

NEWS



**DEDICATED TO
MAKING A DIFFERENCE**

**WINTER 2019
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“
**Learn from yesterday,
live for today,
hope for tomorrow.**
— Albert Einstein **”**

ABOUT BIOMATRIX^{SpRx}

BioMatrix Specialty Pharmacy offers comprehensive, nationwide specialty pharmacy services and digital health technology solutions for patients with chronic, difficult to treat conditions. Our growing family of companies unites leaders in the specialty pharmacy industry to improve health and empowers patients to experience a higher quality of life.

The current BioMatrix family of companies includes:

- Matrix Health
- Factor Support Network
- Medex BioCare
- BiologicTx
- Elwyn Pharmacy Group
- Decillion Healthcare

MISSION + VISION

The **MISSION** of BioMatrix is to provide an individualized clinical approach to specialty pharmacy services that improve health outcomes and empower 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 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:

We created Matrix Health Group News to provide information, current news, upcoming events, educational matters, personal stories, and a variety of opinions and views on topics of interest to the bleeding disorders community. Since our publication made its debut almost 14 years ago, we have published over 50 issues shared with more than 5000 subscribed readers. As a member of the expanding BioMatrix Family of Companies, we have decided to rename our publication. Welcome to BioMatrix News! You can continue to expect the same great content, delivered right to your door. Thank you for your readership!

In addition to announcing our Memorial Scholarship recipients, this issue addresses an especially important topic affecting many of us in the community. Learn about *Copay Accumulator Adjustors* and how the increasing insurance practice may affect our personal finances. Another important article, *When the Going Gets Tough*, addresses depression and how it may affect those with a bleeding disorder. It offers symptoms to look for in ourselves, and how to approach those near and dear to us if we think they may be experiencing such symptoms.

Lastly, we are excited to announce our 2019 *Living a Spectacular Life* calendar is now available! Filled with

cheerful faces of our fantastic community members, our hope is that everyone is reminded of the beautiful lives we live despite the challenges. Request a free copy of our calendar (while supply lasts) by contacting me at maria.vetter@biomatrixsprx.com or contact your local BioMatrix rep!

Have a safe and wonderful winter, and best wishes for the *spectacular* year ahead!

Maria Santucci Vetter
Editor-in-Chief, BioMatrix News
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BIOMATRIX PROUDLY ANNOUNCES THE 2018/2019 MEMORIAL SCHOLARSHIP RECIPIENTS!

In 2018, BioMatrix offered six \$1,500 scholarships for bleeding disorders community members seeking higher education. These scholarships honor the memory of several individuals who impacted the bleeding disorder community in unique ways. Given the growth of our scholarship program, we partnered with Hemophilia Federation of America to administer the program, including independent third-party evaluation of applicants. It is with great pleasure we announce the 2018 recipients of our Memorial Scholarship Program. Thank you to everyone who applied and we wish you great success in each of your bright futures!

Without further ado, we introduce you to our scholarship recipients!

MILES COLE



Joe Holibaugh Memorial Scholarship
Sophomore, Princeton University, Major: Undeclared

Taking his bleeding disorder in stride, Miles has never let severe hemophilia stop him from achieving his dreams. Very athletic throughout his life, he competed internationally with the USA Junior National Water Polo Team. "I grew up believing that as long as I was diligent about my meds, hemophilia did not have to define or limit my activities." Miles adamantly offers, "Take charge of your life to shape it how you want it to be."

Congratulations, Miles!

LENA COOK



Millie Gonzalez Memorial Scholarship
Sophomore, California State Polytechnic University, Major: Kinesiology

Growing up as a female with hemophilia, Lena encountered the challenges of being properly diagnosed and had to learn to advocate for herself. She is dedicated to paving the way for others and has been instrumental in starting a women's support group at her local chapter. "It was a fantastic opportunity to share our stories and reaffirmed my commitment to finding effective treatments for myself and other women with bleeding disorders."

Congratulations, Lena!

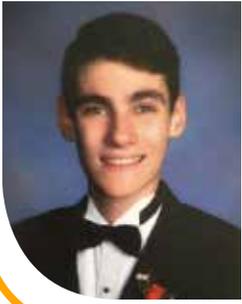
CALEB CROTHER



Mike Hylton Memorial Scholarship
Freshman, Westmont College, Major: Religious Studies

Salutatorian of his high school, Caleb, who has hemophilia, entered college with the same gusto for learning and achieving. In addition to his studies, volunteering and music have been very important in his life. "Having a bleeding disorder has helped me realize that as much as your community helps you, you should go and help your community."

Congratulations, Caleb!



JUSTIN NAJIMIAN

Tim Kennedy Memorial Scholarship

Freshman, Rutgers University, Major: Public Health

Beginning his college years, Justin's plan for the future is to pursue a career focusing on the social and cultural impact diseases have on people. As did his beloved grandfather, Justin lives with hemophilia, and has been inspired to devote his life to helping others. He shares, "I carry my hemophilia gene not as a burden, but as a torch that gives light to the memories of generations past and blazes the trail for a new generation of leaders."

Congratulations, Justin!



ISAIAH REEVES

Mark Coats Memorial Scholarship

University of Iowa Carver College of Medicine: Medicine

Greatly influenced by his childhood physicians who treated his hemophilia, Isaiah is pursuing a doctoral degree with hopes of becoming a pediatric hematologist/oncologist. "As a doctor, I will use my personal experiences, abilities, and knowledge to support and enrich the lives of children, and will seek to emulate those physicians from my own life who have been so impactful on making me the person I am today."

Congratulations, Isaiah!



RACHEL WILE

Ron Niederman Memorial Scholarship

Junior, UCLA, Major: Integrative Biology and Physiology

With significant history of hemophilia in her family and as a diagnosed carrier, Rachel hopes to continue her education past her undergraduate studies and become a physician. The experiences of her relatives have had a marked influence on her goals. Rachel shares, "Through my ongoing education and training, I hope one day to have a positive impact on the lives of those with bleeding disorders in this country and throughout the world."

Congratulations, Rachel!

The 2019-2020 school year application process opens in March, 2019 and will run through August 1, 2019. Apply online by visiting: <http://bit.ly/2018-BioMatrix-Scholarship>



Joe Holibaugh (1971-2006)

\$1500 Scholarship
For MEN and WOMEN with hemophilia AND an Inhibitor



Ron Niederman (1950-1999)

\$1500 Scholarship
For MEN with hemophilia or VWD and their immediate family members



Tim Kennedy (1962-2011)

\$1500 Scholarship
For MEN with hemophilia



Mike Hylton (1945-1998)

\$1500 Scholarship
For MEN with hemophilia or VWD and their immediate family members



Millie Gonzalez (1953-2001)

\$1500 Scholarship
For WOMEN with hemophilia or von Willebrand Disease



Mark Coats (1956-1963)

\$1500 Scholarship
For MEN and WOMEN with hemophilia



COPAY ACCUMULATOR ADJUSTORS: WHAT'S THE DEAL?

By Shelby Smoak

Do you use a pharmaceutical manufacturer's copay card to cover your out-of-pocket cost when you order medicine?

If so, you are not alone. And if so, beware of 2019 as Copay Accumulator Adjustors gain an even greater presence in commercial insurance health plans, including ACA Marketplace plans. In 2018, approximately 17% of employer plans had Copay Accumulator Adjustor programs, but that number is expected to jump to 29% for 2019.¹

DEDUCTIBLES AND THE RISING DRUG COST

Copay Accumulator Adjustor programs jeopardize therapy adherence and create unaffordable health care costs for patients. Basically, an insurer that institutes a Copay Accumulator Adjustor disallows a drug manufacturer's copay card to apply toward a patient's deductible. However, accumulator policies are not always obvious nor clearly understood, so let's discover what these accumulators are and how they work.

Insurance policies over the last several years have been shifting more of the cost burden onto patients. Thus, it is not uncommon for patients to have yearly deductibles and out-of-pocket costs as high as \$6000 or more. To alleviate this burden – and to help market their factor products, the pharmaceutical industry initiated copay cards that could be used in conjunction with the insurance policy to absorb that out-of-pocket cost at the point of sale.

Insurers dislike copay cards because they undermine their ability to control drug costs. For example, if according to the insurer's drug formulary, one drug has a copay of \$25 (perhaps a generic) and another drug has a copay of \$250 (likely a brand medication) to treat the same condition, then the insurer knows patients will be incentivized to choose the \$25 medication for that therapy treatment, thus saving the patient and the insurer money. But if the drug with a \$250 copay has a supported manufacturer copay card, then this financial motivation fails, and it actually becomes cheaper for the patient to choose the more expensive drug, costing the insurer more money. Copay cards push patients away from cheaper drug alternatives.



THE COPAY ACCUMULATOR

Thus the Copay Accumulator Adjustor was born. In this scenario the insurance company accepts a manufacturer's copay card and will apply the card's funds toward a patient's out-of-pocket cost at the point of sale, BUT, and this is a HUGE but, the manufacturer's copay amount does not count toward the patient's yearly deductible because the money did not come out of the patient's own pocket. The insurer will accept the

“...it is not obvious and can be elusive to the patient.”

manufacturer copay cards for specific bills until the maximum value of the card is reached; at that point, with the card exhausted, the balance of the out-of-pocket cost will be the patient's responsibility.

Let's look at an example:

James is a severe hemophiliac with a commercial insurance plan, using a factor product that has a copay card program with a \$12,000 balance. In January, James orders factor from his specialty pharmacy and is told his insurance has an out-of-pocket cost of \$6000. James supplies the copay card from his product's manufacturer assistance program, and James receives his factor without having to pay anything from his own pocket. His copay card now has a balance of \$6000.

