

INFUSING

BONDED BY BLOOD | SPRING 2022



Pregnancy and
Hemophilia

The Importance of
Healthy Boundaries

Learning to Honor
Mother Earth

Our Story

BONDED BY BLOOD

At an early age, our founders Kevin and Scott, met at hemophilia summer camp. As blood brothers, their friendship has spanned three decades of experiences in the bleeding disorders community and healthcare challenges. Over time, they shared each other's struggles and victories of living with a bleeding disorder. As they became professionals, they resolved to create the healthcare experience they wished they had. In mindful pursuit of this dream, they created **BROTHERS HEALTHCARE**, a unique specialty pharmacy, built around exceptional care, personal experience, and integrity. Kevin and Scott are committed to providing pharmacy care experience that is second to none.

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Brothers
HEALTHCARE



Sisters

Leading the Charge

With a growing awareness of women's treatment needs, **Brothers Healthcare** is a leader in advocating for women with bleeding disorders. Historically, women's unique needs are often overlooked when compared to their uncles, brothers, or sons. We support women getting the care they need to be their best selves. **We serve women by listening to their stories and finding creative solutions.**



Brothers
HEALTHCARE




FROM THE EDITOR

While I had planned something light to say here, I feel something far more impactful is necessary considering the recent unjustified acts of war on the innocent people of Ukraine.



Our prayers go out to the Ukrainian people as they endure the horrific and catastrophic attacks by the Russian government. We pray for the safety of the separated families and that they will be reunited and healed from these tragic events.

Brothers Healthcare stands with the people of Ukraine, as they resist invasion, fight for their freedom, and bravely face the dangers of this unthinkable tragedy.

If you have been affected and need support, please reach out to our team. 

Stay healthy and safe,
—Kelle Carthey, RN, Editor

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INFUSING LIFE
SPRING 2022

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ASK US!

Call or email us with any questions you have about sports, life, relationships or your managing your medical condition and we will lend our expertise to help you in any possible way.

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Pregnancy



& Hemophilia



If you have you're pregnant or your doctor recently told you that your child will likely be born with a bleeding disorder, your mind is likely spinning with questions and concerns. First, take a deep breath. You're in the right place. In this newsletter, we'll go over everything you need to know about pregnancy and hemophilia and giving birth to a child with a blood disorder.

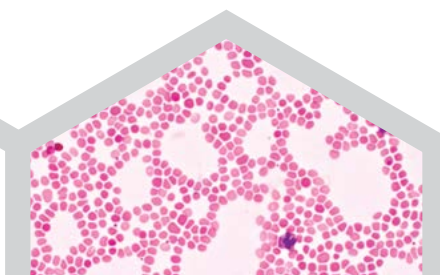
What You Should Know

Here are some important things to know and consider during pregnancy with hemophilia:

Have Your Factor Levels Checked

Women with low factor VIII or von Willebrand disease will naturally experience increased coagulation factor levels during pregnancy. But, they can also dip as birth approaches.

Most pregnant women with bleeding disorders will need some type of treatment with clotting factor to prevent bleeding while they give birth. If you're a carrier who doesn't have bleeding symptoms, you should be able to deliver without any increased risk of bleeding, as long as your factor levels measured in your third trimester were 70 percent or higher.



“Quality care can help prevent some of the serious problems associated with pregnancy, childbirth, and hemophilia.”

Hemophilia Carriers

Just because you are not diagnosed with hemophilia does not mean you can't pass it on to your baby. Women who inherit one affected X chromosome become hemophilia “carriers,” meaning they can pass the affected gene on to their children. What's more, some women who are carriers have symptoms of hemophilia and are considered to have a bleeding disorder.

This is why it's so important that women who carry the hemophilia gene and who display any symptoms are checked and cared for by a hematologist. Quality care can help prevent some of the serious problems associated with pregnancy, childbirth, and hemophilia.

