



DATELINE

F E D E R A T I O N

Issue 57 | Volume 18 | Summer 2018

Encouraging
Women & Girls to
Pursue Science,
Engineering and
Medicine

INSIDE:

**HFA launches new
learning platform**

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Puerto Rican patients**

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Dear Friends,

As the newly-elected HFA board chairman, I had the opportunity to introduce myself to those in attendance at the Symposium luncheon, but have not had the opportunity to meet so many in the community.

My wife Heather and I have three wonderful children – two daughters, Jayla (10), Kinzie (9) and a son, Milo (3). Our girls both have von Willebrand disease – Jayla type 1 and Kinzie type 3. Milo has low factor levels, but to this point has not exhibited symptoms.

We received Kinzie’s diagnosis just after she turned a year old, due to excessive bleeding from a surgery. As a baby she bled longer from immunizations and was always covered in bruises. We were very fortunate to have someone who finally realized her bleeding was not normal. Within a very short amount of time we had answers. If it were not for Kinzie, Jayla would likely not have been diagnosed.

Our family likes to be active and like many, seems to be constantly on the go. The kids are active in soccer, basketball, softball, piano and flag football. My girls both treat, but in different ways. We live with both the prophylaxis and on-demand lifestyle.

I am starting my seventh year of serving on HFA’s board. When I first started it was very overwhelming, but over the years I have continued to be more active and truly feel HFA is where I belong.

During my time as board chairman, my goals are to continue to advocate for the increased awareness and treatment of women with bleeding disorders and ensure HFA continues to be a leader in advocating for access to care within our community. I hope to continue to look toward the future, while honoring the history of the bleeding disorder community.

HFA is a community-focused organization, and I am honored to be able to serve the whole community as HFA’s board chairman.



Josh Hemann
Board Chair



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

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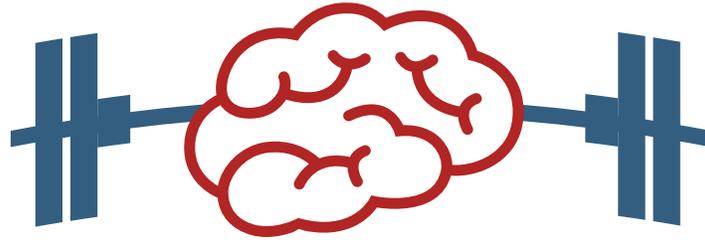
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ON THE COVER. Danielle of Texas, sits in the space shuttle exhibit at the Great Lakes Science Center in Cleveland, which she visited with other teens while at Symposium this April. Growing up in Houston, she loves to visit NASA because of her interest in science. In high school she has an endorsement in STEM Science, which allows her to take college courses to work toward her dream of becoming a marine biologist. “We don’t have a lot of girl scientists and I think the world needs more,” the 14-year-old carrier of hemophilia said. She loves sea animals and looks forward to traveling the world to find new species with her friend, who also wants to be a marine biologist. Photo credit: Gina Richards



Knowledge is Power

HFA creates lifelong learning platform for patients and families

By Emily Roush-Bobolz, staff writer



I wish I had this when my children were born. I do believe my son would be alive today if I had access to this information when my twins were diagnosed in 1998. This gives voice to the questions patients and caregivers may have but may be too afraid to ask or may be getting advice that doesn't feel right.

This is empowering.”

*~Ashley Gregory,
hemophilia mom*



Start Learning!
Visit www.HFALearning.org

Diabetes, heart disease, cancer – they're all, unfortunately, familiar terms, and information about those diseases is readily available on the internet and from doctors. But for rare bleeding disorders, it's a different story.

For the newly-diagnosed and even patients who have handled the disorder for years, understanding and retaining what doctors say can be complicated, and finding information on the internet can be hard.

Parents receiving a child's diagnosis of a bleeding disorder can be overwhelmed and wonder whether they're asking the right questions and learning fast enough to do what's right for their child. Those diagnosed as adults may have limited support from a hemophilia treatment center because some HTC's only have pediatric hematologists. Those who have dealt with bleeding disorders for decades may still be progressing along an increasingly complex learning curve.

Hemophilia Federation of America recognized the need for quality, thoroughly-explained information for all of these scenarios and created a one-of-its-kind, online educational service, called Learning Central.

"I wish I had this when my children were born. I do believe my son would be alive today if I had access to this information when my twins were diagnosed in 1998," said Ashley Gregory of California. "This gives voice to the questions patients and caregivers may have but may be too afraid to ask or may be getting advice that doesn't feel right. This is empowering."

The original concept for the online learning stemmed from an unexpected encounter at the hemophilia treatment center by HFA's President and CEO, Kimberly Haugstad.

While at the HTC, Haugstad met a mom with a young, newly-diagnosed son with hemophilia B. Through conversation, they discovered they lived within blocks of each other in Wisconsin, a state with only about 50 diagnosed patients.

"The statistical likelihood of that happening was tiny," said Haugstad. "I was absolutely shocked to find out that another little boy with severe hemophilia B lives on my street!"

It was the first time the mom had met another hemophilia family, and she was eager to connect and ask a lot of questions. The families made a connection and spent a great amount of time after that initial meeting getting to know each other, and asking and answering questions.

“It is utterly normal with all of the questions we all have when newly diagnosed,” said Haugstad. “The overwhelming reality of life is our new normal.”

It was clear to Haugstad that newly-diagnosed families in the community needed a way to learn more about bleeding disorders. The planning for Learning Central began then and it has grown to include information for established patients and even professionals.

“We’re making the one thing we do best, welcoming new people to the community and creating lifelong learning about bleeding disorders as a culture, even more robust,” said Lori Long, HFA’s Institute Director.

Learn on Your Terms

Learning Central is unlike a simple online data search. The e-learning platform is more like a two-way street, like interacting with an instructor. All of the information in Learning Central is credible and vetted by medical personnel and other professionals.



Participants can register for free at hfalearning.org (or join as a guest) at any time on a computer, tablet or smartphone. It’s meant to address all learners, including



those in rural areas who may not be able to attend a local organization’s education events. The scrollable format allows for easy smartphone use for people who may not have internet or a computer. Registering allows learners to save their spot and go back to where they left off.

Through quizzes and interactive games, participants learn in a way and at a pace that works for them. They can test their knowledge and revisit things they might have missed the first time around until they feel comfortable with the new knowledge about bleeding disorders.

“We wanted to offer a way for those patients to feel engaged and have access to educational programming. We wanted to include them and help them educate themselves to the degree they want to learn,” said Long.

Participants can choose their own path, exploring topics of interest. Learning Central currently includes Bleeding Disorders Basics, where learners can read more about what blood is made of, causes of bleeding disorders, genetics, quality of life and the clotting cascade.

“It helps them understand the science of their situation, so they’ll be less fearful of looking into research or a clinical trial,” she said.

Instead of data-mining all over the internet for what a clotting cascade is, learners can watch a two-minute basic animation or an eight-minute scientific animation – whatever fits their level of learning, interest and time.

Besides Bleeding Disorders Basics, HFA’s Learning Central will soon feature Clinical Trials and Patient-Centered Research. As the online learning platform evolves and grows to fit the learning needs of the community, HFA will add segments on treatments and therapies, inhibitors, advocacy, financial management, mental health and well-being, insurance, fitness and nutrition, and history.

The first phase of Learning Central is geared toward new families and as it progresses, the information will be suited for medical personnel, the bleeding disorders industry and students doing research projects, while still being educational to the general bleeding disorders learner.

Learning Central is part of the HFA Institute, HFA’s e-learning initiative. It is comprised of the Learning Central (for everyone), HFA’s Member Organization online learning (to educate member organization leadership and staff, and HFA board members), and online training for HFA staff. 

STEMMED FROM LIFE EXPERIENCE

Women with bleeding disorders find careers in science because of their disorders

By Emily Roush-Bobolz, staff writer

When someone is diagnosed with a rare disorder, understanding the complexity of the disorder may be hard, but for those with a mind geared toward science, it can lead to a world of fascination.

There has been a push in the last decade or more to encourage the nation's youth, especially young women, to find interest in and essentially pursue a career in science, technology, engineering and math, commonly known as STEM.

Women with a bleeding disorder are in a unique position to understand it on a deeper level, take their passion for STEM — if their mind bends that way — and experience lifelong advancement fueled by that interest.

“I’m really passionate about STEM and think it’s a field where the bleeding disorders community can really be involved,” said Megan Procario of Maryland, a Ph.D. student concentrating on immunology and microbiology.



Ph.D. student Megan Procario works in the laboratory researching viruses which affect kidney transplant patients

“I got the (science) bug early,” said Procario, who was born with moderately severe von Willebrand Disease. She grew up in a home where science was always present — her father was a particle physicist.

Even without scientists in the family, girls, and anyone for that matter, can use what they learn about bleeding disorders to make a living in STEM. Procario was finally diagnosed at the age of 10, after multiple type misdiagnoses.

