

INFUSING

BONDED BY BLOOD | SUMMER 2022



Advocating for you and your child — *Page 6*



What is a
504 Plan?

Can you Hear Me?
Advocating for You and
Your Child at the Doctor

Let's get the Story Straight!
Women are Bleeders Too



**Learn more about our focus
on the rare bleeding disorder
community**

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FROM THE EDITOR

It's summer time! First off, let me say **HAPPY SUMMER!** Nothing is better than spending warm summer days with our family and friends.

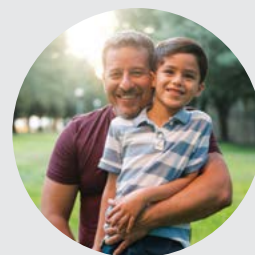


Stay healthy and safe,
—Kelle Carthey, RN, Editor

I know that in my house (I have four kids), that means a lot of noise and endless energy. Kids, friends, summer camps, camping, and late-night movie nights are in the near future in this house! I can't wait! That said, summer also means annual appointments at the HTC, pediatrician, 504 planning, and teacher meetings with the school to prep for the incoming school year. It can be tough juggling everyone being home, keeping up with work, staying on schedule, and ensuring everyone is prepared to return to school by September. We hope that you can take things slow and that our newsletter might be able to support your efforts in some small way.

In this issue of Infusing Life, we discuss talking with your doctor to ensure your needs and concerns are being taken seriously, heading back to school with 504 plans, and ensuring women and girls get the treatment they need.

We hope you enjoy our newsletter and have great summer filled with fun in the sun! ☀️



INFUSING LIFE
SUMMER 2022

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A top-down view of a workspace featuring a silver laptop keyboard in the upper left, a spiral-bound notebook in the center, and a black fountain pen with its cap off in the lower right. The notebook's page is lined and contains handwritten text and checkmarks.

**"504 PLANS PREVENT
DISCRIMINATION AND
PROTECTS THE RIGHTS OF
KIDS WITH DISABILITIES."**

WHAT IS A 504 PLAN?

504 Plan



GOAL



PLAN



ACTION

In preparation for the school year, it is important to contact your child's school to ensure they know your child's medical condition.

There are many reasons your child's school should be made aware of your child's medical condition.

One significant reason is that children with a bleeding disorder may need special accommodation at school. These accommodations help them have a

successful learning experience while managing their bleeding disorder. Kids with bleeding disorders may often miss class due to bleeding episodes or pain related to bleeding. These absences may lead kids to need extra time or help with assignments, have difficulty getting from class to class when they return or may need alternatives to P.E. when they cannot play due to an injury. This is where a 504 Plan can be helpful.

A 504 Plan is derived from section 504 of the rehabilitation act. It is a formal plan intended to give the kids with disabilities the appropriate support they need to accomplish the educational requirements. In addition, the 504 plan prevents discrimination and protects the rights of kids with disabilities. To qualify for a 504 plan, your child must have a disability, and that disability must impact their ability to receive an education. Under Section 504, a disability is defined as a condition that impacts one or more basic life activities and can include physical, emotional, or cognitive disabilities.

HOW TO REQUEST A 504 PLAN:

The parents should ask the school secretary who is responsible for scheduling a 504 Plan meeting.

Obtain the name, phone number, and email of the person in charge of scheduling the meeting.

Send a written request to the staff member in charge of scheduling the meeting. It is important the date the request is made is documented by you and documented when received by the school.

WHAT DOES A 504 PLAN INCLUDE:

- Detailed information about the diagnosis of the student.
- Limitations the student may encounter due to the medical condition.
- Accommodation that will be made in response to the limitations.

- Identifies who is responsible for fulfilling the accommodations.
- Depicts how to react when a medical emergency arises while at school.

WHO CAN PARTICIPATE IN A 504 PLAN MEETING?

- Parent
- Student
- School nurse
- District nurse
- Child's teacher(s)
- Principal
- Support staff such as recess aids
- Hemophilia Treatment Center nurse, specialty pharmacy nurse, or social worker
- Anyone the parent wants to invite to the meeting that can add information or advocate on behalf of the student.

