[BIOMATRIX]

NEWS

DEDICATED TO MAKING A DIFFERENCE

SPRING 2021
VOLUME 16 | ISSUE 2

> **“Choose to be optimistic. It feels better.”** — Dalai Lama

VOLUME 16 | ISSUE 2
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ABOUT [BIOMATRIX]

BioMatrix Specialty Pharmacy is removing burden, improving health, and making life easier for patients with chronic, difficult to treat conditions.

BioMatrix offers accredited, comprehensive specialty pharmacy and support services for a range of chronic health conditions. Our clinicians and support staff offer a tailored approach to every therapeutic category, improving quality of life for patients and producing positive outcomes along the healthcare continuum.

Our services include the clinical monitoring, tracking, and management tools required by today's healthcare stakeholders while providing individualized patient support leading to better health outcomes.

MISSION + VISION

The **MISSION** of BioMatrix is to improve outcomes through individualized specialty pharmacy services empowering patients to live each day to its fullest potential.

Our **VISION** is to set the standard for exceptional care, maximizing the health and satisfaction for each patient served.

Our **Mission** and **Vision** are realized through the value we place in our five guiding principles. These principles represent our commitment to our employees, patients, and the community – driving our organization to excellence.

INTEGRITY – Our professionalism, strength, and stability come from our resolve to operate honestly, morally, and with a higher purpose to meet and exceed the expectations of all.

DEDICATION – Our dedication is evident in our close attention to detail, personal touch, and resolve to advocate from the heart, giving each relationship a close family feel.

COMPASSION – We are sensitive to each individual's unique situation. Our ability to listen, empathize, and support those we work with distinguishes our business practice.

ENRICHMENT – We understand that in order to perform at our best, we must always seek to learn and grow while using our knowledge to assist and empower others.

ENTHUSIASM – Our confidence in the services we provide is illustrated by the energy, drive, and passion we exhibit in all we do.

FINE PRINT

Editor-in-Chief: Maria Santucci Vetter
Editors: Susan Moore and Justin Lindhorst

The purpose of BIOMATRIX NEWS is to provide information such as current news, upcoming events, educational matters, personal stories, and a variety of opinions and views on topics of interest to the bleeding disorders community. The information and opinions printed in this newsletter do not necessarily reflect the views and opinions of the partners, employees, or others associated with BIOMATRIX NEWS or that of BioMatrix.

Health-related topics found in BIOMATRIX NEWS are for informational use only and are not intended to take the place of treatment or medical advice provided by healthcare professionals or hemophilia treatment centers. Please consult with healthcare professionals when medical questions arise.

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A NOTE FROM THE EDITOR

Dear Readers:

As more Americans become vaccinated against COVID-19 every day, the light at the end of the tunnel is growing brighter! I miss being out in the community and seeing my bleeding disorders family and friends, and I hear the same from everyone I speak with. The sooner our country reaches herd immunity through vaccination, the sooner organizations and chapters can begin scheduling in-person events. I am ready for some face-to-face gatherings, even if it means trading big, tight hugs for elbow bumps.

Speaking of gatherings, kids and families everywhere are eagerly looking forward to a return of annual bleeding disorder camp programs – even if in virtual format. In an abundance of caution, many camps have decided to maintain virtual camp programming while others are proceeding to meet in person. Although many have set dates and locations, we all know everything is tentative. However, in keeping with tradition, this issue of BioMatrix News includes a list of camps that have shared their current plans with us. If the camp nearest you is not listed, please check with your chapter to see what plans may have been set since this newsletter was printed. If this year has taught us anything, it is that our community is exceptionally good at being resilient - we are particularly adept at changing and are experienced at having to adjust our plans.

Additionally, the BioMatrix Memorial Scholarship Program is now open! Please spread the word to community members of any age who are attending a college, university, or trade school. Applications will be accepted through August 1st.

With Spring all around us, spend some time outdoors. It does a mind and body good!

Maria Santucci Vetter
Editor-in-Chief, *BioMatrix News*
maria.vetter@biomatrixsprx.com

BIOMATRIX PROUDLY ANNOUNCES THE 2020/2021 MEMORIAL SCHOLARSHIP RECIPIENTS!

In 2020, BioMatrix offered six $1,000 scholarships for bleeding disorders community members seeking higher education. Our program has awarded $56,000 to 60 students since 2013. These scholarships honor the memory of several individuals who impacted the bleeding disorder community in unique ways. BioMatrix partners with the Hemophilia Federation of America for administrative support and independent, third-party evaluation of applicants.

It is with great pleasure we announce the 2020/2021 recipients of our Memorial Scholarship Program. Thank you to everyone who applied and we wish you great success in your bright futures! Without further ado, we introduce you to our scholarship recipients!

RYAN CAMBERDELLA

Freshman, Siena College, NY, Major: Undecided/Medical field
BioMatrix Joe Holibaugh Memorial Scholarship

As a young boy, going to camp and learning to self-infuse helped Ryan gain a sense of control over his hemophilia. Later in life when he was also diagnosed with diabetes, Ryan drew strength from his previous experiences managing hemophilia. He accepted the challenges life has thrown his way and has never let them get him down. "If you were to ask anyone that knows my ambitions, they would tell you that I have never let my disabilities prohibit me from accomplishing something—for it is in our greatest challenges that we have our greatest triumphs."
Congratulations, Ryan!

ALEXANDER CARONNA

Graduate Studies, Rider University, NJ, Master: Business Administration
BioMatrix Tim Kennedy Memorial Scholarship

Crediting his strong sense of self awareness and empathy to having hemophilia, Alexander views his bleeding disorder, not by its limitations but by the opportunities it presents. Through Inalex, a nonprofit organization founded by his father, Alexander feels blessed he was able to travel across the country, share his story and connect with many others in the bleeding disorders community. "If I were to reset my life, I would choose to have hemophilia again in a heartbeat. Though it has presented its fair share of challenges, it has also taught me profound life lessons, lessons that I truly could not imagine life without."
Congratulations, Alexander!

IVAN GIRON

Freshman, University of Phoenix, AZ, Major: Business
BioMatrix Mike Hylton Memorial Scholarship

Diagnosed at birth with moderate hemophilia, Ivan strived to be "normal" despite the challenges in his life. An unstable home life led him to make poor choices – he got into serious trouble and ignored his health. At age 22, he began working at the office of an ophthalmologist who took him under her wing and mentored him. Ivan credits four great women in his life for inspiring him to turn his life around - his wife, his daughter, his mother, and the doctor. "I use the physical and mental adversities I lived through to continue to learn and grow."
Congratulations, Ivan!

AMAYIA GISCOMBE

Sophomore, Elmira College, NY, Major: Nursing
BioMatrix Millie Gonzalez Memorial Scholarship

Diagnosed with von Willbrand disease, Amayia is inspired by the many nurses she encountered during her medical visits as well as her mom who is a nurse. To be sure this was the right career path for her, Amayia spent more than 300 hours shadowing various medical personnel. "As a nurse I want to build on the connections that I hope developed with various patients and hopefully incorporate my passion for art therapy to allow holistic healing." As a student athlete and in her career choice, Amayia will not allow vWD to define her or get in her way. Congratulations, Amayia!

COREY PIERCE

Graduate Studies, Oregon State University, Ph.D. Candidate: Public Health (focus/Epidemiology)
BioMatrix Ron Niederman Memorial Scholarship

Influenced by the tragic history of HIV in the bleeding disorders community, Corey's early life was marked by a grim view of hemophilia and life to come. Through the years as advancements in medical treatment were made, his constrained views of the future dissipated, opening the door for resilience and confidence to grow in him. "Having representation show that a good life is possible is critically important to younger generations, and the families that support them. This is why I stay active in the community, where I hope my presence as a healthy adult will inspire confidence in young people learning to manage their disorder independently." Congratulations, Corey!

SAVANNAH REIMANN

Sophomore, Arizona State University, Major: Applied Biological Sciences
BioMatrix Mark Coats Memorial Scholarship

Along with the diagnosis of hemophilia in several family members as well as herself, Savannah has developed a strong appreciation for the medical field. Through her experiences, she has witnessed the many advances taking place with new treatment and medications. These advancements in the medical field have inspired her to set her sights on becoming a physician's assistant. "Being able to look back and see just how much things have changed for the hemophilia community in the past forty years, I am hopeful that we will be able to learn more and make even more positive changes for our community." Congratulations, Savannah!

The 2021–2022 school year application is now OPEN! Applications will be accepted through August 1, 2021.

Apply online: scholarship@biomatrixsprx.com

Joe Holibaugh (1971-2006)
$1000 Scholarship
For MEN and WOMEN with hemophilia AND an Inhibitor

Tim Kennedy (1962-2011)
$1000 Scholarship
For MEN with hemophilia

Millie Gonzalez (1953-2001)
$1000 Scholarship
For WOMEN with hemophilia or von Willebrand Disease

Ron Niederman (1950-1999)
$1000 Scholarship
For MEN with hemophilia or VWD and their immediate family members

Mike Hylton (1945-1998)
$1000 Scholarship
For MEN with hemophilia or VWD and their immediate family members

Mark Coats (1956-1963)
$1000 Scholarship
For MEN and WOMEN with hemophilia

For the treatment of bleeding episodes in people* with hemophilia A or B with inhibitors[1]

HE'S READY TO MOVE ON

Give your patients rapid, predictable, and reliable bleed control with SEVENFACT 225†[2]

Rapid effect: 3 hour

At 3 hours, 84% of mild/moderate bleeding episodes were controlled with a single dose[2]

Predictable‡ response: 84%

At 9 hours, 84% of mild/moderate bleeding episodes treated achieved bleed control after one dose[2]

Reliable control: 99.5%

At 24 hours, 99.5% of mild/moderate bleeding episodes were resolved[2]

Convenient home use: 98%

98% of bleeding episodes were treated at home[1]

† 225 µg/kg initial dosing regimen in the clinical trial.

‡ As seen in the clinical trial.

Summary of Selected Safety information

WARNING: THROMBOSIS

- **Serious arterial and venous thrombotic events may occur following administration of SEVENFACT.**
- **Discuss the risks and explain the signs and symptoms of thrombotic and thromboembolic events to patients who will receive SEVENFACT.**
- **Monitor patients for signs or symptoms of activation of the coagulation system and for thrombosis.**

Contraindications

SEVENFACT is contraindicated in patients with known allergy to rabbits or rabbit protein, or severe hypersensitivity reaction to SEVENFACT or any of its components.

Warnings and Precautions

There is limited information about the safety of SEVENFACT in patients with a history of arterial or venous thromboembolic disease, because such patients were excluded from SEVENFACT trials. Serious arterial and venous thrombotic reactions can occur with SEVENFACT and have been reported in clinical trials and postmarketing surveillance with a similar class of products.

The following patients may have an increased risk of thromboembolic events with use of SEVENFACT:

- History of concomitant treatment with aPCC/PCC (activated or non-activated prothrombin complex) or other hemostatic agents.
- History of atherosclerotic disease, coronary artery disease, cerebrovascular disease, crush injury, septicemia, or thromboembolism.

Hypersensitivity reactions, including anaphylaxis, are possible with SEVENFACT. Should symptoms occur, patients should discontinue SEVENFACT and seek appropriate medical intervention. Patients with known hypersensitivity to casein may be at higher risk of hypersensitivity reaction.

*Indications and Usage

SEVENFACT [coagulation factor VIIa (recombinant)-jncw] is indicated for the treatment and control of bleeding episodes occurring in adults and adolescents (12 years of age and older) with hemophilia A or B with inhibitors.

SEVENFACT is not indicated for the treatment of patients with congenital Factor VII deficiency.

Adverse Reactions

The most common adverse reactions reported in clinical trials for SEVENFACT were headache, dizziness, infusion-site discomfort, infusion-site hematoma, infusion-related reaction, and fever.

Drug Interactions

Clinical experience with pharmacologic use of FVIIa-containing products indicates an elevated risk of serious thrombotic events when used simultaneously with activated prothrombin complex concentrates.

Please see next page for Brief Summary of Prescribing Information

Brief Summary of Prescribing Information for SEVENFACT [coagulation factor VIIa (recombinant)-jncw], for Intravenous Use

INDICATIONS AND USAGE

SEVENFACT® [coagulation factor VIIa (recombinant)-jncw] is indicated for the treatment and control of bleeding episodes occurring in adults and adolescents (12 years of age and older) with hemophilia A or B with inhibitors.

Limitation of Use: SEVENFACT is not indicated for the treatment of patients with congenital Factor VII deficiency.

WARNING: THROMBOSIS

- **Serious arterial and venous thrombotic events may occur following administration of SEVENFACT.**
- **Discuss the risks and explain the signs and symptoms of thrombotic and thromboembolic events to patients who will receive SEVENFACT.**
- **Monitor patients for signs or symptoms of activation of the coagulation system and for thrombosis.**

CONTRAINDICATIONS

SEVENFACT is contraindicated in

- known allergy to rabbits or rabbit proteins. Exposure to SEVENFACT in these patients can result in severe hypersensitivity reaction.
- patients with severe hypersensitivity reaction to SEVENFACT or any of its components. Exposure to SEVENFACT in these patients can result in severe hypersensitivity reaction.

