

BIO MATRIX

NEWS



**DEDICATED
TO MAKING
A DIFFERENCE**

**SUMMER 2022
VOLUME 17 | ISSUE 3**



**“ We are all broken, that’s how
the light gets in. — Ernest Hemingway ”**

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 **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.

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

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:

It's been wonderful to see our social world resuming after a couple of grueling COVID-19 years. Most bleeding disorders camps have given the green light for kids to attend this summer, local chapters and national organizations are once again hosting events. HFA's Symposium's in April and The Coalition for Hemophilia B Symposium in May both proceeded with relatively few issues. And now many in the community are looking forward to attending NHF's Annual Meeting in August. I'm sure we can all agree it's been awesome to get out and see our bleeding disorders friends again live and in-person!

A reminder to all college and vocational/trade school students, the BioMatrix Scholarship Program is still accepting applications for this school year. The deadline is August 1st so submit your application before time runs out! Apply online at: scholarship.biomatrixsprx.com

Please enjoy reading this latest issue of *BioMatrix News* - lots of great information between these pages!

Have a wonderful summer!

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

BIOMATRIX

Our cookbook brings together recipes from our family to yours!

Our Regional Care Coordinators have provided their very best recipes—from appetizers to entrees and desserts. To get your free cookbook, contact your Regional Care Coordinator or request online:

<https://mailchi.mp/biomatrixsprx/cookbook>





THE GIFT OF *Volunteering*

BY MILYBET CEPEDA, EdD



Volunteering is a gift for you. It can be the best thing you do for your community and for yourself.

Since high school, I have volunteered for various causes - food drives and events for diabetes and cancer, to name a few. When my son, Omar, was born in 2004, I promised myself I would teach him the importance of giving back. Having participated in the AIDS Walk New York since 1998, it was soon to be Omar's first walk in 2005 when he was just 10 months old.

At birth, Omar was diagnosed with severe hemophilia A, giving me a whole new cause in which to be involved. We have since participated in many bleeding disorders events.

We moved from New Jersey to Florida in 2007 and were soon involved with the local hemophilia organizations. In 2015, we moved back to New Jersey and continue our commitment to our local organizations. I have made connections and cultivated many friendships within the bleeding disorders community through these groups and events. These excellent organizations helped my family tremendously with advocacy, education, and emotional support. In turn as a family, we do what we can to help raise funds so they can continue their mission of providing programs and services to enhance the quality of life in the bleeding disorders community.

In addition to participating in and serving on fundraising walk and educational committees, I have been a guest speaker and have emceed while Omar and my husband, Harry, as deejays, get the crowds moving to awesome music! We also gather our friends and family members to join us! We have been able to raise funds in some unique ways - hosting a yard sale, raffling a handmade quilt featuring the school's name at my 20th high school reunion, and my niece donating a portion of her sweet 15 birthday gift money to our local chapter. All these little things can make a difference!

People volunteer for a variety of reasons. It may be to support a cause they are passionate about, to make new friends, for something to do while the kids are at school, or to fill the hours for those who are empty-nesters or retired. We often volunteer to assist groups or individuals who may need the help or to impart our been-there, done-



that experiences. We volunteer because we know it makes a difference in the world in which we live.

Volunteering can have enormous and surprising benefits for you as well. It can provide a sense of achievement and enrichment. It increases self-confidence, offers a sense of community and gives you something to be proud of. It can teach new skills and expand knowledge, help discover hidden talents, and open doors of opportunity by expanding your resume and perhaps increasing career opportunities.

For me, there are mental health benefits in getting involved. When I donate my time and connect with others, I am less likely to feel sad or lonely. It provides me with a sense of purpose and helps me build friendships and a network of people I can rely on. Volunteering serves as a stress reducer and has helped me deal better with painful struggles. It fills my soul and leaves me with a fuzzy feeling in my heart. Volunteering makes me smile.

There are many ways to volunteer within your community. If you're unable to volunteer in person, for example, because of distance, there are other ways to contribute. Serve on planning committees, organize a walk team, write articles for an organization as a way to share your experiences and knowledge, be a contact for a newly





diagnosed family, participate in advocacy projects such as State and Washington Days, volunteer as a counselor at a bleeding disorders camp, or help out at a fundraising golf tournament. There are countless ways to make the most of your time while giving to a worthwhile cause!

Get started by contacting a local or national bleeding disorders chapter and find out what you can do to help. Most are eager to engage volunteers. Seek opportunities that align with your values and experience. Life can be more positive, satisfying, social, and fun when you volunteer!

About Milybet Montijo-Cepeda, EdD



Dr. Milybet Montijo-Cepeda holds a Doctorate in Education specializing in Organizational Leadership from Nova Southeastern University of South Florida. Her dissertation was on: *Resilience Among Parents of Children with Hemophilia*. Dr. Cepeda has served as a special

education teacher for more than 21 years, a motivational speaker, a meditation and mindfulness instructor, and a Walk emcee. Milybet resides in New Jersey with her family.

1 Volunteer...

- ♥ for my son Omar who is destined for greatness. I love you Papo!
- ♥ for those who choose to care, cheer on and be part of my son's life
- ♥ for my dear father who passed away due to hemophilia complications
- ♥ for me... I have hemophilia too
- ♥ for parents whose child was recently diagnosed
- ♥ to help boost hemophilia research and advocacy
- ♥ for the bleeding disorders community because they are my family
- ♥ to never forget how far we've come with resources, effective treatments, and blood safety
- ♥ for the survivors
- ♥ because it takes a village to support all children with a chronic health condition
- ♥ to raise awareness and educate others to better understand bleeding disorders





Across our country the National Hemophilia Foundation is helping local chapters reach fundraising goals with the 2022 UNITE WALK initiative. In addition to helping chapters raise funds to support programs benefitting their members, it also engages the community in a way that helps foster awareness for our cause in the public eye. Get involved - join or start a walk team of your own! Bring everyone together for this worthy cause – enlist your family, friends, neighbors, co-workers and even local businesses.

Listed are the remaining confirmed dates and locations for 2022 along with a contact name, phone and email address. Plans can change though so check in with your local chapter. Some chapters have a virtual component to the Walks as well. Visit www.hemophilia.org/walk/ for registration dates and check-in times, and contact the chapter directly. Your BioMatrix RCC can help guide you as well!



JULY 10, 2022 MISSOURI

DoubleTree Hotel; Chesterfield
Bridget Tyrey, 314-482-5973
bridgettyrey@gatewayhemophilia.org

AUG. 13, 2022 COLORADO

Slogans Lake Park; Denver
Hannah Beary, 646-499-0684
hbeary@hemophilia.org

AUG. 13, 2022 MICHIGAN

Robinette's Apple Haus; Grand Rapids
Ashley Fritsch, 734-544-0015
afritsch@hfmich.org

AUG. 20, 2022 INDIANA

Fort Harrison State Park; Indianapolis
Kristy McConnell, 317-570-0039
kmccconnell@hoii.org

AUG. 20, 2022 OHIO

Mt. Echo Park; Cincinnati
Lisa Raterman, 513-961-4366
cincinnatiinmyblood@gmail.com

AUG. 20, 2022 OHIO

Toldeo Zoo; Toledo
Carla Wells, 419-291-5882
carla@nwohemophilia.org

SEPT. 10, 2022 ALASKA

Alaska Zoo; Anchorage
John Palmatier, 907-343-9292
alaskahemo@gmail.com

SEPT. 10, 2022 MAINE

Parks Pond Campground; Clifton
Tracey Gideon, 207-735-6778
tracey@mainehemophilia.org

SEPT. 10, 2022 MONTANA

Zoo Montana; Billings
Brad Benne, 406-600-2554
brad@rmhbda.org

SEPT. 10, 2022 NORTH DAKOTA

Lindenwood Park Rotary Shelter; Fargo
Emily Ouellette, 701-381-0670
director@bdand.org

SEPT. 10, 2022 OHIO

Akron Zoo; Akron
Dawn Evans, 216-834-0051
dawn@nohf.org

SEPT. 10, 2022 PENNSYLVANIA

North Park Pool Parking Lot; Allison Park
Jessica Lee, 724-741-6160
jessica@wpbdf.org

SEPT. 11, 2022 OHIO

Sharon Woods Metro Park; Westerville
Kristi Harvey-Simi, 402-312-1185
kharvey@hemophilia.org

SEPT. 17, 2022 IOWA

City Park; Marion
Mary Warner, 319-721-1664
m.warner@hemophiliainiowa.org

SEPT. 17, 2022 WEST VIRGINIA

TBD; Charleston
Chelsea Hilty, 304-261-9622
chilty@hemophilia.org

SEPT. 24, 2022 NEBRASKA

Chalco Hills Recreation Center; Omaha
Maureen Grace, 402-499-8025
mgrace@hemophilia.org

SEPT. 24, 2022 WISCONSIN

Milwaukee County Zoo; Milwaukee
Tomi Vandergriff, 414-937-6780
tvandergriff@glhf.org

OCT. 1, 2022 CALIFORNIA

Liberty Station NTC Park; San Diego
Nooshin Kosar, 619-325-3570
info@hasdc.org

OCT. 1, 2022 ILLINOIS

TBD; Brookfield
Bob Robinson, 312-427-1495
brobinson@bdai.org

OCT. 1, 2022 MASSACHUSETTS

Prowse Farm; Canton
Gabrielle Roth, 781-326-7645
groth@nehemophilia.org

OCT. 1, 2022 OKLAHOMA

Broken Arrow Events Park; Tulsa
Tim Grogan, 918-605-2579
tgrogan@okbleedingdisorders.org

