

Matrix Health Group News

Fall, 2015

Volume 10
Issue 4

A quarterly publication

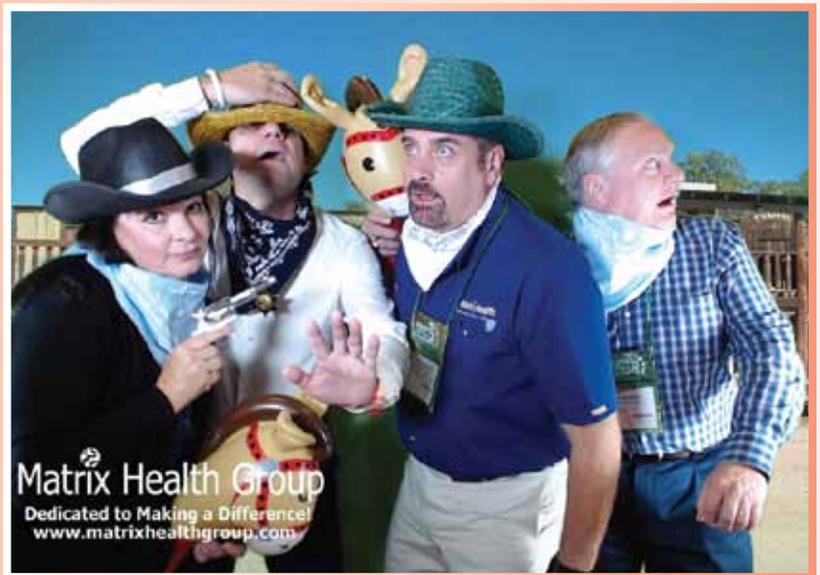
Together,
Making a Difference
by educating, empowering and
enriching the lives of individuals
and families living with hemophilia,
vWD and other bleeding disorders

Matrix Health

MEDEX BIO CARE

FACTOR_x
SUPPORT NETWORK

HOMECARE
FOR THE CURE



Matrix Health Group in Dallas!

*National Hemophilia Foundation's
67th Annual Meeting*

Matrix Health Group Representatives:
Maria Santucci Vetter, Hector Heer,
Stephen Lawrence and Dave Burgeson.
Story on page 5.

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.,
Suite 104
Weston, FL 33331
877-337-3002 Toll Free
954-385-7322 Office
954-385-7324 Office Fax
888-385-2805 Pharmacy Fax

 **MEDEX BIO CARE**

8024 Stage Hills Blvd.,
Suite 107
Bartlett, TN 38133
800-962-6339 Toll Free
901-380-5899 Office
901-382-3091 Office Fax
866-755-6339 Pharmacy Fax

 **FACTOR_x**
SUPPORT NETWORK

900 Avenida Acaso,
Suite A
Camarillo, CA 93012
877-376-4968 Toll Free
805-388-9336 Office
805-482-6324 Fax

 **HOMECARE
FOR THE
CURE**

P.O. Box 4169
24127 Rockview Drive
Crestline, CA
877-836-7832 Toll Free
909-338-3445 Office
909-338-5441 Fax

Matrix Health Group News

Fall 2015 - Volume 10, Issue 4

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.

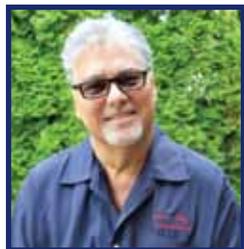
Dedication - Our dedication is evident in our close attention to detail, personal touch, and resolve to advocate from the heart, giving each relationship a close, family feel.

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



Our Condolences

Our sincere condolences to the family and many friends of Joe Caronna who passed away on September 11, 2015. In 2002, Joe founded *Inalex Communications*, a support organization that since inception has provided invaluable resources to members of the bleeding disorder community across the country. His innovative leadership, advocacy and dedication to this community has touched many lives. Joe will be greatly missed and fondly remembered.



A Note from the Editor . . . page 4

NHF 67th Annual Meeting a Great Success! . . . page 5

Living with a Bleeding Disorder: The Challenges . . . page 8

Rising Above . . . page 12



**FAMOHIO
Celebrating 23 Successful Years!** . . . page 14



PPTA . . . page 16

**Hemophilia Foundation
of Southern California** . . . page 17

THE HEALTH ADVOCATE . . . page 18



Matrix on the Move! . . . page 20

Upcoming Events . . . page 34

Time for FUN! . . . page 35



Like us on Facebook!



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!

www.facebook.com/pages/Matrix-Health-Group/140849859422348

A Note from the Editor

Dear Readers,

As summer gives way to fall, I often find myself in a contemplative mood. Even more than celebrating birthdays or New Years, there is something about the start of the school year that signifies another year has passed, and that my kids and I are all another year older. As a family, we have come a long way – from the early days of my boys being diagnosed, first bleeds and target joints to less hemophilia related events like college graduations, leaving home and first real jobs.

In this edition of Matrix Health News, we explore some of the emotions parents may feel raising a child with a bleeding disorder in an article written by a licensed Clinical Professional Counselor who also has a son with hemophilia. Remembering back to when my children were young, I distinctly recall experiencing many of the emotions brought up in this article. My youngest son had an imaginary “other mother” and I’ll never forget his description of her - she was blonde, super nice, let him eat lots of candy, didn’t make him pick up toys and never gave him shots. Apparently she was the opposite of me and as much as I found it funny, that last descriptive item made me feel heartbroken and guilty. Being a parent is already challenging – throw in a bleeding disorder and coping with the additional emotions can be daunting.