“My diagnosis fueled my interest in science,” she said. “I find not knowing what’s going on stressful. I found with vWD, the more I learned about how things worked the more comfortable I became with my bleeding disorder. It got me interested on a molecular level. I feel safer and more informed as a patient because I understand the science.”

That personal experience with a bleeding disorder also sparked a career interest in Alex Gamber, 28, of Michigan. She was diagnosed with vWD at the age of 3 when she ran face first into a door and broke a tooth. The profuse bleeding sent her to a doctor, which led to the diagnosis. Gamber didn’t embrace the bleeding disorders community right away, until she attended Camp Bold Eagle her second year of college. She knew she wanted to become a doctor because of her experiences there.

“I was 19 and struggling socially and going to camp was really one of those right moment, right time things,” she said. “I saw people who were at their best helping kids. Camp encourages people to go beyond their limits despite hemophilia and that struck me.”

Gamber is now halfway through medical school at Central Michigan University College of Medicine.

“At camp, people think ‘can I really swim or shoot an arrow with hemophilia?’ If they can feel that empowerment, then I can become a doctor,” she said.



Alex Gamber of Michigan chose a career in medicine after an experience at Camp Bold Eagle.

She also volunteers at a local bleeding disorders organization. She finds her medical school and volunteer work complement each other, and she gives teen and women's programs locally.

HISTORY OF WOMEN IN STEM

STEM was not always encouraged for women.

Dr. Sherrill Slichter, Professor of Medicine in the Division of Hematology at the University of Washington and Director of Platelet Transfusion Research at Bloodworks Northwest in Seattle, has been in science for more than 45 years. But it wasn't without resistance along the way.

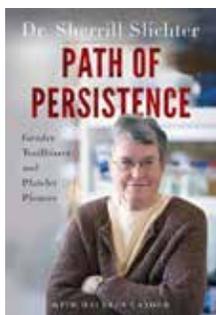
This spring, she honored International Women and Girls in Science Day by giving presentations and doing radio shows to inspire women and girls to pursue science. During her presentations, Slichter explained that when she showed an interest in science in high school, teachers would tell her 'you're just going to fail.'

During a radio interview, she said that on her first day of medical school, she was told women only went to college to find a husband and going into medicine meant she was taking away from a man who needed the career to feed his family. That didn't stop her from forging ahead, and she now has a successful career in scientific fields. She encourages others to do the same.

Initially Slichter wanted to work with patients instead of in research, according to a Bloodworks Northwest blog. That was until she met a patient who died from kidney failure because she couldn't get dialysis, as there was only one dialysis machine at the University of Washington at the time.

The patient had a red blood cell disorder, and because of that death, Slichter approached a professor of hematology at the university who was studying clotting and bleeding disorders to ask if they could study the disorder, hemolytic uremic syndrome. Her research led to improved prognoses for cancer patients and has made bone marrow transplantation possible.

Things have gotten a little easier since Slichter began in the field 45 years ago. The U.S. Department of Education's Office for Civil Rights and the Office of Career, Technical and Adult Education released guidelines for educational organizations, making clear that all students, regardless of their sex, must have equal access to a range of career and technical education programs.



Dr. Sherrill Slichter is a gender trailblazer in the field of scientific research. (Photo credit: Zoist Designs)

Although disproportionate gender enrollment in education does not constitute a violation of federal law, the guidelines push educational organizations to conduct their admission, recruitment and counseling practices in a nondiscriminatory manner.

"A career in science is exciting. It's also demanding! Sometimes your experiments require long hours. It's all part of a balancing act that women in science face. But the rewards are worth the sacrifice if you love scientific research and discovery," said Dr. Jacquelyn Sampson, a retired microbiologist with the Centers for Disease Control and Prevention, on a CDC blog.

Sampson also caught the 'science bug' because of a life experience. Her sister became ill with diphtheria when she was young, and it sparked an interest in microbiology. The CDC has a website which encourages women and girls to make a living in STEM (see resources list) by sharing the experiences of its scientists and researchers.

Procario thinks it's still challenging for women in science. She sees the number of women in microbiology and immunology and the number of female faculty seems to be decreasing.

"I still think there is bias from what I've experienced and witnessed. But I think it's unconscious," said Procario.

In high school Procario did a Werner H. Kirsten Student Internship which allowed her to do basic scientific research at the National Cancer Institute. She later worked as a research technician in infectious disease. She is currently working on the BK poliovirus, a virus which affects the kidney and can be life-threatening to post-transplant patients on immunosuppressants. Her goal is to stop the virus before transplantation.

Gamber encourages women and girls to go into STEM and enjoys serving as a mentor.

"If there's a thing you want to do (like STEM) and it keeps presenting itself to you and it's intimidating to you, it's probably at the back of your mind for a reason," said Gamber. "If it keeps showing up and it seems scary, there's a reason."

Gamber was scared too, but she fought through the fear and has never regretted it. Go for it! 💧

RESOURCES FOR WOMEN AND GIRLS IN STEM:

Centers for Disease Control and Prevention:
www.cdc.gov/women/stem/index.htm

The Committee on Women in Science, Engineering and Medicine: <http://sites.nationalacademies.org/PGA/cwsem/index.htm>

HAPPENING HIGHLIGHTS

LEST WE FORGET

HFA seeks community help in honoring our past

Five years ago HFA started the “Honoring Our Past, Building Our Future” history project to pay tribute to the community’s legacy of advocacy, sacrifice and treatment advances. HFA will continue this project to recognize its 25th anniversary celebration.

HFA collected many documents and articles, but is aware there may be more memorabilia stashed in attics all across the country! HFA is looking for community members and organizations willing to share and work with HFA to preserve a comprehensive record of the community’s history.

Do you have old family photos depicting the reality of life with a bleeding disorder? Or maybe diaries or personal journals that reflect your or a loved one’s personal journey? We’re looking for personal items as well as newspaper articles, key documents, newsletters, posters from advocacy rallies on Capitol Hill or other artifacts that tell our story of endurance and resilience.

Submit a photo of something you have that may be added to the collection. A committee will review all submissions and work with you to collect and return items. Share your historical archives so HFA can continue to shed light on this amazing community.

As part of its 25th anniversary celebration in 2019, HFA will have an enhanced and updated exhibit at the 2019 Symposium in San Diego, Calif., to display the historical items.

Please send to: history@hemophiliafed.org 📧



HAPPENING HIGHLIGHTS



HFA has partnered with American Medical ID to offer a great deal to members of HFA. For each purchase of an American Medical ID bracelet, AMID will offer a 10 percent discount as well as donate 10 percent of the purchase to HFA's Helping Hands program. To become a member of HFA, visit www.hemophiliafed.org.

To make a purchase, visit

<http://www.americanmedical-id.com/hfa>.

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HAPPENING HIGHLIGHTS LETTING THEM FLY



From the time children are born, parents focus on the health and well-being of their children. Having a bleeding disorder is an added stress, which can lead to over-protectiveness. This can cause teens and young adults to be resentful, dependent, and unable to thrive as capable adults.

HFA's inaugural Reach Your PEAK event, held in Colorado in July, sought to break the cycle. The two-day workshop brought together teens and parents for an intensive experience on transitioning into adulthood. Speakers from the bleeding disorders community, medical professionals, and secondary and higher education helped attendees envision their futures and challenged them to set goals for adulthood.

One mom summed it up, "I've got to learn to let go, while giving him the opportunities and resources to grow up. This helped me realize it's not just about sending him off to college, but it's about giving him the tools to be a productive adult." 💧



Photos credit: Michael DeGrandpre



REGISTER FOR HFA's YOUNG ADULT ADVOCACY SUMMIT

Training the Next Generation of Leaders with Bleeding Disorders

October 20-23, 2018
Washington, D.C.

Limited Space Available





AN EXPERIMENT IN FRIENDSHIP

Author brings reality of von Willebrand Disease to life through fictional character middle school girls can relate to

By Emily Roush-Bobolz, staff writer

As a young, third-grade girl, Erin Teagan wanted nothing more than to grow up to be a writer. As an adult, she realistically chose to pursue a career in science.

“I always wanted to be a writer from the time I was in third grade,” said the Washington, D.C.-based author. “But I knew I needed to support myself, so I went into science.”

Years after that young girl dreamed of being a writer, she combined her love of writing and her knowledge of science to write “The Friendship Experiment.” The middle grade novel is about preteen Madeline Little, who has von Willebrand Disease and is dreading the start of middle school.

“It’s about her experience with the difficulties of entering middle school while having this condition to deal with on top of it all,” Teagan said.

As if middle school isn’t hard enough, Madeline has to come to terms with her life with vWD. She would rather help her father in his research lab or write in her lab notebook than hang out with others. Despite her reluctance, some new friends come along, until they discover what she’s written in her secret notebook.

“I thought it was very well-written and eloquent,” said Elsa Kendall, an 11-year-old from Virginia with mild hemophilia A. “You always want to have friends in school and starting a new chapter of school is kind of intimidating at first.”

