



Matrix Health Group

A BIOMATRIX^{SPR} Company



NEWS

WINTER 2017
Volume 12 / Issue 1



Self-Infusion, Facing Your Fear
HOHF event at the Cleveland Aquarium, Page 30.

Dedicated to Making a Difference

by educating, empowering and enriching the lives of people living with a bleeding disorder.

Matrix Health Group

Dedicated to Making a Difference!

Corporate Office

3300 Corporate Avenue, Suite 104
Weston, Florida 33331

877-337-3002 Toll Free 954-385-7322 Office 954-385-7324 Office Fax

www.matrixhealthgroup.com

 **Matrix Health**

3300 Corporate Ave., Ste. 104
Weston, FL 33331

877-337-3002 Toll Free
954-385-7322 Office
888-385-2805 Fax

 **MEDEX BIO CARE**

8024 Stage Hills Blvd., Ste. 107
Bartlett, TN 38133

800-962-6339 Toll Free
901-380-5899 Office
866-755-6339 Fax

 **FACTORx**
SUPPORT NETWORK

900 Avenida Acaso, Ste. A
Camarillo, CA 93012

877-376-4968 Toll Free
805-388-9336 Office
805-482-6324 Fax

 **BiologicTx**

40-D Commerce Way
Totowa, NJ 07512

877-567-8087 Toll Free
973-774-0954 Office
877-567-8089 Fax

Matrix Health Group **NEWS**

A BIOMATRIX Company


Winter 2017 - Volume 12, Issue 1

Editor-in-Chief: Maria Santucci Vetter

Editors: Susan Moore and Justin Lindhorst

The purpose of Matrix Health Group News is to provide an opportunity to connect with others by providing 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 disorder community.

The information and opinions printed in this newsletter do not necessarily reflect the views and opinions of the partners, employees, others associated with Matrix Health Group News or that of Matrix Health Group.

Health related topics found in Matrix Health Group News are for informational use only and are not intended to take the place of treatment or medical advice provided by your health care professionals or hemophilia treatment center. Please consult with your health care professionals when medical questions arise. 

Mission and Vision

The **MISSION** of Matrix Health Group is to provide individualized, focused services to people with bleeding disorders nationwide.

Our **VISION** is to enhance the lives of those we are privileged to serve by providing the best pharmacy and support services possible.

Our **Mission** and **Vision** are realized through the value we place in our five guiding principles. The five values represent the commitment to our employees, patients and the community, driving our organization to excellence. These core beliefs define our culture and provide a means for us to measure our success. By using these principles as a standard for excellence, we become the logical choice for consumers with specialty pharmacy needs. These attributes represent the very best of what our company stands for and they remain at the forefront in all we do.

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

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

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

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

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



CONTENTS

A Note from the Editor . . . page 4

In Memory, Corey Dubin . . . page 5

Memorial Scholarship Program . . . page 5



A Hemophiliac Turns 60 . . . page 6

Hypnosis for Chronic Pain . . . page 10

Dr. Margaret C. Telfer . . . page 11

Pursuing Excellence . . . page 12

THE HEALTH ADVOCATE:
Surprise! You Received *Another* Medical Bill . . . page 14



 . . . page 16

Upcoming Events . . . page 32

Time for Fun! . . . page 35



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Visit us today to learn more about our specialty pharmacy and support services, read popular articles from *Matrix Health News*, view photos, learn about our upcoming events and find information on the bleeding disorders community. "Like" our page to see how we are *Dedicated to Making a Difference* in the lives of individuals with hemophilia, vWD and other bleeding disorders!

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A NOTE FROM THE EDITOR

Dear Readers:

With a New Year, comes a new beginning. We get to wipe the slate clean and start anew, set fresh goals, make new resolutions and open doors to new opportunities. And with the start of a new year, we have taken this opportunity to freshen our look, not just with the design of our newsletter, but also with our website. Visit our new site and see what you think! www.matrixhealthgroup.com.

This is also the time of year many of us in the bleeding disorders community are tasked with learning about changes to our insurance policy. Sometimes those changes come with disappointing news from being forced to use a specific provider, possibly lacking the expertise to which we are accustomed, to lengthy prior-authorizations or even denial of services. If you encounter such issues, please give Matrix Health Group a call and allow our highly skilled Reimbursement Specialists to review your information. We may be able to help.

May 2017 bring you countless blessings and above all, good health. 🍀

Happy New Year!

Maria

Maria Santucci Vetter
Editor-in-Chief, Matrix Health News
maria.vetter@matrixhealthgroup.com

A Moment in Your Spectacular Life! 2017 Calendar



Now Available!

Our calendar features a fantastic collection of photos highlighting spectacular moments in the lives of people with bleeding disorders!

Contact us to receive your complimentary calendar.

877-337-3002
info@matrixhealthgroup.com

Available while supply lasts.

Attention TRICARE Patients

Matrix Health Group is a specialty pharmacy devoted to caring for those with bleeding disorders. We are dedicated, determined and committed to personalize your homecare experience with round-the-clock service and a comprehensive line of factor and ancillary supplies. We offer a unique team of compassionate care coordinators with top-notch pharmacy and reimbursement services. At Matrix Health Group, our goal is to make your life easier!



TRICARE APPROVED!

For more information regarding our services, please call:

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by email:

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or visit our website:

www.matrixhealthgroup.com

- ★ Experienced, compassionate Care Coordination Team with a personal contact assigned to each patient for pharmacy, reimbursement and support services
- ★ Professional Pharmacy Team with extensive knowledge of bleeding disorders available 24 hours a day, 7 days a week
- ★ Pharmacies in Florida, Tennessee, California, New Jersey, and Illinois - our services span across the nation
- ★ 24-hour standard delivery; emergency shipments when needed
- ★ Coordination of home nursing services specializing in bleeding disorder care
- ★ Highly trained billing and reimbursement staff are well equipped to assist with insurance coverage issues, both public and private
- ★ Multifaceted team approach promoting adherence to treatment plans, resulting in positive health outcomes
- ★ Informative quarterly newsletter, *Matrix Health Group News*

In Memory, Cory Dubin

Our community received heartwrenching news that Corey Dubin passed away at his home in California January 5th. Corey, a person with hemophilia, will be remembered as a dynamic and tireless advocate for those with bleeding disorders and HIV. His legacy of advocacy began before himself - Corey's father and role model Al Dubin, helped establish the Southern California Hemophilia Association some 50 years ago. Corey's passion was aimed at finding truth and building grassroots efforts to effectuate change and promote advocacy and empowerment in people.

He was a skilled print journalist, receiving his BA in Journalism from UCSB, as well as host and producer of a weekly talk radio program, Coyote Radio, for many years. Corey's weekly broadcast filled the airwaves with his unique cadence and style. He was a gifted interviewer often having influential guests on his broadcasts covering a range of topics to include Latin America, the plight of Native Americans, and of course hemophilia and HIV issues, to name a few.

Corey served on the Blood Products Advisory Committee (BPAC) of the FDA as a voting community member where he promoted the best interests of those who use blood and blood products. If you ever met Corey, you'd never forget him. His style was typically welcoming, temperate and well informed, but he could become impassioned at times and slightly intimidating with his



March 3, 1955 – January 5, 2017

booming voice and piercing blue eyes. As a founding member, he helped establish both the Hemophilia Federation of America (HFA) and The Committee of Ten Thousand (COTT), serving as President of COTT for many years. Both organizations

have, and continue to play critical educational and advocacy roles within the hemophilia community. His efforts throughout the 1990s helped assure the passage and funding of The Ricky Ray Hemophilia Relief Fund Act and that meaningful changes in the regulation of blood and blood products occurred to prevent a recurrence of those failures which resulted in the HIV infections of those dependent on the blood supply.

Corey was my good friend for 25 years and his passing is difficult; however, I take comfort in the legacy he leaves as an advocate and truth finder; more importantly, the impact he had on me as a friend. Corey leaves behind his wife, Phoebe, three daughters, six grandchildren, a sister and too many friends to count.

Rest easy, my friend...

– Terry Rice



Matrix Health Group Memorial Scholarship Program

A BIOMATRIX Company

Now Accepting Applications for the 2017/2018 School Year!

Matrix Health Group offers nine \$1000 scholarships to assist individuals with bleeding disorders seeking higher education. These scholarships honor the memory of several individuals who touched the bleeding disorder community in unique ways. Additionally, this program aligns with the commitment we hold to *Enrichment*, one of five Guiding Principles forming the backbone of our company value system.

The scholarships made available by Matrix Health Group are unique in several ways. Each is offered exclusively to several demographics within the bleeding disorder community including

men, women, inhibitor patients and immediate family members. Our streamlined application process allows interested parties to complete one simple application for multiple scholarships offered. In addition to tuition, these scholarship funds can be applied toward books, housing, and other college-related expenses.

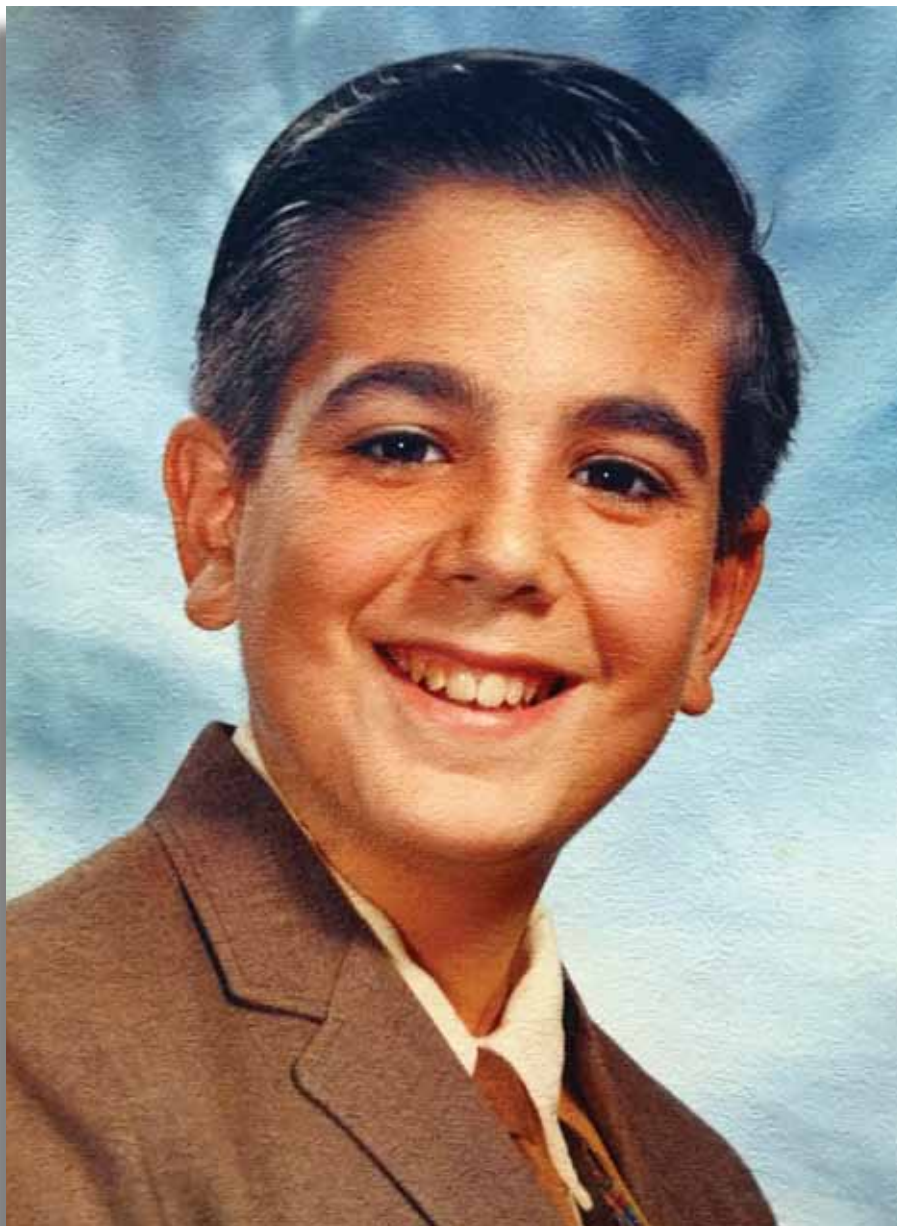
Awards are based on criteria including academic merit, reference letter, and essay. An impartial *Scholarship Committee* will review the applications and decide to whom the scholarships will be awarded. Applicants are not required to be past, current, or future customers of Matrix Health Group or its family of companies.

Please visit our website to download an application and apply by August 1, 2017.

www.matrixhealthgroup.com/scholarships/

A Hemophiliac Turns 60

By Richard Vogel



When I was born in 1956, life expectancy for a man with hemophilia was 20 years. I say man rather than person because in those days it was thought only men could have hemophilia. We certainly have come a long way in 60 years; but in some ways, we haven't.

Growing up in the late 50's and early 60's, therapy for hemophilia was limited to whole blood transfusions, then plasma. It wasn't until 1964 when Judith Graham Pool discovered cryoprecipitate, or "cryo," a breakthrough which revolutionized the treatment of hemophilia, making it easier and safer to manage.