WARNINGS AND PRECAUTIONS

Thrombosis

- There is limited information about the safety of SEVENFACT in patients with a history of arterial or venous thromboembolic disease, because such patients were excluded from SEVENFACT trials. Serious arterial and venous thrombotic reactions can occur with SEVENFACT. Such reactions have been reported in clinical trials and post-marketing surveillance with a similar class of products. Neither arterial nor venous thrombotic events have been reported in SEVENFACT clinical trials.
- The following patients may have increased risk of thromboembolic events with use of SEVENFACT:
  - History of congenital or acquired hemophilia receiving concomitant treatment with aPCC/PCC (activated or non-activated prothrombin complex) or other hemostatic agents
  - History of atherosclerotic disease, coronary artery disease, cerebrovascular disease, crush injury, septicemia, or thromboembolism.
- Monitor patients who receive SEVENFACT for the development of signs and symptoms of activation of the coagulation system or thrombosis. When there is laboratory confirmation of intravascular coagulation or presence of clinical thrombosis, reduce the dose of SEVENFACT or stop treatment, depending on the patient's condition.

Hypersensitivity Reactions

- No hypersensitivity reactions have been reported in SEVENFACT trials; however, hypersensitivity reactions, including anaphylaxis, can occur with SEVENFACT. Symptoms may include hives, itching, rash, difficulty breathing, swelling around the mouth and throat, tightness of the chest, wheezing, dizziness or fainting, and low blood pressure. In the event of hypersensitivity reactions, patients should discontinue treatment and seek immediate medical attention.
- Patients with known IgE-based hypersensitivity to casein may be at higher risk of hypersensitivity reactions. Should signs or symptoms of hypersensitivity occur, treatment should be discontinued. Subsequent treatment with SEVENFACT should be based on a thorough assessment of the risks and benefits.

Neutralizing Antibodies

- In the studies performed, no patients tested positive for neutralizing antibodies. Nevertheless, neutralizing antibodies may occur with the use of SEVENFACT. If treatment with SEVENFACT does not result in adequate hemostasis, then suspect development of neutralizing antibody as the possible cause and perform testing as clinically indicated.
- Neutralizing antibodies to other Factor VIIa-containing products have been observed in congenital Factor VII-deficient patients. SEVENFACT has not been studied in this patient population. [*See limitation of use statement under Indications and Usage (1)*].

Laboratory Tests

Laboratory coagulation parameters (PT/INR, aPTT, FVII:C) do not correlate with clinical response to SEVENFACT treatment.

ADVERSE REACTIONS

The most common adverse reactions (incidence ≥1%) reported in clinical trials for SEVENFACT were headache, dizziness, infusion-site discomfort, infusion-site hematoma, infusion-related reaction, and fever.

Clinical Trials Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in practice.

In two studies of SEVENFACT in patients with Hemophilia A or B with or without inhibitors, 42 subjects (27 subjects in Study 1 and 15 subjects in Study 2) have been exposed to SEVENFACT.

Study 1: The safety of SEVENFACT has been evaluated in a safety and efficacy study of 27 subjects with Hemophilia A or B with inhibitors, which included treatment of 468 bleeding episodes. As described in Table 2, a total of seven adverse reactions were observed in two subjects (7.4%) treated with SEVENFACT. One episode of fever occurred in a 12-year-old subject, lasted two days, and was managed symptomatically.

Study 2: In a study with 15 subjects evaluating the safety and pharmacokinetics of three escalating doses of SEVENFACT (25 mcg/kg, 75 mcg/kg and 225 mcg/kg), a total of three (20%) subjects experienced four adverse reactions (Table 1).

One subject developed an infusion reaction immediately following the infusion of the first dose of 75 mcg/kg; the reaction lasted 45 minutes. Signs and symptoms included flushing, chest tightness, shakiness, transient tachycardia, and mild hypotension. Symptoms resolved without any intervention and did not recur with subsequent administration at 225 mcg/kg dose.

Adverse reactions reported in the two clinical studies are shown in Table 1.

Table 1 Adverse Reactions Occurring in the Two Clinical Studies

Preferred Terms	Number of Adverse Reactions in Study 2 (N=15)	Number of Adverse Reactions in Study 1 (N=27)
Infusion-site discomfort	–	4
Infusion-site hematoma	–	2
Dizziness	2	–
Headache	1	–
Body temperature increased	–	1
Infusion-related reaction	1	–

Immunogenicity

In Study 1, two out of 27 subjects had a positive screening assay for anti-SEVENFACT antibody at baseline, prior to exposure to SEVENFACT, and at follow-up visits. One of these two subjects had a transient SEVENFACT antibody with an additional confirmatory test for anti-SEVENFACT antibody, which was confirmed as non-neutralizing. In Study 2, five of 15 subjects tested positive for anti-SEVENFACT antibody using a screening assay. The confirmatory assay was negative for all subjects at all time points.

No subject developed anti-rabbit milk protein antibodies during treatment with SEVENFACT. As with all therapeutic proteins, there is potential for immunogenicity. The detection of antibodies is highly dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors, including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to SEVENFACT with the incidence of antibodies to other products may be misleading.

DRUG INTERACTIONS

Clinical experience with pharmacologic use of FVIIa-containing products indicates an elevated risk of serious thrombotic events when used simultaneously with activated prothrombin complex concentrates.

USE IN SPECIFIC POPULATIONS

Pregnancy

Risk Summary

There are no adequate and well-controlled studies using SEVENFACT in pregnant women to determine whether there is a drug-associated risk. Animal studies evaluating the embryo-fetal teratogenic potential of SEVENFACT have not been conducted. It is unknown whether SEVENFACT can cause fetal harm when administered to a pregnant woman or can affect fertility. In the U.S. general population, the estimated background risks of major birth defect and miscarriage in clinically recognized pregnancies are 2-4% and 15-20%, respectively.

Lactation

Risk Summary

There is no information regarding the presence of SEVENFACT in human milk, the effect on the breastfed infant, and the effects on milk production. The developmental and health benefits of breastfeeding should be considered along with the mother's clinical need for SEVENFACT and any potential adverse effects on the breastfed infant from SEVENFACT or from the underlying maternal condition.

Females and Males of Reproductive Potential

Risk Summary

In Study 1, male patients cautioned to avoid sexual activity without condoms received SEVENFACT for the treatment of bleeding episodes. No pregnancies from sexual partners were reported. The relative benefits of SEVENFACT should be weighed against any potential risk arising from exposure in sexually active patients.

All clinical studies of SEVENFACT were performed on males, as males are predominantly affected with the congenital form of hemophilia. No adverse effects on the mating index, fertility, or conception rate were observed following administration of SEVENFACT at dose levels up to 13-fold higher than the highest recommended human dose in healthy male rats prior to and during cohabitation with healthy untreated female rats [*See Carcinogenesis, Mutagenesis, Impairment of Fertility (13.1)*].

Pediatric Use

Limited clinical data for SEVENFACT in the pediatric population were collected in an adult and adolescent study (Study 1). A total of 5 subjects aged ≥12 to <18 years of age (range 13-17 years) were dosed with SEVENFACT. These 5 subjects were treated for a total of 79 bleeding episodes (all mild or moderate) that occurred while subjects were still under 18 years of age. Hemostatic efficacy in this subgroup (n=5) was comparable to efficacy observed in the overall population [*See Clinical Studies (14)*].

Geriatric Use

Safety and effectiveness of SEVENFACT in patients >65 years of age have not been evaluated in clinical trials. The presence of age-related comorbidities and the attendant risks associated with thrombotic and thromboembolic events should be considered when administering SEVENFACT to patients older than 50 years of age.

OVERDOSAGE

There have been no reports of overdosage with SEVENFACT. Doses greater than 900 mcg/kg/day have not been studied. Doses greater than 900 mcg/kg per 24 hours may be associated with an increased risk of thromboembolic events.

To report SUSPECTED ADVERSE REACTIONS or product complaints, contact HEMA Biologics at 1-855-718-4362. You may also report SUSPECTED ADVERSE REACTIONS to the FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

References:

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HEMA Biologics™

THE YEAR OF COVID-19

BY SHELBY SMOAK, PhD

I am writing this shortly after the one-year anniversary of the COVID-19 shutdown – and what a year it has been. Over 30 million confirmed cases in the US and over 556,000 deaths.[i]

Luckily, we have the vaccines now to help bring us out of this dark time. But vaccines cannot do it alone. It will take all of us to join in the vaccine effort and continue to practice mitigation strategies like mask-wearing and social distancing to allow America and Americans to begin returning to pre-COVID lifestyles like eating at restaurants and, of course, seeing one another face-to-face at our sorely missed bleeding disorders' gatherings.

HERD IMMUNITY

For anything to be successful, we must achieve herd immunity, the point where a significant portion of the population becomes immune to an infectious disease – in this case, COVID-19. With herd immunity, the risk of spreading COVID-19 from person to person decreases and those not immune (via vaccine or virus exposure) are indirectly protected because of less opportunity for exposure; in this way, the viral spread is diminished.

There are only two ways to achieve herd immunity:

1. Through infection and recovery, or
2. By vaccination

The requirements for herd immunity differ from virus to virus. For example, measles require about 95% of the population to be vaccinated to achieve herd immunity while polio requires 80% to be vaccinated for that result.[ii] In contrast, flu achieves herd immunity when only 33-44% of the population is vaccinated. The "R" factor or number of people each affected person will infect—the virus's spread, in other words—explains the different requirements for reaching herd immunity.[iii]

Sources such as John Hopkins estimate that COVID-19 will require 70% or more of the population to be vaccinated to achieve herd immunity and thereby protect Americans from the spread of COVID-19. Given our current pace of about 3.1 million vaccine shots per day, sources estimate herd immunity could be achieved by early fall 2021; however, that would require all Americans to do their part in receiving the vaccine, and sadly, that would still result in the loss of about 100,000 more American lives.

MITIGATION STRATEGIES

Many questions are surfacing about the behavior of those who are vaccinated: Do I still need to wear a mask? Do I still need to practice social distancing? Can I participate in large group gatherings? The CDC has issued guidance to address these concerns. Fully vaccinated people, they say, can:

- Visit with other fully vaccinated people without wearing masks or social distancing.
- Visit with unvaccinated people from a single household who are at low risk for severe COVID-19 without wearing masks or social distancing. Low risk here means under 65 with no underlying health conditions.
- Refrain from quarantining and testing after a known exposure as the risk for catching COVID-19 post-vaccination is severely diminished.

However, the CDC also warns that fully vaccinated people should still take the following precautions:

- Wear masks and physically distance in public settings.
- Wear masks and physically distance with unvaccinated people who are at risk of severe COVID-19. This would include unvaccinated persons over 65 and unvaccinated persons with underlying health conditions.
- Wear masks and physically distance when visiting unvaccinated people from various households.
- Avoid medium to large-sized in-person gatherings. Multiple exposures at large gatherings can test the vaccine's efficacy and leave even a vaccinated person vulnerable, though that person if they were to yet contract the virus, would likely experience a mild case.

All of the above highlight how much of COVID-19 has been an American experience of trauma and recovery. It also emphasizes the importance of each American in doing their part to help our country achieve the needed herd immunity. Continue to stay safe, practice mitigation strategies like mask-wearing and physical distancing, and get vaccinated as soon as you are able.

THE VACCINE

HOW DOES THE VACCINE PROVIDE IMMUNITY?

COVID-19 vaccine helps develop immunity without getting sick. All vaccines use T- and B- lymphocytes that "remember" how to fight a virus. T-lymphocytes, also called *memory cells*, react when a known virus enters the body and B-lymphocytes produce antibodies to attack them. The vaccine provides a tool for the body to recognize COVID-19 without needing to be directly exposed to the virus.

While persons who get COVID-19 will develop some immunity to the virus, this will not be the same as receiving the vaccine. For one, the vaccine's efficacy is superior to and more reliable at preventing illness from the virus than having COVID.

For another, as the CDC confirms, COVID-19 vaccines are "safe and effective."[iv] In other words, waiting for COVID to strike is a very risky game.

How sick can it make you? What are the side effects of an actual COVID-19 illness? If you have had COVID-19, the immunity is unknown and would depend upon the severity of the case and many other uncontrolled factors; unlike the vaccine, a COVID-19 exposure cannot guarantee protection.

WHAT ARE THE TYPES OF COVID-19 VACCINES AVAILABLE?

1. mRNA vaccines deliver information to cells on how to make a protein that will then trigger an immune response to COVID-19. Unlike other vaccines which may use inactivated virus elements, mRNA vaccines do not contain weakened or inactivated germs.[v] The cells make copies of the protein and will be able to recognize COVID-19 as a threat and attack it. Pfizer (code name: BNT162b2) and Moderna (code name mRNA-1273) vaccines use this technology.

2. Vector vaccines contain a modified version of a different virus (the vector) to deliver instructions to our cells for making a protein that will trigger our body's immune response to COVID-19. Like mRNA vaccines, vector vaccines do not contain live or inactivated virus.[vi] The Johnson and Johnson vaccine (code name: JNJ-78436735) uses this technology.

Ostensibly, both types of vaccines operate in the same way with the vector vaccine adding another layered delivery process. Again, it is important to note neither the mRNA nor vector vaccine contain any actual live COVID-19 virus, making this a significant achievement and leap forward in vaccine technology.

WHAT IS THE BEST COVID-19 VACCINE?

