

INFUSING

BONDED BY BLOOD | SUMMER 2021



NEW MINDSET



NEW RESULTS


Resilience and
Growth in 2021

The Growing
World of CBD

The Importance of
Self Infusion

The Integrated Care Team,
Specialty Pharmacy,
HTC's and Beyond

Clinical Corner:
Power of Prophecy



A Pharmacy Specializing in You.

Complex Home Infusion Therapies & Patient Management

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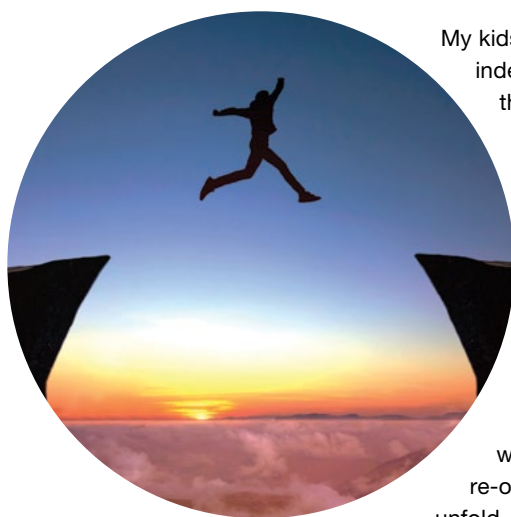
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FROM THE EDITOR


Taking the leap! This leap is a biggie, back to our “old” lifestyles, pre-covid. If I’m honest, I’m scared. I enjoyed the quarantine bubble more than most. I’ve loved having my family united under one roof, REAL quality time together, less spending, less constantly doing.



// Please get out, enjoy life, and appreciate what we have!”

My kids are more independent now than ever. We used the time at home to learn how to cook, do laundry, study independently, and even practice self-infusion. Now, we are heading back into the world, watching the re-opening process unfold, while trying to re-integrate all the things that can sometimes make life hurried and complicated. As we all move forward, I encourage you to hold on to the parts of the quarantine that you enjoyed. Take notice of all the good and bad lessons we “learned the hard way” and hold on to them. Let them guide you as our world re-opens. I know I’ll be holding on to some (like our new family Sunday baseball game and working out in my garage) and letting others go (like our kids not spending enough time with their friends). I can already feel the warm

weather of summer coming. With that, a compounded appreciation for safety, active living, being social with friends, loved ones, and more. So please get out, enjoy life, and appreciate what we have!

In this issue of Infusing Life, and as we get back to our active lifestyles, we are all about resilience and growth. In our Clinical Corner article, we evaluate the Power of Prophylaxis treatment for the bleeding disorders community through the eyes of both a patient and a provider. We discuss self-reliance through independent self-infusion with our social worker and how CBD can help you stay active by helping to treat pain and anxiety. We suggest healthy living through yoga and finally, we explain how Brothers keeps you moving forward as we work in concert with the different industry partners to bring you the best care possible. I hope you enjoy this issue of Infusing Life! 

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



INFUSING LIFE
SUMMER 2021

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POWER OF PROPHY

Interview and facts by Maydeen Merino

Prophylaxis treatment can help you regulate your bleeding disorder, so you have the opportunity to live an active life. Still, exactly what severity of bleeding can use prophylactic treatment, and what results have others gained through this method? Brothers Healthcare has interviewed Amber Federizo, a Nurse Practitioner at the Nevada Hemophilia Treatment Center. Federizo provided immense information about prophylaxis treatment so individuals can better understand the medication.

ABOUT PROPHYLAXIS TREATMENT

Before prophylaxis treatment was readily available, it may have been challenging for someone with a bleeding disorder to continually be active, whether in organized sports or just playing outside with friends. “They would avoid activities that may predispose them to injury, ultimately limiting their experience of life and predisposing them to conditions such as obesity.

In short, they would avoid life,” Federizo said.

So exactly who can use prophylaxis treatment? Regardless of the severity level, an individual can consider using prophylactic treatment. Most times, this treatment is individualized for the patient. “If bleeding is occurring with such frequency that it is impacting activities of daily life and the quality of life one experiences, prophylaxis should be considered regardless of the level of deficiency,” Federizo said. The typical age to begin

using prophylactic treatment varies. Today, many children are beginning treatment early to ensure effective remedies and prevent traumatic medical experiences. “We used to aim to start after the first bleed or around 12 months of age. However, we have progressed to starting before the first bleed to avoid the opportunity for that first bleed to set the stage for that joint,” Federizo said.

