



For Hemophilia A patients,

YOU USE YOUR JOINTS MORE THAN YOU THINK.

That's why you need a Factor VIII treatment you can Count On to protect* you and your joints from bleeds.

1.6

MEDIAN OVERALL
BLEEDS PER YEAR†

0

MEDIAN JOINT
BLEEDS PER YEAR†

#1

PRESCRIBED FACTOR VIII
FOR PROPHYLAXIS IN US‡

*ELOCTATE has been proven to help patients prevent bleeding episodes using a prophylaxis regimen.

†In the A-LONG study, 164 previously treated adult and adolescent males with severe hemophilia A ages 12–65 received ELOCTATE either every 3 to 5 days, once weekly, or on demand.

‡#1 prescribed based on HTC reported data as of September 2020.

INDICATION AND IMPORTANT SAFETY INFORMATION

INDICATION

ELOCTATE® [Antihemophilic Factor (Recombinant), Fc Fusion Protein] is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ELOCTATE when you have surgery.

IMPORTANT SAFETY INFORMATION

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.

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Additional common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.

If you have risk factors for developing abnormal blood clots in your body, such as an indwelling venous catheter, treatment with Factor VIII may increase this risk.

These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, or if bleeding is not controlled after using ELOCTATE.

PLEASE SEE BRIEF SUMMARY OF PRESCRIBING
INFORMATION ON THE PREVIOUS PAGE

YOU HAVE QUESTIONS. CoRes HAVE ANSWERS.



Dedicated
CoRes are passionate about helping people in the Hemophilia community.



Understanding
CoRes are advocates with decades of experience who understand the community's needs.



Accessible
CoRes prioritize face-to-face conversations to get to know you. They're just a call, text, or email away.



Scan with your phone to learn more about how to protect you and your joints from bleeds.

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DATELINE FEDERATION

Volume 23 • Issue 1 • Spring 2022

PROFESSIONAL CYCLIST ALEX DOWSETT ►

page 16



MEET THE EDUCATION TEAM

page 26



GLOBAL TREATMENT IN THE PANDEMIC

page 32

HI FRIENDS,

As we continue through year three of the COVID-19 pandemic, I hope you're doing well. Winter in the Pacific Northwest was dark and dreary, which didn't help my mental health. To be honest, my husband and I kept up our Christmas tree and lights far into February to keep that extra cheer alive a bit longer.

If you're feeling blah or unmotivated at times, I am right there with you. I read about this concept called "languishing" last year, which means an overall feeling of "blah," and I can definitely relate. The pandemic seems like it's never going to end, and it can be hard to get motivated to do much.

Luckily, spring has arrived, and the sun rises earlier and sets later, which means that I can get outside more. I'm starting my second year of gardening in my backyard, and spring pushes me to get outside and tend my plants no matter what the weather is. Sometimes, just the smallest act can bring me out of the "blah" and into a place of joy, which can grow even larger the more I lean into it.

So many of us have had struggles with mental health these past few years. Turn to page 30 to learn how HFA is creating a network of mental health ambassadors.

Celebrating Sports

Love to watch football and cheer on your favorite team? Those of you who are NFL fans will particularly enjoy the story in this issue about Robbie Klein and his family. As part of the NFL's My Cause, My Cleats campaign, players team up with a nonprofit to design a pair of cleats that will be auctioned off to raise money for that nonprofit.

After rookie Patriots quarterback Mac Jones selected Boston Children's Hospital last fall, the hospital reached out to the Klein family. Robbie, who has severe hemophilia A with inhibitors, designed a pair of cleats that Jones wore in the December 6, 2021, game. Read more about Robbie's adventure on page 8.

On page 16, we have a great interview with professional cyclist Alex Dowsett—believed to be the only elite athlete in the world with hemophilia. Dowsett is known for his time trial skills and is the former under 23 European champion for time trials. In his native United Kingdom (U.K.), he was also the national champion multiple times for time trials.

In his interview with *Dateline Federation*, Dowsett talks about how he got into cycling as a kid with hemophilia growing up in the U.K., how hemophilia affects his cycling career and his plans for his charity, Little Bleeders.

Hemophilia Across the Globe

We've all experienced shipping delays and supply chain issues during the pandemic, but *Dateline Federation* editors wanted to explore how these problems have affected people with bleeding disorders around the world—the vast majority of whom don't have access to regular prophylactic factor infusions. On page 32, Jennifer Laliberté, national director of the World Federation of Hemophilia (WFH) USA, talks about how WFH and its member organizations stepped up these past few years to help ensure people got the treatment and supplies they needed.

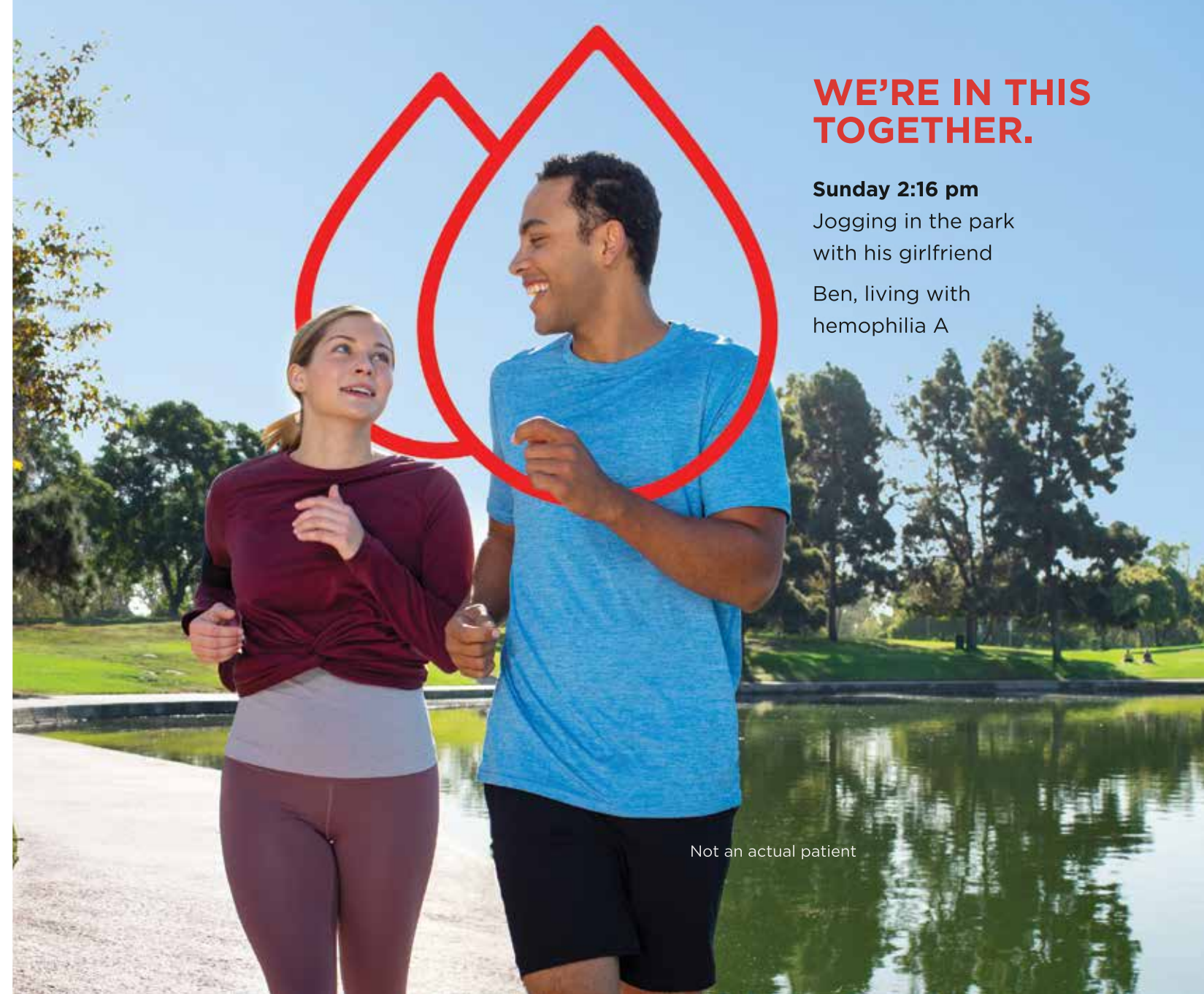
Please enjoy this issue of *Dateline Federation*. As always, if you have questions about anything included within these pages, please reach out to the HFA team. We are here to support you!