As the school years have passed one after the other, I have watched my youngest flourish. He weathers the difficult times with courage and humor, but lives his life fully; determined not to let his condition define him. Having hemophilia doesn’t seem to bother him a fraction as much it does me. He has come to terms with it much better than I have.

How has your family coped? How has your child “risen above” their diagnosis? Please consider sharing your story with our readers. Together our collective experience is what makes us stronger, builds our community and ultimately helps us cope. If you are interested in sharing your story please contact me at maria.vetter@matrixhealthgroup.com.

Sincerely,

Maria

Maria Santucci Vetter
Editor-in-Chief, Matrix Health News

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!

We offer:

- Experienced, compassionate Care Coordination Team with a personal contact assigned to each patient for pharmacy, reimbursement and support services
- Specialized, knowledgeable Pharmacy Staff with a comprehensive line of factor products and complementary supplies
- With pharmacies near Ft. Lauderdale, Florida, Memphis, Tennessee and Los Angeles, California, our services span across the nation
- 24-hour delivery with emergency same-day shipments available
- Interactive physician relationships providing patients with custom treatment plans
- Specialty team of highly trained Billing and Reimbursement Staff dedicating to assisting with private and government insurance reimbursement needs
- Informative quarterly newsletter, *Matrix Health Group News*



For more information regarding our services, please contact us at 877-337-3002.

We look forward to hearing from you!


National Hemophilia Foundation
67th Annual Meeting → a Great Success!


The National Hemophilia Foundation hosted their 67th Annual Meeting from August 13-15 in Dallas, Texas. 'Boots on the Ground' was this year's theme and members of the bleeding disorder community gathered from across the country to participate. The beautiful Gaylord Texan Resort and Convention Center was the venue for 3,000 attendees, more than 90 educational sessions, a larger than life exhibit hall with plenty of space to network, learn, and grow personally and as a community.

Whether attending as an individual or caregiver affected by a bleeding disorder, medical professional or chapter staff person, streamlined education sessions provided an array of relevant and useful information for all stakeholders with an interest in bettering the hemophilia community. Consumers were offered sessions ranging from *Hemophilia 101* to the latest research in gene therapy. First time attendees Erica and James have a two-year-old son with severe hemophilia B. Erica shared, "We learned so many new things from such well-educated individuals and families. I think the most valuable thing we learned is



having a good HTC and staff behind you makes a huge difference. We also enjoyed learning about the *My Life Our Future* program and hope many more join given the benefit for our son's future and the future of generations to come!"



Medical professionals enjoyed sessions addressing *Hot Topics in Hemostasis*, updates on hepatitis C treatments, novel technologies and therapy for individuals with inhibitors and much more. Charmaine Biega, Registered Nurse at Nationwide Children's Hospital Hemophilia Treatment Center in Columbus, Ohio notes, "The nursing sessions at NHF this year were excellent. They provided a lot of insight and discussion regarding ethics and health literacy. So much great information was shared!"

Chapter staff members attended sessions and roundtable discussions aimed at helping their organizations better serve the bleeding disorders



Kelly Gonzalez of Factor Support Network receives the *Chapter Recognition Volunteer Award*, honoring her contribution to the Nevada Chapter of NHF. We are proud of you!



Luke Vannicola of the Brandywine Valley Hemophilia Foundation receives the *2015 Baxalta Spark Award* recognizing young people with bleeding conditions who are creating a positive spark by engaging in service in their community, demonstrating a commitment to health, and being a role model to others in service, volunteerism, health and wellness and academics. Congratulations, Luke!



The Matrix Health Group Booth Team celebrates with Rhoda H. of Georgia, the winner of the Matrix raffle prize, an iPad Air!





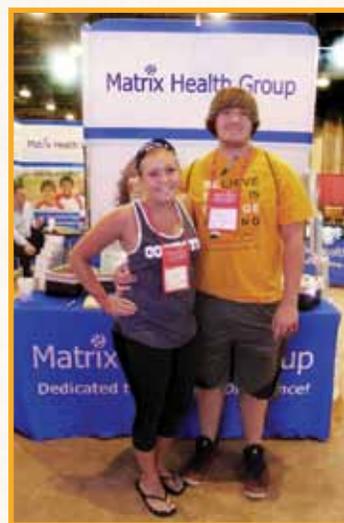
community. Ursela Kamala, Executive Director with the Kentucky Hemophilia Foundation shared, "Although I have been a Chapter ED

for twenty-one years, I continue to acquire helpful 'tricks of the trade' along with valuable tools and best practices for running a viable non-profit organization via the chapter track sessions."

In addition to the many formal educational sessions, there was also much information to be shared in the exhibit hall. From drug manufacturers to specialty pharmacies, non-profit organizations and market research companies, attendees had the opportunity to gather information from the front lines of the bleeding disorders industry. The Matrix Health

Group family of companies - Matrix Health, Medex Biocare, Factor Support Network and Homecare for the Cure - were well represented in the exhibit hall. Attendees learned about our commitment to the bleeding disorders community while also taking part in fun and memorable activities. Whether stopping for a fun photo in front of our southwestern themed "Green Screen," participating in our "Bounty Hunt" for a great prize, or signing up for our award winning newsletter, there was something for everyone at the Matrix Health Group booth. Thanks to all who stopped by!