OCT. 2, 2022 CALIFORNIA

Gibbons Park; Carmichael
Stephanie Hill, 916-910-5769
stephanie@cchfsac.org

OCT. 8, 2022 IDAHO

Hillsdale Park; Meridian
Marlyn Walker, 208-631-9729
mwalker@hemophilia.org

OCT. 8, 2022 NEVADA

Floyd Lamb Park; Las Vegas
Stephanie Dupree, 702-564-4368
sdupree@hemophilia.org

OCT. 9, 2022 NEW YORK

Prospect Park; New York City
Antonio Coppola, 917-722-3887 x703
antonio.coppola@nyhemophilia.org

OCT. 15, 2022 NEW YORK

The Crossings Park; Loudonville
Beth Mahar, 518-729-3577
beth.m@bdaneny.org

OCT. 15, 2022 TEXAS

TBD: Hill Country
Tara Kosh, 832-606-5809
tkosh@lonestארbleedingdisorders.org

OCT. 16, 2022 VIRGINIA

Great Wolf Lodge; Williamsburg
Kelly Waters, 804-740-8643
info@vahemophilia.org

OCT. 22, 2022 HAWAII

Kapiolani Park; Honolulu
Kyra Calbero, 808-284-7417
kcalbero@hemophilia.org

OCT. 22, 2022 KENTUCKY

E. P. "Tom" Sawyer State Park; Louisville
Ursela Kamala, 502-456-3233
ursela@kyhemo.org

OCT. 22, 2022 TEXAS

TBD; Houston
Tara Kosh, 832-606-5809
tkosh@lonestארbleedingdisorders.org

OCT. 29, 2022 CALIFORNIA

LA Coliseum, Los Angeles
Michele Warner, 310-415-2390
mwarner@hemosocal.org

NOV. 6, 2022 PUERTO RICO

TBA
Anthony Llanes, 787-380-7985
hemophilia.aph@gmail.com

NOV. 6, 2022 CALIFORNIA

Lake Merritt Pavilion; Oakland
Ashley Gregory, 831-332-1458
ashley.gregory@hemofoundation.org

NOV. 12, 2022 TEXAS

River Legacy Park; Arlington
Karla Brown, 817-739-6339
karla@texcen.org

NOV. 12, 2022 FLORIDA

TBD; Fort Lauderdale
Deborah Adamkin, 305-793-6841
dadamkin@floridahemophilia.org

MY DECIDING FACTOR:

Making time for what matters most.

vonvendi
[von Willebrand factor
(Recombinant)]

Erica

VONVENDI Use: On-Demand & Surgery

- VONVENDI® is the **first and only treatment approved for routine use (prophylaxis)** in adults with severe Type 3 VWD who previously received on-demand therapy
- VONVENDI is **also approved for on-demand and surgical bleed management** in adults with all types of VWD
- VONVENDI **replaces VWF** (the main issue behind VWD), and **may be used with or without recombinant factor VIII** as instructed by your healthcare provider



Are you ready to ask about VONVENDI for your VWD? Visit VONVENDI.com to learn more, and talk to your healthcare provider.

VWD=von Willebrand disease; VWF=von Willebrand factor.

VONVENDI [von Willebrand factor (Recombinant)] Important Information

What is VONVENDI?

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
- reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy

Detailed 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.

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: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, 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 the VONVENDI Consumer Brief Summary on the following page and talk to your healthcare provider.



Important facts about VONVENDI® [von Willebrand factor (Recombinant)]

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.



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
- Reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy.

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 doctor 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: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, 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 1-877-TAKEDA-7 (1-877-825-3327).

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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Federal health mandates put in place during the COVID-19 pandemic end July 15, 2022.

Millions of Americans, adults and children alike, are expected to lose their Medicaid benefits as the organization goes through a vast re-evaluation of its members.

MEDICAID IS REDETERMINING BENEFITS FOR ALL MEMBERS: WHAT YOU NEED TO KNOW

BY SHELBY SMOAK, Ph.D.

During the pandemic, the federal COVID-19 public health emergency mandate disallowed Medicaid to shed any of its enrollees, which led to a bloated system in which almost 1 in 4 Americans became Medicaid recipients over the past two years.ⁱ This article breaks down the situation and suggests strategies to help ensure eligible Medicaid recipients don't lose insurance coverage.

States are responsible for their Medicaid budget. Before the pandemic, to help balance Medicaid budgets, states would regularly review recipient qualifications, changes in income, job status, age, and disability standing - dismissing those who no longer qualified for Medicaid coverage.

During the pandemic, the government floated federal money - Public Health Emergency (PHE) funds - to suspend this practice and cover a state's growing Medicaid population. Those PHE funds end on July 15, 2022. While the Centers for Medicare and Medicaid Services (CMS) is giving state Medicaid plans up to 14 months to complete these re-evaluations, the reality is most states' budgets will be stressed to support their Medicaid members beyond that July deadline.

Colorado, for example, must review over 500,000 applications and anticipates 30% (150,000 people) losing

Medicaid benefits because of improper paperwork and another 40% (200,000 people) at risk based on changed income; that's 350,000 people in one state alone.

As another example, Utah already reports 120,000 members, including 60,000 children, at risk because of "incomplete renewals." Likewise, Arizona relayed that almost 500,000 people are at risk of losing Medicaid for similar reasons.ⁱⁱ One policy think tank, The Commonwealth Fund, adds, "Nearly 80 million people enrolled from Medicaid will have their eligibility redetermined" over the coming months, "triggering a high risk of coverage losses."ⁱⁱⁱ

WHAT IS THE SITUATION WITH MEDICAID?

- Since Medicaid had not redetermined any of its beneficiaries during the pandemic, it has caused the program to be over-extended under normal operating circumstances.
- The COVID-19 Public Health Emergency funds provided to state Medicaid programs will end on July 15, 2022.
- According to CMS rules, Medicaid must redetermine every beneficiary within 14 months after Public

Health Emergency funds end. However, states will likely disenroll along a faster timeline due to the lack of necessary funds.

- Medicaid offices in most states are understaffed, which means a frenzied workload for employees and less time for “hands-on” follow-ups for missing paperwork or information.

AS A MEDICAID RECIPIENT, WHAT CAN I DO?

If you are still eligible under your state’s Medicaid rules, you’ll be able to keep your coverage.

BUT...

- Read all your mail and email communications from Medicaid. Do not throw any Medicaid paperwork in the trash.
- Be sure to completely fill out all paperwork requests and provide all information Medicaid requires. Medicaid can disenroll a beneficiary simply due to a lack of complete information.
- When dropping off paperwork in person, ask for a receipt. When mailing, consider sending all materials “Certified” so that you have a signed receipt.
- Keep copies of everything you submit.
- Follow up with your Medicaid office regularly to ensure your paperwork has been received.

WHAT IF I AM DISENROLLED FROM MEDICAID?

- Don’t panic.
- If you believe you are still eligible for Medicaid, you can appeal the ruling. Follow this link to read more about the Medicaid appeals process: <https://www.macpac.gov/wp-content/uploads/2018/07/Federal-Requirements-and-State-Options-Appeals.pdf>
- If you are no longer eligible, you have options for post-Medicaid insurance coverage:
 1. You may have access to an employer-sponsored health plan through yours or a family member’s employer. If you are dropped from Medicaid due to family income changes, this may be an option as it will trigger a special 30-day enrollment period.
 2. You may enroll in an ACA marketplace plan. In many of the marketplace plans, former Medicaid beneficiaries will likely be eligible for subsidies to cover premiums. Remember, Medicaid is an all-or-nothing safety-net program and it has a hard earnings cliff: you’re either eligible or you’re not based on income. ACA subsidies have a gradient of coverage up to 400% of poverty level income. Therefore, an ACA plan may reduce the cost of the premium coverage anywhere from 0% to 100%.

Moreover, if you enroll in a Silver Plan, you may be eligible for additional copay coverage if you are within 250% of poverty level income. The window for enrollment in an ACA marketplace plan is 60 days before and after Medicaid termination.

3. Children dropped from Medicaid may be eligible for the Children’s Health Insurance Program (CHIP), which has a higher threshold for eligibility. Visit <http://InsureKidsNow.gov> or call 1-877-KIDS-NOW (1-877-543-7669) for information about CHIP programs in your state.

The primary thing to remember is that if you meet the state Medicaid requirements and complete all the requested redetermination forms in the timeframe requested, your Medicaid will stay in place.

In summary, if you are disenrolled from Medicaid because you are no longer eligible, you will enter a special enrollment period for employer-sponsored and ACA marketplace plans. And if you enroll in an ACA marketplace plan, you will have access to apply for subsidies to reduce the premium amount, and you may be surprised at the amount of coverage offered.

If you are on Medicaid and have questions or concerns, please reach out to your BioMatrix Regional Care Coordinator or email education@biomatrixsprx.com. Our team can help answer your questions and put you in contact with one of our own Medicaid experts.

REFERENCES

- i. Pradhan, Rachana. “Why Millions on Medicaid are at Risk of Losing Coverage in the Months Ahead.” KHN. 14 Feb. 2022. <https://khn.org/news/article/why-millions-on-medicaid-are-at-risk-of-losing-coverage-in-the-months-ahead/>.
- ii. Ibid.
- iii. The Commonwealth Fund. “The Risk of Coverage Loss for Medicaid Beneficiaries as the COVID-19 Public Health Emergency Ends.” The Commonwealth Fund Blog. 23 Sept. 2021. <https://www.commonwealthfund.org/blog/2021/risk-coverage-loss-medicaid-beneficiaries-covid-19>.



