



DATELINE

FEDERATION

Volume 22 • Issue 2 • Summer 2021



FILM SCHOOL

page 20

-

GETTING WIRED WITH RESEARCH DURING A PANDEMIC

page 25

-

HFA LAUNCHES YOUNG ADULT PODCAST

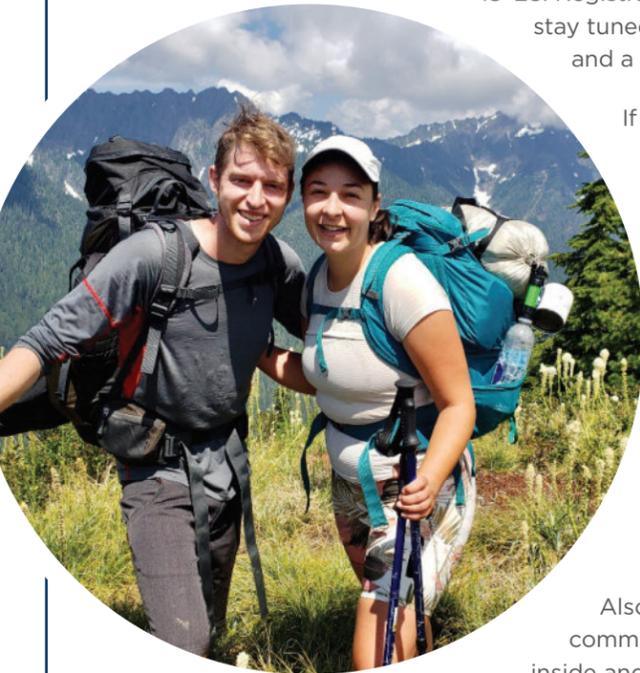
page 28

HI FRIENDS,

I hope you all have had a wonderful summer! One of my favorite parts of summer is enjoying time outdoors, and I've been able to continue gardening in my backyard garden, as well as take lots of walks around my neighborhood. I even had the chance to go backpacking with my husband for three days in the Olympic National Park. Even with a bleeding disorder, there are so many great ways to enjoy the outdoors! As we head back into the school season, I hope your family was able to cherish its summer memories but also look forward to getting back into the school routine.

Have you had a chance to check out our new HFA Hero membership program? I hope that you and your family will join HFA and become official HFA Heroes. All memberships directly support our Helping Hands program, which, as you know, is one of the core support programs that HFA offers. We can all be heroes of the bleeding disorders community! (Learn more on page 4.)

We have officially launched registration for Symposium 2021, and I hope you'll register today! Our team is planning exciting and informative sessions to take place online October 18-28. Registration is free. Join today at www.hfasymposium.org, and stay tuned for more information about speakers, session topics and a final night event you will not want to miss!



If you recall my last Executive Corner, you know that HFA was awarded the 2021 Gold Bell Seal for Workplace Mental Health by Mental Health America (MHA). I am extremely pleased to announce that MHA has updated our status, and we have now officially been awarded the 2021 Platinum Bell Seal. This first-of-its-kind workplace mental health certification recognizes employers who strive to create mentally healthy workplaces for their employees. After receiving the Gold Seal, HFA staff worked to address the areas MHA noted as lacking, leading to our Platinum level seal and further demonstrating our dedication to the well-being of our HFA employees. Learn more about this honor on page 10.

Also in this issue are a couple of features that show how community members are connecting and educating people inside and out of the bleeding disorders community. On page 20, you'll hear about Sushant Sharma Bhattarai, who is learning how to use documentary-style video to shine a light on families with bleeding disorders from around the world. On page 28, read about the new HFA podcast for young adults, The BloodFlow, launched by an HFA 2020 summer intern.

I hope you enjoy this issue of *Dateline Federation*. As always, if you have questions about anything included within these pages, please reach out to the HFA team. We are here to support you!

Allie Ritcey

Chair, HFA Board of Directors



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

Volume 22 • Issue 2 • Summer 2021

EXECUTIVE LEADERSHIP

Board Chair • Allie Ritcey
President & CEO • Sharon Meyers,
EdD, CFRE

PRODUCTION TEAM

Editor • Meghan Lawton
Managing Editor • Melanie
Padgett Powers
Design & Layout • Ashley Williams

Contributing Writers

Whitney Armijo, HFA Staff
Martha Boria, HFA Staff
Ann B. LeWalk, MA, HFA Staff
Kyle McKendall, HFA Staff

The information printed in
Dateline Federation is provided
for general purpose use. HFA does
not give medical advice or engage
in the practice of medicine and
recommends that you consult with your
physician or local treatment center
before beginning any form of treatment.

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

999 N. Capitol Street NE • Suite 301
Washington, DC 20002
202.675.6984
info@hemophiliafed.org

©2021 Hemophilia Federation of America.
All rights reserved.

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



IN THIS ISSUE

ARTICLES

- 10 HFA Recognized for Its Commitment to Mental Health**
HFA is awarded the 2021 Platinum Bell Seal for Workplace Mental Health.
- 14 Dateline LIVE**
Inaugural virtual event brings annual product guide to life.
- 16 Welcome Policy and Government Relations Interns**
Four advocacy interns joined HFA virtually this summer.
- 18 HFA Offers Mental Health First Aid Training**
HFA partners with the National Council for Behavioral Health to train community members in Mental Health First Aid.
- 20 Film School**
Sushant Sharma Bhattarai aims to educate people about hemophilia through documentaries.
- 25 Getting WIRED with Research during a Pandemic**
HFA research team works to empower women to take part in research.
- 28 HFA Launches Young Adult Podcast, The BloodFlow**
The BloodFlow was created and launched by 2020 virtual summer intern Tameelah Dawson.

SPECIAL FEATURES

4
Happening Highlights
Resources are available to help with bleeding disorder management and to provide a community.

Getting to Know HFA Staff
Two new staff members are ready to serve the community.

8

HAPPENING HIGHLIGHTS



Become an HFA Hero!

Purchase a Hemophilia Federation of America (HFA) membership and support all that HFA does for the bleeding disorders community. First and foremost, 100% of your membership dues support the bleeding disorders community. But, there are other great perks of membership too, including:

- Access to Hero-only webinars and meetings
- Invitation to Hero-only meet-ups at HFA events
- Access to a Hero-only email list
- Discount on 2022 Symposium registration
- Be the first to know! Heroes get access to HFA news before it is released to the community.
- Ability to purchase Hero apparel and collateral, available only to Heroes

In addition, you will have access to all the great programs that HFA offers to the entire bleeding disorders community, including:

- Full access to all HFA programs/services
- Subscription to our quarterly magazine, *Dateline Federation*
- Subscription to a multitude of HFA e-newsletters (you choose the topics that interest you!)

Memberships cost \$35 for an individual or \$50 for a family and are good for one year from the date on which you join. Become an HFA Hero today at www.hemophiliafed.org.



