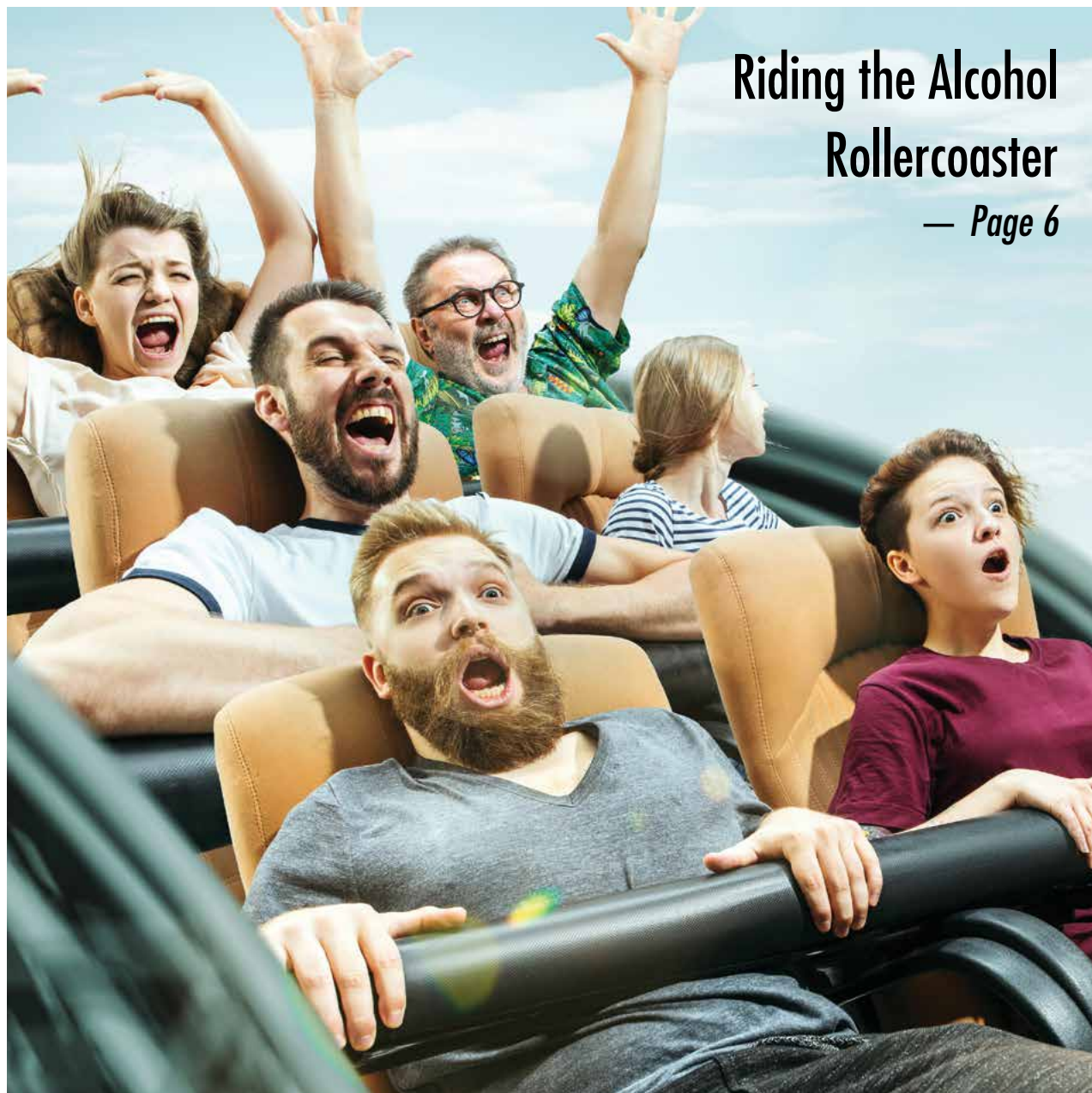


# INFUSING

# LIFE

BONDED BY BLOOD | FALL 2023



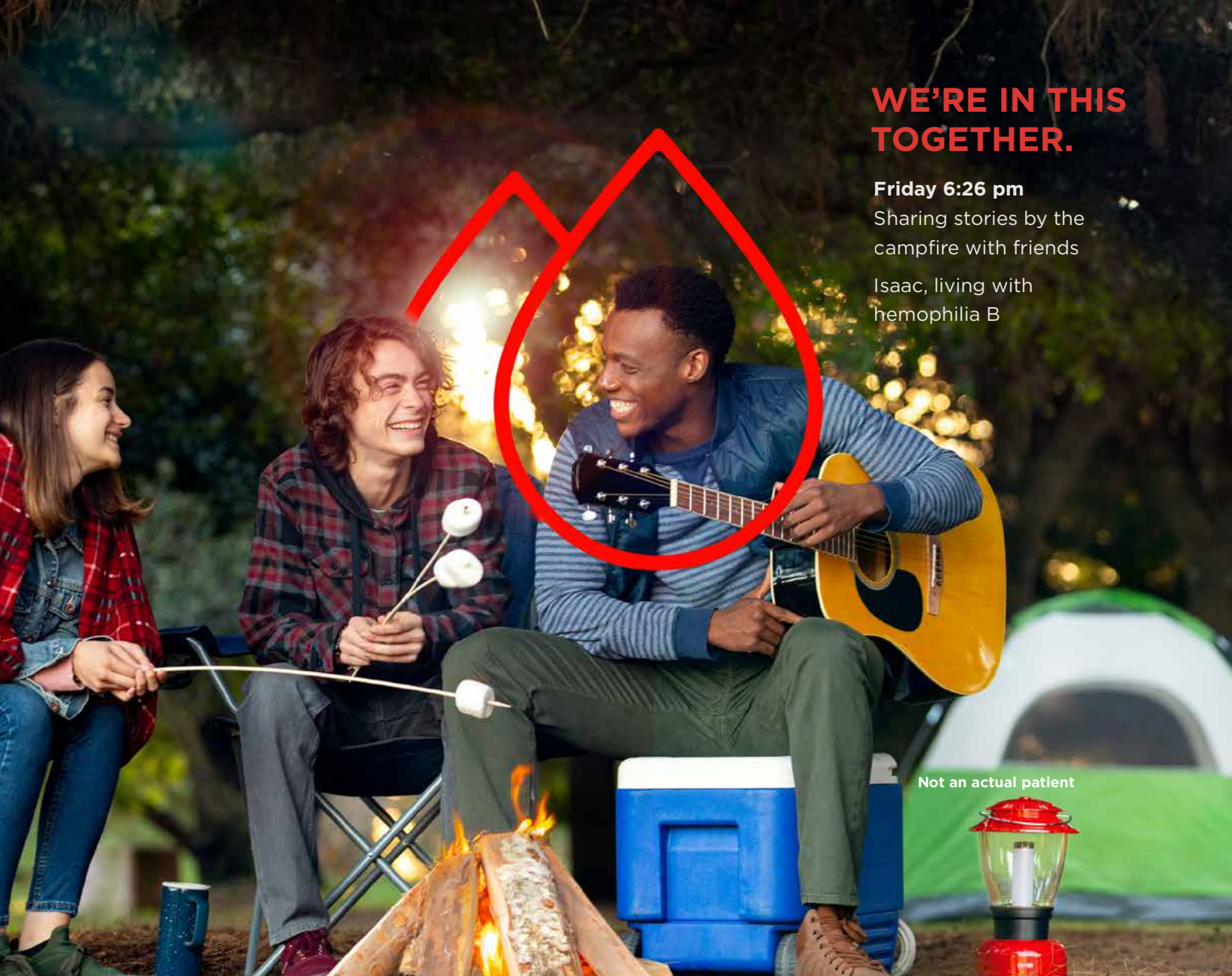
## Riding the Alcohol Rollercoaster

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Riding the  
Alcohol Rollercoaster

Hemophilia  
Educational Plan

Message from  
the Editor



## WE'RE IN THIS TOGETHER.

Friday 6:26 pm

Sharing stories by the campfire with friends

Isaac, living with hemophilia B

Not an actual patient

### Let's make today brilliant.

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

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# FROM THE EDITOR

As the vibrant hues of autumn sweep across the horizon, we welcome you to the latest edition of our Specialty Pharmacy Quarterly Newsletter, *Infusing Life*.