Allie Ritcey



Chair, HFA Board of Directors

Sometimes, just the smallest act can bring me out of the "blah" and into a place of joy, which can grow even larger the more I lean into it.



Not an actual patient

WE'RE IN THIS TOGETHER.

Sunday 2:16 pm

Jogging in the park with his girlfriend

Ben, living with hemophilia A

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

bleedingdisorders.com



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

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We are inspired by people living with hemophilia. Our Community Relations and Education (CoRe) managers are here to help empower you and your family with education and resources.

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World Hemophilia Day April 17

Since 1989, patient groups worldwide have annually marked World Hemophilia Day on April 17 to raise awareness and understanding of hemophilia and other bleeding disorders. This date was chosen in honor of World Federation of Hemophilia (WFH) Founder Frank Schnabel, who was born on April 17.

World Hemophilia Day aims to promote the importance of coordinated and concerted actions to achieve WFH's vision of "treatment for all" and to draw attention to key issues and put hemophilia and bleeding disorders in the spotlight. This year's theme was "Access for All: Partnership. Policy. Progress. Engaging your government, integrating inherited bleeding disorders into national policy." Advocacy is one of the backbones of HFA. We encourage you to assist us in our mission to advocate, educate and assist by making a donation in honor of World Hemophilia Day at www.hemophiliafed.org.



Coffee & Conversations

Have you had the chance to catch Coffee & Conversations on the HFA Facebook channel yet? The first Friday of each month at 12 p.m. EDT, HFA President & CEO Sharon Meyers, EdD, CFRE, and Board Chair Allie Ritcey go live on the HFA Facebook page to talk about all the exciting things happening at HFA in the upcoming month.

This fun, unscripted chat is a great way to connect with HFA leadership, ask questions and win prizes! Join us the first Friday of each month at www.facebook.com/hemophiliafed.

Symposium 2022

We want to thank everyone that was able to join us in San Antonio for our Texas-Sized Family Reunion in April! It was great to be able to reconnect, learn and have some fun along the way. We are cooking up a big Symposium wrap-up article for a future issue of *Dateline Federation*, but until then, we just wanted to thank all our attendees, Board of Directors, volunteers, exhibitors and sponsors for helping us bring back in-person Symposium in style!

2022 SYMPOSIUM SPONSORS



Bleeding Disorders Alliance of North Dakota

The Bleeding Disorders Alliance of North Dakota (BDAND) covers a small population but a large geographic area. Most community members live in remote rural areas in North Dakota and Northwest Minnesota.

Started in 2015, BDAND includes about 80 people with hemophilia and 300 with von Willebrand disease. BDAND Executive Director Emily Ouellette describes this community: "It's common for our patients to be the only person with a bleeding disorder in their town. Many also have to drive several hours to visit the hemophilia treatment center and attend our events," she said.

As you can imagine, winter weather in North Dakota and Minnesota can have a huge impact on the community: "So many people have to drive a long

BLEEDING DISORDERS ALLIANCE OF NORTH DAKOTA

Started in 2015
380 people served
Serves North Dakota and Northwest Minnesota

distance to get to us," Ouellette said. "We have had blizzards affect two annual meetings so far, which were held in March and April. Sometimes we get winter snowstorms as early as October and as late as April."

Because of that, she said, "Learning how to hold virtual events has been a blessing in disguise for us because we can now host programs in the worst winter months without risking driving on icy roads. We look forward to incorporating virtual and hybrid

elements into our future events so that people who live farther away can still participate in some way without needing to drive."

Historically, BDAND's most successful program has been its family retreat, which is held in different locations across North Dakota. "We try to incorporate lots of time for fun and connection building," Ouellette said. "Our best family retreat was in Medora, North Dakota, with Pat Torrey from GutMonkey leading the programming."

During the pandemic and the switch to virtual programs, BDAND created online cooking classes, which became their most popular offerings. 🍷





On the Field

Robbie Klein designs a pair of cleats for Patriots quarterback Mac Jones.

BY MELANIE PADGETT POWERS, MANAGING EDITOR

In gale-force winds on December 6, 2021, the New England Patriots beat the Buffalo Bills during Monday Night Football. But more important to the bleeding disorders community, Patriots rookie quarterback Mac Jones was wearing new cleats designed by seven-year-old Robbie Klein, who has severe hemophilia A with inhibitors.

As part of the NFL's My Cause, My Cleats program, various players wore specially designed cleats during their games that December week. Each player chose a cause to support, and their cleats were later auctioned off to raise money for their charity.

Robbie was contacted after Jones selected Boston Children's Hospital.

Robbie is a "frequent flyer" at the hospital, his mom, Kayla Klein, said, so he was on staff's mind after they learned Jones had selected them. Hospital staff reached out to the Klein family—which includes dad Joel and younger son, Eddie, age 4—to ask if Robbie wanted to help design the shoes.

Hospital staff helped Robbie design the cleats, which are covered in blue swirls. The sides of the cleats say

"Robbie stayed up and watched the whole game, which I don't think he's ever been up that late in his life."

—Kayla Klein

"Boston Children's." Robbie's first name is on the top of the right shoe in his own handwriting. Robbie chose to write the motto "Be Brave," which is on the left shoe.

"We thought 'be brave' spoke to his journey with hemophilia really well," Kayla said.

The Kleins also shot a couple of videos with Robbie and Eddie to raise awareness for Boston Children's Hospital. "Robbie was thrilled, but Eddie was also pumped," Kayla said. "It's important to us to always include Eddie. Eddie's a part of our family too, even though he doesn't physically have hemophilia. In all the videos you see and wherever we are, Eddie's always there."

The day of the game, a local news station interviewed the Kleins before the family sat down to watch the game. "Robbie stayed up and watched the whole game, which I don't think he's ever been up that late in his life," Kayla said. "It was just a really nice experience to be able to watch as a family and share it with the community."

Because of COVID-19 protocols, the Klein family didn't meet Jones during the NFL season, but they are hoping to meet him one day. In a Patriots.com article, Jones said, "I'll eventually get a chance to meet [Robbie] and hang out with him and all that. For now, I just wanted to make sure I had something ... to represent him and show that

I'm playing for him because he can't play football. It seems like he's just a real fighter."

Kayla also wants the public to know "while we have had very sad moments, we are not a sad story." She added, "The more you can raise awareness of any rare disease at a local or national level or in your neighborhood, it can do wonders for building understanding of rare diseases, including hemophilia. ... There's no negative in doing advocacy and awareness work, especially when it's highlighted in such a positive way." ♦



Left: Robbie enjoying winter sledding. Top: the Klein family: Kayla and Joel with their sons, Robbie and Eddie. Bottom right: Robbie and his little brother, Eddie.

GET TO KNOW HFA'S STAFF

Please welcome the most recent additions to the HFA staff.



Nick Clarksen

Advancement Manager, Advancement

Nick Clarksen serves on the Advancement Team working on individual fundraising, including managing Team Resilience events, doing digital fundraising, and managing stewardship and donor engagement.

Clarksen comes to HFA after having worked in politics for the past decade. He spent the past five years raising millions for candidates throughout the U.S. as a fundraising consultant. In that role, he built up campaign fundraising operations, identified new stewardship strategies, and developed and executed aggressive finance plans for clients. He has also served as campaign manager and finance director on congressional races.

Clarksen lives in Washington, DC, and works out of the HFA DC office. In his free time, he loves traveling the country, going for hikes and reading.



Anne Goodman, MPH

Project Director, Education

Anne Goodman, MPH, comes to HFA with over 20 years of public health experience. She has worked at a variety of nonprofits throughout her career, focusing on health promotion and education. She has a bachelor's degree in social work from Ohio University and a master's in public health from Indiana University-Purdue University Indianapolis.

Goodman lives in Ohio with her husband and two children, one of whom has a bleeding disorder. She is excited to join an organization that affects her life directly and cannot wait to work with the bleeding disorders community. Goodman's hobbies include baking with her kids, gardening, biking, kayaking and coordinating parties with her friends and family.