Registration Open for 2021 Young Adult Advocacy Summit

Although Hemophilia Federation of America (HFA) had previously planned to host the Young Adult Advocacy Summit in-person in 2021, HFA now feels it is best to offer the program virtually September 18-21. HFA is excited to be able to offer this training via Zoom and podcasts.

HFA's goal for the Young Adult Advocacy Summit has always been to introduce young adults to legislative and personal advocacy in a safe and supportive manner with hands-on training and peer support to ensure they will develop a bond and continue working together in their daily lives. HFA's outreach to legislative offices on Capitol Hill and federal agencies will empower participants to apply this knowledge and experience in their communities.

Applications for the 2021 Summit are available on the HFA website. Detailed information on the Summit can be found at www.hemophiliafed.org.

Team Resilience Events are Back In-Person This Fall

Hemophilia Federation of America's (HFA) Team Resilience is back on the bikes! Join us in-person or virtually as Team Resilience saddles up for 165 miles of gorgeous C&O Canal trail scenery from West Virginia to DC in September. Rides come with awesome SAG support, and cyclists take breaks every 15-20 miles. Funds raised support the HFA bleeding disorders community.



HAPPENING HIGHLIGHTS

BECOME AN HFA HERO!
Purchase an HFA membership and support all that we do to aid the bleeding disorders community!

Find out how to become a hero at www.hemophiliafed.org.
#HFAHeroes




GO SEEK. GO EXPLORE.
GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com



Discover your sense of go. Discover HEMLIBRA.

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, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



Medication Guide 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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (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, ages newborn and older, with hemophilia A with or without 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.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- 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.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by 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 as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day 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 a total of 7 days or at a temperature greater than 86°F (30°C).
- 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-kxwh

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

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan
©2018 Genentech, Inc. All rights reserved.

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018



HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The HEMLIBRA logo is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The Genentech logo is a registered trademark of Genentech, Inc.
All other trademarks are the property of their respective owners.
©2020 Genentech USA, Inc. All rights reserved. M-US-00007357(v1.0) 09/20

Genentech
A Member of the Roche Group

GETTING TO KNOW HFA'S STAFF

Welcome the most recent additions to the Hemophilia Federation of America (HFA) staff.



Meghan Lawton

Associate Director, Advancement
Preble, New York

Lawton oversees the day-to-day project management of the HFA Advancement Department, which includes the Communications and Development teams.

Why did you want to work at HFA?

"I was at a point in my life where I was beginning to evaluate my career and how I wanted the next 10 years to look when a current HFA employee reached out to me about this open position. Although I had never worked in a health-related industry before (my background was in the tourism industry), I immediately felt that this position was the next step for me, and I've enjoyed every second of it so far."

Lawton loves reading and reads between 30 and 45 minutes each night before bed. "My to-be-read list grows by the day, and I know I'll never get down to zero, but I will give it my best effort!" she says.

She's also a "rabid" sports fan—especially for the NFL's Buffalo Bills and MLB's Boston Red Sox—and her family has season tickets to Penn State football, men's hockey and women's volleyball. However, on most weekends, you can find Lawton, her husband and their English Bulldog, Gertrude, exploring a new winery and/or brewery.



Michelle Enright

Graphic Designer and Social Media Coordinator
Freeville, New York

Why did you want to work at HFA?

"I never considered my love for social media marketing and graphic design could help an organization make a positive impact within a community on a national level. When the opportunity arose for me to work for HFA, I hoped that my knowledge could be used to support its efforts and make a positive difference in the rare bleeding disorders community."

Enright loves to travel. "Can I put travel down twice?" she asked. She grew up taking frequent trips to Europe, which instilled a love of adventure in her. She is always itching to explore—to learn about the history of a tiny village, dive into new cultures or just try new foods.

She also loves to cook and experiment with new recipes, with her husband as the guinea pig. She says she can whip up a "mean batch of pierogies" if need be. Enright has played soccer since she could walk, and competitive sports and being active is important to her. She enjoys weekly hikes throughout the Finger Lakes and has also tackled Mount Washington in New Hampshire and the Tatra Mountains in Poland. In her spare time, she enjoys a glass of wine while watching true crime documentaries.

MEMBER ORGANIZATION SPOTLIGHT

Midwest Hemophilia Association and Gateway Hemophilia Association

The Midwest Hemophilia Association (MHA), which serves Kansas and western Missouri, teamed up with the Gateway Hemophilia Association (GHA), which serves eastern Missouri and southern Illinois, to develop a women's retreat called the FAB Conference, which stands for "females and bleeding."



"The women that attend our regular women's retreat wanted to reach more women and bring awareness to women with bleeding disorders," said Bridget Tyrey, GHA executive director.

"Since MHA and GHA share Missouri in our coverage areas, I think it was a natural and easy collaboration born out of a need to provide women in the community with support," said Angela Brown, MHA executive director. "Both chapters have worked together for several years on Missouri advocacy issues as well."

Because of the pandemic, the inaugural FAB Conference was postponed, but the two associations hosted a virtual happy hour in 2020. "It was our way of saying to

the women in the community, you have value, we are still here for you, and we will continue to be," Brown said.

They are planning to host the FAB Conference in person this year, October 8-10, at Margaritaville Lake Resort, Osage Beach, Missouri. They have also extended invites to neighboring bleeding disorders organizations in Nebraska and Iowa.



Collaboration among bleeding disorders associations can help expand programming and connect more community members together. "My advice for other organizations wishing to team up with another bleeding disorder association would be to stay

focused on the outcome, be flexible in your planning and be willing to think outside the box," Brown said.

Tyrey added: "Listen to your membership—it's their organization, and they bring valuable ideas and feedback."

MIDWEST HEMOPHILIA ASSOCIATION FACTS

- Started in 1991
- 400 households served
- Most popular program: Family Education Weekend in September



GATEWAY HEMOPHILIA ASSOCIATION FACTS

- Started in 1969
- 400 households served
- Most popular program: Three-day annual meeting

HFA RECOGNIZED FOR ITS COMMITMENT TO MENTAL HEALTH

Hemophilia Federation of America (HFA) has been awarded the 2021 Platinum Bell Seal for Workplace Mental Health by Mental Health America (MHA). This Bell Seal is a first-of-its-kind workplace mental health certification that recognizes employers who strive to create mentally healthy workplaces for their employees.



“We are incredibly proud to be among the first organizations to be certified by MHA,” said Sharon Meyers, EdD, CFRE, president and CEO of HFA. “Our status as a Platinum Bell Seal demonstrates HFA’s ongoing commitment to employee mental health and well-being and aligns with our focus on mental health resources and support for members of the bleeding disorders community.”

MHA, founded in 1909, is the nation’s leading community-based nonprofit dedicated to

addressing the overall mental health of all. MHA has spent decades researching mental health in the workplace, and in 2019, introduced the Bell Seal for Workplace Mental Health to recognize companies and organizations that understand the value of addressing mental health at work and that implement policies and practices that support employee well-being.