Stay healthy and safe,  
—Kelle Carthey, RN  
Editor

In a world where information is key, this issue aims to unlock insights and knowledge that empower both patients and caregivers on their unique medical journeys.

In “Riding the Alcohol Rollercoaster: Navigating Risks for Bleeding Disorder Warriors,” we delve into an often uncharted territory – the intersection of bleeding disorders and alcohol consumption. Our experts provide a nuanced exploration of the risks and considerations, arming our community with information to make informed choices. Meanwhile, “Back to School Creating an Educational Plan for a Child with Hemophil-

ia” extends a guiding hand to parents and educators alike, helping them craft an educational journey that nurtures and safeguards the well-being of these young learners.

As the world continues to evolve, we acknowledge the currents of change around us. Current events shape our perspectives, and we must adapt with grace and knowledge. Looking ahead, we eagerly anticipate the dawn of a new year, brimming with promise and the potential for growth. Our commitment remains resolute – to serve you with articles that enlighten, stories that inspire, and information that strengthens. 🌊



## INFUSING LIFE

Fall 2023

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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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**HOW?**



**WHY?**

**WHEN?**

**WHO?**

**WHERE?**

**WHAT?**

**Hemophilia**

# Educational Plan

As a parent of a child with hemophilia (and a wife of 18 years to a man with severe hemophilia), I've come to realize that looking out for our kids involves more than just taking care of them at home. It means being their advocate even when they're at school, where they spend a big chunk of their day. Figuring out the ins and outs of raising a child with a bleeding disorder has shown me that one of the most important hats I wear is making sure my kiddo is safe, happy, and thriving in their school environment. That means having some open conversations about hemophilia, its treatments, and what we're hoping for at school. Talking about medical conditions isn't always a walk in the park, but I truly believe that sharing info and working together is key to making school awesome for my child and others like them.

My goal is to help you go into a meeting at your school with not just the necessary knowledge but also a plan for how to present it in such a way that everyone involved learns from it and acts on it. To help you organize a productive meeting with your child's teachers, we've provided a sample agenda for such a conference.

In addition to the Educational Plan it is equally important to create a 504 plan for your child, should they ever need accommodations at school due to bleeding episodes. You will find additional online resources and ideas to help develop 504 plan at the end of this article.

Together, let's make sure our kiddos have the best school experience ever!

## Educational Plan Hemophilia

### Awareness and Treatment Guidelines

- Explain the purpose of the plan: to provide information about hemophilia, its treatments, and expectations for the school to ensure a safe and supportive environment for the child with hemophilia.

### Understanding Hemophilia

- Define hemophilia (keep it simple, use a print out or infographic you found online)
- Briefly explain the genetic nature of the disorder.
- Highlight the primary issue: reduced clotting factor production and its impact on bleeding. Explain in very simple terms the causes and

types of bleeds your child deals with the most. This might mean: the difference between internal bleeds, external bleeds, and joint/muscle bleeds. Finally, explain the possibility for multiple days/weeks of treatment and the pain associated with bleeding episodes.

### Impact on Daily Life

- Describe the potential challenges the child may face due to hemophilia.
- Emphasize the importance of prevention, monitoring, and quick response to bleeds.
- Describe your personal experience with your child.

### Hemophilia Treatment Overview

- Provide an overview of the treatment your child is receiving.
  - › Clotting factor replacement therapy (IV or Sub Q, port or vein)
  - › Whether your child is on Prophylactic or on-demand treatment (or both)
  - › Role of a medical provider in treatment decisions.

### Emergency Procedures

- Outline what constitutes a medical emergency related to hemophilia (e.g., severe bleed).
- Detail steps to take in case of a bleed or emergency: **EXACTLY WHAT YOU WANT THEM TO DO.**  
**CALL PARENT ALERT THEM OF THE SITUATION.** Provide further instructions to the school.