Some of my earliest memories are of being in the emergency room in severe pain, either my knee was filling with blood or my elbows felt like they were in a vice and someone kept turning it tighter. The pain would be so intense, I couldn't even cry. My father would pace up and down the hallway wondering what the heck was taking so long. I'll always remember the look in his eyes, the look that said, "If I could transfer your pain to me, I would." That look was always in his eyes and got worse the day I was told I had contracted Non-A, Non-B hepatitis, and later, the HIV virus from the blood products I took to control my bleeding.

Sometime the light's all shining on me, Other times I can barely see.

(The Grateful Dead - Truckin, 1977)

In the emergency room, we would wait, first for blood product to come down from the blood bank; then more waiting for it to defrost. Cryo had to be pooled together into one bag before being ready for my transfusion. More hours followed while waiting for the product to slowly drip into my veins. Due to all the foreign proteins in the plasma or cryo, I would usually suffer a reaction after a transfusion and have to be given an antihistamine. More waiting.

In those days, going to the hospital for a transfusion was a last resort. You would wait and endure the pain rather than disrupt everyone for a trip to the emergency room. Not that my family ever made me feel that my health was a disruption. My parents treated me as they did my brother and sister. No special handling. However, it was how I felt – that because of my needs, life was disrupted. A lot of men my age share similar feelings. Even to this day, if I'm out at a play or concert with my wife and have a spontaneous bleed, I will endure the pain rather than ruin the evening for her. Again, she would never begrudge me for disrupting our plans to deal with a

bleed – it's just my feelings.

When I was young, my family would go on vacations with an ice chest full of dry ice and cryo. We couldn't travel far from New York/New Jersey, but we did go to Cape Cod and Expo 67 in Montreal. And during this era of peace and love, a miracle drug was introduced, lyophilized factor VIII. Living in the NY/NJ area, I was luckier than most. My doctor was the very well-known hematologist, Dr. Margret Hilgartner, and I was one of the first to be treated with this miracle drug, and one of the first to learn how to infuse myself.

Now this was a life-changer! We now had the freedom to travel. No more going to the emergency room for a bleed. I could infuse myself at home. In the early days of factor, the vials were 60 ml and you would hang the vial to a hook screwed to the ceiling. I was stuck in a lounge chair in the TV room, but man, I was free.

The 1970's found me living a carefree, normal life, going to Grateful Dead concerts, driving my van cross country, living in Santa Fe, New Mexico in a



Brother Bob, Rich and sister, Diane -1957



1968



With younger brother, Paul - 1972

Hogan, traditional dwelling of the Navaho people, and working for the solar energy commission building solar greenhouses and photo documenting the experience on various Pueblo reservations. I volunteered as a security guard for a Grateful Dead concert when they were playing at Raceway Park in Englishtown, New Jersey. If it wasn't for that gig, I might still be in New Mexico.

Graduating college with degrees in art history and photography, I moved to Manhattan to work for a well-know fashion photographer. I had the opportunity to travel all around the country on photo shoots, one time traveling to Jamaica with a famous Somalian model, Iman, to shoot a photo spread for Essence magazine. I was able to do all this because of the miracle drug, factor VIII concentrate. Life was great - living and working in Manhattan during the late 70s and 80s. No worries about hemophilia - it was all under control, and I was living the life.

Working in the fashion industry, I had many friends in the gay community. Rumblings began spreading about "a gay cancer" that was devastating the homosexual community. Of course, this turned out to be HIV/AIDS. Soon, we learned the hemophilia community was affected as well because the virus was in the blood supply. At that time all the products were plasma-based, so part of me was not surprised when Dr. Hilgartner gathered a group of us together to tell us we were infected with the HIV/AIDS virus. My wife at the time asked, "What about children?" Dr. Hilgartner replied, "Why would you have kids with him? He'll be dead in 5 years." I was 27.

I opened my own photography studio in Manhattan. Doing fashion photography and advertising, I

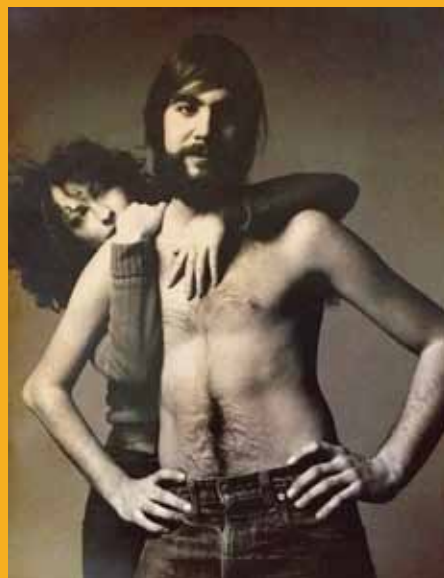
photographed fashion for JC Penny, album covers, and book covers for Simon and Shuster. My wife and I then moved to Sausalito, California, and lived in a houseboat. Soon after we split up – the marriage was over. We had gone through the motions, but the weight of HIV had taken its toll.

Heading back to Manhattan, I decided to look up a childhood sweetheart, Suzanne. We picked up where we left off, and I'm happy to say we recently celebrated 19 years of marriage in October 2016. Together we have traveled the Caribbean and Europe, and have made a happy home in New Jersey. Living in a farmhouse built in 1830, we have filled our lives with cats, dogs, sheep and chickens, all the while trying to keep hemophilia and its complications a manageable disease. And for the most part, we have succeeded. The key is to live your life to the fullest and do the things you can, within your limits.

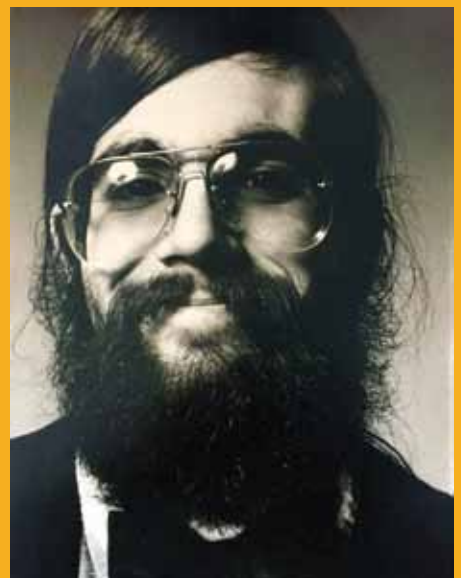
In 1995, my father passed away. He was very involved in the hemophilia community and with his passing, I grabbed the baton, jumping in with both feet and never looking back. My dad had a hand in developing the newly formed *Hemophilia Federation of America* before he passed. I went on to become one of its first presidents. Then I served as president of the Hemophilia Association of New Jersey, followed by a position as a consumer representative for HTC Region II, and was a voting member of the *Blood Safety and Availability Committee* (U.S. Department of Health and Human Services) overseeing the safety of the nation's blood supply. Along with a close friend, I ran the *Blood Brother* program in New Jersey for five years. It is with pride that I served the community in these various positions.



Testing the lights - 1978



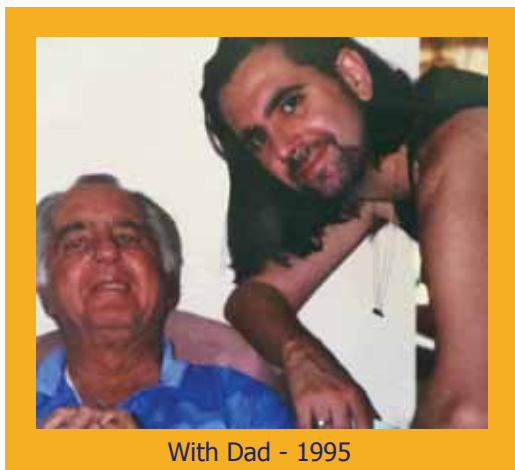
Fashion photography - 1978



Self portrait - 1978

This is not to say everything has been great. There have been challenges. As I turned fifty and then approached 60, things started to get to me. At the age of 54 while working as a videographer, out of the blue, I started acting oddly and very much out of the ordinary. In the middle of videotaping a deposition for an attorney, I began sending gibberish text messages to my wife. Something wasn't right. My colleague wrapped up the job and we headed out. By the time we got to my car, I couldn't speak or comprehend what was being said to me.

My colleague called an ambulance and I was taken to a hospital, where the brain bleed I was experiencing was misdiagnosed. Not having an understanding of hemophilia, the doctors ignored my wife's pleas and insisted I was suffering a psychotic event because of the HIV. Three days passed before I was given clotting factor. The hematologist later asked me how old I was when diagnosed with hemophilia. When I told him at nine months, he asked, "Oh, 9 months ago?"



With Dad - 1995

We've come a long way in hemophilia care, but based on the times I hear stories like mine, I know we have yet a long way to go in raising bleeding disorder awareness.

Now that I've grown older, I face new challenges in my life: it's harder to find venous access because of all the scar tissue developed through the years. Data shows that men with hemophilia have a tendency to develop hypertension because of the vascular changes we go through from years of bleeding into joints, so my hypertension is managed by medication. As young boys, we spent a lot of time being sedentary because of bleeds and minimal therapy. Because of inactivity during the years when our bones were growing and strengthening, we are more prone to developing osteoporosis at a greater rate than typical for our age. A few months ago, I completed treatment for hepatitis C. After 12 weeks of waiting and wondering, I am happy to say I've cleared the hepatitis and am considered cured of it. Lastly, when it comes to my hemophilia and HIV, both are being well managed with new and improved therapies.

As I reflect on my 60 years of having hemophilia, I wouldn't trade my life for a so-called 'normal' one. "Once in a while you get shown the light in the strangest of places if you look at it right" (The Grateful Dead - Mars Hotel, 1974). We are all dealt a hand in life. Some get all aces and some don't. Aces aren't always needed to win – it's not the contents of the hand you're dealt, it's what you do with it that makes you the person you are. Hemophilia has made me into a strong, empathetic person who always looks to a brighter future. "Lately it occurs to me. What a long strange trip it's been" (The Grateful Dead - Truckin, 1977), but I wouldn't have wanted it any differently. 🍀



Wedding Day - 1997



Italy - 2007



With wife, Sue - 2017

Hypnosis for Chronic Pain



By Sarah Henderson

Chronic pain is a common but unfortunate problem in the bleeding disorders community. How to safely and effectively treat this pain without causing negative short or long term side effects can be difficult. One way many people have found relief from chronic pain is through hypnosis, also known as hypnotic analgesia.

Stress and anxiety can increase the amount of physical pain that is experienced. Using hypnotherapy to reduce your stress and anxiety levels can help to lower pain. Hypnotic analgesia is a technique used to change your thought patterns when dealing with pain, thus reducing your perception of the pain, reducing discomfort. Hypnosis can also reduce the anxiety you have about pain, helping relax your mind and body.

During a hypnotherapy session, you will learn a few different techniques. Typically, you will begin by learning to focus on your breathing. Then you will be directed to think about a place or situation that brings you feelings of peacefulness. This is known as "visualization", where you will be directed to concentrate on specific details to create further relaxation. For example, if you are imagining yourself on a beach, you will be guided to focus on details such as the warm sand between your toes, or if you see yourself skiing down a mountain, you might focus on the cool wind in your face. You will learn to focus on whichever specific details about your scenario that brings you peace and tranquility.

The hypnotherapy session will not take your pain away; however, it should lessen the anxiety and stress that can increase perception of pain. During these sessions, the ultimate goal is to learn how to use these techniques so you can engage them anytime necessary.

The American Society of Clinical Hypnosis (ASCH) suggests when looking for a clinician to provide hypnotherapy services, be sure they are well trained and certified. Many hypnotherapists are even covered by insurance. The ASCH provides extensive information about hypnotherapy on their website www.asch.net, as well as information on where you can find a therapist in your area at <https://www.asch.net/Public/MemberReferralSearch.aspx>.

The American Psychological Association reports: "A meta-analysis (a study of studies) in 2000 of 18 published studies by psychologists Guy Montgomery, PhD, Katherine DuHamel, PhD, and William ReDD, PhD, showed that 75% of clinical and experimental participants with different types of pain obtained substantial pain relief from hypnotic techniques."

With the possibility of successful pain relief treatment with no side effects, there is nothing to lose by giving hypnotherapy a try to help bring some relief to your stress, anxiety and chronic pain. 🌟

Resource: www.apa.org/research/action/hypnosis.aspx



Dr. Margaret C. Telfer

50 Years in Medicine

By Robert H Johnson, LCSW
John J. Stroger Jr. Hospital of Cook County
Hemophilia Treatment Center

Dr. Margaret Telfer's life began in medicine and in dedication to service. Her father was a physician in the Commissioned Corps of the U.S. Public Health Service, an elite team of highly qualified health professionals. Growing up, her family moved to various places, such as Galveston, Texas and Seattle, Washington. Dr. Margaret Telfer attended Stanford University in Stanford, California, and received her medical degree from Washington University in St. Louis, Missouri.

Upon completion of her residency at Michael Reese Hospital in Chicago, Illinois, an attending physician who faced a sudden departure in the ranks of his upcoming fellows in Hematology/Oncology approached her one day in a hallway and announced, "Telfer, you're going into hematology." She never even needed to apply. For almost 30 years at Michael Reese Hospital, she took care of patients with hemophilia and did groundbreaking research with the use of factor concentrate. She lived through the horror of seeing patients contract HIV and hepatitis from factor she had prescribed for them.