There are several ways children are taught about prophylactic treatment, which could be at home infusion training classes or attending hemophilia/bleeding disorder summer camps. Prophylaxis treatment can benefit an individual who has the desire to become more active. The treatment can also help prevent injuries and protecting the joint’s health. Also, Federizo explained that patients with inhibitors are available and should be offered prophylactic treatment.

“Without the community, prophylaxis and its possibilities may have never advanced at the swiftness that it did. This community ensures that no one is left behind and that those who go ahead face a better life. In any stage of life, through any adversity, this community is there,” Federizo said.

FIRSTHAND EXPERIENCE USING PROPHYLAXIS

Today, many individuals start prophylaxis treatment at a relatively young age. Scott Carthey, the founder of Brothers Healthcare, began treating prophylactically at 12 years old. However, before Carthey had the opportunity to use the prophylactic treatment, he would have to treat “on-demand.”

“I would treat episodically or “on-demand” as most know it. My parents started doing my infusions, or “shots” as we would call them at home when I was three years old. Before

“It is nice to do physical activities without hesitation or worry that I might get a bleed and be out of the game for any given period.”

“Prophylaxis treatment can benefit an individual who has the desire to become more active.”

that time, we would go to my hematologist's office,” Carthey said. He recalls waiting at the hematologist's office for a long time just so the nurse can do his infusion. However, when he had the opportunity to treat prophylactically at home, he and his parents were excited. Although, in the beginning, it was challenging to find a vein, it was worth the struggle.

Before prophylaxis treatment, life was challenging because Carthey was never sure when his next bleed would emerge. “Before prophylaxis became the standard of treatment, there were certainly challenges. I would often question myself on whether or not I had a bleed. There would be times when I did not think that I had a bleed when in fact, I did, and by the time I figured it out, the bleed

was bigger and more painful,” Carthey said.

Beginning prophylactic treatment at an early age would have been ideal for Carthey because it would have simplified his life. He explained that it would have prevented damage to his joints and allowed him to play sports. “I held back from playing as hard as I would want to and sometimes did not play at all because if I went all out, it would often result in getting a bleed,” Carthey said.

Once undergoing prophylactic treatment, maintaining a schedule was challenging, but he was motivated to prevent bleeds, Carthey explained. Taking factor prophylactically was a life-changing decision for him, allowing him to live an active lifestyle. “It is nice to do physical activities without hesitation or

worry that I might get a bleed and be out of the game for any given period. It also gives me peace of mind to know that further damage is not being caused to my joints,” Carthey said.

Carthey suggests that families beginning prophylactic treatment should try to involve their child with the infusion process based on their age. He provides examples such as having a younger child help unpack their factor and infusion supplies, while older child can take it one step further and mix their factor.

“Involving your child in the process before the actual needle poke may help ease their anxiety and help the infusion process go smoother. It will also help you get your child one step closer to doing their infusions from start to finish and gaining indepen-

dence,” Carthey said. He would also recommend having a friend, mentor, or big brother from the bleeding disorder community that you can call on for advice or emotional support if things get challenging. “Like anything you do for the first time, learning to infuse prophylactically will take time, so be patient with yourself and your child,” Carthey said. “Also, it never hurts to help motivate your child with a reward for a job well done.” Carthey suggests that once you get the routine down, it becomes easier over time for someone hesitant about treating prophylactically. It can feel empowering to take control of your bleeding disorder, he explained.