In trials, Pfizer demonstrated 95% efficacy, Moderna 94.1%, and Johnson & Johnson 85%. However, experts like Dr. Russell Faust of the Oakland County Health Division encourage persons to not let the efficacy difference in Pfizer and Moderna vs. Johnson & Johnson be a determining factor for vaccine choice; the Johnson & Johnson trials were run much later when other COVID-19 variants were active, a variable less involved in the Pfizer and Moderna trials.[vii]

Pfizer and Moderna require two shots while Johnson & Johnson require a single shot. However, the Johnson & Johnson vaccine distribution was briefly paused after six women between 18-48 who had received the Johnson & Johnson shot experienced a rare blood clot.[viii] The CDC and the FDA reviewed the data and after 11 days continued to recommend the Johnson & Johnson vaccine, writing, "A review of all available data at this time [April 25, 2021] shows that the Johnson & Johnson/Janssen COVID-19 vaccine's known and potential benefits outweigh its known and potential risks." At the time of writing, 6.8 million shots have been given.[ix]

WILL I GET COVID-19 FROM THE VACCINE?

No. The vaccines have no live virus and cannot give you COVID-19. However, it takes several weeks for the vaccines to create enough antibodies to protect a person, making it possible to be exposed to and get COVID-19 before the vaccine becomes fully effective.

IS IT SAFE FOR A PERSON WITH A BLEEDING DISORDER TO RECEIVE THE COVID-19 VACCINE?

Yes. According to the National Hemophilia Foundation (NHF), "There are no contraindications to being vaccinated" with any of the vaccines [Pfizer, Moderna or Johnson and Johnson]. NHF recommends reaching out to your hematologist with specific questions adding, "It would be preferable for you to infuse with a factor replacement product prior to or right after the vaccination."[ix]

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A Mother's Love


Stephanie


Victoria


Genny

BY EVA KRAEMER AND KELLY GONZALEZ

For most, mothers are everything. They are the guiding light propelling their children toward their destiny. They are the safe, warm blanket that wraps them when they fall. They are the protectors and disciplinarians. They are the source of encouragement and the teachers of independence.

But what happens when a curveball is thrown into the mix? When child-rearing may include and be complicated by having to be cautious about everyday things, many hospital visits, countless factor infusions, and a more-than-average amount of worrying? Mothers of children with hemophilia or other bleeding disorders don't give up - they become resilient.

Stephanie R., Victoria K. and Genny M. - three women from various walks of life decided their genetic make-up would not hinder their childbearing dreams. They persisted and started families of their own regardless of the chances of passing along a bleeding disorder. An intimidating task for some, but an inspirational journey for others.

For context, hemophilia is passed down on the mother's chromosome. This means when a woman who is a carrier of hemophilia conceives there is a chance she will pass on this genetic disorder to her child. Hemophilia is substantially more prominent in males because it is a recessive sex-linked disorder, but females may also be affected. Deciding to bring a child into this world knowing your genetics may greatly impact your child's life is even more daunting.

Stephanie is from Michigan and has been married to her husband, Jason, for 15 years. They have 4 children, Addison, Ella, Lila, and Ben, who has severe hemophilia. Stephanie has been aware of the bleeding disorders world her whole life because of her family's involvement. "I've been part of my brother's journey, my uncle, my cousin... I have seen the progression of the effects of hemophilia from the older generation to my brother's generation and I wasn't as worried," recalls Stephanie. "To me, there were worse things to have."

Victoria and her husband, David have been married for 20 years and are parents to 16-year-old twins, daughter Grace, and son William who has severe hemophilia. Victoria always knew she was a carrier because her dad had severe hemophilia. She was diagnosed as having mild hemophilia when she was just 10 years old.

Married for 15 years, Genny and John from Illinois were college sweethearts. They have a 6-year-old son, Johnny, who has severe hemophilia. Genny shared, "I knew hemophilia ran in my family since my mom had 2 brothers and a couple of nephews with hemophilia. One of my uncles died as a toddler from a head bleed and we lost one uncle to the HIV he contracted from his clotting factor back in the 1980s. I grew up thinking I couldn't be a carrier since my mom supposedly tested negative when she was family planning back in the 1970s."

When bringing up the obstacle of family planning with their respective spouses, the women were informed about the possible risk associated with conceiving a boy. With their partners, each couple took fate into their own hands.

Stephanie shared that there was almost no conversation because her partner met her family at the very beginning of their relationship and knew right off the bat of their struggles with hemophilia. When asked about having children, Stephanie responded, "We knew God would guide us."

Initially, Victoria didn't want children because as an obligate carrier, she knew the chances of having a child with hemophilia were great. Her husband, however, was undeterred by hemophilia - he wanted children. Eventually, Victoria became pregnant with twins. After bringing her children into the world, Victoria, with tears in her eyes, asked the doctor if her son had hemophilia. When the doctor replied "yes," her husband responded with a statement that would guide them through raising their children, "Hemophilia is like blue eyes, it's just DNA."

Genny's sister had a child with hemophilia. She realized her mom's carrier testing was incorrect and that she had a 50/50 chance of being a carrier. "My nephew was born and diagnosed with hemophilia less than a year after John and I started dating. It was very difficult watching my young nephew struggle with bleed-after-bleed and surgery-after-surgery since he battled inhibitors the majority of his life," stated Genny. "After seeing what my nephew, uncle and others have gone through, we struggled with knowingly taking the risk of having a child whose quality of life could be greatly impacted by hemophilia. Nevertheless, we still longed to have children."

As for starting a life with a newborn diagnosed with hemophilia, each mother had her own journey to dictate. They kept conversations going about hemophilia with their partners and families. They each discovered they weren't about to let a genetic disorder dictate the way they or their child was going to live their life. Those conversations aren't easy and require openness from both parents.

Stephanie's family focused on immersion. "This is our life, our normal, our something unique," she recalls. There was no specific incident or time, but she and Jason jumped in to learn and understand everything they could about hemophilia.

Learning from past experiences was the way to go in Victoria's family. David learned about hemophilia through his relationship and experiences with Victoria's dad before he passed in 1993. Even though he had not experienced hemophilia firsthand growing up as Victoria had, together they have handled every incident and challenge as it has come along.

Genny feels she is blessed as her husband is very knowledgeable and engaged. She recalls before having their own child, her husband was one of the first people in the family to learn how to infuse her nephew. He had even gone on field trips and camping with him without fearing his condition.

Family planning isn't always easy when you have a genetic disorder. There are unpredictable events that can impact life, but these mothers have advice for anyone considering having a child.

"Children are a blessing to our family. I would suggest families with a known carrier mother prepare to have a child with a bleeding disorder by getting involved with your local chapter, educating yourself and learning to be an advocate as you plan and make decisions. Ask questions about doctors and treatment options – take responsibility for the preparation, but have faith everything will be ok," explains Stephanie.

"Do all the research you need and talk to your partner. Do it!" exclaims Victoria.

"Follow your heart. Do what's best for you and your family," states Genny. "If you are faced with bleeding disorders, don't go it alone. Build a squad by meeting others through your local and national bleeding disorders organizations and learn as much as you can."

If you know you are a carrier, family planning doesn't have to be scary or daunting. Get engaged, get educated, take action, and plan for the best. No matter what, know you are among a community of resilient hemophilia moms who will help guide the way. Learn from those who have lived through the experiences in which you may find yourself.

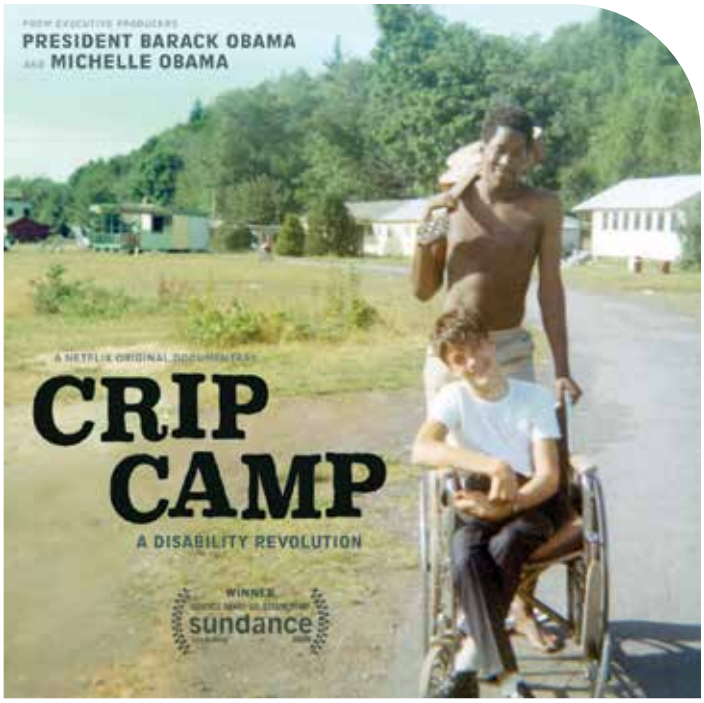
To all the moms in our community and from all of us at BioMatrix, *Happy Mother's Day*!

Addison, Stephanie, Ella, Ben, Lila & Jason

Victoria, Grace, David and William

John, Johnny and Genny

A REVIEW:
CRIP CAMP



BY RICH VOGEL

What do you get when a bunch of kids with disabilities go away to camp, are free to be themselves, and form bonds and everlasting friendships? You just might get a group of kids who go on to change the world!

That's my takeaway from the inspirational Netflix documentary, Crip Camp. This film is rated "R" by the Motion Picture Association of America for "some language including sexual references."

In 1971 a group of young people went to a camp for children with disabilities in upstate New York. Camp Jened was established in 1951 as a campground for people with disabilities - cerebral palsy, blind, deaf, epilepsy, and those stricken with polio, just to name a few. It was a place where kids could be kids, treated with kindness and humanity, unlike the real world where many were put in institutions and not allowed to go to school. As one person said, the problem is not with people living with disabilities, but people living without them – people who refuse to listen to those with disabilities or build a world that accommodates them, who turn a blind eye to their abuse, or limit their opportunities.

The story is told through actual footage of that magical summer interspersed with current interviews with those kids from 50 years ago. We see bonds being made with lifelong friendships, meetings where every voice is heard, compassion, and even first crushes, all the things that go on at a typical camp. But this was the 1970's. The war was going on in Vietnam, there were protests and there was a wind of change in the country.

In 1973, President Nixon signed into law Section 504 of the Rehabilitation Act. Unfortunately, there were no regulations passed. No definition of what discrimination is for people with disabilities.

When the Carter administration came into power still nothing was done. Joseph Califano, U.S. Secretary of Health, Education and Welfare, refused to sign meaningful regulations for Section 504 of the Rehabilitation Act of 1973. After an ultimatum and deadline, a group of activists with disabilities, led by camper Judy Heumann, staged a sit-in at the San Francisco Office of the U.S. Department of Health, Education and Welfare in order to get their voices heard.

The sit-in lasted 28 days, quite a feat for people in wheelchairs, many of whom needed assistance to eat and perform daily functions. In one scene, the Black Panthers are seen delivering food to the protesters. When asked why they were delivering food for free, they said because you are helping the community, trying to change the world.

Judy Heumann at a rally for Section 504 of the Rehabilitation Act in the early 1970s

After mounting pressure around the country, Joseph Califano signed both *Education of All Handicapped Children* and *Section 504* into law on April 28, 1977. It took another 11 years to get legislation introduced in Congress for the *Americans with Disabilities Act* and another 2 years before President Bush signed it into law in 1990 – nearly 20 years after that spark was lit for those young kids at Camp Jenard.

This is an inspiring true story about friendship, perseverance, righting a wrong. Although the film is not about kids with bleeding disorders, it does highlight similar struggles. This is our story. The first residential summer camp, Bold Eagle Highlands, for persons with hemophilia was started in 1969 by Hemophilia Foundation of Michigan.

Since then, many more camps have been created for kids with bleeding disorders and often their siblings. These camps promote independence by teaching self-infusion and leadership skills, guiding many to become camp counselors and advocates for the community, all while fostering camaraderie and lasting friendships with others in a secure and safe environment.

These are just a few reasons why camp is so important for the bleeding disorder community. If you are contemplating sending your child to camp, watch this documentary. Your kid might just change the world.

Hemophilia Federation of America™

Assisting Educating Advocating For The Bleeding Disorders Community.

www.hemophiliafed.org

5 Ways *Specialty Pharmacies* Support Patients

BY TARA KESTER AND JUSTIN LINDHORST

Sixty percent of adults in the U.S. are living with at least one chronic illness. Forty percent of adults have two or more chronic health conditions.[i]

Specialty drugs are often prescribed for people with complex and/or chronic medical condition(s). Because many of these conditions can be life-altering and/or threatening, proper support throughout the patient journey is critical for optimal health outcomes. This article provides five benefits for using a specialty pharmacy to help manage chronic or complex medical conditions.

1. Access to Specialty Medication

Due to the complexity of specialty medications and the unique situations faced by patients who require them for treatment, many specialty drugs are not found at local walk-in retail pharmacies. These medications often require unique patient education tools, patient financial assistance programs, specialized monitoring, advanced packaging, and the ability to get the drug to the patient when and where they need it. BioMatrix has met these obligations to our patients for decades.

Specialty pharmacies ensure patients understand their specialty medication insurance coverage, how to get medication in a timely manner, and what financial support options are available. From therapy initiation, payer outreach, benefits investigation, prior authorization, appeals management, and connectivity to manufacturer patient access services, specialty pharmacies coordinate care between all healthcare providers to help patients promptly begin and maintain access to their medication. We make sure patients understand how to properly store medications, how to take them, and who to contact with any questions.