As Michael Reese closed down slowly in the late 1990s, she obtained a joint appointment with Cook County (later Stroger Hospital of Cook County) and Rush University Medical Center. Two years later, she became a full time attending physician at Stroger, with a special interest in running the Fellowship Program and improving the care of patients with hemophilia.

Her time of doing research was over, but she made up for it with teaching, patient care and advocacy with the hospital administration. She pushed for a dedicated hemophilia clinic, better laboratory support, and moving the hemophilia social worker position

into the regular hospital budget, and was largely successful. During her final month at Stroger Hospital, June of 2015, she celebrated the 50th anniversary of her graduation from medical school.

When Dr. Telfer came to Stroger Hospital, we created a tight working relationship almost immediately. She impressed me with her in-depth knowledge and vast experience, her willingness to share it and her devotion to patient care. She shared with me her marvelous sense of humor and exhibited the virtues of benevolence to a degree that was remarkable even in a medical care system with many dedicated physicians. Even when most frustrated and upset, usually by a computer or an administrative system, she had absolutely no malice – there was never any bite in her bark. In her last weeks of clinic duty, patients came to see her one last time and many tears were shed as they felt overwhelmed by a sense of impending loss, love and gratitude. She is still missed by me and many others.

Upon her retirement, Dr. Telfer moved to San Mateo, California, where she immediately set about caring for ailing siblings and in-laws as well as enjoying freedom from long labors well done.

Dr. Telfer's remarkable contributions have touched the lives of countless people in immeasurable ways. Her daily presence is dearly missed by both colleagues and patients alike, and her dedication to the bleeding disorder community will forever be recognized and appreciated.

After a lifelong commitment to caring for others, we hope Dr. Telfer is fully and happily enjoying her well deserved retirement. 🍷

Pursuing Excellence

By Justin Lindhorst



From cycling to climbing, yoga to martial arts and all things in-between, people with bleeding disorders are more physically active than ever before. Prophylactic treatment, comprehensive care and strong local support systems are allowing members of the bleeding disorder community to excel in areas once considered completely out of reach. Achieving these new heights requires special considerations and careful coordination of care to reap the positive benefits of increased physical activity.

Christian is a South Florida teen with severe hemophilia A, and his story provides a perfect example of the doors opening to the bleeding disorders community. Hemophilia has not stopped Christian from pursuing athletics. His latest interest: triathlons. At the time of publication, Christian has run a total of 7 triathlons, and he's not slowing down yet. His evolution to a triathlete started first with his love for cross-country running. After running for three years, Christian found himself eager for new challenges. He began regularly cycling with his father. During one of their lengthy rides, the two happened upon a training facility for athletes interested in preparing for triathlons and other Olympic endeavors. Having established a good handle on running and cycling, the family decided to tour the training facility. After meeting and establishing a great rapport with one of the coaches, Christian soon began training at the facility. A short time later, he participated in his first triathlon.

Before running that first race, Christian underwent considerable preparation. First and foremost, he maintained his prophylactic factor regimen. He also worked with his hemophilia treatment center, (HTC) modifying his treatment schedule to best suit his training program. This provided the greatest level of protection during more strenuous activities. Christian also worked with his physical therapist, who provided stretching activities, custom orthotic insoles and recommendations for shoes offering the best support. The coach at the training facility became well versed with hemophilia, and consulted regularly with the physical therapist.

Other preparations included always keeping a dose of factor on hand during races and practice, and always wearing a "Road ID," which is similar to a Medic Alert bracelet. Perhaps most important of all is Christian's acceptance that in order to pursue his ambitions, these additional steps need to be taken very seriously. He shares, "Maintaining prophylaxis is number one. I also keep very open communication with my coach and physical therapist about how my body is feeling. I take my stretching very seriously. One big thing I've learned recently is to set specific and measurable goals when it comes to training. My coach has been great helping me with that. He has also helped teach me to build up to new things gradually instead of rushing into them."

Though Christian is well prepared and has learned the proper steps to manage his bleeding disorder, the teen

has dealt with challenges from those who are not as well educated about hemophilia. Recently after registering for a race in Miami, Christian's family was contacted by worried event organizers who were unsure he should participate given his bleeding disorder. This was not the first time for such an occurrence. After continued reassurance and explanation, the organizers eventually allowed him to compete. Christian went on to take 1st place in his age division for the race. He notes, "You have to be prepared to explain to others specifics about your condition. Honestly, I view my hemophilia as a competitive advantage. When dealt a challenge, I've learned to look for solutions rather than accepting defeat. I've overcome so much already living with hemophilia, I don't let other challenges get the best of me."

Christian has learned to balance his athletic ambitions with properly managing his bleeding disorder. By taking proactive steps to minimize risk, Christian's training has strengthened his joints and muscles, protecting him from spontaneous bleeding episodes. He encourages other members of the bleeding disorder community to get out there, get active and above all, "Find something you like. Something you really like to do. If you don't like one activity, try something else until you discover something that is fun for you. Don't let hemophilia hold you back and don't be afraid to try new things!"



Always looking to the next adventure, Christian has already set his sights on future pursuits, "I love competition. I love trying new things and pushing myself to the next level. In the future I'd love to participate in an Ironman competition!" With the proper support, training and care, there is little doubt he'll do just that. 🚴



Matrix Health Group

THE HEALTH ADVOCATE

Surprise! You Received *Another* Medical Bill



Paul R. Brayshaw, M.P.H.

Director of Healthcare Advocacy and Programs
Factor Support Network,
a Matrix Health Group Company
Regional Care Coordinator,
Mid-Atlantic Region

By Paul Brayshaw

I imagine you are on vacation and an emergency occurs that requires immediate medical attention at the nearest hospital. Without time to review your network benefits, you find yourself admitted into the hospital and provided health care services. After diagnosis and treatment, you are discharged to continue on the path of recovery (and to hopefully enjoy the rest of your vacation!). Following several weeks and a return to health, medical bills begin to arrive for the care and services provided out-of-network.

While I value good medicine and am willing to pay my share, the costs and attempts to collect out-of-pocket expenses are incessant and irritating. A recent personal example occurred when my doctor ordered several clinical labs. I had my blood drawn and after several weeks, bills began to arrive, each reflecting various co-pays due. Though some of the tests were covered at 100%, the most critical lab values (i.e. half-life, PK) were not.

According to a 2015 national survey, over the past year, 6% of households with insurance had problems paying medical bills stemming from receiving their care from a provider whom they were unaware was not in their plan's network (Hamel, 2016). In another 2011 national survey, 8% of privately insured adults who received care in the prior year used an out-of-network physician (Kyanko, Curry 2013). Among those, over half (58%) of the hospital-based instances were classified as "involuntary," meaning the patient had no choice due either to emergency, lack of knowledge, or unavailability

of a network physician. Medical emergency was the reason for classifying two-thirds of these hospital instances as involuntary.

In 2015, yet another national survey (Consumer Reports) found that 30% of privately insured people had bills in the past two years where their health plan paid much less than was expected. A quarter of those "surprised" patients received bills from doctors they weren't expecting, and a seventh of surprised patients (or 4% of all privately insured adults) were charged an out-of-network rate when they thought the provider was in-network.

As provider networks grow increasingly narrow, the scenarios described above are becoming more common throughout the United States, especially in the bleeding disorders community. Due to legal requirements for emergency services to be rendered regardless of network participation, surprise medical billing is likely to spread. In addition to an unforeseen emergency room visit, surprise medical bills may result from nonparticipating hospital specialists and facility-based services providing underlying care within the same hospital system, (i.e. separate rehabilitation unit or ambulatory surgery center and out-patient facilities and laboratories that are non-participating, but still involved in the care.

If you are confronted by a surprise medical bill, there is a real risk of financial harm if the bill is ignored or left unpaid. However, when insurers and providers disagree



on what rates are usual, customary and reasonable, the unsuspecting patient is left with the balance. To help prepare for these unanticipated expenses, it is important for patients to be aware of these issues until Federal and State policymakers establish more long-term, sustainable solutions.

Congress and Federal agencies must act to assure protections are implemented in both insured and self-funded policies. Possible solutions may include capping out of network billing rates for emergency services, as well as authorizing states to establish billing policies and dispute resolution procedures between providers and health plans. States may consider separate regulations defining what out of network providers may charge, especially in surprise situations. Other possible solutions must involve sustained efforts to improve the real time information available to consumers involving provider network and out of network changes. Finally, ongoing evaluation to assess the effectiveness of these interventions will help protect consumers, and negate some of the negative consequences of health care delivery in the marketplace.

At Matrix Health Group, we ensure our clients are familiar with various programs available to assist with

insurance out-of-pocket costs as well as organizations that can help with short term, urgent financial necessities such as rent or electricity bills. Matrix also helps support programs such as the Health Insurance Premium and Copay Support Program of Patient Services Incorporated (PSI) (unneedpsi.org), the Helping Hands Program of the Hemophilia Federation of America (hemophiliafed.org), and the Direct Financial Assistance Program of Hope for Hemophilia (hopeforhemophilia.com). Please visit their websites for additional information regarding eligibility. 🌐

Resources:

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Consumer Reports National Research Center. (2015). Surprise Medical Bills Survey. Retrieved from <http://consumersunion.org/wp-content/uploads/2015/05/CY-2015-SURPRISE-MEDICAL-BILLS-SURVEY-REPORT-PUBLIC.pdf>



Matrix on the Move!

Indiana

Enrique Morey

Family and friends eagerly gathered at the Hickory Hall Polo Club in Whitestown for the **2nd Annual Polo at Sunset** Friday, August 19th. Presented



by Hemophilia of Indiana (HOI) and Fit Livin', excited attendees enjoyed a rousing match spanning a 300 x 160 yard field, including a spectator divot stomp during halftime. For those not familiar with polo, a divot stomp is a longtime tradition of having spectators go onto the polo field and "stomp" down the divots in the turf kicked up by the ponies' hooves. After the match, spectators joined riders on field as trophies were distributed. Thanks to HOI for arranging a great time as always!

score of 21 before their opposing team. The exciting tournament wrapped up with awards for the winners and door prize drawings. Participants and spectators enjoyed this exclusive fundraising event, raising more than \$8000 to help support THBDF. Matrix Health Group is a proud sponsor of this unique fundraising tournament, and we look forward to participating again next year!

North Carolina

Peggy Gay

On a very hot and sunny day at Tanglewood Park in Clemmons, over 80 people attended the first ever Hemophilia of North Carolina **Family Fun Day**.



Kevin and Maddy taking a lunch break.

During a delightful lunch August 21st, we learned all about the up-and-coming chapter programs and had fun participating in enjoyable games and activities. The afternoon soon made way for fun-in-the-sun as families headed out to have a refreshing time at the newly renovated, 1100-acre park. One and all had a blast at the Aquatic Center with its swimming pools, winding tubing river, water slides, splash pad, kiddy pool and more. We looking forward to next year's event!



Korbin and Caleb ready to play!

Tennessee

David Tignor

The much anticipated **16th Annual "Pitchin' for Caleb" Corn Hole Tournament** was held August 20th at Centennial Park in Crossville. Caleb is a 13 year-old young man who lives with von Willebrand disease. His parents, Shane and Kelley Wood, organize the event in his honor with the help of volunteers, sponsors and the Tennessee Hemophilia and Bleeding

Disorders Foundation (THBDF). As registration took place, participants had a chance to practice tossing corn bags prior to teams being paired up to play. Choosing numbers out of a bucket, 28 individuals learned who they were partnered with for the tournament. Teams readied for play while many fans took a place on the bleachers to watch all the action.

After the morning Round Robin tournament, teams broke for a hardy lunch provided by local community members, Scotty and Ronnie Webb. Then it was time for the **Elimination Tournament!** Competition was commendable as teams tossed the corn bags trying to reach the winning

Nevada

Kelly Gonzalez

On an unusually hot evening in Reno August 24th, patients and family members were ecstatic to gather inside the air conditioned Black Bear Diner for a **Self-Infusion Clinic**. HTC of Nevada's Nurse Educator, Becki Berkowitz and I helped instruct patients and caregivers in the benefits of self-infusion, and helped



guide them toward a safe and efficient means to infuse! Patients enjoyed a homestyle meal during the presentation and were happy to put the education into practice after dinner. Factor Support Network is proud to sponsor this event in partnership with the HTC of Nevada!



West Virginia

Tina McMullen

West Virginia Chapter of NHF held their **Family Camp Weekend** August 26th to 29th at the beautiful Jackson's Mill in Weston. Hot weather did not

keep anyone from having a wonderful time. Beginning with time to visit industry exhibits and dinner, there was an array of educational topics of interest for all ages with sessions such as *Bullying, Reveal or Conceal: Navigating Disclosure of a Bleeding Disorder, Navigating the Financial Aid Process, Pain Control, and Planning Your Future*. After a day filled with education, the refreshing swimming pool was the place to be! Activities following dinner did not disappoint - a magic show, face painting and s'mores around the campfire. After a huge Sunday morning breakfast, families were off to the water park and exhilarating whitewater rafting.

Chapter Executive Director, Amber Tichnell and her team of volunteers provided a weekend of camaraderie and enjoyment for the 50+ people who attended. Once word gets out about how much fun the weekend was, we can only imagine how this event will grow!