“If you have not already spoken to your hematologist about prophylaxis, I highly suggest you do. Taking just a few minutes in the morning to take your factor can save your life, improve your muscle and joint health and give you one less thing to worry about,” Carthey said. 🐉



Navigation



Fire



Headlamp



Shelter



Sun Protection



Food



First Aid



Water



Knife



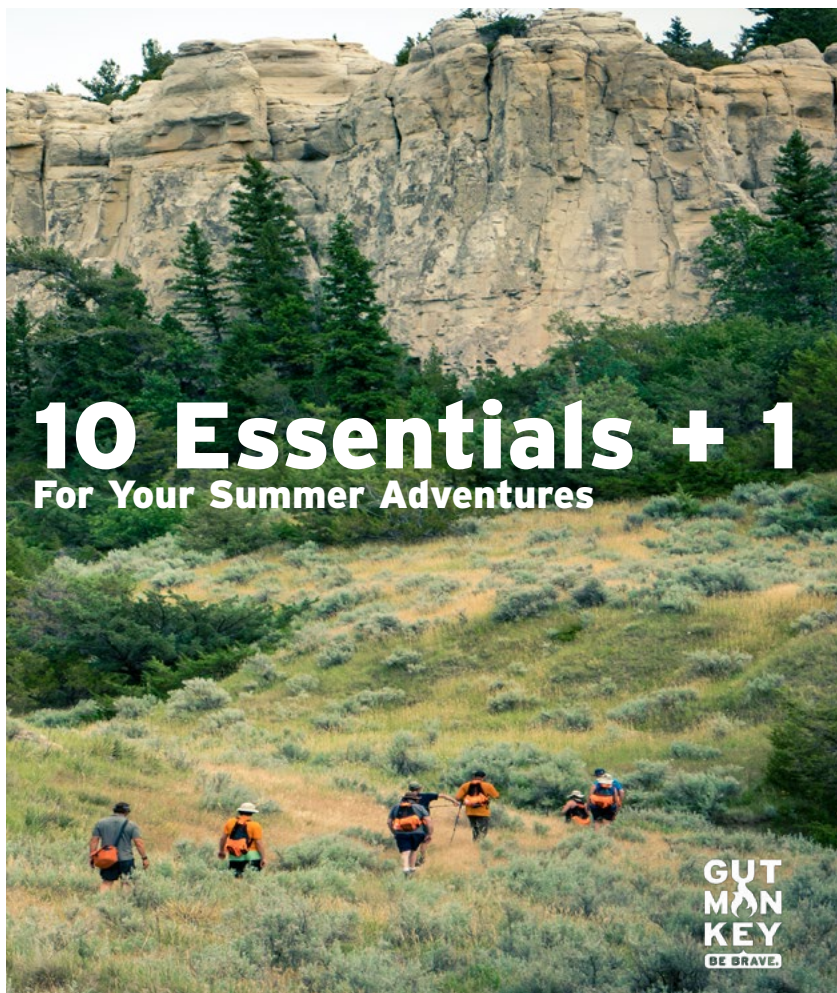
Clothes



Medication

Here's a friendly reminder to play safe in the outdoors this summer. We're all excited to get outside and make the most of the warm weather. Be responsible and pack these 10+ Essentials the next time you venture off the beaten path. Remember to carry with you any important treatment supplies and know how to use them.

GutMonkey provides live and virtual experiential education for the Bleeding Disorders Community. Between keynotes, expeditions, and summer camps, we're ready for a brave and safe summer. Visit GutMonkey.com to learn more.





Yoga Shmoga...

THE TIME IS NOW

By Maydeen Merino

BEING ACTIVE AND EXERCISING IS AN ESSENTIAL HABIT FOR ANYONE'S HEALTH. HOWEVER, SOME MIGHT NOT BE INTERESTED IN HIGH-INTENSITY WORKOUTS SUCH AS WEIGHTLIFTING, CROSSFIT, OR HIIT (HIGH-INTENSITY INTERVAL TRAINING). YOGA CAN HELP SOMEONE STAY ACTIVE AND HEALTHY IF THEY PREFER SOMETHING WITH LOW-IMPACT TRAINING.



“WIDE RANGE OF YOGA PRACTICES SUGGESTS THEY CAN REDUCE THE IMPACT OF EXAGGERATED STRESS RESPONSES AND MAY BE HELPFUL FOR BOTH ANXIETY AND DEPRESSION.”