MEDICAL DEBT AND YOUR CREDIT REPORT

BY SHELBY SMOAK, Ph.D.

Almost 137 million Americans have medical debt, and it is the leading cause of bankruptcy.ⁱ Since the cost of treatment is high and is forever, persons with a chronic illness like a bleeding disorder are certainly at risk of accruing unwanted debt. One study estimated the current cost of factor therapy alone at between \$460,000 and \$600,000, and with insurance and high deductible plans, year in/year out, the financial burden on patients and families can overwhelm.ⁱⁱ Moreover, even if a person's bleeding disorder is "managed," one bad bleed can create a tsunami of costs, especially if it impedes one's ability to work; thus, while costs go up, income goes down. What can one do when faced with seemingly insurmountable medical costs?

What can you do if you have unpaid medical debt?

- Obtain copies of medical bills and review them for any errors.
- Negotiate the bill with your provider. Be honest and let them know your financial situation. Many providers have programs to assist patients.
- Assure that some amount is being paid on the bill. Do not leave the bill unpaid.
- Get an estimate of medical costs beforehand if you are able.

What can you do if you receive a high medical bill that you cannot pay?

- Ask the hospital or provider if you qualify for their financial assistance policy, sometimes known as charity care.
- Ask if you were charged the "chargemaster rate," and if so, request the lower rate given for insurers and Medicare.
- Have the provider go through and explain all charges to avoid mistakes.
- Work out a payment plan.
- File an appeal with your insurance company if a service was denied and you think it should have been covered.



How will medical debt impact my credit score?

- Beginning July 1, 2022, medical debt that has been paid will no longer be included on consumer credit reports according to a recent agreement between the three top credit reporting agencies — Equifax, TransUnion and Experian.
- Medical debt will not be reported on consumer credit reports until it has remained unpaid for a year. Currently, medical debt is reported at six months and is reported whether paid or unpaid.
- Medical debt under \$500 will not be reported.

Should I consider bankruptcy?

- The legal term "medical bankruptcy" does not exist. There is only "bankruptcy."
- Depending on income and other factors, Chapter 7 or Chapter 13 would need to be filed.
 - In Chapter 7, a liquidation bankruptcy, assets are used to repay debts, and debt is discharged after an asset liquidation. It is often less expensive and faster but can result in property loss. Chapter 7 impacts a credit score for ten years.
 - In Chapter 13, debt is restructured and a 3–5-year repayment plan is established. Chapter 13 impacts a credit score for seven years.
- Consider alternatives as many creditors are more willing to work with medical debt.

As difficult as medical debt can be, emotionally and financially, there are services and programs available to help patients navigate those crushing expenses. The move by the three credit agencies is expected to remove approximately 70% of medical debt from consumer credit reports. The key takeaway is that if you do have unpaid medical debt, work with the provider to begin paying some amount towards it to keep your credit score in good standing.

References

- i. "Medical Debts and Collections." Debt.org
- ii. "The High Price of Hemophilia." ASH Clinical News. 1 Feb. 2020. <https://www.ashclinicalnews.org/spotlight/feature-articles/high-price-hemophilia/>



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^{*} Hemophilia FIX Market Assessment, Third-Party Market Research

[†] The average AsBR for people who started and stayed on 7- or 14-day prophylaxis was 0. For people who switched to prophylaxis from on-demand, the average AsBR was 0.7
AsBR-annualized spontaneous bleed rate.

[‡] Once well-controlled (1 month without spontaneous bleeding or requiring dose adjustments on a weekly dose of 140 IU/kg), people 12 years and older can be transitioned to 14-day dosing.

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BDANENY

BLEEDING DISORDERS ASSOCIATION OF NORTHEASTERN NEW YORK, INC.

BY RICHARD VOGEL

Bleeding Disorders Association of Northeastern New York (BDANENY) is dedicated to assisting families with bleeding disorders through education and advocacy designed to enhance their quality of life.

In the late 1960s, a family in upstate New York had a son diagnosed with hemophilia. As they searched diligently for resources, they became aware of a national organization to support those with bleeding disorders. The family along with a few close friends began raising funds to help other families and individuals with hemophilia in the local community, and in 1968, the all-volunteer organization was established as the Upper Hudson Valley Chapter – NHF, Inc.

The 1970s were good years. The miracle drug of the day – concentrated factor VIII – saved many families by allowing them to self-infuse clotting factor at home. Bleeds could be treated quickly and reduced the hours spent at a hospital and for many, nearly eliminated the extreme hardship of having to travel great distances to receive transfusions of plasma or whole blood.

Fast-forward to the 1980s, the chapter continued to operate as an all-volunteer organization. Operating from Troy, New York, they became affiliated with the Hemophilia Treatment Center of Albany Medical Center and expanded to cover the same counties the HTC served. The chapter still covers this area, which includes twenty-two counties extending from Ulster and Dutchess counties, east to the Green Mountains – almost to New York City, west to Oneida County, and north to the American/ Canadian border.

Identifying a need for support, advocacy, and community outreach programs, leadership and their dedicated group of volunteers worked tirelessly to meet the needs of all bleeding disorders patients within the community. Especially during the dark years of HIV, the chapter was there to support and console community members as much as possible.

Striving to encompass all aspects of the bleeding disorders community, in 1999, the chapter updated its name to the Bleeding Disorders Association of Northeastern New York, Inc., also known as BDANENY.

Fifty years from their inception, they have blossomed from an all-volunteer organization working out of their homes to an office with one full-time and one part-time staff and a variety of monthly events hosted. The volunteer base is comprised of dedicated community members including patients, families of patients, and health care professionals.



Annual Family Picnic 2000



Beth Mahar
Executive Director



Patricia Bengraff
Operations Manager



Melissa Deeb
Program Director



Advocacy 1998

BDANENY was the first in the nation to host a carrier retreat bringing women together for a weekend of events tailored to meet their specific needs. Other programs initiated such as the Clinic Travel Assistance Program (CTAP) have been adopted by other chapters nationwide.

The chapter continues striving to meet the diverse needs of a geographically dispersed community through a variety of programs, including legislative advocacy, fundraising, scholarships, camper-ships so affected children can attend bleeding disorders camps, recreational community activities allowing members to gain support and friendship from one another, and an emergency assistance program designed to provide a rapid, non-invasive source of financial relief for emergencies or urgent needs of the members. The programs are focused on improving the quality of life for persons afflicted with genetic bleeding disorders and their associated complications.

BDANENY encourages and helps guide its members to advocate for their own health care. From its inception, the chapter has served on national committees to help guide the future of the bleeding disorders community and address the needs of the individuals and families served. They provide support from advocacy to education and offer an opportunity for community members to voice their concerns from the New York State capital to our nation's capital in Washington DC.

Working with the support of their Board of Directors and extensive volunteer team, the staff at BDANENY

consists of a few key people. With her extensive experience and knowledge of accounting software, Patricia "Trish" Bengraff has been with BDANENY since 2017 and serves as Operations Manager. Her organizational office and project management skills have proved a valuable asset to the organization.

Also with BDANENY since 2017, Melissa Deeb is a part-time Program Director. Melissa attends SUNY Albany full-time as she earns a bachelor's degree in Communications.

With a strong background in non-profits, Beth Mahar became our chapter's Executive Director in 2020. Beth came to us from the Hospice & Palliative Care Association of New York State as Director of Operations, and prior to that was Director of Communications for the New York State Association of Area Agencies on Aging.

Small but committed, the staff helps BDANENY continue to make a difference in the community and the lives of the families that rely on it for resources, education, support and friendship.

Beth Major shares, "We are proud of our history, where we began, and where we are today. Our motto is very dear to us and sums up our service to our community, "We are here for you."

For more information on BDANENY, visit their website, www.BDANENY.org.

To contact, call or email: 518-729-3577, memberservices@BDANENY.org



Black n Blue Bash Planning Committee



Golf Tournament 1989



Bowling 2002



Golf Tourney 1998

AND THE MEN WENT FISHING...

(well, sort of)

BY SHELBY SMOAK, Ph.D.

The folly that follows hemophilia reigned again for a *Men's Fishing Retreat* in Rehoboth Beach, Delaware, May 6-8. Structured around a fishing experience, a veritable Nor-Easter took up camp offshore Friday evening and came ashore Saturday, whipping up waves into 12-foot froths of anger, spewing sheets of rain sideways on the shores and streets of the tiny beach town. I was there. I saw the perfect storm brewing off the coast. I knew no vessel was going out to brave this storm, and if it was, I wasn't going. Nor should any of my blood brothers. And when they arrived and we told participants the fishing boat was canceled, no one questioned the wisdom of that decision.

Yet, more miraculous than the wrath of nature outside, our event space was the spirit of the blood brothers—all adult men with hemophilia A or B. In a group familiar with upset plans, participants redirected the lost fishing opportunity into social hangs, poker tournaments, photography lessons, and, of course, numerous rap sessions sharing our various experiences with hemophilia.

Hosted by Country Boy Fishing and sponsored by Medexus, Octapharma and BioMatrix—men along a cut of the Eastern Seaboard gathered to be together and bond. Fishing was the lure; the people were the real catch. In undistracted conversations, unfiltered honesty emerged and a frequent refrain throughout the weekend was the lack of such opportunities for men with hemophilia to connect directly.