Florida

Peggy Gay

The Hemophilia Foundation of Greater Florida and Shire/Baxalta held an exciting **Educational Event** at Adventure Island August 27th. This well attended event drew many from the Tampa area bleeding disorders community. We partnered into groups and participated in a trivia game that challenged and tested our knowledge about bleeding disorders. What a wonderful way to spend time together and learn at the same time!



Families enjoy the day

Maryland

Paul Brayshaw and Terry Stone

For the first time in a very long time, the Hemophilia Foundation of Maryland (HFM) hosted an overnight **Sleeping with the Fish** educational experience at the National Aquarium in Baltimore August 27th. With exclusive support of Matrix Health Group, HFM was able to offer

this one-of-a-kind experience to nearly 50 members. The overnight included an acrobatic performance by the in-house dolphins, offering a good splash for those of us who chose to sit in the first few rows. The HFM group remained at the aquarium for dinner and an up-close experience, including touching stingrays, handling horseshoe crabs, and patting live jellyfish. We also enjoyed a behind-the-scenes tour, learning how food is prepared for the animals, as well as a brief visit to the walkway above the shark tank! After the tours concluded, attendees stayed the night, awaking to breakfast and a morning dolphin greeting.



New York

Richard Vogel

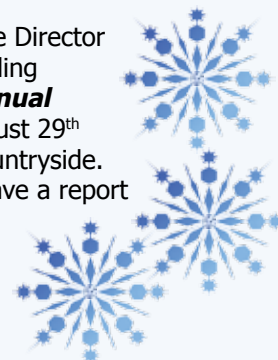
As we all know, if you have a child with a bleeding disorder, school can be difficult to navigate. It's important to be aware of various resources available. Do you need an Individual Education Plan (IEP) or a 504 plan? Maybe both? What's the difference between them? When I was going to school in the 1960s, these resources were not available. My mother went to my school to advocate on my behalf. She talked to the school personnel explaining hemophilia and what to expect. She explained why I might need additional time to get to class because of knee or ankle bleeds, how I may need a tutor if I was absent for extended periods of time, and discussed my limitations for PE.

Well, on August 28th, the New York City Hemophilia Chapter addressed these issues with their first **Bilingual Back to School Education Event**, held at the downtown Marriott Hotel. The first session discussed the difference of, and how to set up a 504 or IEP. The second session involved communicating with school nurses and staff. Both sessions were offered in Spanish and English simultaneously. By knowing the resources available and being prepared when you speak to school officials, your child's experience should be as pleasurable as mine. Many thanks to the New York City Hemophilia Chapter for hosting this much appreciated and enlightening meeting!

Illinois

Eva Kraemer

The Board of Directors and Executive Director Bob Robinson hosted the 2016 Bleeding Disorders Alliance Illinois (BDAl) **Annual Meeting and Awards Dinner** August 29th at the William Tell Holiday Inn in Countryside. Board President, Daniel Contreras gave a report on the state of the organization, touching on upcoming endeavors. Awards were graciously accepted for the following contributions: the





BDAI Staff takes a moment to pose with Matrix Health Group's Regional Care Coordinator, Eva Kraemer.
Charles Price, Bea Carr, Eva Kraemer, Bob Robinson, Lily Schwartz, Adam Hii and Jessica Head

Award of Excellence was given to Kelly Kovak, Clemente Printing, and Ramona Towner. *Outstanding Support to BDAI* was given to Jeff Beck, and to Kathe Gusler for her contribution at Camp Warren Jyrch. The *Cibula Award* for outstanding volunteerism was granted to the Carr family. The Krueger family presented six Bradley Krueger educational scholarships for the 2016/2017 school year. An opportunity to enjoy good food and great company, always a great time at BDAI events!



bleeding disorders community across 41 counties of the chapter's territory. Professional golfer, Perry Parker, offered swing analysis at the driving range and hosted a Beat-the-Pro hole to generate additional revenue and excitement! The event concluded with a wonderful buffet dinner and the announcement of awards in the clubhouse. The day wrapped up fantastically!

Maine Cheryl Ashmore and Justin Levesque

A beautiful 75-degree, early autumn day in scenic mid-coast Maine brought approximately 100 hikers to the 4th



Annual Hike 4 HAM fundraiser September 17th. The Hemophilia Alliance of Maine (HAM) is a dynamic, five year-old organization experiencing a tremendous amount of growth and membership. Folks from all age groups hiked a moderately difficult three mile trail to the top of Mount Battie in Camden. At the summit, the view of the ocean is spectacular and well worth the effort. Afterward, everyone enjoyed a delicious barbecue lunch while taking time to make new acquaintances and visit old friends.

Nevada Kelly Gonzalez

There isn't a more tranquil setting for our community gathering and northern Nevada **NHF Walk** than Bartley Ranch Regional Park in Reno! The picturesque park provided enough shade and scenery to boost everyone's spirits as they prepared for the event. After a lively warm up by some of our young community members, over 125 participants began the 1 mile/5k path of their choosing. At the finish line walkers were treated with participation



Sweet hug between mom, Tracy, and daughter, Caitlyn.



Top Individual Fundraiser
Jacey Gonzalez



Team Photo! (Left to right) Erin Foster Vre-Non, NP - HTC NV; Jennifer Roberts, Compliance - HTC NV; Kelly Gonzalez, Factor Support Network; Becki Berkowitz, RN - HTC NV

Illinois Eva Kraemer

The threat of rain couldn't stop the 500 devoted participants from taking part in the 7th Annual Bleeding Disorder



Team Matrix - Hemo Strong!

Alliance Illinois (BDAI) **Hemophilia Walk** in downtown Chicago September 10th. BDAI hosted the Walk at North Avenue Beach, winding through the picturesque Lincoln Park Zoo. We at Matrix Health Group, a proud sponsor of this event, are always delighted to participate. This fundraising event allows everyone an opportunity to get together to support the community, making



Jen and Jim with Eva Kraemer

this fundraiser successful on many levels. The clouds overhead patiently waited until we all crossed the finish line before giving way to rain, and since we typically do have rain during this event, we will take as a sign of approval for a job well done!

Pennsylvania Paul Brayshaw

Failing to recover nearly a dozen golf balls at the 2016 Eastern Pennsylvania Chapter (EPC) **Golf Classic** did not spoil the purpose of a very enjoyable round of golf to support the mission of the Chapter. One hundred golfers took to the links September 13th at Rivercrest Golf Club in Phoenixville to assist the efforts of Executive Director, Curt Krouse and the staff of EPC as they provide support and services for the



medals and a good ole' fashion barbecue meal! Awards were given to the highest fundraising corporate team, HTC of Nevada, and to Jacey Gonzalez, top individual fundraiser. Congratulations to everyone involved, participants, volunteers, sponsors, and, of course, the organization team! Well done everyone!



Victoria Kuhn (HAM VP) and Jim Boutin, HAM member

Arkansas

LeAnn Wilson

The Hemophilia Foundation of Arkansas hosted its **Annual Meeting and Family Retreat Educational Weekend** at the Clarion Hotel Lake Hamilton in Hot Springs September 23rd to 25th. The fun-filled weekend began Friday night



All smiles for an Arkansas family!

with a meet-and-greet for 155 community members who then visited industry booths before enjoying a buffet style dinner in the hotel ballroom overlooking Hamilton Lake. Fun continued after dinner as everyone delighted in a game of Bingo played with M&Ms, which quickly turned game time into snack time.

Saturday's schedule included three informative breakout sessions providing a variety of educational material to help meet the specific needs of each family. A *Kids' Fishing Derby* followed the sessions. Children thoroughly enjoyed casting hooks from a floating dock. Though this was not the first fishing trip for some, it was for others. I had the honor of helping a little girl and her mom bait her hook and cast for the very first time on her very own 'Frozen' fishing pole. After Saturday night's dinner, everyone gathered for a very entertaining lip sync contest and dance-off, allowing us to let our hair down and enjoy getting to know one another. We said our goodbyes Sunday morning and all went our separate ways knowing that new friendships, relationships and memories had been made.

West Virginia/Washington, DC

Paul Brayshaw

From September 23rd to 25th, I rode my bike 156 miles from Paw Paw, West Virginia to Washington, D.C. with my father, my sister and her husband, and another sister and her boyfriend as part of *Team Blood Riders*. We were successful in overcoming this challenge in part by three days of sunshine and harmony among family and friends. We rode our bikes with courage along a car-free historic corridor of the C&O Canal Towpath as part of the **Gears for Good National Benefit Rides**, and the saddle sores we endured were to help raise critical resources for the Hemophilia Federation of America's (HFA) Helping Hands Program.

Over the past 5 years, Gears for Good has grown from a



Team Blood Riders!

fledgling fundraiser to an important revenue stream. The benefit rides in Connecticut, Ohio and the National Ride are annual events focused on raising funds to help provide a lifeline for eligible individuals and families within the bleeding disorder community in the event of a financial crisis. This past year, Gears for Good successfully raised over \$128,000! In 2016, a plea to 'Bring a Friend' was bestowed on participants for next year. What better way to spend quality time with someone you cherish than riding together for several hours, and for some, several days, in support of such a worthy cause! Please consider riding, and/or donating in 2017 to help someone in serious financial need.

California

Marina Vera

Salsa music could be heard upon arriving to the Hemophilia Foundation of Southern California **Hispanic Celebration Day** event September 24th! Families were treated to a limo ride up the hill to



arrive at Montecillo de Leo Politi Park in Los Angeles where the event was held. A large crowd of 300 guests attended this spectacular event geared toward the Hispanic community. HFA's Spanish Program Coordinator and guest speaker, Martha Boria opened with welcoming remarks and presented a talk on *Nutrition*. Rob Nelson, founder and president of *Hit One Deep Enterprises* and a former first baseman with the Oakland A's, provided a baseball clinic for kids ages 5-11. The event wrapped up with *Folklorico Dance Performances* by Pasion de Mi Tierra and then families were provided tickets to attend a baseball game between the Los Angeles Dodgers and Colorado Rockies at Dodger Stadium. The smiles on all the faces that this event brings is what makes you want to come back next year again to be a part of this event!

Florida

Joe Opalka

The 5th Annual Hemophilia Foundation of Greater Florida **Gator Clot Trot 5k/Fun Walk** kicked off at Tioga Town Center in Newberry early



Family Fun! (Left to right) CJ, Corey, Jashaun, Erica, Barbara and Jakhia



September 24th. The morning began with fresh fruit and pastries while participants mingled and visited industry booths during registration. When the 5k and Walk finished, groups gathered for the awards ceremony after receiving their participation medals and grabbing a slice of pizza. This successful event helped HFGF raise over \$27,000 to benefit the Florida bleeding community. Quite impressive – let’s try to beat that total in 2017!

Nevada
Kelly Gonzalez
Las Vegas NHF Walk
 began September 24th

with early morning fun at Floyd Lamb Park in Las Vegas – a motivational warm up and silly dancing as over 420 participants joined forces to raise money for the local chapter. Decked out in themed t-shirts, costumes and painted faces, participants had one thing in common: the goal of supporting the bleeding disorders community. We thoroughly enjoy the company of so many amazing and inspirational community members. Great job to all the walkers, runners, fundraisers, supporters and planners!



Walk volunteer, Eric with Maddie Lynn.

Ohio
Shelia Biljes
 The sun was shining brightly September 24th as 300 walkers and runners participated in the Northern Ohio **Walk and Superhero Run**



Ready to Walk! David, Batman, Ashleigh, Linus, Miya, Marty and Spiderman.

held at Sunny Lake Park in Aurora. While Spider Man and Batman provided photo opportunities, families stopped at the sponsor tents to visit with manufacturer and homecare company representatives, then worked their way through games and inflatables for a morning of fun. Along with lots of public awareness, the foundation raised \$45,000. The 2017 Walk location has not yet been determined, but regardless of location, it’s an event no one will want to miss!

Virginia
Terry Stone

The Virginia Hemophilia Foundation (VHF) showed some true southern hospitality as they welcomed members from across the state to their popular **Family Retreat Weekend** at the Great Wolf Lodge in Williamsburg September 24th to 25th. Families arrived in the early afternoon and were granted access to the magical world of water before the event began. At every corner there was a wonderful way to get your paws wet. Little wolves

frolicked in the waves that rocked and rolled and they giggled while they wiggled. Teen wolves joined together to ride the lazy river while mustering up their nerve to go down the *Howlin Tornado*. After all, it’s not cool for a teen wolf to turn into a chicken little. Oh, how the cubs grow up fast!



Family Retreat Participants
 Braydn, John, Rhyland

VHF kicked off the evening’s events with a *Core Conversations* program that shined the light on the unaffected sibling in the den. This was certainly a hot topic as parents learned helpful tools to ensure the needs of ALL their cubs are met and how to keep the growling to a minimum. Time was also allowed visit with us at the Matrix Health Group booth as well as the many supporting industry sponsors.

After sunrise, an early family feeding was offered to all, followed by an inspiring presentation by CSL’s *Getting in the Game* athlete Peter Dyson, who energized the crowd with an inspiring presentation about wellness and staying healthy. He spoke about the importance of being active, eating proper nutrition and staying on your prescribed infusion plan while treating bleeds early. His message was well received and gave all the attendees something to think about going forward. Paws down, it was a wonderful weekend and everyone had a howling good time. So until next year...(insert your best howl here!)