Kendall, who is heading into seventh grade and whose favorite subjects are science and foreign languages, discovered the “The Friendship Experiment” at this year’s Symposium where the author was signing books. She read all 240 pages while at Symposium.



Photo credit: Emily Roush-Bobolz

Teagan has a Bachelor of Science in Integrated Science and a master’s degree in biotechnology, and worked for the National Institute of Health Sciences as a scientist in the lab. She worked beside another scientist who was also a doctor with hands-on patient experience with children. Together, Teagan and her colleague worked to discover a more efficient way to diagnose vWD.

That scientific research and her brother’s experience inspired the book. For an entire summer as a child, her brother suffered from a virus called idiopathic thrombocytopenic purpura. The immune response to the ITP virus caused the normal blood clotting process to fail, leading to excessive bruising and bleeding.

Kendall related to the book because of her interest in science. Her science teacher encouraged her to teach fellow students a portion of this year’s genetics unit because of her first-hand experience with bleeding disorders.

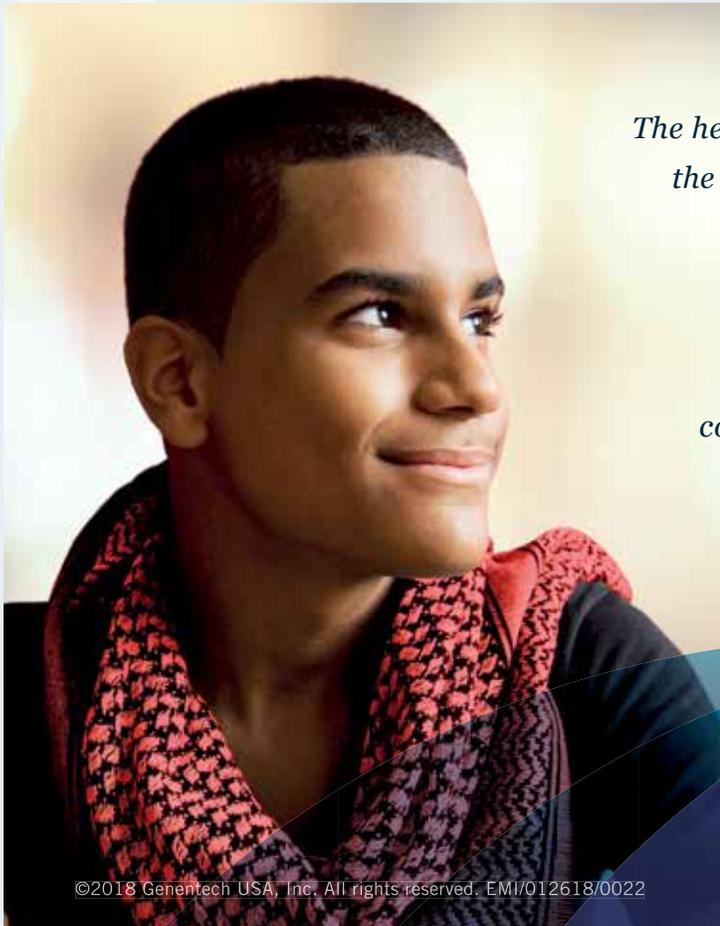
“One of the new students, who is a friend, has been asking a lot of questions,” she said. “I’m very glad she’s interested.”

Her fellow students have been very supportive of her over the years, including participating in activities supporting bleeding disorders. It is Teagan's hope more readers with bleeding disorders like Kendall will find interest in her book.

Earlier this year Teagan released two books for the American Girl® doll of the year, Luciana. Luciana, an aspiring astronaut,

is considered a champion of science, technology, engineering and math for young girls. American Girl reached out to Teagan because of her experience in scientific writing for young girls. She'll release a third book this summer. 📖

Photo credit: Gina Richards



*The hemophilia treatments of today were once
the dreams of yesterday. Proof that when*

SCIENCE AND THE COMMUNITY

come together, great things happen.

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PROJECT CALLS

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www.ProjectCALLS.org



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HFA Will Share Project CALLS Reports With Policymakers.



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With Your Help, Together We Can Build A Case For Improved Access To Care For The Bleeding Disorders Community!



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A LESSON IN UNDERSTANDING

Working relationship with teachers and other school staff leads to better educational experience

By Carrie Koenig, staff writer

As I walk through the aisles of our local office supply store, I can't help but get a tinge of sadness. The smell of fresh paper, pens, pencils and crayons is enough for this former teacher to break down right there in the middle of Office Depot.

I miss some parts of teaching I could never get from any other career — building relationships with and talking to kids who aren't my own, every day. I miss those first day jitters, wondering “Who is going to be in my class, will they have all of their supplies, will they love learning, will they enjoy my class? Will my students know to speak up when there is a problem?”

The jitters that go through your mind as a teacher are very similar to the jitters experienced by parents and even students.

As a parent, I now sit on the other side of the fence. Even though my child has completed a few years of school already, I still feel nervous about sending him to a new classroom with a new teacher who doesn't know anything about bleeding disorders.

Here are a few tips to make the beginning of school go smoothly:

Photo credit: Gina Richards



- 👉 Schedule a meeting before the school year gets underway — meet with the nurse and all teachers (including PE and art) who will come in contact with your child.
- 👉 The My Bleeding Disorders and the What You Should Know resources on the HFA website are great one-pagers for each teacher to keep.
- 👉 Use this time to teach them a few things about your child's bleeding disorder. Use our Back to School Toolkit on our website to help.
- 👉 Remind your child to speak up and tell an adult when an injury happens. Accidents will happen. Teachers try to see and hear everything, and they will miss things. And yes, that is ok!

- 👉 Your child's teacher wants to know about doctor appointments, lab work, and any changes in your child's health. They do not need to know every detail but, if your child has any anxiety when it comes to appointments, teachers can sometimes help ease those fears.
- 👉 When a teacher tells a child they know about an appointment or event in their lives, it provides an opportunity for bonding. Children feel safer when they have a strong relationship with their teacher.
- 👉 Studies have shown that children are more successful when parents are more involved in their education. Teachers can always use some help.
- 👉 Volunteer when and if you can. Try to help from afar, volunteer for field trips, work on things from home, or come to events at school. Show your child you trust and value their school. It makes a world of difference.

As I continue to remind myself of these points, I still have those first day jitters. I know the more I prepare my child and school for his or her bleeding disorder, the better the year will be! 🩸

“Teachers spend most of their day making sure your child is safe. It's their top priority! They want to know about your child's bleeding disorder and what they can do to help.”



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.**

Alex
Hemophilia A
Massachusetts

Shire

bleedingdisorders.com

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LOUD & CLEAR

Patient advocates hit **The Hill** to share their story

By **Sonji Wilkes**, staff writer

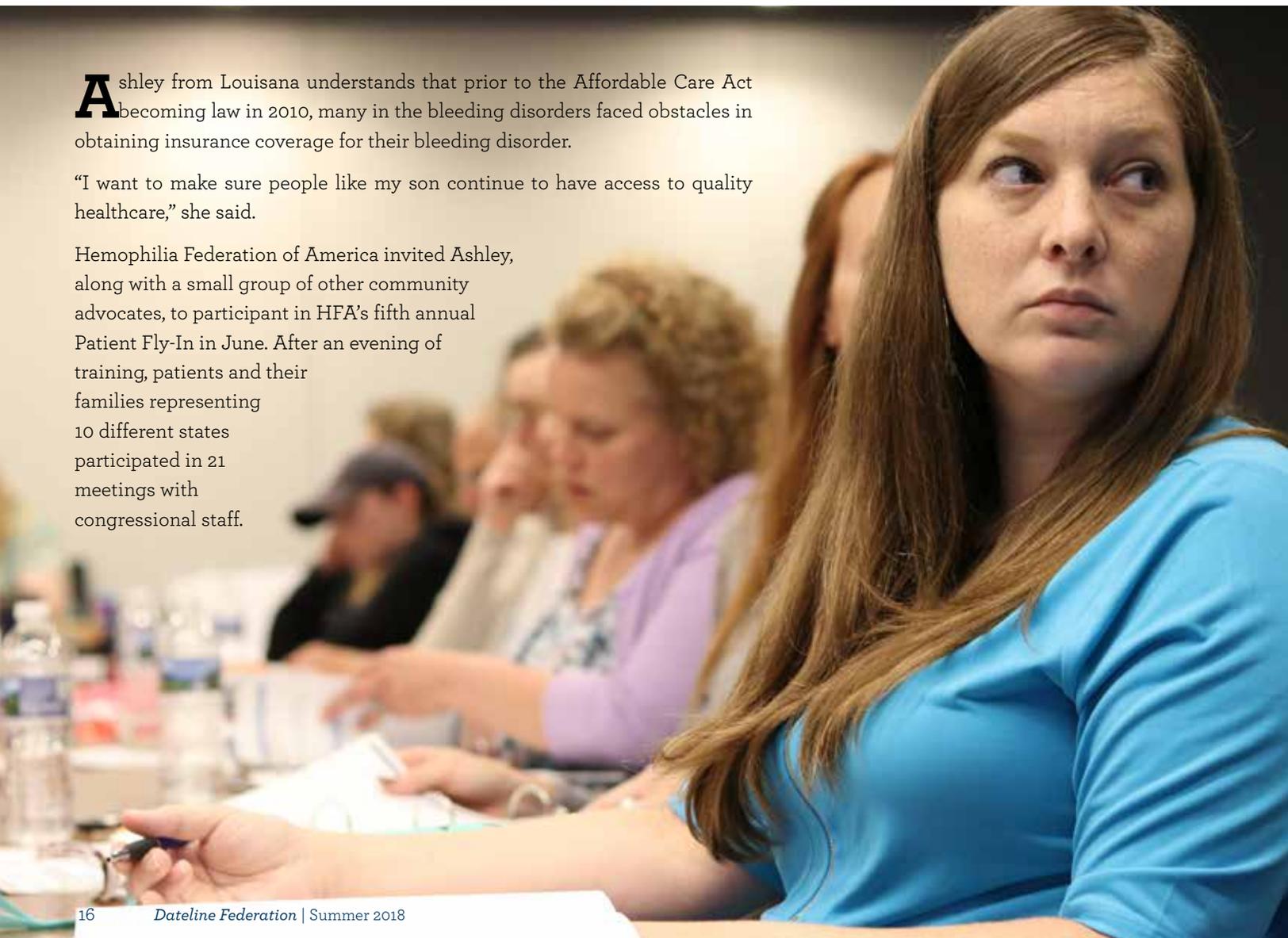
Advocacy is not only confined to the borders of the District of Columbia.