The Bell Seal recognizes employer advances in workplace mental health by awarding recognition levels of Bronze, Silver, Gold and Platinum. HFA underwent a rigorous evaluation of its policies and practices in five areas: workplace culture, benefits, wellness programs, legal compliance, and leadership and community engagement. HFA’s Platinum status demonstrates outstanding scores in workplace culture, employee perks and programs, legal and ethical compliance, and leadership and community engagement.

“HFA chose to pursue the Bell Seal for Workplace Mental Health to see if we are focused on the right things with mental health,” Meyers said. “Our overarching goal was to review everything we are currently doing to get helpful ideas on areas we can improve. We found the process to be thorough, fair and incredibly insightful—Mental Health America is truly the expert in this area. We will continue efforts organizationally and with the larger community to focus on mental health and wellness for people living with a bleeding disorder.”

HFA is committed to providing the best for its employees and looks forward to continuing the work to ensure the organization upholds the standards set forth by the Platinum Bell Seal for Workplace Mental Health.

Learn more about MHA and the Bell Seal for Workplace Mental Health at www.mhanational.org/bestemployers.

7 WAYS TO GET READY FOR BACK TO SCHOOL

Sending your child with a bleeding disorder back to school can be overwhelming. Here are seven tips to help your family prepare to go back to school this fall.



1 ESTABLISH COMMUNICATION EARLY.

Schedule an educational meeting with the school principal, teachers, school nurse and social worker so they can learn about your child’s bleeding disorder.

2 PLAN YOUR CHILD’S EDUCATION.

There are support programs at the school, such as the 504 Plan or the Personalized Education Plan (IEP). A student with a bleeding disorder may be eligible for an IEP or a 504 plan, depending on their circumstances. These plans are:

IEP: A project or plan for special education that a student will receive at school.

504 Plan: A plan of how the school will support and eliminate the barriers faced by the student.

3 WEAR A MEDICAL ALERT BRACELET.

It is recommended that your child always wear a medical alert bracelet. In an emergency, the bracelet will alert urgent care providers to your child’s medical condition and increased risk of bleeding.

4 RETURNING TO SCHOOL AFTER COVID-19

4 ENCOURAGE YOUR CHILD TO SEEK SUPPORT AT SCHOOL.

Encourage your child to build trusting relationships with people at their school they can talk to about their bleeding disorder, especially in an emergency.

6 EMBRACE THE NEW NORMAL.

Use the new normal as an opportunity to teach life skills such as problem-solving, self-care and adaptation.

5 TALK WITH YOUR CHILD ABOUT THE PANDEMIC SITUATION IN YOUR COMMUNITY.

5 TALK WITH YOUR CHILD ABOUT THE PANDEMIC SITUATION IN YOUR COMMUNITY.

Be honest and answer questions with ideas your child can understand and are appropriate for their age level.

7 ESTABLISH ROUTINES.

Establish daily routines for getting up, going to bed, homework time and school transportation. These habits will help your child feel ready for the day.

IXINITY
coagulation factor IX
(recombinant)

Discover more about IXINITY

Visit IXINITY.com

MEDEXUS PHARMA
Medexus Pharmaceuticals Inc.

Medexus Pharma, Inc., Chicago, IL 60606
IXINITY® [coagulation factor IX (recombinant)] and any and all Medexus Pharma, Inc. brand, product, service and feature names, logos, and slogans are trademarks or registered trademarks of Medexus Pharma, Inc. in the United States and/or other countries.
© 2021 Medexus Pharma, Inc. All rights reserved. CM-FIX-0112

It's time to go back to school!
DRAW A PICTURE OF YOU AT YOUR SCHOOL.



*We're counting down the days
for HFA hugs to resume*



Until then, we're here for
you and your family
at www.hemophiliafed.org



HFA HOSTS DATELINE LIVE

Annual Product Guide Brought to Life

BY KYLE MCKENDALL, HFA STAFF WRITER

It was just before 4 p.m. when Hemophilia Federation of America (HFA) President and CEO Sharon Meyers, EdD, CFRE, turned on her webcam and tested her microphone in the organization's office in Washington, DC. More than 1,500 miles away in her home state of Colorado, HFA Vice President of Policy and Advocacy Sonji Wilkes did the same. The two were comparing notes in the presenter studio of Zoom Webinar and were excited to kick off Dateline Live: Navigating Approved Products and Emerging Therapies. With the push of a button, HFA began what would be 11 hours of webinars focused on educating patients about treatment options for people with a bleeding disorder.

Each year HFA compiles a comprehensive list of therapies approved by the U.S. Food and Drug Administration as well as all investigational therapeutic products undergoing clinical trial and publishes that list in a special issue of its quarterly magazine, *Dateline Federation*. Dateline Live took the success and value of the print issue and brought it to life over three days of online education programming.

More than 200 community members registered for the event, which took place June 23–25, 2021.

While the event was a new concept that the HFA team thought of in early 2021, there was unanimous consent among staff on the decision to act quickly to host it. “As patients, we have the right to know our options. But it is our responsibility to educate and empower ourselves about our disorder,” Wilkes said. “From our community's history we know that patients and their families look to advocacy organizations such as HFA to provide the facts and information needed. HFA remains committed to being a trusted source of information for you. We are steadfast in our commitment to ensure a safe blood supply and transparency around treatment options and their efficacy.”

Eric Iglewski, LMSW, moderated a session titled “Get Counted: The Importance of Registries,” in which

a panel of community leaders discussed how registries are a critical way for researchers to monitor safety signals and other trends, learn from the patient experience and predict future needs or concerns.

The panel was comprised of HFA Director of Public Health and Outcomes Projects Mabel Crescioni, DrPH, JD, LLM; National Hemophilia Foundation's head of research, Michelle Witkop, DNP; and Plasma Protein Therapeutics Association's senior vice president of public affairs, Julie Birkofer.

Iglewski also moderated “Shared Decision-Making: Making the Most of the Patient-Provider Relationship.” Longtime advocates and active members of the community Will Hubbert and Cazandra MacDonald joined the panel to provide patient perspectives. The provider perspective was brought by Chris Guelcher, a hematology/oncology

and thrombosis, Department of Pediatrics, Children's Healthcare of Atlanta.

“What to Expect When Participating in Clinical Trials” was presented by Julie Smith, CCRP, who was able to provide the perspective of an HTC clinical research manager. Smith co-manages a team of six clinical research coordinators at the University of Colorado Denver Hemophilia and Thrombosis Center.

David Clark, a retired chemical engineer with more than 35 years of experience in the biotechnology, plasma and tissue industries, hosted the “Emerging Therapies: The Latest in Clinical Trials” session. Patients learned about the ever-changing

landscape of bleeding disorders treatment, basics of clinical trial progression and items of discussion for patients/caregivers to consider with their health care provider when thinking about participation in a trial.

