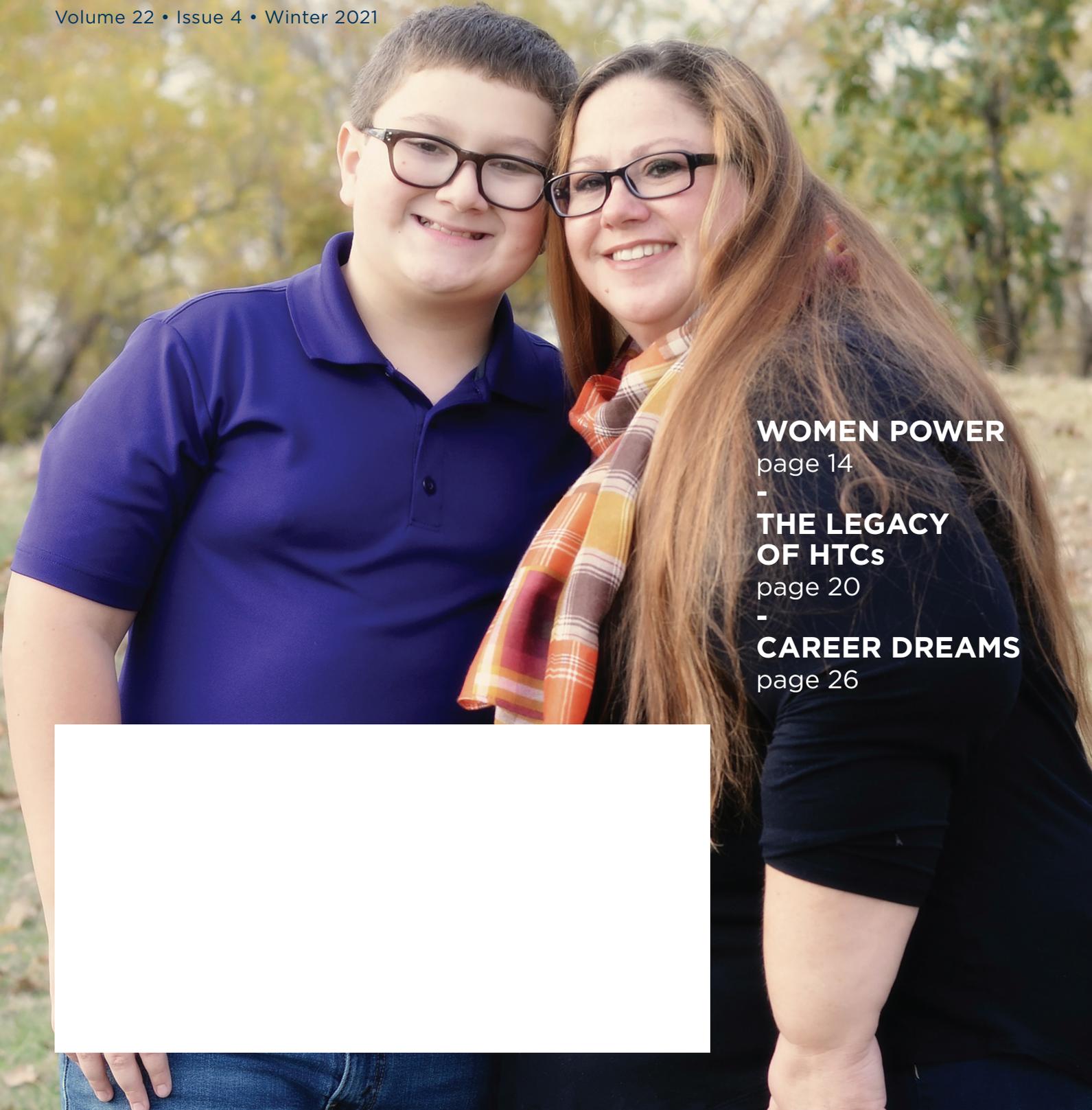




# DATELINE

## F E D E R A T I O N

Volume 22 • Issue 4 • Winter 2021



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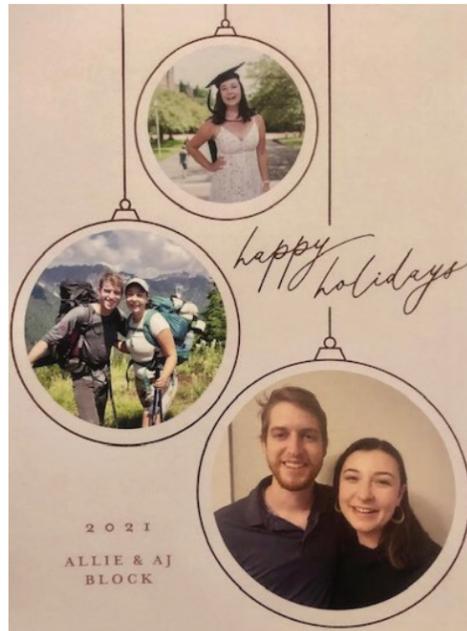


## HI FRIENDS,

I'm not quite sure how it's the beginning of 2022 already, but here we are. I hope you had a wonderful and safe holiday season, getting to have both restful and joyful moments. Some holiday highlights for me included wreath-making with friends, playing many rounds of the game "Codenames" with my family and reading a few wonderful books. I'm hopeful for what this new year will bring and can't wait to meet some of you at our planned in-person events.

"Some holiday highlights for me included wreath-making with friends, playing many rounds of the game 'Codenames' with my family and reading a few wonderful books."

On page 8 of this issue, I think you'll enjoy the photos and story of Hogan Lust. Now a teenager, Hogan has found success through tournaments hosted by the North American One-Armed Golfer Association. Hogan developed left-sided cerebral palsy after a brain bleed as a baby. But he picked up a golf club when he was only 3, learning to swing with only his right arm, and he has been succeeding in golf ever since.



On page 14, you'll find a feature article highlighting just a few of the women in the bleeding disorders community, who often went undiagnosed for years because doctors never suspected a bleeding disorder. This is a common tale for many adult women with bleeding disorders. As awareness continues to grow about bleeding disorders—including hemophilia—in women, I hope our community's girls and future generations are diagnosed much earlier and don't have to suffer the years of excess bleeding that can have such a huge impact on a person's health and quality of life.