In February, James orders factor and is told he still has an out-of-pocket cost of \$6000 from his insurer. The out-of-pocket cost remains because the manufacturer copay card was not applied to his balance. James again supplies the copay card and receives his factor without having to pay anything. His copay card now has a balance of \$0.

In March, James orders factor and is again told he has a \$6000 out-of-pocket cost from his insurer. James gives the specialty pharmacy his copay card, but there is no money left on it. To get his factor, James must pay the \$6000 from his own pocket to meet his yearly deductible.

One can see the confusion in this insurance program because for several months it seemed that James's insurance accepted his manufacturer's copay card. And they did. But unbeknownst to James, the copay card was not helping pay his yearly out-of-pocket cost as it had in previous years, and that financial burden is being shifted back onto James, who must pay the amount to receive his factor.

COPAY CARDS AND YEARLY DEDUCTIBLES

Why don't insurers accepting copay accumulators clearly indicate the money isn't being applied to the patient's yearly out of pocket? Because the accumulator likely only gets flagged in the actual billing process, something that often happens days or weeks after the actual transaction; the use of an accumulator isn't recognized at the point of sale. It will appear on EOBs, but at the point of transaction, it is not obvious and can be elusive to the patient. The insurer authorizes the pharmacist to dispense the medication, but the bill and exchange of actual money will happen later, and at that point, if an accumulator is in place, it will then be applied.

So why do they even accept these copay cards? Why not just block their usage? There were early legislative attempts to block copay cards, but the insurers met stern resistance from the community and disease advocacy groups, so part of that answer is that accepting the copay cards is a PR strategy that alleviates the backlash blocking cards would have.

Another reason insurers accept the copay cards is because it then becomes more expensive for the drug manufacturers who fund the copay programs. In turn, perhaps, so an insurer may think, the manufacturers may stop pouring money into the cards since that money is no longer benefiting the patient in the way it was intended, but is instead going directly into the insurers' pockets.

There is not an industry standard name; it may also masquerade in the following terms, though all names are misleading since the offered protection is not for the patient.

- Copay Maximizer
- Coupon Adjustment Program
- Benefit Plan Protection Program
- Out-of-Pocket Protection Program

IS IT IN MY PLAN?

So, how do you know if your health plan has an Accumulator Adjustor? You could try and read the health plan manual to find it, but it may go by many different names, as noted above, and it may actually be written in the policy but not (yet) being implemented by the insurer. The specialty pharmacy will not immediately know when you order because it will look to them (and you) as if the health plan is accepting the copay card. Your best bet is to consult with your health plan. First, be sure you read all the mailings sent to you. Second, call the number on the back of your insurance card and ask your health plan these questions:

- Does my health plan utilize a Copay Accumulator Adjustor program?
- If I use a manufacturer's copay card to pay for my drug, will that copay card amount be applied to my yearly deductible?



WHAT MORE CAN I DO?

Most health care organizations are aggressively involved with this issue, so let them know if you have been affected by a Copay Accumulator program.

Hemophilia Federation of America is collecting information through *Project CALLS*; contact them at: www.hemophiliafed.org/for-patient-families/navigate-insurance/project-calls/

National Hemophilia Foundation is also involved; contact them at: advocate@hemophilia.org

The Coalition for Hemophilia B has a *B Voice* program for advocacy at: www.hemob.org/advocacy

You can also reach out to your BioMatrix team member who can help you understand Copay Accumulators or put you in touch with our Advocacy Team for more information.

REFERENCE

1. Silverman, Ed. "Backlash Against Copay Accumulators." *Managed Care*. 3 Sept. 2018. www.managedcaremag.com.

A DAD'S VIEW

***Excited!* The first feeling I had when I learned we were having a boy.**



By Joshua Henderson

When dads find out they are having a boy, they can't wait for them to follow in their footsteps and grow up to be just like them. A dad thinks their son will be able to fulfill all the dreams he could not; in my case, it was to make it big in rodeo or horse training. I imagined going to football games together and watching sporting events where he would be playing, of course, without more than the normal concern for his safety.

When I heard my son had hemophilia, my first thought was this was just a little thing we could manage and move on. After all, kids are resilient. I didn't realize how severe his condition could become because we hadn't yet dealt with an inhibitor or even a "real" bleed. As many are during the honeymoon stage, we were ill informed, and it was obviously a much bigger deal. I definitely did not understand the severity or possible consequences of a hemophilia diagnosis and I never, ever dreamt this could place his health in serious jeopardy.



After a life-threatening bleed at one-year-old, it felt like everything was out of control. As he fought through his first major bleed, I prayed I could take on his hemophilia so he would never have to deal with such pain again. I soon realized I could make decisions about his medical care, but no matter what, I could not make his hemophilia go away. It was here to stay.

As I learned more about hemophilia and moved past the initial life-threatening episode, I gained strength. As we continue in our experiences, I believe there is no situation we can't handle as parents or as a family. My worry is not gone, but I definitely don't freak out like I used to!

At times, his bleeding disorder has forced me to stop and drop everything I am doing to concentrate solely on him. Without any distractions, we have the opportunity for true, quality father-son time. While waiting for the factor replacement to run through his pump, we hang out together reading, playing video games, etc. These extra moments of quality time are shared because of his bleeding disorder.

Because of his condition, I believe my son will grow and develop into a humbler and more tolerant person than the average adult. At 6 years old, he already understood how his behavior and choices could result in serious consequences for him. The direct cause-and-effect of living with a bleeding disorder is teaching him the significance of his decisions. What better foundation is there for molding a responsible adult!

If my son did not have hemophilia, I'm not sure I would have been quite as involved as I am, and while the negatives of living with a bleeding disorder remain, there are plenty of positives to hold onto. Now that my son is 12, the future is brighter than ever for someone with hemophilia and inhibitors because of life changing treatments and advancements. My initial dream of having a son has not been ruined; it's just been tweaked a bit!



2018 NHF ORLANDO: IN REVIEW

The bleeding disorders community lives in a dynamic world – one that is complex and continuously evolving. Whether it's a plethora of new clotting therapies or the ever-changing health care and insurance concerns, we need to educate ourselves on all issues. Equally important is to remember our past, learn from our errors and honor those before us.

By Richard Vogel and Maria Santucci Vetter

Celebrating their 70th anniversary, the National Hemophilia Foundation's Bleeding Disorder Conference in Orlando, Florida October 11–13, 2018, helped the community find answers to some of the current issues facing people with bleeding disorders. Whether affected by a bleeding disorder – men, women, spouses and partners, teens or young adults looking forward to managing their own health, those with an inhibitor, Spanish speakers, medical personnel to include physicians, nurses,

social workers, physical therapists, people serving as chapter leadership, or those in bleeding disorder related organizations, there were informative sessions led by distinguished and knowledgeable speakers for everyone. Divided into tracks, sessions were carved out to particular audiences, some by invitation only. Invitation only tracks were geared toward those with very specific interests, for example families affected by a rare bleeding disorder such as factor XIII or factor X deficiencies.



General sessions ranged from Basics of Hemophilia for those new to the community, to more complicated subjects involving new therapies and future treatments for bleeding disorders. We've come a long way since the days of cryoprecipitate, which was an advancement at the time over whole blood and plasma.

There were meetings for men, for women, and for couples. There were meetings for teens and young adults as they transition to adulthood, and for the "veterans" of the crowd. Topics included everything from pain management, addiction, emotional wellbeing, to joint care, ultrasound use in the HTC, blood safety, HIV, hepatitis and access to healthcare. A special *Remembrance and Celebration of Life* session was held so those we have lost in the community are remembered, honored and celebrated.

Some sessions sparked interest just by their creative titles - *Stagnant Waters Breed Mosquitos: Finding Joy in What You Do*; *Research Can Be Sexy*; *Embracing Your Inner Geezer*; and for chapter personnel, *Let's Get Serious AF: Accidents in Fundraising*.

In addition to the variety of formal educational sessions, there was also much information and fun to be shared in the exciting exhibit hall. From a wide array of manufacturers, specialty pharmacies, non-profit organizations and market research companies, there was plenty for consumers and professionals alike to garner even more information.

BioMatrix was well represented in the exhibit hall as the young and nimble as well as the older and tougher crowd alike were drawn to the challenge

and excitement of our arcade classic Dance Dance Revolution video game with prizes offered daily for the highest score. Despite some tender ankles, people with bleeding disorders are not deficient in the "dancing" gene, though much hilarity was had at the expense of us with two left feet!

One special attraction at the BioMatrix exhibit was the launching of our newly published children's book entitled, *This Is My Something*, a sweet story of a young boy with hemophilia who learns about and accepts the special somethings of new friends. The authors, Terry Stone and Michelle Stielper - a mother-daughter duo who both have children with severe hemophilia, were on hand to read and sign copies for their young visitors and interested grownups.

Adding to the knowledge-expanding opportunities, a huge part of the conference revolves around the social aspect of the gathering. There is no better way to party than with people that "get" you!

Early in the conference, NHF provided social receptions for a variety of groups. These included special gatherings for chapter leadership, newly diagnosed families, VWD families, LGBTQIA community members, and one for teens only. Inclusive and diverse, NHF makes everyone feel welcomed and appreciated. The famed *Final Night Event* featured a gourmet dinner of comfort food, games galore and an energizing dance party!