- › Contacting medical provider and emergency contact.
- › Administering clotting factor infusions as instructed by medical provider. (Are you keeping treatment at school or bringing it with you?)
- › Communicating with school staff and transportation personnel.

### School Accommodations and Expectations

- Discuss the need for awareness among school staff about the child's condition. This is usually the primary teacher, PE and yard supervision staff, school counselor, and principle.
- Highlight specific accommodations that can be beneficial:
  - › Frequent restroom breaks to avoid extended sitting.
  - › Seating near exits to facilitate quick movement.
  - › Participation in safe PE activities; possible exemption from high-impact and contact sports.
  - › Accommodations if needed for mobility problems
  - › Extra time on assignments/home studies when treating bleeding episodes
  - › Stress the importance of open communication and collaboration between parents, medical providers, and school personnel.

### Training and Education

- Emphasize the need for training school staff on hemophilia awareness (and be prepared to help facilitate a meeting at school with your HTC or specialty pharmacy nurse)
  - › Identifying symptoms of bleeds.
  - › Administering infusions if trained and authorized.
  - › Responding to medical emergencies.
- Suggest involving medical professionals to conduct training sessions.

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# Navigating Risks for Bleeding Disorder Warriors

# Riding the Alcohol Rollercoaster

**“The link between alcohol and mental well-being is no joke...”**

Imagine facing the challenges of bleeding disorders like hemophilia and von Willebrand disease (vWD). These conditions disrupt the body’s natural clotting process, leading to prolonged and heavy bleeding even from minor injuries. Now, picture how something as common as alcohol can intertwine with these challenges, creating a web of risks and complexities. But don’t worry, we’re about to dive deep and unravel the connections.

### **A Tango of Risks: Alcohol and Blood Pressure**

Although excessive alcohol use is generally discouraged, persons who have bleeding disorders are particularly at risk. You see, not only does alcohol crank up blood pressure, but it also ramps up bleeding tendencies — a risky recipe for those already navigating the challeng-

es of bleeding disorders. The intricate tango between alcohol and heightened blood pressure adds another layer to the complex risks faced by these individuals. In fact, studies reveal that individuals with hemophilia, when compared to their peers in the wider population, often grapple with higher rates of hypertension and elevated blood pressure. But that’s not the end of the story — liver health is

also in the spotlight, with the possibility of alcohol further aggravating the already delicate matter of liver disease.

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### **How Alcohol Elevates the Odds of Injuries**

Let’s get real for a moment — excessive alcohol and bleeding disorders are a pairing that requires some serious attention. You know how they say hindsight is 20/20? Well, it turns out that alcohol has a knack for messing with our judgment, and that’s where things start to get dicey. Ever heard of the *National Institute on Alcohol Abuse and Alcoholism*? They’ve got some stats that might make

you rethink your next drink — alcohol plays a role in a whopping 40% of fatal motor vehicle accidents, not to mention 60% of fatal burn injuries, drownings, and falls. Yikes, right? Now, imagine the scene when you're dealing with a bleeding disorder — the stakes just shot through the roof.

But hey, let's chat about a familiar foe for a moment — joint bleeds. They're the ultimate party crashers in the lives of folks with hemophilia, causing chronic pain and giving the term "disability" a whole new meaning. Picture this: joints taking a hit, joint linings wearing away, and bam, you've got yourself a VIP pass to hemophilic arthropathy, the grandmaster of arthritic troubles. Now, let's add a twist — alcohol's not just messing with our sense of judgment; it's also having a party in our brains. The result? The risk of those unfortunate falls, injuries, and balance issues just got an unwelcome boost.

So, when the universe serves up a cocktail of alcohol and bleeding disorders, it's time to show some smarts. Because who needs those risky moves on the dance floor when your health is the real star of the show?

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## Between Cheers and Choices: Navigating Alcohol's Impact on Decisions and Treatment Regimes

Okay, let's have a little heart-to-heart about binge drinking, especially for folks with bleeding disorders. Now, we're not just talking about the usual aftereffects that everyone knows — there's more to the story.