According to Well and Good, there several popular styles of yoga which include:

- **Ashtanga yoga** is an athletic yoga style, focusing on sun salutations and nine seated positions, a section of hardcore abs, plus inversions.
- **Hatha yoga** is simply any yoga style that involves movement using asanas (body posture) and breathing—combining to create a meditative state.
- **Hot yoga** can be any yoga practiced in a warm climate. The goal of this yoga practice is to increase the intensity and detox the body.
- **Iyengar yoga** is a style that emphasizes alignment and deepening your self-awareness by holding a sequence of standing and seated asanas for several breaths.
- **Kundalini yoga** combines postures, movement, sound currents, breath-work, and meditation into powerful sets.

(<https://www.wellandgood.com/most-popular-yoga-styles-explained/>)

WHAT IS YOGA?

“Yoga is an ancient and complex practice, rooted in Indian philosophy. It began as a spiritual practice but has become popular as a way of promoting physical and mental well-being,” according to the National Institute of Health.

The practice of yoga focuses on several critical elements, including breathing techniques, posture, and meditation. Since yoga is an ancient philosophy, many variations of yoga practices have emerged.

from stiff joints or chronic pain. Yoga can be an excellent choice of exercise due to the practice being low-impact. Since yoga mainly focuses on an individual’s muscles and flexibility, it can relieve some chronic pains or prevent injuries.

Individuals with a bleeding disorder might endure some challenges throughout life, in addition to life’s regular stresses. Yoga is a practice to help de-stress and improve mental health. Since the practice consists of focusing on the breath, it helps relax the mind and the body.

“Wide range of yoga practices suggests they can reduce the impact of exaggerated stress responses and may be helpful for both anxiety and depression. In this respect, yoga functions like other self-soothing techniques, such as meditation, relaxation, exercise, or even socializing with friends,” according to the Harvard Medical School.

Other benefits of yoga include relieving low-back pain, neck pain, tension type-headaches, knee osteoarthritis, weight loss, and chronic disease.

HOW TO PRACTICE YOGA?

If you are a beginner yogi or someone curious about yoga but not sure where to start, there are a couple of ways to begin your yoga journey. Pre-pandemic, there were many yoga classes available at gyms or yoga studios.

However, since most individuals are still staying away from

crowds, some gyms and studios offer virtual yoga classes for all levels—a great choice for individuals trying to learn yoga at home. Many yoga instructors and studios have created apps and /or YouTube channels, where individuals can watch yoga videos, learn and follow along. The benefit of practicing yoga at home allows you to go at your pace and the comfort of your own space. Some great resources with free trials to try are the Pelaton app (that’s right, for YOGA!), Corepoweryoga.com, and YouTube. You can even find videos of yoga routines you can practice during specific types of the day. For example, there are morning or bedtime yoga routines that can provide you with a healthy routine throughout the day.

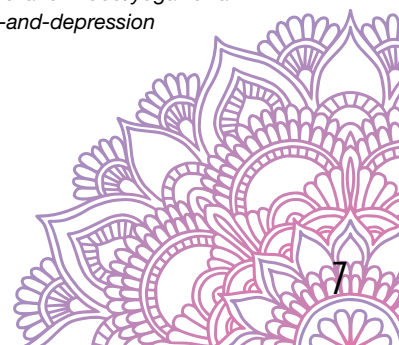
For more information about starting yoga at home, visit: <https://www.gaiam.com/blogs/discover/think-outside-the-studio-starting-a-home-yoga-practice>

However, before beginning your yoga journey, it is essential to speak with your physician to ensure this journey will benefit your overall health. 🌀

Reference:
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HOW CAN YOGA BENEFIT SOMEONE WITH A BLEEDING DISORDER?

There are several reasons why yoga can be beneficial for someone with a bleeding disorder. Typically, individuals with a bleeding disorder might suffer



Importance of Self Infusion

By Veronica Diaz

For Parents

Children are observant. They learn by watching their parents and the adults around them. Since bleeding disorders such as Hemophilia are life-long conditions, it is vital for individuals to learn how to self-infuse. It is a rite of passage for some and plays an essential role towards independence.

There is no definitive age to learn how to self-infuse; every child is different. It is essential to teach them as they grow, watching for their interest in learning, maturity level, and taking care to move at their readiness pace. When they are prepared to learn, they will start to ask questions and be interested or excited to help you set up for the infusion.

Tasks that can help your child learn about their medical condition and the infusion process include:


- Teach him/her the name of the supplies needed to self-infuse.
- Let the child help set up the infusion station.
- Allow them to mix their medication.