The few days in Orlando brought together young families and young adults who truly are the future of this community as well as seasoned people with bleeding disorders who now





worry about high blood pressure and cholesterol. It's always great to see this tight-knit community come together! From across the country, we have the chance to see old friends and make new ones. These developing relationships last a lifetime, offering camaraderie, opportunities to bond and mutual support throughout the stages of our individual and collective journeys.

We look forward to seeing everyone at NHF's 71st Conference October 3-5, 2019 in sunny Anaheim, California!



NHF AWARD RECIPIENTS!

Every year, NHF honors individuals and groups within our community during an Awards Ceremony. This year's esteemed recipients are:

- Physician of the Year – Michael Guerrero, MD of Children's National Health Systems, Washington DC
- Nurse of the Year – Glen Roy, RN-BC, BSN of Maine Medical Center, Portland, ME
- Social Worker of the Year – Eric Iglewski, LMSW of Mary M. Gooley Hemophilia Center in Rochester, NY
- Physical Therapist of the Year – Nancy Durben, PT, MSPT, PCS of The Hemophilia Center at OHSU, Portland, OR
- Genetic Counselor of the Year – Sarah Ryan, MS, CGC of Bloodworks Northwest, Seattle, WA
- Ryan White Youth Award – Jacey Gonzalez, Las Vegas, NV
- Advocate of the Year – Kelly Gonzalez, MBA, M.Ed, Las Vegas, NV
- Humanitarian of the Year – Amber Federizo, APRN, FNP-BC of Hemostasis and Thrombosis Center of Nevada, Las Vegas, NV
- Philanthropist of the Year – Kathryn and Timothy Statton, CA
- Lifetime Achievement – J. Michael Soucie, PhD, Centers for Disease Control and Prevention, Atlanta, GA

We are particularly excited over the awards accepted by Kelly and Jacey Gonzalez. Kelly is a Regional Care Coordinator and Educational Specialist with BioMatrix. Equally impressive and amazing is her daughter, Jacey! Congratulations to both for their extraordinary achievement and devotion to the bleeding disorders community! Congratulations to all!



RECEIVE A SIGNED COPY OF "THIS IS MY SOMETHING"



A charming new 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
Michelle Stielper at michelle.stielper@biomatrixsprx.com





BLOOD WORK

At BioMatrix, one of our very favorite parts of NHF is the annual Blood Work exhibit, an interactive art gallery celebrating creative expression within the bleeding disorders community.

Partnering with NHF, Blood Work is organized by FOLX, a non-profit organization that fosters inclusion and diversity in the bleeding disorders community.

In a September 13, 2018 press release, Tara Marchese, BioMatrix Corporate Director of Marketing shared, "We're pleased to partner again with the National

Hemophilia Foundation and FOLX on the 5th installment of Blood Work. Every year we are amazed at the incredible creativity and talent on display. It is a powerful representation of what it's like to live with a bleeding disorder through the patient's eyes."

A few of the spectacular entries included:

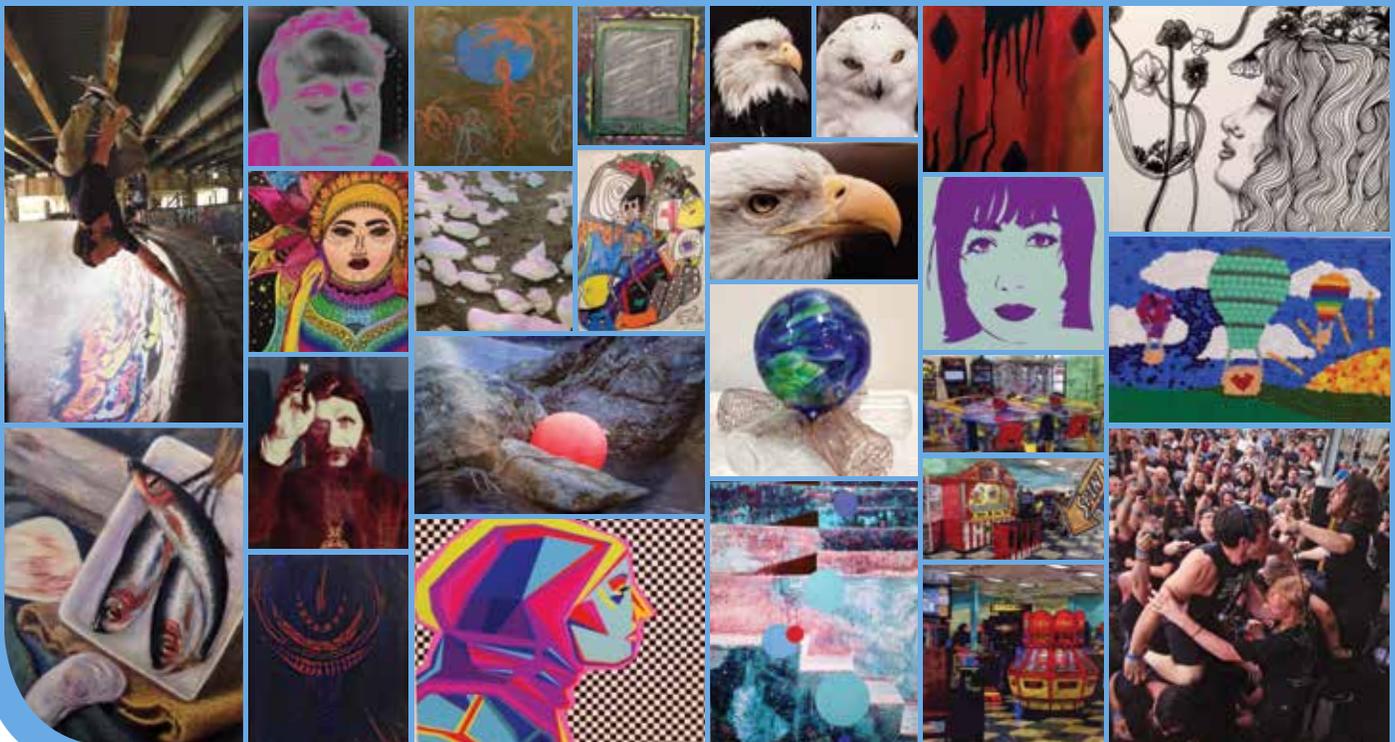
- A new single and video, "Rose in the Rain" by singer/songwriter Shelby Smoak (To view, visit: <http://shelbysmoak.com>)
- Camp Collins Lino Prints from GutMonkey and CHES's

Leverage for Adults with Inhibitors

- A series of acrylic paintings exploring identity and self-representation by Grace Addison

BioMatrix is proud to be a sponsor of the efforts of Justin Levesque, creator of FOLX and the Blood Work exhibits!

For more information on FOLX and how you can participate in Blood Work during NHF 2019, please visit <http://folxfolx.org> or contact Justin Levesque at 207-651-9235 or justin.levesque@biomatrixsprx.com



WHEN THE GOING GETS TOUGH...

HOW TO HELP YOURSELF HOW TO HELP OTHERS

By Gary McClain, PhD

Back in the day, the words of a popular song went something like, “life is just a bowl of cherries.” I don’t know whose life the songwriter was describing. Those words sure don’t describe my life, and I suspect they don’t describe yours either. Life has lots of high points, even days when life does feel like a bowl of cherries, but there are other days when life is pretty hard and the challenges overwhelming. When one down day seems to follow another, when you just aren’t feeling a whole lot of enthusiasm for life... well, that can be a sign of depression.

DEPRESSION AND BLEEDING DISORDERS CAN GO HAND IN HAND

Let’s talk about the connection between bleeding disorders and depression. Recent research has shown that there is a clear connection between chronic conditions like bleeding disorders and depression symptoms. Depression can result from the limitations and challenges that a bleeding disorder can impose on your life, the daily responsibilities of managing your condition, as well as stress that arises along the way.

When untreated, depression can also have an impact on your physical health. People who are experiencing depression don’t always feel like taking the best care of themselves, and this can affect self-care and adherence. Depression can also have an impact on your activity level which can, in turn, affect your wellness.

So why aren’t physicians always identifying and treating depression? There are a few reasons. For one, their patients don’t always tell them about depression symptoms. Patients may feel like it’s “normal” to feel down, given the challenges they are facing and for better or worse, physicians may make the same

assumption about their patients.

Here’s something else to consider: Patients with bleeding disorders may also go through times of “distress” when their symptoms and/or their self-care regimen feel especially challenging. Distress, which can lead to feelings of frustration and sadness, is temporary, and may gradually subside when the patient gets some emotional support. Depression on the other hand, just kind of hangs around.

So if patients and their doctors aren’t talking about emotions on a regular basis, it’s easy to see why there may be assumptions on both sides and, as a result, symptoms of depression may be overlooked. I am not trying to paint a bleak picture here. Instead, I want to inform and encourage you to keep an eye out for depression in yourself and in others. The good news about depression is that it is treatable, resulting in improved quality of life. However, to experience that good news, it’s really important to take the first step.

IF YOU SUSPECT YOU COULD BE EXPERIENCING DEPRESSION, HERE ARE SOME IDEAS TO CONSIDER:

Be aware of the symptoms

The symptoms of depression are too numerous to list here, but some of the key symptoms include lack of energy, lack of interest in activities you normally enjoy, difficulty concentrating, changes in eating or sleeping patterns, feeling sad, feeling hopeless, low self-esteem and other symptoms. As mentioned previously, depression symptoms don't go away on their own. If you are experiencing one or more of these symptoms daily, for a couple of weeks or more, then you may be experiencing depression.