Ask About Options for Pain Relief

Many women look forward to the pain relief that the epidural brings during childbirth. As long as your third-trimester factor levels are above 50 percent, the chances are high that you'll be able to have an epidural. But, if the levels fall below 50 percent, the possibility for prolonged bleeding at the site of the epidural increases. Even if you can't get an epidural, don't fret too much. There are plenty of epidural alternatives that are safe for people with hemophilia and carriers, including oral and IV analgesics.

There are also natural pain relief options, such as birthing classes and Lamaze, to teach you breathing exercises to reduce pain. You can also consider a birthing ball to provide comfort during labor and massage and/or aromatherapy.

C-Section or Vaginal Birth?

The best and safest delivery method is based on whether or

not you know your baby's hemophilia/blood disorder status. The good news is that not every woman who has a bleeding disorder automatically needs a cesarian section.

It's up to your team of doctors, specialists, and nurses to make the recommendation based on your bleeding disorder, your baby's status and carefully weighing the risks and benefits to both mother and baby.

If your baby has a known or suspected severe bleeding disorder, vaginal birth is considered high-risk for a brain bleed known as intracranial hemorrhage — in these cases, C-sections are planned.

It's also important that vaginal births are free from forceps or vacuum extractions to avoid the risk of a brain bleed.

Some women with bleeding disorders are given a medication called desmopressin (DDAVP) or factor replacement before their C-section, depending on their factor levels. These methods will help safeguard you from prolonged bleeding caused by the surgery.

Keep an Eye Out for Excessive Postpartum Bleeding

Although most women bleed for two to six weeks after giving birth, it's still important to be mindful and watchful for anomalies in terms of how much you are bleeding.

For example, if you notice that you're passing large clots after three or four days, if you're experiencing high levels of pain or if you need to change your sanitary pad more than once every two hours, call your doctor immediately.

Most hematologists recommend giving pregnant women with hemophilia clotting factor right before and then one to two weeks after delivery to avoid heavy bleeding and clots. It's often also given to women who are carriers.

Treating Bleeding Disorders During Pregnancy

Treatment depends on each woman's bleeding disorder, overall health and pregnancy, but treatment generally includes:

- Specialized care from a maternal-fetal medicine physician and an OB/GYN who specializes in high-risk pregnancies as well as monitoring and treatment plans with your Hemophilia Treatment Center
- Frequent prenatal checkups for close monitoring.
- A diligently planned delivery, including anesthesia and options that reduce the risk of bleeding.
- Genetic counseling to evaluate the baby's risk of inheriting a bleeding disorder.
- A multidisciplinary health care team that's made up of a hematologist, an anesthesiologist experienced in pregnancies with bleeding disorders and a pediatric hematologist.
- Delivery at a state-of-the-art facility with the resources necessary to address serious bleeding problems should they arise.

Treating Bleeding Disorders After Pregnancy

The Mother

After a woman gives birth, the elevated levels of factor VIII drop. This increases the risk of serious bleeding post-delivery for women with bleeding disorders.

If the mother has low levels of clotting factor such as factor VIII or von Willebrand factor, she can bleed after vaginal delivery or C-section. Some women experience long bouts of bleeding from the birth canal — which is known as postpartum hemorrhage. Treatment is often needed to stop the bleeding.

The Baby

Babies who meet the following characteristics should be tested for hemophilia shortly after birth:

- Born into a family with a history of hemophilia.
- Born to mothers who are hemophilia carriers.
- Displaying symptoms of bleeding at birth.

Cord blood is often used to test for clotting proteins.

Circumcision

According to the CDC (Centers for Disease Control), the most common cause of bleeding among babies with hemophilia is circumcision, which can continue for days after the procedure. Circumcision is often what leads to hemophilia diagnoses in babies who are not diagnosed pre-birth or at birth.

If you have a baby who may have hemophilia or who has already been diagnosed, you're advised to avoid circumcision, if possible.