- Attend summer camp. They will meet others who have similar experiences as they do, which can motivate them to take on self-infusion.
- Allow your adolescent child to help fill out the paperwork when you visit the Hematologist. This will help them learn and become familiar with the information they will need to know when they get older.
- Encourage your child to express their concerns about their medical condition, or medication, listen to them, and encourage them to express their concerns to their Hematology team.

If you believe that your child is ready to learn how to self-infuse, speak to your Hematologist or your specialty pharmacy advocate to get the process started.

For Teens


There are many good reasons to learn how to self-infuse. For some people, learning how to infuse medication independently is scary and daunting, and for others, it's exciting. No matter how you feel about it, learning how to self-infuse will help you become self-reliant, a significant part of growing up. One of the most important reasons for learning self-infusion is in case of emergencies. For example, as you get older, spend more time away from your parents, and do things on your own, it's possible that you may have an emergency. Suddenly, knowing how to talk about your condition with others and infuse factor becomes a vital life skill that you will be grateful that you were ready for. Preparation for emergencies is a crucial element to keeping you safe and healthy throughout your lifetime. If you would like to learn how to infuse, speak to your Hematologist or your specialty pharmacy advocate to get the process started.



**ARE YOU
READY?**

In addition to learning how to infuse your medication, it will be helpful to know the following information about your bleeding disorder:

- What are the name and phone numbers of your Hematologist? Your specialty pharmacy advocate?
- What medical condition do you have? If applicable, what is the severity?
- What medication do you use? What is your dose?
- Are you allergic to any medication?

If you had trouble answering these questions, ask your parents and make it a goal to learn the answers to these questions. You never know when it will come in handy. Learning about your medical condition and learning how to infuse will help you on your way to becoming an independent adult. 

The Growing World of

CBD

What You Need to Know

You may have heard of CBD, maybe even recommended CBD products already. However, before using CBD, you should understand the science, benefits, and side effects of using CBD, and always consult with your physician.

What is CBD?

CBD is short for Cannabidiol, a chemical compound found in marijuana. It does not contain the chemical tetrahydrocannabinol (THC) that produces a high. Much of CBD is extracted into oil but can also be vaporized liquid or oil-based capsules. Many products such as food, drinks, beauty, and even pet products can be infused with CBD. Products containing CBD have become relatively popular. According to Statista in the U.S., consumer sales of Cannabidiol (CBD) will reach around 1.8 billion dollars by 2022.

Is CBD Legal? Many laws referring to marijuana vary from state to state. It is essential to check the laws in your state on regulations of marijuana products. However, many more states are beginning to become lenient about the plant.

What Are the Benefits of CBD for People with a Bleeding Disorder?

What benefits can an individual with a bleeding disorder



gain from CBD products? CBD can be used to overcome several symptoms such as insomnia, anxiety, and chronic pains. Like many with a bleeding disorder, you might be suffering from chronic pain within the joints. CBD is a product you may want to consider to help relieve some pain.

“CBD applied on the skin could help lower pain and inflammation due to arthritis. Another study demonstrated the mechanism by which CBD inhibits inflammatory and neuropathic pain, two of the most difficult types of chronic pain to treat,” according to Harvard Health.

Our bodies contain a system called the endocannabinoid system. The system consists of neurotransmitters regulating functions such as sleep, appetite, pain, and immune system response. A study has shown that CBD interacts with these

neurotransmitters to reduce pain or inflammation by the Journal of Pain Research.

According to the Journal of Pain Research, patients with chronic pain and their health-care provider work together through first and second-line treatment modalities without success. A trial of cannabis or a cannabinoid may be a reasonable next step.

CBD products have the potential to replace over-the-counter painkillers, depending on the pain severity. There are many downsides to using painkillers/opioids, such as depression, addiction, weakened immune system, and many more.

What are the Side Effects of CBD?

Although using CBD is typically sustainable to many, it is essential to speak with your doctor before deciding to use

a CBD product. Some side effects may include diarrhea, fatigue, and a change of appetite. CBD can interact with several different medications as well.

If you take medications or supplements that come with a “grapefruit warning.” Both grapefruit and CBD interfere with cytochromes P450 (CYPs), a group of enzymes essential to drug metabolism, according to Healthline.