Make a list and bring it to your doctor

Consider keeping a journal of what's going on with you emotionally. Any symptoms you are experiencing, what kinds of thoughts you are having, along with how often you feel or think this way. Make an appointment with your doctor and go through your list with him/her. Ask your doctor if he/she is comfortable talking about depression and if they can recommend treatment, and if not, ask for a referral to where you can get help. Some internists would prefer to refer patients to a psychiatrist or other mental health professional.



Consider reaching out to a mental health professional

You may want to make your own connection with a therapist or a counselor. Ask a friend for a recommendation, check out your local community mental health resources, get a list of mental health professionals through your insurance company's website, or do a search on Google for a list of mental health providers in your area.

Most important, get support

Don't go through this alone. Talk to a supportive friend or family member, or with a member of the clergy. Gather people around you who can listen without judging or trying to tell you what to do.

IF YOU HAVE A CONCERN ABOUT A FRIEND OR FAMILY MEMBER, HERE ARE SOME IDEAS:

Express concern

Find a time when the two of you can talk alone. Let them know that you are concerned and want to offer your help.

Be specific

Make sure the person you are concerned about is aware of what is causing your worry. Tell them what you have observed, any depression symptoms you have noticed, as well as any changes you have seen over time that seem out of the ordinary. You might want to recommend a website, such as www.mayoclinic.org that offers information on depression.



Offer to support them in any way you can

This might include being willing to lend a listening ear, to help them find resources for help with depression or even to accompany them to a doctor's appointment or a session with a mental health professional.

Don't push it

Be careful about being perceived as "diagnosing" the person you are trying to help. You can express the concern that the symptoms you have observed could be related to depression but be careful about being perceived as having diagnosed them yourself. That can result in defensiveness. If the person doesn't want to have this discussion, then respect their wishes, though you may want to say that you are there for them if they want to talk further.

When the going gets tough, remember that depression is treatable. If you think you may be depressed, reach out for help. If you think someone you care about may be depressed, offer to help them find help. We're all in this together.

About Gary McClain

Gary McClain, MS, PhD, LMHC, is a therapist, patient advocate, and author in New York City, who specializes in working with individuals diagnosed with chronic and catastrophic medical conditions, their caregivers, and professionals.

He maintains a website, www.JustGotDiagnosed.com



BIOMATRIX ON THE MOVE

TEXAS

Dave Burgeson VWD Empowerment

Weekend September 28th-29th at the Embassy Suites in El Paso was exciting and energizing from the get-go as VWD patients and family members gathered to focus specifically on VWD-related education!

We, along with staff members of Hemophilia Outreach of El Paso (HOEP) and Octapharma representatives, warmly welcomed everyone as they entered the meeting room and began their evening with fun props and a photo booth! After mingling and picture-taking, the group sat down for dinner while Educational Specialist Kelly Gonzalez provided an overview of the weekend before them.



Attention soon turned to the *Ask-The-Panel* session where questions flowed and excitement built. The panel consisted of Dr. Bernstein of Connecticut Children's Hospital, Kevin Griggs, MSL of Octapharma, Daniela Delgado, a young patient, and Kelly Gonzalez. As the first night ended, patients and families looked forward to the next day's experience.

Saturday began with breakfast and more photo booth fun. Kelly Gonzalez presented on *Advocacy* concentrating on how to advocate for yourself or loved one with a bleeding disorder. Dr. Bernstein presented on VWD diagnostics, guidelines and treatment protocols. Kevin Griggs spoke on VWD typing and treatments available and Daniela Delgado held an inspiring breakout session covered overcoming adversity and finding your purpose. After a quick lunch, the panelists returned to answer questions and facilitate conversations covering information shared during the presentations.

The event drew to a close with lots of hugs and appreciation for the valuable information shared. Thank you to Octapharma and HOEP for joining us in making this wonderful event happen!



ILLINOIS

Eva Kraemer

Bleeding Disorders Alliance Illinois and Shire recognized ***Celebrando el Mes de la Hispanidad*** or ***Celebrating Hispanic Heritage Month*** as a tribute to Hispanics/

Latinos throughout the United States. Along with dancers who delivered a marvelous display of traditional dances from all over Colombia in South America, an educational program was provided about resiliency September 29th.

The event was held at the National Museum of Mexican Art in Pilsen, a well-known Mexican neighborhood within Chicago. Approximately 75 community members relished a delectable meal of various Colombian delights as we reminisced about the represented culture and heritage. Good conversation, cultural food and vibrant festivities were enjoyed by all!



Veronica and Miley celebrate with bright colors!

TENNESSEE

Cyndy Coors and David Tignor

The **Annual Fall Festival** of the Tennessee Hemophilia Bleeding Disorders Foundation (THBDF) was held Saturday, September 29th at Kyker Farms Corn Maze in Sevierville. It was a beautiful early fall day for the festivities! Bleeding disorders community members first had the opportunity to visit industry reps and learn about their products and services, then it was time to enjoy lunch and participate in numerous activities including a variety of “kornfusing” mazes, hayrides, a pumpkin patch, tunnel slides, swings, corn hole games, a zipline and more! It was a fun day for all! Many thanks to THBDF for hosting this event!



Debbie and Sean visit the BioMatrix booth!

VIRGINIA

Terry Stone and Michelle Stielper

Along the banks of the quiet waters of Lake Accotink Park in Springfield, families and fans of the Hemophilia Association of the Capital Area (HACA) took in the cool fall air and rallied together to walk and raise funds at HACA's **Annual Fall Festival and Walk** Saturday, September 29th. The lake was glistening, the temperature was not quite sweater weather but comfortable and the event raised a whopping \$90,000 which HACA will put to good use.

There were games and barbecue and lots of time to catch up. Also on hand was Matt Stone, a teen volunteer recruiting teens and mentors to get involved with HACA's Teen Task Force for the new year as they increase their community advocacy and service around the region. Congratulations to HACA and its fearless leader Brenda Bordelon for a successful event!



Spencer, Nina, Sandesh, Ishaan and Namrata enjoying time together at the walk!

OHIO

Shelia Biljes

Colored leaves, pumpkin spice, hayrides and apple cider are just a few things to enjoy in northeast Ohio during the autumn season, but the best thing this year was to combine them all into a full day at Mapleside Farms in Brunswick. Bayer and BioMatrix cosponsored such a day October 6th. This **Educational Event** merged fun fall delights with a brunch, speaker and reunion of community members.



Star and Tony

Christian

Carter

Venkat Charma, a *Kovaltry Conversations* speaker from Wisconsin shared his story of life in India, then of his college days and life here in the U.S. The youth tuned in as he spoke of his adventurous camp days thru marriage and fatherhood. While Venkat spoke, a delectable brunch was served. Though it had been raining, as the speaker concluded, the showers miraculously stopped, and everyone headed out for the activities.

The most efficient way to Pumpkin Valley was to take a ride on the 311' giant slide. Just past Billy Goat Bluff, people gathered for pig races and cheered on Lindsey LoHAM, Kevin Bacon, and Ham Solo. Some chose to ride the pig train, go for a hayride, while others chose to get lost in a corn maze. The petting zoo was entertaining and for those with any energy left, a giant bouncer and tractor tire mountain were waiting just past the pumpkin patch.



Lily and Brooklyn

To complete the day, apple cider, fresh-made pumpkin donuts and caramel apples were waiting near the exit. Some even chose to visit the on-site bakery for fresh apple pies to take home. It was an amazing way to start the fall season!



Mila and Hanna



WEST VIRGINIA

Michelle Stielper

Arriving at Bolivar Pentecostal Church in Harpers Ferry on the afternoon of October 6th, Steve Nick and his **Spokes Men for Bleeders Century Ride** group did not disappoint! Pedaling 100 miles in one day to get there, he and fellow riders really outdid themselves. These bikers trudged through some rainy, muddy conditions for a fantastic cause, the West Virginia NHF Chapter. In combined rider sponsorships, raffles, and silent auction, \$7989 was raised. At the finish line, quite the crowd was waiting to celebrate the riders with a potluck dinner.



Bioerativ Rep Sue Cowell, Michelle Stielper, Steve and Lisa Nick, and Paul and Francis Brayshaw

Steve started this bike ride four years ago after attending a chapter event. He wanted to find a creative way to repay the chapter for the kindness they had shown him and his family and so the idea of a fundraising bike ride was born. That first year, Steve rode the 100 miles solo. Since then, this event has grown far beyond what he thought possible. Congratulations to Steve, his wife Lisa, and the riders for a fantastic event. We look forward to continuing to support Steve in his fundraising efforts, year after year. Helmets off to a fantastic ride!

If you are interested in sponsoring a rider or riding with Steve, please contact him at: spokesmen4Bleeders@gmail.com



OHIO

Rania Salem

Friends and families of the Southwestern Ohio Hemophilia Foundation gathered October 7th at Young's Jersey Dairy Farm in Yellow Springs for their **Annual Fall Outing**. Families began the day visiting with industry representatives and then enjoying a picnic style lunch with delicious homemade ice cream right from the dairy farm. Guest of honor, hematologist Dr. Jordan Wright, led a discussion on the direction of the hemophilia industry. Dr. Wright gave updates on innovative medications potentially becoming available soon to the bleeding disorders community, along with the factor replacements currently offered.