Share your story with your legislators through HFA's NEW Legislative Action Center at www.hemophiliafed.org/advocacy/ at any time. With your help, the voices of the bleeding disorders community voice can be heard year-round!

Ashley from Louisiana understands that prior to the Affordable Care Act becoming law in 2010, many in the bleeding disorders faced obstacles in obtaining insurance coverage for their bleeding disorder.

"I want to make sure people like my son continue to have access to quality healthcare," she said.

Hemophilia Federation of America invited Ashley, along with a small group of other community advocates, to participate in HFA's fifth annual Patient Fly-In in June. After an evening of training, patients and their families representing 10 different states participated in 21 meetings with congressional staff.





Understanding that bleeding disorders occur across the lifespan, the participants ranged from teens to mature adults. Craig, a longtime volunteer at the New England Hemophilia Association's Family Camp, shared why he felt it important to talk to lawmakers.

"I was able to share that I've seen a lot of things that have gone on over the years with treatment. If we lose some of the benefits the ACA mandates, then we could be back to square one," he said.

"It was important for us to participate to try to ensure that my children, along with all who are dealing with a bleeding disorder, have access to coverage," said Diana, who brought her two teenagers, James and Gracie, to Capitol Hill. The teens were effective advocates, unafraid to speak up about how bleeding disorders had impacted their lives.

Thirteen-year-old James adds, "It was important for me to talk with my legislators because the decisions they are making are going to directly affect me and my friends. They needed to hear my story and hopefully see my point of view."

While healthcare may not seem as hot a topic in the halls of Congress as it was in 2017, the policy experts on HFA's team are keenly aware the issues our community cares most about are always at risk.

"Our intent with the Patient Fly-In is to keep an open and continued dialogue with lawmakers so our community is always at the forefront of the minds of decision-makers in Washington, D.C.," says Kim Isenberg, Vice President of Policy and Advocacy for HFA. "We asked our community advocates to share what meaningful, affordable health care means to them as they made their visits. Their voices were clear, strong and heard,"

Miriam Goldstein, Associate Director of Policy for HFA explains, "Right before the Patient Fly-In we learned the Department of Justice had asked a federal court to overturn the ACA's protections for people with pre-existing conditions. Our grassroots advocates came to D.C. at the right time to remind congressional staff and members why affordable, quality coverage — including coverage for pre-existing conditions — is so vitally important for people with chronic and rare disorders like bleeding disorders."

Diana found the Patient Fly-In rewarding. "I was unsure if they listened, but now I am confident they heard us. I have received personal emails from three of the legislative aides we met with during our visit. Now we have to keep the relationship going, so when it is time for them to move forward with legislation they remember us. We are a strong, resilient community that has a huge stakes in these decisions. It is important for our elected officials to hear our stories. If you are unable to come to Washington D.C., please go to the hometown meetings or call, write or tweet your lawmakers." ♦





Day on the Hill in Tennessee

Deema Tarazi, staff writer

In March, HFA attended the Tennessee Hemophilia and Bleeding Disorders Foundation “Day on the Hill.” Twenty-six community members attended the event, which included advocacy training and multiple meetings with legislators and their staff to discuss the importance of access to care for the bleeding disorders community.

The day started with an early morning training on how to talk with legislators and an overview of the talking points. In addition to educating legislators about bleeding disorders, community members advocated about the impact of adding work requirements to TennCare, the Tennessee Medicaid program, for people with bleeding disorders and maintaining the State Hemophilia Program budget, an important safety-net program for many families in Tennessee.

Community members shared their personal stories about living with a bleeding disorder and the importance of having access



to quality healthcare. Participants also discussed the history of hemophilia, how therapies have changed in the last 10 years, and how vital treatment is in protecting an individual with hemophilia from life- or joint-threatening bleeding.

Access to appropriate therapies allows the community to lead healthy, productive lives. Additionally, a community member who has a personal relationship with his senator spoke one-on-one with the senator about the challenges the community would face with added working requirements to Medicaid. Legislators were engaged with participants during the meetings and responded positively to the group’s messages.

HFA was thrilled to be a part of THBDF’s “Day on the Hill.” It was a great day for the Tennessee bleeding disorders community’s voice to be heard in Nashville. HFA encourages advocates to continue building relationships with their legislators to ensure the community has a constant presence at the Capitol. Thanks to THBDF for allowing HFA to join you — we look forward to attending future events! 



Access to appropriate therapies allows the community to lead healthy, productive lives.

WELCOME

HFA introduces you to the 2018 Summer Advocacy Interns. They spent the summer in Washington, D.C., engaged in hands-on activities related to policy and advocacy.

Alexandra and Catherine will receive legislative, policy and advocacy training, attend hearings and Capitol Hill office visits, visit executive branch agencies, and build communications and media skills, among other activities.

Alexandra of New York



- Second-year graduate student at Columbia University School of Social Work
- Obtaining Master of Science degree in social work with focus on policy and international welfare

Q: What excites you about being with HFA?

A: I am looking forward to gaining a deeper knowledge of the hard work that is involved in policy-making and advocacy efforts.

“Being an advocate in the bleeding disorders community is a way to demand better policies and outcomes for those who are members of the community.”

Catherine of Ohio



- Holds Bachelor of Arts in Anthropology from Ohio State University
- Hopes to continue with postgraduate studies with emphasis on health and medicine

Q: What excites you about being with HFA?

A: I’m really looking forward to being part of an organization where it’s normal to have a bleeding disorder! Joking aside, I am excited to be part of a team that is so passionate about advocating for people with bleeding disorders.

“Being an advocate for people with bleeding disorders means using my voice to raise awareness in the public and working with decision-makers to uplift and protect our community.”



HFA’s summer internships are made possible by Shire and an advocacy grant from CSL Behring. 

Insurance strategy harms patients, leaving insurers collecting more

HFA CREATES INFOGRAPHIC TO EXPLAIN HOW AN AAP COULD IMPACT OUT-OF-POCKET SPENDING

By Miriam Goldstein, staff writer

Many in the bleeding disorders community rely on manufacturer-provided co-pay assistance programs in order to afford life- and health-preserving medications. Over the past year, unfortunately, a number of health insurers have adopted a new strategy that limits how much these assistance programs can help patients.

This strategy, named “accumulator adjustment,” has so far appeared most often in high-deductible health plans offered by large self-insured employers. Under an Accumulator Adjuster Program, the health plan **doesn’t count manufacturer-provided co-pay assistance toward the patient’s overall deductible or out-of-pocket maximum.**

The health plan ends up collecting more money from both the manufacturer and the patient for a prescribed medication — and leaves patients on the hook for much higher out-of-pocket costs for medications and care. Confusing? You bet.

HFA created an infographic to explain how an AAP could impact out-of-pocket spending. As a policy matter, many analysts warn that AAPs will harm patients — especially patients

with chronic health conditions who rely on essential specialty drugs.

Research shows when patients face higher cost sharing for their medications, they stop adhering to their prescribed plan of treatment. This nonadherence can lead to worse health outcomes and higher health spending. Regrettably, some health insurers and some employers are choosing to disregard these warnings.