In addition to the more free-form rap session, structured programming provided more opportunities to engage in conversation. Brandon Young, a person with hemophilia, brought his unique brand of engagement in a discussion of mentorship and the support of “older persons with



The Castaways

(Front sitting) Grant Belsham (Medexus), Chris, Brandon Young of Country Boy Fishing, David, and Christian; (middle row) Rich Vogel of BioMatrix, Matt, Carl, Ryan, Felix, Shelby Smoak of BioMatrix, and Art; (back row) Chris, Peter, Everett, Angel, Paul Brayshaw of Octapharma and Terry Rice of BioMatrix.



The sea was angry

hemophilia” (a term this “older” person with hemophilia let slide). Octapharma introduced Dr. Claudio Sandoval who spoke on the importance of adherence to treatment therapies, which led to a myriad of discussions on bleeding and the promises of gene therapy.

Medexus brought in community member and fashion designer Christian Harris who coached us on how to buy clothes that actually fit. (Women may be surprised to learn just how interested we were in picking out appropriately fitting pants and shirts.)



Dr. Sandoval speaks



Chilling out



Music trivia winning team!



Serious fishing... Chris, Angel and David compete for bragging rights



Everyone's a winner!



Important conversations



Important dessert decisions

My role included leading sessions on using photography as therapy, directing games, and sharing a final night singing session with fellow BioMatrix member and self-styled crooner, Terry Rice.

In truth, there was a Gilligan's Island feel to the event in the comradery and mutual friendships that developed. Indeed, we sat back in with our own tale of a fateful trip whose outcome was far more positive than a group of sea goers stranded on a deserted island. These blood brothers – my friends – formed lasting bonds and left empowered, proof that even a perfect storm cannot dampen our spirits!



Sing along

Following our Men's Fishing Retreat, I had the opportunity to speak with Brandon Young, the guy behind *Country Boy Fishing*. His program seeks to be a catalyst for connecting those with bleeding disorders. In arrangements with chapters and industry partners, Brandon shares his message of excelling with hemophilia while imparting his vast knowledge of fishing. Below are a few thoughts he "cast" our way.

Tell us about yourself and your association with the hemophilia community?

As an affected person, I have been active in the community for 33 years. I began attending bleeding disorders camp when I was 7-years old, and as an adult, I continue to support the community I love. They supported me and my family when we needed it, and I feel the need to give back in the best way I know.



What made you start Country Boy Fishing?

I wanted to start a non-profit to share my love of fishing with the community. I first became interested in fishing as a child during my experiences at hemophilia camps. I wanted to create an environment that allowed the whole family to participate in programs to develop fishing basics.

What is the primary message of your organization?

My message is to chase your dreams no matter what life brings you. You have to run after your passions; that will help push you through the pains of life. When you taste the fruits of your labor, it will bring you so much joy! Setting an example can motivate others to do the same.

How would you describe the recent Men's Retreat hosted in partnership with BioMatrix, Medexus, and Octapharma?

The Men's Retreat was fantastic! The guys were open to sharing personal issues and discussing mentorship opportunities and other important topics. It was great to share time with everyone and have a place where everyone felt free to open up.

What's one piece of advice you'd give to a person with a bleeding disorder?

The advice I would like to share with those in the community is to *never give up*. You can achieve whatever you set your mind on, even with a bleeding disorder. I've chased my dreams of being in the fishing industry, and it has been a fulfilling and beautiful experience!

HFA SYMPOSIUM: *Reunited* AND IT FEELS SO GOOD!



BY FELIX GARCIA

The line at the registration table, the name tags with funny labels such as Disruptive, Bro-ster and This Side Up (pointing the wrong way, of course), and new this year, color-coded lanyards to signify contact comfort level given COVID-19, are all familiar parts of entering the HFA Symposium experience. I missed attending the Symposium the last couple of years, though I didn't realize how much until I was there. I even wore my name tag every day. Yes, that was an accomplishment for me! Like someone who has been deprived of basic needs and then values them that much more once they're available, I appreciated being at the Symposium. There was so much to take in this year!

In San Antonio, Texas, April 20-23rd, HFA took precautions to help protect those in attendance from COVID-19. A mask mandate was in place, and as mentioned, our lanyards were color-coded, indicating our contact comfort level. Red meant "Keep your distance, please!" Orange, "Let's talk but no hug." And green signified, "Get over here - I missed you!" Okay, maybe green didn't mean that exactly, but that's what it felt like! As expected with our caring and compassionate community, everyone was respectful of each other's preferences. I wore green - what can I say? I'm a hugger, missed my bleeding disorder family and threw caution to the wind. Also, attendees could exchange their lanyard for another color if they opted to change comfort levels during the event.



Felix tries to photobomb Jesus E.

Throughout the Symposium, attendees wore masks except while eating, so there was a lot of looking at someone almost sure you recognized their eyes but needing a peek of their face to



Angelica, Alfonso, Elizabeth, Jenni, Bernadette, Delana, and Maria



GREAT smiles from Steve Calderon, Felix Garcia and Alfonso Jaramillo

be positive. It was a little funny to reunite with friends after flashing our faces.

If the Symposium was only about reuniting community members, the event was entirely successful. Lucky for us, they didn't stop there. The variety of sessions was a hit and the diversity of subjects, topics of inclusion and the realization of all who are included in our community was impressive.

As an adult with severe hemophilia, I looked for particular topics like joint health and aging with hemophilia; as an adult who grew up in the 70s and 80s, I'm interested in other areas such as coping with co-morbidities and the remembrance ceremony. They were both available. Thank you, HFA, for remembering that we, the 3H generation - hemophilia, hepatitis and HIV - still exists, and we needed a session of our own to attend with our spouses, partners and loved ones.

Looking through the agenda schedule, most could find something of interest. Parent programs? Check. Children's programs? Check. VWD programs? Check. Bleeding disorders and the LGBTQIA+ community? Check. How about sessions for rare bleeding disorders? Check again! No matter your perspective or how a bleeding disorder impacts your life, HFA planned a session for you.



Good friends catching up! Ryan, Brian, Hope, Orson, Michael, Steve and Alfonso

As others had mentioned, this year's exhibit hall felt different. It had nothing to do with the booth setups or the give-away items. It took me two days of the designated hours to get through the hall because it was a time to reunite and catch up on the last few years. It was a wonderful opportunity to visit the booths, talk with the representatives and learn about new products and services that have been introduced over the past couple of years. Though I've attended Zoom sessions with many of the people I saw at HFA, the exhibit hall provided a chance to catch up face-to-face. It was a breath of fresh air, even through a mask!

The HFA Annual Symposium has always represented a family reunion for me. Seeing brothers and sisters from all over the country and having the chance to share our family and life issues is a beautiful thing. Our bleeding disorders family is unlike any other. Blood family is cherished, and our bleeding disorders family holds a special place in our hearts and lives. We were finally reunited, and it felt so good!



See y'all later!

Bravo HFA, you did us proud!

**HEMOPHILIA FEDERATION OF AMERICA
2023 SYMPOSIUM
APRIL 13-16 | ORLANDO, FLORIDA**



HFA: A TEXAS-SIZED FAMILY REUNION

BY RICHARD VOGEL



It was wonderful seeing so many old friends – blood brothers and sisters with their families at HFA's 2022 Symposium. The meeting was aptly named *A Texas-Sized Family Reunion*. Running into old friends at the airport was the start of the reunion!

Particularly enjoyable was Zander Masser presenting the keynote address, *Unburying My Father*. He recounts the story of his father, Randy, a professional photographer who had severe hemophilia B. When Zander was 14 years-old, his dad passed away from AIDS-related illnesses. As an adult, Zander “unburied” more than 10,000 photo slides of his dad's work and took us through his process of exploring grief through creativity with the goal of helping others find ways of sharing their own grief. This was a pertinent topic when many of us are struggling and may have suffered losses through the pandemic.

Another interesting topic was *On the Horizon*, which focused on where we've been and where we are going with treatment and therapies for bleeding disorders. Presenters Dr. Allison Wheeler, Dr. Robert Sidonio, and David Clark, Ph.D, discussed long-lasting factor products, bypassing agents and gene therapy. Certainly, an exciting time for new therapy treatments in the world of bleeding disorders!

In addition to many great sessions, there were *Open House* gatherings for Blood Brothers, Blood Sisters, Blood Families, and Sangre Latina! Closing out the event was a showing of the movie *Bombardier Blood*, depicting the inspiring story of Chris Bombardier, a mountain climber with hemophilia.

The best part of a family reunion is just that – reuniting! We all had a lot of catching up to do! People could be seen engaged in conversations over breakfast, lunch, dinner, between meals and in the evening at the lobby bar. For the first big national event in a while, this Texas-sized family reunion did not disappoint, and I'm already looking forward to next year's Symposium!

Congratulations to HFA on their keen insight and detailed planning!

B TOGETHER

THE COALITION FOR HEMOPHILIA B SYMPOSIUM

BY MICHELLE STIELPER AND TINA MCMULLEN



It is always good to “B” together; however, NOTHING has felt as sweet as *The 2022 Coalition for Hemophilia B Annual Symposium*. After two years of virtual meetings, bingo games, and *On the Road* meetings, we all came together at the Renaissance Orlando

at SeaWorld May 19-22nd. Many precautions were implemented by the fabulous and exceptionally hardworking Coalition staff to help keep us healthy - COVID-19 tests, masks, and red, yellow or green lanyards indicating each person’s interaction level of comfort. However, this meeting was not short of tapping elbows, high fives, or welcomed hugs. It was an event filled with love and gratitude simply to be together.