Adrian Palau-Tejeda

Senior Manager for Health Disparities & Engagement, Public Affairs

Adrian Palau-Tejeda is a successful health care policy leader, driven by community engagement, data and congressional relationships. Coming from a background in community organizing and campaign work, Palau-Tejeda has worked previously in the rare disease space to promote the equitable access to treatments and cures for underserved communities.

Since joining the HFA team, he has helped relaunch the Health Disparities Council and is excited to work to drive forward the cause of health equity in the bleeding disorders community.



Shira Smillie

Services Coordinator, Helping Hands

Shira Smillie is from Philadelphia. Her passions include travel, reading, writing and hiking. She joined HFA to continue her passion of advocacy. Previously, she coordinated resources and programs for her school. Her favorite part of her work is listening to the stories of others. She says compassion and empathy guide her work, and she looks forward to being able to grow in her role as services coordinator with the Services Team.

Aside from work, Smillie enjoys travel writing and is currently traveling around the United States writing about the different places she visits. In her spare time, you can catch her at a local seafood restaurant trying out delicious dishes.

Where Are They Now?

HFA caught up with its former policy and government relations interns to see what they’re up to, how they reflect on their HFA internship and advice they have for future interns.

BY LINDSAY COX, HFA SENIOR MANAGER FOR ADVOCACY AND OUTREACH

Eric Burgeson

Gainesville, Florida
2016 Intern

Nowadays: I’m an education manager at HFA! I’m also about halfway through a master’s of public health at the University of Florida, concentrating on population health management. I’m involved in a CDC cooperative agreement with HFA, and I currently manage HFA’s Blood Brotherhood program.

My internship: It was the experience that took me from a raw, directionless college student to start my gears turning to think about where I wanted my career to lead. It also served as the base of learning how to comport myself in a professional setting.

Advice for HFA interns: Take advantage of the networking opportunities, and live up every second you can in DC. It’s a phenomenal city, and two months is all you need to explore it.

Paul Heinrich

Phoenix
2017 Intern

Nowadays: I graduated with a degree in professional writing in 2020. Currently, I run my own production company and have had the opportunity to work with

prominent clients. The work involved in telling individual stories is incredibly rewarding.

My internship: I love DC, and I am very grateful for being there during the controversial time I was there. My favorite part about the experience was exploring the Smithsonians in my free time.

Advice for HFA interns: Don’t be afraid to suggest new things, and always bring your own perspective and talents to the work you do! HFA has picked you for a reason—they know that you have valuable insight and abilities to share with the bleeding disorders community, and you should do everything you can to take advantage of that opportunity.

Dylan Edwards

Sauk Rapids, Minnesota
2019 Intern

Nowadays: Since the summer of 2019, I earned my master’s of public administration from The Ohio State University, focusing on nonprofit finance. Currently, I serve as the



district executive for scenic district at Central Minnesota Council Boy Scouts of America. In that role,



I ensure the district meets its goals for membership, personnel, programming and community philanthropic support. I manage over 200 volunteers that provide outdoor leadership learning experience to 900 youth in Stearns County, Minnesota.

My internship: My time at HFA is what swayed me to work for a nonprofit as opposed to a governmental agency or private company. It was a defining moment in my life. I will always remember attending the congressional briefing where Sonji Wilkes testified on surprise billing and realizing our work was putting bleeding disorders issues at the front of the national dialogue on health care.

Advice for HFA interns: Every second of that internship is a treasure and opportunity to transform yourself into a better advocate, co-worker and person. Make the most of the work you are given, learn something new and take those lessons back to your communities and put them into action. HFA is making an investment in you, so make it pay off.

Jasmin Wyatt

Berkeley, California
2019 Intern

Nowadays: I graduated from UC Berkeley in the spring of 2021 with a degree in political science and a minor in public policy. At Berkeley, I spent a lot of time organizing around grassroots campaigns and writing about California politics. Once I graduated, I began working as a campaign coordinator for an organization focused on environmental issues. Recently, I have started a job as a fundraising associate for California political campaigns. In this role, I am able to assist amazing campaigns



and candidates in reaching their fundraising needs, helping them have the resources to win.

My internship: My HFA internship was an amazing experience for me. The program and the team helped me grow my policy and communication skills enormously. I really appreciate the effort the staff puts in to make the internship such a success and the flexibility they offered to fit each intern’s interests.

Advice for HFA interns: Get involved with projects from all the areas of the nonprofit at some point to get a great picture of the overall organization!

Tameelah Dawson

Tallahassee, Florida
2020 Intern

Nowadays: I graduated from college in April 2021 and started the community



psychology graduate program at Florida A&M University in Tallahassee in August 2021. I am working on my thesis in hopes to graduate in May 2023 with my master’s in community psychology. I am also a research graduate assistant for one of the psychology professors.

My internship: I enjoyed my time as an intern for HFA, even though I was in the virtual world. It was all such an amazing experience.

Advice for HFA interns: Keep on pushing and stay positive! It’ll all be worth in the end.

Will Hubbert

Arlington, Virginia
2020 Intern

Nowadays: I graduated from the College of William and Mary in 2021, where I majored in history and wrote my honors thesis on the history of



hemophilia and AIDS. I’ve since gone on to apply the lessons I learned from the bleeding disorders community

generally, and the HFA internship specifically, to a new context by working for the National Psoriasis Foundation (NPF) as their grassroots and advocacy manager.

My internship: The HFA internship brought me into closer contact with the incredible advocacy team at HFA, who taught me just how rewarding it is to work in a field where you get to use your voice to speak up for the needs of others. I don’t know that I would have applied for (or been hired for) my current job at NPF without my time at HFA.

Advice for HFA interns: Don’t be afraid to suggest new things, and always bring your own perspective and talents to the work you do!

Ryan Bernstein

Portland, Oregon
2021 Intern

Nowadays: I am still a college student. I am working on a children’s book about hemophilia that will be published next year, and I hope/plan to turn this into an advocacy project



with HFA.

My internship: I really enjoyed the internship and plan to keep contributing to HFA and community in a meaningful way. I learned a lot about governance and advocacy. I met some amazing people, and the HFA staff is incredible.

Advice for HFA interns: Enjoy the program and try to meet as many people as possible!

Silas Teasdale

Madrid, Spain
2021 Intern

Nowadays: I worked on a guest ranch for a few months before moving from Montana to Madrid. Here, I teach English and learn Spanish.

My internship: I remember the learning, and I appreciate the youth experience my capstone and local partnership gave me in my current job as a primary school language educator.

Advice for HFA interns: Prepare meetings with staff, map out your work and use a planner. Make the most of every week because it goes quickly!



Makayla Dawkins

Storrs, Connecticut
2021 Intern

Nowadays: I am completing an individualized major in gender, sexuality and global reproductive health and anticipate completing an accelerated

master of public health program in fall 2022. I am currently a sexual health and education advocacy coordinator, while also working with my school’s LGBTQIA+ center.

My internship: I enjoyed attending sessions and learning about history. I also liked getting to know my fellow interns during our weekly meeting.

Advice for HFA interns: Never be afraid to ask for help and to collaborate with your peers; you don’t have to do everything alone. 💎



In Memory of Val Bias

Val Bias, community member and longtime CEO of the National Hemophilia Foundation, died on December 30, 2021. His friend and fellow community member, Dana Kuhn, shares this tribute.

BY DANA KUHN, COMMUNITY MEMBER

In October 1992, there were five men in the National Hemophilia Foundation (NHF) community who were determined to change the NHF narrative. The men, as seen in the photo on page 15, were Jonathan Botello, me, Val Bias, Rich David and Donald Colburn.

At the peak of growing concern about HIV infection among men with hemophilia, the Women's Outreach Network of the NHF was created to educate women to



Val Bias

protect themselves from infection. Through similar life experiences, Val and I decided we needed to create a men's advocacy group. The pandemic of HIV called for a change in narrative of the national organization.

The five men realized it was their responsibility to teach men with HIV how to protect women from HIV infection and empower men to educate others to become leaders in their

communities. These men convinced NHF to create the Men's Advocacy Network of the NHF, which brought altering changes to NHF. The change was training and placing men with hemophilia in places of leadership.

As a result, Val became chair of the NHF board of directors, and Glenn Pierce became NHF president. Many of us became directors on the NHF board. Under new leadership, NHF began to work through its decisions and responsibilities of the HIV pandemic.