Photo credit: SWOHF Facebook page

Amazing weather held up this year for some fall fun in the sun. Families chose activities from corn mazes, hay rides, slides, a pumpkin patch, visiting the animals, seeing how the dairy farm operates, and much more. Big thanks to Executive Director Kay Clark for a fun filled day!

PENNSYLVANIA

Tina McMullen

There were big changes this year for the October 7th Eastern Pennsylvania Chapter of NHF's (EPC) **Annual Trick or Trot Family Walk**. The first change was the location. Previously held at the Pfizer campus, this year found us enjoying the sights and sounds of the Philadelphia Zoo. Secondly, the event was changed from a Trick or Treat Trot 5k run/walk to a family walk. And these changes were positive – drawing approximately 400 attendees – well over previous years!

The weather started out a little gloomy, but that did not deter the wonderful community members of this vibrant chapter from attending. While music pumped everyone up, children of all ages enjoyed a morning packed with plenty of activities from face painting, glitter tattoos, and moon bounces to a roaming magician and lots of snacks and drinks. Meanwhile, everyone had the opportunity to visit a variety of industry vendors under the exhibit tents. The walk began before the zoo opened to the public, so families had time to see the wonderful animals without the crowds! Then it was time for awards!

The top fundraising team won a trip for two to NHF's 2019 Conference in California, which includes registration, round trip airline tickets and hotel. Awards were also given for best costumes as well as one for the best family costume.



Bella and Megan

The event concluded with Executive Director Curt Krouse presenting a grant of \$20,000 to Children's Hospital of Philadelphia, \$7,650 to University of Pennsylvania, and \$27,500 to Penn State Hershey. Part of ECP's mission is to support research and these donations help make a difference in funding various projects.

Thank you to Curt and his amazing team, Lindsay Frei and Kat Kocsi, for putting together this beautiful day at the zoo!

TENNESSEE

David Tignor

Shire and BioMatrix hosted an **Educational Dinner** October 15th at Knoxville's Copper Cellar West restaurant. April Morris, MSN, FNP presented *Resilience: Growing Through Life's Changes*. April discussed the meaning of resilience, stressors in life that make us resilient, and how to manage those stressors. She closed the program with a problem-solving activity, which involved the audience dividing into teams and completing a challenge within a given length of time. After the activity, the group discussed how it made them feel, what stressors were triggered, and importance of group collaboration. Due to the popularity of our educational dinners, we look forward to hosting more!



Sebastian sweetly naps through the event



Tyler

Brantley and Joe

ILLINOIS

Eva Kraemer

Set on Lake Michigan at the Columbia Yacht Club, Bleeding Disorder Alliance Illinois (BDAl) hosted their annual **Autumnal Wine Dinner and Auction** October 19th. Jim Hurster of CSL Behring, the Champagne Sponsor, superbly selected red and white wines to sample for nearly 100 guests. Many generous and talented people donated their time and talent, making baskets to be auctioned in support of BDAl's mission to continue providing education to the Illinois bleeding disorder community. While we enjoyed the alluring backdrop of the Chicago evening skyline, the chill in the lake air made for a cozy environment inside. Everyone indulged on delectable food, exquisite wine pairings and especially the superb company. Many thanks to CSL Behring, BDAl, and all those who came out to make the evening a success!



Warm smiles all around!
Jim, Alvaro, Jen, Marianne, Thomas and Sandra

WEST VIRGINIA

Michelle Stielper and Tina McMullen

Even though it was a chilly, rainy day at Marilla Park in Morgantown for the **Unite for Bleeding Disorders Walk**, the West Virginia Chapter of NHF (WVNHF) did not disappoint! Rallying despite the weather, WVNHF successfully raised over \$20,000 to benefit the chapter's services. Team Spokesmen for Bleeders raised over \$8,000 alone and were celebrated as the top fundraising team. Bill Kawecki, Mayor of Morgantown, even made an appearance to support their efforts! Congratulations to everyone involved!



Michelle Stielper and Tina McMullen with Morgantown Mayor, Bill Kawecki.

NEVADA

Kelly Gonzalez

Families gathered for an assortment of important educational programs at Springs Preserve in Las Vegas at the **2nd Annual Fall Fam Jam - Family Empowerment Weekend** October 20th-21st. The Nevada Chapter of NHF event included sessions *Insurance 101*, a mini *Parent Empowering Parents (PEP)* program and an infusion



Emily, Ethan and Jeff practice self-infusions

class led by Becky Berkowitz, RN of the Hemostasis and Thrombosis Center of Nevada. In addition to the sessions, community members were able to visit booths hosted by various industry sponsors. Best of all, the weekend included the opportunity for families to interact and get to know each other!

Thank you to NV Chapter of NHF, the Hemostasis and Thrombosis Center of Nevada and industry sponsors who made this event possible!

MICHIGAN

Moe Hoque

Another fabulous **Community Night** was held at Incredible Mo's in Traverse City October 26th! Hosted by Hemophilia Foundation of Michigan (HFM), the evening offered education and family fun! The event began with a session on dental hygiene, which was very well received by the group, especially so close to Halloween with all its sweet treats. Then it was time for fun – Incredible Mo's is a family entertainment center full of all sorts of amazing activities including arcade games, laser tag and bowling. They also serve great pizza! Thanks to HFM and sponsors for hosting this evening!



NEW MEXICO

Felix Garcia

In New Mexico, fall brings about the famed Balloon Fiesta, leaves changing colors, and Sangre de Oro Hemophilia Foundation's **Patient and Family Education Weekend**. The bleeding disorders community traveled from across the state to converge on the Crown Plaza



Sandra and Fernando

Felix Garcia

Hotel in downtown Albuquerque. Patients with bleeding disorders, their caregivers, parents, siblings and loved ones – approximately 300 community members – united for this annual meeting.

The event included product and educational presentations from pharmaceutical companies and specialty pharmacy partners. I was honored to be given the opportunity to present an advocacy session entitled, *I'm Here, Now What?* The goal of my presentation was to inspire people to take their place in the bleeding disorder community and advocate where they feel most comfortable.

This event is always a lot of fun! Thanks to those who worked hard to bring it all together!

NEW YORK

Richard Vogel

With the threat of a nor'easter looming in the air, the bleeding disorders community weathered the storm to attend the Bleeding Disorders Association of Northeastern New York's (BDANENY) **Annual Meeting**. With the leaves changing colors, community members dressed in their Halloween best turned out for a day of fun and information at historic Queensbury Hotel in downtown Glens Falls October 27th.



Angelina, Elijah, Lucienne & Michael

Jake and Dennise

After gathering information on new products and services from vendors in the exhibit hall, new board president Michael Deeb spoke on the direction in the years ahead for BDANENY while remembering and celebrating the past 50 years of service to the community. History boards took us through a time line, including photos from events over the past half-decade.



April, Carl, Dennis and Leyla

Concluding the event, everyone attended *Boo 2 You*, a special Halloween event hosted by the town of Glens Falls. Taking place near the Queensbury Hotel, children enjoyed trick or treating, a parade and plenty of bounce house fun!

PENNSYLVANIA

Tina McMullen

Spooky Nook Sport and The Warehouse Hotel in Manheim was the place to be Saturday, October 27th. That's where the Eastern Pennsylvania Chapter of NHF held ***Adventures in Learning***. Before educational sessions began, a wonderful buffet lunch was offered and a chance to visit industry exhibits and speak with company representatives.

Dr. Surbhi Saini and Social Worker, Meredith Getz, both of the Central Pennsylvania Hemophilia Treatment Center at Penn State Hershey Medical Center gave a bit of information about their backgrounds as well as the services of the treatment center. Sessions then kicked off with *Been There, Done That*, facilitated by the Hemophilia Federation of America. Breakout session titles included *My Story of Resilience*, *Importance of Community Connections* and a discussion relating to the formation of a new *Teen Group* being implemented by the chapter.



Ashley, Eli, Robin, Tina McMullen, Andrew and Nicholas

After a day of learning and interacting with other community members, attendees burned off some energy by playing volleyball, basketball, backyard games and bubble ball at the sports center. It was a great day for the bleeding disorders community of Eastern Pennsylvania. Thank you to Curt Krouse and his staff along with the Central Pennsylvania Hemophilia Treatment Center Consumer Advisory Board for hosting such a fantastic event.

VIRGINIA

Terry Stone and Michelle Stielper

Change can be hard to navigate for some, however not for the Virginia Hemophilia Foundation (VHF) as they transitioned their Annual Trick or Trot fundraiser to a grand inaugural ***NHF Unite for Bleeding Disorders Walk*** October 28th at Robious Landing Park in Midlothian. Although walkers and runners left their costumes behind this year, they wore their lucky running shoes and walked/ran their hearts out to the applause and praises of local cheerleaders and generous onlookers.

Teams let their creative juices flow with cool custom shirts and innovative ways to bring in funds. Turnout was impressive, and everyone was treated to a special food truck offering warm drinks and treats by Krecek Kakes Bakery, one of the chapter's "sweet" families. Change proved to bring great success to VHF who took a bold step to grow their annual walk fundraiser and it paid off one thoughtful donation at a time.



MICHIGAN

Moe Hoque

Hosted by the Hemophilia Foundation of Michigan (HFM), the 4th and final ***Community Night*** of the year was held November 2nd at Spare Time Entertainment Center in Lansing. Along with a session on dental hygiene, everyone had a chance to visit industry exhibits and speak with representatives to learn about their products and services. This family friendly venue provided the group their own space and private bowling lanes to play to their hearts content.



Thank you to HFM for providing this series of informational and enjoyable opportunities to learn and socialize with other community members!