Whether for religious or personal reasons, some parents will still decide to have their babies with bleeding disorders circumcised. If you make this decision, it's important to consult a pe-

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**THE IMPORTANCE
OF LEARNING & SETTING**

HEALTHY BOUNDARIES

**FOR OURSELVES
& OUR KIDS**



Why Setting Boundaries for Your Child is Actually a Good Thing.



Dear Parent,

How often have you felt guilty or upset for establishing boundaries for your child? Especially when your kid comes home from a terrifying visit to the doctor or a stressful school exam? You might over-analyze your decision and feel like a villain. The good news is that it's entirely normal to feel this way.

As parents, we love and seek what's best for our children. We want to remain the pillar in their lives as they endure countless challenges during their formative years. Saying no to a child's behavior (even when it's highly undesirable) throws us off as kindly caregivers and role models.

Secretly, many of us fear losing the respect and love of our children when we enforce a sense of discipline, rules, or guidelines. You might even think back to the happy times of laughter and joy, worrying that a set of boundaries would tarnish the perfect parental image you have built from the bottom of your heart.

Yet, setting healthy boundaries for our children is necessary for their developmental process. The keyword here, however, is "healthy." An overly restrictive regime

will only worsen your child's tantrums and behavior as they eventually muster the courage to challenge and overthrow "the system."

Healthy boundaries function just like contracts between adults, although in verbal form. The most beneficial boundaries involve an agreement between all parties (in this case, you and your child) made in a friendly and non-coercive manner.

While setting boundaries means the eventual need to say no to your child, it does not mean you should say no all or most of the time. You will need to examine the details for each situation, providing your child with a balance of autonomy and intervention with good intentions.

As with any form of relationship building, setting boundaries with your child will be challenging initially. However, consistent guidelines will ultimately strengthen your child's resolve and improve their understanding of expectations.

Reaping the Benefits of a Necessary Process

Children are highly reactive, generally more so than most adults, mainly because they lack the rich life experiences and coping mechanisms for

responding to life's most frustrating challenges. It is common to hear stories about children yelling or engaging in violent and destructive behavior (e.g., tossing household objects) when they fail to get their way.

Setting healthy boundaries prepares your child for societal norms and teaches a load of valuable values and life skills that polish their personalities. Some of the most meaningful learning objectives of boundaries include:

PROBLEM-SOLVING –

Boundaries challenge children to think creatively to develop alternate routes and solutions when facing an issue. They will eventually foster the mentality of seeking new doors when one closes.

RESPONSIBILITY –

Boundaries teach children to develop a sense of responsibility for their thoughts and decisions. For example, they will connect the dots on how action has repercussions. They will ask essential questions and rationalize before acting on impulse.

PATIENCE – Setting boundaries helps your child pause and reflect on logic and reasoning. While your child will initially rebel against the idea of rules and regulations, they will eventually realize that they can make better decisions with a calm mood and lucid mind.

SELF-DISCIPLINE – Your child will eventually become a member of public society and communities (e.g., daycare, school, interest groups) with specific rules and laws. Setting boundaries provides them with the self-discipline to comply with guidelines and reject inappropriate behavior so that they can assimilate with others without fuss.

Parental Tips on Setting Boundaries

Getting started on setting boundaries can be an overwhelming process, and you

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MOTHER E

Although April 22 is Earth Day, it's important to honor, respect, and love Mother Earth 365 days per year. If you're unsure about making eco-friendly changes because you think it costs too much money or will take too much time, don't worry. There are plenty of simple, low-cost, and even free changes you can make today to start reducing your carbon footprint.

Incorporating Earth-Friendly Practices into Your Daily Routine

Here are some earth-friendly practices that you can start doing daily.

Reduce Medical Waste

Medical waste is a massive — and growing — problem. Statistics show that hospitals in the United States produce nearly 6 million tons of medical waste every year — not including waste from home care, dental,

veterinary, pharmacy, and other smaller quantity generators.