HOW TO PREPARE FOR THE 504 PLAN MEETING:

- Obtain a letter from your child's hematologist describing the medical condition and limitations for their child due to the medical condition.
- Don't assume they know about your child's diagnosis. Take handouts and information about your child's medical condition to hand out at the meeting to educate the staff.
- Be open to discussing your concerns about your child while they are at school
- Have a list of problems your child may encounter during the school year. This may include excessive absences due to doctor's appointments, arriving at school with bruises due to bleeds, going to school with an IV attached due to treating an internal bleed, etc.

AFTER THE 504 PLAN MEETING:

- Check in with your child to ensure that the agreed-upon accommodations are met. If you see that the accommodation is not being met, ask for a meeting to address the concern.
- If the school does not contact


you to schedule an annual meeting, you can call them to schedule it.

- Update the 504 Plan when there are changes to your child's condition.

THE 504 PLAN LOOKS DIFFERENT FOR EACH CHILD BECAUSE THE NEEDS AND ACCOMMODATIONS ARE SPECIFIC TO YOUR CHILD. HOWEVER, HERE ARE SOME EXAMPLES OF ACCOMMODATIONS FOR BLEEDING DISORDERS:

- Due to heavy menses, the student will have permission to use the restroom when needed without being penalized.
- When P.E. involves contact sports, the student will be given a modified activity to obtain full credit.
- Student will be allowed to keep a set of clothing at school in case she bleeds through her clothes while on her menses.
- Parent or guardian to be allowed to attend field trips with the student.
- Student to be able to keep medication at school.
- Extra time on assignments when class is missed due to doctor's appointments or bleeding episodes.

WHERE TO OBTAIN MORE INFORMATION ABOUT THE 504 PLAN:

If you need assistance preparing for the 504 Plan meeting, you can find appropriate resources on the Hemophilia Federation of America's website (<https://www.hemophiliafed.org/home/for-patient-families/resources/toolkits/back-to-school/>). You can also speak to your specialty pharmacy advocate, HTC social worker, or your local hemophilia foundation for resources pertaining to the 504 Plan. 

Sources:

<https://www.hemophiliafed.org/home/for-patient-families/resources/toolkits/back-to-school/>
https://oley.org/page/IHP_IEP_Difference
<https://www.understood.org>

Quick TIP

Doing infusion on yourself or your child can be tricky! Here are a couple "quick tips" that you can use to help.



- **Take a Deep Breath**—By asking the patient to take a deep breath just before the stick, you can help keep them calm and distracted. A person will often feel more in control of the situation if you give them something to do. This may work as the needle is being removed, too.
- **Anchors Away**—Stretching the skin by "anchoring" the vein doesn't just help you stick the vein on the first try, it also helps make the stick less painful. Remember, your thumb goes below the venipuncture site, and give yourself plenty of room so you don't accidentally jab your own fingers.



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.

(800) 291-1089
info@brothershealthcare.com



Can you
hear me?

Advocating for you and your

Parents know their children best and take on the heavy responsibility of managing every healthcare need and decision throughout their growing years. Making the right medical decisions for your child involves asking questions or seeking further information when a doctor's consultation or recommended treatment seems unclear.

Standing up as an advocate means you will effectively become the trusted mouthpiece and representative of your child. As such, your conversations need to go beyond managing your child's medication and healthcare visits. Familiarizing

yourself with the details of the latest healthcare processes, scientific research, and your child's medical history can give you the confidence to advocate efficiently during doctor visits across all scenarios.

Conduct Thorough Research

Effective advocacy for your child requires accurate data. There are several ways to gather the healthcare information you need to support your child's treatment and guide them on the road to recovery.