Acronyms abound in the bleeding disorders world—how do you make sense of FVIII, FIX, vWF, QoL, HCV, MASAC, ISTH, EHC, AAV and the plethora of others? To help community members learn what these letters mean and represent, HFA's director of policy

and principal legal counsel, Miriam Goldstein, JD, along with Wilkes, hosted an interactive session called “Bleeding Disorders Alphabet Soup: What Do These Letters Mean?”

In addition to the educational

webinars presented by HFA, representatives from four pharmaceutical manufacturers—CSL Behring, Genentech, HEMA Biologics and Sanofi Genzyme—hosted sessions that provided community members with updates and information about available treatment options. In keeping with their mission of connecting patients, HFA also hosted rap sessions, led by an HTC nurse, that were open to community members and caregivers as an opportunity to meet with other community members and discuss their experiences. Rap sessions were grouped by diagnosis of hemophilia A or B, von Willebrand disease, inhibitor or other rare bleeding disorder.

When asked why this event was made a priority for the HFA team, Wilkes said, “It was 17 years ago when I was choosing a treatment option for my newborn son with severe hemophilia A. The overwhelming feeling remains vivid. It was a confusing and scary process, despite having wonderful support from the staff at our local hemophilia treatment center. I was a mom, unsure of how to even spell hemophilia at that point, just wanting to make the right call for my baby's health. But, I didn't know what questions to ask, what specifics to consider or even what our options were.”

Recordings of each session and biographies about each speaker are available on HFA's website at www.hemophiliafed.org/dateline-live. Subscriptions to the quarterly print magazine are free; sign up today at www.hemophiliafed.org. To request a copy of the 2021 Product Guide & Emerging Therapies Special Issue, please send your name and address to info@hemophiliafed.org.



Read now!

welcome

POLICY AND GOVERNMENT RELATIONS INTERNS

The Hemophilia Federation of America (HFA) team welcomed a new group of students to its summer 2021 internship program. The students participated in this annual advocacy internship virtually, developing their passion in health care policy and self-advocacy. They participated in regular webinars and online training about legislative, policy and advocacy issues, as well as learning about legislative hearings and what it means to work on Capitol Hill. Throughout all these tasks they built communications and media skills.



Justin Najimian

Rising senior at Rutgers University, studying public health and taking part in a dual program that allows him to take courses toward a master's degree in epidemiology.

Throughout Najimian's life, he has always made an effort to be involved in the bleeding disorders community. He has assisted in infusion workshops at his local hemophilia treatment center (HTC), volunteered with HFA as a teenager and also served as a counselor and volunteer at the Hole in the Wall Gang Camp in Ashford, Connecticut. After taking part in the 2020 Youth Adult Advocacy Summit, he was eager to expand his advocacy horizons and become an HFA intern.

Exploring policy and the federal side of the bleeding disorders community is a new area of involvement for Najimian that he is excited to explore.

Throughout his internship, Najimian looks forward to strengthening his own role as an advocate in the bleeding disorders community.



Makayla Dawkins

Rising junior at University of Connecticut double majoring in human development and family sciences, and women, gender, sexuality studies, with a minor in Africana studies.

At UConn, Dawkins has worked with the Undergraduate Student Government Student Services as a sexual health and education advocacy coordinator, where she has implemented a menstrual care package program and created legislation in solidarity with the UConn queer community. She is also a resident assistant in arts learning communities and has worked with LGBTQ people through the Rainbow Center. Dawkins hopes to become a health administrator overseeing a health facility while also serving families impacted by incarceration. She also serves as an intern at Free All My Suns Inc., a nonprofit that connects families to the imprisoned and oversees their various programs. Additionally, she destigmatizes mental illness as an intern with the Holistic Huskies, a mental health podcast where she advocates for suicide prevention and mental health in communities of color. 🩸



Ryan Bernstein

Rising junior at Stanford University studying psychology and biology, with plans to attend medical school.

Bernstein enjoys studying the brain and behavior.

He is active in his community as a tutor for both college and high school students, as well as being a disability advocate. He is currently working on a children's book about hemophilia. In his free time, he likes to read, solve crossword puzzles and go on walks with his family.

Bernstein wanted to be an HFA intern because "I wanted to learn more about the community and support an organization I believed in, as well as meet new people, and learn how to be a more effective advocate."



Silas Teasdale

Graduating in August 2021 with a bachelor's in political science from Montana State University.

In Montana, Teasdale did not grow up with a nearby

HTC, so his dad and a hemophilia community in Denver taught him how to live a healthy and self-sufficient life with a bleeding disorder. After high school, Teasdale knew he wanted to study political science. This internship will provide him the opportunity to explore advocacy and policy on the national level while simultaneously working for a cause he is passionate about. In his free time,

Teasdale enjoys music, painting, cameras, local politics and activism, ultimate frisbee, nature and trying to keep houseplants alive. After college graduation, he hopes to move to Madrid, Spain, to work in the public school system.

READ ABOUT THE HFA INTERNS' EXPERIENCES THROUGH BLOG POSTS AT www.hemophiliafed.org/news-stories/category/hfa-news.

HFA OFFERS MENTAL HEALTH FIRST AID TRAINING



TOGETHER PROJECT

It is safe to say that throughout the past 18 months, most of us have become increasingly aware of the importance of fostering and maintaining our own mental health, while also trying to look out for that of others. We have also come to know that “good health” includes both physical and mental well-being.

While new and emerging treatments continue to be developed to address the physical effects of bleeding disorders, the psychological effects of chronic health issues, coupled with the isolation of a pandemic, can be more difficult to identify and treat.

The words “community” and “family” are often used to describe the relationships among people with bleeding disorders. And, with community, comes a strong sense of responsibility to look out for one another because when one part of the community is struggling, the whole community feels the strain. We know how to assist when members are struggling financially or how to educate when information is what they need. But too often, we feel powerless when someone is struggling with a mental health challenge.

After listening to the community, the member organizations, board members and staff, Hemophilia

BY ANN B. LEWALK, HFA VICE PRESIDENT FOR EDUCATION

Federation of America (HFA) decided it was time to open up a dialogue about mental health and well-being in the bleeding disorders community.

HFA wanted to begin its commitment to mental health and well-being by providing an opportunity for members of the bleeding disorders community to learn skills they could use in all aspects of their life. Knowing this community likes to take action and make an impact, HFA saw a great opportunity in working with the National Council for Behavioral Health to train community members in Mental Health First Aid (MHFA).

Since the course’s inception in 2008, 2.5 million people in the U.S. have participated. The vision of this educational program is to ensure that mental health first aid is just as commonplace as CPR. The opportunity, brought to HFA by Debbie de la Riva, LPC, certified MHFA instructor and community member, allows us to offer this internationally renowned program with a unique focus on the bleeding disorders community.