As a patient, you can reduce medical waste in many ways, including:

- Choosing generic prescription drugs when possible.
- Choosing e-sign options for signing documents instead of printing out the paperwork.
- Filling out paperwork electronically before doctor's appointments rather than filling out physically printed

paperwork in-office.

- Choose telehealth appointments when available/applicable.
- Reduce the use of single-use items. Ask your provider to tell you about multi-use alternatives and options.
- Double-check your supplies before opening a new one.
- Use recyclable papers, plastic containers, and wrappers.
- Use your dedicated SHARPS container for only sharp objects, including needles, needle pens, and lancets.

- Don't flush medicines down the toilet because sewage treatment systems have a very hard time breaking down drugs, and when the medicines get into the environment, they have damaging side effects.

Reuse and Recycle

According to the Environmental Protection Agency (EPA), 75% of the waste generated in the U.S. can be recycled or composted, but only about 32% is. Recy-

cling is easy and, in most cases, very low-cost or even free. Some facilities will even pay you to bring in your recyclables!

To recycle, you can take the traditional route of sorting your plastics, papers, cardboard, and other recyclables and placing them into a designated bin that's picked up or that you take in each week. Or, you can take a DIY approach. For example, turn that old jam jar into a pencil holder. Some of the most commonly recycled items include:

- Plastic bottles
- Plastic containers
- Milk cartons
- Cardboard boxes
- Paper
- Cans
- Glass jars
- Glass bottles

Do you regularly throw away your soda cans, Amazon boxes, or anything else on the list above? If so, try setting them aside for recycling. You'll get the added benefit of not filling up your trash so quickly, in addition

Start a Compost Bin

About 39% of all waste is compostable, including most commonly used items around the house, such as:

- Eggshells
- Banana peels
- Orange peels
- Fruits and vegetables
- Leaves
- Coffee grounds
- Teabags
- Dryer lint
- Food scraps
- Cardboard
- Shredded newspaper
- Yard trimmings
- Sawdust
- Wood chips
- Hair and fur

Composting takes organic matter and puts it through a process that allows it to decompose naturally. Once the material decomposes, you can use it as a soil fertilizer.

Instead of throwing away your leftovers from dinner, challenge yourself this Earth Day to start composting — your garden will thank you! You can create your own compost pile outdoors, or you can collect the material in an airtight composting container and when it gets filled up, take it to a nearby composting facility.

There are many benefits associated with composting, including:

- Enriches the soil and helps it retain moisture while suppressing plant diseases and pests.
- Reduces the need for fertilizers that contain harsh, environment-damaging chemicals.
- Encourages the production of good bacteria and fungi that break down organic matter to create nutrient-rich humus.
- Reduces methane emissions from landfills.
- Lowers your carbon footprint.

Adopt "Meatless Monday"

Vegetarian or vegan diets are much better for the environment than diets filled with meat. In fact, a recent study found that the average vegetarian is responsible for **half the greenhouse gas emissions** that the average meat-eater is.

What's more, diets that include meat require 2.5 times more space compared to vegetarian or vegan diets. Meat diets also require more water. According to the Vegetarian Society, just one small 8-ounce chicken breast requires more than 143 gallons of water to produce!

Now, we're not asking you to go entirely vegan or vegetarian. Some people adopt "meatless Monday"; meaning on Monday, you are committed to not eating any meat. Of course, you can make this any day of the week, not just Monday.

Turn It Off!

Turning off the lights and other electronics when you're not using them is another simple — and free — change that goes a long way toward helping the environment, and it will save you money on your utilities! What's not to love? Make an effort this Earth Day, and beyond, to be conscious about turning off lights and TVs, unplugging the kettle or toaster when it's not in use, etc. While you're at it, swap out your lightbulbs for environmentally friendly LED lights.