Under Val's leadership, positive change was made. The community was unified to work on the Ricky Ray Hemophilia Relief Fund Act of 1995. New, improved and safer hemophilia products were coaxed into coming

to market. The safety of the nation's blood supply became a priority, especially through blood/plasma collection processes. Government agencies and cabinet-level committees accepted hemophilia consumer members to these positions, turning a listening ear to their concerns and perspectives.

NHF created initiatives under Val and Donald Colburn that challenged the raising of funds for research in gene therapy for a cure. Under Val's leadership "chapter development" was made a priority, and programs were implemented. Chapters became stronger and more universally developed. I could go on with much more.

How can I impress upon the bleeding disorders community the passion and compassion Val had for his community and the awesome change

How can I impress upon the bleeding disorders community the passion and compassion Val had for his community and the awesome change he facilitated coming out of NHF's challenges with the HIV pandemic?

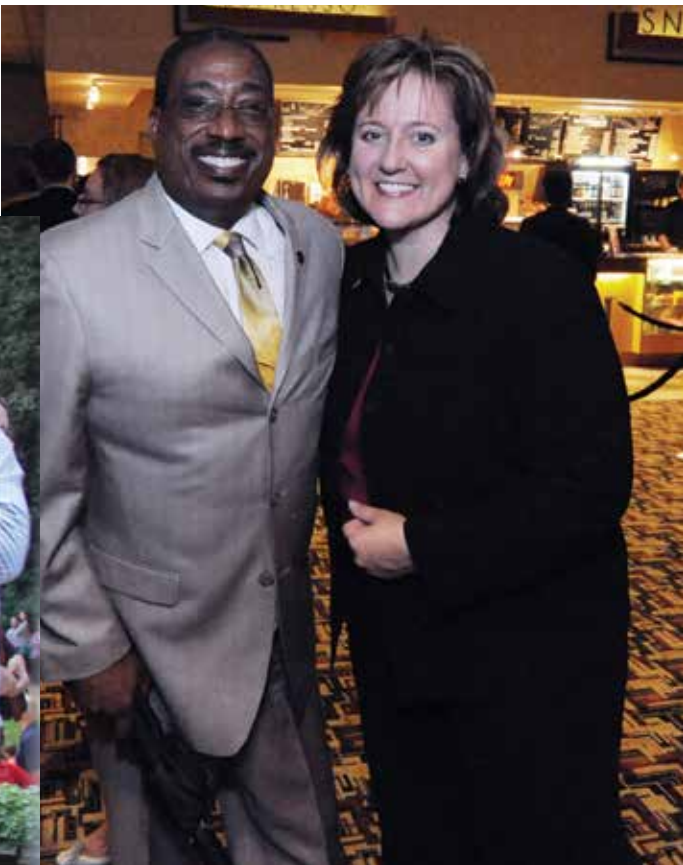
he facilitated coming out of NHF's challenges with the HIV pandemic?

We need to honor this leader and the work he accomplished to help make this community better. The NHF board and leadership, chapters, youth leadership programs, cure for the disease programs, educational programs, and relationships with donors would not be where they are today without his leadership.

Lastly, the photo below on the right depicts our friendship over 30 years. Through similar tragic

experiences, we were drawn to friendship. No matter the different paths our lives led us, we never lost our friendship and always found the time to talk about our goals and passions for the bleeding disorders community.

I encourage you to express your appreciation for his leadership, which created positive change for you and your family. As I look at this photo below of five men, I am the only one living. These other leaders and heroes of the bleeding disorders community lived their lives and gave their lives for the changes and benefits we experience in our everyday lives. I will be forever grateful. 💧





ELITE LEVEL

Alex Dowsett has been a professional cyclist—with severe hemophilia A—for 14 years.

BY MELANIE PADGETT POWERS,
MANAGING EDITOR

Alex Dowsett, age 33, is a professional British cyclist known for the time trial. He also has severe hemophilia A and is thought to be the only professional athlete in the world with hemophilia. Dowsett and his family—fiancé Chanel and their one-year-old daughter—split their time between Dowsett's hometown of Essex, England, and Andorra, in the Pyrenees Mountains.

Racing season began in February, but *Dateline Federation* caught up with Dowsett by Zoom in January. He was in Girona, Spain, with his Israel Premier Tech teammates for a 10-day training camp. (This interview has been condensed and edited for clarity.)

MP: Tell us how you first got involved in cycling when you were a kid.

AD: I think without realizing it, I was trying to find a sport I was good at. I wasn't on prophylactic treatment, and the doctors had said to my parents to make sure I stayed fit and healthy, so I was swimming a lot. But I wasn't very good. I enjoyed the social aspect to it, but I just didn't enjoy how bad I was at it. And no amount of "try hard" enabled me to be anywhere close to the lofty heights I had set for myself.

As I got bigger, there were sports I had to sit out at school: football, rugby. It's quite hard as a schoolkid to sit those things out and be told you can't, even though you feel like you can. Hemophilia is normally not a visible condition, so it's quite tough. I think I was trying to find a sport I could do, and I could do well, so Mom and Dad really encouraged and supported that.

Then, my dad started going mountain biking every Thursday night with a load of his friends. When I was 11, I asked Dad if I could come along, and he said I could. So, I started mountain biking with my dad and his mates. And then, when I was 13, one of his friends had a road bike, and I said, "Can I have a go on one of your road bikes?" And they took me to a local race. I watched the race and just rode the road bike, and it was fun. Then, the following Tuesday, I did one of the races and I did OK. Nothing special. But I enjoyed it, and I seemed to be progressing fast. Each week I went back, I went faster.

When I was 14, I entered the national championships for 10 miles for 16 years old and younger. Because I qualified badly I was one of the early starters, and I set the fastest time, but then you wait. The guy who starts last should be the one that wins it [because he qualified the fastest]. I remember it like it was yesterday: I started at number 33, and it was 120 schoolkids. On paper, I should've finished 87th.

“Hemophilia is normally not a visible condition, so it’s quite tough. I think I was trying to find a sport I could do, and I could do well, so Mom and Dad really encouraged and supported that.”

—Alex Dowsett



The final guy started and got to the halfway mark, and I was faster than him. And then, he got to the finish, and he just beat me by enough. It was like 13 seconds, but I'd finished second. And I remember looking at that finishing board, and everyone in the top 10 was 16 [except me], and I was 14. And I look at it thinking, "I think I found my thing." And that's when I dropped everything else and switched solely to cycling.

I don't think I'd have started cycling if I'd been allowed to do those sports at school, and I don't think I'd have been fast or quite as fast—and then getting faster quite quickly—if I hadn't been swimming as much as I was. That was under the guidance of the doctors to help with my hemophilia, just to keep me fit and healthy and keep my weight reasonably low so there's less stress on my joints. If it wasn't for my hemophilia, I definitely would not have ended up cycling or ended up as fast as I was from the word go.

MP: You're known for your time trials. How did you get involved in time trials?

AD: I just loved it. The first race I ever did was a time trial. I've just thoroughly enjoyed the process of trying to go faster, and just being good at it is what I enjoyed. And then, I ended up enjoying the sport as a whole as well.

When I turned pro, time trialing was still something I was good at. I was the under 23 European champion for time trials. I was national champion multiple times for time trials. It's what I was known as being a specialist in.

There's a lot of different disciplines within cycling: BMX, mountain biking, the track, the road. Time trialing is a part of road cycling, and in road cycling, there are two main subdisciplines: the time trial and road racing. Road racing is where everyone starts together, and, quite simply, the first person to cross the finish line first wins. And different riders will win dependent on the terrain, whether it's hilly, or flat, or windy, or whatever.

A time trial is where everyone starts at one-minute intervals and you are riding alone. You won't gain the benefit of the slipstream, or the draft. It's about discipline, focus, being able to be in a bit of a hurt zone, right on that limit of effort. And then, there's a lot of technology



involved because you're traveling quite fast—usually, speeds will be over 50 mph, or over 30 mph on average for a race. And a race will be up to 30 miles. So, there's a lot of aerodynamics and specialist equipment involved in making your speed as high as possible.

MP: How does hemophilia affect your cycling?