Some useful offline sources of information include your local library, primary healthcare

provider, and attending events such as parent group meetings and medical talks. If you have a busy schedule, online sources can provide the information you need to understand your child's medical condition from the convenience of your mobile devices. However, since the modern digital age enables any untrained or unqualified individual to create inaccurate online content, you should always check a site's reliability and verity before accepting its information. Consider narrowing your search to websites with URLs that end with .gov or .org when searching for healthcare data.

Similarly, social media can provide a significant source of online healthcare information. Specifically, consider looking for interest groups created and managed by parents with children undergoing similar health conditions. Joining these groups provides you with varied parental perspectives and valuable real-world advice on managing your child's healthcare and engaging trusted medical specialists.

Also, it is essential to learn about the medical terminologies and jargon commonly used by medical practitioners when describing your child's condition.

For example, there are specific words often used by doctors specialized in treating bleeding disorders. These terms include baseline, immune tolerance induction, inhibitors, and half-life.

Familiarizing yourself with these words will give you a better grasp of your child's condition and improve communications with a qualified expert. Through seamless conversations, you can work closely with healthcare practitioners to discover the best available treatment for your child.

Constantly Ask Questions

Asking your doctor questions whenever you are in doubt can help refine your advocacy skills. Remember to frame your questions in a friendly manner, focused on seeking the best medical solutions for your child as a team.

A trustworthy doctor should offer clarity and patience with every consultation to guide your child's healthcare action plan. Some discerning questions you might ask your child's doctor to further the conversation include:

- What are the potential side effects of a drug or treatment?
- Are there contraindications when mixing the medication with other prescriptions?
- How long does it typically take before we see treatment results?
- Are there changes that we should make to my child's diet?
- How much is the treatment cost, and are there alternatives?
- What is the follow-up plan in case the treatment fails?
- May I have more information regarding the treatment and drug?
- What are the typical symptoms

to expect with the health condition?

- Can we seek a second opinion?

If your healthcare practitioner constantly disregards your concerns or seems to quickly mount on the defense, it might be time to seek another doctor. Professional practitioners should always act in the capacity of dedicated partners and allies in treating your child's condition and never trivialize or brush off your opinions.

Living in a rural or small community might limit your options for qualified healthcare specialists, especially for rare conditions such as bleeding disorders. In such scenarios, feel free to reach out to your hemophilia treatment center to request telemedicine alternatives that can significantly broaden your search for a suitable expert.

Keep up with the Latest Medical Breakthroughs

Healthcare researchers constantly develop drug and treatment breakthroughs that could significantly improve or supple-

ment your child's treatment plan. Some discoveries may even provide viable solutions for previously untreatable conditions. Scientific journals and medical forums are some effective sources for getting the latest scoop on healthcare advancements. You can find up-to-date product details available on the National Hemophilia Foundation site, hemophilia.org, or gain in-depth information by visiting the official websites of bleeding disorders drug manufacturers.

Additionally, as much as possible, cross-reference available study data to determine the feasibility and safety of novel medication or treatment. You could refer to the research

Maintain Proper Healthcare Documentation

As your child's healthcare advocate, you will need to have a list of documents available and accessible. These documents may include your child's bleed logs, drug allergy journals, diet plans, medical history, insurance information, and contact details (e.g., personal and specialty pharmacy information). You may choose to carry originals or copies of the documents or scan them as soft copies that you can seamlessly access from a secured cloud platform.

If you are heading to the ER, you should also bring your child's emergency medication and a record of the prescribed dosage. The added measure will help medical practitioners respond quickly and decisively in getting children the medication they may need without delay.

Finally, any documentation for your child's specialist visits, immediately drawing attention to a prioritized health concern should be included in the information you bring.

Take Notes During Consultations

The practice of note taking avoids the fallibility of human memory and the loss of valuable information. Also, recording the key points discussed in a doctor's visit can help you reduce the risks of misinterpretation and misinformation.

You can effectively expedite follow-up doctor visits and track your child's health recovery by revisiting a summary of your previous sessions. Often, doctors also keep consultation notes with each appointment, and requesting a copy of the notes before you leave keeps the main points of the appointment

concise and accessible for future use if needed.