On page 20, we're excited to bring you an article about the history and current status of hemophilia treatment centers (HTCs). Do you know when they were created and why? How are they funded? And how can you access their services if there isn't an HTC near you? The story is a fascinating look at the past and present of HTCs.

On page 26, see how HFA has helped community members achieve their career goals, and provide more financial stability to their families, through new Job Readiness Grants. These are truly inspiring stories.

Please 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 4 • Winter 2021

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Cover photo: Leisa MacDougall and her son, Jayden

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New HFA Job Readiness Grants help community members reach their career goals and improve their lives.

## Support the Work of HFA this Holiday Season

As we move through this season of giving, we ask that you think of HFA while making your end-of-year donations. As you know, living with a bleeding disorder presents a lifelong series of “what if”s. These unknowns can be very scary for a new parent or a seasoned community member. Bleeding disorders can bring health issues and frequent trips to the hospital, as well as a battery of situations forcing families to make tough choices. The good news is that for more than 25 years, HFA has been a support system to hold up families after a “what if” becomes a reality. HFA is a comforting resource where families can get answers—answers that bring relief and stability to a family struggling to adapt to their reality. Our Helping Hands program was designed specifically to help community members who are experiencing a financial crisis with basic living expenses.

The financial need in our community is persistent. The coronavirus is relentless. The flow of referrals to our programs is continuous. This year, we’ve helped hundreds of families in need, but there is so much work left to do. Helping Hands is there for our families. Now, we need your help. Would you consider making an unrestricted gift to HFA to help a family with emergency assistance or to purchase a necessary medical item? Please make your secure gift online at [www.hemophiliafed.org/donate](http://www.hemophiliafed.org/donate) or send a check made out to Hemophilia Federation of America to 999 N. Capitol Street NE, Suite 301, Washington, DC 20002. Make a gift that will profoundly change a life.



## Kick Off the New Year with Team Resilience

Lace up those running shoes and plan to join Team Resilience in the most magical place on earth: Walt Disney World! Two big racing weekends remain in our 2021-2022 runDisney schedule: Princess Half Marathon weekend, February 24-27, 2022, and Spring Surprise Weekend, March 31-April 3, 2022. Choose from a multitude of race lengths or sign up for a challenge event and compete in multiple races over the course of one weekend!

Team Resilience is HFA’s endurance fundraising team, participating in various athletic and competitive events to raise awareness about bleeding disorders and funds for Helping Hands, our financial relief program for families in crisis. Having a bleeding disorder presents many challenges that individuals and families must overcome. It is their resilience that inspired HFA to create Team Resilience.

Sign up today at [www.hemophiliafed.org](http://www.hemophiliafed.org).



## Have Fun Indoors!

With winter here in most of the U.S., now is a good time to try new activities and games indoors with your family. Here are 5 ideas:

### 1 Camp Out in Your Family Room

Put on your pajamas, grab your sleeping bags and your favorite stuffed animals, and camp out in the living room. Make s’mores in the microwave and drink hot chocolate. Instead of telling ghost stories, share some of your happiest family memories.

### 2 Watch a Movie Marathon

Over several nights or weekends, choose a new movie to watch followed by its sequels. Depending on the children’s ages, this could be a cartoon series or a Marvel Comics or D.C. comics movie series.

### 3 Try No-Tech Fridays

On a weekend night when everyone is home, maybe Friday nights, create a “no tech” rule. But be sure to create a night of family activities, like making pizzas or tacos together, followed by playing board or card games.

### 4 Create a Winter Scene Indoors

Get out the craft supplies and spend a weekend afternoon decorating the house. Create a winter wonderland by making paper snowflakes, puffy paint snowmen or winter scenes with watercolors.

### 5 Embrace Dancing

Add the fun, sometimes silly, and healthy activity of dance to your weekly activities. Try out new music, create your own playlists, learn Tik-Tok dances or play “freeze dance” (like musical chairs except you dance until the music stops and everyone freezes and tries to hold their pose).

Feel free to tear out this activity sheet.

What do you like to do for fun with your family? Draw a picture of it!



Feel free to tear out this activity sheet.

## The Connecticut Hemophilia Society

The Connecticut Hemophilia Society (CHS) is a small but mighty organization. Started in 2010, CHS serves members throughout Connecticut. Most CHS members also belong to the larger New England Hemophilia Association (NEHA), which benefits members because they have the support of both organizations. They can choose smaller-scale programs with CHS and take advantage of larger events with NEHA, said Executive Director Meagan Murray.

CHS has several successful and popular programs. One of these is a very New England-type of event: the Alpine Walk. Participants walk through the snow with snowshoes and raise awareness for bleeding disorders. It brings the community together to enjoy a weekend of snow and camaraderie and is the biggest fundraiser of the year.

Another premier event is the Hartford Yard Goats CHS Member Appreciation Night. Members are treated to a local baseball game and tailgate cookout. Former Board President Dennis Mackey mans the grill in the lot, and then the community members all walk together to the game. In 2021, 59 people took part—which is particularly remarkable because it was the day before an impending hurricane. Members of all ages attend this bonding event for free and look forward to it every year.

CHS members are also active in HFA's Gears for Good. CHS brought it

back in 2021, and people came from all over New England—and as far as Illinois—to ride or volunteer. “We raised funds for both ours and HFA’s Helping Hands funds,” Murray said. “This was quite successful, and we are already planning for 2022.”

Community engagement in CHS has been steadily increasing in recent years, despite the pandemic. Murray

### THE CONNECTICUT HEMOPHILIA SOCIETY

Started in 2010

150 people served

Serves Connecticut



pointed to the quote, “When you love what you do, you don’t really work.”

“Having a blood disorder myself, I know how it feels when you are scared and feel like no one can relate. For the past eight years I have been very involved in the bleeding disorder community on a local and national level. It is inspiring to be around others like me,” Murray said. “Every event or program that we have planned we keep members in mind. We have reached out to members to ask what they would like to see or learn about, and we are very open with communication. Our members are at the heart of our success.”

CHS also works closely with other local chapters such as NEHA to plan joint programming and to ensure their programs do not overlap. The relationship with NEHA has been critical to CHS’ success, Murray said, and members like having many options available to them.

Volunteers are the backbone of CHS. Kristin Elliott was a member who reached out to Murray to help however she could. She thrived as a volunteer and was then hired as the part-time CHS director of development.