No community gathering would be complete without honoring the hard work and effort of those who step up and lead, those who go above and beyond to make a lasting difference for the hemophilia community. From outstanding doctors, nurses, social workers and genetic counselors to tireless advocates, volunteers and youth leaders, the awards luncheon recognizes the exceptional individuals working hard on behalf of the community every day. We are pleased to share our own Kelly Gonzalez (Regional Care Coordinator,



Kali and Billy, siblings from Wisconsin stop for a visit!

Homecare for the Cure Represent!



Paul Brayshaw and Kelly Gonzalez hold up the Factor Support booth.



Factor Support Network), was the recipient of the *Chapter Recognition Volunteer Award*, honoring her contribution to the Nevada Chapter of the NHF. Congratulations Kelly! We would like to congratulate all of those honored during this year's award luncheon.

What would a meeting of the National Hemophilia Foundation be without fantastic networking, entertainment and social opportunities? After a long day of educational sessions attendees were welcome to socialize and enjoy camaraderie with fellow community members in a variety of ways. Whether an impromptu meeting in the hotel lobby, attending the *Afterglow Lounge*, or enjoying one of the many hotel amenities, bonds were formed and friendships made throughout the course of the meeting. There was even the opportunity to rub elbows with a celebrity! American Idol season six finalist Melinda Doolittle serenaded the crowd with her fantastic vocals and mingled with community members for the duration of the meeting. The Final Night Event saw attendees whisked away to experience a true taste of Texas at the *Circle*

R Ranch. Memories were made as participants enjoyed a variety of activities from line dancing, learning to lasso, armadillo racing and watching an authentic rodeo!



From the unforgettable venue, to the informative education sessions, bustling exhibit hall and invaluable networking and social opportunities, the National Hemophilia Foundation's 67th Annual Meeting had something for everyone. This symposium allows the bleeding disorders community the opportunity to come together, share like experiences and grow as a community. The importance of this cannot be overstated! Our thanks to the National Hemophilia Foundation for providing a fantastic means to do just that. See you next year in Orlando! ➔



Paul Brayshaw meets up with Curtis Reid Coleman.



Karl Score looking for Dorothy and the Lion.



GJ Walley takes aim.



Brad Nolan strikes up a conversation with Tony R. from Mississippi.

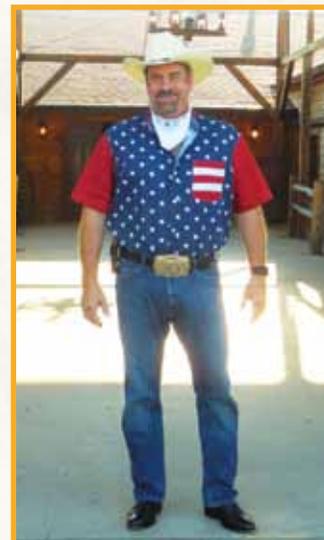


Green Screen Texas Style!





Melinda Doolittle and her backup dancers take center stage.



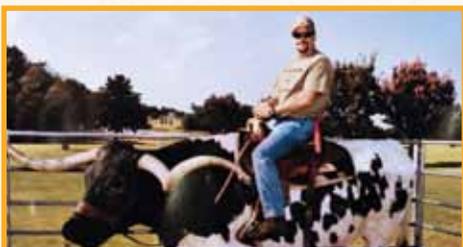
Stephen Lawrence looking more Tennessean than Texan.



The wheels on the bus... Kristine of Maryland and Eric Lambing on the way to the Circle R Ranch.



Final Night Dinner.



David Tignor going for a ride.



Maria Vetter and Tina McMullen find new friends.



From left, Biogen reps Sue and Christine, Brandywine Valley Hemophilia Foundation board members Jill and Gail, and chapter member Luke find a cowboy at the Circle R Ranch for NHF's Final Night Event.



Carlos, Angelica and Andriana enjoying the rodeo with Kelly Gonzalez.

Living with a Bleeding Disorder.

Living with a bleeding disorder can present various medical, financial, and emotional challenges. As a Licensed Clinical Professional Counselor, Certified Grief Counselor and mother of a child with severe hemophilia A, I see and experience the emotional impact of caring for a child with a bleeding disorder. I truly understand the challenges of this affliction from the perspective of the caretaker, the individual and the counselor. These roles present various challenges and interpretations on a daily basis. Bleeding disorders have several stages that elicit a variety of thoughts and feelings. Navigating through and learning how to cope with these thoughts and feelings, is essential.

When you have a child diagnosed with a bleeding disorder, you may feel like you have been hit by a tornado. I am sure you can

remember back to when you were initially informed your child had this condition. Were you totally blind-sided by the diagnosis? Did you know if you were a carrier or had a family history of this disorder? From the initial diagnosis that your child has a bleeding disorder and throughout the process of learning about the condition, not to mention the analysis, identification and remedy during each experience (whether it is a joint/muscle bleed, infusions, clinic appointments, blood draws, surgeries or emergency visits, etc.), most individuals and families experience the stages of grief and its wide range of emotions.