AAPs leave people who live with expensive chronic conditions, like bleeding disorders, in a tough financial bind. If you find yourself in this situation, please check out the options listed in HFA’s Resource Library: Navigating Patient Assistance Programs.

Please, too, get in touch with us. **If you have received a letter from your employer or benefit manager stating your co-pay cards will no longer be applied to your deductible, HFA needs to hear from you.** Please fill out a Project CALLS survey with your story. Collecting data about these issues is the only way to fight their implementation! 💧

RESEARCH SHOWS WHEN PATIENTS FACE HIGHER COST SHARING FOR THEIR MEDICATIONS, THEY STOP ADHERING TO THEIR PRESCRIBED PLAN OF TREATMENT.

ACCUMULATOR ADJUSTERS



Jack has a high deductible health plan (HDHP) with a deductible of **\$4,000** and a limit on his maximum out-of-pocket spending of **\$6,000**.

- Jack has to pay the **full cost** of all doctors' appointments and prescription drugs (including clotting factor) until he meets his \$4,000 deductible.
- After he meets his deductible, Jack pays **30% coinsurance** on his prescription drugs (including clotting factor) until his out-of-pocket (OOP) spending reaches the \$6,000 maximum.

Jack has a copay card from the manufacturer who makes his clotting factor. The card has a value of up to \$15,000.

Without Accumulator Adjuster (copay card counts toward patient deductible and OOP):



- \$30,000:** Cost of January clotting factor order
- \$4,000:** Manufacturer copay card is used to satisfy Jack's deductible
- \$26,000** Remaining cost of January clotting factor order
- x30%** Potential coinsurance amount owed on January clotting factor order
- \$7,800** Potential coinsurance amount owed on January clotting factor order
- \$2,000** Manufacturer copay card is applied toward coinsurance amount

Jack has met his annual OOP maximum (\$6,000). Using his copay card, he has satisfied his \$4,000 deductible plus the additional \$2,000. He does not owe any more in copayment or coinsurance for January or for the rest of the plan year.

With Accumulator Adjuster (copay card does NOT count toward patient deductible or OOP):

- \$30,000:** Cost of January clotting factor order
- \$15,000:** Health plan draws down full value of manufacturer copay card
- \$0** of that manufacturer copay assistance counts toward Jack's deductible
- \$4,000** Jack must pay full deductible in order to get his factor order AND what's more...
- \$11,000:** Remaining cost of January clotting factor order
- x30%** → \$3,300: Potential coinsurance amount owed on January clotting factor order
- \$3,300:** Potential coinsurance amount owed on January clotting factor. Jack has already paid \$4,000 toward his \$6,000 maximum OOP, so he *only* has to pay \$2,000 toward the \$3,300 coinsurance amount.

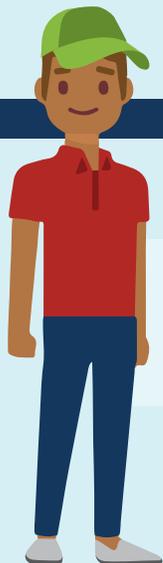


Jack has to pay \$6,000 in personal funds in order to get his first shipment of clotting factor in January.

Let's say Ted is not an adult with his own insurance, but a child (with lower factor dosing and lower Rx costs).

- Ted's monthly factor shipment costs \$10,000
- Ted's family's plan also has a \$4,000 deductible
- Ted's family's plan also has a \$6,000 individual OOP maximum/\$12,000 family OOP maximum
- Ted's family also has a \$15,000 manufacturer copay card

With Accumulator Adjuster (copay card does NOT count toward patient deductible or OOP):



- \$10,000:** Cost of January clotting factor order
- \$10,000:** Manufacturer copay card is applied to cover full amount, but \$0 counts to deductible

- \$10,000:** Cost of February clotting factor order
- \$5,000** Health plan draws down the \$5,000 remaining on the copay card

- \$5,000** Remaining cost of February clotting factor order
- \$4,000** Ted's family owes full deductible (assuming no earlier health expenses)

- \$1,000**
- x30%** → Ted's family owes an additional \$300 (30% coinsurance on remaining \$1000)

Ted's family needs to pay \$4,300 in personal funds to get Ted's February shipment of factor.



- \$10,000:** Cost of January clotting factor order
- x30%** → Ted's family owes potentially \$3,000 (30% coinsurance)

Family has paid \$4,300 toward Ted's OOP maximum,* therefore **Ted's family needs to pay \$1,700 in personal funds to get Ted's March shipment of factor.**

Note *: Once spending on Ted's care reaches the individual OOP maximum, the health plan must bear all costs for Ted, even if spending on other family members' health care has not yet reached the combined family OOP maximum.



BEARING THE BURDENS

Data reveals menstrual, pregnancy and hysterectomy issues in women with hemophilia A or B

By Wendy Owens, Consultant to HFA

Every two years hematologists, researchers, patients and caregivers from all over the world come together at the World Federation of Hemophilia meeting.

As in past years, Hemophilia Federation of America staff attended the meeting, this year in Glasgow, Scotland, to share ideas, gain new knowledge, see old friends and colleagues, and make new ones. For the second WFH meeting in a row, HFA had a poster presentation.

The poster “Understanding Gender-Specific Disease Burden of US Females with hemophilia A or B: insights from the results of the CHOICE Project into gynecological, obstetric and quality of life issues” was packed full of data about the issues unique to women with hemophilia. Authored by Wendy Owens, Anissa Cyhaniuk, Elaine Chan, Janet Chupka and Kimberly Haugstad, the poster was presented by Owens at the WFH meeting on May 21.

The poster contained data from the Community Having Opportunity to Influence Care Equity Project. The CHOICE Project was a national survey run by HFA in partnership with U.S. Centers for Disease Control and Prevention.

As part of the CHOICE Project, HFA surveyed people with bleeding disorders in the U.S., and a subset of the people surveyed were women with bleeding disorders. CHOICE asked women questions about the gynecological and obstetric issues associated with their bleeding disorder. A first-of-its-kind data set revealed new insights into gender-specific disease burdens of U.S. women with bleeding disorders.

HFA’s poster focused on women with hemophilia A or B. It revealed 90 percent of women with hemophilia A or B reported heavy periods. Because of heavy periods, 31 percent of these

women lost days of work and school as well as days of recreational activity, directly impacting their quality of life.

In addition, hysterectomy rates among women with hemophilia A or B is 32 percent. The average age of those having this surgery is 38.6 years old. Women with hemophilia A or B between the ages of 35 and 55 and those over 56 reported the highest rate of hysterectomies at 35 percent and 43 percent, respectively.

The data shows some women with hemophilia A or B struggle to become pregnant (36 percent) and when pregnant, they experience miscarriages in both the first and second trimester at rates above the national average.

Once pregnant, 28 percent of women with hemophilia A or B reported pre-term or premature births (birth before the 37th week of pregnancy). Though two-thirds of pregnancies for women with hemophilia A or B are normal, 37 percent of these women had problems with bleeding during pregnancy and 71 percent had bleeding during birth or post-partum that resulted in monitoring or treatment by a healthcare provider.

HFA concluded that further investigation is needed to determine how to improve life for women with hemophilia to solve obstetric issues, including achieving full-term pregnancies and avoiding complications in pregnancy, delivery and post-partum complications due to bleeding, as well as lowering the rate of hysterectomies.

HFA continues to get the results of the CHOICE survey published, and it is available to the bleeding disorders community and healthcare providers. HFA encourages community members to help identify and address issues faced by the bleeding disorders community by participating in the CHOICE 2.0 survey, which is now available on the Research section of the HFA website. 



Understanding Gender-Specific Disease Burden of US Females with hemophilia A or B: insights from the results of the CHOICE Project into gynecological, obstetric, and quality of life issues

Authors: Wendy E. Owens¹, Anissa Cyhaniuk¹, Elaine Chan¹, Janet Chupka¹, Kimberly Haugstad¹

Affiliations: ¹Hemophilia Federation of America, Washington, DC, USA

Introduction

- The CHOICE Project was conducted in partnership between the US Centers for Disease Control and Prevention (CDC) and Hemophilia Federation of America, a non-profit, community-based organization, to survey persons with bleeding disorders (PWBD) in the US.
- Participants in the CHOICE Project included both FWH receiving care at federally-funded hemophilia treatment centers (HTC) and those who do not receive care at HTCs (non-HTC PWBD).
- CHOICE data provides additional insights into non-HTC PWBD as data on this group are not collected on a regular basis nor maintained in a central database.
- Survey elements included diagnosis, treatment regimen and treatment products used, inhibitor status, joint function and disease (invasive orthopedic procedures, use of pain medication), bleeding history, HIV and hepatitis infection and other comorbidities, health services utilization (usual source of care, frequency of care, barriers to regular care, delay of care, emergency room utilization and hospitalizations within the past 12 months), demographics, and patient satisfaction (RAND PSQ-18).

