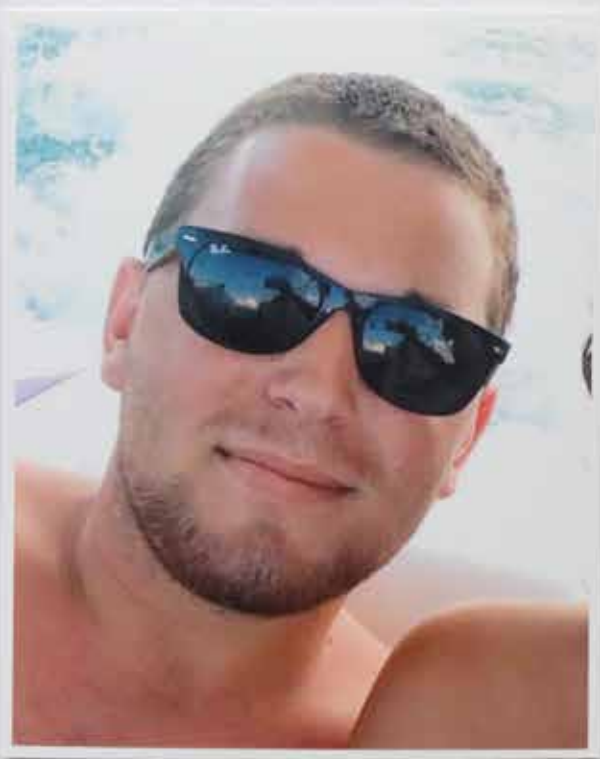


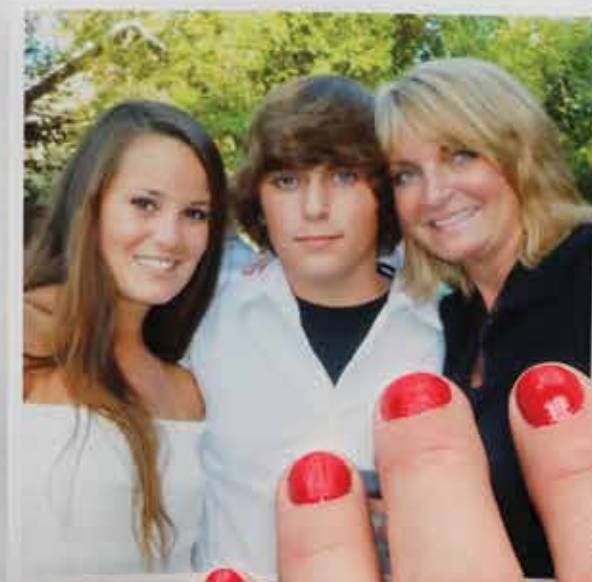


DATELINE

F E D E R A T I O N



A Mother's Love



EXECUTIVE CORNER

Dear Friends,

My wife is a mother of two daughters with von Willebrand Disease!

When Kinzie was first diagnosed, I knew Heather was just as nervous as I was, but honestly she managed better than I. As we started to infuse at home, Heather was the first to learn to infuse. She is a nurse and accustomed to starting IVs, but starting them on your child is a very different situation.

These days we are deep into sports, music and pre-teen issues. Heather runs lead on many of the latter conversations. As a mom she wants to protect her children, but help encourage ownership of their condition.



Kinzie has done well thus far in managing her infusions and bleeds. She loves sports, taking ownership over her vWD, knowing when to treat and when she may need to sit out of sports, as hard as that may be. That is something that makes us both proud!

My wife has led the way through some of our journey and helped me become an empowered parent. **When I step back to view what she has meant not only to our daughters with their bleeding disorders, but our kids overall, a few things come to mind: comfort, strength and encouragement.**

She is there for our kids whether it is for homework, an infusion, someone to cheer them on during sports/music or just a shoulder to lean on.

Josh Hemann

Board Chair

Above: Heather, wife of HFA Board Chair Josh Hemann, with their two daughters, Kinzie, left, and Jayla.



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

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ON THE COVER. Kathy Dunham of California talks about her son's death in a tragic shooting and the emotional days to follow. Her son, Jake, who was born with hemophilia, never let the risk of bleeds stop him from living life. Top left: The late Jake Dunham enjoying boating with family and friends; top right, bottom, left: Jake enjoying dirt bikes in the California desert. Bottom right: A young Jake with his sister, Alexis, and mom, Kathy.

HAPPENING HIGHLIGHTS

HFA Introduces New Toolkit

To continue the commitment to providing educational resources to families and individuals with bleeding disorders, Hemophilia Federation of America has created the New Parents Toolkit to add to the library of toolkits available on the website.

Having a new baby is a joyful, yet challenging, time in a parent's life. When the new baby is diagnosed with a bleeding disorder, it adds a whole new layer of stress to the growing family. The new toolkit can help new parents tackle the future, familiarize themselves with bleeding disorders and the bleeding disorders community, and learn more about the baby's new diagnosis.

More than a dozen toolkits can be found on the HFA website – each with valuable resources, downloadable materials and webinars.

Visit www.hemophiliafed.org/toolkits to find the New Parents Toolkit, as well as HFA's other helpful toolkits.



Charity Songwriting Competition Supports Bleeding Disorders

Music for the Cause National Charity Songwriting Competition is now accepting entries for 2019! Six winners will be decided by music professionals, include Chris Mann from NBC's The Voice, and will share a \$13,000 cash prize. This national fundraising event supports the bleeding disorders community. Deadline to enter is May 15. Enter online at MusicForTheCause.org.



PPTA Names New President and CEO



The Board of Directors of the Plasma Protein Therapeutics Association has named Amy Efantis as its next President and Chief Executive Officer.

She most recently served as Vice President, Global Public Policy & Government Affairs at Biogen. Efantis joins PPTA following the retirement of President and CEO Jan M. Bult on Dec. 31, 2018. PPTA is a trade association that represents more than 750 human plasma collection centers in North America and Europe as well as the manufacturers of life-saving plasma protein therapies.



Chris Bombardier Joins Save One Life as Executive Director



Save One Life, an international nonprofit that assists people with hemophilia in developing countries, welcomed Christopher G. Bombardier as their new executive director earlier this year.

Bombardier, who has severe hemophilia B, is known for being the first person with hemophilia to climb the Seven Summits. He began his Seven Summits climbs in 2011 to raise awareness globally of the disparity in treatment for those with bleeding disorders in developed and developing countries. Along the way, he joined the board of Save One Life, and raised more than \$100,000 for the nonprofit.

Previously he was program facilitator with GutMonkey, an outdoor adventure leadership company. He earned a master's degree in global health from Northwestern University, which will help him evolve and grow Save One Life's programs. 💧



Peer-to-Peer Collaboration Improves Services to Women and Girls

Article Provided by Foundation for Women and Girls with Bleeding Disorders

In the fall of 2013, the Foundation for Women and Girls with Bleeding Disorders was contacted by Oregon Health and Science University's Hemophilia/Thrombosis Treatment Center to assist them in creating a designated young women's clinic.



FOUNDATION FOR
Women & Girls
with Blood Disorders

The OHSU center staff had been seeing an increasing number of young women with heavy menstrual bleeding within their regular hemophilia/thrombosis clinic, and they wanted a designated clinic day for young women. The FWGBD board and staff identified the Women and Girls with Bleeding Disorders Learning Action Network as the mechanism for assisting OHSU.

Collaboration is Key

That year FWGBD launched the WGBD LAN with the goal of bringing together hematologists, OB/GYNs and other reproductive medicine specialists in an integrated and collaborative peer-to-peer exchange of ideas, problem solving of common challenges, as well as discussion of current and best practices in the areas of diagnosis, treatment and management of women and girls with bleeding disorders. This network would engage professionals established in serving women and/or girls with blood disorders with those who want to begin or to improve their center's services for women and girls.

On a cost-effective web platform, the WGBD LAN is an exchange of key information and best practices in the care of women and young women with blood disorders. WGBD LAN participants are representatives of hemophilia/hemostasis and thrombosis centers that have a clinic or services for women/young women or which wish to start a designated women's or young women's clinic.

The WGBD LAN started with seven clinician/members and today the network has 160 clinician/members at 56 distinct institutions within 27 States. It also has one member each in Canada and the Netherlands.

Outcomes to Date

In addition to the education and best-practice exchange that the LAN platform is achieving, two important outcomes have taken place.

1. Designated WGBD Clinic

The first main outcome of the WGBD LAN has been the establishment of a designated clinic for women/young women. WGBD Clinics are identified by the components implemented by the clinic, following the WGBD Clinic of Excellence model, which is described below. Typically, these clinics offer both hematology and adolescent reproductive health or adult OB/GYN expertise in a single setting to diagnose and treat bleeding disorders and the heavy menstrual cycles that accompany them. Since 2013, 17 WGBD Clinics have been created through members' participation in the WGBD LAN.

2. WGBD Clinic of Excellence Model

In 2014, members, along with the FWGBD board, identified the essential elements for a Women's and Girls' (Young Women's) Clinic of Excellence. The model highlights the collaborative hematologic and obstetric/gynecologic care for women and girls with bleeding disorders delivered through the comprehensive care model – a model deemed optimal for women as it has been demonstrated for men with hemophilia and people with cystic fibrosis and other chronic diseases.

The model's five essential components are:

1. Coordinated and Combined Clinical Care (between hematology and OB/GYN, adolescent medicine services)
2. Collaborative Care Team (Multi, Interdisciplinary)
3. Assessment of Patient and Clinic Outcomes
4. Ongoing Education and Awareness (Internally, Other Departments, Externally)
5. Collaborative Clinical, Translational, Laboratory Research (effectively using the WGBD LAN for cross-institutional collaboration) ♦

For more information about patient resources for women and girls with blood disorders, visit HFA's Blood Sisterhood Program at www.hemophiliafed.org/bloodsisterhood.

Healthcare providers can learn more about research and treatment options for women and girls with blood disorders at fwgbd.org.

Hemo Moms Face Challenges Greater Than Just Bleeding Disorders

Did you know children spend more time with their siblings than with friends, parents, teachers or even alone?