As always, the educational sessions and breakouts did not disappoint - men’s and women’s gatherings, breakouts to harness the power of togetherness and strength in adversity, and sessions about being brave and using your voice and story to advocate for yourself, your child, or future generations within the bleeding disorders community.

There were excellent inspirational speeches by Zander Massar, Debbie de la Riva, Natalie Sayer and Kelly Gonzalez, to name a few. There was also an informative presentation by Dr. Sidonio focused on understanding Factor IX’s role in the body. Hope Woodcock-Ross and Dr. Mike Zolotnisky led an infusion class combined with KT tape strategies for protecting joints. The list goes on with meaningful, impactful, and much needed educational programming.

The BioMatrix booth was buzzing all meeting long with a steady stream of contestants lining up for *Jeo-Parody*, our Jeopardy-inspired game. With the incredibly talented gameshow host, Shelby Smoak, participants answered questions to enter a drawing for an awesome cooking-themed gift basket filled with our BioMatrix favorite family cookbook and bunches of useful kitchen doodads.



Regional Care Coordinators Michelle Stileper and Tina McMullen staff the BioMatrix booth

For “fun points” and just because, we made it a friendly competition between the ladies and gents.

Each day featured a different themed game board, and we soon found out just how many of our hemophilia B families are diehard Jeopardy fans! Smiles, laughs and cheers erupted all around as game points were added to the scoreboard. In the end, the gents were close, but the ladies won at the final hour. Girl Power! Congratulations to all our players and especially to the winner of our gift basket.



Raffle winner Elizabeth went home with our cooking-themed gift basket!

The Symposium’s final night event is always an evening to remember, but *The Bleeders* (essentially the Coalition B house band) really outdid themselves this year. Moved indoors due to rain, our own *Doc of Rock* Shelby Smoak and the whole band brought the atrium of the Renaissance hotel down! No one gets the party going like our bleeder band! Many thanks, guys, for always giving us great tunes to sing along to while we wear out our dancing shoes. When does the album drop?! With top notch music, the party went strong well into the night!

This was truly the greatest Symposium meeting in years, well, because it has been years! We never need a reminder to know how impressive our B community is, but it sure was amazing to “B” together again! Here’s to a great 2022, and we are already looking forward to what the Coalition has in store for Symposium 2023!



A few of the fabulous faces visiting our BioMatrix booth!



Michelle and Deisie



Michelle and April L. share a hug and much laughter!



Tina with long-time friends, Mandy, Ryan and awesome kids, Brook and Cooper



Tina and Michelle with Michelle B (center)



Edward, Vincent and Stephanie!



Christopher and Shelby ham it up at the Jeopardy game



Cooper added tons of banners to his name tag!



Big smiles! April H. and Michelle



Michelle and Tina with Jeron, a frequent BioMatrix Zoom attendee!

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BIOMATRIX

ON THE MOVE!

This past quarter has seen the return of many events to in-person gatherings and we at BioMatrix have been thrilled to meet with community members out and about! We've been making the transition to in-person events carefully with everyone's best interest at the forefront. Our Education Team continues to be at the ready to provide in-person or virtual programs as the need arises. Read on to see what we've been up to! If your group of any size is interested in scheduling an education session with our team or for a current list of programs available, please contact your Regional Care Coordinator or message us at education@biomatrixsprx.com.

FLORIDA

Justin Lindhorst and Hector Heer

Conducted in partnership with Bayer, BioMatrix held a special interactive presentation March 8th at Mission Barbecue in Fort Myers. Following dinner, amateur photographer and BioMatrix Education Specialist Shelby Smoak, Ph.D., presented *Camera On: Healing and the Art of Photography*, a hands-on program where participants learned about the healing power of photography. Shelby explained elements of framing, composition, lighting, depth, dimension, and lines used in the creative process. Everyone was thrilled to learn tips and tricks for capturing high-quality, eye-catching photos of objects and moments using just their smartphone camera. The evening concluded with the group sharing and discussing their best photos.



FLORIDA

Marcy Foertsch and Peggy Klingmann

BioMatrix and Bayer collaborated for an in-person **Educational Program and Dinner** on the evening of March 9th. Held at Seasons 52 Restaurant in Tampa, the event was very well attended. Presenting an informative session, *Pandemic Dialogue*, focused on our new normal living with COVID-19 was Bayer's Hemophilia Community Executive, Barbara Arrebola. BioMatrix Education Specialist Shelby Smoak, Ph.D., gave a lively and engaging discussion about traveling with a bleeding disorder during a pandemic. Community members connected with Shelby and Barbie, asking questions and sharing their experiences.



Selfie time for Marcy and Barbara!



Shelby Smoak presents

Thank you to Barbie and Bayer for sponsoring this event! We look forward to hosting many more programs with our Education Team. Come join us!

OHIO

Shelia Biljes and Donna Garner

Despite unexpected snow flurries, everything was coming up daisies March 25th as women of



Great friends – Jen, June and Marie

Northern Ohio gathered for our monthly **Ladies Lunch**. The Garden Room at Clementine's Victorian Restaurant, located in the Grand Pacific Junction Historic Shopping District in Olmstead Falls, is the perfect venue for an

early spring gathering. Enjoying soup and fancy salads followed by a variety of tasty tarts kept everyone occupied as Novo Speaker and Social Worker Cathy Tiggs presented *Women with Bleeding Disorders*.

The two-hour time slot was not nearly enough for the deep conversation that followed, though we did make time to laugh through a round of *What's In Your Purse* and other fun games! Through it all, we share stories of joy and heartaches. We celebrate milestones and the small wins and always manage to laugh about something! Several new faces who joined the usual group have promised to come back and be part of our amazing sisterhood. I think the ladies would agree – we leave each monthly event anticipating the next! Many thanks to Novo Nordisk for sponsoring our luncheon!



Lovely smiles from the "A" team: Allyson and Amber



Shelia and Connie

NEW JERSEY

Richard Vogel and Carolina Luna

It's good to be back..., back at iPlay America in person! On March 27th, bleeding disorders community members made their way to iPlay America in Freehold for Hemophilia Association of New Jersey's **Community Connections**. We enjoyed education, a little fun, and most importantly, some much-needed human connection after two years of isolation due to the pandemic. During a continental breakfast attendees were able to gather information and ask questions of the exhibitors on site. The choice of breakout sessions that followed had something for everyone, including sessions in Spanish for our Latino community.

Carolina and I provided fun games for kids to test their knowledge of bleeding disorders. Resulting in a very tight score, we started with a rousing set of *Friendly Feud* questions with Team

Apple Sauce edging out Team Bananas in the final round. Carolina led kids in a few rounds of *Loteria*, a Latino version of Bingo where images replace numbers and – in our custom-made game – most images have something to do with bleeding disorders. Everyone had fun and gained a bit of knowledge and a few stuffed animal prizes to boot.

After a buffet lunch where families had a chance to meet and network, everyone was treated to one of New Jersey's largest indoor arcades. They were able to choose from amusement rides, bumper cars, and typical boardwalk games made famous at the Jersey Shore. To quote The Boss, New Jersey native Bruce Springsteen, "Down the shore everything's all right." And on this Sunday in March, everything certainly was.



Community member, Debora visits with Richard Vogel and Carolina Luna

NEW MEXICO

Felix Garcia

Good food, great friends and terrific educational information were in store March 30th at El Pinto in Albuquerque as BioMatrix teamed up with HEMA Biologics for a **Family Educational Dinner**. In addition to community members, Sangre de Oro, Bleeding Disorders Foundation of New Mexico (SDO) Executive Board members were invited as well.



Raffle winner, Dave

Guest Speaker Dr. Guy Young gave us the 411 on SEVENFACT, HEMA Biologic's product to treat inhibitors. As he went along, he fielded questions from the audience, pausing just long enough to enjoy the delicious sopapillas on the table in front of him. We all appreciated his enthusiasm and interaction.

The fun continued with a few rounds of BioMatrix's special bleeding disorders-themed *Loteria*, a Hispanic game much like Bingo but with images. Streaming in from Nevada, we had our very own Kelly Gonzalez, Education Specialist, appear virtually to call out the game images. The group even asked for a final round of Blackout (similar to Blackout in Bingo), which came down to five people waiting on one last image to be called. Sorry everyone, but there can only be one winner, and this time it was Jessie Hernandez, former President of SDO!



Dave put the raffle prize to good use!

We wrapped up the evening with a raffle prize of a Mexican-made platter and serving bowl with all the ingredients to make fresh guacamole. Congratulations to winner Dave A! We appreciate the "after" picture, Dave - that guacamole looks delicious!

Many thanks to Dr. Young and Angelica Flores, HEMA Biologics representative, for sponsoring! Due to COVID-19 space limitations, we realize not everyone who wanted to attend was able to. That's why we will be back out to host more families with more education and certainly more fun. Be sure to sign up early. Can't wait to see you then!

NEW YORK

Richard Vogel

Winters can be tough on the east coast, especially when a pandemic that isolated everyone for two years is an issue. With relaxed mandates, BioMatrix joined with Novo Nordisk and the Bleeding Disorders Association of Northeastern New York (BDANENY) for an afternoon of education, food and fun April 2nd.

We gathered at *Different Drummer's Kitchen Company* in Albany for a **Cooking Class** where we prepared and shared a meal.