Additionally, it also helps to practice notetaking at home. For instance, you might record your child's eating habits, temperature, symptoms, and vitals to provide your doctor with a quick analysis of your kid's overall health.

Alternatively, you might invite a reliable relation to accompany you and your child during your doctor visits. Having another person in the room can help affirm the information provided by your healthcare practitioner. However, you should first check with the policies of your healthcare facility as some places only permit one adult with each child patient.

Keep Your Options Open

Including a highly regarded healthcare specialist can significantly improve your child's treatment outcome. Instead of relying on convenience and affordability as sole factors, consider reaching out to advocacy organizations that can guide you in the right direction based on your child's medical history. Alternatively, another great option is reaching out to parent communities to seek firsthand accounts of their experiences with leading doctors. A committed specialist will have a reputation for taking the time to listen and factor in your child's lived experiences into their treatment plans. Finally, a trusted doctor will respect your fears and concerns while prioritizing your needs rather than rushing through a consultation.

As a parent, you constantly seek the best for your child, and you can often detect the slightest physical and behavioral anomalies that indicate something amiss. Always attempt to raise your concerns if your instincts tell you that something might seem off even if it does not seem like a priority to your doctor at the time.

While some medical practitioners may dismiss or downplay

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child at the doctor.



Let's Get the Story Straight.

Women Are Bleeders Too.

Did you know that women can have hemophilia? Many women with a bleeding disorder may not even realize it. This is partly because medical professionals and others have historically regarded hemophilia as a disease only men suffer from. Until recently, medical professionals used the term “symptomatic carrier” to describe women with hemophilia. However, this outdated term is no longer accurate, and women should be aware of the options available for treating girls and women with bleeding disorders.

“Symptomatic Carriers”

In genetics, a carrier is someone who has the mutation for a disease. The carrier can pass the condition to their children.

Many carriers of genetic diseases never experience any symptoms themselves. However, many women do and don't understand why. The problem with calling women with hemophilia “symptomatic carriers” is that it implies that they are not symptomatic and do not need treatment. This is simply not true. Many women that “are carriers” of the gene for hemophilia, also themselves have low clotting factor levels. While the symptoms of hemophilia may be different in women than in men, this does not mean that women do not experience symptoms, need treatment, or that their health is not at risk.

Hemophilia Affects Women

Hemophilia is usually more severe in men. However, most women with hemophilia experience symptoms like those in men with mild hemophilia. For example, many women with hemophilia bleed for a longer time than usual after an injury or surgery.

Clotting factor levels of the women who have the gene that carries hemophilia can often be considerably low and are often unchecked by providers who do not have specialized experience in bleeding disorders. This can make it challenging to diagnose and get treatment for their symptoms.

Symptoms of Hemophilia in Women

All too often, women who have the gene mutation also have low or borderline clotting factor levels, and these low/borderline levels can lead to symptoms. These low levels are not true for all carriers, so here are some signs to look out for.

Heavy menstrual periods (menorrhagia) are one of the most common signs of hemophilia in women. A woman is considered to have menorrhagia when:

- She bleeds for more than a week.
- The blood gushes or floods.
- The blood has clots larger than a quarter.
- She needs to change her tampon or pad at least every two hours on the heaviest day of her period.

**You are not alone in this journey—
there is a whole community of women
with bleeding disorders who understand
what you're going through.**

Other symptoms of hemophilia in women include:

- Being low in iron
- Heavy bleeding after surgery or childbirth
- Nosebleeds that don't stop for at least 10 minutes
- Prolonged bleeding from a cut or scrape
- Bruising easily and badly
- Joint bleeds
- Gum bleeding

How Are Women with Hemophilia Diagnosed?

The first step in diagnosing hemophilia in women is to perform a blood test to measure the level of clotting factor in the blood.

If the clotting factor level is low, further testing may be needed to confirm the diagnosis.

What Are the Dangers for Women with Hemophilia?