Overall, CBD oil can provide an individual with a bleeding disorder with many benefits. There have been studies to prove the oil can ease several symptoms and reduce chronic pain. Recent studies also find the oil to be safe to use. However, it is essential to speak with your physician before using the oil and conduct some research about each CBD oil product, as some may include THC. Instead of using painkillers and non-natural medications, CBD is a way of replacing harmful products by using a natural holistic product of healing the body. 🌿

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SCHOLARSHIP WINNERS

Brothers Healthcare is proud to present the **Brothers Healthcare scholarship winners of 2021**. Each of the recipients will receive a \$1000 dollar scholarship to aid in the expense of furthering their education. We are very proud to support the bleeding disorders community and are already looking forward to next year's applications.




Aidan Blakla is from Philadelphia, Pennsylvania where he

attends Holy Family University and is pursuing a bachelor's degree in nursing. Aidan is an honors student and has made the Dean's list the last 4 semesters. Aidan carries a diagnosis of Von Willebrand's Disease, type 1. He hopes to one day work with children with bleeding disorders and show them they

can do anything if they put their mind to it. Despite his diagnosis, Aidan does not let that define him or affect his pursuit of a college education. He volunteers at his local community recreation center, tutors elementary school kids, serves meals at the local Ronald McDonald House several times a year, and is involved with the Alex's Lemonade Stand fundraiser at The Children's Hospital of Philadelphia. Aidan is an honest, kind, and hard working young man. In his spare time he likes fishing, playing golf, swimming, traveling with his family, and playing video games.

Emma Rudell a first generation college student and originally from Cheyenne, Wyoming, she will be attending Casper College in Wyoming this fall to compete on the Forensics Team. She is the Wyoming High School Activities Association two-time State Champion in Duo Interpretation and is ranked 5th in the nation for the National Speech and Debate Association in the same event. She is looking forward to continuing speech and debate at the collegiate level and for her home-state. While attending Casper College, she will pursue a degree in Criminal Justice with a strong desire to work for the FBI after her studies have been completed. Her career passion is to advocate and support survivors of sexual and domestic violence while

studying serial rapists. Emma has Von Willebrand's Disease

(severe) and has overcome some pretty serious personal challenges in her young life already. She learned to infuse herself at a young age and helped teach younger children at her summer camps as well as her high school speech and debate coach. She is a very hard worker with a strong drive to succeed in life. In her spare time, she enjoys being creative as a makeup effects artist as well as hiking, kayaking and camping with her family and friends. 



LET'S TALK ABOUT IT!

2021 WEBINAR SERIES

Feeling isolated? Ready to feel connected?

Join us! Brothers Healthcare's very own

Veronica Diaz, LCSW hosts a casual video chat series!

Topics include but not limited to:

- Goal Setting
- Mental Illness in Children
- Healthy Nutrition
- Managing Sibling Dynamics
- 504 and IEP plans
- Signs and Symptoms of Drug Addiction

Dates for 2021:

1/13	7/14
2/10	8/11
3/10	9/8
4/14	10/13
5/12	11/10
6/9	12/8

**All meetings take place at
4:30 PM & 6:30 PM**

To register:

<https://forms.gle/Pv5vidFC1FogGrgL9>



Brothers
HEALTHCARE

The Integrated Care Team, Specialty Pharmacy, HTC's and Beyond...



By Adrian Flores

At **Brothers Healthcare**, our years of experience and dedication have taught us that the management of chronic conditions, such as bleeding disorders, requires an integrative approach to care. Multiple entities must work in concert to ensure that your needs are met, and expectations are exceeded. That is why we are more than your Specialty Pharmacy. We are your advocates for care, and we work with all other elements of your care team so that you may be confident in the service that you receive.

“We will be proactive in advocating for you to make sure your physician is aware of any concerns or questions...”

