



DATELINE

F E D E R A T I O N

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Pregnancy Prep

With bleeding disorders, starting a family means planning ahead with a collaborative health care team.

BY RISA KERSLAKE, FREELANCE WRITER

Diane Bruno was 26 when she discovered she was a carrier of hemophilia, six months after giving birth to her son. Ten years later and living in Methuen, Massachusetts, the mom of three lives with mild bleeding disorder symptoms.

"We didn't have any history of bleeding disorders in my family when my son was born," Bruno explained. "He was diagnosed at four days old with severe hemophilia A, and it was only after the fact that some of my own symptoms during delivery made more sense."

Bruno knew she wanted more children, but her experience with heavy bleeding and a third-degree tear requiring multiple surgeries postpartum made her more hesitant. She and her husband had several conversations with her son's hematologist and her ob-gyn to be sure they were being proactive about bleeding risks.

Facing page, Diane Bruno with her infant son, who was born with hemophilia 10 years ago.

"Once we had a pretty good handle on our son's bleeding disorder, we decided we would go all in and take a big risk in hopes that the outcome would outweigh the risks,

Photos on this page: The Bruno family.



and it certainly did," Bruno said. "I trusted [my ob-gyn's] judgment and had two successful C-sections with both of my daughters. Although there was a bit more bleeding during the process of stitching the incisions, I did not need factor and I healed successfully."

One of the most important things Patricia Huguélet, MD, clinical medical director of the Spots and Dots bleeding clinic and associate professor at the University of Colorado School of Medicine and Children's Hospital Colorado, wants people to understand is they can still have a safe and healthy pregnancy despite a bleeding disorder.

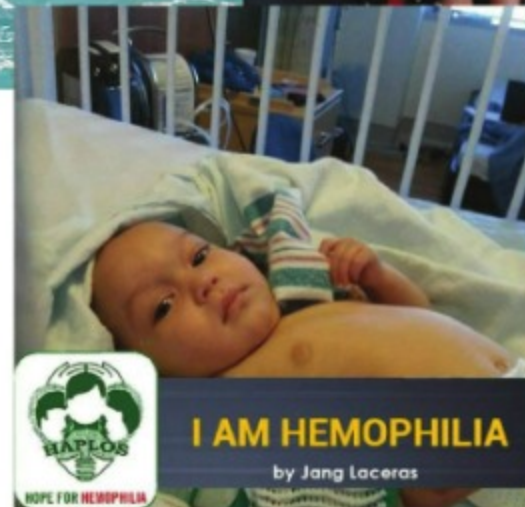
"So many women live in fear because they've struggled their whole lives with bleeding," Huguélet explained. "They assume pregnancy is something they can't do or that would be catastrophic."

The key is having a diagnosis and planning in advance. While a person may be young and healthy, there are still increased chances for bleeding, from first-trimester complications, second and third-trimester placental problems, and postpartum hemorrhage at delivery, Huguélet said.

Academic medical centers are usually well-equipped to manage high-risk pregnancies in collaboration with hematology. If a clinic doesn't have this type of multi-disciplinary care, it's a matter of having an ob-gyn and hematologist working together, to nail down a plan for any pregnancy complications and develop a plan for delivery.

Sometimes though, that planning can be difficult for women to advocate for, as Brandi Worthington knows. Living in Lake Elsinore, California, the 38-year-old mother of four is a carrier of and has mild hemophilia A. But she bleeds heavier than someone with mild hemophilia, she said, which was only discovered when she was seven months pregnant with her third child.

Worthington said she didn't get the care she should have had. All of her pregnancies were considered high risk due to a number of different health complications. Having grown up with "outrageous" periods, doctors told her



Photos on this page: Brandi Worthington's family.

she wasn't anemic and didn't have hemophilia, but they didn't know what was going on with her. Despite having a nephew with hemophilia, she and her twin were never tested. It wasn't until she was pregnant with her third child, a son, that her doctor decided to have her tested.

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“Historically, carriers were under-recognized and undervalued,” said Patricia Huguelet, MD. But some in the medical community are starting to realize carriers don’t have normal factor levels and can have significant bleeding.