The training provides participants with knowledge regarding common mental health conditions, how to identify when someone is struggling emotionally and how to communicate with someone in despair. In addition, the curriculum provides training on suicide prevention and information on national mental health resources for care and support.

Thanks to financial support from Colburn Keenan Foundation, since April 2021, HFA has supported the

training of 36 individuals from across the United States who are community members, member organizations’ staff, hemophilia treatment center (HTC) staff and HFA staff. There are two more trainings this year—September 25 and November 13—open to anyone in the bleeding disorder community who is 18 or older. This means people with bleeding disorders, as well as parents and caregivers, HTC staff, member organization staff, etc.

The aim is to create trained MHFA ambassadors across the country who can serve to support and assist local community members who may be

THIS COURSE LITERALLY COULD SAVE SOMEONE’S LIFE. I LEFT WITH MORE CONFIDENCE ON HOW TO LISTEN AND BE HELPFUL FOR SOMEONE EXPERIENCING A MENTAL HEALTH CHALLENGE.

— Jeremy Griffin, Executive Director
New York City Hemophilia Chapter

struggling with mental health concerns. These ambassadors are not meant to replace professional care; they are meant only to assess, listen and stay with someone until professional help arrives or appropriate resources can be found.

By making Mental Health First Aid training available to the bleeding disorders community, HFA hopes to begin a movement in which members of the bleeding disorders community have the knowledge and the skills to support each other through mental health challenges.

Learn more about the training at www.mentalhealthfirstaid.org. And apply for HFA MHFA Training on September 25 at bit.ly/HFA_MHFA. 🩸

2021 VIRTUAL SYMPOSIUM

OCTOBER 18–28, 2021 • FREE TO ATTEND



The same content you know and trust, delivered in our exciting and cutting-edge virtual experience!

The same great information and networking, all online:

- Latest information on medicine and technology, mental health care, access to financial resources and barriers to care.
- Sessions in Spanish
- Virtual research poster exhibit
- Children and teen programming
- A Final Night Event not to miss!



Join Us For This Amazing Virtual Experience!

Learn more and register to join us by visiting our website and following all of our exciting updates on social media!



Register Now! www.hfasymposium.org



FILM SCHOOL

SUSHANT SHARMA BHATTARAI AIMS TO EDUCATE PEOPLE ABOUT HEMOPHILIA THROUGH DOCUMENTARIES

BY MELANIE PADGETT POWERS, MANAGING EDITOR

As a kid growing up in Nepal with hemophilia A, Sushant Sharma Bhattarai, now 22, wasn't allowed to run around, ride bikes or play sports. Factor replacement therapy wasn't available in his country, and the risk was just too great.

Later, living in California as a teenager, he still didn't play sports or go outside much. He had severe arthritis in both legs, and the muscles in his right leg had never fully developed. Instead, Bhattarai turned to videos. First, he watched movies and YouTube videos and played video games. But then he started filming himself playing video games, something he saw other people doing and sharing on YouTube.

"I wanted to do that too because it looked pretty fun, and it also looked like a great way to reach out to other people," he said.

Later, in community college, he took classes in a lot of subject areas to see what he liked. "And film really stuck out to me," he said. "The subject of

storytelling and imaging really struck me, so that's how I knew that's what I wanted to do."

Bhattarai graduated in May 2021 from the University of California (UC), Santa Cruz with a bachelor's degree in fine arts and a minor in economics. He began working for a company that is connected to Netflix. One day he would like to have his own video production company and make documentaries and films.

Bhattarai has been making short films for a few years, first teaching himself, then learning through his college classes. His latest creation is a 13-minute film called "Bleeders Mums." (Watch the film at bit.ly/BleedersMums.)



Bhattarai (left) with his older brother, Subodh.

"It's about these two mums whose kids and whose family have bleeding disorders," he explained. "It spans from their grandfather to their father to their kids now having those bleeding disorders. And it just focuses on how mothers leave their life behind to support their family. ...

For mothers, just handling a normal family is pretty hard, but on top of that, having this bleeding disorder throughout your family is pretty

"THE SUBJECT OF STORYTELLING AND IMAGING REALLY STRUCK ME, SO THAT'S HOW I KNEW THAT'S WHAT I WANTED TO DO."

intense. And taking care of that is really hard so I wanted to cover that in a documentary."

THE BLEEDING WON'T STOP

Bhattarai grew up just outside Kathmandu, the capital of Nepal, in a valley surrounded by the Himalayan mountains. He lived with his pharmacist dad, schoolteacher mom and older brother. No one in his family had a bleeding disorder.

When he was nine months old, Bhattarai fell on some stairs and cut the inside of his lip. In a story familiar to a lot of families with undiagnosed bleeding disorders, the wound would not stop bleeding. His dad took him to the hospital where he worked.



“FOR ME AND MY FAMILY, NO ONE KNEW ANYTHING ABOUT HEMOPHILIA. AND NOW THAT WE KNOW SOMETHING ABOUT IT, I WANT TO REACH OUT TO ALL THE PEOPLE WHO DON’T KNOW ABOUT HEMOPHILIA OR ABOUT THESE BLEEDING DISORDERS AND I WANT TO MAKE THEM AWARE.”

“They gave me all their regular medications that would have stopped me from bleeding,” Bhattarai explained. “But after two weeks I was not able to stop the bleeding; the blood would not clot.”

He was then transferred to a bigger hospital in Kathmandu City. And by luck, a nurse working there happened to have someone in her family with hemophilia. She told Bhattarai’s dad that his son could have the disease. The little boy’s blood was sent to India to be tested. While they waited, Bhattarai’s father donated his blood to his son.

“COMING FROM A NEPALI BACKGROUND, THERE’S THIS THING THAT YOU HAVE TO GO TO COLLEGE, YOU HAVE TO ALWAYS FINISH YOUR EDUCATION.”

The diagnosis came back: hemophilia A. The Kathmandu hospital had a hemophilia care unit, but plasma infusions were the only treatment. It was expensive, and insurance wasn’t available. Bhattarai’s family had to pay for any treatments.

His family and other families with bleeding disorders would wait “until it gets to be an emergency, or else they just try to stay home and get rest and get iced up,” he said. It was important to try to prevent injuries and bleeds as much as possible.

When Bhattarai was about seven years old, he fell from a swing at

school. He had a large bleed on his right side and in his right knee joint. His parents took him to the hospital, where they had only some expired factor products. He was given the treatment anyway, but it didn’t do much to clear the bleeds.

From then on, his parents restricted his activities. He considers it an accomplishment that he was able to go to school, usually only when he could hitch a ride on a classmate’s bicycle. During his childhood, he developed target joints in his left ankle and right knee. He spent a lot of time at home with his mom, who had quit teaching and started a small orphanage at their house for other kids in need.