So, imagine this scenario: you've had a couple of drinks, and suddenly your judgment's

doing a funky dance. Yep, alcohol's notorious for this, and guess what? Bad choices might just be waiting in the wings. Suddenly, you're in the danger zone, walking on the tightrope of mishaps and potential injuries. But hold on, there's more! Your treatment routine could also get caught in the crossfire. Alcohol messes with your decision-making skills, making it a real challenge to stick to those all-important medication schedules. It's like trying to navigate a maze blindfolded — tough and confusing.

And here's the kicker: skipping out on those preventative infusions? Not such a great idea. It's like missing a key step in a recipe — you might not notice it right away, but down the line, things could get messy. Bleeding issues could sneak up on you, and next thing you know, you're facing a health hurdle you could've dodged.

So, when it comes to the party scene, it's time to play it smart. Because who needs to deal with the aftermath of bad choices and missed treatments? When you're rolling with a bleeding disorder, the dance floor is better left for the good times, not the health risks.

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## Beyond the Cheers: Unmasking Alcohol's Toll on Mental Well-Being

So, we've talked about how alcohol shakes hands with bleeding disorders, but there's another layer to this story — the mind. Yep, you guessed it, alcohol doesn't just throw a wild party in your body; it's also got its sights set on your mental well-being. Brace yourself for a rollercoaster ride, because we're diving into the mind-altering effects of alcohol,

especially for those grappling with bleeding disorders.

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## The Mood Shift: Alcohol's Sneaky Effect on Mental Health

Now, here's the scoop: The bleeding disorders community is proven to have depressive tendencies and for good reason. The mental load of dealing with bleeding, injuries, isolation and infusions is tough. We're talking anxiety, despair, and stress — they can all get a little crazier when alcohol's in the mix. Imagine this: you're already juggling the challenges of a bleeding disorder, and suddenly, alcohol decides to join the party, making these mental struggles even more pronounced. It's like adding extra weight to a barbell you're already lifting.

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## Vicious Cycle Alert: Alcohol and Your Mood

Here's the kicker — alcohol and mental health can form quite the dynamic duo, but not in a good way. You see, some folks might turn to alcohol as a temporary escape from their mental struggles. But guess what? In the long run, alcohol can be that party crasher that makes

things worse. It's like inviting chaos into a calm room.

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## So, What's Next?

Alright, so now you're probably nodding along, recognizing a thing or two. But hey, chin up, there's a lot you can do about it. Ready to tackle this head-on?

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## Crafting a Safe Path: Navigating Informed Choices

Sure, the dance between alcohol and bleeding disorders is complex, but there's a method to the madness. **Check out these tips to steer clear of the danger zone:**

**No Pressure to Sip:** Trust us, you don't need alcohol to have a good time. Next time you're out, opt for "mocktails" or non-alcoholic beverages — they're just as fun minus the risk.

**Plan for Fun:** If you do decide to sip, set your limits and always have a designated driver in tow. Oh, and that medical alert ID? It's your superhero cape in case of emergencies.

**Open Up:** Letting your close pals know about your bleeding disorder is key — especially

*Continued on page 9*



## Regular Communication

- Highlight the importance of ongoing communication between parents and school:
  - › Updates on treatment plans or changes.
  - › Sharing emergency contact information.
  - › Addressing any concerns or questions.
  - › Discussing how your child is feeling and how mental health is affected during difficult bleeding episodes

## Parental Responsibilities

- Outline the parents' role in ensuring the child's well-being at school:

- › Providing updated medical information.
- › Promptly informing the school about changes in treatment or condition.
- › Collaborating with the school to address the child's needs effectively.

## Review and Revision

- Specify the frequency of plan review to ensure its effectiveness.
- Explain the plan's flexibility in adapting to the child's changing needs.

## Conclusion

- Reiterate the shared goal of providing a safe and supportive educational environment for the child with hemophilia.