In addition to the stages of grief, bleeding disorders may present various challenges and emotions throughout life's cycles. During the initial sequence of learning about your child's diagnosis, you may experience shock or denial



The Challenges

that your child has this affliction. Through each phase you may experience emotions of feeling shocked, numb, angry, guilty or depressed. These are all normal human feelings that may be experienced and it is totally acceptable to feel this way. Sometimes we may feel anxious and question whether we are doing everything exactly the way we are supposed to. Does my child have a bleed? Do we infuse? Sometimes as parents we feel frustrated or sad when our child is experiencing a bleed or has to endure a medical procedure. Having to educate and re-educate medical professionals, school professionals and the community at large about a bleeding disorder can be a common time-consuming frustration.

When your child is in the toddler and preschool age, they may not understand why they have to get “poked” or have painful joint/muscle

bleeds. This may weigh heavily on the parents and they may experience feelings of guilt or sadness. We can't forget that our child/children may experience a range of emotions as well. Their body and mind experience is something other children do not have to be subject to. Your child may feel anxious with infusions and medical procedures. As they reach the school years, your child may be worried about what their peers will think about them and their bleeding disorder, and if they will be accepted as a “normal” kid. Some parents may have concerns about how the school will respond to their child, their disorder and the education they are providing them. Thinking about playing sports also presents various challenges. The possibility of not being able to participate in certain activities or sports may be a constant disappointment.



“With all of the challenges a bleeding disorder presents, it is important to learn ways to cope with the challenges.”

As the adolescent years approach, there are the normal challenges of the tween/teen years, which can be extremely challenging in and of itself in regards to hormonal changes, peer interactions, rebellious behavior and the need to fit in and not be different. Through these years and challenges, it is important to teach your children ways to cope with their emotions. Whether it is sadness, anxiety or anger, your child needs to feel listened to, validated and just like any other kid their age.

As parents, we tend to forget that our children are the same as any other child. We need to find a balance between normalcy and bleeding disorder safety. Our children need to live “normal” lives in order to strive and achieve their goals. Overall, living with a bleeding disorder or being the parent of a child with a bleeding disorder presents various hardships: it’s okay to have your moments of weakness. The most important thing to remember is to utilize your strengths to help you cope and move past the obstacles.

With all the demands a bleeding disorder presents, it is important to learn ways to cope with the challenges. First we need to identify what steps we take to help us get through each challenge.

The first step is to become knowledgeable about your child’s bleeding disorder:

- *Education is powerful and empowering:* The first step in coping with your child’s bleeding disorder is to become educated and learn as much information as possible.

The unknown can create fear, anxiety, sadness, loss of control and helplessness. Becoming educated can help you and your child feel more in control of the condition and enable you to advocate for your child.

Once educated about your child’s bleeding disorder, parents need to be able to:

- *Develop relationships with your child’s health care team:* Ask your child’s health care team as many questions about the chronic illness as you can. You are a parent, not a doctor; you still need time to become the expert of your child’s bleeding disorder. As your child develops additional questions will arise. By developing a relationship with professionals you will feel more comfortable asking questions about your child’s condition and you will also feel more at ease knowing you have someone you can call and count on.



- **Advocate for your child/children:**
As parents, you are your child's voice at the doctor's office, hospital, school and with family and friends. At the end of the day, you know your child best and you are in control of being an advocate for your child's best interest. Don't let anyone make you feel like you are a bad parent because you are standing up for your child.
- **Connect with others and attend support groups, workshops and events:**
Gaining support from others going through similar experiences can be liberating. At times you may feel alone and like no one understands what you are going through because they do not have a child with a bleeding disorder. By gaining the support of others and learning about their similar experiences, you realize you are not alone. Look into your local chapter for events and educational opportunities, check with local hospitals for support groups, or think about joining an online support group as a means of connecting with others.



- **Accept support from others:**
Bleeding disorders can have an emotional impact on the entire family. It may be difficult for you to be able to support your whole family while trying to learn how to cope with your own anxiety, sadness and grief. It is important to understand that you do not have to do this alone. Reach out to other family members, friends, and support groups for help. Asking for help does not mean you are weak, it shows how strong you are to be able to reach out and ask for guidance. Everyone needs to feel listened to and validated.

- **Self-care and attending to your own needs:**
It can be easy to forget about yourself when caring for a child, but it is important to realize you are human and you can only do so much. You need to take care of your own needs and take time to exercise, meditate, socialize with friends and family, or just do something you enjoy! Having a family member with a bleeding disorder can be exhausting and stressful; it's important to do activities (art, music, sports, journaling, exercising) to help relieve your stress. Learn how you and your family members can best cope with stress.

Living with a bleeding disorder can be an emotional roller coaster for parents, children and family members. You will be presented with obstacles that you may be unsure of how to overcome and you may experience a range of emotions that some people may never understand. At the end of the day, try to find a balance, learn how to cope with thoughts, emotions, challenging situations and most importantly, make time for self-care. 🌀



About the Author:

Jennifer Budruweit is a Licensed Clinical Professional Counselor, Certified Grief Counselor and the Owner/Clinical Director of Life Balance Counseling, Inc. in Schaumburg, Illinois. She specializes in working with children, adolescents, adults and families experiencing various mental health concerns, including; anxiety, depression, chronic illness, and grief and loss. Jennifer helps her clients identify the barriers that prevent them from leading fulfilling lives by providing them with support, guidance and helpful tools to help them learn ways to cope with thoughts, feelings and experiences in order to become the best version of themselves.