New Jersey
Richard Vogel

Matrix Health Group proudly hosted an **Educational Dinner** with Pfizer at Sophie’s Bistro in Somerset September 25th. Our group was in a private room and made for an intimate cozy environment. The atmosphere was comfortable, unpretentious and everyone felt right at home. A very informative program, *Planning Your Future with Hemophilia*, was presented by Theresa Coia, BSN, RN, Nurse Educator Specialist with over 25 years of clinical nursing and nursing education experience. Theresa’s clinical experience spans from the care of the most critically ill of patients to managing their chronic diseases at home.



The talk focused on challenges persons with a bleeding disorder face as they grow old. We discussed financial planning, long-term care, changes in our support system, and the normal aches and pains of getting old, and various

available resources. I think we all came away with a better understanding of what to expect as we age and the realization that we are not alone in our journey.

South Carolina

Peggy Gay

Hemophilia of South Carolina held their **"Keeping It Coastal" Family Camp Educational Weekend**. Approximately 50



families arrived at the Ocean Creek Resort and Conference Center in Myrtle Beach September 30th–October 2nd. Once the guests settled in, President Lisa Bordelon and Executive Director Sue Martin made opening welcome remarks and acknowledgements. After dinner, the evening gave way to *Family Fun Night Games and Social Hour*, a movie as well as pool and resort time.

Saturday morning began with breakfast and time to visit the industry exhibits. Breakout sessions followed and families were able to select the topics that pertained to them personally. One of the topics in the adult's program was *Creating your Goals and Living Your Vision* presented by Inalex Communications. Sessions for kids and parents included *To Reveal or Conceal: Navigating Disclosure of a Bleeding Disorder*, *How Not to Marry Your Mother*, *Are You Smarter Than a 5th Grader?* and *How to Communicate with Your Child's School*.

The evening included dinner and a poignant presentation, *Remembrance Celebration, Poem and Name Reading*. Lighthearted entertainment closed the event with lots of fun for everyone – karaoke, Disney trivia, dancing, plenty of snacks – something for everyone!

Pennsylvania

Tina McMullen

Though the weather was gloomy, rain held out for the biggest turn out ever for the **Eastern Pennsylvania Chapter's Annual Trick or Trot 5K Run/Walk** held in



Fae, Brooklyn, and Lindsay ready for a fun time!

Collegetown on October 8th. With 15 teams and 300 runners, it was by far the largest attendance for this event! The day started out with participants having the opportunity to visit industry vendors under the exhibit tent. Children also had time to jump in the bounce house before the race/walk



began. Everyone enjoyed the live deejay and refreshments. After the run/walk, awards were given to the top runners in each category. Each child

received a medal for finishing. Making the event even more entertaining, many came dressed in their best costumes and awards were given for the scariest, funniest and most creative attire. There was even a prize for the best group costume!



The day ended with Executive Director Curt Krouse presenting Dr. Bhavya Doshi of the Children's Hospital of Philadelphia with a \$20,000 grant. Due to the hard work and dedication of Curt, his staff, Fae Ehsan and Lindsay Frei, and all the dedicated volunteers, this event has grown year after year and is widely anticipated by the community!

Tennessee

Amy Maddy and Teresa Nothan of THBDF

Held at Loveless Barn in Nashville, more than 130 people attended Tennessee Hemophilia and Bleeding Disorder



Foundation's (THBDF) **Annual Gala** October 14th. During a delicious sit down dinner, guest speaker Megan Overby, spoke about growing up with a father who had hemophilia and of his passion to help found THBDF in order to connect members of the community. She then discussed her role as the parent of a son with hemophilia, and the struggles and triumphs associated with that responsibility.

This year, Shane and Kelley Woods, hosts of the annual Pitchin' for Caleb event in Crossville, were awarded the prestigious *Victoria's Cup* for distinguished service to the bleeding disorders community. Over the past ten years, the Woods' have raised more than \$80,000 to benefit St. Jude Children's Research Hospital and THBDF, while bringing public awareness to bleeding disorders. The highlight of the evening was a silent and live auction, raising an impressive \$30,000, which will all be used to help sponsor THBDF's *Camp Freedom*.

West Virginia

Tina McMullen and Eric Lambing

It was a gorgeous fall day in the beautiful mountains of West Virginia for the West Virginia Chapter of NHF's 2nd annual **Hemophilia Walk**. The event took place October 15th at the Waterfront Place Hotel in Morgantown. With over 100 attendees the day began with a *Monster Dash Kids Fun Run* followed by the featured walk. During lunch, awards were handed out for Top Fundraising Team and Top Fundraising Individual. Children and adults alike enjoyed the day's entertainment with live music, face painting and a cartoonist. Executive Director Amber Tichnell and her many volunteers did an amazing job organizing this event. There's absolutely no doubt everyone is looking forward to it in 2017!



Corrina stops to visit with Factor Support's Tina McMullen.

California

Heather Messerly

Held at the lovely La Canada Flintridge Country Club in LaCanada October 17th, the Hemophilia Foundation of Southern California hosted its **33rd Annual Golf and Tennis Tournament**. This tournament is the chapter's most successful fundraiser with proceeds sending children to bleeding disorders camp.



Heather Messerly and Grace at the wine pull table.

The day consisted of one fun-filled activity after another! It started cloudy, but turned into perfect weather for golf and tennis – not too hot, not too cold. After the rounds and matches, the group had opportunities to bid on the wonderful baskets of items at the silent auction table.

Moving into the dining room, we feasted on a wonderful meal of prime rib and were enlightened by speakers who shared stories of their bleeding disorder. Most notable were three boys sharing camp tales. The youngest, an 8 year-old, shared how he learned to self-infuse at camp and received his brave stick just this past summer. The entire room joined in celebrating this great accomplishment, moving many to tears. The entire day was filled with fun, camaraderie, and great conversation, all for a wonderful and praiseworthy cause.

Illinois

Eva Kraemer

The annual **Autumnal Wine Dinner and Auction** for Bleeding Disorder Alliance Illinois (BDAI) was held October 21st in Chicago at the Columbia Yacht Club. Jim Hurster of CSL Behring, the Champagne Sponsor, superbly selected Italian wines to sample for 120 guests as Lake Michigan and the dazzling backdrop of the Chicago evening skyline captivated all. We feasted on a four-course meal; each paired with an exquisite wine. Many generous and talented guests donated time and money making baskets for auction in support of BDAI to continue providing education to the Illinois bleeding disorder community. Thanks to CSL Behring, BDAI and all those who came out to make the evening a success.



Dressed to the Nine's!
Kathi and Carl D.
and Eva Kraemer

Oregon

Jeff Johnson

Hemophilia Foundation of Oregon (HFO) hosted its annual **Shooting for the Stars Benefit Auction** and dinner at Portland's Multnomah Athletic Club October 21st. HFO's biggest fundraiser, proceeds support programming such as summer camp at *Camp Tapawingo*, teen



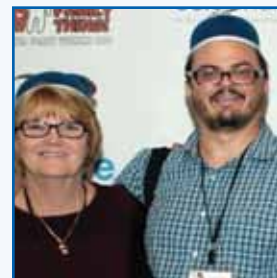
initiatives, family support groups and advocacy drives. In attendance were many members from around the Pacific Northwest bleeding disorders community, as well as numerous invitees from the local business and philanthropic communities in metro Portland.

During the course of the evening, attendees enjoyed a delicious prime rib dinner, casino gaming, a photo booth, raffle drawing, silent auction and a raucous and fun live auction. Among the items up for grabs were weekend get-away packages, a football autographed by Richard Sherman of the Seattle Seahawks, wine packages, an autographed photograph of Katy Perry, Disneyland admission tickets, gift baskets from many local businesses and even vacation trips to South America! I had a wonderful time supporting the local bleeding disorders community and even walked away sporting a fine new red tie from the *NHF Red Tie Challenge!*

Maryland

Paul Brayshaw

The 2016 Hemophilia Foundation of Maryland (HFM) **Family Weekend** took place October 21st to 23rd in Cambridge at the Hyatt Chesapeake Bay. Sixty-three families enjoyed the event; twenty of these being first time attendees. Everyone enjoyed a welcome reception, as well as a Mardi Gras-themed carnival party for the evening fun. During the day, educational sessions included information on inhibitors, the status of the Johns Hopkins HTC, a presentation on the PSI Access program and a final session by the Hemophilia Federation of America called *Be Smart: Mastering Social Media, Advocacy, Relationships and Treatment*.



Ryan N. and Executive Director, Emma Miller arriving at the HFM Family Weekend and getting ready for a great time!

HFM's Family Weekend is made special by Emma Miller, Executive Director. Emma deserves a tremendous amount of appreciation for her tireless efforts to help patients and their families feel welcome during this event, as well as throughout the year. With her dedication and commitment to assisting families, our community is blessed to have Emma working on our behalf.

Indiana

Enrique Morey

The secret's out...Hemophilia of Indiana's **Mystery Bus Tour** is a blast! On October 22nd, friends, family and perfect strangers set off to eat, enjoy beverages of choice and compete in fundraiser games, all while being transported from location to location via luxury coach with minimal details revealed.

For the first stop on the tour, unknowing guests were taken to the *Indianapolis City Market Catacombs*, treated to a tour, learning the history of an underground labyrinth kept hidden from public view, right in the center of downtown Indianapolis. Another stop landed guests at the Indiana Grand Casino, where they set

out for Vegas style gaming and other opportunities for entertainment offered.

There was no better way to end the amazing mystery lovers' evening than a final stop with dancing and cocktails. The night wrapped up with live music and the laid back atmosphere of Indy's Tin Roof bar and dancehall. Proceeds raised go directly toward helping kids attend bleeding disorders camp. Thank you to Hemophilia of Indiana for an amazing time as usual!

Ohio

Rania Salem

Fall was definitely in the air October 22nd – a bit chilly, but a beautiful day at the Cincinnati Zoo and Botanical Gardens. Friends and families of the Tri-State Bleeding Disorder Foundation



(TSBDF) gathered to share in education, food and fun for **Family Day at Cincinnati Zoo**. After a delicious barbecue picnic lunch, Chris Poytner from Shire held a very important session on *Insurance*. With all the upcoming changes in the insurance world, Chris informed us all on how to be savvy consumers. She is extremely knowledgeable in this arena and patients were able to participate in a Q & A session and learn of the challenges that face our community, and ways to overcome them.

TSBDF does a fine job advocating for our community and reiterating the importance of patients staying involved and informed about insurance issues by being educated and learning of upcoming changes to policies. After the important details were taken care of, families took to the amazing Hall-ZOO-ween fall festivities that lay ahead around the park. A fun time was had by all!



Tennessee

Shannon Cassada

Music and live performances by community members highlighted Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF) **Fall Festival** at Harlinsdale Park in Franklin October 22nd. With over 100 people in attendance, families enjoyed hayrides, face painting, a photo booth, family pictures, pumpkin decorating, games, food, goodies and so much

more! The costume contest was a big hit again this year. In the 0-3 year-old category, a most adorable bumblebee was the big winner. In the 4-9 year old, a mad scientist took the prize and in the 10+ group, the cutest jester in an awesome homemade costume won the prize.

On a more solemn note, a presentation of photos was displayed of three special members of the Tennessee community who were lost this past year. The event was



dedicated to their memories and was a nice way to celebrate their lives and share stories in remembrance.



Washington, DC

Terry Stone and Paul Brayshaw

There was a chill in the air. Well, let's get real...it was absolutely freezing! Despite the unexpected visit from ole Jack Frost whose frozen touch brought in the frigid temperature, friends and families of the Hemophilia Association of the Capital Area braved the elements and huddled with their teams to walk for bleeding disorders.



Team Harley Heroes huddling to stay warm at the DC Walk!

HACA's 4th Annual NHF Walk

Saturday, October 22nd was once again on the grounds of the National Mall at the foot of the Lincoln Memorial. Although the weather was frightful, the view was so delightful as the colors of fall circled around the reflecting pool and warmed the spirits of every walker!



Blood Brothers Matt and Ishaan having a ball on the mall!

There were approximately 100 walkers comprising more than 22 teams. There were even a few fur-baby walkers whose cute little faces and worthy sponsors helped raise more than \$65,000. "This walk is very important as it's our largest annual fundraiser, which helps HACA provide many diverse educational programming and networking events for our families," said Brenda Bordelon, Executive Director.

Team Harley Heroes, fueled by Matrix Health Group, joined the cast of beautiful bleeding buddies and all who

love us. Together we warmed up our engines, drove our teams forward, braking only for the arrival of an honor flight veteran crossing through to enter the "AH-MAZING" WWII Memorial. It was a thoughtful reminder that all types of history can be made through service, advocacy and support. Hats off to HACA for making history on sacred grounds for an amazing group of people whose history will fuel future triumphs!

New Jersey

Richard Vogel

Members of the community returned to Forno's of Spain, a Spanish/Portuguese restaurant in the Ironbound district of Newark where Matrix Health Group hosted an **Educational Dinner** Sunday, October 23rd.