According to Nursingschools.net, by the time children reach age 11, they're spending about 33 percent of their free time with siblings. With all the time together, siblings are bound to have some arguments and disagreements.

Sibling rivalry isn't a unique or a new concept. However, when one child is diagnosed with a bleeding disorder, that sibling rivalry can affect the entire family dynamic. Sometimes unaffected siblings feel resentment, left out, jealous, scared and confused. As one Infusing Love Moms Blog blogger pointed out, she has tried her best to give equal attention to both of her boys.

~Carrie Koenig, HFA Programs Manager



Zachary, right, occasionally feels neglected when his brother, Myles, gets attention due to severe hemophilia A.

When I committed to writing this blog, I had no idea what I would blog about until I went to see the movie "Wonder." It is about a boy born with a facial disease known as Treacher Collins syndrome. Due to his medical needs, which require the attention of his family, his older sister states several times she feels forgotten. As a mother, we often struggle with treating our kids fairly. There is often a gray area between meeting each child's needs and treating each child the same.

The sister's admission in the movie of feeling like the left out, neglected sibling in her family sounded familiar to how my older son, Zachary feels. I tend to favor my youngest son, Myles, who has severe hemophilia A. While it's unintentional that I show any favoritism, I can't help but spend more time with Myles, as it is my duty as a stay-at-home mom to be his primary caregiver. Needless to say, I spend much of my time with Myles and it causes Zachary to feel that I don't love or want to be with him as much as I'm with his brother.

Zachary is constantly feeling lost and left out and refuses to do things or go places with Myles and me. He has voiced he feels unloved and unheard. I am constantly reminding Zachary that I love him and that there are no favorites. Despite this, Zachary is observant, and he sees how much time I

spend with Myles. I try to include him in more activities, such as helping with shopping, meal preparation, date nights or special time with either my husband or me. I feel extremely guilty because I never want to be that parent who favored one child over another.

Besides relating to this movie via my children, I am the oldest of three; my younger brother was diagnosed with developmental delays and Pallister-Killian Mosaic Syndrome or PKS, which is a chromosome abnormality. At times throughout our childhood I felt my parents spent more time and made family decisions based on his abilities and likes. I can say while growing up, I sometimes felt left out. Now that I am a mother, I know what Zachary is feeling.

~Lindsay, hemophilia mom 💧



The Coping with Sibling Issues Toolkit offers helpful resources. Visit www.hemophiliafed.org/toolkits!

With Mother's Day around the corner, we asked hemo moms what they really want for Mother's Day!

"A day when nothing has blood on it!" ~Maryann

Maryann →



Kimberly →

"For my boys to be confident young men and believe in themselves, to hear spontaneous, genuine affection from the heart once in a while and for them to just vacuum and put the dishes away without being asked." ~Kimberly



"A spa gift card for pedicure, massage and facial, to sleep in with breakfast in bed, a cleaning lady, for my children to behave, a night out with girlfriends, and for husbands to actually remember and celebrate Mother's Day!" ~Lindsay

← Lindsay



"An unlimited supply of coffee with IV hook-up, a worry free day at gym class, a day free from hassle when placing an order for factor, a bleed free day, a clean house, and a day full of love, laughter and massages! Chocolate is good too!" ~Jen

Jen →



"My biggest wish is that my daughter learns to navigate through the many hardships of life with a strong attitude of positivity and hopefulness. Naturally, children take after the example we gave them, so I guess it's up to us once more to become these strong, positive people who they emulate. Every way in which we can prepare by having useful information and skills for life is something that I wish for. I hope to participate and take part in activities that will make me a better person for the sake of my children and others to come." ~Sylvia

← Sylvia



"Sleep! Also for my children to appreciate me one day, my children to grow into independent, strong, self-advocates, my children's happiness and a less complicated health insurance system." ~Sonji

Sonji →



Bikepackers Raise Funds Virtually

Chris Seistrup has been active in cycling for many years. During Hemophilia Federation of America's Gears for Good charity bicycle ride in 2018, he chose to be a virtual rider, cycling a total of 483 miles with his friend, Scott Dunham.

"My personal mission of 'ride bikes, help people' guides me to do whatever I can to help those in need," said Seistrup, who has mild hemophilia B.

'ride bikes, help people'

Seistrup and Dunham are bikepackers – they load up bikes and the bare necessities, a little bit of camping gear, some tools and layers for clothing to endure all kinds of weather while cycling. Their journey through Illinois during Gears for Good included a visit to Seistrup's grandfather, who has hemophilia B, sleeping on top of picnic tables in a state park, and about as much as their bodies could handle.

The two set a goal to raise \$1,000 but were able to raise \$1,500 for Gears for Good. In 2016, Seistrup also raised money for HFA by riding the Pacific Coast highway from Vancouver, British Columbia, to Imperial Beach, California. 📍



Chris Seistrup, right, and Scott Dunham

A large advertisement for Shire. It features a woman, Michelle vWD, standing on a blue block and reaching out towards a large mural of the US Capitol building. The mural is set against a colorful, starry night sky. The text "Your dreams. Our dedication." is written in blue. Below it, a paragraph describes Shire's commitment to improving the lives of members of the bleeding disorders community. The Shire logo is in the bottom left, and the website "bleedingdisorders.com" is in the bottom center. A small text block on the right identifies the woman as Michelle vWD from Nevada.

Your dreams. Our dedication.

At Shire we are driven to help improve the lives of members of the bleeding disorders community. You inspire us. Each pioneering new product and program represents another step toward our ultimate goal: **a life full of dreams and free of bleeds.**

Shire

bleedingdisorders.com

Michelle
vWD
Nevada

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S33467 07/17

Getting Hairy to Raise Awareness for Hemophilia

“No-shave November” has become a modern social media movement. Men stop shaving their facial hair and share pictures of their rapid hair growth (or not)!

John Bruno is using a similar concept to raise money and awareness for hemophilia with Beards for Bleeders. Anyone who wanted to make the commitment stopped trimming their beards in September, committing to staying away from a razor for six months.

The concept for Beards for Bleeders grew when John and his father-in-law noticed a cousin’s big beard at a family gathering in 2014. They had the idea to grow out their own to raise awareness.

“We figured the longer our beards got, people would ask and make comments, just like we did with my cousin’s beard,” said Bruno. “It would then give us the opportunity to talk about hemophilia.”

They started to promote their endeavor on social media, thinking they’d get a few family members or friends to join in, but it soon grew to 56 men in six different countries participating. They developed a Facebook group, created a logo and website, and offered T-shirts and buttons.

That year, beard-growers raised and collected their own money, donating to a hemophilia organization of their choice. They raised a little more than \$15,000. Bruno was convinced by a friend to bring it back, so in September of 2018, he used the same Facebook page to begin the fundraiser again, this time to benefit Hemophilia Federation of America.

“It has definitely helped raise awareness,” said Bruno. “We have had the opportunity to have many conversations when people say ‘hey, nice beard.’ We follow up with ‘Thanks! Let me tell you why I’m growing it.’”

About 20 men in nine states and Canada grew their beards and posted pictures to raise money for HFA. 🩸

Greg Hogan spent six months growing a beard for Beards for Bleeders. Photo Credit: Ashah Smith Photography



Community Participation in Research Reveals Important Information About Pregnancy, Menstruation and Hysterectomies

Hemophilia Federation of America ran the Community Having Opportunity to Influence Care Equity Project, in collaboration with the Centers for Disease Control and Prevention, from 2011 to 2015 to understand care needs for those within the bleeding disorders community.

More than 150 community members helped in the development of the CHOICE survey and along the way, we learned a lot, especially about women with bleeding disorders. Participants provided forthright and insightful feedback on women's issues on a local and national level.

Since 2016, HFA has presented more than 10 posters on the CHOICE data at conferences throughout the United States and beyond. The following highlights a poster HFA presented at the World Federation of Hemophilia's World Congress in Glasgow, Scotland, in 2018.

The poster, "Understanding Gender-Specific Disease Burden of US Females with hemophilia A or B: insights from the results of the CHOICE Project into gynecological, obstetric, and quality of life issues," highlights some of the issues women in the bleeding disorders community are experiencing.

Community Participation Essential

Participation in research studies and projects can provide valuable insights in advocacy efforts and advancement in quality of care for not only those involved, but for the community as a whole. HFA uses this information to further our advocacy efforts, and to inform our educational programming at both the local and national level.

Participation in research is a deeply personal decision. As opportunities arise to participate in research projects, be sure to ask questions and be informed of the goals of the project and how the results will be disseminated.

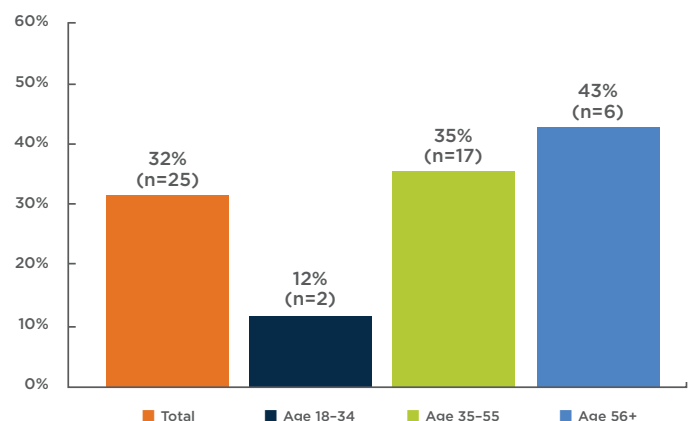
FWH = Females with hemophilia

Disclaimer: The data below is not representative of all females with bleeding disorders. Participants in CHOICE included females diagnosed with a bleeding disorder and undiagnosed females with bleeding disorder symptoms, but this data reflects specifically those with a single diagnosis of hemophilia A or B.

90% of FWH reported ever having a "heavy" period



Hysterectomy rate among FWH is 32% with surgery taking place at an average age of 38.6, with FWH between the ages of 35-55 and 56+ reporting the highest rate of hysterectomies



11.7% According to the Centers for Disease Control and Prevention, from 2006-2010, 11.7 percent of women between the ages of 40-44 had a hysterectomy.