On the menu were *Dumplings Around the World*. Everyone worked together to make dumplings from scratch, including tasty dipping sauces.



Chefs busy at work!



The Chefs!



Novo Rep Sarah... like a pro!

We made Chinese mushroom dumplings with soy-ginger broth, Polish sweet potato pierogies with caramelized onions, Greek spanakopita, and El Salvadorian pork and cheese pupusas.

As everyone chopped, grated and filled the various doughs, we reconnected, offering friendship and support to one another. Sitting down to share the meal, we discussed tips on *Living Well with Hemophilia* led by Novo Nordisk speaker Cathy Tiggs, MSSA, LISW.

We thoroughly enjoyed the company, the food and the education. Thanks to BDANENY and Novo Nordisk for their support.

OHIO

Shelia Biljes

Flashing lights, loud noises, cheers and laughter – that’s what you find at Dave and Buster’s in Westlake! Fun was on overload as Northern Ohio Hemophilia Foundation (NOHF) teamed up with BioMatrix, Novo Nordisk, Bayer and Octapharma April 6th to present a **Family Education** evening.

With two buffets to choose from, plates and mouths were full as guests attentively listened while guest speaker Debbie Shijo, Physical Therapist at Akron Children’s Hospital, outlined safe sports for those with a bleeding disorder. Debbie also led the group through a few safe stretching techniques.

To wrap up the evening, everyone received game cards to have fun in Dave and Buster’s game room. The enthusiasm made it evident we were all eager to get out and get together. Thank you to NOHF for making this event happen!



Twins, Max and Alex, play Wheel of Fortune as mom Amber cheers them on



Kylin dreams of driving fast cars when he grows up



OHIO

Shelia Biljes

Dinner time is set aside to share events of the day, good and bad, and find comfort in those around us. And so it was that BioMatrix and Novo Nordisk co-sponsored **Family Education Dinner Pain Matters** at Berlin’s Farmstead Restaurant April 7th. With more than thirty-five in

attendance, the night started with the best food ever followed by the best pie ever!

We were honored with Jennifer Domm, MD, Novo Nordisk speaker and Pediatric Hematology-Oncology Specialist from Nashville, TN, to share her knowledge of pain management. She focused on methods of pain relief from using meditation techniques to pain relief drugs. Dr. Domm also explained how to accurately describe your pain to the physician.



Zach arrived early and ready for a meal and education,

Time flew as we shared stories of injuries and tips for coping with pain. It was a perfect gathering with many new attendees to our BioMatrix family dinner! Thank you, Dr. Domm and Novo Nordisk representative Judy Doyle, for sponsoring our get-together!

DELAWARE

Tina McMullen

Wilmington’s Columbus Inn was the place to be April 8th for an informational **Education Program and Dinner**. BioMatrix and Bayer teamed up with the Brandywine Valley Hemophilia Foundation to present a program on *Co-Pay Accumulators* to the chapter’s bleeding disorder community.

Our evening began with Gail Novak, Foundation President, giving a brief report on upcoming events in the community. Following was Terry Rice, BioMatrix Director of Advocacy and Education, who spoke about co-pay accumulators – what they are and how they may affect bleeding disorder patients. Gail also shared her experience relating to the subject. The topic sparked many questions from the attendees.

Thank you, Gail, for seeing the need for this topic in your community as it affects so many. Many thanks to Bayer representative Margarita Llibre Rogers for the delicious meal and co-sponsoring this highly enlightening and interactive evening.



Happy smiles from Matthew, Tina and Gail.



A fantastic team! Margarita Llibre Rogers with Bayer, Tina McMullen and Terry Rice with BioMatrix and Gail Novak of Brandywine Valley Hemophilia Foundation

WASHINGTON

John Martinez

One of the biggest challenges of dealing with the recent health crisis has been managing the sense of disconnection many of us feel in the bleeding disorders community. Over the past two years, virtual programming has provided an alternative outlet for our need to feel connected and as a means to learn and grow. However, we all looked forward to a live, in-person event. With that in mind April 9th, BioMatrix and Bayer co-sponsored **Reconnecting in 2022**, a bilingual, in-person event where families discussed their history and the trials and successes of living with a bleeding disorder.

Following delicious Italian cuisine, a fun-filled BioMatrix rendition of *Loteria* entertained us all. Both adults and children participated and thoroughly enjoyed the game as they learned bleeding disorder terms while practicing Spanish. Everyone involved was enthusiastic about attending future events in Tacoma and the surrounding area. Thanks to Bayer for their support of this event!

NEW YORK

Richard Vogel and Carolina Luna

It was great to again be live and in-person at the New York Marriott Downtown with our bleeding disorders family! The New York way to get together with old friends and meet new ones is brunch. And that's just what the New York City Hemophilia Chapter did with a Mimosa Mixer to start the April 10th **In-The-Know Patient Decision Making Summit**.



Avigail, Yael, Mantserat, Dulce, Giovanni and Jose stop to take a photo with Carolina Luna (far right) at the BioMatrix booth

After catching up with friends we dug into some serious education. Keynote speaker Dr. Glenn Pierce spoke about *Future Treatments for Bleeding Disorders* and Angela Forsyth, PT, DPT, presented *Anatomy ABCs* for the youngsters and teens. During lunch consumers mingled with exhibitors and caught up with friends. The afternoon sessions had plenty to choose from, gene therapy, overcoming adversity, prophylaxis for VWD, new products – some launched during the pandemic that many consumers did not know about, and sessions for our Spanish-speaking community. There was even a session on a new clinical trial for hemophiliac arthropathy.

Our event ended with another New York thing, a raffle for tickets to various New York City shows and happenings. Winners were thrilled to be handed another chance to get out and have fun!

OHIO

Shelia Biljes

Here comes Peter Cottontail hopping all the way to Strongsville's Brew Garden April 12th to join a **Family Education Dinner** sponsored by BioMatrix and Bayer. Wendy Perkins, Bayer Hemophilia Community Consultant, presented an interactive presentation, *And Now Back to You*, focusing on the mental state two years of COVID-19 has left us in. She touched on ways to rebuild and clear the mind. Young adults in attendance were able to vent about missing proms, graduations, sports events, and time with friends, and conversation followed on tips to get over the anger and disappointment.

Soon it was time for fun and games in the restaurant's outdoor courtyard. Hula hoops, bunny hopscotch, a child's golf putting game, and an exciting egg hunt resulted in filled egg prizes for everyone! Taking the opportunity to spin the "Wheel of Supplies" also gave children a chance to earn more filled eggs by identifying all of the supplies needed for an infusion.

No one wanted to leave, and we actually closed the place down! Thanks to all who helped run the games and clean up after! And a big thank you to Bayer for sponsoring our Spring event!

Kids and adults alike visited with the very popular Mr. Peter Cottontail!



Maddie, Ben and Kylan get their Hula Hooping on!



Dorinda and grandson, Eli



Scotty G.

Emir, Emon, Eli with parents

Selina and mom, Jen

Alaina

Kylan and Brayden

Carter

NEW JERSEY

Richard Vogel

We are living in exciting times with the emerging medical advancements for genetic diseases such as bleeding disorders. There are new factor products on the market and gene therapy on the horizon. The New Jersey/New York bleeding disorders community came together April 13th at Bella Napoli Restaurant in Bloomfield for an evening of **Gene Therapy 101** education. I teamed up with my old friend and fellow blood brother Tommy Russomano from BioMarin Pharmaceutical.



Tommy Russomano presents on Gene Therapy

As an ice breaker, BioMatrix emceed a round of *Bleeding Disorders Friendly Feud*. Tommy then walked us through the basics of transfer gene therapy. Currently, only two FDA-approved gene therapies are available, one for retinal dystrophy and one for spinal muscular atrophy. There is no approved gene therapy for hemophilia as of yet. Community members came away with a better understanding of how gene therapy works. Then over a choice of Italian dinner options, we reacquainted and shared how we've managed through these last two years.

Thank you to BioMarin and Tommy for partnering with us! It was a great evening to be out and about with our "family" on this warm New Jersey night.



Activities were paused to wish community member, Milinda a happy birthday!



Do we have a Loteria winner?

CALIFORNIA

John Martinez

The bleeding disorders community is taking 2022 by storm. Community members gathered April 27th at the Shadowbrook Restaurant in Capitola for **Education and Dinner**. Sponsored by Novo Nordisk, this event was coordinated by Hemophilia Foundation of Northern California, supported by BioMatrix and proved an unmitigated success. Everything, including the

tram ride to the restaurant, prepared everyone for an exceptional event and dining experience. Families arrived in good spirits, excited to reconnect with old friends and open dialogue with new acquaintances. Every level of community member was present, from families with over 20 years of volunteering and attending events to families

with a newly diagnosed member. As introductions were made, several expressed how much these events mean to them.



Kevin and Stephanie enjoy the evening.

The evening kicked off with an informational overview of Novo Nordisk's newest product presented by Kim Shaeffer, NP from UC Davis. Kim gave an animated presentation and was open to participation and questions. Throughout the evening, families connected, and conversations were lively as patients and caregivers shared experiences and gained support from one another. After a delicious meal, BioMatrix provided a game of *Loteria*. Adults, teens and children participated in this fun-filled version of Latino Bingo that encourages new knowledge of Spanish and bleeding disorders vocabulary.

The night ended with family photos and a decadent chocolate cake that threatened to cause sugar overload. Reluctance to say goodbye was evident in the time spent interacting and conversing at the "exit" door. With new connections made, families left feeling unified and ready to face any challenge presented by their bleeding disorder.