Sponsored by Octapharma, 30 community members and caregivers attended, sharing a delicious dinner and a discussion on *Advocacy—Then and Now*. Instead of a formal presentation, we decided to make it a rap session. Our speaker/moderator for the round table discussion was Kayla Klein, mother of a young son with severe hemophilia A and member of our community since childhood. Her father, David Matyuf, had hemophilia and contracted HIV during the 1980's AIDS crisis. This community-wide tragedy made her passionate about advocating for the bleeding disorders community. Kayla's dedication to inspiring and empowering the lives of others within the community through educational talks and symposia was evident as a lively discussion, in which all participated, ensued.

We discussed advocacy for young and old. We talked about 504s and IEPs, and how even



though they weren't law until the 1970s with the passage of the Americans with Disabilities Act, the parents of us 'old geezers' went to the schools and explained hemophilia with school personnel, and asked for special arrangements. We talked about advocating for oneself with doctors, treatment centers, and educating local and federal legislators about hemophilia. As one attendee texted me after the event, "The afternoon was very informative, with lots of sharing." The diverse age group allowed everyone to see what hemophiliacs of all stages of life go through.



Ohio

Shelia Biljes

All Beading, No Bleeding was the theme of the night as Matrix co-sponsored with Shire's True Identity speaker, Rhea Hoston for a **Ladies' Night Out** on October 27th. Bonefish Grill in Westlake served an amazing dinner while the ladies used beads of all colors to design beautiful bracelets that showed their true



Allison and Rich Vogel sharing grins!

identity! Jewelry makers Kim and Shelby, relatives of a local chapter family, provided the expertise, but the creativity came from within. Rhea spoke on how her son inspired her through his



June, Maddie, Judy, Jan, Rhea, Kitty and Edna show off their creations!

difficult years of bleeds, and the ladies shared their own stories as well as they fashioned their masterpieces. The blustery October weather did not keep anyone away and we enjoyed our time together at this special event, which is sure to become a local community tradition.

Ohio

Shelia Biljes

Little ones were the stars at the Cleveland Clinic **Infusion Event** co-sponsored by Matrix Health Group October 29th. A yummy lunch was provided by TGI Friday's as the kids showed their artistic abilities on fall crafts. Matrix Health Group employees, Kelly Gonzales and Rania Salem, RN led



a demonstration on self-infusing. Those willing and brave enough then gave it a try. 8-year-old Maddie was able to get her grandmother's vein on her on first try, while her 3 year-old brother Carter learned to put a tourniquet on his mom. 5 year-old Tony succeeded in getting his mom's vein with just a little assistance. Way to go, kids!



Virginia

Terry Stone

Who said a Halloween fundraiser needs to be scary? There was cuteness overload at Robious Landing Park in Midlothian October 29th, as goblins, superheroes and princesses made their way to the starting line to run for a great cause. The annual **VHF Trick or Trot 5k Monster Dash**



Terry Stone catching up with Sabrina before the run.

benefitting the Virginia Hemophilia Foundation was a haunting success. More than 120 dedicated runners and costumed crusaders tall and small came out to run, walk, play games and catch up with old friends. What a wonderful way to kick off Halloween weekend. This event

continues to grow each year. VHF welcomed 30 additional runners than the year before and overall this benefit raised \$37,000 – an impressive \$8000 more than 2016, and there is nothing spooky about that!

Music filled the fresh morning air while coffee, donuts and bagels helped to fuel all the little goblins running the Monster Dash, as well as the dedicated runners preparing to hit the trail. Congratulations to VHF on another successful event where fundraising is so much fun!



Washington

Jeff Johnson

Members of the Bleeding Disorders Foundation of Washington (BDFW) gathered in Seattle October 29th for their largest annual fundraiser, the **Bloody**

Fun Run. It was a brisk, chilly, typical Seattle day, but that didn't dampen anyone's spirits as a few hundred walked the 5k loop around Green Lake. The walk was a huge success this year, with teams raising \$146,000 to benefit programs such as summer camp, teen programs, advocacy initiatives and other efforts by BDFW. Many thanks to all those who joined in the walk, sponsored walkers and sent donations from around the country!

Vermont

Cheryl Ashmore

More than 270 folks from six states gathered at the Burlington Hilton for the New England Hemophilia Association's (NEHA) **Fall Fest and Annual Meeting** October 29th - 30th. Under the leadership of Rich Pezzillo, NEHA's new Executive Director, the event was expanded to two days of programming. The chapter featured a *Resource Room* for consumers to access an array of information offered by national, regional and local non-profit organizations.

Saturday morning attendees participated in the keynote with dynamic speaker, Pat "Big Dog" Torrey from GutMonkey. His predominant message is to be brave and engage intentional challenges. A wide range of educational sessions followed throughout the remainder of the day. Dinner brought a Halloween costume party along with an informative presentation about gene therapy and clinical trials by Dr. Stacy Croteau. Everyone took a train ride that included a craft activity for the kids and a ghost walk through downtown Burlington.

Sunday brought a *Morning Reflections* session led by Hemophilia Alliance of Maine's Vice President, Victoria Kuhn. Afterward, more educational and rap sessions were offered. This event was a true testament to the commitment of the New England community, some of whom drove 7+ hours to spend time with blood brothers and sisters in a vibrantly colored venue!

Florida

Peggy Gay and Marcy Foertsch

The Hemophilia Foundation of Greater Florida (HFGF) held its **Orlando Creepy Crawl 5k and Fun Walk**

October 30th. The day started bright and early at Harbor Park, a lovely lakefront park in Orlando. 225 runners and walkers were encouraged to dress up for Halloween and many went all out! Winners received a pumpkin trophy and all received a beautiful medal for participating. Everyone visited the sponsor's booths and enjoyed snacks and drinks. HFGF successfully reached their goal of \$45,000 benefiting the bleeding disorders community.



(left to right) David, Randy, Frankie, Nick and Trent in costume. Frankie finished 1st and David 3rd in their respective age groups!

Ohio

Shelia Biljes

It's like coming home again! Each year, old friends gather and new ones made at Northern Ohio Hemophilia Foundation's **Annual Sponsorship and Family Fall Fest**. This year's

homecoming took place November 4th to 5th at the Hilton Doubletree Hotel in Independence. With over 200 in attendance, this year had an amazing number of new faces. This is a positive sign that the chapter is doing a great job! Friday began with a social hour, dinner and wrapped up with a movie and ice cream social. Saturday brought LA Kelley Communications', Laurie Kelley to present a *Pulse Program* with speakers Kelly Lynn Gonzales, Patrick James Lynch and Michelle Rice, which was followed by an exciting game of *Factor Feud*.



Rhonda and Crystal stop to pose with Shelia Biljes (center).



Michelle Rice, Laurie Kelley, Kelly Gonzalez and Patrick James Lynch.

California

Gaby Zamora

The Latino Hemophilia Foundation presented **Una Comunidad Unida en Celebracion** where 200+ attended to hear keynote speaker Dr. Vanessa Salinas, City of Hope Pediatric Hematology and Oncology cover the topic of new therapies for bleeding disorders. Held at Granada LA in Alhambra November 5th, this special event began with a wonderful breakfast, which included a Latino favorite, *Pan Dulce Mexicano*, a scrumptious sweet bread. Children gained knowledge as Shire's Amy Vega presented *My Factor, My Body for Kids* and participated by answering questions

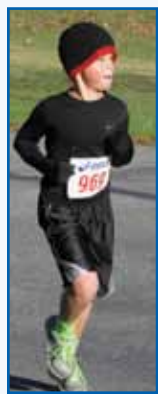


as the presentation took place. Geared to preparing teens on how to tell their personal story to Congress, Shire's Director of Advocacy, Rodney Dickson provided a work shop on *How to Craft Your Story*.



Matrix Health Group Care Coordinators, Gaby Zamora and Marina Vera.

During lunch, a Juan Gabriel look-alike lip-synched some of the late singer's greatest hits, while the crowd sang along. Folklorico dancers, with their beautiful costumes and colorful makeup, presented a regaling performance! Following lunch, kids were off to watch movies while adults listened to Michelle Torres of Las Vegas as she shared her experience with von Willebrand and her struggles as a young girl. Salsa dance lessons wrapped up the event, leaving all with a smile.



Tennessee David Tignor

November 5th, a crisp, sunny morning, was just perfect for a nice run. The scenery was striking along the rolling hills of Jonesborough where the **9th Annual Race for Ian** took place. Michael and Sarah Bates founded and spearheads this 5k and 1-mile fundraiser benefitting people with bleeding disorders in Tennessee, on behalf of their son Ian. Made possible by the hard work of the Bates family, volunteers and

race coordinators, Jonesborough welcomes this major event and provides police on scene to insure the safety of all the runners. Though many of the participants are seasoned runners, everyone finished, and as each runner crossed the finish line they were greeted with cheers and applause!



Jerry and Mary Stop by the Matrix Health booth.

After run times were tallied, everyone headed to Trinity Baptist Church where Michael and Sarah expressed their deepest gratitude for everyone involved before announcing the race winners. Everyone watched a slide show of last year's race as well as images of Ian and his family. This is where the importance of this fundraiser sinks in as the images of Ian's swollen joints, bloody nose and infusions are shown.



But as we know, that's not all there is when living with a bleeding disorder. More photos were shown depicting Ian having fun, playing and being a typical boy.

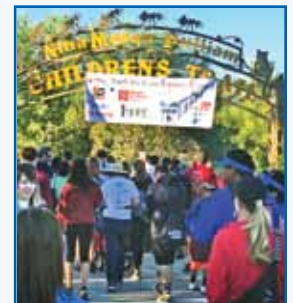
Every year, camaraderie between the bleeding disorders, running and local communities grows, raising more awareness for this worthy cause. This event is made yet more successful by its sponsors, and Matrix Health Group is delighted to continue supporting this commendable undertaking!

West Virginia Tina McMullen

The beautiful Stonewall Jackson Resort in Roanoke was the setting for the West Virginia Chapter of NHF's **Annual Meeting** held November 4th - 5th. The meeting kicked off Friday evening with an educational dinner *Exploring Emotional Wellbeing in the Hemophilia Community* presented by Pfizer. Families explored the exhibit hall on Saturday morning and then took advantage of sessions such as *Bleeding Disorders and Child Abuse Allegations*, presented by the Kanawha County Prosecuting Attorney's Office, an outline of the valuable services offered to families by Patient Services Incorporated (PSI), a *Healthcare Insurance Roundtable* held by Baxter, and a session on *Essential Oils and Bleeding Disorders*. Executive Director, Amber Tichnel and everyone involved in this year's event did a wonderful job!

Arizona Gaby Gonzalez

With over 300 patients and family members in attendance, the Arizona Hemophilia Association kicked off the 9th annual **Arizona Hemophilia Walk** at the Phoenix Zoo November 6th. Though the weather was a bit cool, everyone thoroughly enjoyed the day among community folks and animal exhibits. So much fun was had walking and visiting the exotic animals along



the path of this non-competitive, family friendly 5k, which raises awareness and funds to benefit programs, services, advocacy and education for members of the bleeding disorders community of Arizona.



Ready to Walk!

Illinois Eva Kraemer

Bleeding Disorders Alliance Illinois (BDAI) and Shire recognized "*Celebrando el Mes de la Hispanidad*" or **Celebrating Hispanic Heritage Month** as a tribute to Hispanic/Latinos throughout the United States. Along with dancers who delivered a marvelous display of traditional dances from all over Mexico, an educational program was also provided for the Latino bleeding disorder community November 6th at the National Museum of Mexican Art. Deep in the heart





Eva Kraemer (left) pauses for a photo with an Illinois family!

of Pilsen, a well known Mexican neighborhood in Chicago, around 100 community members listened to a presentation about self-advocacy both in Spanish and English. Pedro Angel from Angel's Restaurant

prepared a delectable meal of many different Mexican delights for all to relish as we reminisced about the culture and heritage being represented. Good conversation, food and festivities were enjoyed by all!

Ohio

Rania Salem and Shelia Biljes

The evening of November 9th, friends and families of Central Ohio Chapter of NHF gathered for the longest standing event of the chapter, **Der Dutchman Annual Dinner** in Plain City. It brings out people from all over Central Ohio to gather with old friends, meet new ones, get yearly updates of the chapter and share in the best Amish style all-you-can-eat family dinner. Families visited vendors and caught up on the latest and greatest news from both pharmaceutical and homecare companies. This popular event never disappoints!



Cuteness overload!

Ohio

Eric Lambing

The Tri-State Bleeding Disorder Foundation hosted their **Annual Ask-the-Doc** event November 9th at the Phoenix Event Center, a historic Cincinnati landmark. This year's event featured the introduction of Dr. Saulis Girnius, the next great hematologist at Cincinnati's Adult HTC. Dr. Girnius will follow and learn from a great mentor and colleague, Dr. Joseph Palascak. Dr. Girnius is an Assistant Professor of Medicine in the department of Hematology/Oncology and Bone Marrow Transplant at the University of Cincinnati. He comes with an extensive background in plasma cell dyscrasia, including multiple myeloma, AL amyloidosis, and light chain deposition disease. He graduated at our own University of Cincinnati College of Medicine, followed by his residency and fellowship training at Boston University. Well over 50 colleagues and patients welcomed Dr. Girnius with open arms and look forward to working with him!