Objective

- This analysis describes gender-specific disease burdens of females with hemophilia A or B (FWH) by age (<18, 18-34, 35-55, and 56+) using data from the CHOICE Project.

Materials and Methods

- Demographic and clinical information was collected through CHOICE by survey in the US from 04/2013-07/2015 among PWBD, including adults (>18 years) and caregivers of children (<18).
- Participants were recruited to take a 20-minute survey in English or Spanish, online or on paper.
- Non-HTC PWBD were solicited specifically but others were not excluded from participation.
- Participants' status as non-HTC PWBD was determined using an algorithm based on responses to specific survey questions.
- HFA opened the CHOICE survey to women with doctor diagnosed hemophilia and undiagnosed women with symptoms and a family history of bleeding disorders.
- This study analyzes a portion of the CHOICE data set for the gynecological, obstetric, and quality of life issues for FWH.
- X-STAT version 18.07 year 2017 and Microsoft Excel[®] was used to compute frequencies for all elements, as well as the Pearson chi-square or Kruskal Wallis test to check for the association between certain outcome variables.

Results

DEMOGRAPHICS

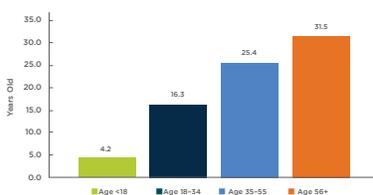
- Of the 719 eligible CHOICE surveys, 576 participants were identified as having a single diagnosis of hemophilia A or hemophilia B.
- Of 576 participants, FWH accounted for 20% (n=113); 61% (n=57) of FWH with hemophilia A reported mild severity and 58% (n=10) of FWH with hemophilia B reported mild severity. FWH ethnicity was 13% Hispanic and race: 59% White, 4% Black/African American, 0% Asian, 4% other (Table 1); 71% reported having commercial health insurance; 48% were employed full-time, 5% permanently disabled.

Table 1. Demographics of FWH (n=113)

| FWH by Diagnosis | AGES | | | | |
|---------------------------|---------|--------|---------|---------|---------|
| | ALL FWH | <18 | 18-34 | 35-55 | 56+ |
| Hemophilia A | # (%) | # (%) | # (%) | # (%) | # (%) |
| Mild | 57 (61) | 3 (50) | 12 (50) | 30 (59) | 12 (92) |
| Moderate | 8 (9) | - | 2 (8) | 5 (10) | 1 (8) |
| Severe | 23 (24) | 3 (50) | 7 (29) | 13 (25) | - |
| Do not know severity | 6 (6) | - | 3 (13) | 3 (6) | - |
| Hemophilia B | | | | | |
| Mild | 10 (56) | - | 1 (25) | 7 (64) | 2 (67) |
| Moderate | 5 (28) | - | 2 (50) | 3 (27) | - |
| Severe | 2 (11) | - | 1 (9) | 1 (33) | - |
| Do not know severity | 1 (6) | - | 1 (25) | - | - |
| Race | | | | | |
| White | 67 (59) | 3 (43) | 14 (50) | 36 (58) | 14 (88) |
| Asian | - | - | - | - | - |
| Black or African American | 4 (4) | 1 (14) | 1 (4) | 2 (3) | - |
| Other | 4 (4) | - | 1 (4) | 3 (5) | - |
| Prefer not to answer | 38 (34) | 3 (43) | 12 (43) | 21 (34) | 2 (12) |
| Ethnicity | | | | | |
| Hispanic | 15 (13) | - | 3 (18) | 10 (23) | 2 (15) |
| Non-Hispanic | 60 (53) | 4 (80) | 13 (76) | 32 (74) | 11 (85) |
| Prefer not to answer | 3 (3) | 1 (20) | 1 (2) | 1 (2) | - |

- For all ages, 87% of FWH were diagnosed with hemophilia A or B more than 24 hours after birth.
- The average age of first diagnosis varied by age groups with the average of 4.2 years for children under 18, 16.3 years for adults 18-34, 25.4 years for adults 35-55, and 31.5 years for adults 56+ (Figure 1).
- A majority of FWH (86%) reported a family history of hemophilia.

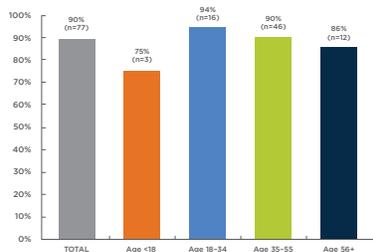
Figure 1. Average Age of First Diagnosis with Hemophilia A or B for FWH



GYNECOLOGICAL INFORMATION

- 90% (n=77) of FWH report ever having a "heavy" period. For FWH reporting a heavy period, they reported heavy periods starting at an average age of 14.2 (Figure 2).

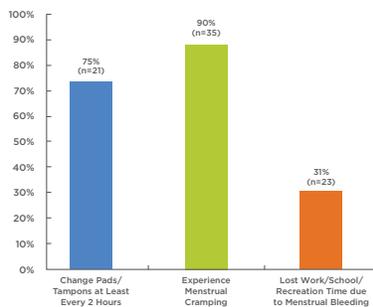
Figure 2. Menstruating FWH reporting ever having a "heavy" period.



- The average age of menarche for FWH was 12.4 years.

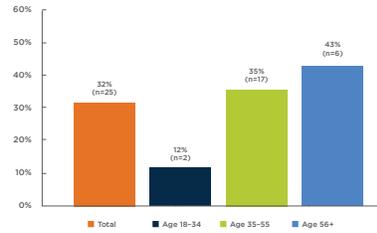
- For menstruating FWH, 75% (n=21) currently change menstrual hygiene products at least every 2 hours and 90% (n=35) experience menstrual cramping (Figure 3).
- 31% (n=23) of menstruating FWH have lost work/school/recreation days due to menstrual bleeding in the past 12 months (Figure 3).

Figure 3. FWH reporting issues to menstrual bleeding.



- Hysterectomy rates among FWH is 32% (n=25) with surgery taking place at an average age of 38.6, with FWH between the ages of 35-55 (55%, n=17) and 56+ (43%, n=6) reporting the highest rate of hysterectomies (Figure 4).

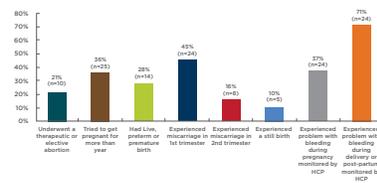
Figure 4. Hysterectomy rates among FWH.



OBSTETRIC INFORMATION

- Related to pregnancy for FWH, 82% (n=65) have been pregnant with an average number of pregnancies of 3.9; of these pregnancies, an average of 2.0 were full-term.
- 36% (n=25) tried to get pregnant for a full year without becoming pregnant (Figure 5).
- 21% (n=10) of FWH have undergone a therapeutic or elective abortion (Figure 5).
- 28% (n=14) of FWH of childbearing age had live, pre-term or premature infants. A pre-term or premature infant is a baby born before 37 weeks of pregnancy (Figure 5).
- 32% (n=24) of FWH experienced a miscarriage in the first trimester of pregnancy. A first trimester miscarriage is the loss of a pregnancy from natural causes in the first 13 weeks of pregnancy (Figure 5).
- 16% (n=8) experienced a miscarriage in the second trimester of pregnancy. A second trimester miscarriage is the loss of a pregnancy from natural causes between 14 and 19 weeks of pregnancy (Figure 5).
- Still births were experienced by 10% (n=6) of FWH. A stillbirth is the loss of a pregnancy from natural causes at or after 20 weeks of pregnancy (Figure 5).
- 37% (n=24) of FWH had any problem with bleeding during pregnancy and 71% (n=45) had bleeding during birth or post-partum that resulted in monitoring or treatment by a healthcare provider (Figure 5).

Figure 5. Fertility/Pregnancy/Delivery/Post-partum related complications of FWH



TREATMENT & HEALTHCARE UTILIZATION

- Of FWH, 77% (n=34) use recombinant FVIII, 20% (n=9) plasma-derived FVIII containing vWF, and 11% (n=12) hormonal contraceptives.
- Of FWH using factor products, 23% (n=10) use it to prevent bleeds, 20% (n=2) use it on a regular schedule, and 57% (n=49) infuse at home, while most FWH self-infuse (77%, n=26).
- For care utilization, 63% (n=52) of FWH reported receiving care for their hemophilia at least once per year and 23% (n=19) receive care only prior to a medical procedure.
- For usual care, 40% (n=31) visit an HTC, 29% (n=22) a doctor's office, and 10% (n=8) an ER.
- In the prior 12 months, due to their hemophilia 14% (n=10) were admitted to a hospital and 28% (n=19) visited an ER.

