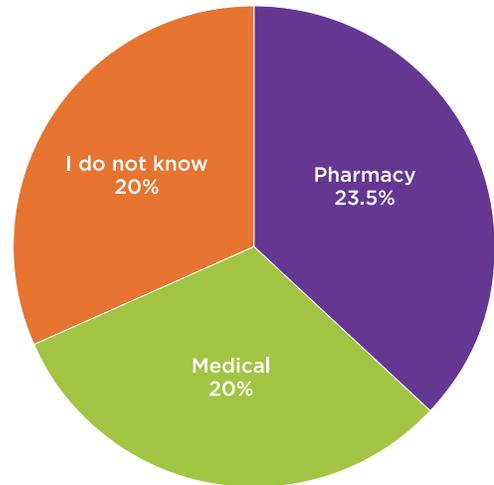


[www.hemophiliafed.org](http://www.hemophiliafed.org) • This report is for the use of HFA and its Member Organizations and should not be distributed without the consent of HFA.

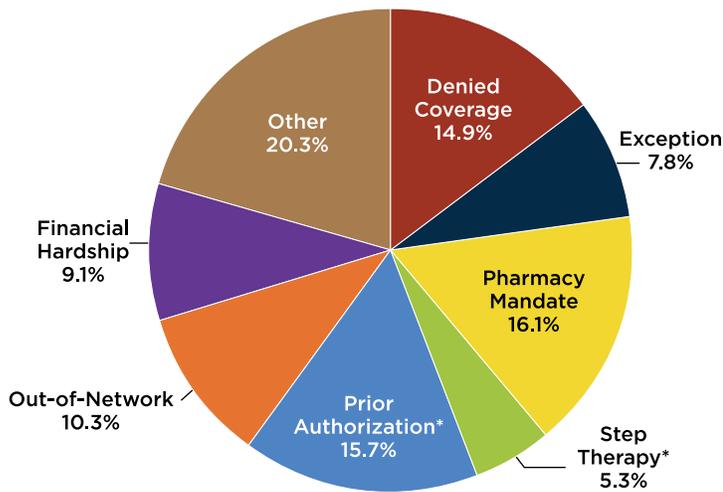
### Specialty Pharmacy Mandate



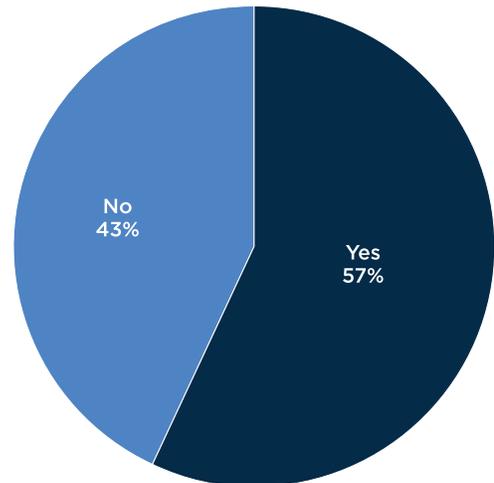
### Pharmacy or Medical Billing for Product?



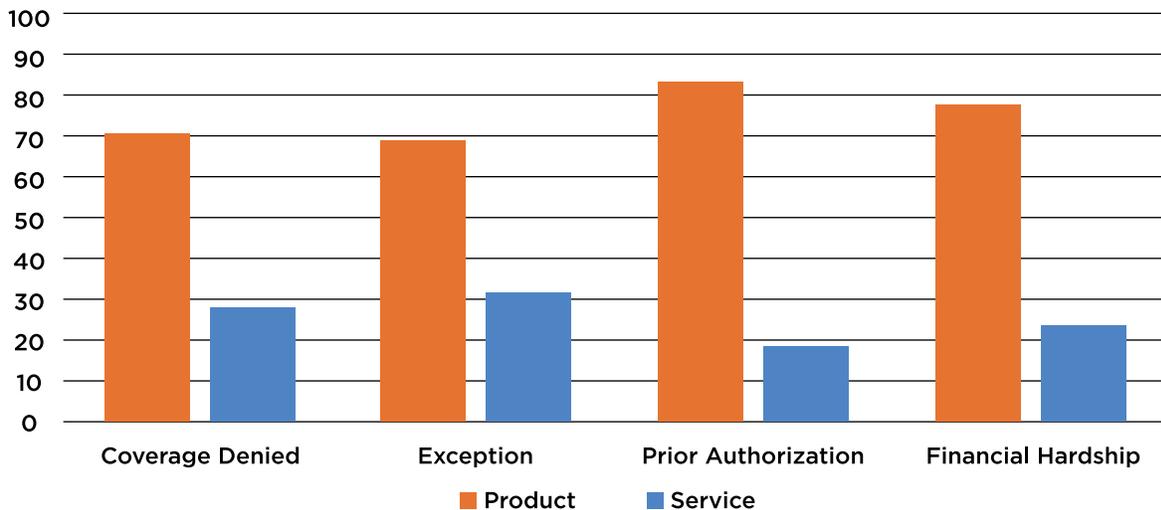
### Issue Reported\*\*



### Delayed Care



### Product or Service





# Round Up Your Change for HFA

DOWNLOAD ROUND UP APP OR COIN UP APP FROM THE APPLE STORE OR GOOGLE PLAY STORE AND START DONATING TO HFA TODAY!

Each time you make a purchase with a designated credit or debit card, your transaction will be rounded up to the nearest dollar, and the difference donated to HFA, your charity of choice.

Example:	Purchase	Amount Rounded Up
Coffee Shop	\$2.89	\$ .11
Grocery Store	\$125.10	\$ .90
Gas Station	\$30.51	\$ .49
<b>Amount donated to HFA:</b>		<b>\$1.50</b>

## CREATING AN ACCOUNT AND DONATING IS EASY:

- 1 Download your application of choice.
- 2 Create an account using your name and email address.
- 3 Select Hemophilia Federation of America as your organization.
- 4 Register a debit or credit card and verify your account.
- 5 Use your debit or credit card to make purchases as you normally would.
- 6 Donate! At the end of each month, the app will round up your purchases and donate to HFA.

Hemophilia Federation of America is a registered 501c3 nonprofit organization.  
Your charitable contributions to the organization are tax-deductible to the full extent of the law.