“I started going to CHS events and saw that

I was learning and having fun,” Elliott said. “CHS has become a second home. This is the first job where I look forward to being on a Zoom call and I know I will leave happy. It’s great having a voice, feeling valued and knowing that I am making a difference.”

## Fore the Love of the Game

Hogan Lust has become a teenage standout in one-arm golf association tournaments

BY MELANIE PADGETT POWERS, MANAGING EDITOR

Hogan Lust, age 16, of Tucson, Arizona, has been playing golf since he was a toddler. His parents, Daniel and Corby, are golfers too, so it was only natural their oldest child would play the sport.

“He had a golf club in his hand since he could walk,” Daniel said. However, Hogan had to learn golf a bit differently, as he can only use one arm to swing. After his birth, Hogan had a brain bleed, but with no

family history of hemophilia, it was unexpected and went undiagnosed until he began to have seizures during his first week of life.

Hogan was diagnosed with severe hemophilia A. A neurosurgeon had to evacuate the bleed, which included removing his right frontal lobe and part of his parietal lobe to relieve the pressure on his brain.

The surgery left the baby with cerebral palsy, causing weakness on

his left side, particularly his left arm. Throughout Hogan’s childhood, the Lusts encouraged him to try certain sports and activities, adjusting them as he needed. In fact, in November 2021, Hogan rode the 27-mile El Tour de Tucson bike race with an adaptive recumbent bike.

But it is golf that became his passion. When he was younger, he competed in the PGA Junior League as a member of his local country club’s team before aging out of the program. Several years ago, the Lusts heard about the North American One-Armed Golfer Association, but there was no youth program. But by January 2019, the association had started a youth program and Hogan played, for the first time, with other teenagers who played with one arm because of a physical disability or limb deficiency.

“It was different. I was playing with kids my age, but I had never competed before with people playing with one arm like I play with,” Hogan said. “I was playing with people who play like me.”

In June 2021, Hogan competed against adults at a one-armed golfer regional event in Kentucky—and he excelled. “I feel grown up that I can compete with the adults,” he said. Next, he headed to the national event in Michigan in September, where he wanted to compete with the adults again.

At nationals, Hogan became the youngest one-armed player ever to medal in stroke play. After 36 holes

on two courses, he qualified as #8 in his flight, the youngest to ever do so, qualifying him to play in the match play championship. (A golf flight is a small group in a tournament that plays directly against each other.)

Hogan went on to play in the 18-hole championship. But weather was a challenge for the Arizona family. Daniel chuckled as he explained they didn’t have heavy jackets or rain gear, not even an umbrella, for that third cold, rainy day of golf.

Although Hogan didn’t medal, a highlight was that Daniel was his caddie for part of the tournament. “I was very proud that he was competing,” Daniel said. “I caddied for him a little bit, so we could talk strategy and club selection and types of shots and where to land the ball. But it was up to him to go up and hit the ball and play his game.”

Hogan has also competed twice in CSL Behring’s Gettin’ in the Game sports event for kids with bleeding disorders.

His first year he won longest golf drive, and his second year, he won second place overall for golf.

Hogan practices at his local country club, where he uses the golf handicap scoring system to compete with his dad—they play for 25¢ a hole, and Hogan has beat his dad twice.

Through the one-armed golfer association, Hogan has been able to take clinics from top one-armed adult players, who have taught him new techniques. “Since Michigan, we’ve cut his clubs down. He’s learned some different types of swings and practiced his short game,” Daniel said.

“I like golf because it’s something I can do, and the fact that I’m competing with other people with my disability and being able to be a part of the association—it’s pretty special,” Hogan said. “I just want to keep playing and play in as many events as I can and eventually become a national champion.”



ABOVE: Caddie Daniel and Hogan at the little boy’s first golf event at age 3. RIGHT: Hogan on day one of stroke play at the national championship in Michigan in September 2021.

In June 2021, Hogan played with one-armed adult golfers for the first time. Here, Dan Aldrich, president of the North American One-Armed Golfer Association (NAOAGA), presents Hogan with a new golf bag with his name on it to welcome him to the organization.

Hogan, on the left, with other one-arm junior golfers at a NAOAGA fundraising tournament in South Carolina in July 2021.

## GET TO KNOW HFA'S STAFF

Please welcome the most recent additions to the HFA staff.



**Jeanette Jones**  
Education Manager

Jeanette Jones lives in somewhat rural Guthrie, Oklahoma, with her husband, two children and two dogs. She enjoys music, gardening, anthropology and movies. She studied religious education and missions at Oklahoma Christian University and has a master's degree from the University of Central Oklahoma in linguistics and English education, which was the focus of her career for many years.

Jones has a rare bleeding disorder and has been involved with the community since 2011. She worked with her local bleeding disorders organization as communications director for more than two years and joined the HFA education team in September 2021. She works closely with member organizations as an education manager and leads the Blood Sisterhood Program.

"As a community member, I have been a longtime fan of HFA and know how vital our efforts are for the bleeding disorders community," she said. "The opportunity to join HFA's education team came to me at the perfect time. I feel very fortunate to have the chance to make a difference in the lives of my blood family."



**Lindsay Cox**  
Senior Manager, Advocacy and Outreach

Lindsay Cox joins HFA from the New York City hemophilia chapter, where she was responsible for programming, community engagement, volunteer management and organizational strategic planning as the director of engagement and strategic innovation. Cox also served as coalition manager for the New York State Bleeding Disorders Coalition in her dual role.

Cox is a graduate of Binghamton University with a dual bachelor of arts in political science and philosophy, politics and law. Cox joined the bleeding disorders community with extensive experience in volunteer management, facilitating educational and leadership workshops, and advocacy work. In her free time, she enjoys traveling, volunteering, playing board games, watching women's soccer and playing the guitar.

"I've seen firsthand the wide-reaching positive impact that HFA has had on the bleeding disorders community, and I'm so grateful to now be able to contribute to that in my new role on the public affairs team. I've enjoyed every moment so far, and I look forward to meeting even more of the community going forward!"



**Keith Gee**  
Development Officer

Keith Gee joined the HFA team in October 2021. Keith has worked in the nonprofit sector for 30 years in various fundraising capacities. He is excited to take HFA to a new level and help the organization serve even more people living with a bleeding disorder. Gee will be focused on connecting with individual donors, working events and helping out wherever needed.

Gee calls sunny Florida home and can't imagine living anywhere else. When he is not working, he is staying in shape and driving his 1996 Corvette to the beach. He also loves music and movies. Gee has lived in three different countries and has traveled the world.