Get Rid of Single-Use Plastics

Vow to stop using single-use plastics this Earth Day to make a big difference. Instead, opt for reusable water bottles, straws, cups, plates, cutlery, and so forth. You don't have to throw away all of your single-use plastics at once or spend hundreds of dollars purchasing reusable things. Start with a small, conscious, and concerted effort, and build on it. For example, the next time you're at the grocery store, pick up some reusable straws. Then, the next month or week, aim to buy something else reusable, such as plastic bags, and go from there.

Use Water More Efficiently

One of the easiest ways to conserve water is to cut down your shower time. No more dilly-dallying in the shower — get in, do what you need to do, and get out. Also, turn the faucet off while you're brushing your teeth and washing your face. Wait until the dishwasher is full to run it, and wash what you can by hand.

Happy Earth Day!

We hope this newsletter has inspired you to make a few minor changes this Earth Day. If everyone makes even the smallest of changes, we can see some real progress in the fight against climate change. Remember, small steps help build a better tomorrow. 🌱



Mother's Day Dedication

"Dear Mom of a child with special needs,
I want you to know that I see you.

I see you running your child to therapy
when your friends are running their kids to
Little League.

I see you slipping out the of conversation
when your friends are all chiming in about
milestones and test grades.

I see you juggling appointments and
meetings, always making sure you do the
best for your child.

I see you sitting at your computer for
hours researching what your child needs.

I see you cringe when people whine about
the petty things that pale in comparison
to your day.

I see you spread thin, but still going the
extra mile for your family, and managing
to do it with a smile.

I see you digging for depths of strength
you never dreamed you had.

I see you showing appreciation to the
teachers, therapists and medical profes-
sionals who serve your child with you.

I see you reluctantly rising early in the
morning to do it all again after another
chaotic night.

I see you when you're hanging on to the
end of your rope for dear life.

I know you feel invisible, like nobody
notices any of it. But I want you to know
that I notice you. I see you in the trenches,
relentlessly pushing onward. I see you
keep choosing to do everything in your
power to give your child the best possible
care at home, in school, at therapy, and
the doctor. What you're doing matters. It's
worth it. On those days when you wonder

if you can do it another minute of being a
mom of a child with special needs, I want
you to know that I see you. I want you to
know that you're beautiful. I want you to
know that it's worth it. I want you to know
that you aren't alone. I want you to know
that love is what matters most, and you
have that nailed.

And on those days when you have
breakthroughs, those times when the
hard work, pays off and success is yours
to cherish, I see you then too, and I am
proud of you.

Whichever day today is, you're worthy,
you're good, and I see you."



**See more from
Alethea Jo on Facebook
and Instagram.*

Continued from page 5

diatric hematologist before the
procedure to ensure the baby
receives proper treatment to
prevent excessive bleeding.

Vaccines

It is recommended that all
babies, even those who are born
with hemophilia, receive a vita-
min K shot at birth in addition to
all other routine vaccines. You
should always apply pressure
to the vaccine site or site of
the heel stick after your baby
receives a vaccine or heel prick
to prevent excessive bleeding.
Make sure that you have a plan
with your hematologist or He-
mophilia Treatment center when
preparing to give vaccines for
pre- or post treatment options.

Head Bleeding

The CDC says the head is the
second most common place
of bleeding for babies with
hemophilia. This is because of
how the head is squeezed as it
passes through the birth canal,



which
can cause
bleeding.

Forceps or vacuum extractors
used to help pull the baby from
the birth canal can also lead to
head bleeding in newborns.

Head bleeding takes place on
the scalp or even into the brain.
The problem with brain bleeding
during birth is that its symptoms
are non-specific, making it hard
to diagnose.

Once diagnosed, it's critically
important to treat head bleeding
ASAP with clotting factor re-

placement/ When left untreated,
head bleeding is life-threatening
and can even lead to long-term
brain damage.