31%

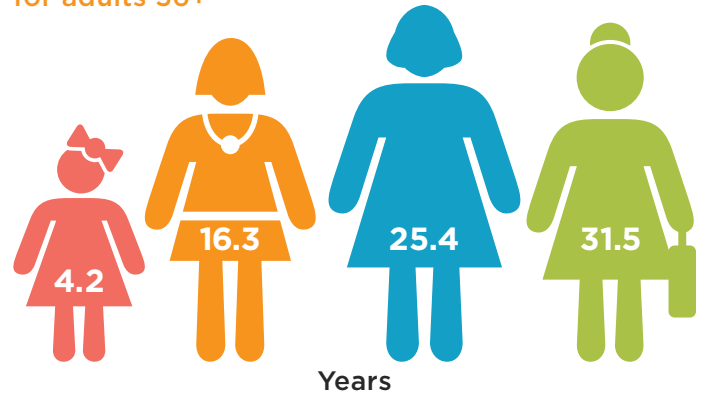
of menstruating FWH have lost work/school/recreation days due to menstrual bleeding in the past 12 months

RESEARCH PORTAL



High levels of menstruation related issues among FWH, including heavy periods, resulted in lost days from work, school and recreational activities, directly impacting the FWH's quality of life

The average age of first diagnosis for FWH varied by age groups with the average of 4.2 years for children under 18, 16.3 years for adults 18-34, 25.4 years for adults 35-55, and 31.5 years for adults 56+



45% of FWH experienced a miscarriage in the first trimester of pregnancy. A first trimester miscarriage is the loss of a pregnancy from natural causes in the first 13 weeks of pregnancy

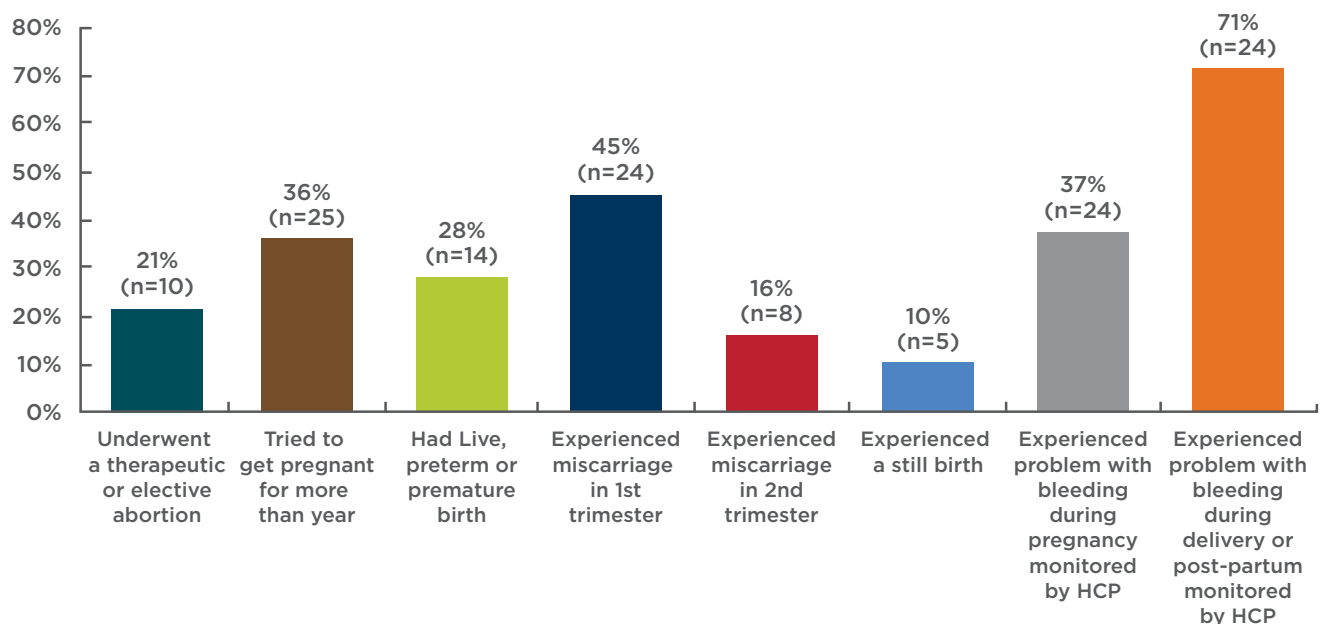


37% of FWH had any problem with bleeding during pregnancy and 71% (n=46) had bleeding during birth or post-partum that resulted in monitoring or treatment by a healthcare provider



23% of FWH receive care only prior to a medical procedure

Fertility/Pregnancy/Delivery/Post-partum related complications of FWH



Visit www.hemophiliafed.org/research to learn more about the research process and how you can get involved!

Living Full Throttle Despite Hemophilia

MOM REMEMBERS SON KILLED IN SHOOTING AMID CHAOS OF CALIFORNIA WILDFIRES

BY EMILY A. ROUSH-BOBOLZ, STAFF WRITER

“Hold ‘er wide” Jake Dunham and his off-road-loving friends used to say. It’s a term similar to pedal to the medal—riding full throttle with maximum speed and effort. That’s exactly how Jake lived his life!

That full bore lifestyle was cut short in November of 2018 when Jake, a 21-year-old with hemophilia A, was shot at the Borderline Bar and Grill in Thousand Oaks, Calif.

It was one year after the widely-publicized Route 91 Harvest Festival shooting in Las Vegas. Jake and his friends headed to college night at the local establishment to line dance and enjoy each other’s company. Because it was college night, it was busy. A few of Jake’s friends decided to head home for the night, but Jake and his good friend Blake Dingman decided to stay.

Just before midnight a 28-year-old man with a gun approached the front door, shooting a female cashier and a bouncer before making his way inside where he’d continue his rampage. As shots rang out, Jake picked up his phone and called 911. But the call only lasted two seconds. What cut that

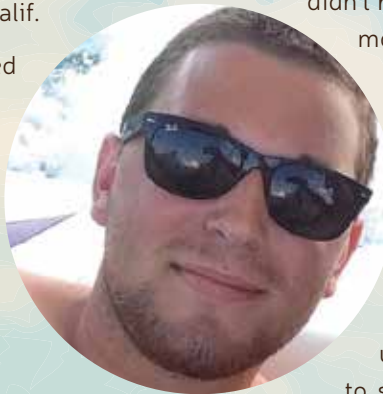
call short isn’t entirely certain — witnesses say some people were pushed, knocked down in a crowded rush to escape, others ran in multiple directions, and others were in the line of fire. The shooter killed 12 people that night, including Jake and Blake, before turning the gun on himself.

Jake’s mom, Kathy Dunham, recalls she and her husband didn’t really know what was going on until 1:30 in the morning. When the news said the incident had happened nearly two hours earlier and they still had no word from Jake, they expected the worst.

They made their way to a nearby teen center, where families started to gather, waiting for answers from police. After an excruciating 12 hour wait, police started ushering families to another area of the center to speak privately, and they knew their son had died. The local media had caught wind and converged on Thousand Oaks, and even interviewed Jake’s dad, Ken.

But before they could truly wrap their head around what had just happened, deal with media coverage, and handle calls to and from family and friends, California’s wildfires began to rage out of control. Coverage of the fires took over the news and coverage of the 12 victims began to fade. Within days of their son’s death, the Dunham’s were told to evacuate their home and more chaos set in.

“I grabbed every picture of Jake I could find,” said Dunham, throwing the pictures in the family vehicle. All I have left of this kid is pictures!”



They eventually realized fires were still about five miles from their home and chose not to evacuate and instead stay home to deal with the unspeakable.

Living Life Full Throttle

"He was a kid who shouldn't have been born with hemophilia, because he was always a daredevil," jokes Dunham. "He was fearless!"

He was diagnosed with hemophilia as a newborn. Although Dunham was a nurse, she was a paranoid and fearful mom, always being told by her husband that she was overreacting. She didn't think she was overreacting. Her son had hemophilia after all.

As a little boy, Jake was always riding bikes and getting injured. He broke his nose and other bones. But it didn't stop him. He never made it to hemophilia camp as a kid because he was always injured. And then he grew up too fast, his mom says, and got to a point where he didn't want to go to camp. As he got older, he moved from bicycles to BMX bikes and eventually dirt bikes – anything bigger and faster. He also had a love of big trucks. He was a joker and the life of the party, stubborn, and he persevered.

"He was phobic of needles, but had no fear of getting injured," said Dunham. "I was always wondering what would happen next."

He didn't talk about his hemophilia. Some of his friends didn't even know. He always felt there was nothing wrong with him, his mom recalls. There were even times he'd end up at the hospital after injuring himself during one of those daredevil moments and when doctors asked for his medical history, he wouldn't even mention he had hemophilia. Dunham was quick to speak up and add it to his medical history on her son's behalf. "You have to tell them about your hemophilia, Jake!" she remembers telling him.

Despite not truly acknowledging his hemophilia, Jake and his family, including a sister who is a carrier, were involved in the bleeding disorders community through Hemophilia of Southern California. Following Jake's death, the community made shirts as a fundraiser.

"The whole community stepped up with so much support," said Dunham. "It's been amazing the way everyone has come together for us."

Jake had a large group of friends who loved to go to the desert to ride dirt bikes. That group was a large part of life for about a month after Jake's death, filling the Dunham's home, eating the food people had made for the family until his funeral in December last year.

"His friends and my neighbors have so many stories," she said. "My son had the biggest heart in the world, and he would be the first to be there for anyone in need!"


After his death, his friends held a truck procession to remember his love of trucks and built a memorial in the desert where they used to ride with him. They joined Jake's dad in fixing up a truck he had been in the process of restoring when he died. They're keeping his memory alive!

"I keep thinking he's going to walk through the door," said Dunham. 💧



THE EXTENDED-HALF-LIFE rFVIII WITH PROVEN PROTECTION AND UNIQUE STEP-WISE DOSING^{1,2}

For patients ≥ 12 years

Start simply	TWICE WEEKLY	For all prophylaxis patients: Recommended starting regimen is Jivi twice weekly (30-40 IU/kg) ¹
Step up	EVERY 5 DAYS	Based on bleeding episodes: Less frequent dosing of Jivi every 5 days (45-60 IU/kg) can be used ¹
Fine tune		Based on bleeding episodes: The dosing frequency may be further adjusted up or down ¹

IU, international units; kg, kilograms; rFVIII, recombinant Factor VIII.