CONCLUSIONS:

- Preliminary data from CHOICE offers new insights into gender-specific disease burdens of US FWH.
- Earlier age of hemophilia diagnosis among FWH under 18 compared to other age groups demonstrates greater healthcare provider awareness that females also do have hemophilia.
- High levels of menstruation related issues among FWH, including heavy periods, resulted in lost days from work school and recreational activities, directly impacting the FWH's quality of life.
- Further investigation is needed into how to improve FWH's obstetric issues, including achieving full-term pregnancies and precluding pregnancy, delivery, and post-partum complications due to bleeding, as well as lowering the rate of hysterectomies.
- Regional differences in survey outreach may have contributed to the sample from the CHOICE data over representing some patient demographic and treatment types.
- Also, since the CHOICE Project survey includes both HTC and non-HTC FWH, the demographic, gynecological, and obstetric related information is unlikely to be widely divergent from the US hemophilia population.
- However, no definitive subgroup inferences can be made from the demographic data due to the non-random nature of the survey.
- Longitudinal assessments of disease burden in FWH could serve as a means of measuring improvement in patient self-care and treatment effectiveness for treating gynecological and obstetric issues.

Presented at the World Federation of Hemophilia (WFH), Glasgow, Scotland, UK, May 20-24, 2018.

¹Address: New York, NY, copyright 2017; ²Address: Bethesda, MD, copyright 2017; ³Address: Rockville, MD, copyright 2017. The authors have no conflicts of interest to disclose.

Llego el Verano

Los Cuerpos Sanos de Verano Sangran Menos

By Martha Boria Negrón, staff writer

Llegó el verano, se acabó la escuela y ahora nuestros niños y niñas están en casa. Ahora más que en otra temporada del año nosotros los adultos probablemente nos preocupamos más por su nutrición. Esta preocupación es genuina pues ellos tendrán más tiempo libre, más tiempo con los amigos y menos obligaciones. Es posible divertirse, descansar y a la vez, conservar una buena nutrición. Aquí les comparto algunos consejos que les pueden resultar útiles en este verano para que nuestros hij@s mantengan una buena nutrición y una dieta balanceada.

1

Planifiquen las comidas de la semana — Escriban el menú semanal que prepararán. Simplifiquen las recetas y usen alimentos de la temporada.

2

Comiencen el día con un buen desayuno. La primera comida del día proporciona energía necesaria para realizar actividades diarias. Diviértanse cocinando juntos.

3

No omitan comidas y planifiquen meriendas nutritivas.

4

Durante el calor, cuidado con las bebidas carbonatadas, ¡evítelas! 8 vasos de agua diarios es lo recomendable. El agua tiene muchos beneficios, entre ellos: hidrata, no tiene calorías, ayuda a regular la temperatura del cuerpo y ayuda a que los nutrientes lleguen a todos los órganos.

5

Realicen juntos actividades al aire libre. Aprovechen el sol para la vitamina D y fortalece el cuerpo ejercitándose ya que ayuda los huesos y músculos. Hacer actividades al aire libre también ayuda a minimizar el riesgo de depresión, entre muchos otros beneficios. 💧



TREATMENT OPTIONS WIDEN WITH NEW AND EMERGING SCIENCE

The latest in antibodies, gene therapy explained

By Lori Long, staff writer

The number of available treatments and therapies for bleeding disorders is on the rise – fast! Do you ever feel overwhelmed by all the possibilities?

We have antibodies, genes and subcutaneous treatments, oh my! Some organizations are even working on producing factor using milk from transgenic (genetically-engineered) rabbits and lettuce, though not at the same time.



One antibody treatment is already available for those with hemophilia A and an inhibitor. It is a biconal antibody, which means when a patient is given the antibody, it goes through the blood stream connecting activated factor IX and factor X, which would normally be factor VIII's job.

Another antibody treatment is in clinical trials and is a monoclonal antibody that inhibits tissue factor pathway inhibitor (TFPI). TFPI is one of the proteins that slows down thrombin in the clotting cascade, so the theory is that more thrombin would be produced, which would allow for better clot formation.

There is also a treatment being researched that inhibits protein C, another protein that slows down thrombin production.



Speaking of thrombin, an RNA interference therapy is in clinical trials for hemophilia A and B. Just like TFPI and protein C, antithrombin circulates in the blood stream regulating thrombin and slowing it down. This therapy targets the RNA of antithrombin, causing the body to make less of it. Again, more thrombin, more clotting.

Gene Therapy

Then there's gene therapy. To be clear, gene therapy is not gene editing. If you receive gene therapy of any sort, you can still pass your bleeding disorder on to future generations. So, what is gene therapy?

In simple terms, so far for bleeding disorders, they package the gene that makes the applicable clotting factor in an adeno-associated virus (AAV) and put it into the bloodstream. This method is known as “direct delivery” with a targetable, injectable vector (the AAV). Even though AAVs are not generally human viruses, one can still have antibodies to them.

Research appears to be proving that even higher titers of antibodies will not prevent this treatment from helping a patient. Once in the bloodstream, the AAV-packaged clotting factor gene makes its way to the liver where it binds to a cell nucleus and “unpacks” the gene. The unpacked clotting factor is then expressed into the bloodstream as a protein, raising the clotting factor level.



With so much new science emerging, the treatment options are widening, which is wonderful and scary all at once. The best way to feel comfortable with making treatment and therapy decisions with wider and wider choices is to do your research and to talk it over with each other and your medical providers. 💧

HERE ARE SOME ADDITIONAL RESOURCES TO HELP YOU OUT.

- Register on HFA's Learning Central at www.hfalearning.org, where you can learn all about the clotting cascade. More courses are currently in development.
- Connect with the community by registering for our programs at <http://www.hemophiliated.org/for-patient-families/get-connected-join/register/> so that you can connect with other community members and stay up to date on events where programming might be provided on emerging therapies.
- If you are interested in participating in clinical trials, go to www.clinicaltrials.gov and search for your bleeding disorder to see if any trials are currently taking place for which you might be eligible.

BEYOND OUR BORDERS

FROM DEVASTATION TO HOPE

By Emily Roush-Bobolz, staff writer

The bleeding disorders community is a strong, resilient group, and in 2017 that resilience was tested again when a number of natural disasters in the United States and its territories hit families in the community.

Hurricanes Irma and Harvey on the U.S. mainland and Hurricane Maria in Puerto Rico left bleeding disorders families without electricity, water, medication, basic necessities and even left a family without a roof over their heads. This emergency situation led to a discussion of how bleeding disorders organizations like Hemophilia Federation of America could help the community.

HFA, the National Hemophilia Foundation, the Hemophilia Alliance, Hemophilia Alliance Foundation and LA Kelley

Communications, as well as a national network of hemophilia treatment centers quickly came together to form the Together We Care disaster relief assistance fund.

Because HFA had been intimately involved in providing support during Hurricane Katrina many years ago, the organization offered to facilitate the support program. Through the Helping Hands program, HFA created the Together We Care disaster relief assistance fund, designated only for disaster relief.

“Since the hurricanes last fall, we’ve also seen wildfires in California take the home of at least one of our families and flooding in Kentucky was a crisis for some. We need to be here on an ongoing basis,” said HFA President and CEO, Kimberly Haugstad.



It became clear the disaster relief efforts and need to raise support would have to continue beyond last fall's hurricanes. The support for the fund has grown — as soon as the campaign became public, a number of member organizations and chapters stepped up to raise money locally.

"I know how much our community cares," said Haugstad. "We understand how one crisis can be devastating. I have been thrilled to see our member organizations step up. They have such wonderful, big hearts."

Helping Hands staff has processed 94 applications for assistance and distributed more than \$34,000 to families in Texas, Florida, California and Puerto Rico. Forms of support range from short-term urgent funds for food, water, batteries, gas, clothing and transportation, to long-term funds for home repairs and replacing damaged furniture. Helping Hands has four trained social workers and counselors providing critical assistance to the families who apply.

Building Relationships Beyond the Mainland

Besides disasters on the mainland, HFA has recognized a serious need for help for families in Puerto Rico, where governmental help and resources have not been as readily available.

A Harvard University study revealed the death toll in Puerto Rico to be 70 percent higher than officials originally reported. Nearly 50 percent of those cases were because of the lack of access to medicine, treatment and other emergency services.

Getting help to the island proved a challenge in itself. In the beginning, communication was a significant barrier. It was difficult to get in touch with community members to determine their needs, because of damage to electricity and other services. A team of bilingual HFA staff and volunteers visited Puerto Rico and proceeded the only way they could — by going door-to-door to conduct needs assessments.

With multiple visits to Puerto Rico, HFA is reaching community members in need, providing basic necessities and even in one case replacing a roof. They visited children,

providing support and coloring books to make life seem a little more normal.

"After Hurricane Maria, Helping Hands gave me the opportunity to serve the Puerto Rican families within bleeding disorders community," said Martha Boria Negron, programs coordinator for HFA. Martha is originally from Puerto Rico and traveled with HFA to help with communication.

"I rejoice every time I receive a hug and words of gratitude and when I see big smiles on their faces. It let me know that we are touching hearts and above all we are contributing to the benefit of these families," she said.