AD: My doctors have kept me on the same factor since I started professional cycling in 2008—just a case of “if it ain't broke, don't fix it.” I've broken quite a few bones now: collarbone, elbow, ribs, shoulder blade, thumb. Hemophilia's never been an issue in any of those bone breaks. A couple have required surgery, but I've recovered like a normal person would.

I take about 2,000 units every second day. And in races, I have a slightly higher dosage. I alternate between 2,000 and 1,000 daily because we found the peak and the trough in factor levels. The trough would coincide with the end of a race.

If I join a new team, I inform them I have hemophilia. And the team will have a team doctor, so he'll understand what hemophilia is. Normally, he'll do a lot more research

on it as well. I have medication in the car that follows the race. In the event of an accident, it will be given to the medics to go with me to hospital. Otherwise, that's it really. That's the only difference.

(Dowsett also wears a medical ID necklace and has an exception from the governing body, the Union Cycliste Internationale, or UCI, to use needles, which are banned in cycling as part of the anti-doping rules.)

MP: Let's talk about the hour record. For one month, you held the prestigious world record for riding the farthest in one hour. Then, someone else broke it, and you tried again in November 2021. Tell us what the hour record is and about your attempts to break it.

AD: It's the ultimate time trial. It's an aspect to cycling that is steeped in history. If there was a Tour de France for time trialing, it would be the hour record. Before 2014, the governing body for cycling, the UCI, kept the rules so that if you wanted to attempt to break the hour record, you had to ride the same style bike as they did in the 1970s and '80s, which just wasn't possible. [But, in 2014, the UCI changed the rules to allow modern bikes and equipment.] That rejuvenated the record, and suddenly everyone could

“When I turned pro, time trialing was still something I was good at. I was the under 23 European champion for time trials. I was national champion multiple times for time trials. It's what I was known as being a specialist in.”

—Alex Dowsett

go for it. I broke the record in 2015 with about 33 miles (52.937 km) in one hour.

You do the laps in a velodrome (a steeply banked indoor oval track), and you stick to a schedule of lap times, and the schedule we set was enough to break the record. If you go too fast at the start, you can really fall off a cliff in pace and go slower than you could've done. When I got to the finish of the hour, I'd broken the record, but I knew deep down I hadn't gone as far as I could've gone. It was a bit too easy. Since then, I've been wanting to do it again.

It's a huge undertaking—probably the actual organization of it is a far greater challenge than the actual record attempt. And my trade teams were never really willing to put the full effort in to do it again. Chanel, my fiancé, and I decided if we wanted to do it before I retire, we were going to have to do it ourselves. So, we organized it, decided to do it in Mexico in 2021, and got the sponsorships together. We realized it was a really nice opportunity to showcase to the world, outside of the rare disease community and the hemophilia community, what hemophilia was, how far it's come and what we can do now. It became a really great project in that respect.

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Ultimately, I failed to break the hour record, but I think I was a third of a mile an hour in speed off of breaking it. I was close, and I went as far as I could go. Thirty-four miles was what I covered—a massive step forward from what I did last time.

But the much bigger victory was putting hemophilia so much more on the map than it was before. And that ended up being a massive win.

MP: You ended up raising 50,000 pounds (about \$67,000) for bleeding disorders.

AD: Yes, and we split that between the U.K. Haemophilia Society, for the incredible work they do, and my own charity, Little Bleeders. It was so nice because I got off the bike in a lot of pain, and we'd already seen that the

[fundraising] page had gone from about 3,000 pounds when I started to 21,000 pounds when I finished. And then, it was just pouring in. It was quite incredible.

In Little Bleeders, we recently set up a sports fund. Until now, a lot of what we've done has been all policy change in government—trying to make sure there's equal care across the country, access to rehabilitation and physiotherapy, and making sure parents are well-informed of what [people with hemophilia] can do.

With Little Bleeders [our goal] is to share positivity around hemophilia and how it's changed. I think the doctors have the difficult job of having to deliver a lot of worst-case scenarios, and we try to use my example to say, "Well, this is also the other end of the spectrum. This is where hemophilia can be now." And promoting health, fitness, staying in shape.

Sports, especially during COVID times, have been difficult. We found parents have said it's been very difficult to take their kids to swim classes. Whether it be lockdown, or finances, or getting them to these activities, we provide some financial aid to young people with hemophilia to help them keep fit and healthy.

MP: You are now on the Israel Premier Tech team. What's up next?

AD: It's quite nice to have just a regular season, without an hour record or fighting for Olympic selection. There are 31 riders on my team, and eight go to the grand tours, which are the Giro d'Italia, Tour de France and Vuelta a España. Provided I'm in shape and not unwell, I would be very surprised if I'm not in the Giro [in May 2022]; that's the target.

After that, it's just the rest of the season, [which includes races in Poland and China]. And the Commonwealth Games as well, which are happening in the U.K., That could be good, but I need to get selected for that.

MP: Could you be selected to race in the Tour de France or Vuelta a España?

AD: I wouldn't rule it out. My skill set lies in helping sprinters, so if Israel Premier Tech decides to take a sprinter to the Tour de France, then there'd be a chance that I would go also. I wouldn't ever rule either race out because other riders will get ill or injured. There's a possibility. 💧



We can't wait to see you again!



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





Join Team Resilience in 2022!

Join Team Resilience, HFA's peer-to-peer endurance fundraising team, for what is gearing up to be our best year yet!

Lacing up your sneakers as you prepare to run through the Magic Kingdom. Strapping on your bike helmet as you get ready to head down the C&O Canal in the DC area. Donating to a friend who is about to complete a momentous physical activity. All are ways you can join and support Team Resilience, which launched in 2018.

Supporters of Team Resilience either participate in—or monetarily support participants—various athletic and competitive events across the country. These events help to raise awareness about bleeding disorders and raise

funds for Helping Hands, HFA's financial relief program.

Throughout the pandemic, Team Resilience has truly embraced the spirit of resiliency, adapting to provide a mixture of in-person, virtual and hybrid events. The program hosted two in-person Gears for Good bicycle rides in 2021. The National Gears for Good ride moved to a hybrid model, with riders participating in person in DC and in their hometowns. Team Resilience was also able to return to Walt Disney World for the 2021 *runDisney* Wine & Dine Half Marathon Weekend in November.

A Year of In-Person Events

While 2021 was a year of transition for Team Resilience, we are gearing up for 2022 to be our best year yet! A full year of in-person events is already on the schedule, with more being added as the weeks continue.

2022 started off strong with the *runDisney* Walt Disney World Marathon Weekend, January 4–7. Team Resilience runners completed 48.6 miles through the parks of Walt Disney World over the course of four days, completing a 5K, 10K, half marathon and marathon, also known as “the Dopey Challenge.” This true feat of strength was a wonderful way to kick off the year. Two more *runDisney* events are on the calendar for 2022 (the Princess Half Marathon Weekend and the Springtime Surprise Weekend), and we hope to be back in the Disney parks this fall for more *runDisney* events.

Two Gears for Good events are lined up for this year, with additional events in the planning stages. Team Resilience

will once again return to Ohio for the Gears for Good member organization event on June 4. Additionally, our flagship event, the National Gears for Good ride, will return this September, back to its former glory: 150+ miles over three days, from West Virginia to Washington, DC, on the C&O Canal.

We are also pleased to be partnering with our Northern California Member Organization on the return of that group's Fitness Challenge, a multi-week event featuring all kinds of fun fitness challenges along the way.

We look forward to all of these events, plus a few more we haven't announced yet! If you are interested in joining Team Resilience for any of the upcoming 2022 events, or if you would like to support our Team Resilience participants, visit www.teamhfa.org for the most up-to-date information. We can't wait to see you on the trails! 💎



Introducing the HFA Education Team

HFA's Education Team takes a holistic approach to creating tailored, accessible education for our bleeding disorders community. We provide community-driven education that is timely, relevant, engaging and intentional: We meet our people where they are.

BY HEATHER E. CASE, MED, DIRECTOR OF EDUCATION

To continue to be on the “bleeding edge” (pun intended!) of learning, the Education Team (formerly known as the Programs Team) has spent the past year gathering feedback from the community and speaking at length with our member organizations. We have looked closely at all our educational sessions to update content, identify possible places for new curricula and expand our Speakers Bureau. We have also come to the realization that we need to emphasize education. For us, that means teaching and learning from our community members.