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“A carrier who has a level of 20% versus 50% is going to bleed quite differently,” Huguelet said. “So knowing individual factor levels is what matters the most. Those who truly carry the disease because they have such low levels are at higher risk for bleeding, but carriers definitely still do as well, and we see it a lot.”

Genetic Testing

It’s hard to say if genetic testing before pregnancy would have helped prevent Worthington’s complications. But having a plan after birth would have been crucial, she said. After he was born, her son was bruised all over from multiple needle pokes. When the medical staff wanted to give him the vitamin K shot, Worthington asked them not to.

“I had some inkling,” Worthington said. She told the staff she’d prefer someone knowledgeable in hemophilia assess him first. “They gave him the shot and had a hematoma right away. I’m like, boom, he’s a hemophiliac.”

Despite her concerns, Worthington was dismissed. As a female, she had the impression hemophilia wasn’t a concern for the medical staff. They appeared to assume that only males could have hemophilia. “It was a struggle.”

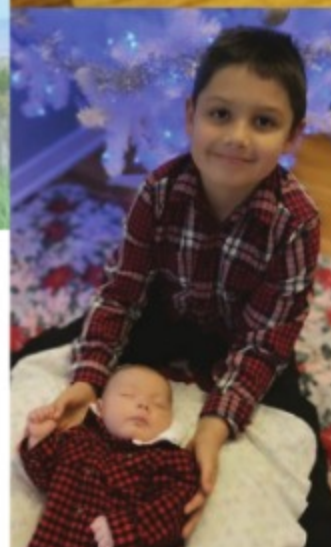
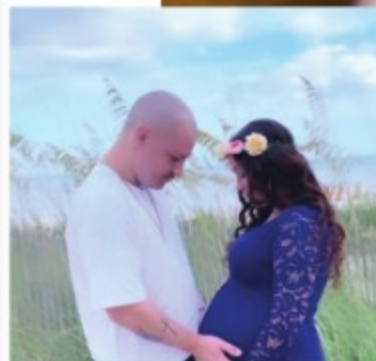
Kaylee Dollerschell, MS, is a certified genetic counselor at the Hemophilia and Thrombosis Center at the University of Colorado. She regularly meets with families to provide genetic education about hereditary bleeding and clotting disorders.

The benefit of meeting with a genetic counselor prior to pregnancy, explained Dollerschell, is that not everyone will need genetic testing because not all bleeding disorders are inherited. If it’s suspected that a bleeding disorder is hereditary, Dollerschell supports families through the challenges of having a child with a genetic bleeding disorder.

“There’s a benefit in being able to prepare for delivery,” she said, “not only for Mom, if she’s affected, but also for the baby.” Knowing someone’s bleeding status in advance can help the clinical team and pregnant person plan for special considerations during delivery or postpartum care.

“People can feel guilt for passing on a disorder to their children,” Dollerschell said. “There’s no control over what we pass on, but those things don’t necessarily get addressed by other providers [but] can potentially get addressed by genetic counselors.”

Photos on this page: The Fox family.



Understanding how a genetic disorder is inherited can help people discover if other family members or future children may have the same condition and how to best test them. If a family is interested, genetic counselors can also review family planning options related to hereditary disorders.

As a genetic counselor, Dollerschell respects that testing options might feel like a fit for some families and not for others. “We just provide the information,” she said. Genetic counselors provide support and guidance to help patients decide if or which genetic testing option feels best for their family.

Being Proactive

Ashley Fox, 29, always knew she was a carrier because her father had lived with hemophilia A. Fox has two sons and lives in Pittsburgh. Her infant son has mild hemophilia A, while her older son does not have hemophilia. As a symptomatic hemophilia carrier, Fox said her youngest son’s pregnancy was a pleasant surprise after two heartbreaking miscarriages.

Still, Fox was concerned about her bleeding risk and whether her son would inherit hemophilia. She and her husband declined prenatal testing and decided to wait until he was born to find out.



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“Maybe finding out his diagnosis during pregnancy would have made it a little easier, maybe not.”

—Ashley Fox

In her second trimester, Fox went to the emergency department with excessive bleeding and was diagnosed with a subchorionic hemorrhage (SCH), in which blood collects in the space between the placenta and uterus. This can cause bleeding, sometimes significantly. Fox was relieved to see her baby healthy and moving on the ultrasound. Fox was placed on modified bed rest, and the SCH resolved in six weeks. “I tried to take it easy, but I never fully got over the fear of something going wrong,” Fox said.