OHIO

Shelia Biljes

Northern Ohio Hemophilia Foundation's annual fundraiser **Black and Blue Ball** took place April 29th at the Renaissance Hotel Gold Ballroom in downtown Cleveland. Dressed to the nines, over 200 were in attendance! A live auction kicked off the evening, which earned ten lucky guests an upgrade to a particular table where they were treated like royalty.



Aaron and Ashley always looking sharp!



Marie with BioMatrix's Shelia Biljes and Joe Piscitello



Shelia presents her handmade quilt



Forrest is pleased to offer his fantastic artwork for the NOHF silent auction



Jarrett (center) enjoys the Ball with dad, Scott and mom, Cheryl Happy auction basket winners! Bernadette and Rich

There were a variety of silent auction baskets including a *Tour of Ohio Package*, to a Jay Tursler Resonator Electric Guitar, and several volunteered their talents to create unique items. I made an Ohio-themed 66" x 89" quilt while another community member, Forrest, donated several of his incredible signed canvas paintings. A wine pull, 50/50 raffle and Heads-or-Tails game assured everyone could be donors on their own level and have a great time in the process. Dinner and a late night of dancing added to the spectacular evening!

As the ball came to a close, no one wanted the evening to end. Since the weather cooperated, many opted for a downtown evening stroll or saunter to the Jack Cleveland Casino next door.

DELAWARE

Tina McMullen

Did you hear? Wilmington's Hunter Barn at Bellevue State Park was the place to be April 30th for Brandywine Valley Hemophilia Foundation's annual **5K Big Red Run**, where BioMatrix was proud to be a Silver Sponsor! Beginning with everyone socializing and visiting sponsor exhibitor tables, Board Member Kim Hamstead provided breakfast, which included a wide array of drinks and other items from Wawa convenience stores. Then it was time for the race!

After enjoying snack and lunch also provided by Kim Hamstead and Wawa, prizes were awarded for various categories based on gender and age. Top fundraising team, *Cousins for a Cure*, raised a whopping \$6595 and earned a \$1500 grant to attend NHF's 74th Conference in August, while *Team Bolinski* placed 2nd with a remarkable \$4115 raised, receiving \$1,000 to attend NHF's Conference. The event was wildly successful for the Brandywine Valley



Rob with his favorite walking buddies, Arthur and Walter



Gail Novak about to start the 5K! Allison is ready for the run!

Hemophilia Foundation. Twelve sponsors, 180 donors, and 76 walkers and runners raised more than \$33,000! That number is extraordinary, especially for our wonderful volunteer-based foundation! Board President Gail Novak, the Brandywine Board, community members and generous donors deserve a huge round of applause for a job well done!

TENNESSEE

Cyndy Coors

BioMatrix and Bayer joined May 3rd to host an **Educational Dinner** at the Doubletree Hotel in Chattanooga's beautiful downtown area.

As dinner was served, Bayer Hematology Brand Speaker, Zach, presented *My Journey to Jivi* and shared his engaging story. Beth Owens, Bayer's Executive Hematology Consultant, discussed the variety of products now available to the bleeding disorders community.

With her calming demeanor and easy-to-follow instructions, Michelle Stielper of BioMatrix led the group through an art lesson. While talking about how art can be therapeutic when living with a chronic condition, Michelle demonstrated how to draw anime-type facial features and hair.

Everyone enjoyed the evening, and most were surprised at their hidden artistic talents! Many thanks to the Bayer team for partnering with us!

FLORIDA

Marcy Foertsch and Peggy Klingmann

BioMatrix and Bayer came together with members of the hemophilia community May 4th at Maggiano's Little Italy in Tampa for an **Educational Dinner**. Barbara Arrebola, Hemophilia Community Executive for Bayer, spoke about *Safe Travels* addressing the need for preparing as we begin to travel post pandemic. Following Bayer, BioMatrix presented *Camera On: Healing and the Art of Photography*, demonstrating different photography techniques using a cell phone. With instructions by Shelby Smoak, Ph.D., great photos emerged, and the participants expressed excitement to apply what they had learned to future photo taking.

We enjoyed bringing community members together with Bayer for an evening of delicious food, valuable information, and fantastic company!



Justin and Jenifer display their work with Beth Owens (center)



Ava is an artist!



Shelby Smoak presents *Camera On*

OHIO

Shelia Biljes

With Mother's Day quickly approaching, BioMatrix teamed up with Bri Vieke of Octapharma and Nicole Henry of HEMA Biologics May 6th for a **Women's Lunch and Education** to spoil our moms with sweet treats, fellowship and lots of fun! b.a. Sweetie Candy Company in Cleveland is the largest candy store in North America with 4,500 different items – \$3,000,000 worth of sweets! It also carries over 250 flavors of bottled soda and a retro toy department. My favorite area is the Pez Wall. It has hundreds of Pez dispensers to choose from!



Kitty likes Sugar Babies!



Nicole Henry, Charlene, Kristen and Bri Vieke, "We found the Charleston Chews!"

Over lunch, Bri and Nicole spoke to us about the current products they each represent. Afterward, I shared a study that describes one's personality according to the type of candy they prefer. We shared quite a few laughs determining if the study was true. A quick game of "What's in Your Purse?" followed and then we grouped into teams for a scavenger hunt in the candy warehouse! Each team had to solve 10 candy riddles, find the coordinating candy in the warehouse, and take a selfie. Everyone went into sugar speed, racing thru the warehouse. First team back was declared the winner! We gathered in the parlor to enjoy homemade ice cream, shakes and bottled sodas.



Ben found the candy for his riddle

Our bleeding disorders ladies group meets once a month and has so much fun! Many thanks to Octapharma and HEMA Biologics for sponsoring our time together!



A very "sweet" group of women (and one boy!)

TENNESSEE

David Tignor

BioMatrix was honored to be one of the **Be a Factor 5K** sponsors May 7th in Loudon. This wonderful fundraising program helps support the Tennessee Hemophilia and Bleeding Disorders Foundation's Camp Freedom and other programs. What makes this event so special is that it's a consumer-led fundraiser put together by the Jameson family, whose family member, Karson, has hemophilia. This was their 11th year of organizing this event! BioMatrix is grateful for the Jameson family and their dedication to supporting THBDF programs. We look forward to supporting this event again!



Greg, Karson and Dusty



OHIO

Shelia Biljes

To help usher the season's sunny days, BioMatrix partnered with Bayer May 11th for a **Family Dinner** at Brio Italian Grille in

Columbus. Venkat Chama, Bayer Patient Advocate Speaker, shared his intriguing story of having hemophilia and being born and raised in India, ultimately coming to America as a mechanical engineer. He referred to the hemophilia community as a small village with a large family, and how this family has shaped his life and who he has become.

Venkat encouraged the young boys and girls present to take ownership of their bleeding disorder – to be more self-reliant with their treatment and learn to self-infuse. His presentation was followed by a review of Bayer products and support programs from Wendy Perkins and Jeanine Smith, local Bayer representatives. Families were happy to stay late and visit with one another. It's good to be back in person!

OHIO

Shelia Biljes

With soaring gas prices and inflation, it makes sense to talk about finances while dealing with a chronic medical condition. BioMatrix teamed up with Novo Nordisk for an **Educational Meeting** May 12th to offer advice and share expertise on this topic. Northern Ohio families gathered at the Aviator Club overlooking the Cleveland Hopkins Airport in Brook Park. Novo Patient Advocate Judy Doyle opened the evening with a presentation focused on eight tips for improved financial

stability. She discussed savings plans, interest rates and credit scores. Ending her program, she turned the floor over to Terry Rice, BioMatrix Director of



Jarrett, Charles and Aaron flash their candy cash

Education and Advocacy, who shared his expertise. As an economics major, his topic *The Greatest Wealth is Health*. Terry shared his knowledge on life insurance, employee plans for saving funds for medical care and even tips on car insurance policies that could cover factor should there be an accident with an underinsured person. It was a lot of information, and everyone took notes on what interested them.

Each family took home copies of a living will, and financial and medical power of attorney forms. We will definitely plan a part two to answer more questions and go deeper on the topic. \$1,000,000 Hershey bars decorated the tables and brought smiles. Thank you, Judy and Terry, for sharing tips to make the changing times a bit more bearable!

ILLINOIS

Eva Kraemer

Bleeding Disorder Alliance Illinois (BDAl) hosted **Community Connections Weekend**, formerly known as *Statewide Education Weekend*. Held May 14-15th at Countryside's William Tell Holiday Inn – this is the first BDAI in-person event since the onset of COVID-19. Executive Director Bob Robinson welcomed everyone back after a two-year hiatus, followed by a keynote address by Stacy Feuer, Ph.D., discussing *Resilience and Recovery: Living and Growing with Rare and Chronic Medical Illness*. After lunch we heard from BioMarin and played a bleeding disorders-related game. Everyone then attended roundtable discussions on *Reproductive Health, Pain Relief Though Physical Therapy, Community Voices in Research, and Benefits of Positive Mental Health*. The evening brought *Family Fun Night* hosted at the hotel pool. The weekend promoted networking, camaraderie and a welcome relief from COVID.



Family photo time at the BioMatrix booth!
Isabel, Basil, and children, Christian, Julia, Grace and Tony



Assisting Educating Advocating For The Bleeding Disorders Community.