Rising Above

By Justin Lindhorst

Joshua Williams is definitely not scared of heights. In fact, the twenty-eight year old has been making himself quite comfortable in an environment many of us might not fare so well in. As a flight nurse who also has hemophilia, Josh has learned to save others while managing the personal challenges life with a bleeding disorder can present. His hard work and perseverance in overcoming these obstacles have literally allowed him to reach new and impressive heights.

Inspired by his hematologist, Doctor Ralph Gruppo at Cincinnati Children's Medical Center, Josh knew he wanted a career in the medical field and he began taking college level classes during his junior and senior years of high school. Though he was always interested in medicine Josh noted, "I knew I had to pursue a career that gave me great health insurance. I had to think of my future - as a person with hemophilia I knew I could not do manual labor for forty years and not expect to have damage to my joints."

Once out of nursing school, Josh thrived in the emergency room setting. Starting in a small rural hospital, he soon moved to a level 3 trauma facility, which sees 170 patients per day. He recalls, "It had everything I wanted, the fast pace, different people most of the time, and work shifts consisting of what I consider organized chaos. Though I loved it, from the start I knew I wanted to become a flight nurse."

Recently when the opportunity arose, Josh never looked back. After a very intense three week program, which included corporate training in Missouri, night vision goggle training, intensive patient simulator training and much more, Josh noted, "In just under three weeks I had what felt like years of school slammed into my brain." Though he's earned his initial set of wings, the intense training will continue for the next five months. This will be followed by a formal meeting with the medical director, who after six months will evaluate whether continued training is needed. Though intense, the training and hard work has paid off. Josh recalls, "My first flight was nerve wracking to say the least. We received a call that a patient needed to be transferred from an outlying hospital into the city. It was such a great feeling to transfer this person to a higher level of care."

On a daily basis Josh is working hard with his peers to save lives. At the same time, he has had to learn to successfully care for himself and his hemophilia in order to best serve others. Josh learned to strike a special balance between managing his bleeding disorder and meeting the demands of his job. "I stay as fit as I can as I've noticed the healthier and more physically active I am, the less bleeds I experience. I'm in the gym lifting four times a week, two of those days with a personal trainer. She understands my limitations with hemophilia and knows when to push, and when things need to be

modified.” Fortunately, Josh’s managers have also been very understanding when modifications to job duties have been necessary. Recalling one experience Josh shares, “My target joints are my shoulders. One day I experienced a dislocation and was unable to do any lifting. My managers put me in a role where I was not required to perform any heavy lifting. My fellow staff members have always been helpful when I need to infuse on the job. Given the flexibility in nursing, most of the time I can continue to work even while having a bleed, though I do all I can to avoid that from happening. In nearly six years, I have been fortunate to have missed only one shift because of my hemophilia.” This can certainly be attributed to Josh’s commitment to health and taking steps to manage his bleeding disorder to the best of his ability.

“I’ll never forget the skyline over Cincinnati as I returned from my first flight,” Josh reflects. “The sun was rising and it was as though I had never seen a sunrise before. When you’re 1500-2000 feet above the ground and lives are in your hands, everything changes. Thinking of the patient we transported, knowing I did something that really mattered is a feeling and a rush not soon forgotten.” As Josh and others in our community have demonstrated, having a bleeding disorder should never stop us from pursuing great and lofty heights. We must learn to manage our condition the best we can,



taking consideration of our limitations and making modifications when necessary. We must learn that in order to do good for others, we must first learn to care for ourselves. There are always circumstances beyond our control, but by managing what we can to the best of our ability, the sky is the limit. 🌀





FAMOHIO

Appreciating our Past, Building our Future

was the theme for the *Family Annual Meeting of Hemophiliacs in Ohio* held August 7-9 at the Columbus Marriott Northwest. Twenty-three years under their belt and FAMOHIO continues to deliver a fantastic meeting. In usual fashion, the Board of Directors and Planning Committee hosted a weekend to be remembered.

The educational tracks boasted a wide array of informative topics such as *Bleeding Disorders 101*, *Ask the Doc*, the latest advocacy updates, a session in Spanish and a fantastic plenary

led by Glenn Pierce, MD, PhD, who shared his experience as an individual with hemophilia who was inspired to lead an amazing career in medical research.

Youth programming kept the children and teenagers busy while providing information and tools to effectively participate in managing their bleeding disorder. The annual fitness walk encouraged everyone to get active while the *Women's Comfort Room* provided solace and relaxation. The latest and greatest industry

Matrix Health Group was honored to receive the "Dirk Scheerhorn Communications Award" for our newsletter this year at FAMOHIO. The award recognizes "individuals or organizations for communicating useful information to the Ohio bleeding disorders community." Thank you FAMOHIO for this great honor!



Celebrating 23 Successful Years!

By Justin Lindhorst and Rania Salem

updates were available in the exhibit hall and we were proud to represent Matrix Health Group.

Saturday night included a trip to the *Center of Science and Industry* (COSI), providing an opportunity for community members to enjoy each other's company in one of the premier *Centers of Science* in the country. Finally, Pat Torrey of *Gut Monkey* led an engaging Sunday morning session challenging participants to think outside the box in setting, meeting and surpassing personal and professional goals. The weekend did not fail to deliver fun, education

and empowerment for all who attended.

Community member Vanessa, regularly attends FAMOHIO and she sums up the impact of the organization by sharing, "As a child, FAM was a weekend where I was around other families like mine. As an adult, I now get to see my son be around kids who can relate to him and what he is going through. FAMOHIO is a wonderful weekend full of fun, education and lifelong friends."