Get the Right Team Set Up

If you're pregnant and have a
history of hemophilia or bleeding
disorders in your family or you're
a suspected carrier, we know
that this can be an overwhelm-
ing — and downright scary —
time. But, it's important to know
you're not alone. Talking openly

and honestly with your doctor
and getting in contact with your
nearest Hemophilia Treatment
Center is the first step to ensur-
ing a safe pregnancy and birth.
Your doctor will answer any
questions you have along the
way and work to create a birth
plan to protect you and your
baby.

If you or someone you know
needs help finding a Hemophilia
Treatment Center, please reach
out to us! We can help connect
you!

**"It's important to know
you're not alone. Talking
openly and honestly with
your doctor is the first step
to ensuring a pregnancy..."**

“Choices give children a semblance of control in their lives, reducing the restriction of boundaries.”

might find yourself unsure of the first step. As much as possible, you should keep the process natural and comfortable for you and your child, and there is never a need to rush through it. We have gathered some valuable tips to help you start with minimal obstacles.

ALWAYS PLAN – Rather than improvising a response, it is advantageous to anticipate your child’s possible scenarios and reactions/behavior toward a given situation. For instance, if a trip to the clinic usually evokes lousy behavior (e.g., shouting, crying, or kicking up a fuss), you could prepare a response accordingly, such as a concise, logical explanation (for the doctor visit) or an activity that soothes them.

OFFER CHOICES – Choices give children a semblance of control in their lives, reducing the restriction of boundaries. For example, you may convince your child to go for medical treatment, and in exchange, they may choose the scenic route with a stop for ice cream for the car ride home. Small victories in choices can go a long way toward building your child’s independence and self-confidence while conforming to appropriate behavior.

FOCUS ON THE DO’S RATHER THAN THE DON’TS

– Nobody enjoys being told what they can or cannot do. It is a concept that applies to adults too. Therefore, while you will need to enforce discipline and guidelines when setting boundaries, you should focus on making the process educational rather than positioning it as a form of punishment. Always clarify the reasoning behind a set boundary instead of insisting on a specific behavior without explanation (e.g., “stop screaming” versus “lower your voice, or you’ll hurt your throat and upset the people around you.”). Children will begin to respond better once they realize the magnitude and power of their words and actions.

Remember, you will likely face “tests” from your child as they attempt to break the rules. However, you should not give up on boundaries as these challenges form a natural part of the familiarization process.

Instead, stay calm and patient, maintain firm control of the situation, and clarify your boundaries, consequences, and choices. Remind yourself that these boundaries will help your child in the long term, and there are lasting consequences from not following through with them.

Overcoming Guilt in Boundaries

Yes, you may feel guilty when enforcing boundaries, especially when children start to scream, cry, or direct their rage toward you. Yet, these reactions are temporary, and boundaries are necessary for your child’s long-term development.

Rather than doing away with them, you should consider alternatives to ease your child through a difficult situation. The good news is that there are various coping rituals and mechanisms to help your child overcome the fear of completing a task or medical event without losing their temper or expressing signs of defiance.

Distraction is an effective method of preventing a tantrum, such as using a fidget toy or Rubik’s cube that redirects a child’s attention from the source of fear or pain.

Another simple but effective way to soothe your child involves holding their hand or hugging them when they encounter a stressful situation

(e.g., receiving an injection). Children might feel better knowing that they are not alone (similar to accompanying younger children until they fall asleep once the lights go out).

Another method involves positive reinforcement in the form of rewards. Inform your child that something special awaits them once they overcome the challenge. But of course, you will need to uphold the end of the bargain every time. Trust is an extremely precious ingredient in healthy parent-child relationships. So, only make promises that you can keep, or you’ll risk further strains on your communication.

With perseverance and consistency, you and your child will gradually observe and learn from the positive and negative effects of boundaries, strengthening your bond through mutual respect.

Ultimately it is all a part of the learning process as your talented child develops into an amazing adult. 