Dr. Saulis Girnius

Louisiana

LeAnn Wilson

Hope for Hemophilia Foundation staff members shared achievements, goals and visions for the future at the first **Hope Annual Meeting** November 11th to 12th in Metairie. The well attended event opened Friday night with a meet-and-greet, live pianist and tasty hors d'oeuvres. After enjoying our fill of a Cajun dinner, a presentation followed focusing on siblings and how they are affected by bleeding disorders. Examples were shared on how parents can address various situations and help siblings with the struggles they may face.



Matrix Health Group Care Coordinators, Brad Nolan and LeAnn Wilson visit with Ezar (right).

The next day began with an educational session on healthy eating and the importance of daily exercise. Everyone then broke into groups to discuss a variety of topics and hear inspiring stories shared by patients who have been helped by Hope. In closing, Hope personnel discussed how their meetings are conducted, who can host them and how Hope groups have brought support to families and patients in several states. Hope for Hemophilia offers assistance to families throughout the U.S., most recently giving support to families in Louisiana affected by the recent flood. Congratulations to Hope for Hemophilia for hosting a very successful and informative inaugural meeting.

Pennsylvania

Tina McMullen

An exceptionally glorious day was the backdrop for the Eastern Pennsylvania Chapter's **Turkey Trot 5k Run/Walk** November 12th in Lancaster. Starting off a bit chilly, the sun was shining and warmth spreading by the time the race began. Before the walk, everyone had the opportunity to visit industry vendors under the exhibit tent. Led by mascot Kate Kiley adorned in her turkey costume, the 1/2 mile kid-run began with 20 children participating. Following the kiddos, 150 adult participants took their mark.



Tina McMullen hanging out with EPC's Turkey.

In addition to the Run/Walk, the day included face painting, a live deejay and refreshments. Awards were shared with the winners of various categories, but in this race, everyone was a winner! Participants did not go home empty handed – everyone received a medal for completing the race. Due to the hard work and dedication of Executive Director Curt Krouse and his staff, Fae Ehsan and Lindsay Frei, this year's run/walk was a huge success. Congratulations!

Florida

Hector Heer

Lago Mar Country Club in Ft. Lauderdale was the place to be to soak in some of that Florida sunshine! Hosted by the Florida Hemophilia Association (FHA) November 14th, **Swing for the Kids Golf Tournament** was sold out! The day started with registration, a quick lunch and a few practice swings before players teed off. When rounds wrapped up, everyone gathered for a delicious dinner and an energetic live auction. FHA's Executive Director, Debbi Adamkin presented awards to the tournament winners. A silent auction and raffle prizes followed, wrapping up the enjoyable day. Funds raised at this event benefit the important programs of FHA.



Hector Heer and Pro, Perry Parker.

Tennessee

Donna Garner and David Tignor

Interesting information was shared November 17th on how living with a bleeding disorder can influence how you might respond to emergencies such as a natural disaster, trauma or accident. At an **Educational Program** hosted by Shire and Matrix Health Group at The Butcher Shop in Cordova, April Morris, MSN, FNP gave a presentation on *Expecting the Unexpected: Emergencies Happen*, covering different types of emergency plans for unexpected urgent situations. A few items discussed were on the importance of creating an emergency folder or bag with pertinent information such as list of physicians, insurance cards, list of allergies and medications, Medic Alert identification, a letter describing the medical condition and treatment protocol from your local HTC or hematologist, which also lists the difference between a regular factor dose and an emergency dose.



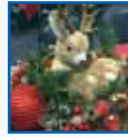
Big smile from Jason!

Of particular importance, April suggested including *Medical and Scientific Advisory Council (MASAC) emergency care guidelines with particular emphasis on MASAC 175 Guidelines for Emergency Department Management of Individuals with Hemophilia*. During and after the presentation, guests shared experiences that had helped them during emergency situations, lending more examples of how to best be prepared for emergencies. Handouts and brochures regarding emergencies and preparedness were available for all to take. Overall, the evening proved to be very informative.

Nevada

Kelly Gonzalez

Fall Education Day and Holiday Party was indeed filled with education! Over 275 people from our community traveled to Henderson to learn more about bleeding disorders November 19th. Children



went to day camp while adults rotated through breakout sessions including *Relationship Intimacy and Education for Empowerment: Your Key to Self-Advocacy*, and a general session with various announcements for the year.



These children were on Santa's "nice" list!

After the full day of education, families gathered for holiday fun! Dinner overlapped with crafts, photo booth fun and, of course, a visit from the jolly ole' Santa! While Santa handed out presents to the children, parents participated in a raffle and voted on centerpieces to select the best handmade piece! Fun and education combined is the very best way to spend a fall day. Thank you to all involved!

New York City

Richard Vogel

A sold out crowd took over the Manhattan Penthouse to admire the the New York city skyline November 19th for the New York City Hemophilia Chapter's **Gala and Education Day**. The goal was to raise funds in support of bleeding disorders with advocacy, travel grants and education for the NYC Chapter. The evening began with cocktails followed by a sit down dinner. Executive Director, Jeremy Griffin emceed the event and was very entertaining, making everyone comfortable, relaxed and giving the event a family vibe.



Community member Kea with Rich Vogel

Longtime advocate for women with bleeding disorders, Jeanette Cesta, was given the *Award of Distinction* and Julia Martin Alvarez was honored as the *2016 Susan Galligan Volunteer of the Year*. Guest speakers Patrick James Lynch and Christopher Ambrosio then inspired the crowd by sharing stories of their lives with a bleeding disorder. Despite the age differences, their stories were very similar. A raffle followed, which included sports memorabilia, sporting event tickets and restaurant dinners, and then the crowd danced the night away surrounded by Manhattan's beautiful views.

Morning began with an infusion party and breakfast at the Crowne Plaza in Times Square with plenty of time to visit with industry and specialty pharmacies before the educational workshops started. There was a topic for everyone, whether you were new to the bleeding disorders community or an old timer like myself. Attendees then selected break out sessions featuring pain management, sports injuries, bleeding disorder camps, identifying bleeds and more. A general session on *New Directions in Treatment* was led by 3 well known doctors in our community; Drs. Christopher Walsh, Catherine McGuinn and Suchitra Acharya. Break out sessions continued in the afternoon, featuring



workshops on financial aid, joint protection, factor and its purpose, and perspectives on vWD.

There was excitement in the air and you could feel the electricity in the room as the education day came to an end and the holiday celebration began with the arrival of Santa Claus and his elves! There were gifts for all children, breakdancers, and a fun photo booth to add to the festivities. This was another successful weekend for NYCHC and the 350+ guests. What a great way to start the holiday season and look forward to the New Year!

Arizona

Kelly Gonzalez and Gaby Zamora

Although 40 degrees at the start of the day, December 1st was beautiful, the company inspirational, and the cause worthy for the Arizona Hemophilia Association's **Annual Charity Golf Tournament**

at Ocotillo Golf Club in Chandler. After enjoying the beautiful course, 144 participants gathered for lunch, a silent auction, and to hear speakers from the community including professional golfer, Perry Parker, who spoke about persevering and never succumbing to the difficulties his bleeding disorder has presented. We are grateful for the opportunity to participate and support the community, and are especially pleased at NOT being the worst golfers, having come in at par!



Santa is everywhere!



Fancy Golf Outfits!

Louisiana

LeAnn Wilson

The Louisiana Hemophilia Foundation (LHF) held their **40th Annual Meeting & Educational Symposium** December 2nd-3rd at the Crowne Plaza Hotels & Resorts in Baton Rouge. Family and friends of LHF joined for a weekend of educational sessions, meet up with old friends and meet new ones. The night kicked off with a meet and greet for vendors and families. New faces and new stories were shared as the room filled with laughter and joy. Following a tasty Cajun style dinner, the foundation presented several awards notably the President Award, which was presented to the one and only Dr. Tami Singleton.



Kyle, Lauren, Delaina and Kylee visit with LeAnn Wilson

Pat Torrey from GutMonkey gave an incredible presentation, including a slide show depicting his passion for this community. Through his talk, he had the group participate in a fun exercise to further his point. Pat gave us a greater

understanding of what GutMonkey is really all about - finding the guts to do something that scares you and BE BRAVE!



Louisiana suffered devastation from the floods in 2016. With families scattered and even having to come together in one home, Louisiana has not lost their spirit and it was evident this weekend. This was a great event for everyone to learn and enjoy being with families that share common ground. We look forward to more events in 2017!

California

Cindy Picos

A great time was had by all at Central California Hemophilia Foundation's **Annual Holiday Event** December 3rd at the Gibbons Park Recreation Room in Carmichael. Over 250 people attended and families enjoyed visits and photos with Santa, craft making, cookie decorating and a Mexican cuisine including homemade tamales! Each child received a specially chosen gift presented by Santa. Thank you to Event Coordinator, Sean Hubbert, sponsors, and special appreciation for the countless volunteers who shopped, wrapped gifts and worked on event day.



Little Ashley shares her list.



Jacob savors his cookie!



Indiana

Enrique Morey

Hemophilia of Indiana was host to the H.O.I.I. **Annual Holiday Party** December 3rd at the Madison County Shrine Club in Anderson where families gathered for festivities and a holiday meal. All was for the children, who joined in crafts, games and a surprise cameo from Santa, with all kids parting the night with a gift. Definitely a joyful time for all and the perfect way to wrap up the year!

South Carolina

Peggy Gay and Brenda Montgomery King

193 guests representing 39 families gathered at the Embassy Suites in Columbia December 3rd for Hemophilia of South Carolina's (HSC) **Year-End Meeting and Holiday Event**. Along with appetizers and a dinner buffet, informational programs and time to visit festively decorated industry booths were available for all. Meanwhile, kids had many craft projects to keep them busy,



Peggy and Brenda in a holiday mood!

such as activity books and decorating holiday stockings. Younger children were very excited as they searched for *Jingles*, HSC's *Elf on the Shelf*. A traditional storybook time kept the children patient while anxiously awaiting Santa's arrival. And arrive he did in all his jolly red glory with gifts for everyone! This was a wonderfully joyous way to end the year with a look toward a fantastic 2017!

Washington

Jeff Johnson

An **Educational Discussion** hosted by the Bleeding Disorders Foundation of Washington (BDFW) at Bloodworks Northwest Hemophilia Treatment Center in Seattle took place December 3rd. The topic of the night was the Affordable Care Act, specifically in regards to the outcome of the Presidential election, and how those living with a bleeding disorder might be impacted. After an ACA overview, discussion turned to how BDFW plans to prepare for changes to the law, and what advocacy efforts will look like going forward.

The main takeaway was that, with all the uncertainty, BDFW and community leaders are already preparing strategies to address any issues that may present roadblocks to medical care for our Washington families. BDFW has a regular presence in the state capital, and if federal protections that currently benefit bleeding disorders patients fall, efforts will continue at the state level to overcome situations relating to pre-existing conditions, lifetime and annual caps, etc. As developments unfold, BDFW will continue to reach out to the community for input, help with advocacy efforts and more educational opportunities to better prepare families to deal with challenges. The most important message of the night was that our community will still stand strong together, and organizations like BDFW will rally in the effort to maintain the level of care that bleeding disorders patients require.

Maine

Justin Levesque and Cheryl Ashmore

Hemophilia Alliance of Maine (HAM) hosted their annual **Winterfest** at cozy Samoset Resort in Rockport December 2nd to 4th. The event serves as both an educational opportunity and as the area's holiday season celebration. This year HAM was excited to announce that bleeding disorder hero and cycling legend, Barry Haarde, would be delivering the keynote presentation. As expected, Barry did not disappoint, captivating the audience with tales of his life's journey.

The Samoset Resort is a small campus nestled within tall pines and sits right up against the quintessentially rocky



Maine coast, offering meditative views for the event participants. Best of all, you can absolutely forget about receiving a cell phone signal here. Surprisingly, not one teenager reacted in utter terror! They instead seized the moment to offer great leadership, participation and insight to those around them throughout the Winterfest weekend. Many of them even had an opportunity to enjoy the great outdoors as they bravely hiked the 4000 foot jetty to Rockland Harbor Breakwater Lighthouse in blustery winds. With cookie decorating, a visit from the North Pole, swimming and great food, Winterfest truly has it all and is a wonderful time for both family and friends. Until next year!

Ohio

Shelia Biljes

Northern Ohio Hemophilia Foundation packed the house at a **Holiday Event** co-sponsored by Matrix Health Group and CSL Behring December 4th as we teamed together to hold a **Self-Infusion, Facing Your Fear** event at the Cleveland Aquarium. When we toured the venue during the planning, we were informed we would be permitted to have a diver in the shark tank. Well, who wouldn't come to see that?



Kingston hangs out with a *much* less scary shark!

Following a wonderful meal and several rounds of shark trivia, the group was escorted to the shark tank to watch as I dove into the home of six different species of sharks along with stingrays, eels and beautiful fish. My favorite part of the experience was placing my hand on the glass to touch the hands of my patients and children in the bleeding disorder community. The kids waved and blew me kisses, which took my mind off the big sharks circling my head. It proved to be an absolutely amazing, though somewhat terrifying, event! A shark feeding, and a tour of the filtration system and behind-the-scenes rooms followed the dive.



With over 170 in attendance, this was a wonderful way for northern Ohio families to kick off the holidays.