Congratulations to FAMOHIO on another successful year. We look forward to 2016! ➡



Devoted FAMOHIO Planning Committee

Top Row: Krista Crossgrove, Secretary; Dwanna Rutter, Trustee; Jeanette Noll, Event Coordinator; Sandy Hibner, VP Planning; Marge Gaffin, Les Memorial Scholarship; Jodi Skinner, VP Community Outreach Coordinator & Fundraising; and Rick Sites, VP Legal

Bottom Row: Josh Crossgrove, Board President; Coy White, VP of Fundraising & Treasurer; and Teresa Rutter, Trustee

Not pictured: Kathleen Cadmus, Fundraising; Elizabeth Miller, Les Memorial Scholarship; Gloria Gutter, Les Memorial Scholarship; Charmaine Biega, Trustee; Linda Casto, Trustee; and Monica Snider, Trustee



One of the original FAMOHIO founders, Coy White, with Matrix Health Group Regional Care Coordinators, Rania Salem and Justin Lindhorst.

PPTA

Plasma Protein Therapeutics Association

By Julie Birkofer

Plasma protein therapies are unique, biologic medicines that are either infused or injected to treat a variety of rare, life-threatening, chronic and genetic diseases. Every day, people around the world living with hemophilia and other inherited bleeding disorders rely upon the lifesaving therapies produced by member companies of the Plasma Protein Therapeutics Association (PPTA).



PPTA and its members work tirelessly to ensure the quality and safety of these life-saving therapies. To do this, PPTA works globally to advocate on behalf of patients with these disorders. Additionally, PPTA collaborates with patient organizations in both the United States and Europe, through its stakeholder meetings, publications and advocacy events.

PPTA represents more than 500 human plasma collection centers in North America and Europe, as well as the manufacturers of life saving plasma protein therapies. Our members produce approximately 80 percent of the plasma protein therapies in the U.S. and 60 percent of those manufactured in Europe. PPTA also administers standards programs that help ensure



the quality and safety of plasma collection and manufacturing and protect both donors and patients.

Additionally, PPTA works globally to:

- Advocate for access to and affordability of therapies for patients
- Engage in constructive dialogue with regulatory agencies
- Collaborate with more than 20 patient advocacy organizations

Finally, there's the Patient Notification System, which is administered by PPTA. The Patient Notification System is a free, confidential 24-hour system that provides the latest information on plasma-derived and recombinant analog therapy in the event there is ever a withdrawal or recall.



Because it is funded entirely by the manufacturers of plasma-derived and recombinant analog therapies, there is no cost to sign up. If a therapy is withdrawn or recalled, the company involved immediately contacts Stericycle Inc., which then directly notifies patients and caregivers.

For more information about the lifesaving benefits of plasma protein therapies, visit www.PPTAglobal.org.

To sign up for the Patient Notification System, visit www.patientnotificationsystem.org.

The Author:

Julie Birkofer is PPTA's Senior Vice President, North America and Global Health Policy. Contact her at jbirkofer@pptaglobal.org.

Our Mission:

To improve the quality of life and build community for families and individuals living with hemophilia or other bleeding disorders by offering a variety of programs and services that educate, advocate and support the needs of the bleeding disorders community in Southern California.



The Hemophilia Foundation of Southern California (HFSC) has experienced a makeover! The office recently moved to Pasadena and is now accessible by public transportation, and offers meeting space and a family resource room. In addition, the staff is completely new - leading the helm is Michelle Kim, Esq., Executive Director. Also on staff is Program Director, Rosario Villavelazquez, who is fluent in Spanish, and Laura Desai, Operations Manager.

To keep our community up to date with all the chapter's happenings, HFSC now releases an email to notify its members of upcoming events. On our calendar, you will find the October 19th fundraiser, *Golf and Tennis Tournament* benefitting Camp Brothers and Sisters at the Painted Turtle; on October 24th, *College Bound!* a college essay writing seminar and financial aid presentation for families with students looking forward to college; and November 7th brings a *New Family Reception* where all community members are invited.

For more information, please contact the new HFSC at 626-765-6656 or by e-mail, info@hemosocal.org.

Hemophilia Foundation of Southern California
959 East Walnut Street, Ste. 114; Pasadena, CA 91106



Michelle Kim
Executive Director



Rosario Villavelazquez
Program Director



Laura Desai
Operations Manager

Board of Directors

President

Michael Franzen

Secretary

Sandy Davis

Board Member

Carol Jung

Medical Advisor

Doris Quon, MD (Non-voting)

Interim Treasurer

Richard Metz, MD

Board Member

Judy Mangione

Board Member

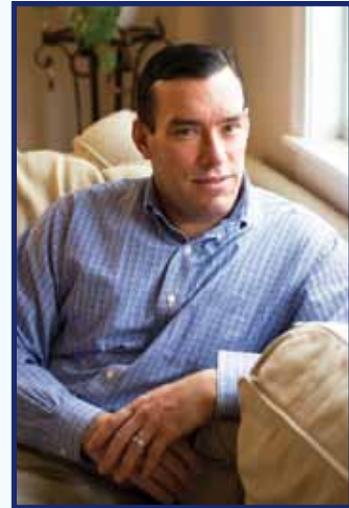
Kelvin Lee



Matrix Health Group

THE HEALTH ADVOCATE

RIGHT TO TRY



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

People with chronic conditions must depend on life sustaining medical therapies as a way of life. With plasma and recombinant clotting factor replacement therapies, people with bleeding disorders are able to rely on a plentitude of backup options if one therapy fails. Bleeding disorders are classified as a rare disease (defined as under 200,000 Americans). According to the National Institutes of Health, there are approximately 6800 rare diseases. For many people affected by a rare disorder, access to multiple effective therapy regimens is not typical. What happens when salvage therapies are ineffective, as in cases of inhibitors, a patient is intolerant to a medication or no therapy exists at all.