**G. Shellye Horowitz**  
Associate Director, Education

G. Shellye Horowitz comes to HFA with over 25 years of experience in the field of K-12 education, working as both a school counselor and principal. She worked in three U.S. states and was head of school at an American international school abroad.

Horowitz has strong ties to the bleeding disorders community with six traceable generations of hemophilia A in her family, affecting both men and women. She has given presentations and served on numerous committees focused on increasing awareness of diagnosis and treatment for women with bleeding disorders. Horowitz's hobbies include international folk dance, geocaching, knitting, hiking, home improvement projects and walking her dog, Hope, on the beach.

## HFA's Virtual Symposium 2021

Over 10 days, hundreds of community members tuned in for this year's virtual Symposium.

October 18-28 marked the 2021 edition of HFA's Annual Symposium. Over the course of 10 days, hundreds of community members tuned in via computer screens and mobile devices to educational sessions unlike any Symposium before. Even though we could not gather for this year's Symposium, it was of the utmost importance to



HFA that we provide the familiar family-gathering feeling that Symposium evokes, even across the computer screen.

Highlights of Virtual Symposium included two keynote speakers, industry-led sessions, a robust poster session, informational educational sessions and a cozy final night event that will be talked about for Symposiums to come!

If you missed Symposium sessions, or would like to watch them again, the majority of the 2021 sessions are available via the HFA YouTube page, [www.youtube.com/HemophiliaFederationofAmerica](https://www.youtube.com/HemophiliaFederationofAmerica). We would encourage you to scan through the list of videos and watch, or rewatch, them all.

Thank you to our 2021 Symposium sponsors! This event would not have had the success it did without the support of our sponsors.

Please save the dates for Symposium 2022, April 20-23, as we shine our boots, saddle up and head to San Antonio for what is shaping up to be our biggest and best Symposium yet.



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**10** days of programming

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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](https://www.hemophiliafed.org)





Kristin Voyles with her family

# WOMEN POWER

Traditionally, women often wait years for a proper bleeding disorders diagnosis. But more awareness, advocacy and treatments are improving things now and for future generations.

BY RISA KERSLAKE, FREELANCE WRITER

**K**ristin Voyles didn't know growing up that she had von Willebrand disease (VWD). Looking back though, it made sense. She bruised easily and had heavy periods. "At 18, I had bursitis in my shoulder as bad as an almost 80-year-old," she said.

Voyles is now 43 and living in Broken Arrow, Oklahoma, with her husband and children. Both she and her husband have type 1 VWD, and her youngest son has type 3. The search for answers for her son's excessive bleeding after circumcision began at five days old.

"That's when my anxiety started," Voyles said. "I just put up a wall and didn't know what to think. I was scared to death."

Her son was six months old when he received a diagnosis. Voyles and her husband were tested next. Looking back, she remembered that both her paternal grandfather and dad hemorrhaged after being diagnosed with cancer. Her father died soon before her son's diagnosis.

"We didn't hit that diagnosis in time to save my father," Voyles reflected. Not only was she in disbelief, suddenly finding herself with a bleeding condition, but her son had one too. "It was devastating, knowing that we've changed my son's life forever."

Voyles opted to have a hysterectomy to control her heavy periods. She has arthritis from years of no treatment for a condition she didn't know she had. "I haven't had to take a lot of factor," she said. "If I have surgeries I'll have to treat, but I've been pretty lucky."

Traditionally, the bleeding disorders community hasn't focused on women and the unique symptoms and complications they can have. Many women go years without proper diagnosis, sometimes being told their excessive menstrual bleeding is normal. Fortunately, there have been strides in the medical community that have given more recognition to women with bleeding disorders in recent years. With this, comes more opportunities for women to get diagnosed—and treated—earlier, share their stories and empower others to advocate for themselves and their families.

### Challenges in Diagnosing

For Rachael Robinson, 53, of Owasso, Oklahoma, her Factor 13 carrier status was a surprise as well. She had heavier periods growing up but didn't think it was abnormal enough to tell her doctor. "I never had nosebleeds, but I do bruise easily," she said.

After an uneventful birth, her son experienced bleeding complications after his circumcision. They saw a pediatric urologist and there was talk of a possible bleeding disorder, but testing was never done.

As her son grew, he bruised and had a lot of bumps under his skin. Several times she'd take him to the local pediatric hematologist only for her concerns to be dismissed. Factor assays, timed bleeding tests, platelet aggregation—all of them were normal, but only because Factor 13 wasn't included.

The family was sent to a bleeding disorder center in Oklahoma City when her son was five, where he was finally diagnosed with severe Factor 13 deficiency. Robinson and her husband were never tested since it was implied both of them were carriers.

Growing up, Leisa MacDougall, now 43 and living in Enid, Oklahoma, had no idea it wasn't normal for her menstrual cycle to last more than two weeks. Her mother always told her they were a family of bleeders. It wasn't until MacDougall's son, Jayden, was four years old and had tonsil surgery that there was a concern, as he was still bleeding 10 days post-op.



Rachael Robinson with her family

After being cleared by the surgeon, MacDougall's son made two visits to the emergency department for vomiting blood and for a 3.1 hemoglobin level. The surgeon asked MacDougall about a family history of bleeding disorders; in his 40 years, he had never had a child bleed like that, he told her.

But, according to MacDougall, her son's pediatrician refused to run tests, stating they were not necessary. MacDougall's surgeon was the one who referred the family to the Jimmy Everest Center for Cancer and Blood Diseases in Children in Oklahoma City. That's where her son was diagnosed with VWD type 1 and mild hemophilia B. MacDougall and her mom were also diagnosed: Her mom had mild hemophilia B, and MacDougall had type 1 VWD and was a hemophilia B carrier.

"It felt wonderful to be validated," MacDougall said. Like others diagnosed later in life, she could look back and see the patterns. As a child, she remembered pinching her nose closed during a bleed for what seemed like hours. "There have been occasions as an adult where I have nosebleeds in the middle of the night and wake up with the pillowcase soaked."

"The advocacy is so important for healing because it empowers you to be able to move forward and help others. How much better can their life be if I advocate for this, if I work with organizations in my community?"