Nevada

Kelly Gonzalez

Despite freezing cold temperatures and a wintery blizzard, 55 people joined for the annual **Elko Family Day & Winter Celebration** at the Hilton Garden Inn in the small town of Elko November 7th. We were treated to amazing food, crafts to create, time to spend with other community members, and of course, a much anticipated visit from Santa himself! A special thanks to the HTC of Nevada and the NHF Nevada Chapter for their hard work in putting this merry time together!



Kelli NHF; Kelly FSN; Becki HTC Reno; Lisa HTC Reno, join Santa for a photo!

Nevada

Kelly Gonzalez

Over 100 members of the northern Nevada bleeding disorder community and their families enjoyed a cozy and fun-filled **Family Education and Holiday Event** December 8th at Kathleen Dunn Elementary School in Reno.



Kelli, Lisa, Becki, Richard, Kelly, Lizzy, and John took a break from volunteering to share with Santa!

The evening began with an educational piece on advocacy and educational rights, which was followed by an address by Kelli Walters, Executive Director of the NHF, Nevada Chapter. Families feasted on Italian cuisine, participated in arts and crafts, a raffle, and best of all, enjoyed a visit from a well-dressed Santa Claus! We are so thrilled to be invited to participate in this event year after year!

Idaho

Gaby Zamora

Wohooz Family Fun Zone in Meridian was the meeting place for over 80 members of the Idaho Chapter of NHF for its **Annual Family Conference**. The snowy weather the evening of December 9th did not deter families from attending this highly anticipated event. Guests had the opportunity to visit industry booths and learn about the latest products and services from manufacturers and homecare companies. After enjoying a satisfying sit down dinner, adults listened to an educational program on *Power of Empowerment* presented by Biogen while children were excitedly relishing the rides and games in the *Fun Zone*. Thank you to the Idaho Chapter for hosting this delightful event!



California

Gaby Griffin

Every year the holidays prove to be the time people find to come together. Hundreds gathered December 10th at the Southern California Hemophilia Foundation's **Snowflake Festival**, enjoying the Long Beach oceanfront view from the Maya Hotel and each other's company. Before having a delicious lunch, the children partook in various activities including cookie decorating. We met seasonal characters like Elsa and Olaf, but the big man in the bright red suit brought everyone holiday cheer!



Elsa helps Ruby decorate her holiday cookie.

Illinois

Eva Kraemer

While a fire burned brightly at the hearth, about 90 bleeding disorder community family and friends feasted on a generous buffet. The flames and the camaraderie warmed our hearts as we celebrated the Bleeding Disorder Alliance Illinois (BDAI) at the annual **Holiday Party** December 10th at the William Tell Holiday Inn, Countryside. Guests made merry while creating handmade ornaments and decorating cookies. Santa surprised children of all ages and sat for keepsake photos to be cherished for years to come. I was jubilant to have been able to spend time with families, sharing stories from the year gone by while looking forward to a very happy and healthy 2017!



Eva Kraemer, Shari, and brothers, Cory and Cortez take a moment to pose with Santa.

California

Heather Messerly and Gaby Griffin

A lovely afternoon at Hotel Irvine was the place to be for the **2nd Annual Hemophilia Alliance of Orange County Holiday Party**. With the sun shining brightly December 9th, games set up outside were enjoyed by kids, young and old. Inside, we were able to partake in craft making and were served a lovely dinner,



Gaby Griffin and community member, Laura share holiday laughter!



followed by tasty ice cream. The party wasn't over until a bearded man in a red suit made a special visit! A wonderful turnout of about 100 people from the Orange County and surrounding areas made this event even more special! ❄️



UPCOMING EVENTS

January 24-25, 2017 Texas

Lone Star Chapter of the NHF
713-686-6100
lonestarhemophilia.org
Austin Legislative Days
Hampton Inn and Texas State Capital;
Austin
Contact: Felix Garcia 915-740-6415
Habla Español

February 4, 2017 Maryland

Hemophilia Foundation of Maryland
410-661-2307, hfmonline.org
Annual Meeting and Educational Dinner
Four Seasons; Baltimore
Contact: Terry Stone 703-795-6269 or
Paul Brayshaw 202-271-4252

February 4, 2017 Ohio

TriState Bleeding Disorder Foundation
513-961-4366, tsbdf.com
Winter Education Program
Dave and Busters; Cincinnati
Contact: Rania Salem 513-470-5500

February 9, 2017 New Mexico

Sangre De Oro Chapter
505-341-9321, sangredeoro.org
Men's Night
Location TBA; Albuquerque
Contact: Felix Garcia 915-740-6415
Habla Español

February 10, 2017 Indiana

Hemophilia of Indiana
317-570-0039
hemophiliaindiana.org
Hearts for Hemophilia Gala
Union Station Grand Ballroom;
Indianapolis
Contact: Enrique Morey 317-999-7912

February 13, 2017 New Mexico

Sangre De Oro Chapter
505-341-9321,
sangredeoro.org
New Mexico State Days
The Roundhouse
New Mexico State Capital Building;
Santa Fe
Contact: Felix Garcia 915-740-6415
Habla Español

February 17-20, 2017 Maine/New England

Hemophilia Alliance of Maine
207-862-2434, mainehemophilia.org
New England Hemophilia Association
781-326-7645, newenglandhemophilia.org
Winter Family Camp 2017
Camp Mechuwana; Winthrop
Contact: Justin Levesque 207-651-9235

February 18, 2017 California

Central California Hemophilia Found.
916-448-0730, cchfsac.org
Surf and Turf Crab Feed
Elks Lodge; Sacramento
Contact: Cindy Picos 916-223-5970

February 18, 2017 Florida

Foundation Hope & Life USA
786-534-2900, fhflusa.org
Annual Walk; Zoo Miami
Contact: Hector Heer 954-940-1248
Habla español

February 24, 2017 Nevada

NHF Nevada Chapter
www.hfnv.org, 702-564-4368
Winter Wine Fest and Silent Auction
Tivoli Village; Las Vegas
Contact: Kelly Gonzalez 702-858-2524

February 25, 2017 California

Hemophilia Found. So. California
626-765-6656, hemosocal.org
Advocacy Forum
**SoCal EmPOWERment and 2nd
Annual Bloody Hot Salsa Challenge**
Pickwick Gardens; Burbank
Contact: Gaby Griffin 626-278-7143
Habla Español

February 25, 2017 Kentucky

Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
Vegasville Gala
Olmsted Building; Louisville
Contact: Rania Salem 513-470-5500

February 25, 2017 Pennsylvania

Eastern Pennsylvania Chapter - NHF
215-393-3611
hemophiliasupport.org
Bowling for Fun
Thunderbird Lanes; Philadelphia
Contact: Tina McMullen 805-233-5037

February 28, 2017 Maine

Hemophilia Alliance of Maine
207-862-2434, mainehemophilia.org
State Day, Capitol Building; Augusta
Contact: Cheryl Ashmore 207-479-0288

March TBD, 2017 Ohio

Northern Ohio Hemophilia Foundation
215-834-0051, www.nohf.org
NOHF Amish Quilting Party
Walnut Creek
Contact: Susan Moore 330-472-2289

March 4, 2017 Virginia

Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Winter Fundraiser Bowling for Bleeding Disorders Two Locations!
AMF Sunset Lanes; Richmond
AMF Sunset Lanes; Chesapeake
Contact: Terry Stone 703-791-6023 or
Paul Brayshaw 202-271-4252

**NATIONAL
EVENT!**



March 8-10, 2017 Washington, DC

National Hemophilia Foundation
800-424-2634, hemophilia.org
NHF Washington Days
Hyatt Regency on Capitol Hill; DC
Contact: Dave Burgeson 239-784-4565
or Paul Brayshaw 202-271-4252

March 18, 2017 Illinois

Bleeding Disorders Alliance Illinois
312-427-1495, hfi-il.org.org
Spring Gala-A Night at the Races
William Tell Holiday Inn; Countryside
Contact: Eva Kraemer 608-852-3777
Habla Español

March 18, 2017 California

Hemophilia Assoc. of San Diego County
HASDC Family Education Day
619-325-3579, hasdc.org; San Diego Zoo
Contact: Heather Messerly 619-787-0916

March 24-26, 2017 Nevada

HTC of Nevada, Becki Berkowitz
702-732-1956, http://pepprogram.org
Parents Empowering Parents En Español
Location TBA; Reno
Contact: Kelly Gonzalez 702-858-2524

We look forward to seeing you!

March 25, 2017 New England

New England Hemophilia Association
781-326-7645, newenglandhemophilia.org
Consumer Medical Symposium
Sheraton Portsmouth Harborside Hotel;
Portsmouth
Contact: Cheryl Ashmore 207-479-0288

March 25-26, 2017 Arizona

Arizona Hemophilia Association
602-955-3947, salsachallenge.com
My Nana's Best Tasting Salsa Challenge
Steele Indian School Park; Phoenix
Contact: Kelly Gonzalez 702-858-2525
or Gaby Zamora 925-234-2451
Habla Español



**NATIONAL
EVENT!**

March 31–April 2, 2017 Florida

The Coalition for Hemophilia B
917-582-9077, hemob@ix.netcom.com
11th Annual Symposium
Sawgrass Marriott Golf Resort & Spa;
Ponte Vedra Beach
Contact: Terry Stone 703-795-6269



**NATIONAL
EVENT!**

April 6-9, 2017 Rhode Island

Hemophilia Federation of America
800-230-9797, hemophiliafed.org
HFA Annual Symposium
RI Convention Center; Providence
Contact: Lisa Miller 630-698-8775 or Eric
Lambing 513-607-2033



April 21, 2017 Ohio

Northern Ohio Hemophilia Foundation
216-834-0051, nohf.org
NOHF Black and Blue Ball
Downtown Ritz-Carlton Ballroom;
Cleveland
Contact: Shelia Biljes 440-813-1626

April 21-23, 2017 Michigan

Hemophilia Foundation of Michigan
734-544-0015, hfmich.org
SpringFest
Ann Arbor Marriott Ypsilanti at Eagle
Crest; Ypsilanti
Contact: Shelia Biljes 440-813-1626

April 22, 2017 Missouri

Midwest Hemophilia Association
913-220-9687, midwesthemophilia.org
**Ozarks Pull for a Cure – A Sporting
Clay Event**
Ozark Shooters Sports Complex;
Walnut Shade
Contact: Dan Hicks 913-220-9687

April 22-23, 2017 Illinois

Bleeding Disorders Alliance Illinois
312-427-1495, www.hfi-il.org
Statewide Education & Fun Weekend
Naperville Marriott; Naperville
Contact: Eva Kraemer 608-852-3777
Habla Español

April 23, 2017 Virginia

Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Spring Fundraiser & Silent Auction
Branch Museum; Richmond
Contact: Terry Stone 703-791-6023 or
Paul Brayshaw 202-271-4252

April 30, 2017 New Jersey

Hemophilia Association of New Jersey
732-249-6000, hanj.org
HANJ Hemophilia Walk
Raritan Valley Community College;
Branchburg
Contact: Richard Vogel 732-991-7373

April 30, 2017 Texas

Texas Central Hemophilia Association
972-386-3865, texcen.org
Texcen Family Fun Night
Location TBA
Contact: Felix Garcia 915-740-6415
Habla Español

April 30, 2017 Virginia

Hemophilia Assoc. of the Capital Area
703-352-7641, hacacares.org
Annual Wine Tasting
Hunter House/Nottoway Park;
Vienna
Contact: Paul Brayshaw 202-271-4252
or Terry Stone 703-795-6269

Answers to puzzles on page 35

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

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

COMPRESSION = + + - +

INFUSION = + + -

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A BIOMATRIXSM Company



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We are a nationwide organization committed to providing outstanding services with a family feel. Matrix Health Group is helping individuals and families improve health and successfully manage life with a bleeding disorder.

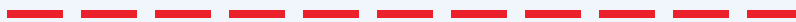
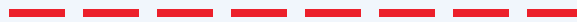
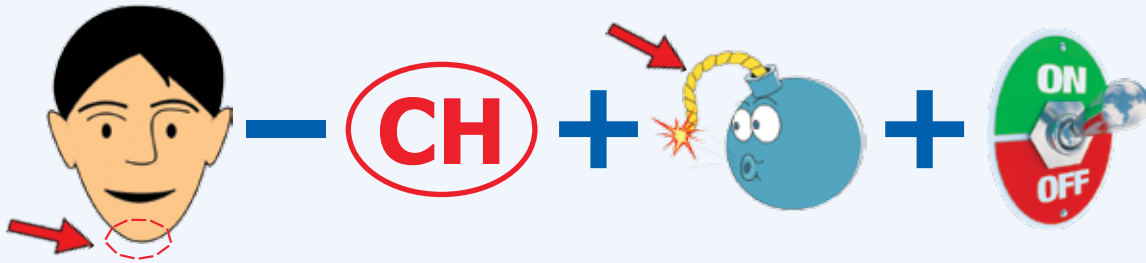
To learn more about our services, please call or visit our website:

**Toll free: 1-877-337-3002
www.matrixhealthgroup.com**

Hi Kids!

Time for Fun!

Can you decipher the picture puzzles below? Each answer relates to a common bleeding disorder word. Answers are on page 33.



	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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is free to patients and their families, health care professionals, bleeding disorder organizations and other interested parties.

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Dedicated to Making a Difference

by educating, empowering and enriching the lives of people living with a bleeding disorder.