For patients who cannot be enrolled in a trial due to medical status or geographic barriers, a second option allowing expanded access to treatments is available by applying to the FDA under the compassionate care program.

To allow access to experimental drugs under state law, several state legislatures have introduced *Right to Try* bills seeking to allow patients to obtain experimental drugs without first obtaining federal approval. Twenty-five states now have *Right to Try* laws that aim

to reduce regulators' role in the decision on whether terminally ill patients get unapproved drugs, and bills in several more states are awaiting governors' signatures, according to the Goldwater Institute, which advocates for the legislation.

Opponents of *Right to Try* legislation note that providing experimental drugs to terminally ill patients may create a false sense of hope. There is concern that such bills attempt to undermine FDA's authority and medical expertise in the regulation of pharmaceutical products. They also say that patients may be exposed to the dangers of drugs with limited testing and that the best way to get drugs to patients is through widespread clinical testing — a process the *Right to Try* legislation may undermine. Other critics claim that these bills won't have an effect because they don't require the companies to provide the investigational medication to patients.

Supporters say "any hope is better than the alternative of no hope, which is inevitable when no treatments are made available for terminal patients. Patients should be free to exercise a basic freedom — attempting to preserve one's own life. The burdens imposed on a terminal patient who fights to



Tennessee

Donna Garner, David Tignor and Stephen Lawrence

Jim's Place Restaurant in Memphis was the location on Monday, May 18th where Baxter presented a **Facts First Program** led by Scott E. Miller, CPA, Esq. The topic of *Financial Planning* was a great enforcement of Matrix Health Group's dedication to go beyond just providing pharmaceutical care.

Often the immediate expenses of joint bleeds and health insurance override our thoughts of savings and establishing credit. Mr. Miller gave so many excellent points regarding financial health that it is difficult to list them all, but here are just a few that sparked the most discussions:



David Tignor with long time bloodbrother, Jimmie.

- How does a good credit score assist with good insurance?
- What is the difference of a *want* versus a *need*?
- How much should we have in our rainy day savings?
- When should you start saving for retirement?
- What are our short, medium and long-term goals and how do we plan for them? How do these categories differ from person to person?



If you have an opportunity to attend this insightful presentation for all ages that Baxter's Mark O'Brien and Lea Lanaman have made available, we encourage you to attend. You just might find the answer to one teenager's question of, "If you should never charge more than you can pay off at the end of the month, why should you use a credit card?"



Baxter's Mark O'Brien discusses the program with attendees.

Scott Miller's credentials are plentiful and include board member of Western Pennsylvania Chapter of the NHF, Dean of the School of Business at Edinboro University of Pennsylvania, Chair of the Department of Business and Economics, Professor of Accounting, and legal practice where he provides services in estate, tax, and complex business and corporate matters.

Ohio

Rania Salem

A fun filled weekend was in store for families of the Central Ohio Chapter of NHF at the **Annual Family Camp** at Camp Akita in Logan. It was time for some fun in the sun as families chose to participate in swimming, the Alpine Tower, giant swing, canoeing or a



lively scavenger hunt. A very valuable session was available for new parents and the younger set to learn to infuse. Plenty of time was also available to share life stories with new and old friends. Everyone seemed to really have a great time and look forward to this event again next year. Lastly, we can't go without mentioning the chapter's executive director, Amanda Turner and husband Blake, to whom we offer a huge congratulations on the arrival of their first child, a precious baby boy!

California

Heather Messerly

On Saturday May 30th, an **Industry Symposium** was hosted by the Hemophilia Association of San Diego. Each pharmaceutical company represented was given equal time to inform consumers about their products, what may soon be available in their pipelines and the services they offer to the bleeding disorders community. Speakers from Baxter, Bayer, Novo Nordisk, Octapharma, CSL Behring, Pfizer and Biogen were all in attendance. After the event, everyone walked to Petco Park to watch some baseball between the San Diego Padres and the Pittsburg Pirates. This is an amazing chapter... providing education, family fun and good will to the San Diego community.



Pharmaceutical representative panel.

Kentucky

Rania Salem

Yes indeed, it was time again for the annual **Kentucky Zoo Day** for families and friends of the Kentucky Hemophilia Foundation! It was a perfect, sunny day



Group hug! Georgia, Landen and Logan with Rania Salem.

at the beautiful Louisville Zoo until the clouds rolled in, but the rain that ensued did not stop us from having a wonderful time! Picnic style lunch in the gazebo area, carnival games and up close and personal visits with our furry zoo friends were just part of the day's fun. Families then enjoy the rest of the afternoon

visiting the interesting animals and meandering the grounds of Kentucky's beautiful zoo. Many thanks to Ursela Kamala and her staff for a superb job making this year's Zoo Day memorable!