INDICATIONS

- Jivi is an injectable medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A.
- Jivi is used to treat and control bleeding in previously treated adults and adolescents (12 years of age and older) with hemophilia A. Your healthcare provider may also give you Jivi when you have surgery. Jivi can reduce the number of bleeding episodes in adults and adolescents with hemophilia A when used regularly (prophylaxis).
- Jivi is not for use in children below 12 years of age or in previously untreated patients.
- Jivi is not used to treat von Willebrand disease.

IMPORTANT SAFETY INFORMATION

- You should not use Jivi if you are allergic to rodents (like mice and hamsters) or to any ingredients in Jivi.
- Tell your healthcare provider about all of your medical conditions that you have or had.
- Tell your healthcare provider if you have been told that you have inhibitors to Factor VIII.
- Allergic reactions may occur with Jivi. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, or nausea.
- Allergic reactions to polyethylene glycol (PEG), a component of Jivi, are possible.
- Your body can also make antibodies, called “inhibitors,” against Jivi, which may stop Jivi from working properly. Consult your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.



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to step up to the challenge
with Jivi®

Ask your doctor if Jivi® may be right for you. Learn more at www.jivi.com.

IMPORTANT SAFETY INFORMATION (CONT'D)

- If your bleeding is not being controlled with your usual dose of Jivi, consult your doctor immediately. You may have developed Factor VIII inhibitors or antibodies to PEG and your doctor may carry out tests to confirm this.
- The common side effects of Jivi are headache, cough, nausea, and fever.
- These are not all the possible side effects with Jivi. Tell your healthcare provider about any side effect that bothers you or that does not go away.

For additional important risk and use information, please see the Brief Summary on the following page.

You are encouraged to report side effects or quality complaints of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

References: 1. Jivi® Prescribing Information. Whippany, NJ: Bayer LLC; 2018.
2. Data on file. Tx Review 0918. Bayer; 2018.

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antihemophilic factor
(recombinant) PEGylated-aucI
LET'S GO

HIGHLIGHTS OF FDA-Approved Patient Labeling Patient Information

Jivi (*JHIV-ee*) antihemophilic factor (recombinant), PEGylated-aucI

This leaflet summarizes important information about Jivi with vial adapter. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about Jivi. If you have any questions after reading this, ask your healthcare provider.

Do not attempt to self-infuse, unless your healthcare provider or hemophilia center has taught you how to self-infuse.

What is Jivi?

Jivi is an injectable medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A (congenital Factor VIII deficiency).

Jivi is used to treat and control bleeding in previously treated adults and adolescents (12 years of age and older) with hemophilia A. Your healthcare provider may also give you Jivi when you have surgery. Jivi can reduce the number of bleeding episodes in adults and adolescents with hemophilia A when used regularly (prophylaxis).

Jivi is not for use in children < 12 years of age or in previously untreated patients.

Jivi is not used to treat von Willebrand disease.

Who should not use Jivi?

You should not use Jivi if you

- are allergic to rodents (like mice and hamsters).
- are allergic to any ingredients in Jivi.

What should I tell my healthcare provider before I use Jivi?

Tell your healthcare provider about:

- All of your medical conditions that you have or had.
- All of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.
- Pregnancy or planning to become pregnant. It is not known if Jivi may harm your unborn baby.
- Breastfeeding. It is not known if Jivi passes into the milk.
- Whether you have been told that you have inhibitors to Factor VIII.

What are the possible side effects of Jivi?

The common side effects of Jivi are headache, cough, nausea and fever.

Allergic reactions may occur with Jivi. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, or nausea. Allergic reactions to polyethylene glycol (PEG), a component of Jivi, are possible.

Your body can also make antibodies, called “inhibitors”, against Jivi, which may stop Jivi from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

If your bleeding is not being controlled with your usual dose of Jivi, consult your doctor immediately. You may have developed Factor VIII inhibitors or antibodies to PEG and your doctor may carry out tests to confirm this.

These are not all the possible side effects with Jivi. You can ask your healthcare provider for information that is written for healthcare professionals.

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

How do I store Jivi?

Do not freeze Jivi.

Store Jivi at +2°C to +8°C (36°F to 46°F) for up to 24 months from the date of manufacture. Within this period, Jivi may be stored for a period of up to 6 months at temperatures up to +25°C or 77°F.

Record the starting date of room temperature storage clearly on the unopened product carton. Once stored at room temperature, do not return the product to the refrigerator. The product then expires after storage at room temperature for 6 months, or after the expiration date on the product vial, whichever is earlier. Store vials in their original carton and protect them from extreme exposure to light.

Administer reconstituted Jivi as soon as possible. If not, store at room temperature for no longer than 3 hours.

Throw away any unused Jivi after the expiration date.

Do not use reconstituted Jivi if it is not clear.

What else should I know about Jivi and hemophilia A?

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

This leaflet summarizes the most important information about Jivi that was written for healthcare professionals.

Resources at Bayer available to the patient:

For Adverse Reaction Reporting, contact Bayer Medical Communications 1-888-84-BAYER (1-888-842-2937)

To receive more product information, contact Jivi Customer Service 1-888-606-3780

Bayer Reimbursement HELpline 1-800-288-8374

For more information, visit <http://www.Jivi.com>

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Diagnosis and Treatment of vWD

Organizations collaborate to establish clinical guidelines

BY EMILY A. ROUSH-BOBOLZ, STAFF WRITER

While many advancements have been made in the diagnosis and treatment of bleeding disorders, a widely-observe procedure for diagnosing and treating von Willebrand Disease has gone mostly undefined. A group of bleeding disorders organizations hope to change that through a collaborative effort to develop clinical practice guidelines.

The American Society of Hematology is collaborating with the International Society of Thrombosis and Haemostasis, National Hemophilia Foundation and World Federation of Hemophilia. To conduct the study to develop evidence-based guidelines, panelists, made up of U.S.- and international-based hematologists, patients with vWD and scientists, identified questions. The questions are based on common situations and questions that arise in clinics and with emphasis on improving care and health outcomes of patients and their caregivers.


“What’s really interesting about this is the patient involvement,” said Dr. Nathan Connell, Assistant Professor of Medicine at Harvard Medical School, Associate Physician in Hematology at Brigham and Women’s Hospital, and vice chair on a panel in the collaborative study. “We’re involving patients and caregivers of those living with vWD. They serve on a panel with clinicians, and it’s interesting to see what

clinicians see as important compared to what patients say is their experience.”

Those differing points of view will help to develop a more comprehensive guide. With vWD as the most common bleeding disorder, affecting approximately one percent of the world’s population, common guidelines could lead to earlier diagnosis and treatment.

Because symptoms can vary greatly from patient to patient and even change in a single patient over their lifetime, diagnosis and treatment can be all over the board. Primary care providers, pediatricians, obstetricians and gynecologists observing unusual bleeding often refer patients to hematologists for further testing and diagnosis. Some patients, especially with mild symptoms, may experience a long delay in diagnosis and could go untreated for years.

“Diagnosis can change based on who you see and that can be frustrating,” said Dr. Christopher Ng, Assistant Professor at the University of Colorado Denver, with UCD’s Hemophilia and Thrombosis Center. “There are a fair number of patients with vWD who are undiagnosed or misidentified. Some people don’t meet certain criteria, but they all share the risk of bleeding.”



“We would love to do an evidence-based guideline that covers every question, but there are questions out there that really don’t have good data,”

Those patients deserve attention, diagnosis and treatment. Ng says patients tend to be treated in a one-size-fits-all approach, but as more is known, treatment will improve.

“Understanding better algorithms and better diagnosis leads to better treatment,” said Ng. “The more widely agreed upon diagnosis nomenclature there is, the less confusing it is for patients.”

The idea for the vWD study came after ASH began developing other clinical practice guidelines for various hematological disorders, most recently venous thromboembolism. They identified vWD as another hematological disorders needing guidelines. When they discovered the National Hemophilia Foundation was in the process of revisiting its guidelines from 10 years ago, the timing seemed right.

Results of the study will be made available sometime in 2020. Recommendations will be made public for individuals

to provide feedback through a portal to further hone the guidelines before a complete guide is written.

“We would love to do an evidence-based guideline that covers every question, but there are questions out there that really don’t have good data,” said Connell. If gaps are discovered through portal feedback, it could offer direction for research in the hematological field.

Once the final guidelines are published, handouts will be created, written in a way patients can understand, and the guidelines will be available in English, Spanish and French for global distribution. With the global reach of the organizations involved in the collaborative study, it is the hope the guidelines will be widely adopted by clinicians worldwide. Patients will also be encouraged to share the study with their treatment team to further spread the word. 🩸



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

IsthTM
International Society on
Thrombosis and Haemostasis

Women in Community Use *Strength and Leadership* to Make a Difference

BY ANN LEWALK, STAFF WRITER

Randi Clites, State Representative, General Assembly of Ohio

As a bleeding disorders community advocate, Randi Clites of Ohio, has spent a lot of time at the statehouse. Over the past ten years, she has testified in committees, participated in workgroups and stakeholder groups, has served on many issue-based coalitions and was appointed to a legislative task force.

She had not realized the impact her participation was making on a local level until her then State Representative asked if she had ever thought of running for office. She liked the advocacy work, but the thought of engaging in the political side made her rather nervous. That was, until she started noticing she knew more about what was happening at the Statehouse than many of the local politicians. At that point, she decided to give it a shot.

Acting upon her belief in the need for equal representation in local, state and national government, Clites mounted a campaign to represent her district in the Ohio State assembly. Prior to the 2018 election, the Ohio State legislature was 22 percent women. In This past election, Clites, along with five other women, picked up legislative seats to increase their representation to 26 percent. Looking to the future, she remarked, "We are hopeful that we will get to 50 percent soon."

Clites is confident that being a mom of a child with a bleeding disorder had everything to do with her run for public office and shared her motivation:

"Healthcare decisions are being made by administration and lawmakers that don't live healthcare challenges every day. Our bleeding disorder community is living on the front lines of the decisions being made at the federal and statewide level. We must step up to share our stories as a catalyst for change to make our health care system work to increase the quality of life and make sure it is a fair playing field for those living with chronic medical conditions."