2. Better Adherence and Treatment Outcomes

We know chronic health conditions can complicate daily life. Treatment is often complex, time-consuming, expensive, and comes with side effects further complicating things. For all these reasons, up to 50% of chronically ill patients do not take their medication as prescribed.[ii] Our goal is to make thing easier – including working with patients to provide preferred ancillary supplies. By working together, we help make complicated treatment plans more manageable.

Studies show patients who use specialty pharmacies have higher treatment adherence compared to those using a retail option.[iii] Our data proves this claim. Over the course of one year, BioMatrix conducted a study of patient-reported outcomes. Our research found participating patients had an adherence rate of 96.2%. The study showed our services helped to improve both adherence and quality of life. The case study can be downloaded at: https://bit.ly/3s2xKyM.

3. In-Home Treatment

Due to cost, convenience, and COVID-19, more patients and their providers are opting for home-based treatment. Up to 80% of patients with conditions such as cancer now receive care in the outpatient setting and new healthcare models incentivize at home treatment.[iv] (read about the healthcare model at: https://bit.ly/2OzmXxz).

Specialty pharmacists play an important role in helping to manage and monitor treatment in the home environment. We educate patients on what to expect from their

prescribed medication and how to properly store, handle, and administer their specialty drugs. Our therapeutically focused clinical assessments collect and analyze key data while allowing our team to monitor side-effects, medication adherence, barriers to care, and overall response to therapy.

4. Reduced Cost

Living with a chronic condition is costly. When patients have to pay high out-of-pocket costs for their treatment, they're more likely to skip optional care and delay critical care. This leads to both poorer treatment outcomes and overall health. Poor health can lead to lost workdays and potential loss of employment.[v]

Research shows specialty pharmacies drive down the cost of care in a variety of ways by promoting adherence to therapy, identifying utilization or dosing mistakes, helping to avoid unnecessary hospitalizations and connecting patients with financial support programs.[vi] For more information, visit: https://bit.ly/3bV4gNp.

BioMatrix is committed to helping patients identify and obtain financial support so treatment can begin without delay. We help identify co-pay assistance programs and connect patients with the right resources for enrollment. From manufacturer co-pay programs to charity-based financial assistance, we provide resources and support helping patients access specialized healthcare without breaking the bank.

5. Patient-Centric Care

A strong relationship between a patient and their health care provider can positively affect the patient's ability to cope, especially in an outpatient setting.[vii] In a large study, patients who perceived their health care providers as "knowing them as a person" had higher rates of treatment adherence, more positive beliefs about the effectiveness of their therapy, fewer missed doctor appointments, and a higher quality of life.[viii] Pharmacists who take the time with each patient to understand needs, challenges, and preferences are better positioned to support, educate, and serve.

BioMatrix Specialty Pharmacy is proud to make a difference in the communities we serve, one patient at a

time. Our clinicians and support staff offer a tailored approach to every therapeutic category, improving the quality of life for patients and producing positive outcomes. Our entire team is committed to maintaining the health and wellbeing of those we are privileged to serve.

To learn more visit: https://www.biomatrixsprx.com/bleeding-disorders-overview

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[BIOMATRIX]
Meet the Team!

BioMatrix is dedicated to making a difference in the bleeding disorders community. Our team of Regional Care Coordinators and Patient Care Specialists provide support that draws on personal experience and a genuine commitment to the bleeding disorders community. Our "Meet the Team" segment invites you to get to know our incredible staff a little bit better.

In this edition, we feature Terry Stone!

Terry Stone
Regional Care Coordinator

Terry comes to our organization with years of experience in sales and public relations that started in the Washington DC tourism industry. However, after her son was born with hemophilia, she discovered a greater calling and acted on her new passion to serve patients dealing with chronic conditions and help to ensure they have education, support, and an enhanced quality of life.

Living in Manassas, Virginia, Terry and her husband of 36 years have a grown daughter, Michelle, who has two children of her own, and a 19-year-old son, Matthew. Terry has served on the Board of Directors for her local chapter and continues to be an involved member of the bleeding disorders community. As a Regional Care Coordinator at BioMatrix, Terry brings a feeling of family support and compassion to patients in Virginia, Maryland, and the Washington DC area.

What is your connection to the bleeding disorders community?

My introduction to the bleeding disorders community was as abrupt as it was shocking. After more than seven years of wanting to grow our family, my husband and I were excited to welcome a new long-awaited son Matthew to our family in October 2001. Our then 14-year-old daughter Michelle would have the little brother she always dreamed of - a real live baby doll to love and rock to sleep.

Something, however, was not quite right. During a feeding not long after birth, I noticed a large bloodstain on Matthew's blanket and alerted the nurse. After a trip to the NICU and 48 very long hours, the diagnosis was a tough one, "your son has severe hemophilia B." With those simple words, life changed for us. Although we felt sad and alone, we soon realized there was a community of families just like us, ready to embrace, teach and support us as we struggled to navigate our way to what would be our family's new normal.

What brought you to BioMatrix?

My family was warmly embraced by the local hemophilia chapter and other families in the community, and I was so inspired that I transitioned my career path to serve a community that I unexpectedly found myself a part of. I experienced firsthand how education and support can make a difference in the lives of patients dealing with a chronic health concern and I wanted to offer the same. After working for another specialty pharmacy, I found myself a home with BioMatrix in 2011.

I reflect on my former career as a sales director for a sightseeing and charter bus company, then go back even further to working after school at my parent's bus station selling tickets and stocking soda machines. I grew up in transportation, and although a career in tourism in our Nation's Capital was really fun, I much prefer helping patients to transport themselves to successful therapy at home and to their best life possible.

Grandson Mason, daughter Michelle and son Matt

With her favorite gals: daughter & mom

How do you feel you are *Making a Difference*?

Patients are so unique in every way. It's my mission to learn all about their needs and challenges so that we ensure they have what they need to be comfortable with their home therapy and educated as to all of the great resources that are available to them. You need to take great care of the patient, but don't forget to embrace the entire family so that together they are supported, educated, and resilient.

What is the most cherished part of your job?

There's no better gift than making a difference in someone's life, particularly during a time of great need or concern. I have found immense joy and a true calling assisting patients and their families who are navigating their own path with other chronic disorders.

Matthew was young, we always explained his hemophilia as a unique part of who he is. Matthew came to understand that everyone has a "something" and hemophilia was just his, and that was cool. From this lesson he never felt odd or different, he just felt like, well... MATT! So, our story is about a little boy who learns to embrace his "something." With support from BioMatrix who printed the book, it's now available for families to share and enjoy. It's a wonderful story for parents to read to their children, or to share at school as part of their school and class education.

What would you say to a newly diagnosed family?

You are not alone! There is a community of folks who share this path through life, so join up, walk with them, and share the journey. Certainly,

You need to take great care of the patient, but don't forget to embrace the entire family so together they are supported, educated and resilient.

I find that although the diagnosis of their loved one may be different than my own family; our concerns as parents, family members and caregivers are typically the same. We worry about health insurance, copayments, experienced care, and how to juggle doctor appointments, work, and after-school activities. Living with a chronic disorder and the challenges and blessings it brings are so uniquely personal. Yes, there can be blessings too!

What personal accomplishment are you most proud of?

My daughter Michelle and I wrote a book for the hemophilia community called *This is My Something*. When I wish my family was not affected by hemophilia, but what a gift it has been to have met so many amazing people along the way, and the joy of so many experiences we have shared as a family. And let's not forget hemophilia camp for Matthew, which was a monumental event every year for him. He counted the days until camp each summer and has made lifelong friends. Living with chronic illness comes with challenges. I get it. Everyone has a "something," so embrace it!

Contact Terry:

Mobile: 703-795-6269

Email: terrystone@biomatrixsprx.com

Terry and Dave - 36 years and counting!

Making her radio debut

Making her acting debut!

Terry with her son, Matthew, the inspiration for *This Is My Something*

REQUEST A SIGNED COMPLIMENTARY COPY!

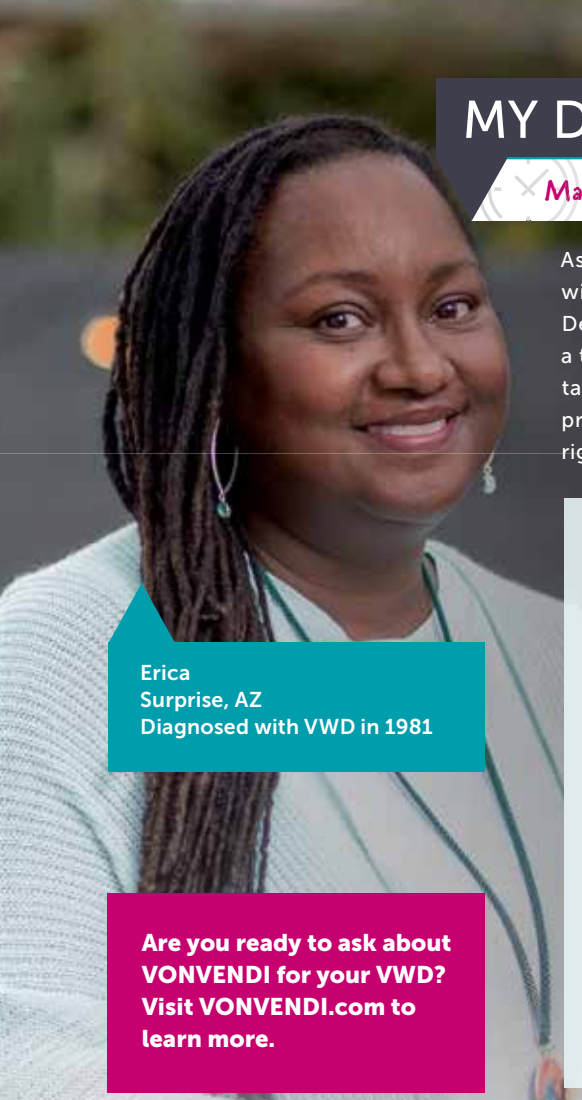
A charming children's book whose main character has hemophilia, *This Is My Something* is written to help children understand and accept their bleeding disorder as a unique and special part of who they are. Receive a complimentary copy for your family!

Contact: Terry Stone
terry.stone@biomatrixsprx.com

MY DECIDING FACTOR:

Making time for what matters most.

vonvendi [von Willebrand factor (Recombinant)]



Erica
Surprise, AZ
Diagnosed with VWD in 1981

Are you ready to ask about VONVENDI for your VWD? Visit VONVENDI.com to learn more.

As an adult living with von Willebrand disease (VWD), you may share a bleeding disorder with others, but you have your own life, and your own needs. You may also have your own Deciding Factor—something that drives you to talk to your healthcare provider about finding a treatment that's right for you. For Erica, it was that her frequent bleeding episodes were taking time away from things that mattered most to her. She talked with her healthcare provider, and together they decided that VONVENDI® [von Willebrand (Recombinant)] was right for Erica's VWD.

VONVENDI

- Is used in adults (age 18 and older) diagnosed with VWD to **treat and control bleeding episodes** and **prevent excessive bleeding during and after surgery**
- **Is the first and only recombinant von Willebrand factor (VWF),** meaning it is manufactured without human plasma or blood
- **May be used with or without a recombinant factor VIII (rFVIII),** as instructed by your healthcare provider

VONVENDI Important Risk Information

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

Please see additional Important Risk Information below.

Important Risk Information (continued)

How should I use VONVENDI?

Your first dose of VONVENDI for each bleeding episode may be administered with a recombinant factor VIII as instructed by your healthcare provider. Your healthcare provider will instruct you whether additional doses of VONVENDI with or without recombinant factor VIII are needed.

What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What else should I know about VONVENDI and von Willebrand disease?

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop VONVENDI or factor VIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

What are the possible side effects of VONVENDI?

You can have an allergic reaction to VONVENDI.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with VONVENDI include: nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate.

Tell your healthcare provider about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see VONVENDI Consumer Brief Summary on the following page and talk to your healthcare provider.

Takeda

Important facts about VONVENDI®:

This leaflet summarizes important information about VONVENDI. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.

vonvendi
[von Willebrand factor (Recombinant)]

What is VONVENDI?

VONVENDI is a recombinant medicine used to replace low levels or not properly working von Willebrand factor in people with von Willebrand disease. Von Willebrand disease is an inherited bleeding disorder in which blood does not clot normally.

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- Treat and control bleeding episodes
- Prevent excessive bleeding during and after surgery

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What is the most important information I need to know about VONVENDI?

VONVENDI can cause blood clots particularly in patients with known risk factors for blood clots. Discuss this risk with your healthcare provider.

You can have allergic reactions to VONVENDI. Symptoms may include generalized itching; rash or hives; rapid swelling of the skin or mucous membranes; chest pain or tightness; tightness of the throat; low blood pressure; shock; drowsiness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; wheezing and/or difficulty breathing; lightheadedness; dizziness; or fainting. If symptoms occur, stop using VONVENDI immediately and get emergency treatment right away.

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, they may stop VONVENDI or FVIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

What are the possible side effects of VONVENDI?

Side effects that have been reported with VONVENDI include: nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate. These are not all the possible side effects with VONVENDI. You can ask your healthcare provider for information that is written for healthcare professionals.

Tell your healthcare provider about any side effects that bother you or do not go away.

What else should I know about VONVENDI and von Willebrand Disease?

Consult with your healthcare provider to make sure you are carefully monitored with blood tests to measure levels of von Willebrand factor and factor VIII so they are right for you.

You may infuse VONVENDI at a hemophilia treatment center (HTC), at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or HTC. Many people with von Willebrand disease learn to infuse VONVENDI by themselves or with the help of a family member.