PENNSYLVANIA

Tina McMullen

Party with a Purpose was held at the picturesque Crossing Vineyards and Winery in Newton Friday November 2nd. Hosted by Eastern Pennsylvania Chapter of NHF (EPC), the evening included music, silent auction, award winning wines, Yards beer, and a fabulous catered dinner by Colonial Farms.

Silent auction items included Philadelphia 76ers NBA tickets, 40" TCL Smart TV, and a wine and cheese tasting for 10, just to name a few! Proceeds from this event go towards patient support and program services. Thank you to Curt Krouse Executive Director and his entire staff for making this event so special!



(Left side front to back) Nicholas, Megan, Robin, Tom, Right side front to back: Jeanine, Eli, Tina McMullen and Karen



Jenny and Jake know their trivia!

MISSOURI

Eva Kraemer

Gateway Hemophilia Association hosted its **Annual Trivia Night Fundraiser** November 3rd at Jefferson Barracks Park in St. Louis. Around 150 of The Missouri bleeding disorders

community came out to support this worthy cause, showing their high school team spirit as most of the trivia questions transported many of us back to our high school days of homecoming, prom and sporting events. Friendly competition between teams and a delicious potluck dinner was bountiful. The evening was a huge success and I was overjoyed to participate!

NEW HAMPSHIRE

Cheryl Ashmore

In early November, a bitter wind and a deluge of rain chased 324 attendees to the Radisson Hotel in downtown Manchester. Faded leaves covered the ground with a thick blanket, insulating the earth from the snow to come. **Fallfest**, New England Hemophilia Association's (NEHA) largest annual event, came November 2nd – 4th, just in time to renew spirits and energy.



Congratulations Impact Award Recipients!

Chris Bombardier and Patrick James Lynch kicked off the weekend with a screening of *Bombardier Blood* to a packed house. That's a hard act to follow, but NEHA rose to the challenge and presented a weekend of significant, relevant programming to 4 age groups. Rap sessions, a medical provider panel and breakouts for VWD, teens and kids set the pace Saturday. After a break, the evening found folks mixing it up on the dance floor 80s style, where big hair competed with neon colors, parachute pants and hair scrunchies.

Sunday was a lovely wind down of several comforting sessions, including topics such as writing to heal, jump starting a healthy diet, and being mindful of emotional



NEHA Blood Brotherhood Session

well being. The event truly was a testament to the commitment of the New England community, some of whom drove more than 7 hours to spend time in a vibrant fall venue with fellow blood brothers and sisters. Thank you, NEHA, for a meticulously planned event!

SOUTH CAROLINA

Xaviette Pointer-Kincy

It was time for the annual **Turkey Trot** November 3rd at Saluda Shoals Park in Columbia! This is Hemophilia of South Carolina (HSC) largest fundraiser and it very successfully raised over \$55,000! The funds benefit the chapter's 900 members by supporting advocacy initiatives to help educate and empower South Carolina's bleeding disorders community members. HSC also uses this event to gather non-perishables to contribute to Harvest Hope Food Bank and each attendee was encouraged to participate. Food, music, and games were in no short supply. Kudos to HSC for hosting another perfect event!



OHIO

Rania Salem and Shelia Biljes

The highly anticipated Central Ohio Chapter of NHF **Annual Meeting** was underway November 7th at the famous Der Dutchman Restaurant in Plain City. Beginning the day, families visited industry representatives to learn about their services and products, while competing for raffle prizes with a game of Bingo. At each exhibit the rep marked the attendees' game card. Completed cards were entered in a raffle, and BINGO – prizes were won!



A family-style dinner was served – the food is amazing and never disappoints at Der Dutchman! After dinner annual updates were given and 2019 plans were revealed. Kudos to Hazen's Heroes, raising \$5000 to be 2018's biggest fundraising walk team winners! The new year will welcome Margie Miller as Board President. Many thanks to Executive Director Tauna Bastiste, for her enthusiasm and hardworking crew for all their efforts in support of our community!

OHIO

Sheila Biljes

A “family reunion” is the best way to describe the Northern Ohio Hemophilia Foundation’s (NOHF) **Annual Meeting**. This year’s overnight gathering took place at the Independence Holiday Inn November 9th-10th. During dinner, chapter leadership presented on the state of the organization, including fiduciary details and upcoming plans for 2019. After dinner, BioMatrix sponsored a special family carnival enjoyed by all.

Representatives from manufacturing companies were invited to volunteer and run game and food stations. Snacks galore – cotton candy, nachos, hot dogs and popcorn – were available, with snow cones being a big hit! Two busy balloon benders were sure to leave everyone with a balloon of their choice. The talented face painter duplicated balloon choices in her artwork



Amber and Joe the Clown ham it up!

displayed on tiny faces and everyone laughed at the caricature artist’s rendition of her subjects. By the end of the evening, circus-themed tattoos were also visible on the hands of most children and adults alike.

What’s a carnival without games? Plinko, ring toss, a duck pond, can toss, bowling and a basketball game – everyone walked away with bragging rights and fun prizes! And with a chance to wear colorful wigs and big glasses, the selfie station proved to be a popular hotspot!

As the kids began to tire, the adults were just gearing up for a dance party. No one seemed to mind that Saturday’s sessions were starting at 7:30 am. Enjoying each other’s company and having a blast was more important! Thank you to everyone who participated and to those that worked so hard to bring the fun together!



Is that Stevie?

TENNESSEE

David Tignor

An elegant evening sponsored by the Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF) was held November 16th at Nashville’s acclaimed Loveless Barn. The **19th Annual Royal Gala** gathered folks together for a sophisticated evening featuring a fantastic dinner, silent and live auctions and live chamber music from Viva La Strings ensemble playing popular tunes.



David and Christy Tignor



Brock, Janet and Stephen looking sharp!

The gala has become a longstanding, much-loved tradition and is the largest fundraiser for THBDF. BioMatrix is pleased to have sponsored a table and invited community members to share and enjoy the evening!

VIRGINIA

Terry Stone

All the little wolves of the Virginia Hemophilia Foundation (VHF) were happy to come to the Great Wolf Lodge in Williamsburg for the chapter’s Family Weekend November 17th-18th, after it was rescheduled from September when severe weather came howling to the area. More than 200 people with big paws and small



Malakai and Jayden’s first Great Wolf Lodge event with VHF. So nice of you to bring your parents too!

enjoyed an educational afternoon with dinner, followed by time to enjoy the water park until the moon made its appearance.

Lisa Green, BS CCP, presented the keynote topic, *Balancing Quality of Life with the Burden of Care*. It was a discussion that resonated with the audience. Kids of all ages participated in conversations about fitness and bullying, while teens had time for a social hour to reconnect with friends. Always a popular weekend, families enjoyed the educational programming for themselves and their children, while equally grateful for the time to be with their community friends.

WEST VIRGINIA

Tina McMullen and Michelle Stielper

This year, a location change was in store for West Virginia Chapter of NHF's **Annual Meeting**. Previously held at the Stonewall Resort in Roanoke, the chapter decided to reach out to other areas of the community and host the event at Charleston Conference Center in Charleston November 16th and 17th.

The meeting kicked off Friday evening with an educational dinner sponsored by Genentech. Saturday dawned bright with families exploring the exhibit hall, followed by informational sessions beginning with *Exploring Emotional Well-Being in the Hemophilia Community* sponsored by Pfizer and *Evaluating Your Insurance Options* by Bioerativ.



Harmony, Omari and Harper - so very sweet!

While grown-ups were in educational programs, children enjoyed playing Xbox and other games. When the programs wrapped up, families were treated to a fabulous Greek lunch at the Olive Tree Café (some seriously good Baklava).

The day ended with Executive Director Ryan Wallace and chapter board members presenting the **2019 Member Planning Session**. It's going to be a great year!

NEW YORK

Richard Vogel

Sleigh bells ring, are you listening, in the lane snow is glistening, a beautiful sight, we're happy tonight, walking to the New York City Hemophilia Chapter (NYCHC) **Gala**. November 17th, NYCHC celebrated community and friends at The Broad Street Ballroom in NYC's Wall Street area in support of bleeding disorders.



The event raised money to support NYCHC's mission of advocacy, travel grants and education. Beginning with cocktails and hors d'oeuvres followed by a sit-down dinner, we celebrated with NYCHC *Advocate of the Year* Kim Spalter; *Volunteer of the Year* Sara Louie; and Wendy Chou recipient of the *Award of Distinction*.



Kim became very involved in 2016 attending Washington and Albany Days when her first-born was diagnosed with hemophilia. She helped launch the regional Advocacy Captain program and in-district Legislator Breakfasts. Sara is that special breed of people in our community who, although has no direct relationship to bleeding disorders, becomes part of the community through generosity and caring. Wendy helped launch the chapter, serving on its board since 2008, most recently serving as President.

Special guest speakers spoke of growing up with hemophilia. Elliot, a man in his 60s, told his story of living with hemophilia in the days before factor. Porus, a teenager, also spoke of life in India where he had no factor to treat his bleeds. The stories were generations apart and from very different perspectives, yet similar.

After an evening of dancing, the morning of the 18th



had NYCHC holding their **Educational Day and Holiday Celebration** at the Crowne Plaza in Times Square, NYC. The day started with plenty of time to visit and talk with industry and specialty pharmacy representatives before the educational workshops began. There was a workshop for everyone whether you were a family new to the bleeding disorders community or an old timer like me. No matter how experienced you are, there is always something to learn from this community.