She saw a need for informed representation and took the opportunity to meet it.

"I want to serve my term with one simple goal in mind: making sure that when decisions are made around access to healthcare for Ohioans, there is a voice for those of us that make every family decision based on how to make sure to continue to provide access to quality, affordable healthcare," Clites expressed as her accomplishment goal as State Representative.

When asked to sum up her feelings about the importance of supporting advocacy, Clites said, "When my son was born in 2002, I honestly felt like I was the least likely person to become a strong voice for the bleeding disorders community, but the leaders in this community supported and encouraged me to get involved and stay engaged over the years. I hope to do that for others."



She saw a need for informed representation and took the opportunity to meet it.

continued on page 20...

Barbara Dittrich, State Representative, Wisconsin State Assembly

As a parent whose young adult children are entering the workforce, Barbara Dittrich was primarily driven to run for office to keep Wisconsin a great place to live and work.



"We have been on a positive trajectory and I committed myself to continuing the momentum." Having founded a nonprofit to serve parents of kids with complex diagnoses, having been a small business owner and a financial advisor, as well as a legislative advocate both at the federal and state level, I thought I was uniquely-equipped to take on the challenge."

Dittrich feels strongly that in addition to the great need for a variety of women's voices to be heard in leadership, it is helpful to be a woman in the legislature because she believes that women are hard-wired to view things in a more global manor versus the compartmentalized way men tend to view things. Dittrich points out the advantage she feels female lawmakers have: "There are unintended consequences in everything a lawmaker does. I think women may have an ability to see those things coming before our male counterparts do."

Having been trained as a legislative advocate in the bleeding disorders community increased her level of comfort in the political arena. Throughout her time as an advocate, she experienced victories which she believes prepared her for the challenges of a political campaign and of eventually

holding elected office. Dittrich reflected to 2008 when, after having diligently advocated, she was fortunate enough to have witnessed The Genetic Information Non-Discrimination Act being signed into law. The experience watching GINA become law made her realize that the average person could still make a difference in the world around them.

"As a conservative woman, I also see that our experiences as a family have enabled me to bridge political parties when it comes to healthcare policy," Dittrich shares, reflecting on the impact of her experiences.

In her role as a State Representative, Dittrich hopes to get people past the contentious rhetoric and come to solutions that are the most affordable for taxpayers.

"We have been in one of the longest uninterrupted stretches of economic health in history. I want to continue to get citizens on solid ground, so they are in a better position when the economy takes an inevitable downturn." She also hopes to bring people together to find reasonable solutions to the continued healthcare challenges. Emphasizing her commitment to serve, Dittrich quips, "It seems like a very uphill battle in our state with a polarized government, but I will not give up!"

Dittrich urges the community to remember that bleeding disorders know no political party. She concludes with these thoughts about the importance of community advocacy, "The vast majority of both parties want to help our most vulnerable citizens, so people of every political persuasion should get off their couches and get involved!"

"It seems like a very uphill battle in our state with a polarized government, but I will not give up!"

Ashley Gregory, Chairperson, The Female Factor

Ashley Gregory is a spirited member of the bleeding disorders community who became involved for the same reason many donors give... because someone asked her to!

Back in 2014, a group of women in northern California were drawn together by the fact there was no programming for women who were not just moms or women with bleeding disorders but those who were affected and connected. This was the birth of The Female Factor, a program of the Hemophilia Foundation of Northern California, which provides outreach, leadership guidance, advocacy

opportunities, networking, education and support to all women in the bleeding disorders community.

It has been widely-recognized that many mothers, daughters and sisters within the bleeding disorders community go undiagnosed for many years. The Female Factor works to affect change for proper diagnosis and treatment for all women affected. Gregory, the program's chairperson, a hemophilia



“My personal experience influenced my decision because I knew that many other women would walk a path similar to mine and I could smooth the road ahead of them by blazing the trail.”

mom and symptomatic carrier with a recent diagnosis, shared, “My personal experience influenced my decision because I knew that many other women would walk a path similar to mine and I could smooth the road ahead of them by blazing the trail.”

Gregory’s involvement in the Female Factor came about when she was asked by community members who were looking for a non-industry volunteer to run a women’s group. The timing was just right as she had some free hours during the day. Recognizing the importance of having a woman from the community in this position, she agreed to be the chairperson. She continues to see the value in her role, “...because to be in this position, advocating for and creating programming for women, I can approach programming and grant requests from a woman’s perspective, which is unique.”

The first Female Factor Women’s Retreat in 2014 was an intimate group of 11 affected and connected women. Clearly there was a need and an interest in networking and learning

with other women because, by 2018, the annual educational event had grown to more than 60 mothers, daughters, sisters, grandmothers and friends. As the retreat transforms into a regional program, collaborating with other member organizations in California and other neighboring states, Gregory anticipates the 2019 event to have upward of 100 participants!

Gregory may have come into her role as chairperson of The Female Factor “because someone asked her,” but she has nurtured the program as though it were her own. Her impact on the bleeding disorders community is felt beyond her work with The Female Factor. She serves on the Hemophilia Federation of America Executive Committee and works to promote HFA’s Blood Sisterhood program wherever and whenever able. Gregory sees herself as an agent of change who looks to provide women with opportunities to be heard.

“I hope to show women in the bleeding disorder community that there is a place, voice and resource here for them that serves their unique needs and concerns,” she said. 💧



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Advocacy Day Prep: How to Make the Most Out of Your Legislative Visits

Visiting your state capital or Washington, D.C., is an exciting experience. However, meeting with your legislator can be intimidating for new and experienced advocates alike. Hemophilia Federation of America is here to help! Tear out these pages and use it as a guide to prepare for your advocacy day.

Know the Lingo: The following terms are commonly used during advocacy days.

- **Appropriations:** Appropriations are decisions made by Congress or a state legislature about how the government spends some of its money. In general, the appropriations process addresses the *discretionary* portion of the budget. At the federal level, for example, discretionary spending includes money for programs ranging from national defense to food safety to education to federal employee salaries — but excludes mandatory spending, such as Medicare and Social Security, which is spent automatically according to formulas.
- **Coalitions:** A coalition is an alliance or partnering of groups in order to achieve a common purpose or to engage in joint activity. Forming coalitions with other groups of similar values, interests, and goals allows members to combine their resources and become more powerful than when they each acted alone. You can see a list of the coalitions HFA is a part of on our website (search “Coalitions”).
- **Committee:** Committees are where many of the details of legislation are hammered out and where much of the oversight of the executive branch agencies takes place. During advocacy days, you may receive information on which committee your legislator is assigned to.
- **Constituent:** This term refers to an individual voter within an electoral district. During advocacy day meetings with lawmakers, the constituent(s) usually take the lead because a major role for legislators is to provide services to them. Not to mention, constituents equal votes!
- **Legislation:** Legislation refers to the preparation and enactment of laws by a legislative body through its lawmaking process. The legislative process includes drafting, evaluating, amending, and voting on proposed laws and is concerned with the words used in the bill to communicate the values, judgments, and purposes of the proposal. An idea becomes an item of legislative business when it is written as a bill. A bill is a draft of what might become part of the written law. A bill that is enacted is called an act or statute.
- **State Legislature** (known in some states as the **General Assembly, General Court or Legislative Assembly**): With the exception of Nebraska, State Legislatures are bicameral bodies consisting of a lower house (for example, the **House of Delegates** or **House of Representatives**), and an upper house, known as the Senate. At the federal level, the bicameral body is called the **United States Congress**.
- **Sponsor/co-sponsor:** A sponsor is the first member of the House or Senate to be listed among the potentially numerous lawmakers who introduce a bill for consideration. Committees are occasionally identified as sponsors of legislation as well. A co-sponsor is a senator or representative who adds his or her name as a supporter to the sponsor’s bill. If you’re talking about a specific bill, it’s important to know if a legislator has already become a sponsor/co-sponsor so we can thank them for their support.

Talking the Talk: Tips for Communicating with Your Legislator

Develop your Elevator Speech

- Introduce yourself and share one to two sentences describing your bleeding disorder.
- Use common, relatable phrases including: access, rare and chronic condition, prevention, quality and affordable care.

ADVOCACY PROFILE

- Avoid using abbreviated or complex words including: prophy or HTC's. Alternatively, explain these terms and how they relate to your story.
- Pick one or two advocacy issues you can relate to. This may include education about bleeding disorders and access to care. You do not need to be a policy expert to have a successful legislative meeting.

Things to focus on:

- Make it local. For example, where do you work or go to school? What hemophilia treatment center do you use? Are you affiliated with any local organizations or community groups?
- Personalize your presentation!
- Discuss how access to medication and providers has affected you.
- What is the personal cost of having a bleeding disorder?

Relationship Building:

- Before you leave, always take a photo with your legislator or their staff. Post the photo on social media to say thanks and follow up.
- If your legislator asks a question and you don't know the answer, use this as an opportunity to reach out after the meeting. Contact your state or national organization if you need help figuring out how to answer your legislator's question.
- Maintain the momentum! Keep in touch with your legislators by email and social media, attend events or town hall meetings, and invite them to events hosted by your local bleeding disorders organization. Legislative meetings are just the tip of the iceberg!



Do Your Homework

- Prepare materials in advance. Materials to have ready include photos of you and your family, especially family members with bleeding disorders, recent Explanation of Benefits, expired or empty medication containers
- Research your legislator (including a photo if you don't know what they look like)

Fill in the Blanks:

Who is your State Senator?

Who is your State Representative?

Who is your U.S. Representative?

Who is your U.S. Senator?

Advocacy Toolkit: Available 24/7 on HFA's website, www.hemophiliafed.org

- Visit HFA's **Take Action Center** to find your legislators and talking points. (Search "Take Action Center.")
- HFA's **Legislative Day Toolkit for Patients and Caregivers** includes a presentation on talking to your legislator, documents on how a bill becomes a law, tips on writing your legislator and a podcast series. (Search "Legislative Day Toolkit.")
- HFA's **Storytelling for Advocacy** webinar is a great tool for developing your elevator speech and communicating effectively, whether you're a seasoned pro or novice. (Search "Framing Your Story.")