HFA has had the opportunity to build stronger relationships with a hemophilia treatment center on the island and work with local hemophilia associations. Members of the HFA staff met with Puerto Rico's Secretary of Health to improve support for the bleeding disorders community.

"I'd encourage everyone to have some sort of family plan, even if only a rough one for disasters that could



strike," said Haugstad. "What really struck me during this process is how little preplanning is in place, even at the government level. A little advance planning can go a long way."

HFA and the Together We Care partners will continue to raise funds and provide help to those in Puerto Rico and throughout the rest of the United States and its territories as unexpected events happen. 📍

LEARN MORE ABOUT TOGETHER WE CARE AT WWW.HEMOPHILIAFED.ORG/DONATE/TOGETHER-WE-CARE/

The tiny house in Puerto Rico, where J* lives with her aunt, uncle, grandma and cousins lost a roof when Hurricane Maria devastated the island in September 2017. The family's belongings were left in ruins and a temporary blue tarp covered the house until May this year.

We met her at a Puerto Rican hemophilia treatment center — a beautiful young woman of 20 years with a sad look, shy, in pain and frustrated by the situation troubling her. In addition to losing her belongings, she was hospitalized with an infection on her left hand. She is a factor V deficiency patient.

She was the first person we met and helped through Together We Care. Honestly, she was in a better

situation in the hospital where there was food, drinking water and electricity. At her house, there was no electricity, no drinking water, no beds to sleep in and no roof to cover them, like most Puerto Ricans at that time.

Communications on the island were established little by little and we communicated frequently. After eight months and two more visits, with an alliance made with Baptists on Mission from North Carolina and through the generosity of donations to Together We Care, we covered the cost of repairing the roof of her house. 💧

- Kimberly Haugstad, HFA President and CEO

**J's name has been changed for privacy purposes*

Thank you to the partners in Together We Care*

- Hemophilia Federation of America
- National Hemophilia Foundation
- The Hemophilia Alliance
- The Hemophilia Alliance Foundation
- LA Kelley Communications Inc.
- Mary M. Gooley Hemophilia Center
- Arizona Hemophilia Association
- New England Hemophilia Association
- New York City Hemophilia Chapter
- The Coalition for Hemophilia B
- Hemophilia Association of New York
- Virginia Hemophilia Foundation
- Hemophilia of Iowa
- Hemophilia of North Carolina
- Hemophilia Foundation of Arkansas
- Louisiana Hemophilia Foundation

**The fund is administered by the Hemophilia Federation of America, utilizing the infrastructure of HFA's Helping Hands program*



Meeting in Puerto Rico

In April, HFA had the opportunity to meet with Puerto Rico's Secretary of Health, Rafael Rodríguez Mercado, and his team. The meeting with President and CEO, Kimberly Haugstad, as well as HFA coordinators Kay Sar and Martha Boria, came together quickly, building a relationship and igniting a conversation about how HFA can work with Puerto Rico to support bleeding disorders families in the area.



Philippines Meets in Scotland

HFA is excited to be building bridges with international partners in the bleeding disorders community. HFA President and CEO, Kimberly Haugstad, and Helping Hands Coordinator, Kay Sar (far right), as well as Kimberly's son Jonnie, had the opportunity to meet with Andrea and Kay from Hemophilia Advocates Philippines while in Scotland for World Federation of Hemophilia's 2018 World Congress in May.

MEMBER ORG SPOTLIGHT

HFA WELCOMES OUR NEWEST MEMBER ORGANIZATIONS!



Western Pennsylvania Chapter of the
National Hemophilia Foundation

WPCNHF EDUCATION | ADVOCACY | SUPPORT

Western Pennsylvania Chapter of NHF

Executive Director: Alison Yazer

“We joined HFA because they offer so many benefits and opportunities for our members. HFA membership it is a worthwhile investment.”



ASOCIACION PUERTORRIQUEÑA DE
HEMOFILIA
Y CONDICIONES DE SANGRADO

Puerto Rican Association of Hemophilia and Bleeding Conditions

Executive Director: Anthony Llanes Rodriguez

“Con el fin de buscar el desarrollo y las necesidades de nuestra comunidad, decidimos que unirnos a HFA era el paso correcto para dirigir a nuestra organización hacia un futuro mejor.”

“In order to look for our community development and needs, we decided that joining HFA was the right step to address our organization to a better future.”



SWOHF
SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

Southwest Ohio Hemophilia Foundation

Executive Director: Kay Clark

“We are joining HFA because when my board president and I attended Symposium in Cleveland, we experienced such warmth and friendliness, there was such a personal touch. HFA programs are people-focused, which is where we live day-to-day. Something our members can relate to.”

Utah Hemophilia Foundation

Executive Director: Scott Muir

“The Utah Hemophilia Foundation is pleased to be one of HFA's newest member organizations. The decision to join HFA was driven by the Hemophilia Federation of America's patient-centric focus. With its greater emphasis on direct patient support, HFA is most closely aligned with the focus of our initiatives and objectives in the areas of education, advocacy and outreach. The Utah Hemophilia Foundation welcomes the opportunity to partner with a national organization of the caliber of the Hemophilia Federation of America in championing and meeting the needs of the bleeding disorders community both at the local and national level.”



Annual charitable bicycle ride raises emergency funds



This June, riders gathered on the towpath of the Cuyahoga Valley National Park in Ohio to show support of the Hemophilia Federation of American's Gears for Good Northern Ohio Ride.

The weather was spectacular, and riders of all ages enjoyed a leisurely seven-mile ride, some utilizing the Bike Aboard train, while more adventurous bikers pedaled the full 50 miles!

After everyone returned, riders and attendees enjoyed a delicious lunch. One hundred percent of the contributions raised by the riders and individual donors directly supports HFA's Helping Hands and the Northern Ohio Hemophilia Foundation's emergency assistance programs. Both programs provide families and patients in need with immediate financial assistance.

Special thanks to our national sponsors: CSL Behring, Aptevo, Grifols and CVS Specialty.

Thank you to our local sponsors: Akron Children's Hospital, Accredo, Bayer, Bioverativ, Diplomat, Novo Nordisk and Shire. 📌



Delves for Donors

Shawn Nease of Maryland has taken his passion for Dungeons and Dragons and turned it into Delves for Donors, a one-day D&D tournament which raises funds for HFA's Helping Hands Program.

Over the past four years, Nease and his friends have raised \$3,425, this year alone raising \$1,156!

"Not too bad for a bunch of people just sitting around rolling dice and telling stories," said Nease.

Thank you to Nease, the players and the companies which provided prize donations/services for the event: ACTWD, Arcknight, Critical Hit Games, Erin Miller, Fower Games, Goodman Games, Paizo.com, PolyHero Dice, SkullSplitter Dice, UPS Store #6643, and Wyrmwod Gaming. 📌



INSPIRING IMPACT

CROWDFUNDING MADE EASY

HFA starts Do-It-Yourself site to support fundraising

By Kyle McKendall, staff writer

HFA is excited to announce the launch of our online fundraising tool designed to make do-it-yourself fundraising events easy for community members to host.

If you're one of the many people who have thought about hosting or participating in an event to raise money for HFA but have shied away because of the complexity or frustrations in handling money or credit card payments, this tool is for you! With just a few clicks in your web browser, you can create a customized webpage, set fundraising goals, and begin promoting it to your friends and family. The best part? HFA handles all the back-end financial processing while you simply monitor who's participating in your fundraiser. This tool is free to use and 100 percent of the monies raised will benefit HFA's financial assistance program, Helping Hands.

Consider celebrating an upcoming birthday or milestone by supporting our efforts to strengthen the community. Creating a page and asking friends and family to donate to your fundraiser instead of opting for traditional gifts is just one of the many ways to use this tool.

We've seen community members host a range of events to benefit HFA. From traditional fundraisers such as golf tournaments or endurance challenges that include biking, running or walking to unique themed events such as a Dungeons and Dragons tournament.

"I was inspired to do something to raise awareness among people who don't know about hemophilia and raise money for people in our community who need it most," said Chris

Seistrup, a community member from Arizona, who used this model to raise money as he biked 1,900 miles along the West Coast.

When we celebrate the people we love on social media, friends and family often ask "what can we do to help?" Honoring someone who has had an impact on your life by establishing a memory page on an anniversary creates an opportunity for others to contribute.

Helping Hands provides families within the bleeding disorders community with urgent basic living expenses, the reimbursement of durable medical items, and medical/educational travel as well as educational support for families affected by inhibitors.

The number of ways to utilize this new tool seems endless. Your creative ideas and passion for the community coupled with a secure and easy-to-use tool are all it will take to make a difference. Visit www.bit.ly/HFADIYFundraising today to check it out for yourself! 📌





Join HFA in the Marine Corps Marathon October 28!

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.

Register at bit.ly/HFAMCM2018!

TEAM Resilience
Hemophilia Federation of America



NEXT ISSUE:

Quality of Life

- Pain and the use of opioids
- Latest legislative action on medical marijuana
- Why we love nurses and more.