- Express appreciation for the school's partnership in achieving this goal. 🏆

## Creating a 504 plan online resources

[https://www.hemophiliaca.org/wp-content/uploads/2020/02/HFSC-Listof-504-Accommodations-2018-09-03\\_V01-01.pdf](https://www.hemophiliaca.org/wp-content/uploads/2020/02/HFSC-Listof-504-Accommodations-2018-09-03_V01-01.pdf)

<https://hemaware.org/life/back-school-what-are-ieps-and-504-plans-and-how-can-they-help-child-bleeding-disorder>

[https://stepsforliving.hemophilia.org/sites/all/themes/stepsforliving/pdf/504\\_accommodation\\_plan.pdf](https://stepsforliving.hemophilia.org/sites/all/themes/stepsforliving/pdf/504_accommodation_plan.pdf)

# 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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when alcohol is in play. Think college roommates, drinking buddies, and anyone who needs to be in the know. Safety first, right? It can literally save your life.

---

## Raising Your Glass to Change: A Refreshing Approach

Feeling inspired? Great! It's time to embark on a journey of reevaluating your relationship with alcohol. **Consider these options:**

**Sober Curious Lifestyle:** Ever heard of this one? It's like a trial period without alcohol — a chance to see how life changes when you're not raising a glass. New experiences, new fun, and no booze required.

**Damp Lifestyle:** If quitting alcohol entirely isn't your jam, that's cool too. A "damp" lifestyle means drinking in moderation, keeping it chill and mindful. It's all about finding your balance.

Now that you have some options for slowing down the alcohol train, it's only proper that you know the goodness to come!

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## Physical Upgrades:

**1. Hello, Healthy Liver:** So, turns out, when you give your liver a break from alcohol, it's like a mini vacation for it. Your liver gets to do its job better and keep you feeling tip-top.

**2. Shedding the Pounds:** Guess what? Those sneaky calories hiding in alcoholic drinks? They can make you feel like you're carrying extra baggage. But cut back on the drinks, and you might just



wave goodbye to some of that weight.

**3. Sweet Dreams:** Ever heard the phrase "sleeping like a baby"? Well, alcohol can mess with that. When you cut down, you're not just waving goodbye to those late-night shenanigans; you're saying hello to better sleep and waking up feeling refreshed.

**4. Heart Happiness:** Your ticker deserves some love, right? Well, less alcohol can mean lower blood pressure and a happier heart. It's like a hug for your cardiovascular system.

**5. Immunity Boost:** Picture this — a superhero shield for your body. Yep, that's what cutting out alcohol can do for your immune system. Fewer sick days and more feeling awesome? Sign us up!

---

## Mental Magic:

**1. Anxiety Out the Door:** We've all been there — stress and anxiety get the best of us. But guess what? Less

alcohol can mean less fuel for those worries, leaving you feeling more Zen.

**2. Brain Power Unleashed:** You know those moments when you feel like your brain's hitting snooze? Well, without alcohol throwing a party in there, you might find yourself thinking clearer, making better choices, and nailing that memory game.

**3. Happy Feels:** No one likes being on an emotional rollercoaster. Well, cutting back on alcohol can help stabilize your moods, so you're not going from laughing to crying in a flash.

**4. Rock-Solid Relationships:** Ever had one too many and said something you regretted? Yeah, us too. By cutting back, you're not just doing yourself a favor; you're also making sure your relationships stay rock-solid.

**5. Supercharge Your Day:** Ever wished you had more hours in the day to get stuff done? Well, alcohol can throw a wrench in those plans.

But with less of it, you'll find yourself more motivated and ready to tackle anything.

Just remember, these changes can vary from person to person, and it's all about finding what works for you. If you're thinking about cutting back on alcohol, a friendly chat with a healthcare pro can be a great idea — they're like your health's personal cheerleaders!

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## Conclusion: Cheers to Your Well-Being

And there you have it — a peek into the world of alcohol and bleeding disorders that's more than just surface-level. The link between alcohol and mental well-being is no joke, but hey, you've got this. By embracing a new perspective on alcohol and exploring alternative approaches, you're taking charge of your health and happiness. So, here's to informed choices, mindful sips, and a journey that leads you to a place of well-being that's all your own. Cheers to you! 🍷



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