—Tammy Jones

Sarah O'Brien, MD, a pediatric hematology-oncology specialist at Nationwide Children's Hospital in Columbus, Ohio, often finds frequent nosebleeds are a part of a woman's history with bleeding disorders. But because nosebleeds aren't that rare, the bleeding disorder isn't often caught at that stage, she said. It isn't until adding in heavy menstrual bleeding that the picture begins to emerge.

"We know that there can be delays in diagnosis for both men and women with bleeding disorders," she said. "One huge barrier is not enough women recognize what is or

isn't a normal menses." It's not something often taught, unlike the extensive education new parents get bringing a baby home from the hospital. By the time that baby is a teenager, neither parents nor teenagers may know the signs to watch for.

Health care providers also don't often know the questions to ask. The only question a woman might get from her doctor is if her period is normal or if there are concerns. According to O'Brien, providers should be asking more specific questions, such as how many days a period lasts, if they're going

through more than four to five pads a day, or if they're getting up at night to change a pad. "If a patient answers yes to any of those questions, it's a red flag there may be an underlying issue."

Robert Sidonio Jr., MD, a hematologist and associate professor of pediatrics at Emory University in Atlanta, said there is a shortage of hematologists with the expertise to perform a workup for a bleeding disorder and properly interpret the results. There are good providers in every state, but many people, especially in more rural areas, have no choice but to drive long distances to find one that understands the complexities of their condition.

Sidonio explained that the hematology field is trying to shorten the gap from bleeding symptom to diagnosis, but "we need to do a better job at educating primary care and emergency room doctors, possibly with a lecture series." After all, they are the ones on the front lines for heavy bleeding episodes and a person's entry point into bleeding disorder specialty care.

Leisa MacDougall and her son, Jayden



## Being Told 'It's Normal'

Tammy Jones, age 61, of Greenwood, Arkansas, lived with heavy bleeding from her first menses into her early 30s. She and her four daughters have VWD. Bleeding—from her nosebleeds and bruising, to her heavy periods—wasn't talked about when she was younger. Then, after the birth of each of her children, she bled much longer than she thought she should.

"At my six-week check-up I was still bleeding," Jones explained. "I would nurse the babies and I would have gushes." Once, after nursing her third daughter, she stood up, and "blood just went everywhere. I screamed, my husband came in, and we called the doctor." Get in the shower, she was told, elevate your feet. It's normal.

When she was 34, her doctor brought up the idea of a hysterectomy. Jones wasn't ready.

But by the time the next year came around, she could hardly function. "I couldn't leave the house because I would bleed through a tampon and through doubled overnight pads and onto my clothes." When she went back to her appointment, she agreed to the surgery.

Afterward, she became depressed. "We're brought up and taught that our bodies are made for having children, and [after] that was taken away from me, I had a really hard time," she said.

When her third daughter started having frequent heavy nosebleeds, she was sent to the children's hospital. Jones requested testing for herself and all her daughters. They were all diagnosed with moderate Type 1 VWD.

After that, Jones' daughters each dealt with their own bleeding episodes and complications with heavy periods and hysterectomies. "I see my children not being able to have children because of this bleeding disorder," Jones said. "It's very hard because I go back to the fact they got this from me." Still, she said, her goal is to make sure her kids and two grandchildren don't struggle the way she did growing up. A grandson was also diagnosed with VWD.

Getting connected with organizations such as HFA can provide education and support. When her son was seven months old, Voyles became involved in HFA. She read everything she could on VWD. "If HFA had an article come out, my husband and I were reading it." While her



son's condition has leveled out in the past few years, the past decade was rough. She is thankful for the support she had.

That connection helped MacDougall cope also. HFA provided an opportunity to learn more about VWD and hemophilia B, she said. "It's just one of the most wonderful tools in the world to be connected with other people that have the disease that I have."

Jones agreed: "The advocacy is so important for healing because it empowers you to be able to move forward and help others. We can't stay in that anger zone or that depressive state thinking, 'I have this and I passed it to my children.' How much better can their life be if I advocate for this, if I work with organizations in my community?"

## Treatment Trends

HFA works to stay on top of the latest research in VWD and other bleeding disorders. According to O'Brien, more women are deciding to go with an intrauterine device (IUD) as a first-choice treatment option. IUDs are long-term, reversible contraception placed inside the uterus. "In general, IUDs work best compared to birth control pills in reducing bleeding," O'Brien said.

Doctors are working to break down barriers to IUD treatment, to make them more accessible to younger patients and provide education on misconceptions. "There are concerns IUDs affect your fertility or they can only be used if you're sexually active—or they're associated with infection. [But that] isn't the case for IUDs on the market today," O'Brien said.

In many pediatric hospitals, young patients can be placed under sedation for the IUD insertion. "That removes the barrier of a patient being scared to have a pelvic exam," she explained.

Sidonio said some situational prophylaxis can be used for menstrual bleeding, but it's not for everybody. "There's a role for factor concentrates in heavy menstrual bleeding, but women and girls should consider hormone therapy and antifibrinolytics as the first-line therapy unless there are contraindications."

If those don't work, menstrual bleeding factor prophylaxis can be considered. "We have a national study called ATHN 9, and it's focused on severe and clinically severe VWD," he said. The study is examining the use of von Willebrand factor (VWF) concentrate for various situations, including nosebleeds, joint bleeds and heavy menstrual bleeding. VWF can be a consideration if other options have failed or hormone therapy cannot be used, he said.

"I try to look for the positives," Jones said. "The answers are getting better. The care is getting better. All the new things that started this year from my advocacy are mind-boggling, and I'm so excited." 💧

## Knowledge = Power

Whether you're newly diagnosed or have been living with a bleeding disorder for years, knowledge is key when it comes to managing your health. Here are a few things to keep in mind:

### TAKE NOTES

Document bleeding events and the treatments that worked. Take photos of bruising and the amount of blood you're experiencing to show your provider, even if you feel awkward or embarrassed. "You need to use your organizational skills to take ownership of your own health care," said hematologist Robert Sidonio Jr., MD. This helps build the case to allow clinicians to perform more interventions and better understand what's going on. It also helps them advocate on your behalf to insurance companies to cover certain treatments.

### KEEP AN OPEN MIND

Your bleeding symptoms may not be related to your bleeding disorder. For example, your joint pain may need to be treated with orthotics and not have to do with a bleed, Sidonio said. Be willing to try new strategies and treatments.