LOOKING FOR TREATMENT

Twice as a child, Bhattarai and his father traveled to India where Bhattarai spent six months total doing physical therapy (PT). But there

was still no treatment, and the PT didn’t help much. Bhattarai’s parents began to talk of going to the United States, where they had family. They were connected with the Mayo Clinic in Rochester, Minnesota, and were offered a spot to stay for free at the nearby Ronald McDonald House.

In 2011, at age 13, Bhattarai headed to Minnesota with his father for surgery. “When I came to the U.S., my problem was my right knee was bent to 120 degrees and I was not able to straighten it out.” Mayo surgeons removed a piece of bone and inserted screws that enabled Bhattarai to bend his knee again. He underwent PT and was given prophylaxis factor treatment the entire six months he was there. As he prepared to return to Nepal, he was given a big box of factor to ration out when he got home. (The factor lasted more than a year.)

However, his dad stayed behind in the U.S., moving to California to be near family, and starting a plan to move his entire family to the States. In 2013, the family was able to obtain visas to move to the U.S. based on Bhattarai needing better hemophilia treatment.

In Nepal, Bhattarai had finished seventh grade, but because he was 14, the school system placed him in high school. He was suddenly a sophomore who knew only a little English. He’s thankful his school had a program called English Language Development. Known as “sheltered

instruction,” it taught him and his classmates—who were from all over the world—how to read, write, speak and understand English.

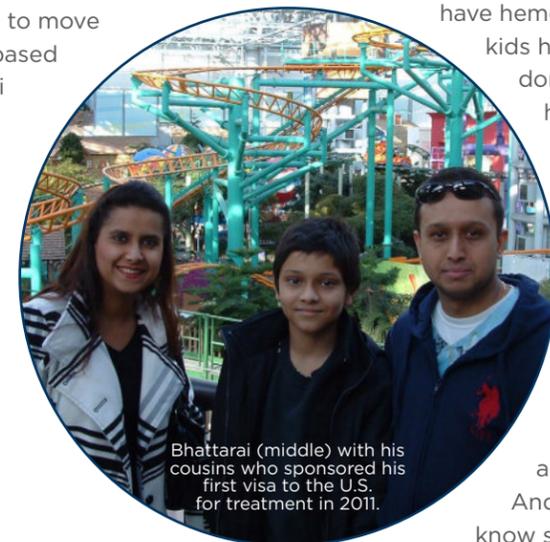
He gradually became fluent and caught up with his classmates. After graduating high school, he headed to community college for three years before heading to UC Santa Cruz. “Coming from a Nepali background, there’s this thing that you have to go to college, you have to always finish your education,” he said. (He also had right knee surgery in high school and then right knee replacement surgery during community college.)

TEACHING THE WORLD

Through his films, Bhattarai wants to educate people around the world about hemophilia and also show what it’s like growing up with a bleeding disorder in countries that don’t have access to prophylaxis or hemophilia treatment centers.

“In Nepal, not a lot of people know about hemophilia,” he said. “I’m imagining that there are a lot of countries where a lot of people who have hemophilia, or whose kids have hemophilia, don’t even know they have hemophilia—or they don’t even know what the proper treatment is or how to help their kids.”

“For me and my family, no one knew anything about hemophilia. And now that we know something about it, I want to reach out to all the people who don’t know about hemophilia or about these bleeding disorders and I want to make them aware.”



*We're counting down the days
for HFA hugs to resume*



Until then, we're here for
you and your family
at www.hemophiliafed.org



GETTING WIRED WITH RESEARCH DURING A PANDEMIC

BY WHITNEY ARMIJO, RESEARCH PROJECT COORDINATOR

In the past two years, two Hemophilia Federation of America (HFA) projects have aimed to empower women in the bleeding disorders community to take part in research and advocate for their own health.

In 2019, the HFA research team created Females In Research Sharing and Translation (FIRST) to gather more details about how women in the bleeding disorders community feel about research, what prevents them from participating in research, and what researchers can do to encourage more women to participate in research. FIRST was funded by the Patient-Centered Outcomes Research Institute (PCORI).

FIRST included four in-person focus groups of women with bleeding disorders or symptoms of bleeding disorders. A fifth focus group was done over Zoom and included women from across the country. One of the themes observed in these conversations was

that women do not participate in bleeding disorders research because they simply are not aware of any research opportunities that include women.

After the focus groups were conducted in late 2019 and early 2020, the next step in the FIRST project was to hold an in-person training to provide information about bleeding disorders and about patient-centered outcomes research to women. The aim was to empower women to engage in research in the future.

However, because the COVID-19 pandemic prevented any large gatherings in 2020, HFA applied for and received funding from PCORI to promote virtual engagement. This funding was used to create a virtual, web-based academy where women could safely engage with each other and receive education on bleeding disorder topics.

The academy—called Women In Research Engaged while Distanced (WIRED)—was an educational platform created by HFA and tailored for women

with bleeding disorders. It ran from October 26 to November 24, 2020.

WIRED ACADEMY

In designing WIRED, the research team used what we learned from the FIRST focus groups to encourage as many women as possible to attend. To facilitate that, the program was designed to be mostly self-paced, allowing women to engage whenever their busy schedules allowed. In addition, live meetings were scheduled on weekday evenings, monetary compensation was offered, and women with all forms of bleeding disorders were included, all as requested by women during the FIRST focus groups.

Eighty-eight women were enrolled in the program and divided into eight groups of 11 women each. One woman from each group was selected to serve as a peer mentor. After researching different engagement platforms, we chose Crowdstack as the home for WIRED Academy. This was mainly due to its focus on user conversations, its ability to show leaderboards (including a points system to award members for

their activity within the site), and its participant privacy security features.

A curriculum was designed to best help women have the knowledge base to confidently participate in future research. Four learning modules were created:

1. Bleeding Disorder Basics
2. Women's Health
3. Research and Clinical Trials
4. Engaging while Socially Distancing

The educational material for the first three modules was based in HFA's Learning Central platform (the content can still be accessed at www.hfalearning.org), while the fourth module's curriculum included articles published by PCORI about the importance of continuing research while social distancing measures are in place.

WIRED Academy was also designed to inspire engagement among the women via discussion board prompts posted twice a week by peer mentors and via live Zoom webinars. Group members were encouraged to share thoughts and impressions from the week's curriculum with each other. In addition, a group of all the women participating in the WIRED Academy was created to foster relationships and discussion across all focus groups.

Women were also provided opportunities to talk with bleeding disorders experts. A Furthering Education Seminar was held for each module in which an expert presented on the topic covered and then answered participants' questions.