Call your healthcare provider right away if your bleeding does not stop after taking VONVENDI.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use VONVENDI for a condition for which it is not prescribed. Do not share VONVENDI with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider or pharmacist about Vonvendi. The FDA approved product labeling can be found at https:\\www.shirecontent.com/ PI/PDFs/ VONVENDI_USA_ENG.pdf or call 1-800-828-2088.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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Takeda

2021 BLEEDING DISORDER CAMPS ACROSS THE COUNTRY

Year after year, many in the bleeding disorders community look forward to camp season with much anticipation and gusto. As we have done in previous years, we reached out to camps, chapters and other organizations to obtain camps dates and locations. Of course, with the pandemic of the last year, physical camps were cancelled with many organizations doing their best to replace in-person camps with virtual ones.

It goes without saying and it is of no great surprise that whether bleeding disorder camps take place in-person this year is still under much uncertainty. Although progress is being made with what we know about COVID-19 and with the growing availability of the new vaccines, it is still too early for some camps to confidently book dates for this summer.

Given what we know at this time, our annual list includes camps that are planning to host them one way or another. You will find some have dates scheduled for in-person camp (keeping fingers crossed!), some forecasting dates with a resounding "to-be-determined," while others planning to hold camp virtually. In an abundance of caution, a few have cancelled camp altogether and are not included in our 2021 list.

Understandably as summer approaches, current camp decisions may change week-to-week and state-by-state given CDC guidelines and recommendations. Please be sure to reach out to your local camp organization to learn specifically how your camp is proceeding - if, how and where it will be held, and when registration may take place.

1. Alabama Camp Clot Not

Date: July 24–29, 2021
Open to: Boys and girls with a bleeding disorder and carriers
Ages: 6–18
Location: Children's Harbor Mariner's Adventure Camp Alexander City, AL
Contact: Amanda Jennings, Consumer Relations Manager, 334-478-7822 amandajennings525@gmail.com
Host: Hemophilia and Bleeding Disorders of Alabama, Inc., www.hbda.us


Clot Not

1. Alabama Camp Harvest Family

Date: October 22–24, 2021
Open to: Active HBDA families with a parent or child with a bleeding disorder
Location: Children's Harbor–Harbor Lodge; Alexander City, AL
Contact: Amanda Jennings, Consumer Relations Manager, 334-478-7822, amandajennings525@gmail.com
Host: Hemophilia and Bleeding Disorders of Alabama, Inc., www.hbda.us

2. Alaska Camp Frozen Chosen


Frozen Chosen

Date: TBD - Planning a fall/winter Family Camp
Contact: Michelle Palmatier, Camp Director
907-229-6017
907-917-9235
alaskahemo@gmail.com
Host: Alaska Hemophilia Association and Bleeding Disorder Center
www.facebook.com/Alaska-HemophiliaAssociation-210132535692257/

3. Arizona Camp HONOR

Date: TBD
Open to: Boys and girls with a bleeding disorder, siblings and children of an affected parent
Ages: 8–17
Location: Prescott Pines; Prescott, AZ
Contact: Vickie Parra
vickie@arizonahemophilia.org, 602-955-3947
Host: Arizona Bleeding Disorders
www.arizonahemophilia.org

Honor

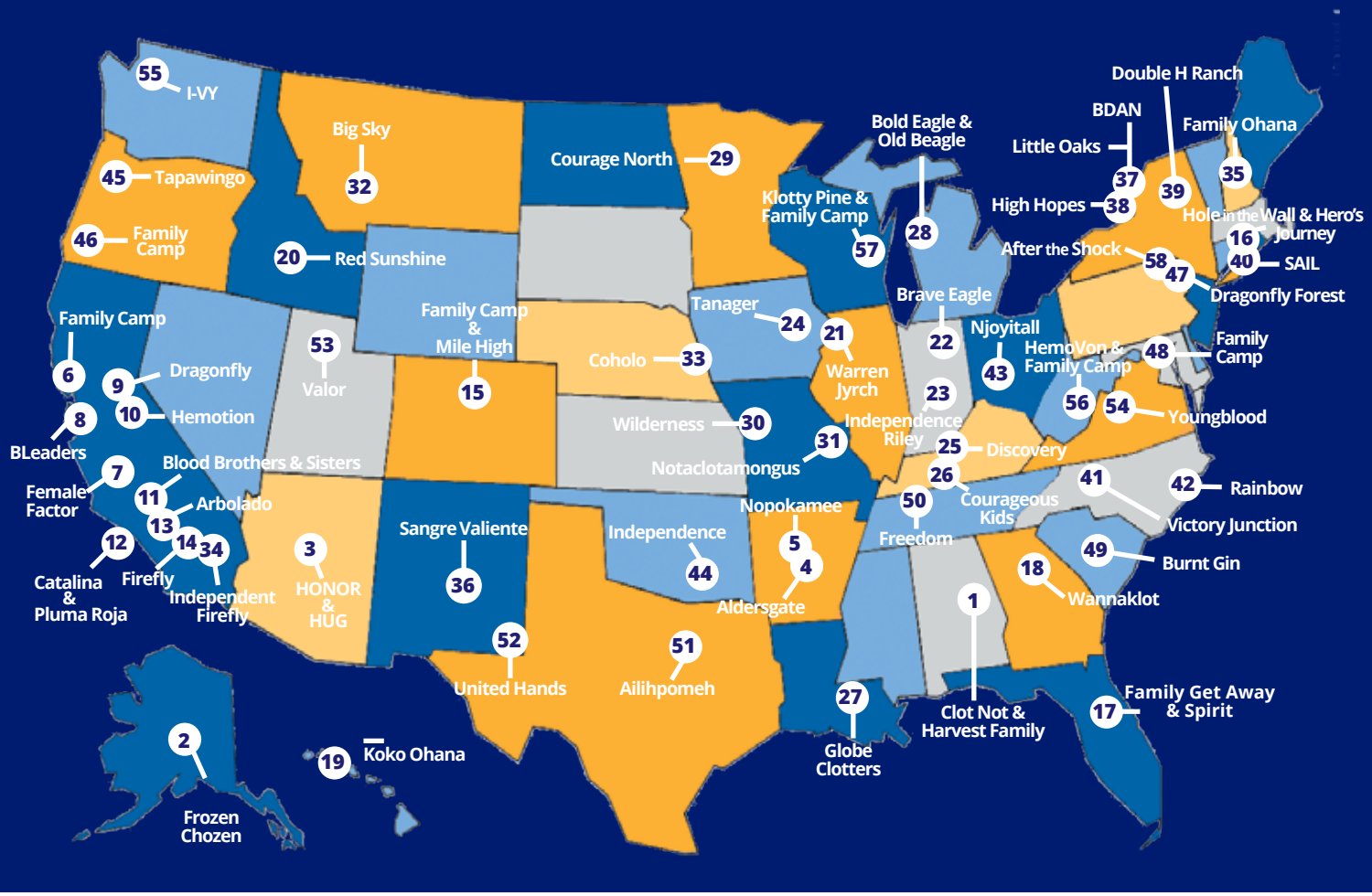
3. Arizona Camp HUG Family Camp

Date: TBD - mid-late October
Open to: AZ families with a parent or child with a bleeding disorder
Location: Prescott Pines Prescott, AZ
Contact: Vickie Parra
vickie@arizonahemophilia.org, 602-955-3947
Host: Arizona Bleeding Disorders
www.arizonahemophilia.org

4. Arkansas Camp Aldersgate

***Virtual* Date:** June 20–25, 2021
Open to: Boys and girls with a bleeding disorder, carriers and siblings
Ages: 6–18
Location: *Online*

In-Person Camps:
Date: July 11–16, July 18–23, July 25–30, Aug 1–6, 2021
Open to: Boys and girls with any medical condition (bleeding disorder, MS, cancer, spina bifida)
Ages: 6–18
Location: Camp Aldersgate; Little Rock, AR
Contact: Katie Jenkins
kjenkins@campaldersgate.net
Ali Miller, amiller@campaldersgate.net
501-225-1444
Host: Camp Aldersgate
www.campaldersgate.net



5. Arkansas Camp Nopokamee

Date: August TBD
Open to: Boys and girls with a bleeding disorder, carriers and siblings (space permitting)
Ages: 8–18
Location: 4H Vines Center; Little Rock, AR
Contact: Angela Hodgdon, 501-428-5754
secretary@arkhemofoundation.org
Host: Hemophilia Foundation of Arkansas
arkhemofoundation.org

6. Northern California Family Camp

***Virtual* Date:** March 27–28, 2021
Open to: Newly diagnosed families affected by a bleeding disorder and all other families in the HFNC region
Location: *Online*
Contact: Bryan Anderson, 510-658-3324
bryan.anderson@hemofoundation.org
Host: Hemophilia Foundation of Northern California, www.hemofoundation.org

7. California The Female Factor Retreat

***Virtual* Date:** April 23–25, 2021
Open to: Local, national and international women/teens/identifying affected and connected to the bleeding disorders community
Ages: 12 & up
Location: *Online*
Contact: Ashley Gregory, 510-658-3324
ashley.gregory@hemofoundation.org
Host: Hemophilia Foundation of Northern California, hemofoundation.org

8. California BLeaders Teen Retreat

***Virtual* Date:** May 1, 2021
Open to: Youth with a bleeding disorder and siblings residing within HFNC's service area
Ages: 14–19
Location: *Online*
Contact: Bryan Anderson, 510-658-3324
bryan.anderson@hemofoundation.org
Host: Hemophilia Foundation of Northern California, www.hemofoundation.org


BLeaders Teen Retreat

9. California Camp Dragonfly

Date: TBD
Open to: Boys and girls with a bleeding disorder, siblings and carriers (space permitting)
Ages: 14–17
Ages: 21+ General Staff
Location: South Fork of the American River Lotus, CA
Contact: Nooshin Kosar, ED, 619-325-3570
info@hasdc.org
Host: Hemophilia Association of San Diego County, www.hasdc.org

10. California Camp Hemotion

***Virtual* Date:** June 13–19, 2021
Open to: Youth with a bleeding disorder and their siblings
Ages: 7–14 Campers
Ages: 15–20 Jr. and Assistant Counselor Program
Location: *Online*
Contact: Bryan Anderson, 510-658-3324
bryan.anderson@hemofoundation.org
Host: Hemophilia Foundation of Northern California, www.hemofoundation.org


Hemotion


Hemotion


Blood Brothers and Sisters

11. California Camp Blood Brothers and Sisters

***Virtual* Date:** TBD
Open to: Boys and girls with a bleeding disorder
Ages: 7–16
Ages: 17–18 Leader-in-Training

Sibling Camp
***Virtual* Date:** TBD
Open to: Siblings of boys and girls with a bleeding disorder
Ages: 7–16

Location: *Online*
Contact: Cynthia Chavez, 626-765-6656
cynthia@hemosocal.org
Host: Hemophilia Foundation of Southern California, www.hemosocal.org

12. California LHF Catalina Family Camp

Date: TBD
Open to: Latino bleeding disorders families
Location: Campus by the Sea Avalon, CA
Contact: Rocio Nunez, ED
rocio@hemolatino.org, 626-427-2735
Facebook: https://www.facebook.com/latinohemophiliafoundation/
Host: Latino Hemophilia Foundation

12. California LHF Camp Pluma Roja

***Virtual* Date:** August 28–30, 2021
Open to: Latino boys and girls with a bleeding disorder
Ages: 7–16
Location: *Online*; register in July to receive a supply box
Contact: Rocio Nunez, ED
rocio@hemolatino.org, 626-427-2735
Facebook: https://www.facebook.com/latinohemophiliafoundation/
Host: Latino Hemophilia Foundation

13. California LHF Camp Arbolado

Date: October 8-10-2021 / TBD (if registration is not open by July, camp will be postponed to next year)
Open to: Latino bleeding disorders families
Ages: 7–16
Location: YMCA Camp Arbolado Angelus Oaks, CA
Contact: Rocio Nunez, ED
rocio@hemolatino.org, 626-427-2735
Facebook: https://www.facebook.com/latinohemophiliafoundation/
Host: Latino Hemophilia Foundation

14. California Camp Firefly

Date: TBD
Open to: Boys and girls with a bleeding disorder, siblings and carriers (space permitting)
Ages: 7–14
Ages: 16–17 Jr. Counselors
Ages: 18+ Counselors and General Staff
Location: YMCA Camp Oakes Big Bear, CA
Contact: Nooshin Kosar, ED, 619-325-3570
info@hasdc.org
Host: Hemophilia Association of San Diego County, www.hasdc.org


Firefly

15. Colorado Family Camp

Date: TBD, likely October
Open to: Adults with bleeding disorders and their family, families with a child with a bleeding disorder too young for camp, and young adults
Location: Rocky Mountain Village at Easter Seals; Empire, CO
Contact: Hanna Beary, Program Manager
646-499-0684
hbeary@hemophilia.org
Host: Colorado Chapter of the NHF
www.cohemo.org

15. Colorado Mile High Camp

Date: TBD, likely October
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 7–18
Location: Rocky Mountain Village at Easter Seals Empire, CO
Contact: Hanna Beary, Program Manager
646-499-0684
hbeary@hemophilia.org
Host: Colorado Chapter of the NHF
www.cohemo.org