If undiagnosed or untreated, women with hemophilia are at risk for:

- Anemia
- Chronic pain
- Joint damage
- Muscle weakness
- Soft tissue bleeds
- Complications during childbirth
- Heavy menstrual bleeding
- Arthritis from untreated bleeds

What Happens When Healthcare Providers Misdiagnose Hemophilia in Women?

When doctors and other healthcare providers don't consider the possibility of hemophilia in

women, it can lead to dangerous consequences.

For example, a medical professional may tell a woman with heavy menstrual bleeding that she just has a "heavy flow" and should try over-the-counter medication or birth control pills to manage her symptoms.

However, this approach does not treat the underlying cause of the heavy bleeding, which is hemophilia. As a result, the woman's symptoms may continue or worsen over time.

Another example is when a woman with hemophilia experiences joint pain. Doctors may diagnose her with arthritis and prescribe medication to relieve her pain.

However, this medication will

not treat the underlying cause of her joint pain—bleeding in her joints.

When surgery is performed on a woman with hemophilia without a suitable treatment plan, it can lead to significant complications. For example, a woman with hemophilia who needs a cesarean section (C-section) may bleed excessively during and after the surgery.

This can cause dangerous complications for both the mother and the baby.

A woman with hemophilia who is pregnant may also have an increased risk of bleeding during childbirth.

How Can Women with Hemophilia Get the Care They Need?

Women with bleeding disorders and their families should consider seeking care from a hemophilia treatment center (HTC) with doctors who have experience helping women. These centers are staffed by teams experi-

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PK; Pharmacokinetics

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your fears, you will know best regarding your child's general behavior and health. Therefore, it is essential to stand firmly on your intuition and seek a thorough medical examination to address a specific concern.



Promote Self-Advocacy

There will come a time when children develop into young adults to stand out for themselves in the healthcare system. As a parent, it is never too early to guide your child through the process, building their confidence and gradually explaining the steps and procedures involved in managing their health conditions.

Problem-solving and communication skills will prove invaluable in your child's journey toward self-advocacy. For example, you might encourage your child to ask questions and approach disagreements calmly and logically when in doubt. However, consider guiding the transition through a gradual process, balancing your role as a caregiver while empowering your child.


"Including a highly regarded healthcare specialist can significantly improve your child's treatment outcome."

Closing Thoughts

Advocating for you and your child at the doctor's might feel like an exhausting process but doing so gets your voice heard and concerns addressed. While you will eventually pass on the mantle of advocacy to your child, it is vital to set a solid example that they can benchmark, emulate, and recreate with confidence.

In summary, you can become a more efficient advocate by storing up valuable data on your child's condition, systematically managing medical documentation, vetting through the most

suitable doctors based on cross-referencing and research, and eventually imparting the skills for self-advocacy.

Ultimately, the patient-doctor role transcends an obligatory consultation. With carefully driven advocacy, your child will gradually build lasting relations with healthcare practitioners with the dedication and expertise to provide them with the specialized treatment they need. With these steps in place, you can educate yourself, be prepared, and optimize the health and safety of your child for future healthcare visits. 

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enced in diagnosing and treating patients with bleeding disorders.

If you are a woman with a bleeding disorder, it is crucial to find a hematologist familiar with the options available to women and girls. Your hematology treatment team should listen to your symptoms and treat you based on your individual needs.

Having a medical team who understands your specific challenges and needs is crucial to managing your bleeding symptoms and living a life with the least amount of hassle. With proper diagnosis and treatment, you can live a full, uninterrupted, and healthy life.

Your hematologist can develop a comprehensive treatment plan that meets your individual needs and ensures you're getting the best possible care. Remember, you are not alone in this journey—there is a whole community of women with bleeding disorders who understand what you're going through. You may also want to reach out to your local hemophilia foundation for support and resources.

Treatment Options for Women with Hemophilia

It is important to be a part of a hemophilia treatment center to best manage your care. A typical team can include:

- A hematologist
- A nurse coordinator
- A physical therapist
- A social worker
- A genetic counselor
- A dietitian

Typical treatments for bleeding symptoms include IV factor replacement, hormone treatments (such as the pill), and desmopressin, a nasal spray.