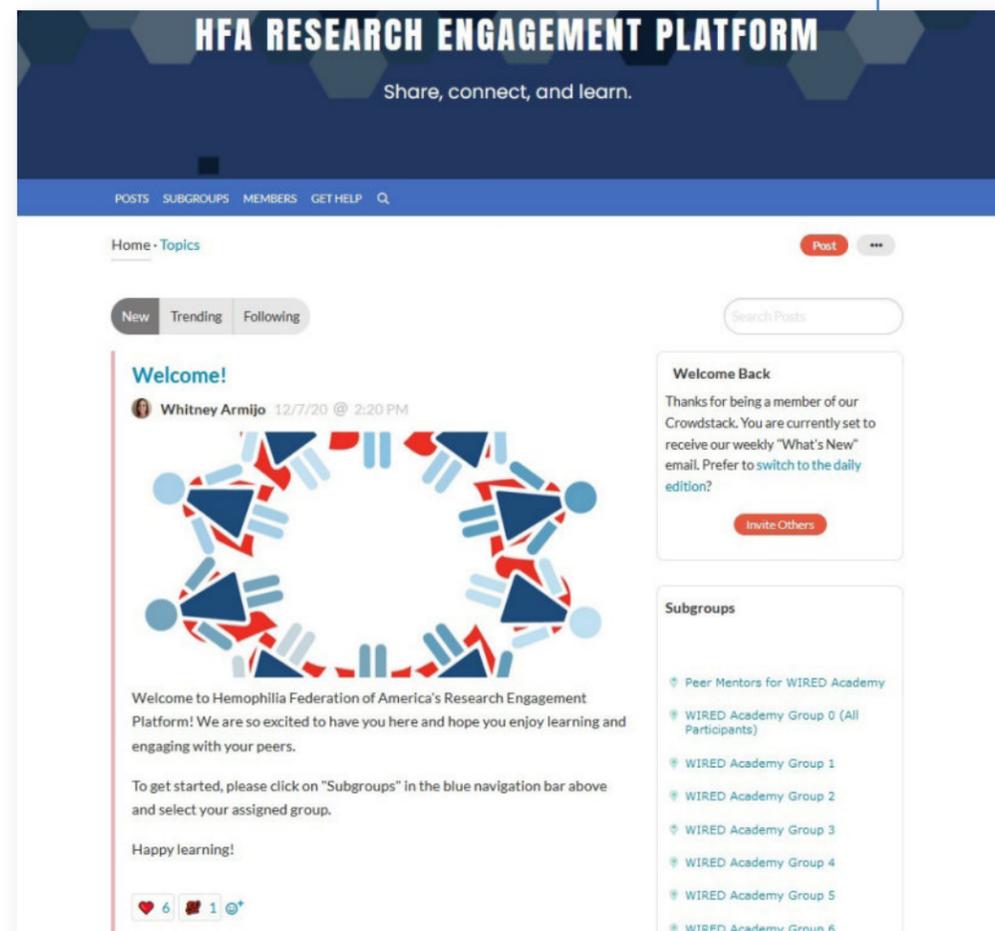
Most participants felt that the WIRED Academy was a good resource for better understanding their bleeding disorders

from a woman's perspective and for giving them tools for advocating for their own health. As one of the participants said: "I learned so much from the women involved with WIRED. I found out what it is like for those who had bleeding disorders that are not usually talked about. I appreciate all the personal stories. I have seen so many of you reach out and support each other. ... Let's keep the ball rolling!"

Many women also reported an increased desire to participate in research and greater confidence that their voices are essential in the research process.

FUTURE IMPLICATIONS

Through participation in this program, we now have a better-informed cohort of



HFA used the Crowdstack platform to create an engaging, interactive space for women enrolled in WIRED Academy to gather as a community.

“I LEARNED SO MUCH FROM THE WOMEN INVOLVED WITH WIRED. I FOUND OUT WHAT IT IS LIKE FOR THOSE WHO HAD BLEEDING DISORDERS THAT ARE NOT USUALLY TALKED ABOUT. I APPRECIATE ALL THE PERSONAL STORIES. I HAVE SEEN SO MANY OF YOU REACH OUT AND SUPPORT EACH OTHER. ... **LET'S KEEP THE BALL ROLLING!**”

women in the bleeding disorders community who are able to not only better advocate for their own health but also participate in patient-centered research design and implementation.

Their increased knowledge of research and of the importance of patient input during the research process results in informed community members. These women can now help researchers examine what matters most to people in the community, understand the importance of participating in research and advocate for other women in the bleeding disorders community. Participating in this program also allowed women the opportunity to create bonds with other women in the community and support each other as they continue to face their daily challenges.

After the completion of the WIRED Academy, we recruited four graduates to participate in our FIRST project's Community-Based Research Network (CBRN). We worked with this network from January through May of 2021 to identify topics across the lifespan of women with bleeding disorders that need to be researched further. It has helped us create a research agenda that will be distributed to funders, researchers and other stakeholders across the U.S. to encourage more research on women.

The four women from WIRED Academy were integral to this process. They shed light on what kinds of research matter most to women in the bleeding disorders community.

HFA is now seeking further resources to continue to engage with the members of the CBRN, further refine the research agenda and broadly disseminate it in the coming year. Stay tuned! 💧





HFA LAUNCHES YOUNG ADULT PODCAST, THE **BloodFlow**

BY MELANIE PADGETT POWERS,
MANAGING EDITOR

Podcasting is considered a more personal form of communications. Listeners feel like they know the podcast host, who seems to be talking directly into their ears on a regular basis.

That personal connection allows podcasters and their fans to build a community around whatever the topic is. Last summer, Hemophilia Federation of America (HFA) embraced this unique and very popular platform to educate and connect young adults in the bleeding disorders community.

The BloodFlow is a young adult podcast created and launched by 2020 virtual summer intern Tameelah Dawson, under the guidance of Kimberly Ramseur, HFA senior manager for policy and advocacy.

Dawson graduated with a psychology degree in May 2021 from Claflin University in Orangeburg, S.C. This fall, she is heading to Florida Agricultural and Mechanical University to earn a master's degree in community psychology. She hopes to work as a community psychologist in an urban area.

A MENTAL HEALTH FOCUS

Because of Dawson's interest in mental health, that's what she focused the first podcast episode on. In that episode, released July 23, 2020, she interviewed bleeding disorders advocates and young adults Ashley Johnson and Bradley Odac about how growing up with a bleeding disorder affected their mental health.

In the bleeding disorders community, Dawson said, "We don't ask questions about mental health, like, 'how is your mental health dealing with a bleeding disorder?' I wanted to take it from a young adult perspective and see how it affected young adults."

While mental health conversations increased during the pandemic, it's still not always comfortable to talk about. "Bradley and Ashley were great about speaking out," Dawson said. "It felt good to not only talk about mental health while having a bleeding disorder, but they also spoke about relationships and how it was when mentioning your bleeding disorder within a relationship or when you were going to college."

Dawson has received positive feedback about the show. "A lot of people said the podcast was helpful. I know a few young adults who would like to come on the show."