One of the most vital components in the delivery of your care is your Hemophilia Treatment Center, or the physician treating your bleeding disorder. Your physician—and their team—ensure that you are maintaining an appropriate treatment regimen and will work with you to address any needs or concerns related to your disorder. Occasionally, however, a visit to your physician may not be possible, or you may have so many questions on your mind that one or more might not make it into your discussion with your doctor when you do see them. Many of these questions—“am I treating aggressively enough?”;

“Is my current medication the right one for me?”; “what if I am planning a change in the level of my physical activity?”; to name a few—are sometimes communicated to your Brothers Healthcare patient advocate, after the visit. We understand as we are your touchstone to the rest of your care. Your patient advocate is probably the part of your care team with whom you speak most often. While we cannot offer medical advice, we can document your concerns and incorporate them into your care plan, which is then communicated to your treating physician. Sometimes, a conversation with your Brothers Healthcare patient advocate might bring a concern

to light which you did not realize existed! Again, in this case, we will ensure that the appropriate documentation and communication occurs. As a Specialty Pharmacy and individual patient advocates, we have spent a lot of time building open, trustful relationships with HTC's and treating physicians across the country. We will be proactive in advocating for you and stop at nothing to make sure that your physician is aware of any concerns or questions which might not have made it into your appointment.

Your insurance provider is also an integral part of your care team and can often be the least understood by a patient. It can

feel overwhelming when picking a provider and plan, determining which aspects of your care are covered, and whether or not your benefits are being used in the most efficacious way. We understand, and that is why Brothers Healthcare has built a network of relationships and contracts insurance providers. Our reimbursement team stays up to date on all facets of your coverage and will advocate on your behalf if you encounter concerns with your coverage. Your patient advocate will work closely with our reimbursement team to ensure that you are equipped with all of the informa-

See “Integrated Care” on page 12

“We rely on our experience and vast network of connections with all your care team members to ensure that your patient experience exceeds your expectations and happens as seamlessly as possible.”

“Integrated Care” continued from page 11

tion you need to feel confident in your coverage. Additionally, suppose the reimbursement team determines there is an issue with your coverage or in the application of your coverage. In that case, our long-standing relationships with insurance providers often allow Brothers Healthcare to work with those providers toward a resolution in your best interest.

So far, we have seen how Brothers Healthcare works with your physician and insurance provider to ensure high-quality, efficient delivery of care. When you speak with your patient advocate and confirm your need for an order, the chain of events that ensues behind the scene is a highly fluid and integrative one. Your advocate will submit an order form with your current needs, questions, or concerns to our pharmacy and reimbursement teams. Respectively, these

teams will work with your treating physician to ensure that their plan for your care is current and appropriate and will advise them of any changes or challenges which you might have communicated to your patient advocate. Meanwhile, your insurance coverage will be checked against your current needs so that by the delivery date you have requested, your order from Brothers Healthcare will arrive complete and with the appropriate components to successfully manage your bleeding disorder. The pharmacy and reimbursement teams will communicate these statuses with your patient advocate, who, in turn, will keep you updated.


Brothers Healthcare also establishes and maintains comprehensive working relationships with the manufacturers of your much-needed medications. While we cannot provide you with medical advice, always work with manufacturers

to stay abreast of the latest product developments so that we can equip you with all of the information you need to confidently discuss the most appropriate treatment regimen or product with your physician. We maintain a library of product literature and have open lines of communication with manufacturers so that we can guide you through enrolling in any copay assistance programs offered by the manufacturer (where applicable).

As part of our commitment to the community, the entire team at Brothers Healthcare actively engages with Foundation Chapters and Associations. Our Licensed Clinical Social Worker works with these groups— as we all as with social workers at your HTC—to investigate any available resources which might fall outside of the normal flow of care. These resources might include housing assistance, transportation help, access to

behavioral health resources, or even information on scholarships for those community members looking to further their education.

When one considers this network of relationships behind ensuring your best level of care, the analogy of a well-oiled machine might come to mind. With all of the fluid and dynamic parts of this machine working independently, Brothers Healthcare has worked tirelessly to help coordinate its proper functioning. We strive to be more than your specialty pharmacy. We rely on our experience and vast network of connections with all your care team members to ensure that your patient experience exceeds your expectations and happens as seamlessly as possible. None of this would be possible without the proactive building and fostering of these strong working relationships, from your physician to your insurer, to the manufacturers of your medication and resource groups, such as Foundation Chapters and Associations.

At Brothers Healthcare, our dedication to your care is the driving force behind all that we do. 



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



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