In some cases, surgery may be necessary to treat damage from past bleeds or prevent future ones.

It's Time to Take Women with Hemophilia Seriously

It's time to change how we think about hemophilia and how it affects women. Too often, women with hemophilia are not taken seriously by doctors or family members. This can lead to delays in diagnosis and treatment, which can be devastating.



If you are a woman with hemophilia, don't give up until you get the care and treatment you need. You deserve to be taken seriously and to receive the best possible care.


How Brothers Healthcare Can Help

Hemophilia and other bleeding disorders can be challenging to understand and manage, especially if you're not a medical professional.

Managing a bleeding disorder can feel like a full-time job. Between treatments, doctor's

appointments, and learning about your condition, it can be hard to find time for anything else.

Brothers Healthcare is here to help. We provide unparalleled care and support to patients and families living with hemophilia and other bleeding disorders. With our expert team of pharmacists, nurses, social workers, and educators, we are dedicated to helping you live your best life.

For support around hemophilia and other bleeding disorders, contact us. 

SCHOLARSHIP WINNERS

James Cosman

After high school, James will be completing his undergraduate at Southwestern University, double majoring in biochemistry and biomolecular engineering. His aspirations are in protein synthesis and helping solid-cell transplant patients avoid rejection.

James grew up all over the United States as a military child. As a senior, the family moved to Fallon, Nevada where James embraced the educational opportunity provided by Oasis Academy College Prep, where he was able to complete 57 college credits through the jump start program. While at Oasis, he worked with the local community leaders and the local community to hold outreach events to bring awareness to bleeding disorders as well as other rare conditions.

He also is a competitive swimmer in the pool and open ocean and will continue his swimming career at Southwestern.



Ramona Jalomo

Hi! Nice to meet you! My name is Ramona Jalomo and I was chosen to be the recipient of this scholarship! I am 18 years old and after graduation this year I will be heading off to California State

University Monterey Bay; the home of the Otters, to study psychology in hopes of becoming a clinical psychologist!

My story of when I was diagnosed started when I was about 3 years old with Von-Willebrand's. Throughout my life, it was always a constant struggle, especially with school and society. I had always felt like the odd one out, but I always had a strong support system, which was my family. With their strength and encouraging words, I was able to get through the beginning of the new chapter in my life with ease.

I want to mention this once again, thank you so much for presenting me with this opportunity. It helped not only me but my family as a whole.

Sincerely,
Ramona Jalomo



Make this 4th of July
different than the others.

This 4th of July make a promise
to yourself to always fight against
violence and injustice in the society.

May you have a Promising
4th of July.

Specialty Pharmacy 340 (B) PROGRAM



Welcome to Brothers Healthcare 340 (B) Program

Our dedicated care team *specializes* in supporting the bleeding disorders community.

Brothers Specialty Pharmacy care model includes:

- Assist with high-needs patients; responsive communication, social work and nursing coordination.
- Convenient single point of contact for patients' pharmacy needs.
- Working as an extension of your team, our program will increase the operational efficiency of your staff.
- Secure and documented Inventory management system to support audit requirements.
- Program promotion at local and national events.



We're here to help

We look forward to scheduling a consultation with you to discuss how Brothers Healthcare can better serve you and your pharmacy program.

Ian Corona

Director of Sales & 340 (B) Programs

(775) 741-0004

ian@brothershealthcare.com



Please call us to discuss how Brothers Healthcare can support your 340 (B) growth plans.

BROTHERSHEALTHCARE.COM

HAPPY

Father's Day

My Dad

Mi papá

My dad is as cool as _____
Mi papá es tan genial como _____

My dad is as strong as _____
Mi papá es tan fuerte como _____

My dad is as handsome as _____
Mi papá es guapo como _____

My dad is as funny as _____
Mi papá es tan gracioso como _____

My dad is as nice as _____
Mi papá es tan bueno como _____

My dad is as smart as _____
Mi papá es tan inteligente como _____