### FOCUS ON YOUR MENTAL HEALTH TOO

Take care of your own mental health. "That's the thing I've struggled with the most is knowing it's OK to ask for help," said Kristin Voyles, who has von Willebrand disease (VWD). "To take time for me to sit in a hot bath and relax and get my mental clarity back." Allow yourself to step back and focus on things other than your bleeding disorder.

### GET A SECOND OPINION

"If you aren't getting the answers you want with one doctor, go to a different doctor," said Leisa MacDougall, who has VWD. "There's somebody that will listen to you and get the answers you need. Don't stop until you get those answers."



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# THE LEGACY OF HTCs

**A**t 58, Michael Birmingham, of Tacoma, Washington, is old enough to remember what life was like for kids with bleeding disorders before the advent of hemophilia treatment centers (HTCs). Diagnosed with severe hemophilia A at 13 months, he spent his early years going to the hospital whenever he needed infusions. Then he and younger brother, Pat, began getting care through a Stanford University pilot program that offered home infusion, which would become a hallmark of HTCs.

That care produced such great results that in 1973, when Birmingham was 10, his family traveled to Washington, D.C., to testify before a congressional subcommittee looking at legislation to create comprehensive hemophilia programs.

“Each of us boys had about a minute, and Dad talked for two or three minutes,” remembered Birmingham, who now works as a sales territory manager for a specialty pharmacy. The contrast between the Birmingham boys and others was striking. “The other kids brought in had obvious problems or talked about how hemophilia had caused limitations and problems,” Birmingham said. “We were just normal boys.” Although that bill didn’t pass, the boys’ testimony was an early step in the advocacy efforts that eventually led to the creation of today’s HTC system.

**Hemophilia treatment centers have been around for almost 50 years. Learn about their history, successes and new challenges.**

**BY REBECCA A. CLAY**





that a child has a bleeding disorder and know how to respond to their needs. HTC staff can also consult with other clinicians to ensure they know how to provide services safely, whether it's a teenager having wisdom teeth removed or a person having a baby.

Long-term, trusting relationships are a hallmark of HTC care, said Taniguchi, who, as a 43-year-old with type 2 von Willebrand disease (VWD), is an HTC patient himself. "When I need something, I'm able to call my team," he said. "They know me. That's a big deal."

Even if you don't live close to an HTC, you can still get care, said Angela Blue, MBA, program director of the Hemophilia and Thrombosis Center at the University of Colorado's School of Medicine in Aurora.

Local hemophilia groups often provide financial assistance—food, hotel rooms, even plane tickets—for patients who must travel for care. HTCs also travel to patients, bringing the entire team to provide services at outreach clinics. And while insurers are beginning to tighten up regulations that were loosened during the pandemic, telemedicine has proved to be a great way to expand access to patients with geographic or other barriers.

"I would encourage patients to ask for what they need; it would be unfortunate if a patient thought that some service wasn't available where they were and so just didn't bring it up," Blue said. "If the HTC knows what their needs are, many times we can be creative in figuring something out."

Patients also benefit from all the other activities that HTCs and the regional networks carry out, including research and the collection of data to monitor and better understand patients' health and outcomes. Workforce development is also critical. Webinars, working groups and mentoring not only help HTC staff develop new skills but also overcome professional isolation.

### Successes and Challenges

The kind of comprehensive, multidisciplinary care that HTCs provide pays off, according to researchers.

Research by the U.S. Centers for Disease Control and Prevention (CDC), which uses HTC data to monitor the health of patients, has found that patients treated at an HTC are

"The first HTCs received federal funding in the mid-1970s, modeled after published examples of new interdisciplinary approaches to providing care to individuals with hemophilia," according to a written statement provided to *Dateline Federation* by the U.S. Health Resources and Services Administration (HRSA), which helps fund the program through grants from its Maternal and Child Health Bureau. "Based on their success, HRSA started providing funding for organized regions of HTCs in the mid-1980s."

Today, there are 149 HTCs across the United States, organized into eight regions. Their goal? To provide coordinated, team-based specialty care to meet the physical, psychosocial and emotional needs of people with hemophilia and other rare inherited bleeding and clotting disorders.

### What HTCs Provide

"You'll hear this word 'comprehensive' care, and what that means is that you have full service," said Zuiho Taniguchi, administrator of the HTC at Mount Sinai in New York and regional administrator for the New England region within the HTC network.

Patients typically come in annually for a full work-up by a core team comprised of a physician, nurse coordinator, social worker and physical therapist, with additional in-person, phone or video visits as needed. While the HTC itself focuses on specialty care, centers partner with clinicians and other providers to ensure patients get everything they need, whether it's genetic counseling, access to a specialized pharmacy, or referrals to primary care physicians, orthopedists, dentists, gynecologists and other providers comfortable serving this patient population.

The care doesn't just focus on physical issues, and it isn't just for patients. "All kinds of parenting issues come up," for example, said Judith Baker, DrPH, MHSA, public health director at the Center for Inherited Blood Disorders in Orange, California, and regional administrator for the Western States Region within the HTC network. "Some parents have tremendous guilt, thinking, 'I gave this to my child,'" she said. "Siblings may feel ignored and act out."

Educating patients, families and others in a patient's orbit is another key function. Nurses teach parents of pediatric patients how to infuse their children and teach young patients how to infuse themselves. HTCs also work with local groups to get the word out about developments in the field, with staff giving talks on topics such as new products or insurance issues. HTC nurses and social workers even visit schools to ensure that staff are aware

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“I would encourage patients to ask for what they need; it would be unfortunate if a patient thought that some service wasn’t available where they were and so just didn’t bring it up. If the HTC knows what their needs are, many times we can be creative in figuring something out.”

—Angela Blue, MBA

40% less likely to die of hemophilia-related causes than those who received their care at other kinds of health care settings. Other research has found reductions in bleeding-related hospitalizations and the use of emergency room services, which means less absenteeism from school or work and lower health care costs. Plus, HTC patients like the care they receive, with 96% of respondents to a national patient satisfaction survey reporting that they were always or usually satisfied with their HTC.

But despite those successes, HTCs are facing challenges that could potentially threaten the existence of some centers, said Baker, who, along with local clinicians and hemophilia groups, helped establish HTCs in Nevada, Hawaii, Guam and California.

For one thing, the population of patients that HTCs serve is growing and evolving, making the care required more complex. Women with VWD comprise a large proportion of that patient population growth, which has led some HTCs to establish specialized women’s clinics to meet their unique needs.