Retiro Para Madres e Hijas

BY MARTHA BORIA NEGRÓN, STAFF WRITER

¿Anhelas conectarte con otras madres? ¿Te gustaría sentirte apoyada? ¿Te gustaría hablar libremente de tu trastorno de sangrado sin ser juzgada? Los retiros para mujeres con trastornos de sangrados te ofrecen apoyo, te sientes apreciada y te empoderan.

Esta semana hablaba con mi amiga Vicky, y le decía cuanto extraño asistir a los retiros de madres e hijas. Mi capítulo, al noreste de Nueva York, organiza estos retiros, pero debido a que mis niñas están muy ocupadas con la universidad, se nos dificulta asistir.

Durante varios años, mi hija menor Juliemar y yo hemos participamos del retiro para madres e hijas de la Asociación de Trastornos de Sangrados del área Noreste de Nueva York (BDANENY por sus siglas en inglés). Hemos compartido información y establecido relaciones cercanas con mujeres, jóvenes y niñas dentro de esta comunidad. Estos eventos suelen estar abiertos a mujeres con trastornos de sangrados, portadoras, cónyuges y cuidadoras.

Estas actividades son muy divertidas y relajantes ya que las conferencias y sesiones son un oasis para las mujeres que asistimos. A menudo somos ignoradas por la comunidad médica y tener un espacio aparte sólo para nosotras en donde somos escuchadas, entendidas y no juzgadas nos sirve de gran ayuda.

Los retiros para mujeres ofrecen un foro para discutir temas médicos que pueden a lo mejor no hablarse en otros lugares. Las pláticas han incluido opciones de tratamiento, cuidando de ti, comunicaciones sanas y positivas, sexualidad y nutrición. También hay charlas divertidas, arte terapia y baile.

A las madres y a sus hijas adolescentes la programación nos da la oportunidad de hablar sobre los desafíos relacionados con la menstruación y otros temas. Así mismo, en el último retiro al que nosotras asistimos un hematólogo ofreció recomendaciones para hablar con los ginecólogos / obstetras sobre los trastornos de sangrados. Además, aprendimos a cómo desarrollar un plan personal para incorporar a el obstetra / ginecólogo y a el hematólogo para una mejor salud y calidad de vida.

Los programas en estos retiros también ayudan a las mujeres a convertirse en mejores autogestoras cuando navegan por el sistema de salud. Las mujeres a menudo no son escuchadas por sus médicos, pero cuando tenemos las herramientas, eso puede cambiar. Es una manera segura de empoderarnos y nos ayuda a hablarle con seguridad a el médico para que escuche nuestros problemas y nos trate como a alguien con un trastorno de sangrado.



La gerente de programas de HFA, Martha Boria Negrón, con sus hijas, Alexandra, a la izquierda, y Juliemar, a la derecha, y su esposo, Julio.

El autocuidado es una parte esencial para nosotras tan importantes como los aspectos educativos. Los retiros de mujeres tienen beneficios emocionales ya que tenemos la oportunidad de juntarnos y compartir experiencias, hablar de luchas comunes, y reírnos. Además, nos da espacio para expresar sentimientos incómodos, desde ansiedad hasta ira y la culpa de pasar un trastorno genético a nuestros hijo e hijas.

Siempre es un fin de semana de risas, lágrimas, discusiones y autoevaluación. Aprendo mucho de estas mujeres. Ya cuando concluye el retiro, la tristeza siempre nos embarga, pues el viernes éramos prácticamente extrañas y ya para el domingo nos sentimos como hermanas. Las alegrías y los desafíos únicos de las madres e hijas de la comunidad con trastornos de sangrados es lo que jamás pensamos que nos uniera y que nos hace más fuertes en la vida. 💧

HFA and its Member Organizations Welcome:

Bleeding Disorders Alliance of North Dakota

Executive Director: Emily Ouellette

“We look forward to utilizing services and resources that HFA has to offer. For us, one of the key benefits is HFA’s Blood Brotherhood. It will help us reach a group of men that don’t attend our events. In the past, our events have focused on children and families. With Blood Brotherhood, we will have a reason for these men to come together and bond.”



Midwest Hemophilia Association

President and Acting Executive Director: Amy Hoyt

“Every nonprofit organization can use all the help and resources that they can get. MHA saw the value that HFA has provided to other chapters and community members. We finally came to the conclusion that we just might be missing out on a great opportunity to help ourselves and others. We are looking for more education opportunities. We are also seeking council and other methods of board development.”



**Midwest
Hemophilia
Association**

BDAND and MHA join these other member organizations:

United Hemophilia Foundation • Sangre de Oro/Bleeding Disorders Foundation of New Mexico • Alaska Hemophilia Association • Hemophilia Alliance of Maine • Louisiana Hemophilia Foundation • Wisconsin Bleeding Disorders Network • Bleeding Disorders Association of the Southern Tier • Rocky Mountain Hemophilia and Bleeding Disorders Association • Hemophilia of Iowa • Bleeding Disorders Alliance Illinois • Hemophilia Foundation of Oregon • Western Pennsylvania Chapter of NHF • Texas Central Hemophilia Association • New England Hemophilia Association • Hemophilia Association of New Jersey • Bleeding Disorder Foundation of Washington • Hemophilia Outreach of El Paso • Hemophilia Foundation of Northern California • Florida Hemophilia Association • Hemophilia of South Carolina • Lone Star Hemophilia Chapter • Northern Ohio Hemophilia Foundation • Hemophilia of Indiana • Hemophilia Foundation of Arkansas • Blood Bond Bleeding Disorder Network • Hemophilia Foundation of Minnesota/Dakotas • Southwestern Ohio Hemophilia Foundation • Hemophilia of North Carolina • Tennessee Hemophilia and Bleeding Disorder Foundation • Snake River Hemophilia & Bleeding Disorders • New York City Hemophilia Chapter • Hemophilia Association of New York • Oklahoma Hemophilia Foundation • Hemophilia Foundation of Maryland • Hemophilia Foundation of Southern California • Arizona Hemophilia Association • Virginia Hemophilia Foundation • Mary M. Gooley Hemophilia Center • Central California Hemophilia Foundation • Gateway Hemophilia Association • Utah Hemophilia Foundation • Eastern Pennsylvania Chapter • Hemophilia Association of the Capital Area • Bleeding Disorders Association of Northeastern New York • Connecticut Hemophilia Society • Hemophilia Foundation of Michigan • Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado



BOB has hemophilia A with inhibitors.

What is NovoSeven® RT?

NovoSeven® RT (coagulation Factor VIIa, recombinant) is an injectable medicine used for:

- Treatment of bleeding and prevention of bleeding for surgeries and procedures in adults and children with hemophilia A or B with inhibitors, congenital Factor VII (FVII) deficiency, and Glanzmann's thrombasthenia with a decreased or absent response to platelet transfusions
- Treatment of bleeding and prevention of bleeding for surgeries and procedures in adults with acquired hemophilia

Important Safety Information

What is the most important information I should know about NovoSeven® RT?

NovoSeven® RT may cause serious side effects, including:

- **Serious blood clots** that form in veins and arteries with the use of NovoSeven® RT have been reported
- Your healthcare provider should discuss the risks and explain the signs and symptoms of blood clots to you. Some signs of a blood clot may include pain, swelling, warmth, redness, or a lump in your legs or arms, chest pain, shortness of breath, or sudden severe headache and/or loss of consciousness or function
- Your healthcare provider should monitor you for blood clots during treatment with NovoSeven® RT
- You should not use NovoSeven® RT if you have ever had allergic (hypersensitivity) reactions, including severe, whole body reactions (anaphylaxis) to NovoSeven® RT, any of its ingredients, or mice, hamsters, or cows. Signs of allergic reaction include shortness of breath, rash, itching (pruritus), redness of the skin (erythema), or fainting/dizziness



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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In hemophilia with inhibitors,

Bleeds happen:

Take control with NovoSeven® RT



Controlling bleeds, whenever they happen

- Proven effective to treat hemophilia A or B with inhibitors, at home and in the hospital

Safety supported by clinical trial data

- Low rate (0.2%) of unintended blood clots^a

Speed when it's needed

- Fast to mix, fast to infuse, and fast to control bleeds^b

NovoSeven® RT—committed to your experience

- More than 30 years of research and long-term clinical experience^c

^aFor people with hemophilia A or B with inhibitors.

^bAdminister as a slow bolus injection over 2-5 minutes, depending on the dose administered.

^cCompassionate use, also known as expanded access, began enrolling in 1988; FDA approval received in 1999.

Visit NovoSevenRT.com today to learn more

What should I tell my healthcare provider before using NovoSeven® RT?

- Tell your healthcare provider if you have any of the following, as these may increase your risk of blood clots:
 - congenital hemophilia and are also receiving treatment with aPCCs (activated prothrombin complex concentrates)
 - are an older patient particularly with acquired hemophilia and receiving other agents to stop bleeding
 - history of heart or blood vessel diseases
- Tell your healthcare provider and pharmacist about all the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies

What are the possible side effects of NovoSeven® RT?

- The most common and serious side effects are blood clots
- Tell your healthcare provider about any side effects that bother you or do not go away, and seek medical help right away if you have signs of a blood clot or allergic reaction

Please see Brief Summary of Prescribing Information on the following pages.

NovoSeven® RT
Coagulation Factor VIIa
(Recombinant)



NOVOSEVEN® RT
Coagulation Factor VIIa (Recombinant)

Rx only

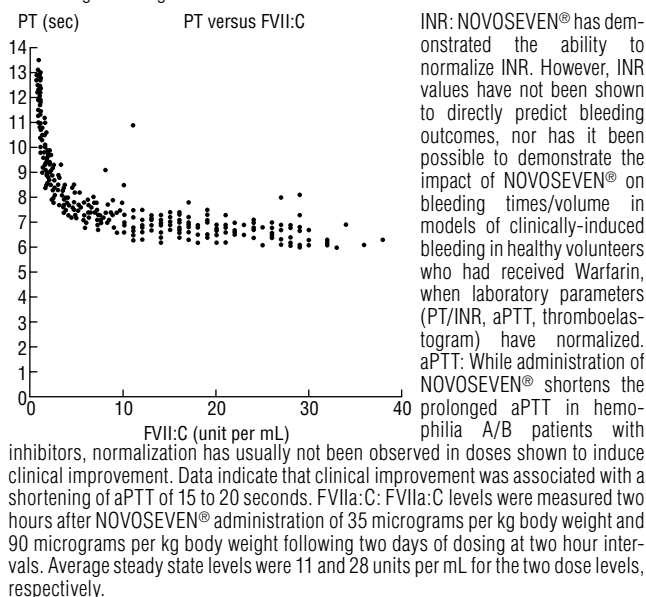
BRIEF SUMMARY. Please consult package insert for full prescribing information.