Education sessions throughout the day included *Understanding Gene Therapy Research and It's Potential*, *VWD, Birthing Plans, Understanding 340B*, along with children and teen sessions, with various sessions presented in Spanish.

The electricity in the air peaked with the arrival of Santa Claus and his elves! The gala and Education Day weekend were a great way to start the holiday season. This was another successful weekend for NYCHC!

LOUISIANA

LeAnn Wilson

The bleeding disorders community gathered at the Renaissance Hotel in Baton Rouge for Louisiana Hemophilia Foundation's (LHF) **42nd Annual Meeting and Educational Symposium** November 30th – December 1st. *Oh, What a Circus* was the theme this year! The event began Friday evening with, of course, a delicious Cajun-style dinner. It was a great opportunity to welcome everyone and get in the mindset of the next day's activities.



The next morning guests began the day visiting industry booths as they made their way to breakfast where chapter updates were announced. Enlightening and on point breakout sessions followed. In one session about *Resilience*, teams worked together to build towers out of noodles symbolizing strength.

Sharing his life story and experiences, Terry Rice presented *It's OK to Not Be OK*. This session empowered community members to be comfortable in sharing and discussing difficult topics with each other and with health care providers. Following Terry was local community member, Bobby Cannon, a very honorable member of the local chapter as well as a local Law enforcement officer. His session covered low-impact self defense, which isn't as hard on joints as other defense techniques many be.

Saturday evening the group met at Webb Park for a holiday celebration. Awards were presented to individuals spotlighting their volunteer work throughout the year. Noteworthy was Sean Noel who started *Sean's Factor* to help pay for kids to attend camp. Sean addressed the group about his mission and goals.



Terry Rice held the audience captive with his presentation of *It's Ok to Not be Okay*



Holiday smiles from Benjamin Jr., Brenda Montgomery King, Brent, Jennifer and Benjamin

This young man is an inspiration and it doesn't look like he is stopping any time soon. Great job, Sean, and thank you for your service to our community!

Adding to the fun, circus games were played, raffles drawn and prizes won.

Executive Director Erica Simpson closed the event by thanking each for all the work everyone contributes to help the foundation succeed.

This event was well attended and very informative. Families were able to grow deeper connections with each other and develop friendships with new members. Friendships like these will help our community grow stronger. We look forward to all the great things ahead for our community and for the LHF in 2019!

CALIFORNIA

The Central California Hemophilia Foundation (CCHF) rang in the season with an enjoyable **Annual Holiday Party** December 1st at Gibbons Park in Carmichael. Santa was sure to share in the festivities, arriving to present personally selected gifts to more than 125 children. Each family also received an emergency kit to assist with crisis preparedness. CCHF Families enjoyed crafts, cookie decorating and a savory Mexican buffet lunch hosted by the Mexican Market. Many thanks to CCHF for ushering in the holiday spirit!



NEVADA

Kelly Gonzalez

Lights were shimmering, the faux fireplace was crackling December 1st as more than 200 Nevadans were gathering with the Nevada Chapter of the NHF to celebrate the season with education, empowerment, advocacy and a holiday visit from a very jolly Santa at the East Las Vegas Convention Center!

As the *Annual Family Conference and Holiday Celebration* began young ones gathered to have a little fun, do some crafts and prepare for Santa's exciting arrival. Teens jumped into a session learning about clotting factors while adults participated in various educational sessions.

When the education was absorbed, the room opened with

tables for families and friends to gather over traditional Mexican food, a drawing of a variety of prizes, and then the guest of honor joined us... Santa arrived in great style carrying gifts for all!

Thank you to the Nevada Chapter of NHF for hosting such a delightful holiday event where the community was enriched with education while having fun!



Jacoby and Jaxon loved sharing their wishes with Santa!



Kelly, Ariana and Amber get in a festive holiday mood!



Kelly and Amber spread the truth, or so Kelly reports!

OHIO

Sheila Biljes

Here comes Santa Claus, just not in the usual fashion! Hot pink, lime green and purple are the holiday colors at Kringle's Inventionarium in Cleveland. There was nothing traditional as the Northern Ohio Hemophilia Foundation gathered December 1st for its annual *Holiday Extravaganza!* With over 100 in attendance, it was close quarters as families enjoyed pizza, chips and cookies.



Mackenzie and Mika design a toy. Tyler and Miya have wishes!

One of Santa's workers directed each family to the start of the Inventionarium where they were given a secret password to open each door in search of secret words. Along the way, everyone participated in projects such as making snow, designing a new toy, creating paintings that disappear and working in the science kitchen. The imagination takes control, and everyone is transported to a zany Christmas laboratory. Each child told Santa their wishes and received a photo with him as he gave them a special gift. To keep the little ones busy as they

waited their turn, train rides were available through Tower City Mall in the old Higbee building, renowned for their elaborate animated holiday window scenes for decades.

After families finished their laboratory tour, everyone gathered at the mall entrance where Lolly the Trolley had 4 trollies waiting to take the group on a tour of Cleveland Lights and to the film site of the famous movie, *A Christmas Story*. Each sponsor, Bayer, Shire, CSL and BioMatrix hosted a trolley for an eventful, day and a most perfect way to kick off the holiday season!



Tyler, Miya, Mika and Mackenzie get a magical painting lesson.

PENNSYLVANIA

Tina McMullen

What a wonderful end-of-year celebration it was for the 180 people who attended the Eastern Pennsylvania Chapter of NHF *Annual Holiday Party!* The event was held at the Cannstatter Volksfest Verein in Philadelphia Saturday, December 1st and began with a holiday feast including a full turkey dinner. Following the meal, families had the opportunity to engage in an array of fun activities. Holiday cookie decorating was featured at our BioMatrix table. Other activities included creating

NORTH CAROLINA

Xaviette Pointer-Kincy

Hemophilia of North Carolina (HNC) hosted their **2018 Holiday Celebration** December 1st at the Charlotte Motor Speedway in Concord. Anita Smith, Pediatric Nurse Practitioner of Wake Forest Baptist Hemophilia Treatment Center, spoke about the changes in bleeding disorder treatments over past generations. A special visitor from the North Pole also attended, bearing gifts of course! Over 150 guests revisited the past and learned the many pathways to play an active role in HNC. Afterward everyone enjoyed the nearly 4-mile holiday light show hosted annually at the Speedway. Thank you to HNC for bringing everyone together to enjoy this warm holiday event!



Peyton and Tiffany by the light of the tree!



Big, happy family! Dad Tom, Johnny, Jake, Santa, Gianna, Tommy Jr, Mom Vickie and baby Milo

Christmas trees from ice cream cones, designing ornaments, and decorating a stocking and Santa hat. Festivities included a magic show and making ice cream sundaes. Then the eagerly awaited star of the day appeared! Santa Claus presented each child with a gift card. This event was a fantastic way to start the holiday celebrations for the families of the Eastern Pennsylvania Chapter.

TEXAS

Felix Garcia

Of all the bleeding disorder gatherings I drive to, the **Winter Educational Event** in McAllen is the furthest. And it's one of my favorites. The Lone Star Chapter of NHF hosted their annual event December 2nd and BioMatrix



Alexander, Alexis and Giselle

was thrilled to attend. Everyone is always eager to gather for the final hemophilia hurrah of the year, and speaking with families with all the cheerfulness of the atmosphere is what I like best! At our booth, special Christmas stockings were given to all the children (and a couple of adults too!) Also available were lip balm and hand sanitizer – after all 'tis the season for dry lips and spreading germs! Young adults visiting the booth also learned about BioMatrix scholarship opportunities.

During the event, it was excitedly announced that Griselda Martinez from south Texas was the recipient of the Phil Blomquist Volunteer of the Year!

Though a white winter is not in store for south Texas, this event has us all looking forward to the holidays. Special thanks to Melissa Compton and the Lone Star Chapter of the NHF for always including south Texas families in the festivities!

NEVADA

Kelly Gonzalez

A wicked white snowstorm, 2-degree temperature, unplowed roads and the uncertainty of having a bleed didn't stop nearly 100 people from making their way to the



Kelly Gonzalez, Elizabeth, Soleo; Becki and Lisa, Nevada Hemostasis and Thrombosis; and Betsy, NHF NV took a break to tell Santa what they wished for and visit with Mrs. Claus!

Hilton Garden Inn for the **Elko Family Day and Winter Celebration** December 5th to spend time together and enjoy a visit with Santa! There is no better sense of togetherness than that of our close-knit community during the holidays! Thank you to everyone involved for making this event possible!

NEVADA

Kelly Gonzalez

The snow in Reno may have stopped falling December 6th by the time the **Reno Family Day and Winter Celebration** began at Hunsburger Elementary School, but the chill in the air encouraged our already close



Kelly Gonzalez, Elizabeth, Becki and Lisa visit Santa and Mrs. Claus!

bleeding disorders family to snuggle up a little closer!

Following an educational discussion on coping skills led by Bioverativ's Becky Ibarra, everyone gathered around bowls of hot soup, salad, pasta and desserts, while creating memories chatting, crafting and, of course, visiting with Santa! After singing a few holiday jingles and taking photos with Santa, families were motivated to start the new year with an eye on more education and advocacy! We can't wait to see the growth in our community in 2019!

PENNSYLVANIA

Shelia Biljes

Snowy weather set the mood December 6th for the Pittsburgh Chapter **Annual Holiday Dinner**. With the combined efforts of BioMatrix and Grifols, a fun-filled evening in Mars was planned at Luciano's Restaurant with a buffet dinner that included salad, rigatoni and many types of pizza. While adults engaged in a conversation about inhibitors with nurse educator Virginia Kraus from Grifols, children made snowman crafts, including creative stockings. Our kids proved to be a talented group!