The adult patient population is also growing—and aging. AIDS deaths of thousands of adults with hemophilia skewed the population toward pediatrics, which contributed to a scarcity of adult hematologists

committed to hemophilia care, Baker said. One of today’s challenges is rebuilding the workforce to ensure sufficient numbers of providers for adults as well as children.

While the complexity of care is increasing, funding is not. One issue is the erosion of support from hospitals, which house most HTCs. In the 1990s, Baker said, hospitals began shifting toward a for-profit model, with specialized, prevention-oriented, team-based inpatient care for rare disorders increasingly viewed as unprofitable.

Another problem is the way reimbursement is structured. “Reimbursement favors inpatient stays, what’s called ‘heads in beds,’ and procedures like chemotherapy infusions and other things that can be done in hospitals,” Baker said. In contrast, many key HTC services—care coordination and telephone consultations, for example—are often poorly reimbursed or not billable at all.

Meanwhile, federal funding hasn’t kept pace with increased needs. “Congress has not increased funding for our grants from HRSA or the CDC for many years,” Baker said. The HRSA Regional Hemophilia Network grant, which supports comprehensive bleeding and clotting disorder care, doesn’t cover the cost of a full-time nurse, she pointed out, while the CDC grant, which supports surveillance to monitor

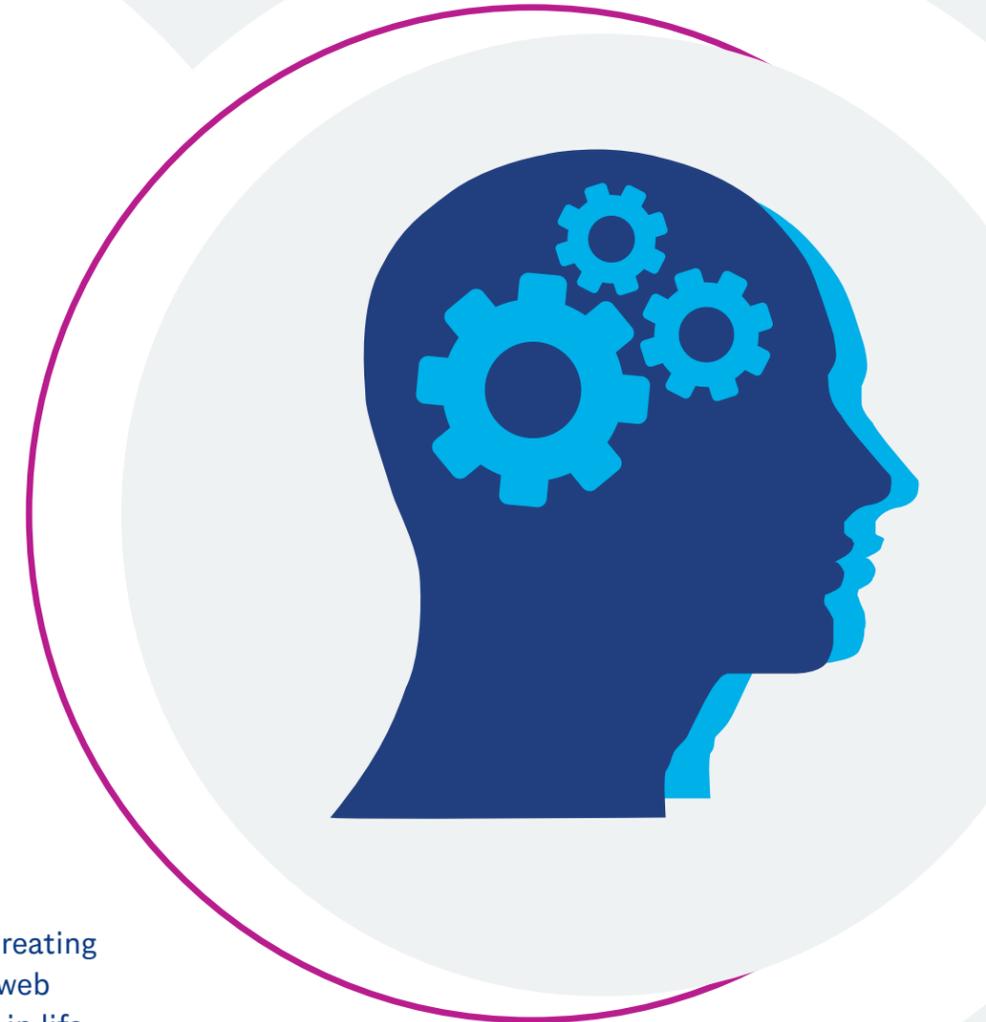
health outcomes, barely covers the cost of a full-time data manager or clinical research associate.

To help make up the shortfall, most HTCs participate in the federal 340B drug pricing program, which allows HTCs and other entities to purchase outpatient drugs at discounted prices, sell them to patients and use the margin to help support care.

“Per Congress, all pharmacies that use 340B prices must reinvest program income to stretch scarce federal resources to provide more services and reach more patients,” Baker said. But even that income stream is threatened, she added. Some state Medicaid agencies and other insurers set reimbursement rates for outpatient drugs at sub-optimal levels, and newer drugs that require fewer doses can mean less revenue when the reimbursement model is solely based per prescription.

Patients and families can help ensure that HTCs can survive and thrive, she said. “Connect with Hemophilia Federation of America and National Hemophilia Foundation chapters and work within a team of advocates to make your voice heard,” she suggested. “You can tell your story as part of a unified message to ensure that everyone has access to an HTC who needs one.”

# WHAT’S NEXT? YOU DECIDE.



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# CAREER DREAMS

New HFA Job Readiness Grants help community members reach their career goals and improve their lives.

BY ALLISON HARRISON, MSW, ASSOCIATE DIRECTOR OF SERVICES

**H**ave you ever felt stuck in your career with low pay, limited opportunities that fit your needs or lack of advancement potential? You're not alone.

"Between my physical health and the socioeconomic challenges I face, finding and keeping employment has been a challenge," said Anastasia Wright, who has von Willebrand disease. "I had to withdraw from university because my body could not handle the many hours commuting required. The small town in which we live has a primarily physical labor-based job market, most of which do not pay enough to cover my medical expenses even if I was able to work with them."

Wright's story is one of many the HFA Services team (which runs the Helping Hands program) has heard over the course of 20+ years. Through our Helping Forward program, we seek to address these and other employment and financial challenges faced by the bleeding disorders community.