16. Connecticut The Hole in the Wall Gang Hero's Journey

Young Adult Camp and Young Adult Sibling Camp combined
***Virtual* Date:** TBD
Open to: Adolescents with bleeding disorders and other serious illnesses, and siblings who have previously attended Hero's Journey.
Ages: 16–18
Location: *Online*
Contact: Paige Breton, 860-429-3444 x121
paige.breton@holeinthewallgang.org
admissions@holeinthewallgang.org
Host: Hole in the Wall Gang
www.holeinthewallgang.org

17. Florida Family Getaway Weekend

Date: April 23–25, 2021
Open to: Families with a bleeding disorder
Location: Camp Boggy Creek Eustis, FL
Contact: Fran Haynes, ED, 407-629-0000
800-293-6527
franhaynes@hemophiliaflorida.org
info@hemophiliaflorida.org
Host: Hemophilia Foundation of Greater Florida, www.hemophiliaflorida.org

17. Florida Camp Spirit

Date: TBD
Open to: Boys and girls with a bleeding disorder
Ages: 7–16
Location: Camp Boggy Creek; Eustis, FL
Contact: Fran Haynes, ED, 407-629-0000, 800-293-6527
franhaynes@hemophiliaflorida.org
info@hemophiliaflorida.org
Host: Hemophilia Foundation of Greater Florida, www.hemophiliaflorida.org


Spirit

18. Georgia Camp Wannaklot

Date: TBD
Open to: Boys and girls with a bleeding disorder
Ages: 7–12 Junior Camp
Ages: 13–17 Teen Camp
Location: Camp Twin Lakes Rutledge, GA
Contact: Kim Williams, 770-518-8272
kawilliams@hog.org
Host: Hemophilia of Georgia
www.hog.org/camp/

19. Hawaii Koko Ohana Family Camp

Date: September 10–12, 2021 (tentative date)
Open to: Families and individuals with a bleeding disorder
Location: Camp Moluke'ia; Waialua, HI
Contact: Kyra Calbero, Program Manager
808-284-7417, kcalbero@hemophilia.org
Host: Hawaii Chapter-NHF
www.hawaiinhf.org


Virtual Koko Ohana

20. Idaho Red Sunrise Family Camp

***Virtual* Date:** June TBD
Open to: Families affected by a bleeding disorder
Location: *Online*
Contact: Marlyn Walker 208-344-4476 208-631-9729, mwalker@hemophilia.org
Host: Idaho Chapter of NHF
www.idahoblood.org

21. Illinois Camp Warren Jyrch

***Virtual* Date:** TBD
Open to: Boys and girls with a bleeding disorder, diagnosed carriers
Ages: 7–17
Location: *Online*
Contact: Hannah Noelle Simpson, 312-216-1142 hsimpson@bdai.org
Host: Bleeding Disorders Alliance Illinois
www.bdai.org/campwarrenjyrch

22. Indiana Camp Brave Eagle

Date: June 13–18, 2021
Open to: Boys and girls with a diagnosed bleeding disorder and carriers
Ages: 7–17
Location: Camp Crosley YMCA North Webster, IN
Contact: Angel DiRuzza, Program Director, ADiRuzza@hoii.org, 317-570-0039 x102, Scott Ehnes, sehnes@hoii.org
Host: Hemophilia of Indiana, Inc., www.hoii.org, www.campbraveeagle.org

23. Indiana Riley Camp Independence

***Virtual* Date:** June 26–July 2, 2021
Ages: 8–18
Open to: Boys and girls with hematological disorders
Location: *Online*
Contact: Debbie Bell 317-948-3111 rileyhemnurse@iuhealth.org
Host: Riley Hospital for Children at IU
www.bradwoods.org/campriley/index.html

24. Iowa Bleeding Disorder Summer Camp at Camp Tanager

Date: TBD
Open to: Boys and girls with a bleeding disorder and one guest per family
Ages: 6–17
Location: Camp Tanager; Mount Vernon, IA
Contact: Mary Warner, ED m.warner@hemophiliaofiowa.org or Hemophilia Nurses Michelle Krantz and Karla Watkinson, 319-356-4277
Host: Iowa Hemophilia and Thrombosis Center
https://medicine.uiowa.edu/pediatrics/research/pediatric-centers-and-programs/iowa-hemophilia-and-thrombosis-center

25. Kentucky Camp Discovery

Date: July 25–29, 2021 (TBD if in-person or virtual)
Open to: Boys and girls with a bleeding disorder and siblings (space permitting)
Ages: 7–15
Ages: 16–17 Jr. Counselors-in-Training
Location: Cedar Ridge Camp; Louisville, KY
Contact: Ursela Kamala, ED, 502-456-3233 ursela@kyhemo.org
Host: Kentucky Hemophilia Foundation, info@kyhemo.org, www.kyhemo.org

26. Kentucky Center for Courageous Kids Family Camp

Date: July 30–August 1, 2021 (tentative)
Open to: Families with bleeding disorders (hemophilia, vWD, ITP, SCA)
Location: The Center for Courageous Kids Scottsville, KY
Contact: Hannah Reckart 270-303-1338 hreckart@courageouskids.org
Host: CCK, www.courageouskids.org

27. Louisiana Camp GlobeClotters – Tulane Transitions Retreat

Date: TBD June or July TBD in-person or virtual
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 7–18
Contact: Ashley Castello, ED, 225-291-1675 director@lahemo.org or Danielle Rowley outreach@lahemo.org
Host: Louisiana Hemophilia Foundation
www.lahemo.org

28. Michigan Camp Bold Eagle

***Virtual* Date:** July 5–30, 2021 (Monday-Friday)
Open to: Boys and girls with a bleeding disorder
Ages: 6–9 , 10–12, and 13–17
Location: *Online*
Contact: https://hfmich.org/camp/
Host: Hemophilia Foundation of Michigan
www.hfmich.org

28. Michigan Camp Old Beagle

Date: September 10–12, 2021
Open to: All former staff and campers of Bold Eagle, Eagle Outpost, Eagle Expedition and Eagle Quest
Ages: At least 18 years old, includes their immediate family and spouse/significant other
Location: Pioneer Trails; Holton, MI
Contact: https://hfmich.org/camp/
Host: Hemophilia Foundation of Michigan
www.hfmich.org

29. Minnesota Camp Courage North

Date: July TBD
Open to: Boys and girls with a bleeding disorder
Ages: 7–17
Location: Camp Courage North Lake George, MN
Contact: Melissa Andrisani, Event Coordinator, melissaa@hfmd.org or James Paist, ED, 651-406-8655, jamesp@hfmd.org
Host: Hemophilia Foundation of Minnesota/Dakotas, www.hfmd.org

30. Missouri Camp Wilderness

Date: August 2–6, 2021
Open to: Boys and girls with a bleeding disorder and carriers
Ages: 7–17
Location: Lake Doniphan Retreat Center Excelsior Springs, MO
Contact: Luke Saulsberry, Camp Director 816-315-7308 mhacampdirector@gmail.com or Angela 816-479-5900, info@midwesthemophilia.org
Host: Midwest Hemophilia Association, https://midwesthemophilia.org/


Wilderness


Notaclotamongus

31. Missouri Camp Notaclotamongus

***Virtual* Date:** June 9–11, 2021– PHASE 1
Open to: Boys and girls with a bleeding disorder
Ages: 7–17
Location: *Online*

Day Camp Date: July 10, 2021 PHASE 2 (TBD In-person or virtual)

Location: DoubleTree Hotel Chesterfield, MO

Bonfire Date: October 2, 2021 – PHASE 3
Location: Camp Wyman; Eureka, MO
Contact: Bridget Tyrey, 314-482-5973 info@gatewayhemophilia.org
Host: Gateway Hemophilia Foundation www.gatewayhemophilia.org

32. Montana/Wyoming RMHBDA BIG SKY Family Camp

Date: August 13–15, 2021
Open to: Families or caregivers managing a bleeding disorder
Location: Flathead Lake Methodist Camp; Rollins, MT
Contact: Brad Benne, ED, 406-586-4050 brad@rmhbda.org
Host: Rocky Mountain Hemophilia Bleeding Disorders Association, www.rmhbda.org

33. Nebraska Camp CoHoLo Children's Cancer Camps

Open to: Boys and girls impacted by cancer or blood disorders
Date: July 18–21, 2021 **Ages:** 6–11

Teens Date: July 21–25, 2021 **Ages:** 12–17

Siblings Date: Sept. 10–12, 2021 **Ages**: 6–13

Location: Eastern NE 4H Center; Gretna, NE
Contact: Berta Ackerson, Camp Director 402-707-2154, director@campcoholo.com
Host: Camp CoHoLo, www.campcoholo.com

A NEW ERA FOR CAMP!

BY SARAH SHINKMAN, NEHA PROGRAM DIRECTOR

Family Camp is a beloved tradition for families in the New England region to learn self-infusion skills and connect with others in the bleeding disorders community. It is also an opportunity for attendees to spend time with friends and family, away from work and other responsibilities. Simply put, camp is special and making the decision to turn it into a virtual experience was difficult, but necessary to protect the health of patients in our community. With the help of our Camp Medical Team and Planning Committee, NEHA began transitioning our Family Camp in April 2020 from in-person to online.

The goal was to offer a fun alternative to in-person activities that incorporated core principles of education and connection. Our initial approach was to find a creative way to make beloved traditions virtual and accessible from anywhere. Using the mobile app, GooseChase, we created a Scavenger Hunt with many favorite camp activities reimagined. Trivia games and arts and crafts were included, and families made the most of the activities while creating new memories. We were thrilled with the engagement from all campers!

Offering interactive programming online was another major component of Virtual Family Camp. To respond to the needs of our community, we purposefully limited live programming to four sessions held on June 27 and 28, 2020, which included a welcome session, bleeding disorders educational activity with our Camp Medical Team, and two simulated campfires.

Incorporating lively presentations, camp songs, and a culminating slideshow allowed us to maintain the spirit of camp. With everyone isolated because of the pandemic, virtual programming is an outlet to see and hear from others with a shared experience.

35. New England Hemophilia Association Annual Family Ohana

Date: August 15–21, 2021
Open to: All families with a bleeding disorder living in New England
Location: Geneva Point Center Moultonborough, NH
Contact: Sarah Shinkman, Program Director, 781-326-7645 sshinkman@nehemophilia.org
Host: New England Hemophilia Association, www.nehemophilia.org

Although virtual, upholding this connection was so important to us. These events also allowed us to engage a wider audience from across our region. While we are hopeful to be able to return to in-person camp this year, it is good to know that alternative methods deliver fun and meaningful opportunities no matter where we are.


Annual Family Ohana

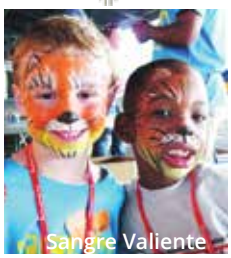
34. Nevada Camp Independent Firefly

***Virtual* Date:** June 15–18, 2021
Open to: Boys and girls living in NV with a bleeding disorder and siblings
Ages: 7–17
Ages: 16–17 Leaders-in-Training
Location: *Online*
Contact: Maureen Salazar-Magana
702-564-4368, mmagana@hemophilia.org
Host: Nevada Chapter of NHF, www.hfnv.org

Independent Firefly

36. New Mexico Camp Sangre Valiente

Date: June 6–11, 2021
Open to: Children with a bleeding disorder and siblings
Ages: 7–17
Location: Camp Oro Quay; Sandia, NM
Contact:
Alfonso Jaramillo
505-341-9321
alfonso.jaramillo@sangredeoro.org
Host: Sangre de Oro, Inc. Bleeding Disorders Foundation of NM, www.sangredeoro.org


Sangre Valiente

37. New York BDAN Family Camp

Date: October 9–11, 2021
Open to: Families and adults with a bleeding disorder
Location:
Aldersgate Camp & Retreat Center
Greig, NY
Contact:
Bob Graham
315-396-2944
bdaninc@gmail.com
Host: Bleeding Disorder Advocacy Network
www.bdaninc.org


BDAN Family

37. New York Camp Little Oak

Date: July 25–31, 2021
Open to: Girls with a bleeding disorder, carriers and sisters of boys with a bleeding disorder
Ages: 7–17
Location: Aldersgate Camp and Retreat Center; Grieg, NY
Contact: Hannah Russell, Camp Director
425-770-1801
hannah.m.russell.p@gmail.com
Host: Camp Little Oak
https://camplittleoak.org/

38. New York Camp High Hopes

Date: July 25–31, 2021
Open to: Boys with a bleeding disorder, male siblings and male family members of women with a bleeding disorder
Ages: 7–17
Location: Camp Aldersgate Brantingham, NY
Contact: Joe Brennan
607-226-5474
jbrennan@camphighhopes.org
Hope Woodcock-Ross, Health Director
607-222-8412, hope@camphighhopes.org
Host: Camp High Hopes Inc.
www.camphighhopes.org

39. New York Double H Ranch

Date: TBD Summer 2021
Open to: Boys and girls with a bleeding disorder
Ages: 6–16
Location: Lake Luzerne, NY
Contact: Tara Bogucki, 518-696-5676 x222
tbogucki@doublehranch.org
Host: Double H Ranch
www.doublehranch.org


Double H Ranch


Double H Ranch

40. New York Camp SAIL

***Virtual* Date:** June 5, 2021
Open to: Boys and girls with a bleeding disorder, carriers and siblings in New York State.
Ages: 13–18 One parent mandatory for each attendee under 18
Location: *Online*


SAIL

Contact:
Tyshawn Constantine, Program Director
212-682-5510
tconstantine@hemophiliany.com
Host: Hemophilia Association of New York www.hemophiliany.com