WARNING: THROMBOSIS: Serious arterial and venous thrombotic events following administration of NOVOSEVEN® RT have been reported. [See *Warnings and Precautions*] Discuss the risks and explain the signs and symptoms of thrombotic and thromboembolic events to patients who will receive NOVOSEVEN® RT. [See *Warnings and Precautions*] Monitor patients for signs or symptoms of activation of the coagulation system and for thrombosis. [See *Warnings and Precautions*]

INDICATIONS AND USAGE: NOVOSEVEN® RT, Coagulation Factor VIIa (Recombinant), is indicated for: Treatment of bleeding episodes and peri-operative management in adults and children with hemophilia A or B with inhibitors, congenital Factor VII (FVII) deficiency, and Glanzmann's thrombasthenia with refractoriness to platelet transfusions, with or without antibodies to platelets; Treatment of bleeding episodes and peri-operative management in adults with acquired hemophilia.

CONTRAINDICATIONS: None known.

WARNINGS AND PRECAUTIONS: Thrombosis: Serious arterial and venous thrombotic events have been reported in clinical trials and postmarketing surveillance. Patients with congenital hemophilia receiving concomitant treatment with aPCCs (activated prothrombin complex concentrates), older patients particularly with acquired hemophilia and receiving other hemostatic agents, or patients with a history of cardiac, vascular disease or predisposed to thrombotic events may have an increased risk of developing thrombotic events [See *Adverse Reactions and Drug Interactions*]. Monitor patients who receive NOVOSEVEN® RT for development of signs or symptoms of activation of the coagulation system or thrombosis. When there is laboratory confirmation of intravascular coagulation or presence of clinical thrombosis, reduce the dose of NOVOSEVEN® RT or stop the treatment, depending on the patient's condition. **Hypersensitivity Reactions:** Hypersensitivity reactions, including anaphylaxis, can occur with NOVOSEVEN® RT. Patients with a known hypersensitivity to mouse, hamster, or bovine proteins may be at a higher risk of hypersensitivity reactions. Discontinue infusion and administer appropriate treatment when hypersensitivity reactions occur. **Antibody Formation in Factor VII Deficient Patients:** Factor VII deficient patients should be monitored for prothrombin time (PT) and factor VII coagulant activity before and after administration of NOVOSEVEN® RT. If the factor VIIa activity fails to reach the expected level, or prothrombin time is not corrected, or bleeding is not controlled after treatment with the recommended doses, antibody formation may be suspected and analysis for antibodies should be performed. **Laboratory Tests:** Laboratory coagulation parameters (PT/INR, aPTT, FVII:C) have shown no direct correlation to achieving hemostasis. Assays of prothrombin time (PT/INR), activated partial thromboplastin time (aPTT), and plasma FVII clotting activity (FVII:C), may give different results with different reagents. Treatment with NOVOSEVEN® has been shown to produce the following characteristics: PT: As shown below, in patients with hemophilia A/B with inhibitors, the PT shortened to about a 7-second plateau at a FVII:C level of approximately 5 units per mL. For FVII:C levels > 5 units per mL, there is no further change in PT. The clinical relevance of prothrombin time shortening following NOVOSEVEN® RT administration is unknown.



ADVERSE REACTIONS: The most common and serious adverse reactions in clinical trials are thrombotic events. Thrombotic adverse reactions following the administration of NOVOSEVEN® in clinical trials occurred in 4% of patients with acquired hemophilia and 0.2% of bleeding episodes in patients with congenital hemophilia. **Clinical Trials Experience:** Because clinical studies are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug product cannot be directly compared to rates in clinical trials of another drug, and may not reflect rates observed in practice. Adverse reactions outlined below have been reported from clinical trials and data collected in registries. **Hemophilia A or B Patients with Inhibitors:** In two studies for hemophilia A or B patients with inhibitors treated for bleeding episodes (N=298), adverse reactions were reported in ≥2% of the patients that were treated with NOVOSEVEN® for 1,939 bleeding episodes (see Table 3 below).

Table 3: Adverse Reactions Reported in ≥2% of the 298 Patients with Hemophilia A or B with Inhibitors

Body System	# of adverse reactions (n=1,939 treatments)	# of patients (n=298 patients)
Reactions		
Body as a whole		
Fever	16	13
Platelets, Bleeding, and Clotting		
Fibrinogen plasma decreased	10	5
Cardiovascular		
Hypertension	9	6

Serious adverse reactions included thrombosis, pain, thrombophlebitis deep, pulmonary embolism, decreased therapeutic response, cerebrovascular disorder, angina pectoris, DIC, anaphylactic shock and abnormal hepatic function. The serious adverse reactions of DIC and therapeutic response decreased had a fatal outcome. In two clinical trials evaluating safety and efficacy of NOVOSEVEN® administration in the perioperative setting in hemophilia A or B patients with inhibitors (N=51), the following serious adverse reactions were reported: acute post-operative hemarthrosis (n=1), internal jugular thrombosis adverse reaction (n=1), decreased therapeutic response (n=4). **Immunogenicity:** There have been no confirmed reports of inhibitory antibodies against NOVOSEVEN® or FVII in patients with congenital hemophilia A or B with alloantibodies. The incidence of antibody formation is dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to NOVOSEVEN® RT with the incidence of antibodies to other products may be misleading. **Congenital Factor VII Deficiency:** Data collected from the compassionate/emergency use programs, the published literature, a pharmacokinetics study, and the Hemophilia and Thrombosis Research Society (HTRS) registry showed that 75 patients with Factor VII deficiency had received NOVOSEVEN®: 70 patients for 124 bleeding episodes, surgeries, or prophylaxis; 5 patients in the pharmacokinetics trial. The following adverse reactions were reported: intracranial hypertension (n=1), IgG antibody against rFVIIa and FVII (n=1), localized phlebitis (n=1). **Immunogenicity:** In 75 patients with factor FVII deficiency treated with NOVOSEVEN® RT, one patient developed IgG antibody against rFVIIa and FVII. Patients with factor VII deficiency treated with NOVOSEVEN® RT should be monitored for factor VII antibodies. The incidence of antibody formation is dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to NOVOSEVEN® RT with the incidence of antibodies to other products may be misleading. **Acquired Hemophilia:** Data collected from four compassionate use programs, the HTRS registry, and the published literature showed that 139 patients with acquired hemophilia received NOVOSEVEN® for 204 bleeding episodes, surgeries and traumatic injuries. Of these 139 patients, 6 patients experienced 8 serious adverse reactions. Serious adverse reactions included shock (n=1), cerebrovascular accident (n=1) and thromboembolic events (n=6) which included cerebral artery occlusion, cerebral ischemia, angina pectoris, myocardial infarction, pulmonary embolism and deep vein thrombosis. Three of the serious adverse reactions had a fatal outcome. **Glanzmann's Thrombasthenia:** Data collected from the Glanzmann's Thrombasthenia Registry (GTR) and the HTRS registry showed that 140 patients with Glanzmann's thrombasthenia received NOVOSEVEN® RT for 518 bleeding episodes, surgeries or traumatic injuries. The following adverse reactions were reported: deep vein thrombosis (n=1), headache (n=2), fever (n=2), nausea (n=1), and dyspnea (n=1). **Post marketing Experience:** Adverse reactions reported during post marketing period were similar in nature to those observed during clinical trials and include reports of thromboembolic adverse events.

DRUG INTERACTIONS: Avoid simultaneous use of activated prothrombin complex concentrates. Do not mix NOVOSEVEN® RT with infusion solutions. Thrombosis may occur if NOVOSEVEN® RT is administered concomitantly with Coagulation Factor XIII. [See *Warnings and Precautions*]