Ramseur oversaw the technical aspects of the show—creating a logo, selecting the recording and hosting software, submitting the podcast to podcast directories (Apple, Spotify, Google podcasts, etc.). She provided guidance, and she and Dawson worked together to recruit guests and develop interview questions. But, Ramseur encouraged Dawson and other young adults to run with their ideas.

"We wanted young adults to take the lead and be the voice behind the podcast," Ramseur explained.

Dawson "did a phenomenal job," she said. "It was nice to hear them express themselves in the ways they did. She did a great job in making them feel comfortable about having a conversation about mental health and their bleeding disorder."

ADVOCACY-FOCUSED EPISODES

Will Hubbert, also a 2020 HFA advocacy intern, got involved too, developing and hosting six episodes in 2020 and 2021 so far. Hubbert graduated in May 2021 with a history degree from the College of William & Mary in Williamsburg, Virginia.

"Podcasting is very familiar [to listeners]," Hubbert said. "Writing is a skill that takes a lifetime to master, especially writing with a distinct voice in a way that's engaging and entertaining, but also conveys actionable information. But there's something very conversational about sitting down and just having a chat with someone."

Hubbert's episodes showcase his interest in advocacy. In the August 18, 2020, episode he interviewed a staffer from Young Invincibles, a nonprofit that advocates for young adults about navigating the health insurance market with a chronic illness. In the November 9, 2020, episode he interviewed a congressional staffer from Sen. Joe Manchin's (D-WV) office. In his April

PODCAST LISTENING SKYROCKETS

The number of people listening to podcasts surged in late 2020 and in 2021, according to Edison Research, the leading podcast research company.

Initially, podcast listening declined slightly when the COVID-19 pandemic hit the U.S. in spring 2020—as anxiety and fear took over, adults lost their "podcast listening" commutes, and people had to rearrange their work, home and school lives. But, as the pandemic wore on, Americans returned to podcasts by the fall of 2020, and many of their friends and neighbors joined in.

In 2021, 80 million Americans, or 28% of the population 12 and older, listen to podcasts every week, Edison reports. That is a 17% increase from 2020. In fact, the weekly audience for podcasts has almost doubled since 2017—and more people listen to podcasts than who have ever used Twitter, Snapchat or TikTok, according to Edison. Furthermore, 41% of the U.S. population age 12 and older listened to at least one podcast in the past month.

Podcasts have also become more diverse: 43% of the monthly podcast audience is non-white. Podcasts themselves have also become much more diverse, as almost anyone can start a podcast without investing a lot of money. When podcasting first started 15 years ago or so, the audience was mostly white and mostly male. That has changed significantly.

20, 2021, episode, he interviewed California public school science teacher Hector Moreno about finding and managing employment with hemophilia.

Hubbert said he had experience with in-person facilitation and being interviewed but not with recording a podcast—which was done over the phone. “It was trial by fire, figuring out the cadence of the show and getting into that groove of producing content for an exclusively audio, after-the-fact, edited format,” he explained. “I was used to doing stuff live.”

One of the challenges, he said, was balancing going straight through his list of questions versus responding organically to what guests were saying. He also was aware of not monopolizing the conversation and learning how to build rapport with guests.

Ramseur has been impressed with the preparation Hubbert undertakes before recording each interview. “It’s more like a conversation,” she said. “He takes the time to do the research and really get involved in the conversation. He asks some awesome in-depth questions.”

MORE EPISODES TO COME

A new episode of The BloodFlow has been released every month or two, based on guest and host availability. There will likely be new episodes this year with a 2021 advocacy summer intern as a host. In addition, the HFA Young Adult Advocacy Summit this fall may offer an opportunity to record episodes and/or recruit participants. The Summit will be held virtually September 18–21 in Washington, DC.

While the primary podcast audience is young adults, Ramseur would like the audience to expand. Listening to young adults’ experience can be helpful to others in the community as well.

“Moving forward, it would be nice to see it grow,” she said. “Maybe it’s not only young adults who hear it, but providers, parents and younger teens so they get a better idea of the issues young adults may not express to others and have a better understanding of what’s going on with them. We would all benefit from that.”

If you have episode ideas or questions about The BloodFlow—or would like to get involved or be a guest on the show—email advocacy@hemophiliafed.org. To listen to the podcast, search “The BloodFlow” on any podcast app. 📌

HFA VIRTUAL SYMPOSIUM 2021: 100% ONLINE. 100% FREE.

Join family, friends and your Hemophilia Federation of America (HFA) community for Virtual Symposium 2021 taking place online

October 18–28. After the challenges of 2020, HFA will address the current issues facing parents, adult men and women, young adults and kids in our bleeding disorders community. The HFA team is bringing you the latest information on medicine and technology, mental health care, Spanish resources, access to financial resources, barriers to care, and so much more. More information and the registration link is at www.hfasymposium.org.

HOW MUCH DOES IT COST TO REGISTER?

Nothing! Symposium 2021 is a free event, although registration is required. There are no costs or fees associated with your participation; we’re just happy to have you join us for 10 days of programming.

DO I NEED TO ATTEND ALL OF THE SESSIONS?

No. Registering for Symposium will provide you with access to 10-days’ worth of programming, but you can choose to attend any sessions that interest you. Almost all sessions will be

recorded and available on the Symposium website within a few days of the initial session date so that you can watch at your leisure.

DO I NEED SPECIAL TECHNOLOGY OR MOBILE APPS TO ATTEND?

All of the sessions will be hosted on Zoom Webinar, making it easy for you to access. With just the click of a button from the agenda page of the website, you will be able to enter the session. We recommend you download Zoom onto your computer/phone beforehand for a more seamless experience.

WHEN WILL SYMPOSIUM BE BACK IN PERSON?

Shine those boots and saddle up! We are heading to San Antonio for what is shaping up to be our biggest and best Symposium yet. Mark your calendars for April 20–23, 2022, and plan to join us deep in the heart of Texas for our first in-person Symposium since 2019.

We’ve missed seeing you all so very much and hope you are as excited as we are to meet up in-person. Registration information will be released during Virtual Symposium. Register today at www.hfasymposium.org. 📌



Connected to what matters.

Our admiration for the hemophilia community knows no bounds. It pushes us to discover, advocate, and support you in ways big and small. So more moments like this are possible.



Let’s connect.
rareblooddisorders.com
📍 @HemophiliaCoRes
1-855-SGZHEME

© 2020 Genzyme Corporation. All rights reserved.
MAT-US-2019890-v1.0-09/2020



Connected to you.

As Community Relations & Education Managers, our work with the hemophilia community is deeply personal. It unites us in our efforts to help educate and support you and your family.



Reach out to your local CoRe to learn more.
rareblooddisorders.com
@HemophiliaCoRes | 1-855-SGZHEME

SANOFI GENZYME 

© 2021 Genzyme Corporation. All rights reserved. MAT-US-2101737-v1.0-03/2021