41. North Carolina Victory Junction Family Day Camp

Date: TBD
Open to: Families of boys and girls ages 6–16 with a bleeding disorder
Location: Victory Junction Randleman, NC
Contact: Victory Junction Camper Admissions Team, 336-498-9055
camperadmissions@victoryjunction.org
Host: Victory Junction
www.victoryjunction.org


Victory Junction

42. North Carolina Camp Rainbow

Date: June 6–12, 2021
Open to: Boys and girls with a bleeding disorder treated by the Brody School of Medicine at East Carolina University
Ages: Jr High/Sr High Students only
Location: Don Lee Camp & Retreat Center Arapahoe, NC
Contact: Jacquelyn Sauls, MS, CCLS
252-744-3304
saulsj@ecu.edu or
Tamika Mackey, BS, CLS, 252-744-1170
Host: East Carolina University Hemophilia Treatment Center


Rainbow

43. Ohio Camp Njoyitall

Teen Week
***Virtual* Date:** July 19–23, 2021
Open to: Current patients of Cincinnati Children's Hospital Medical Center/Cancer and Blood Diseases Institute
Ages: 12–17
Location: *Online*

Kids Week
***Virtual* Date:**
July 26–30, 2021
Ages: 7–12
Location: *Online*


Njoyitall

Contact: Abbie Caplinger, Camp Director
513-636-NJOY (6569)
cbdi.camp@cchmc.org
Host: Cincinnati Children's Hospital Medical Center, https://www.cincinnatichildrens.org/service/c/cancer-blood/patients/camp

44. Oklahoma Camp Independence

Virtual **Date:** TBD
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 6–18
Location: *Online*
Contact: Nathan Holloway, Camp Program Co-Chair, 918-804-8184
nathan@okhemophilia.org
Nate Anders, Camp Activities & Leadership Co-Chair, 405-833-1730
nateanders2@gmail.com
Lindsey Russell, Camp Admin Co-Chair, 479-306-8115, russell@okhemophilia.org
www.campindependence.org
Tim Grogan, ED, 918-605-2579
tgrogan@okbleedingdisorders.org
Host: Oklahoma Hemophilia Foundation
www.okhemophilia.org

45. Pacific Northwest Camp Tapawingo

Date: August 1–6, 2021 (TBD Virtual or in-person)
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 8–17
Location: TBD *Online* or location
Contact: Madonna McGuire Smith 541-753-0730
m.mcguiresmith@pnwbd.org
Host: Pacific Northwest Bleeding Disorders
www.pnwbd.org

46. Pacific North West PNWBD Family Camp

Date: June 17–20, 2021
Open to: All families living with a bleeding disorder
Location: TBD Virtual or in-person
Contact: Madonna McGuire Smith 541-753-0730
m.mcguiresmith@pnwbd.org
Host: Pacific Northwest Bleeding Disorders
www.pnwbd.org

47. Pennsylvania Camp Dragonfly Forest

Date: July 18–23, 2021
Open to: Boys and girls with a bleeding disorder, sickle cell or asthma
Ages: 7–14

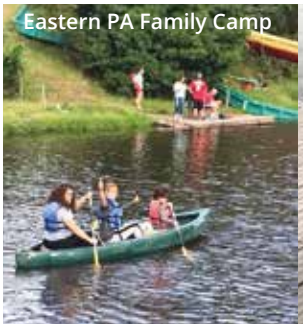
Teen Leadership Program
Date: July 11–23, 2021
Ages:15–16

SibShop Camp
Date: August 8–13, 2021
Open to: Siblings of children with special needs
Ages: 7–14

Location: YMCA Camp Speers Dingmans Ferry, PA
Contact: 570-828-2329, Kelly Daly, ED
kelly.daly@philaymca.org or
Jackie Pentecharsky
jackie.pentecharsky@philaymca.org
Host: Camp Speers YMCA
www.dragonflyforest.org

48. Eastern Pennsylvania Hemophilia Foundation Family Camp

Date: September 17–19, 2021
Open to: Families of children with a bleeding disorder in Eastern PA (max 6 per family)
Location: Camp Kweebec Schwenksville, PA
Contact: Lindsay Frei, 484-445-4282
lindsayf@hemophiliasupport.org
Host: Eastern PA Hemophilia Foundation
www.hemophiliasupport.org



49. South Carolina Camp Burnt Gin

***Virtual* Date:** July TBD
Open to: Boys and girls with hemophilia, sickle cell and other blood disorders
Ages: 7–15
Contact: Marie Aimone, Camp Director
803-898-0784
campburntgin@dhec.sc.gov
Location: *Online*
Host: South Carolina Department of Health and Environmental Control
www.scdhec.gov/health/child-teen-health/services-children-special-health-care-needs/camp-burnt-gin

50. Tennessee Camp Freedom

Date: TBD
Open to: Boys and girls with a bleeding disorder and carriers
Ages: 7–15
Ages: 16–17 Leaders–in–Training
Location: Brandon Spring Group Center Dover, TN
Contact: Teresa Nothan, ED
teresa@thbdf.org
Robby Bond, Project Asst., 615-900-1486
robby.bond@thbdf.org
Host: TN Hemophilia and Bleeding Disorders Foundation, www.thbdf.org

51. Texas Camp Ailihpomeh

***Virtual* Date:** Multiple dates and activities visit www.campjohnmarc.org
Open to: Boys with a bleeding disorder
Ages: 7-15
Location: *Online*
Contact: Meaghan White
214-360-9084, mwhite@campjohnmarc.org
info@camp-ailihpomeh.org
Host: Texas Bleeding Disorders Camp Foundation, www.camp-ailihpomeh.org
www.campjohnmarc.org

52. Texas Camp United Hands

***Virtual* Date:** July 19–23, 2021
Open to: Boys and girls affected by a bleeding disorder and siblings
Ages: 7–17
Location: *Online*
Contact: Jesus Escobedo, 915-540-4569
915-621-8285, jescobedo1.hoep@gmail.com
Host: Hemophilia Outreach El Paso
www.hemoelp.org
www.hemoelp.org/campunitedhands.html

53. Utah Camp Valor

Date: August 2–5, 2021
Open to: Children with a bleeding disorder and carriers
Ages: 8–13
Ages: 10–11 Siblings of children with a bleeding disorder and children of affected parents
Location: Camp Wapiti; Tooele, UT
Contact: Jan Western, 801-484-0325
western@hemophiliautah.org
Host: Utah Hemophilia Foundation
www.hemophiliautah.org

54. Virginia Camp Youngblood

***Virtual* Date:** TBD
Open to: Children with inherited bleeding disorders, siblings and children of inherited bleeding disorder community members in VA and the Capital area
Ages: 7–17
Location: *Online*

Camp Holiday Trails Day Camp
Camp Youngblood
Date: TBD
Open to: Children and teens with a medical need and their siblings
Ages: 7-17
Location: Camp Holiday Trails
Charlottesville, VA

Camp Holiday Trails
Everywhere: Pop-Up Camp
Taking CHT on the road. A van will take camp counselors & camp activities to partners throughout the Mid-Atlantic region for programs in outdoor spaces. Available to new and previous campers, children and teens with bleeding disorders and other medical needs.

Contact: Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
HACA 703-352-7641
Host: Camp Holiday Trails Tina LaRoche, 434-305-0929 or Katrina at
campisgood@campholidaytrails.org
https://campholidaytrails.org/campers/

55. Washington Camp I–Vy

Date: TBD
Open to: Children affected by a bleeding disorder (no siblings this year)
Ages: 7–15
Location: Camp Huston; Gold Bar, WA
Contact: Erica Duke, Camp Director
206-533-1660, general@bdfwa.org
Host: Bleeding Disorder Foundation of Washington, www.bdfwa.org

56. West Virginia Camp HemoVon

Date: June 14–18, 2021
Ages: 7-17
Open to: Open to West Virginian children with a bleeding disorder or pediatric oncology diagnosis
Location: Camp Twin Creeks
Marlinton, WV
Contact: Anita Graham, 304-293-1205
agraham@hsc.wvu.edu
Host: West Virginia University Hemophilia Treatment Center

56. West Virginia Family Camp

Date: June 18–20, 2021
Open to: Open to all West Virginia families with a bleeding disorder
Location: Camp Twin Creeks
Marlinton, WV
Contact: Fernando Andrzejevski
681-212-9255
fandrzejevski@hemophilia.org
Host: West Virginia Chapter of the National Hemophilia Foundation, www.wvnhf.org

57. Wisconsin Camp Klotty Pine

Date: August 10–14, 2021
Open to: Boys and girls with a bleeding disorder and diagnosed carriers
Ages: 7–15 (age exceptions made case-by-case)
Ages: 15–18 Leaders-In-Training Program for former campers from Wisconsin, Minnesota, Michigan or Illinois
Location: Campbellsport, WI
Contact: Karin Koppen, 414-937-6782
kkoppen@glhf.org
Host: Great Lakes Hemophilia Foundation
414-257-0200, www.glhf.org

57. Wisconsin Camp Klotty Pine Family Camp

Date: TBD
Open to: ALL families living with a bleeding disorder
Location: Campbellsport, WI
Contact: Karin Koppen, 414-937-6782
kkoppen@glhf.org
Host: Great Lakes Hemophilia Foundation
414-257-0200, www.glhf.org

58. National Inhibitor Family

Camp Program: After the Shock
Date: August 27–30, 2021
Open to: Families with a child (ages 0-18) managing a currently active or previously active inhibitor within 3 years regardless of what bypassing agents and/or factor products they use. Those who have tolerized greater than 3 years will be accepted space permitting.
Location: Camp Zeke; Lakewood, PA
Contact: CHES, 781-878-8561
info@ches.education
Host: nSpiration Foundation
https://nspiration.foundation/after-the-shock

Time for Fun!

ANSWERS TO PUZZLES ON PAGE 35

1. **c.** Plenty of cash
2. **c.** Michigan
3. **c.** Hemophilia spelled backwards
4. **b.** Elephant racing
5. **d.** All of the above
6. **d.** All of the above
7. **c.** Other kids with a bleeding disorder
8. **a.** Around a campfire
9. **b.** Camp No-No-Clotter
10. **a.** Camp Notacclotamongus

3	6	1	5	4	9	8	2	7
4	9	8	6	7	2	5	3	1
7	2	5	8	3	1	6	4	9
2	8	3	1	5	7	4	9	6
5	7	4	3	9	6	2	1	8
6	1	9	2	8	4	7	5	3
8	3	7	4	1	5	9	6	2
9	4	2	7	6	3	1	8	5
1	5	6	9	2	8	3	7	4

5	1	3	9	8	4	6	7	2
6	9	4	2	5	7	8	3	1
8	7	2	6	1	3	5	4	9
9	2	6	3	7	8	4	1	5
1	5	8	4	2	9	7	6	3
3	4	7	5	6	1	9	2	8
4	6	9	8	3	2	1	5	7
2	8	1	7	4	5	3	9	6
7	3	5	1	9	6	2	8	4

BIOMATRIX ON THE *Virtual* MOVE!

We are all looking forward to the day we can have in-person meetings. Until then, though we're not yet on the physical "move," we've been busy hosting all sorts of fun-filled and informative educational Zoom meetings! Read on to see what we've been up to, and until we can meet in person again, plan on joining us soon!

#BioMatrix Mug Club

Curl up with your favorite warm beverage and BioMatrix virtual programming! BioMatrix offers a variety of educational and entertaining topics in small or large groups and in individual settings. All program participants receive one of our fantastic coffee mugs along with a few other useful items!

Have you participated in BioMatrix educational programming? Post a photo using the hashtag #biomatrixmugclub.

Visit us to learn more!

https://www.biomatrixsprx.com/bleeding-disorders-education

* Please note: California Medicaid, Medi-Cal, CCS, and GHPP patients are not eligible to receive a BioMatrix gift box.

Awareness for Advocacy

This program highlights the need for record keeping, health literacy and tools when faced with challenges such as appeals, denials and problems with access to care.

JANUARY 31, 2021
Presenter: Shelby Smoak
RCC: Terry Stone and Michelle Stielper
Host: HACA Teen Advocacy

FEBRUARY 23, 2021
FEBRUARY 24, 2021
FEBRUARY 25, 2021
Presenter: Kelly Gonzalez
Host: NHF Nevada State Days

SCHOLARSHIP 101

This workshop-style program is designed to assist high school students and those already in college to identify available scholarships, what items are needed, how to apply, and how to keep track of applications. Attendees were also given a list of available bleeding disorders community scholarships.

FEBRUARY 18, 2021
WEST COAST
Presenter: Kelly Gonzalez
Comms Manager: Maria Vetter

FEBRUARY 23, 2021
EAST COAST
Presenter: Kelly Gonzalez
Comms Manager: Maria Vetter

INSURANCE ✓ Basics

If you've ever faced insurance challenges, this program is for you. Learn about insurance policy-making and how to appeal decisions made by your health insurance plan.

JANUARY 21, 2021
Presenter: Shelby Smoak
RCC: Justin Lindhorst
Partner: Octapharma

MARCH 16, 2021
Presenter: Terry Rice
RCC: Eva Kraemer
Partner: Octapharma
Host: Blood Bond Bleeding Disorder Network

Tea Time!