Not knowing the status of her son and his own risk for bleeding, Fox scheduled a Cesarean delivery. “In case he did have hemophilia, they felt it was a safer option for him due to the risk of cranial hemorrhaging with vaginal delivery.”

“Frequently, women experience lacerations with delivery, particularly during the first delivery,” Huguélet said. “But your average patient isn’t going to have a vulvar or vaginal hematoma because they have the ability to stop themselves from bleeding.” In someone with a bleeding disorder, though, those chances can be higher.

If it’s not known if a baby has a bleeding disorder, but it’s suspected in the mother, providers aim to avoid two birthing interventions: invasive fetal monitoring and operative vaginal delivery, Huguélet said.

Fetal heart tones can be traced using a monitor on the woman’s abdomen. However, it’s not perfect because the woman’s heartbeat can be picked up instead of the baby’s. The most accurate method is a fetal scalp electrode in which a clinician places a small electrode on the fetal scalp. However, Huguélet said, this can also cause a significant hematoma on the baby if the baby were to have a bleeding disorder, so it is generally recommended to use the less invasive external monitoring in these situations.

The same goes with an operative vaginal delivery, such as vacuum-assisted deliveries or the use of forceps. “Operative delivery puts a lot of force on the fetal

head, which can result in scalp trauma and potential subdural and intracranial hemorrhage,” Huguélet said. If there isn’t progress in labor, providers may move to a Cesarean delivery faster because of the increased risk of complications with the baby during operative deliveries.

Fox had blood work done at the local hemophilia treatment center (HTC) to check her factor levels in anticipation of the Cesarean delivery. The levels came back high enough that her care team was comfortable that she wouldn’t experience complications.

The HTC also provided Fox with a cord blood kit to take with her to the hospital because she had declined prenatal genetic testing. Cord blood kits can quickly diagnose hemophilia in newborns by medical staff drawing blood from the umbilical cord and getting rapid results from the test sample. She ended up using the kit and found out two days after her son was born that he had hemophilia A.

“Maybe finding out his diagnosis during pregnancy would have made it a little easier, maybe not,” Fox said. Despite the challenges faced, she, along with Worthington and Bruno, agreed: Having a bleeding disorder does not have to interfere with having a healthy pregnancy.

How to Plan Ahead

If you’re living with a bleeding disorder and you’re thinking about getting pregnant, there are plenty of resources to help you make the best decision for your family. Here’s what you need to know.

ASK QUESTIONS

“Be proactive and ask questions,” Bruno said. “If your ob-gyn doesn’t have the answers, find someone who does. You can have a successful pregnancy and delivery with the right monitoring and open communication between you and your care team.”

“Keep in close contact with your HTC,” Fox said. “They’re your best ally and will support you every step of the way.”

CONNECT WITH COMMUNITY

“I never realized how valuable having allies who know what you’re going through can be,” Bruno said. “This community is very supportive and always willing to share the name of an outstanding doctor. You can get the care you need, but it may mean more advocating and educating along the way.”

ADVOCATE FOR YOURSELF

Sometimes, women “have to fight from the get-go before they even find out they’re pregnant,” Worthington said. Find a bleeding disorder community and talk to people. Figure out a plan and work closely with your providers. Know where you’ll deliver and if they have the level of care you need. “Don’t be scared to voice your opinion.”

CREATE A CARE PLAN

Getting care in place before you’re pregnant can help alleviate the fear and worry. Your provider will look at your factor levels and ask about your past medical and surgical history. They will want to know if you’ve had

any major bleeding complications. People with bleeding disorders do have an increased chance of heavy first-trimester bleeding, but having a plan before pregnancy is ideal, Huguélet said.

REFRAME YOUR MINDSET

“Once you have a handle on what living with a bleeding disorder looks like, if you have another child with a bleeding disorder it can actually benefit the family because the kids have each other to lean on,” Bruno said.

Worthington’s son who has hemophilia is treated the same as her other kids, even if the experience is a little different. “If you want to have a baby, I don’t think hemophilia should stop you.” ♦

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