A New Way of Thinking

One key change: We have moved away from a track model (hemophilia versus von Willebrand disease, for example) to an inclusive model that seeks to provide education to all members of the community regardless of diagnosis or severity. To this end, we have amended the structure of our existing education into five core areas:

1. Clinical
2. Psychosocial
3. Rap sessions
4. Transitions
5. Community networks

Community networks (aka the Blood Brotherhood, Blood Sisterhood, Families and Sangre Latina) are all still strong and active. The objective for this shift in name to community networks is to create language that more clearly expresses our intentions as a patient-focused and community-driven organization. We have heard time and again that people want quality, timely, engaging education. Instead of setting up programs (no one wants to be programmed!), we are getting back to our roots: support, education and advocacy. And, we're speaking to our heart: our bleeding disorders community.

Education in Action

One example of our active and engaged community is the robust return of HFA's SisterSpace—a monthly forum for Blood Sisters to gather for support, education and networking, with a bit of fun included. Our new Blood Sisterhood manager, Jeanette Jones, has reunited women from across the country to share their experiences, receive education and provide peer support.

In addition, our Blood Brotherhood chats are a monthly staple and have been the cornerstone of HFA's education

New in 2022, HFA will host monthly educational webinars focused on hot topics, conducted by nationally recognized speakers, with specific targeted audiences.

for many years. The Blood Brotherhood chats offer an invaluable connection for peer support and understanding and are led monthly by our Blood Brotherhood manager, Eric Burgeson.

Our Spanish-speaking community has continued to meet monthly for its Hablando Contigo virtual meetings and has seen consistent growth in participation. We want to extend many thanks to our volunteers, Laura Portales and Monica Diaz, who have led Hablando Contigo through the fall and winter.

New in 2022, HFA will host monthly educational webinars focused on hot topics, conducted by nationally recognized speakers, with specific targeted audiences. Topics include a comprehensive review of joint replacements for patients with bleeding disorders, X-linked inactivation in women and “milds matter,” to name a few. These webinars will be available in English and Spanish. Our new associate director of education, Shellye Horowitz, has been instrumental in identifying strong topics and securing new speakers and teachers.

The HFA Education Team is also focused on promoting blended learning opportunities. Blended or e-learning allows HFA community members to have access to our online asynchronous learning platform, Learning Central, at any time. Access is free. The patient-facing educational sessions include Women's Health and Wellness, Emerging Therapies, Basics of Bleeding Disorders and much, much more. Go to www.hfalearning.org to visit HFA's Learning Central.

Let's Connect Now

Do you want more information about our Community Networks? Please email HFAEducation@hemophiliafed.org. 📧



Research Revealed

Genetic counselor Caylynn Carls, MS, CGC, was awarded first place in the 2021 HFA Annual Symposium Poster Session. Here, she explains her work.

Growing up with von Willebrand disease, I quickly learned how to become an advocate for my own health needs. I had tried multiple medications, but as the bleeding episodes were beginning to get in the way of my day-to-day activities, I knew that I must be missing something.

I began to educate myself and my family by researching on my

own. That's when I discovered the bleeding disorders community. My family and I had always felt very isolated, as we didn't know anyone else who truly could understand our experience with von Willebrand disease. After connecting with an online support group, I realized just how much information we truly lacked about our disorder.

Connecting with individuals who had similar experiences led me to new treatment and management options, such as factor infusions and hemophilia treatment centers (HTCs). Since then, my quality of life has improved beyond belief, and it all started with the simple act of awareness. From this experience, I discovered my true passion of advocating for the bleeding disorders community.

As a practicing genetic counselor, I have the opportunity to educate and support patients and families that are seeking more information about various genetic conditions, including bleeding disorders. Within the bleeding disorder community specifically, genetic counselors ensure patients are receiving appropriate genetic testing and accurate interpretation of results. Genetic counselors can also help patients and families better understand their diagnosis and provide any support they may need. I truly believe that knowledge is power! With all the information, patients and families are equipped to make their own health decisions and take charge of their own lives.

While attending graduate school for genetic counseling, I connected with my research team: Sumedha Gbate, MS, CGC; Stefanie Dugan, MS, CGC;

Radhika Sawh, MS, CGC; and DeBran Tarver, PhD, MPH. Genetic awareness for patients and providers is an important and required part of the comprehensive care provided by HTCs. However, genetic counselors are not always involved. As a team, we felt it was important to address the paucity of research surrounding the involvement and perceived value of genetic counselors in the bleeding disorder community.

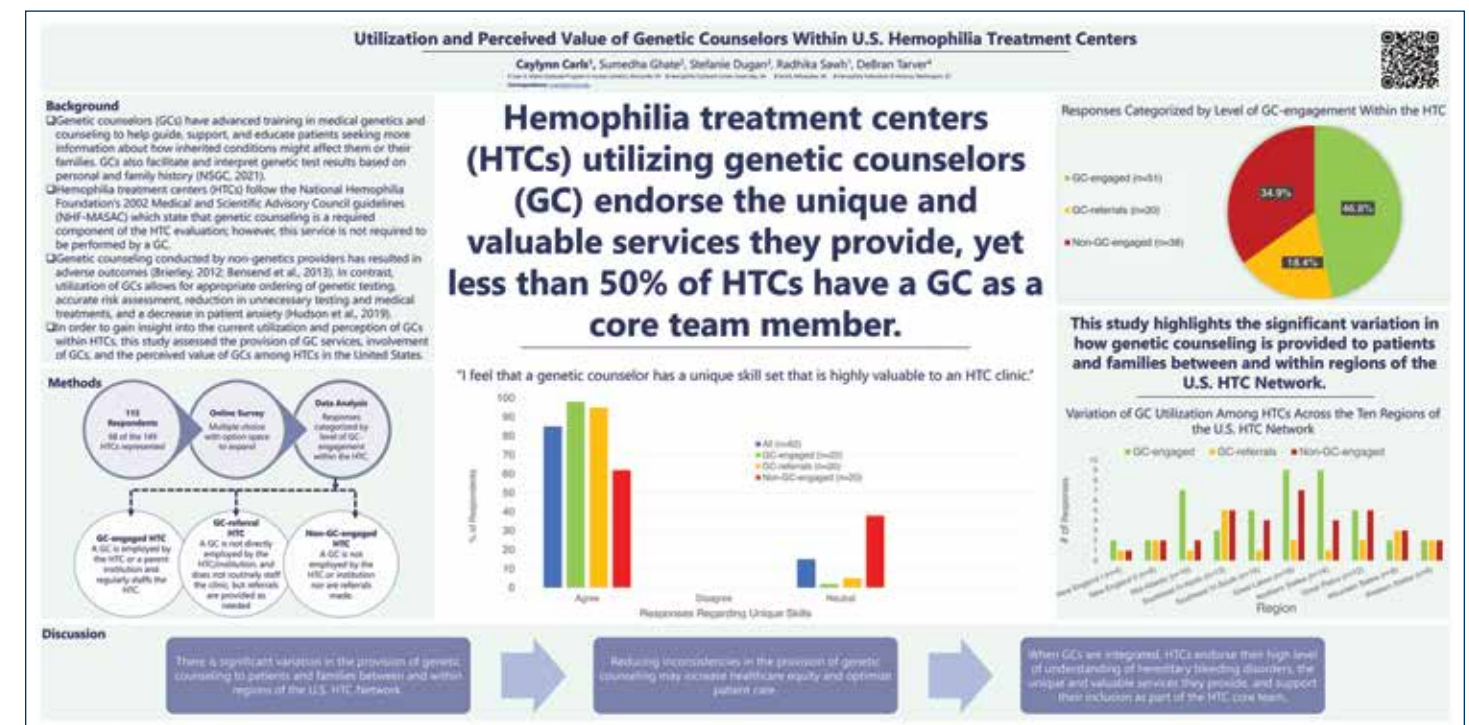
Genetics has become an integral part in the management and treatment of hereditary bleeding disorders. As the uptake of genetic testing increases, providers must be increasingly proficient in many aspects of genetics, such as test selection, interpretation of various genetic testing and nuanced inheritance implications—all while optimally integrating genetic results into clinical care and relaying accurate information to patients and their families.