MARCH 18, 2021
Presenter: Kelly Gonzalez
RCC: Shelia Biljes

Times of stress can be made even more taxing by many factors, including not being able to be with people face-to-face who we care about. This past year has been challenging for everyone. One way to work through the chaos of emotions and uncertainties that roll over into our personal lives is to reach out more often and work on meaningful connections. While enjoying facetime and candid conversation, a few women from several states (OH, MI, NV, IL) joined to do just that with an afternoon *Virtual Teatime.*

The group reflected on some helpful guidance for maintaining healthy relationships with loved ones under the cloud of COVID. The ladies enjoyed tea and a snack while Kelly Gonzalez, Senior Educational Specialist, facilitated the discussion. As the ladies shared how the lack of in-person time together has affected their family relationships, friendships, and mental well-being – Kelly offered tips on keeping interactions strong during these stressful times. Everyone enjoyed sharing so much we went well over the allotted time just to be together. Thank you to the wonderfully strong women who attended!

Feed Mind + Body — WITH CHEF MIKE!

Mike Hargett is a professionally trained chef, double transplant recipient, and person with hemophilia. He has gained fame within the bleeding disorder and transplant communities as a fantastic cooking demonstrator. Chef Mike shares his enthusiasm for cooking and his "zest" for life as he elevates ordinary household ingredients into savory, restaurant-enviable meals. As the world's first person with hemophilia to receive a heart and a kidney transplant, Mike's positive attitude, good-humored personality, passion for cooking, and perseverance embody his spirit of "cooking with heart."

JANUARY 28, 2021
Putting the Mask on First
Recipe: The OG Pasta Fasul - AKA Pasta E Fagioli
Presenter: Terry Rice
Program: *Advocacy 101*
RCCs: Eva Kraemer and Rania Salem

FEBRUARY 4, 2021
Recipe: *Chicken Pot Pie 2.0 - AKA Handheld Chicken Pot Hand Pies and Simple and Delicious Side Salad*
Presenter: Terry Rice
Program: *Putting the Mask on First*
RCC: Bill Wilbert
Host: KY Hemophilia Foundation

FEBRUARY 13, 2021
Valentine Special!
Recipe: *Light and Fluffy Beignets*
Presenter: Kelly Gonzalez
Program: *Safe Travels*
Host: BioMatrix Education Team

MARCH 17, 2021
St. Patrick's Day Special!
Recipe: *Beer Braised Corned Beef Hash with a Beer Horseradish Honey Mustard and a Perfectly Poached Egg*
Presenter: Shelby Smoak
Program: *Insurance Basics*
RCC: Jeff Johnson
Host: BioMatrix Education Team

Learning from a Pro!

BIOMATRIX GAME NIGHT

Looking for fun? Join us for a future Game Night! Below are a few of our past get-togethers.

JANUARY 8, 2021
Family Feud
Presenter: Shelby Smoak
RCC: Richard Vogel
Host: New England Hemophilia Association

FEBRUARY 19, 2021
JeoParody
Presenter: Shelby Smoak
RCC: Rich Vogel
Host: Hemophilia Association of New Jersey

FEBRUARY 25, 2021
Family Feud "Battle of the Beards"
Presenter: Shelby Smoak
RCCs: Rania Salem and Eva Kraemer


MARCH 4, 2021
JeoParody
Presenter: Kelly Gonzalez
RCC: John Martinez
Host: Hemophilia Foundation of Northern California

MARCH 12, 2021
Family Feud
Presenter: Shelby Smoak
RCC: Richard Vogel
Host: Connecticut Hemophilia Society

For information about our educational sessions and game nights, or to schedule a session for your group (large or small!), please contact us at:
(877) 337-3002 ext. 1515, https://www.biomatrixsprx.com/contact

Attend and Win!

Attend our educational and fun Zoom events and have your name entered into a participation raffle for a $50 gift card!

Raffle Winners First Quarter 2021!

January 26 - Glenn Rosenwald
March 11 - Courtney Thomas

Spring Cleaning MEDICAL SUPPLIES

BY SARAH HENDERSON

Spring is in the air! As windows are thrown open to let the fresh air in, many are inspired to do a deep cleaning around the house. As you tackle your spring cleaning tasks, make sure to give your medicine storage area be it a cabinet, shelf, drawer or closet a thorough inspection as well.

While I love the feeling of a good cleaning, I love even more the feeling I get when I look at my clean and orderly factor and supply storage! Here are some tips for spring cleaning your medicine storage:

- First and foremost, store all medications and in a cool, dry and dark area that is inaccessible to children. Avoid storing in a bathroom cabinet where humidity, heat and light can cause medications to lose their efficacy.
- Check expiration dates on *everything*. Medications lose effectiveness and can even become toxic once expired.
- Check all ancillary supplies - saline, butterfly needles, port supplies, disinfectant swabs, etc., for a printed expiration date. *Yes,* many supplies may also have expiration dates.
- Arrange clotting factor so the boxes with the longest expiration date are in the back and factor expiring soonest is at the front to be used first. This will keep the stock fresh and lessen the chance of allowing valuable factor to go to waste. Each time a new factor order is received, place the new boxes behind the existing ones.
- Take this time to double-check manufacturer recommendations on how, where and how long to properly store clotting factor and medications.
- If a pump is used to infuse, be sure to insert fresh batteries and determine if it's time for the pump to be calibrated or updated.
- Go through all medications that may be used infrequently but are just as important to always have at their best. For example, if Amicar is kept on-hand, reorder as it nears its expiration date. Then when needed, it will be available and at its best efficacy.
- Check any topicals, over-the-counter medications, vitamins, and supplements as well. If there is any change in color or smell, toss it.
- If a medication is not in its original container and it isn't 100% known what it is, dispose of it.
- For any medications with a "use within X days of opening," write the date it was first opened on the lid, so it's easy to remember when that was.
- Dispose of medications properly. Here are a few suggestions on how to determine the best way to dispose of them:
    - The FDA offers advice on how to properly discard medications. Visit: www.fda.gov/ForConsumers/ConsumerUpdates/ucm101653.htm
    - Law enforcement sponsors a drug take-back day where unneeded prescription medication can be safely disposed of. Contact the Drug Enforcement Agency at 1-800-882-9539 or visit their website for dates and locations: https://www.deadiversion.usdoj.gov/drug_disposal/takeback/index.html
    - Local police stations will often properly discard old medications as well.
    - Many neighborhood pharmacies offer disposal programs. Visit http://disposemymeds.org to find a location near you.
- Consider donating factor product that has not expired but will no longer be used to *Save One Life*, where it will be sent to help patients in developing countries: https://saveonelife.net/how-you-can-help/project-share.

Now that the task is complete, sit back, congratulate yourself on a job well done and relax!

References:

- "Where and How to Dispose of Unused Medicines." U.S. Food and Drug Administration, FDA, www.fda.gov/consumers/consumer-updates/where-and-how-dispose-unused-medicines.
- Nkf. "6 Tips to Help 'Spring Clean' Your Medicine Cabinet." National Kidney Foundation, 30 Mar. 2018, www.kidney.org/newsletter/6-tips-to-help-%E2%80%9Cspring-clean%E2%80%9D-your-medicine-cabinet.

Time for Fun!

Hi Kids! How much you know about bleeding disorders camp? Answers are on page 29.

1. **When you go to bleeding disorders camp, which of these items should you leave at home?**
   a. Shoes
   b. Your toothbrush
   c. Plenty of cash
   d. Extra socks and underwear

2. **In which state was the very first hemophilia camp held?**
   a. Alaska
   b. California
   c. Michigan
   d. Hawaii

3. **Where did the Texas camp name "CAMP AILIHPOMEH" come from?**
   a. In honor of Tommy Ailihpomeh
   b. Scrabble letters left on a board
   c. Hemophilia spelled backwards
   d. A famous Texas river

4. **Which of these activities is NEVER found at camp?**
   a. Dance party
   b. Elephant racing
   c. Rock climbing
   d. Star gazing

5. **Which of these activities are often found at camp?**
   a. Swimming
   b. Archery
   c. Hiking
   d. All of the above

6. **What might you learn at camp?**
   a. How to row a canoe
   b. How to self-infuse
   c. How to act in a skit
   d. All of the above

7. **Who are you most likely meet at camp?**
   a. Zookeepers
   b. Famous sports stars
   c. Other kids with a bleeding disorder
   d. Professional boxers

8. **A popular place where songs might be sung at camp is where?**
   a. Around a campfire
   b. In the mess hall
   c. In the swimming pool
   d. In a canoe

9. **Which of these is NOT the name of a real bleeding disorders camp?**
   a. Camp Clot Not
   b. Camp No-No Clotter
   c. Camp Hot-To-Clot
   d. Camp Wannaklot

10. **Which of these IS the name of a real bleeding disorders camp?**
    a. Camp Notaclotamongus
    b. Camp Stoppableed
    c. Camp Wishaclot
    d. Camp Infusableed

Sudoku!

Fill in the grid so every row, every column, and every 9 by 9 box contains the numbers 1 through 9.

3	6	1	5	4	9			
		8			2	5	3	
	2		8		1			
2						4		6
				9		2	1	
					4	7	5	
8	3	7			5	9	6	
9		2	7				8	
1	5		9			3	7	4

5		3			4	6	7	
	9		2	5		8	3	1
		2	6		3			9
	2		3	7			1	5
		8		2		7	6	
3			5	6				
4	6					1		7
2	8	1		4				
		5		9			8	

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DEDICATED TO MAKING A DIFFERENCE

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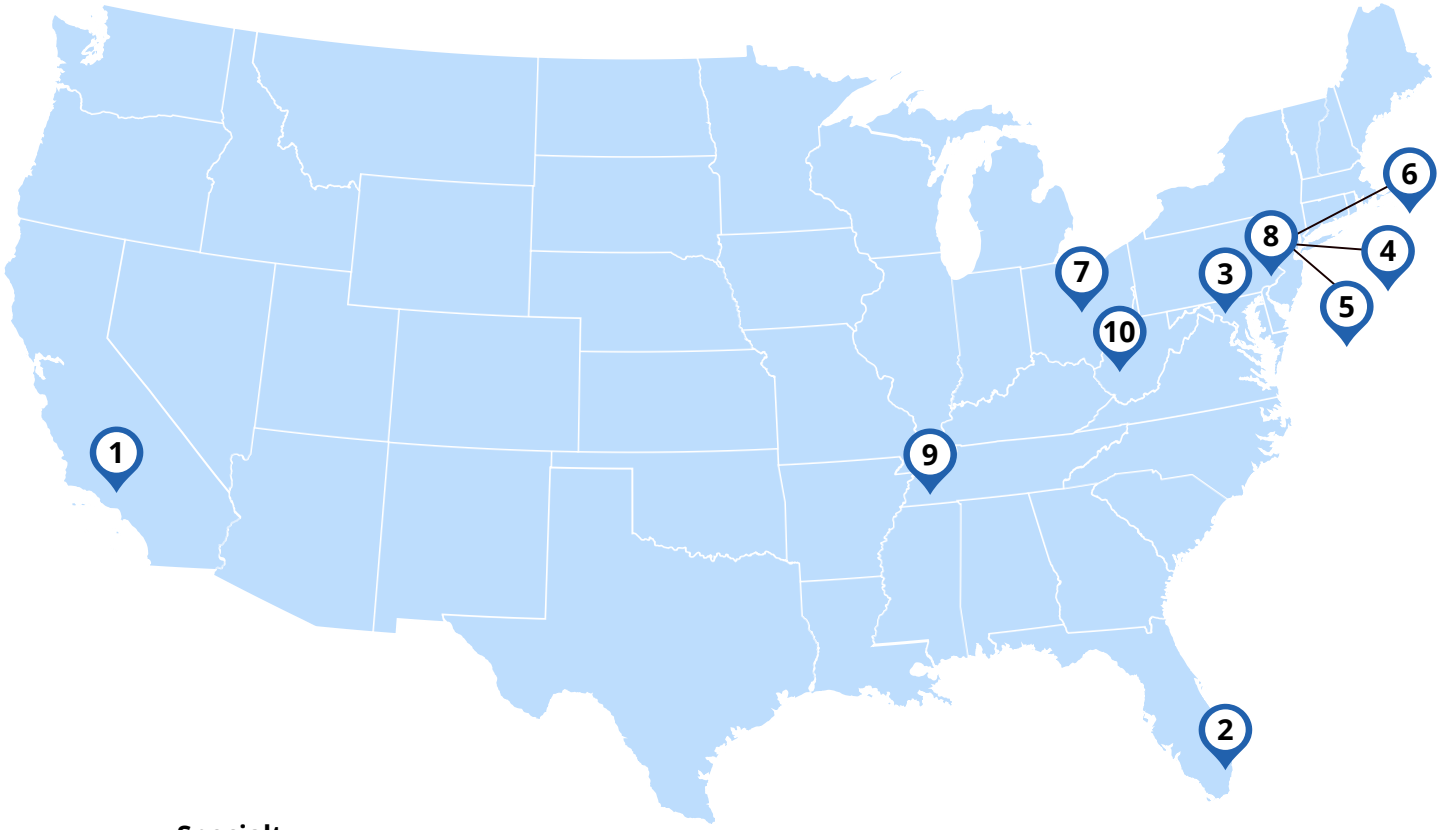

Specialty Pharmacies

1. Canoga Park, California
2. Plantation, Florida
3. Columbia, Maryland
4. Glen Rock, New Jersey
5. Totowa, New Jersey
6. New York, New York
7. Dublin, Ohio
8. Garnet Valley, Pennsylvania
9. Bartlett, Tennessee
10. Charleston, West Virginia

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