Upcoming Events

JULY 16, 2022 NEW JERSEY

Summer Wellness Gathering

Hemophilia Association of New Jersey
732-249-6000, <https://hanj.org/>
Eagles Landing Camp; North Brunswick

JULY 21, 2022 PENNSYLVANIA

Annual Meeting

Western PA Hemophilia Foundation
800-819-0862, <https://wpbdf.org/>
Dave and Busters; Homestead

JULY 22, 2022 OHIO

Ladies Lunch "Transitioning Thru Motherhood"

BioMatrix and Bayer
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Tony K's Bar & Grille; Berea

JULY 27, 2022 FLORIDA

Educational Dinner "Safe Travels"

BioMatrix and Bayer
Contact: Marcy Foertsch, 941-518-7063
marcy.foertsch@biomatrixsprx.com
Brio Tuscan Grille; Tampa

JULY 31, 2022 VIRGINIA

Community Picnic

Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Little Island Park; VA Beach

AUG. 2, 2022 OHIO

Back to School Family Event

BioMatrix, Octapharma and HEMA Biologics
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Swings-N-Things; Olmsted Falls

AUG. 06, 2022 FLORIDA

Back to School Awareness

Foundation Hope and Life USA
786-374-6143, <https://fhlusa.org>
Topgolf; Doral

AUG. 13, 2022 TENNESSEE

16th Annual Pitchin' for Caleb

Tennessee Hemophilia & Bleeding Disorders Foundation
615-900-1486, <https://www.thbdf.org/>
Centennial Park; Crossville

AUG. 13, 2022 VIRGINIA

Community Picnic

Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Deep Run Park; Richmond

AUG. 14, 2022 MARYLAND

HACA Community Picnic

Hemophilia Association of the Capital Area, 703-352-7641, hacacares.org
Watkins Regional Park; Upper Marlbor

AUG. 14, 2022 MASSACHUSETTS

Wheels for the World

Mountain bike ride led by Chris Bombardier
Save One Life, 978-352-7652
saveonelife.net/wheels-for-the-world
Ipswich (Check website for additional dates and locations)

NATIONAL EVENT!

AUG. 25-27, 2022 TEXAS

Annual Bleeding Disorders Conference

National Hemophilia Foundation
212-328-3700 ext. 728
<https://events.hemophilia.org>
Marriott Marquis and Hilton Americas; Houston

SEPT. 9, 2022 DELAWARE

Blue Rocks Baseball

Brandywine Valley Hemophilia Foundation, 302-598-4632
www.brandywinehemophilia.org
Timothy's Riverfront Grill and Daniel S. Frawley Stadium; Wilmington

SEPT. 9-10, 2022 VIRGINIA

Annual Women's Retreat

Hemophilia Association of the Capital Area
703-352-7641, hacacares.org
Meadowkirk at Delta Farm; Middleburg

SEPT. 21, 2022 FLORIDA

Educational Dinner

"Transition to Self-Infusion"

BioMatrix and Bayer
Contact: Marcy Foertsch, 941-518-7063
marcy.foertsch@biomatrixsprx.com
Seasons 52; Tampa

OCT. 7-8, 2022 OHIO

Family Education Weekend Camp

Northern Ohio Hemophilia Foundation
216-834-0051, <https://nohf.org/>
Maumee Bay Conference Center; Oregon

OCT. 14, 2022 PENNSYLVANIA

Ladies Sewing for Stress Relief

BioMatrix and Medexus
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Amy Baughman Quilt Store; Harmony

OCT. 15, 2022 OHIO

Women's Retreat - A Full Day of Crafts, Food, Nature and Education!

BioMatrix with Medexus, Octapharma and Northern Ohio Hemophilia Found.
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Green Cabin Berea Metroparks; Berea

OCT. 15, 2022 VIRGINIA

Medical Symposium

VA Hemophilia Foundation
804-740-8643, vahemophilia.org
Great Wolf Lodge; Williamsburg

OCT. 16, 2022 VIRGINIA

Unite for Bleeding Disorders Walk

VA Hemophilia Foundation
804-740-8643, vahemophilia.org
Great Wolf Lodge; Williamsburg



OCT. 23, 2022 OHIO





Cleveland Browns Watch Party





Lunch, Browns game, kids activities
BioMatrix and Bayer
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Brew Garden; Strongsville



Time for Fun!

Puzzles on Page 31

FACTOR  + 

5 CLOTTING  +  -  - 

INFUSION  +  +  - 

NEEDLE  + 

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

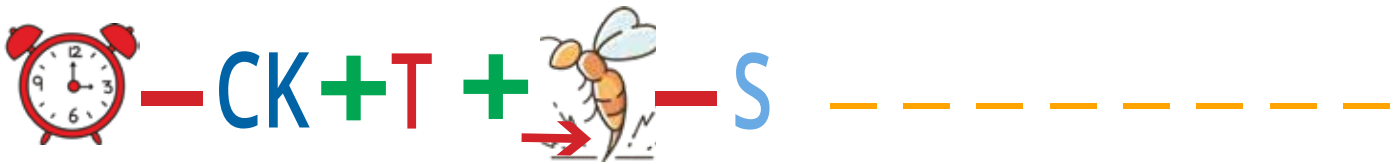
Time for Fun!

Hi Kids!

Can you decipher the picture puzzles below? Each answer relates to common bleeding disorder words. Answers can be found on page 30.



2 Words



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

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



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

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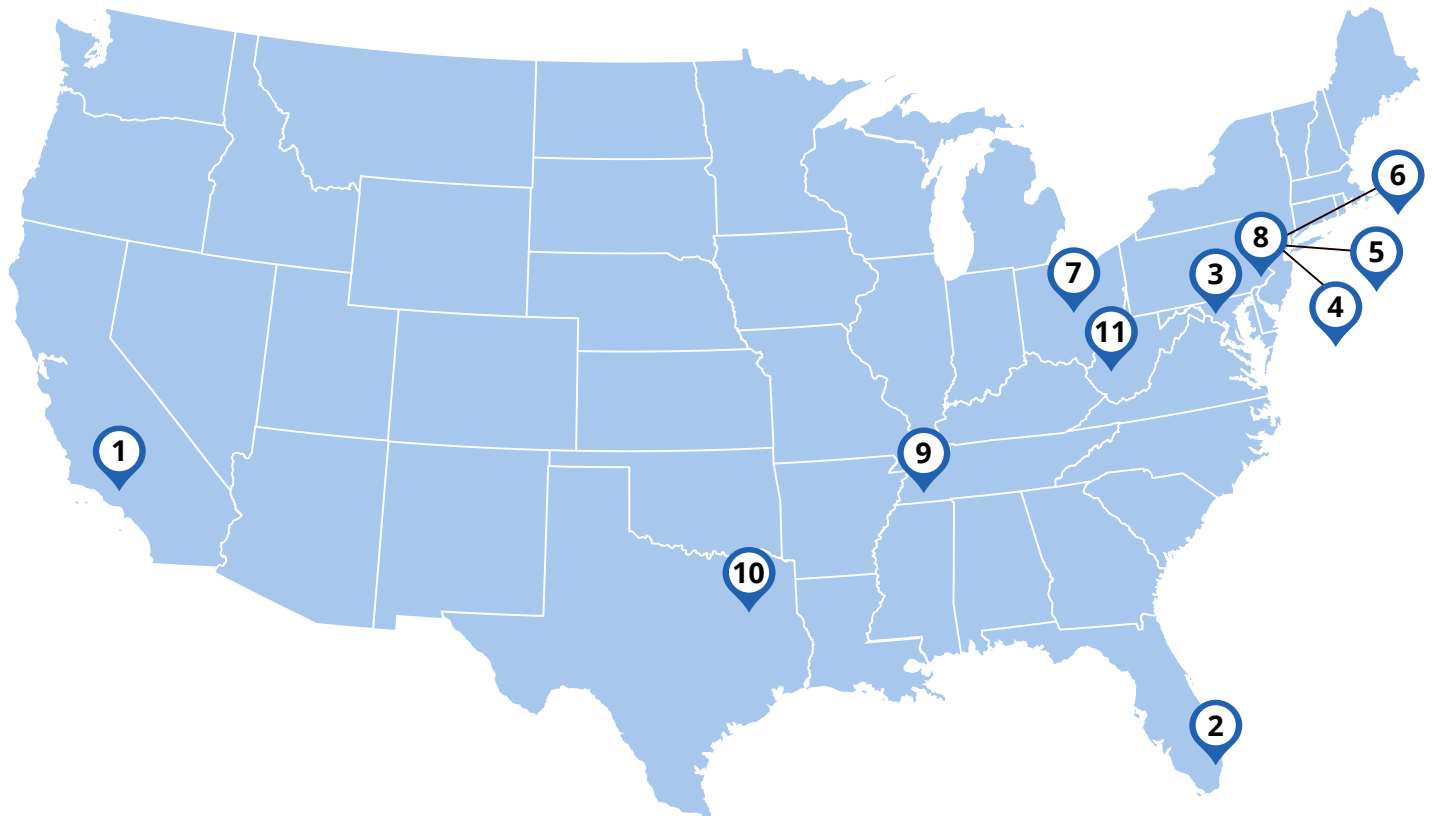
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Specialty Pharmacies



1. Canoga Park, California
2. Plantation, Florida
3. Columbia, Maryland
4. Totowa, New Jersey

5. Totowa, New Jersey (Reproductive)
6. New York, New York
7. Dublin, Ohio
8. Garnet Valley, Pennsylvania

9. Bartlett, Tennessee
10. Tyler, Texas
11. Charleston, West Virginia