Helping Forward, started in 2019, addresses root causes of the financial insecurity our community members face year after year, empowering them to move forward from crisis into a sustainable future through career planning and financial management.

“One of the biggest barriers I have faced securing financial sustainability was finding employment that would allow me to either work remotely and/or miss a reasonable amount of days due to a bleed or hospitalization.”

—Rene Pimentel

Through Helping Forward, HFA launched career planning and employment rights digital education courses on HFA Learning Central. Courses feature the voices of bleeding disorder community members, interactive activities and valuable information about how people with bleeding disorders and their caregivers can navigate career planning, job training, job searching, workplace issues and accommodations. (See the article in *Dateline Federation*, fall 2020, for more information on Helping Forward.)

### Job Readiness Grants

In 2021, HFA offered its first round of Job Readiness Grants to provide community members with grants toward technical training or certification that supports applicants' career goals in a field sustainable for them. A technical skill is the practical ability and knowledge needed to perform a specific task. HFA distributed more than \$7,000 in grants to 11 awardees.

Wright was one of the grant recipients. “This grant means a chance to move towards a career that is friendlier on my joints and allows me to help others and find a much more dependable source of income,” said Wright, who used the grant toward Russian language certification to pursue a career in translation and interpretation.

Oswaldo Vega, who has Factor V deficiency, was awarded a grant for an insurance adjuster course. “With this grant I will get certified and licensed as a state adjuster. Having this license will open many doors and opportunities for me,” said Vega, whose position in a different sector was cut in 2020 after 15 years with the same company. “At the same time, I will be an example to my son that no matter the circumstance or age, you can still learn and grow in a different area.”

Grant recipients are pursuing a variety of careers, including veterinary assistant, community association manager, peer support specialist and more. April Marie Driesse, who has hemophilia B, is pursuing certifications in network security. “As far as barriers go, the biggest one is financial,” Driesse said. “I am in a family of five people with low income. My fiancée is unemployed—he lost his job due to COVID-19—and I have two special needs children and a newborn. I have hemophilia and other conditions. I use all my income to pay for my bills or my children's medical attention.”

Driesse is planning to land her dream job in cybersecurity, which will enable her to be part of an in-demand sector she is interested in and provide her family with financial stability. The Job Readiness Grant covered study

guides and exam vouchers so she can complete certification exams that are stepping stones to more advanced cybersecurity certifications required for her dream job.

Rene Pimentel has been an assistant property manager for five years, but he hasn't always had such stability. “One of the biggest barriers I have faced securing financial sustainability was finding employment that would allow me to either work remotely and/or miss a reasonable amount of days due to a bleed or hospitalization,” he stated in his application. “I have thankfully found a job that will allow me to take the necessary amount of time to recuperate and make sure I don't sustain prolonged joint damage and/or pain. There are days I am unable to make it to work due to joint pain or a bleed and I am able to work remotely and still get all my property management work done.”

Pimentel's grant is being used toward a certificate course that will allow him to take the state exam to get a community association manager license. “With that license, I can even open my own property management business and be financially independent. It's always been a goal of mine to own and operate my own business, and this would be another step in that path,” he said.

HFA is inspired by the inaugural Job Readiness Grant recipients and honored to play a role in their work to overcome barriers and achieve their career and financial goals.

HFA plans to offer a second round of Job Readiness Grants in 2022 and (pending funding) offer webinars, peer networking spaces and additional digital education on topics related to career and financial

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for HFA hugs to resume

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planning. Watch HFA emails and social media to find out more.

Thank you to Genentech for their support of Helping Forward and the Job Readiness Grants.

For more information, see [www.hemophiliafed.org/helpingforward](http://www.hemophiliafed.org/helpingforward).

## Congratulations to the 2021 Job Readiness Grant Recipients!

**Ahmed Tareq Al Badri**, Lean Six Sigma Green Belt Certification Course



*"I will gain certification after finishing these courses ... and will hopefully find a full-time job, especially since I just recently got married! I need a stable job for myself and my new family."*

**Daniella Cabello-Martinez**, Veterinary Assistant Diploma



*"This grant means a lot to me because I can actually do something that I love, as I will learn and be in the field that I have always wanted to be in since I was little."*

**April Marie Driesse**, Network+ and Security+ Certifications Exams and Study Guides



*"This grant is going to not only allow me to obtain certifications, but it will also allow me to be able to provide my family with financial stability due to a better paying job."*

**Ivan Giron**, Certified Ophthalmic Medical Technologist Exam Prep Course



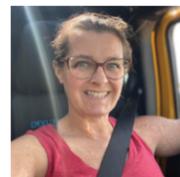
*"I want to set the example for my teenage kids that education is one of the keys to a successful life."*

**Ashley Holland**, Veterinary Technician Pre-Courses



*"Becoming a certified veterinary technician will allow me to find a job much easier, compared to those who are just trained at a job."*

**Pamela A. Migliore**, Phlebotomy Certification Course



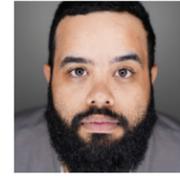
*"I hope that, as a hemophiliac myself ... I'll be able to provide compassionate care for all of my patients and that I'll be able to raise awareness of bleeding issues amongst other members of the medical community."*

**Milybet Montijo-Cepeda**, Meditation & Mindfulness Teacher Certification Course



*"This grant will benefit my son (who has severe hemophilia), special needs students, co-workers, family, friends and the bleeding disorders community."*

**Rene Pimentel**, Community Association Manager Pre-License Certificate Course



*"I'm finally going to be on my way to the financial freedom I've been fighting for."*

**Oswaldo Vega**, Accredited Claims Adjustor License Course



*"Having this license will open many doors and opportunities for me. ... At the same time, I will be an example to my son that no matter the circumstance or age you can still learn and grow in a different area."*

**Carl A. Weixler**, Adult Peer Support Specialist Certification Training



*"I am very grateful to be one of the recipients, and my goal is to serve the bleeding disorders, HIV/HCV, depression and substance use communities with the knowledge I gain from becoming certified."*

**Anastasia Wright**, Russian as a Foreign Language Specialization Courses



*"This grant means a chance to move towards a career that is friendlier on my joints and allows me to help others, particularly those in underserved areas of the bleeding disorders community, and find a much more dependable source of income." 🩸*



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# 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.



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