Our research and recent publications have revealed that when genetic counselors are integrated within a comprehensive care team, other providers endorse the unique and valuable services they provide.

Our research and recent publications have revealed that when genetic counselors are integrated within a comprehensive care team, other providers endorse the unique and valuable services they provide and support their inclusion as part of the core team in comprehensive care. Our research also identified a significant disparity in the provision of genetic counseling, creating unequal access to genetics expertise. This signifies the need to reassess the role of genetic counselors among HTCs to reduce inconsistencies in the provision of genetic counseling and increase health care equity. 💧

The HFA Research Team would like to thank all the wonderful presenters who chose to share their research during HFA's 2021 Annual Symposium Poster Session, as well as all those who voted for their favorite posters.

Caylynn Carl's award-winning poster explains her research that showed less than 50% of hemophilia treatment centers have a genetic counselor as a core team member.



HFA Creates Network of Mental Health Ambassadors

Mental Health First Aid trainings will continue throughout 2022.

BY ANN B. LEWALK, MA, HFA VICE PRESIDENT FOR EDUCATION

HFA is continuing the commitment it made last year to raise awareness on the issue of mental health challenges in the bleeding disorders community. HFA President and CEO Sharon Meyers, EdD, CFRE, provided her vision: “Though we’ve shied away from it in the past, we now realize that HFA is uniquely positioned to provide mental health resources from credible sources and to create much-needed dialogue to shine a light on mental health in the bleeding disorders community.”

HFA made an immediate impact on supporting those who face mental health challenges by creating a network of ambassadors through quarterly Mental Health First Aid (MHFA) trainings.

“I’ve already been able to use the skills that I learned to help identify signs of those struggling with their mental health around me and provide them with additional resources and support. It’s no exaggeration to say that this course could literally help save someone’s life.”

—Lindsay Cox, HFA staff member

“Many times, when people experience a mental health crisis, we want to help, but we fear that our efforts will make the situation worse,” Meyers said. “The MHFA training provided a structured approach to alleviate my fears so that I can confidently help others experiencing a mental health crisis.”

While MHFA-trained individuals are not meant to take the place of mental health professionals, they are equipped to identify when someone is struggling and are able to provide them with accessible mental health resources, such as crisis hotline numbers or program referrals. As of the end of 2021, HFA had funded the training of 59 mental health ambassadors across the U.S. through four virtual training opportunities.

As an organization, it is important that HFA walks the talk while encouraging its community to focus on mental health and wellness. Meyers’ goal for HFA is to have most of the organization’s leadership team, staff and Board of Directors complete the MHFA training. Currently, almost all the leadership team, half of HFA staff and many of the Board members have completed the training.

Thanks to support from the Keenan Coburn Foundation and the Hemophilia Alliance Foundation, HFA will continue to expand its reach in 2022. The first training was held in February, and the second training will

be focused on HFA Board members, who will be invited to take part in the training in person during HFA Symposium, April 20–23 in San Antonio. In addition, HFA will host a reception at Symposium for those who have been certified in MHFA over the past year, so they can connect with one another in person.

“I have enjoyed the collaboration with HFA in bringing Mental Health First Aid to our community over the past year. Thank you to HFA for all your efforts to normalize the conversation about mental health!”

—Debbie de la Riva, LPC, MHFA instructor

“It is important to work together in the bleeding disorders community to position mental health as a valuable partner in overall health,” Meyers said. “If HFA can continue to provide opportunities for MHFA training for people in the community, as well as those serving the community, we can recognize the warning signs of a mental health crisis sooner and work together to destigmatize mental illness so that no one in this community suffers in silence.” 💧

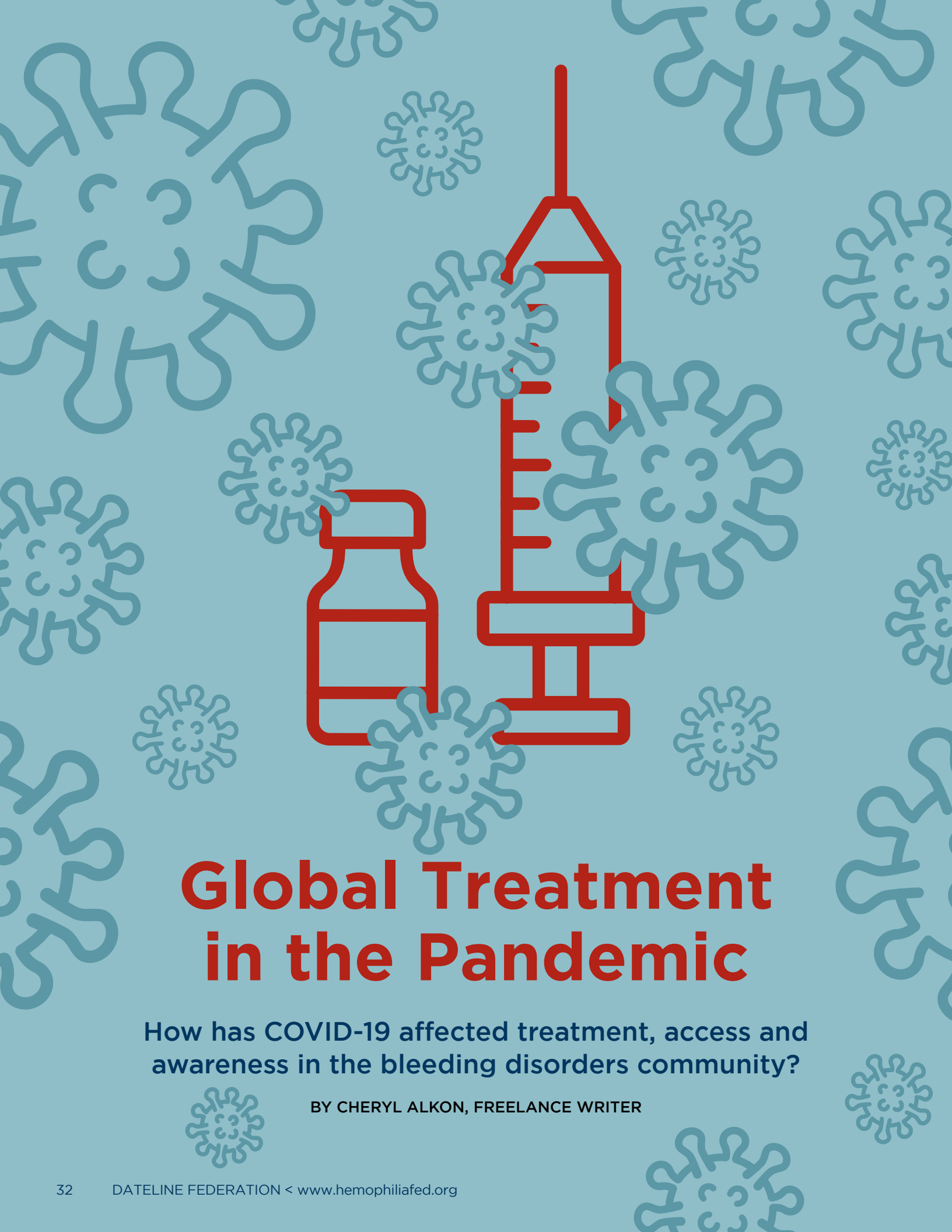
Additional MHFA trainings will be open to the community in late summer and fall of 2022. Be sure to check www.hemophiliafed.org for more information.

We can't wait to see you again!



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





Global Treatment in the Pandemic

How has COVID-19 affected treatment, access and awareness in the bleeding disorders community?

BY CHERYL ALKON, FREELANCE WRITER

As the COVID-19 pandemic marched across the globe in early 2020, people in the bleeding disorders community worried how it would affect treatment, advancements and access for those who needed it. The pandemic has taken its toll on the bleeding disorders community globally: It restricted access to health care providers, sent people online to interact virtually, and for some, limited or cut off access to treatment centers and potentially lifesaving treatment.

Now into year three of the pandemic, it's clear that COVID-19 has had a tremendous impact on the community, but it's also brought people together, said Jennifer Laliberté, national director of the World Federation of Hemophilia (WFH) USA.