Children were reunited with their parents for a family activity. Daniela Delgado, a community advocate from Connecticut, presented her story, then led the group in an entertaining cake decorating activity. Following Daniela's instructions, everyone made an adorable melting snowman cupcake. The evening was enjoyed by young and old alike. The snowy ride home was the best scene for little ones to envision making their own real snowman.

CONNECTICUT

Rich Vogel

Connecticut Hemophilia Society (CHS) held its **Annual Meeting** December 8th at the Wyndham Southbury. The 15-degree winter chill didn't deter the community from coming out for education, camaraderie and fun. After all, hemophilia and northeast weather have a lot in common, you must be prepared and be tough because things can change from hour to hour.



Jonathan greets Santa



Gwendolyn shared her wishes with Santa



Theresa Coia presents!

The morning started with a breakfast buffet where members could gather information and ask questions from the various industry exhibitors. After opening remarks from President Dennis Mackey and Executive Director Maryann May, Theresa Coia, Genentech Hemophilia Community Clinical Educator, explained the very complicated clotting cascade in an easy to understand presentation.

Lisa Greene, a certified family life educator who specializes in working with families with chronic disorders, spoke about *Quality of Life*. Using a

Q of L wheel, Lisa had us run through a score card of questions. There were no right or wrong answers as each person is unique and answers will change throughout life. A few key takeaways were *Being Efficient with Time*, *Creating Routines* and *Being Mindful* by staying in the present, finding joy, gratitude, purpose and pleasure in each day and always focusing on the positive. Great words to live by for all, not just those with chronic disorders.

You could feel the anticipation building as Santa's arrival approached. Festivities in Connecticut continued as all indulged in hot chocolate and cookies while Santa handed gifts to the children. Many thanks to CHS for getting us all in a holiday state of mind!

ILLINOIS

Eva Kraemer

The Bleeding Disorder Alliance Illinois (BDAI) celebrated its annual **Holiday Party** Saturday, December 8th at the William Tell Holiday Inn in Countryside. Over 100 bleeding disorder community members, family



In holiday cheer - Elizabeth, David, Santa, Hiro and Jessica.

and friends feasted on a bountiful buffet, while a fire glowed at the hearth and in our hearts. Everyone felt jolly while creating homemade ornaments and reindeer headbands. Before the evening ended, Santa made a special appearance to spread good will and presents

to children of all ages, sitting for keep-sake photos to be cherished for years to come. We delighted in story sharing from the year gone by while looking forward to a very happy, healthy 2019!

MAINE

Cheryl Ashmore

The Hemophilia Alliance of Maine (HAM) hosted their annual **Winterfest** at the cozy Samoset Resort in Rockport, Maine December 8th – 9th. The event began several years ago as an afternoon holiday celebration, but over time developed into a full weekend of relevant programming.



Terry Rice and Justin Levesque visit with Travis Mills (center).

This year HAM was especially excited to announce that SSG Travis Mills, veteran and quadruple amputee, would be delivering the keynote speech. Unexpectedly humorous and refreshingly unrestrained, Travis captivated the audience with the tale of his journey as a warrior in his prime who sustained catastrophic injuries from an IED while serving in Afghanistan six years ago. Today, Travis is not only a motivational speaker, actor and advocate, but also founded a non-profit to provide an experiential camp experience in Maine for severely wounded veterans throughout the nation. Travis' story is truly an example of resilience and determination in the face of overwhelming adversity.



Syrus and Travis Mills

The Winterfest theme was multi-faceted, combining advocacy, volunteerism and community. Adults and children were encouraged to choose areas of community need that piqued their interest. It was truly inspiring to see many of them volunteer on the spot for future events. There were also valuable sessions about advocacy, new product/therapy session and discussion, and depression and anxiety were highlighted. It was deeply touching to observe the enthusiasm and engagement on peoples' faces increase as they moved through the weekend, reuniting with old friends, having "lightbulb" moments in sessions or simply meeting each other's littles and finding common ground.

Throughout the weekend, families were treated to panoramic views of the sea from almost every

window. The Samoset Resort sits right up against the rocky Maine coast and offers meditative views along with a subtle challenge – a walkable 4000-foot jetty to Rockland Harbor Breakwater Lighthouse. Although Sunday morning saw temperatures at 10 degrees with brisk winds, a few brave adults led a hike out and back for several teens.

With top notch education, ample visiting time, friends from the North Pole, swimming, non-stop hugs and rock star chapter staff and volunteers, Winterfest truly had it all and is a wonderful time for both family and friends. Until next year!

OHIO

Shelia Biljes

Holidays are a special time to gather with friends and December 8th ladies from the Northern Ohio Chapter came together to start a new crafting tradition. After a potluck lunch, the wreath-making lesson began. Even the non-crafters did a wonderful job! Conversation was light and the laughter never stopped. Step-by-step, each lady created a beautiful decoration to take home and hang on their door. Before the meeting ended a decision was made on what the 2019 craft will be, and how to involve more ladies. Leftover food was divided, and secret recipes shared. It looks like we have a new tradition in the Cleveland area!



June showcases her beautiful wreath!



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

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

Answers to puzzles found on page 31.



UPCOMING EVENTS

FEB. 2, 2019 MARYLAND

Hemophilia Foundation of Maryland
410-661-2307

hfmonline.org

Annual Meeting & Educational Dinner

Four Seasons; Baltimore

FEB. 9, 2019 CALIFORNIA

Central California Hemophilia Foundation

916-549-3125, cchfsac.org

Surf & Turf Crab Feed

Sacramento Elks; Sacramento

FEB. 23, 2019 CALIFORNIA

Hemophilia Foundation of South CA
626-765-6656

hemosocal.org

EmPOWERment Forum and 4th Annual Bloody Hot Salsa Challenge

Pickwick Gardens; Burbank

FEB. 23, 2019 ILLINOIS

Bleeding Disorders Alliance Illinois
312-427-1495, bdai.org

Advocacy Retreat

Crown Plaza; Burr Ridge

FEB. 23, 2019 KENTUCKY

Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org

Vegasville Gala

Olmsted Building, Louisville

FEB. 23, 2019 PENNSYLVANIA

Eastern Pennsylvania Chapter - NHF
215-393-3611, hemophiliasupport.org

Bowling for Fun, Devon Lanes; Devon

FEB. 28, 2019 NEW JERSEY

Hemophilia Assoc. of New Jersey
732-249-6000, hanj.org

Winter Membership Gathering

iPlay America; Freehold

MARCH 2, 2019 NORTH CAROLINA

Hemophilia of North Carolina
800-990-5557, hemophilia-nc.org

Annual Meeting

Sheraton Charlotte Airport

MARCH 3, 2019 FLORIDA

Foundation Hope & Life
786-374-6143, fhflusa.org

2nd Annual Family Educational Rally

Milander Park; Miami

MARCH 9, 2019 VIRGINIA

Virginia Hemophilia Foundation
804-740-8643

vahemophilia.org

2019 Medical Symposium

Virginia Crossings Hotel; Glen Allen

MARCH 15-17, 2019 CONNECTICUT

Connecticut Hemophilia Society
860-997-4525

cthemophilia.org

Alpine Walk

Mt. Snow; West Dover

MARCH 30, 2019 VIRGINIA

Hemophilia Assoc. of the Capital Area
703-352-7641

hacacares.org

Family Education Day

Northern Virginia Community College; Annandale

APRIL 13, 2019 ILLINOIS

Bleeding Disorders Alliance Illinois
312-427-1495

bdai.org

Spring Gala

Itasca County Club; Itasca

NATIONAL EVENT!



MARCH 14-17, 2019

FLORIDA

Coalition for Hemophilia B
212-520-8272
www.hemob.org

ANNUAL SYMPOSIUM

Renaissance Orlando at SeaWorld

NATIONAL EVENT!



MARCH 27-29, 2019

WASHINGTON, DC

National Hemophilia Foundation
800-424-2634
hemophilia.org

NHF WASHINGTON DAYS

Hyatt Regency on Capitol Hill

NATIONAL EVENT!



APRIL 4-7, 2019

CALIFORNIA

Hemophilia Federation of America
877-734-2726
www.hemophiliafed.org

ANNUAL SYMPOSIUM

Sheraton San Diego Hotel & Marina

TIME FOR FUN!

Billy has a bleeding disorder. He keeps supplies for his infusions and for when he has a bleed in a special cabinet in his home. Every so often, it gets a little messy and needs to be cleaned out.

Can you help Billy decide which items should be taken out of the cabinet?

Circle the items that should be removed.

Answers can be found on page 29.

Have fun!



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

Sudoku!

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

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

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BIOMATRIX FAMILY OF COMPANIES

Matrix Health

FACTOR^x
SUPPORT NETWORK

MEDEX BIO CARE

BiologicTx

Elwyn
PHARMACY GROUP

DECILLION



Pharmacy Locations

- | | | | |
|-------------------|---------------------|---------------|------------------------------|
| 1 Camarillo, CA | 5 Charleston, WV | 9 Memphis, TN | Digital Health Office |
| 2 Canoga Park, CA | 6 Garnet Valley, PA | 10 Weston, FL | San Francisco, CA |
| 3 Chicago, IL | 7 Glen Rock, NJ | | |
| 4 Dublin, OH | 8 Totowa, NJ | | |