USE IN SPECIFIC POPULATIONS: Pregnancy: *Risk Summary:* There are no adequate and well-controlled studies using NOVOSEVEN® RT in pregnant women to determine whether there is a drug-associated risk. Treatment of rats and rabbits with NOVOSEVEN® in reproduction studies has been associated with mortality at doses up to 6 mg per kg body weight and 5 mg per kg body weight respectively. At 6 mg per kg body weight in rats, the abortion rate was 0 out of 25 litters; in rabbits at 5 mg per kg body weight, the abortion rate was 2 out of 25 litters. Twenty-three out of 25 female rats given 6 mg per kg body weight of NOVOSEVEN® gave birth successfully, however, two of the 23 litters died during the early period of lactation. No evidence of teratogenicity was observed after dosing with NOVOSEVEN®. In the U.S. general population, the estimated background risk of major birth defect and miscarriage in clinically recognized pregnancies is 2-4% and 15-20%, respectively. **Lactation:** *Risk Summary:* There is no information regarding the presence of NOVOSEVEN® RT in human milk, the effect on the breastfed infant, and the effects on milk production. The developmental and health benefits of breastfeeding should be considered along with the mother's clinical need for NOVOSEVEN® RT and any potential adverse effects on the breastfed infant from NOVOSEVEN® RT or from the underlying maternal condition. **Pediatric Use:** Clinical trials enrolling pediatric patients were conducted with dosing determined according to body weight and not according to age. **Hemophilia A or B with Inhibitors:** During the investigational phase of product development NOVOSEVEN® was used in 16 children aged 0 to <2 years for 151 bleeding episodes, 27 children aged 2 to <6 years for 140 bleeding episodes, 43 children aged 6 to <12 for 375 bleeding episodes and 30 children aged 12 to 16 years for 446 bleeding episodes. In a double-blind, randomized comparison trial of two dose levels of NOVOSEVEN® in the treatment of joint, muscle and mucocutaneous hemorrhages in hemophilia A and B patients with and without inhibitors 20 children aged 0 to <12 and 8 children aged 12 to 16 were treated with NOVOSEVEN® in doses of 35 or 70 micrograms per kg dose. Treatment was assessed as effective (definite relief of pain/tenderness as reported by the patient and/or a measurable decrease of the size of the hemorrhage and/or arrest of bleeding within 8 hours [rated as excellent = 51%], within 8-14 hours [rated as effective = 18%] or after 14 hours [rated as partially effective = 25%]) in 94% of the patients. NOVOSEVEN® was used in two trials in surgery. In a dose comparison 22 children aged 0 to 16 years were treated with NOVOSEVEN®. Effective intraoperative hemostasis (defined as bleeding that had stopped completely or had decreased substantially [rated as effective = 86%] or bleeding that was reduced but continued [rated as partially effective = 9%]) was achieved in 21/22 (95%) patients. Effective hemostasis was achieved in 10/10 (100%) patients in the 90 mcg/kg dose group and 10/12 (83%) in the 35 mcg/kg dose group at 48 hours; effective hemostasis was achieved in 10/10 (100%) in the 90 mcg/kg dose group and 9/12 (75%) in the 35 mcg/kg dose group at 5 days. In the surgery trial comparing bolus (BI) and continuous infusion (CI) 6 children aged 10 to 15 years participated, 3 in each group. Both regimens were 100% effective (defined as bleeding has stopped completely, or decreased substantially) intra-operatively, through the first 24 hours and at day 5. At the end of the study period (Postoperative day 10 or discontinuation of therapy) hemostasis in two patients in the BI group was rated effective and hemostasis in one patient was rated as ineffective (defined as bleeding is the same or has worsened). Hemostasis in all three patients in the CI group was rated as effective. Adverse drug reactions in pediatric patients were similar to those previously reported in clinical trials with NOVOSEVEN®, including one thrombotic event in a 4 year old with internal jugular vein thrombosis after port-a-cath placement which resolved. **Congenital Factor VII deficiency:** In published literature, compassionate use trials and registries on use of NOVOSEVEN® in congenital Factor VII deficiency, NOVOSEVEN® was used in 24 children aged 0 to <12 years and 7 children aged 12 to 16 years for 38 bleeding episodes, 16 surgeries and 8 prophylaxis regimens. Treatment was effective in 95% of bleeding episodes (5% not rated) and 100% of surgeries. No thrombotic events were reported. A seven-month old exposed to NOVOSEVEN® and various plasma products developed antibodies against FVII and rFVIIa [see *Adverse Reactions and Overdosage*]. **Glanzmann's Thrombasthenia:** In the Glanzmann's Thrombasthenia Registry, NOVOSEVEN® was used in 43 children aged 0 to 12 years for 157 bleeding episodes and in 15 children aged 0 to 12 years for 19 surgical procedures. NOVOSEVEN® was also used in 8 children aged >12 to 16 years for 17 bleeding episodes and in 3 children aged >12 to 16 years for 3 surgical procedures. Efficacy of regimens including NOVOSEVEN® was evaluated by independent adjudicators as 93.6% and 100% for bleeding episodes in children aged 0 to 12 years and >12 to 16 years, respectively. Efficacy in surgical procedures was evaluated as 100% for all surgical procedures in children aged 0 to 16 years. No adverse reactions were reported in Glanzmann's thrombasthenia children. **Geriatric Use:** Clinical studies of NOVOSEVEN® RT in congenital factor deficiencies and Glanzmann's thrombasthenia did not include sufficient numbers of subjects aged 65 and over to determine whether they respond differently from younger subjects.

OVERDOSAGE: Dose limiting toxicities of NOVOSEVEN® RT have not been investigated in clinical trials. The following are examples of accidental overdose. One newborn female with congenital factor VII deficiency was administered an overdose of NOVOSEVEN® (single dose: 800 micrograms per kg body weight). Following additional administration of NOVOSEVEN® and various plasma products, antibodies against rFVIIa were detected, but no thrombotic complications were reported. One Factor VII deficient male (83 years of age, 111.1 kg) received two doses of 324 micrograms per kg body weight (10-20 times the recommended dose) and experienced a thrombotic event (occipital stroke). One hemophilia B patient (16

years of age, 68 kg) received a single dose of 352 micrograms per kg body weight and one hemophilia A patient (2 years of age, 14.6 kg) received doses ranging from 246 micrograms per kg body weight to 986 micrograms per kg body weight on five consecutive days. There were no reported complications in either case.

More detailed information is available upon request.

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NovoSeven® RT
Coagulation Factor VIIa
(Recombinant)



Communication is Key: Intimacy and Bleeding Disorders

BY ANDY ANDERSON, STAFF WRITER

While honest communication about health is important, it's a woman's right to decide how, when, why and to whom she discloses details of her health status. This includes friendships as well as romantic and intimate relationships.

"I think the most important thing to remember is why and how you are sharing," says Sarah Watson, a sex therapist based in Michigan, who has spoken around the country and written about her experience as a woman with a bleeding disorder.

"Make sure you are sharing in a way that is meaningful to you. When I told my now-husband seventeen years ago about my bleeding disorder, I made sure I included to tell him why I was sharing," said Watson.

One of the most common challenges Watson has heard from other people with bleeding disorders is explaining bleeding during intimacy.

"If you aren't comfortable talking to your partner, you might need to take a step back and figure out why," she said.

The stigma associated with menstruation and chronic illness can make this a difficult subject to approach. Women might even feel shame in comparing their bodies to those perceived to work "normally."

A bleeding disorder doesn't have to dictate a person's sexuality. Taking the time to explore what one is personally comfortable with and derives pleasure from is an important part of developing a healthy relationship with the body. This insight into what makes one feel good is the biggest gift individuals can give themselves when it comes to intimacy.

Though having a bleeding disorder does not need to define someone's sexuality, it can certainly have an impact. For many, the biggest barrier to "being in the moment" is stress. On a physiological level, stress makes it difficult to experience pleasure. The part of the brain that responds to stress uses a fight or flight reaction to ensure survival. For most of human history, stress meant something like seeing a lion and our uncontrollable desire to flee from the lion to safety.

That primal part of the brain evolved so long ago that it is not fine-tuned enough to tell the difference between a lion and a deadline or fire and a pile of laundry. Whatever the cause, stress impacts the brain and body the same way. Until the source of stress is recognized or feelings of stress are resolved, our body puts pleasure on the backburner as something that is not essential to survival in this moment. When we want to be intimate with a partner, the physical and mental stress of living with a bleeding disorder can feel like trying to drive with the parking brake on.

Sometimes it's not just the stress of all of the other aspects of our daily lives that gets in the way—intimacy can be a source of stress in itself! The fear of bleeding during or as a result of intimacy can be especially challenging.

Couples can make an agreement that if something doesn't feel right, they can speak up without fear. Using a "stoplight system" during intimacy is one way to keep the verbal communication going. Green light that it feels good and to keep going! Yellow light to slow down. Red light to stop and evaluate the situation to consider making adjustments before proceeding.

During intimacy, one could phrase their desire to make changes by saying something to the effect of, "The genital contact feels good, but my knee is hurting and really distracting me. Let's try something else." Work together to develop a plan to help manage the risks for pain by using pillows or blankets to support parts of the body and laying down a dark towel in case of vaginal bleeding.

What if sex isn't a part of the picture? Whatever the reason, sex may not be a part of someone's intimate life for extended periods of time. There are many ways to engage in intimacy with a partner, and with self-reflection and communication, couples can find alternative ways of developing and maintaining feelings of closeness with one another.

If physical affection with a partner does not include sex, a couple can consider trading massages to appreciate each other's bodies. Cuddling or taking a walk are also ways to share a physical and emotional moment.

Extended breaks in physical intimacy are an opportunity to develop mental and emotional closeness, too. Couples should discover their individual "love language" and use it to understand how to show love to each other. One option is to create something together in the kitchen as a way of nourishing not only the relationship, but bodies, too.

Intimacy is by no means limited to genital penetration. Couples should stay open to the possibility of exploring other ways of sharing pleasure, knowing what feels good and what is likely to cause discomfort.

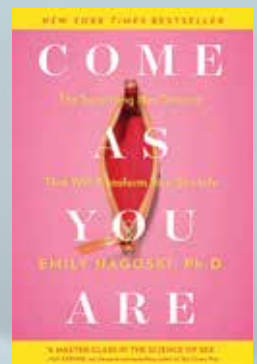
Pain is a familiar experience for people with bleeding disorders, but it shouldn't be a part of sex. If one experiences pain during intimacy, *stop, evaluate the situation and make changes to continue*. If pain during intimacy is a regular occurrence or if new pain develops, consult a healthcare provider. Depending on the treatment plan, there may be steps to take before or after engaging in intimacy to prevent or manage pain or bleeding.

Just like bodies, relationships evolve over time. Keeping the lines of communication open to discuss intimacy creates a strong foundation for partners to grow close with one another in a healthy way. 💧

Tips for Intimate Moments

- ✋ Bleeding in the vaginal tract doesn't necessarily mean pain or injury, but it can be frustrating. In addition to communication, a dark-colored towel can come in handy.
- ✋ Using lubrication significantly decreases the likelihood of pain during and after penetration.
- ✋ Topical treatments or an ice pack wrapped in a towel may be used to relieve pain and swelling. Perineal ice packs and witch hazel pads are ideal for bringing relief to sensitive areas between the legs.
- ✋ Try the "stoplight system" to keep communication going.

Sex therapist Sarah Watson recommends
**"Come As You Are:
The Surprising New
Science That Will
Transform Your
Sex Life"**
by Emily Nagoski, Ph.D.





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*Note, our membership is on a calendar year, so if you have not paid dues this year, you are up for a renewal.



NEXT ISSUE: COOL DADS

Dads play an important role in the lives of children with bleeding disorders, whether it's taking an active role in their medical care or just being the "fun" dad. The support and love dads give to moms cannot be discounted. We'll look at how dads are involved, plus some cool stories of what young boys with hemophilia have experienced lately. **We'll also do a recap of our Annual Symposium!**