WFH exists to improve and sustain care for people with inherited bleeding disorders—no matter where they live—and includes member organizations in 147 countries. In 2020, the organization created the COVID-19 Relief Fund to help member organizations continue to provide programs and services and ensure that people with bleeding disorders could safely access treatment and care.

The fund raised \$90,000 with 27 national member organizations and other partners contributing. From that, WFH has been able to provide funding to 24 patient organizations in every region of the world. The money has been used for groups to find new and innovative ways to maintain vital programs, purchase personal protective equipment (PPE), and facilitate access to treatment and care.

"We've also seen an incredible resilience and solidarity from the community in response to our call to action, and we are proud to have supported organizations and communities across the globe," Laliberté said.

Such efforts have highlighted the shared concerns and queries the global bleeding disorders community faces. "In my conversations, the folks who were in Georgia or New York were saying many of the same things and asking the same questions as those who were in Nepal or in Zambia," she said. "They all wanted to know, 'What would the pandemic mean for our hemophilia treatment centers? Would the product supply chain be disrupted? What effect was this going to have on our government's commitment, or lack thereof, to investing in bleeding disorders care over the long term?' It was amazing to see that similarity around the world. As a part of an international organization focused on capacity building, our No. 1 priority has been to ensure our community stays safe and is well-supported, as they continue to advocate for the standards of care that

every person living with a bleeding disorder deserves, no matter where they live."

Treatment Availability Still Geographically Based

Both currently and historically, access to treatment for bleeding disorders has very much depended on where people live, Laliberté said.

"Globally, the overwhelming majority of people living with inherited bleeding disorders still struggle to access diagnosis, treatment and care," she said. "Our estimates tell us that over 75% of people with hemophilia worldwide are undiagnosed." Citing 2020 data from WFH's Bleeding Disorders Registry, Laliberté said that in Europe, 81% of the expected number of people with hemophilia have been diagnosed, compared to only 8% in Africa. Worldwide, only 14% of all adults and 16% of children with severe hemophilia receive prophylaxis treatment. (The 2021 data are being analyzed now and won't be published until later in 2022.)

While prophylaxis factor has long been established as the standard of care in the United States, it is not accessible to the overwhelming majority of people living with inherited bleeding disorders around the world. Access to diagnosis and care is the global community's most significant challenge, Laliberté said, and the pandemic has only further complicated things.

What few trained health care providers a person had access to pre-pandemic became even less available because they were called to respond to the pandemic. Plus, some health care workers became sick with COVID-19 or there was a lack of PPE to allow for treatment, she said. "So, if you're not able to access treatment, and you're living with longer-term effects of uncontrolled bleeding, complications can be worse."

Comparatively, "if you had access to a high standard of care and services in the first place, like most people in the United States and much of Western Europe, the pandemic required you to adapt to a new reality: community events, clinic consultations were probably all virtual, or maybe it takes you a little longer to get the kind of services you're used to. But generally, you're still being treated as you need to be," she said.

In the United States, prophylaxis treatment occurs at home, so people have a certain amount of their medication on hand and treatment is self-administered. Around most of the world, that's not the case. "Home treatment is largely nonexistent. So, if you're in lockdown, and you can't get to a hemophilia treatment center to get treated for an acute

“We’ve also seen an incredible resilience and solidarity from the community in response to our call to action, and we are proud to have supported organizations and communities across the globe.”

—Jennifer Laliberté

bleed, or to receive your prophylactic dose, there can be serious consequences.”

Some member organizations have seen this as an opportunity to galvanize their advocacy efforts to improve access to home treatment. In Brazil, home treatment has been extended during the pandemic, and patients are using an app to facilitate remote care and to track adherence and health outcomes, Laliberté said. “If I was living in a place where home treatment was not possible, I now have a strong argument to make why it would be important for me to have product at home,” she said.

During the earlier part of the pandemic, some hemophilia treatment centers provided patients with a few doses to use to try and mitigate the issue. The WFH supported these efforts by providing virtual webinars and other information to help people learn how to self-infuse. As a result, “We have seen a rise in the use of home treatment reported in the countries where we provide humanitarian aid product,” Laliberté said. “We know this trend is going up, so that’s really encouraging.”

Moving this and other training and information sessions online has allowed WFH and others in the bleeding disorders community to reach more people than ever before too, she said. “We are definitely seeing the number of people participating in our events from various parts of the world going up.”

Supply Chain Concerns

Early on in the pandemic, there were concerns about medication supply and supply disruptions. However, Laliberté said, the industry found solutions.

WFH is the largest supplier of donated treatment products for bleeding disorders, sending medication to 74 countries in 2021. Recipient countries witnessed an increase in home treatment that ranged from a 40% increase in countries

such as Barbados, Dominican Republic and Guyana to an 80% increase in countries such as The Bahamas, Nicaragua and Paraguay.

“Our supply routes were severely affected by flight cancellations and route changes, and we saw considerable delays in delivering treatment to various parts of the world, particularly to emerging countries,” she said. Costs rose exponentially as a result of increased shipping costs, delays causing storage costs to rise, and so on.

Collaborative efforts helped get medication to where it was needed, too. “We saw national member organizations come and support each other,” Laliberté said. “In one case, airport closures meant we couldn’t get product into Nepal, but working with our member organization in India, we were able to get a shipment across the land border.

“It might have taken longer, it might have cost more, it might have been a little more complicated—but in the end we were always able to get it where it needed to go. We were very fortunate to be able to count on partners who helped us deal with the rising costs.”

Despite all the pandemic’s challenges, Laliberté noted that from 2016—when the program was expanded—through 2020, WFH has distributed 1 billion international units (IUs) of factor and non-factor replacement therapy. In 2020, the organization distributed 146 million IUs of treatment product to people who would otherwise receive no treatment at all.

“Though it’s a little less than in previous years, it’s still a significant amount—and certainly has a significant effect on the lives of those who receive those donations,” she said. WFH expects to return to its normal standard levels this year.

For more details about WFH, visit www.wfh.org.



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Please read this information carefully before using ELOCTATE and each time you get a refill, as there may be new information. This information does not take the place of talking with your healthcare provider about your medical condition or your treatment.
WHAT IS ELOCTATE? - ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency). - Your healthcare provider may give you ELOCTATE when you have surgery.
WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT ELOCTATE? - You should not use ELOCTATE if you are allergic to ELOCTATE or any of its other ingredients. Tell your healthcare provider if you have had an allergic reaction to any Factor VIII product prior to using ELOCTATE. - You can have an allergic reaction to ELOCTATE. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives. - Your body can also make antibodies called, “inhibitors” against ELOCTATE. This can stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors. - If you have risk factors for developing abnormal blood clots in your body, such as an indwelling venous catheter, treatment with Factor VIII may increase this risk.
THE MOST COMMON SIDE EFFECTS OF ELOCTATE INCLUDE: joint pain, general discomfort, muscle pain, headache, and rash, in previously treated patients, and Factor VIII inhibition, device-related blood clotting, and rash in previously untreated patients. Talk to your healthcare provider for more information and about any side effect that bothers you or does not go away.
WHAT SHOULD I TELL MY HEALTHCARE PROVIDER BEFORE STARTING ELOCTATE? Tell your healthcare provider about all your health conditions, including if you: - Have or have had any medical problems. - Are taking any prescription and non-prescription medicines, including over-the-counter medicines, supplements, or herbal medicines. - Are pregnant or planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby. - Are breastfeeding. It is not known if ELOCTATE passes into breast milk and if it can harm your baby.
AFTER STARTING ELOCTATE: - If your bleeding is not controlled and you experience a lack of clinical response to Factor VIII therapy, call your healthcare provider right away. - Medicines are sometimes prescribed for purposes other than those listed here. Do not use ELOCTATE for a condition for which it was not prescribed. Do not share ELOCTATE with other people, even if they have the same symptoms that you have.
HOW SHOULD I USE ELOCTATE? ELOCTATE should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia A learn to infuse ELOCTATE by themselves or with the help of a family member. See the booklet called “Instructions for Use” packaged in your ELOCTATE for directions on infusing. If you are unsure of the procedure, please ask your healthcare provider.
QUESTIONS? The risk information provided here is not comprehensive. To learn more, talk about ELOCTATE with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at www.eloctate.com or 1-855-MyELOCTATE (693-5628). You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch , or call 1-800-FDA-1088.
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