Nevada

GJ Walley

The third annual **Golf 4 The Kids** event was held in Las Vegas on June 1st. The event, which supports two charities, *Cure 4 The Kids Foundation* and *Nevada Chapter of the National Hemophilia Foundation*, was held at the Red Rock Country Club. Boasting a full attendance of 36 teams, golf participation and generous corporate sponsorship resulted in raising over \$72,000 for the two charities. Factor Support Network provided a hole sponsorship and two foursome golf spots. A beautiful day was enjoyed by all!



Jeff, Lance, Sid and Factor Support's GJ Walley.



Jason, Dick, Lynn and Frank.

Indiana

Eva Kraemer and Donna Garner

Matrix Health Group and Novo Nordisk had the privilege of providing a program to the local bleeding disorder community near the Illinois/Indiana border on June 5th at Gino's Steakhouse in Merrillville. Jim Munn, RN, MS, facilitated a round-the-dinner-table discussion about



Jim, Jen, Joi, Sue, Debby, Pedro, Pedro Jr., Katie with Donna Garner.

Transition to Independence, which put everyone at ease, allowing for exactly the kind of spirited and frank conversations we tend to have over a meal, especially when talking about a young adult learning to manage his or her bleeding disorder. Families shared with one another, making the entire night even more meaningful. We could not have been happier to be a part of such a great group of families.

South Carolina

Peggy Gay

The **42nd Annual Statewide Meeting and HELLO Conference Education Day Helping Embrace Life's Learning Opportunities** was held by Hemophilia of South Carolina Chapter on June 5th-6th. At the Embassy Suites Greenville Golf and Conference Center in Greenville on Friday evening, families gathered together for a warm welcome by Sue Martin, Executive Director and Lisa Bordelon, President of the Chapter. During the buffet dinner that followed, special awards and scholarship winners were announced.



Hemophilia of South Carolina Lisa Bordelon with Felicia Alexander

Educational sessions began Saturday morning with topics such as *Managing Chaos*, *MVP Program with AMA Partnership*, *Communicating in the Workplace* and *Collaborating in Care NHF*. While lunch was served, community members had the opportunity to visit a variety of industry vendors in the exhibit hall. Afternoon sessions had many options to choose from: *Meditation for Anxiety and Stress*, *Pain Management*, *vWD 101*, *Education for Caregivers of Individuals with Hemophilia and Bleeding Disorders*, *Living Fit - A Joint Effort* and concluded with

round table discussions and more time to visit the exhibit hall. The sessions boasted wonderful speakers who presented helpful information on bleeding disorders issues. Wrapping up the event, a lovely dinner and sentimental good-byes were shared.

Massachusetts

Cheryl Ashmore and Brad Nolan

On Saturday, June 6th, we attended the New England Hemophilia Association's (NEHA) **Annual Walkathon** held at historic Prowse Farm in Canton, just south of Boston. The largest gathering of the bleeding disorders community in New England, this is a major fundraising event with over 600 participants and more than 30 teams walking to help raise funds and awareness of bleeding disorders. The event included multiple family-oriented events including a deejay, animal farm, face painting, walk team's t-shirt contest and a large barbeque meal at noon. Overall, a fun day benefitting the programs of a great chapter!



Tennessee

Stephen Lawrence and David Tignor

Relevant in many of Tennessee Hemophilia and Bleeding Disorder Foundation's (THBDF) programs, the theme for this year's **Annual Meeting** was *Together We Rock*. No matter how large or small the contribution, one might not realize how much effort is involved in planning, organizing and implementing such an event by the chapter staff, volunteers and financial supporters. It is truly a group effort! Most of the programs would not be successful if not for our community working together, and that is why *We Rock!*

As families arrived from near and far at the Hilton Memphis Hotel in Memphis, it was fulfilling to see and hear the joyous greetings and affection people have for one another. For many, this is the one time of year to gather with others who share so much in common. Especially important for families that are new to our community, this is a perfect chance to network and get to know each other.



PJ and Stephanie with David Tignor

Along with socializing, the annual meeting is a great opportunity for enrichment and education. The weekend was filled with programs and sessions for all ages. Activities and childcare for little ones were provided so adults could attend programs and sessions with peace of mind. The meeting also included the *CEO Program (Career, Education and Opportunities)* specifically for individuals between the ages of 14-20. The purpose of the program is to help teenagers and young adults develop skills necessary in career planning and gaining financial independence. Sessions were also available to adult patients and parents covering topics such as summer bleeding disorder camp, development of hemophilia therapies, gene therapy research, and how to be a HERO (Hemophilia, Experiences, Results and Opportunities) to others in our community.

Between sessions and meals, community members had time to visit with the many industry representatives. Generous contributions from the exhibiting companies assist THBDF in funding this engaging and crowd-pleasing event. The Matrix Health Group team of Regional Care Coordinators was on hand to offer information regarding the range of services provided by Matrix. Congratulations to THBDF for hosting another well-received and enjoyable event!

Wisconsin

Karl Score and Leslie Kaminski

Hosted at the Kalahari Resort in Wisconsin Dells, the annual **Bleeding Disorders Conference** was held by the Great Lakes Hemophilia Foundation of Wisconsin June 12-14. Over 300 people from the state's hemophilia community attended with a wish to be to be further educated by the experts on many hemophilia related subjects including: *Adolescence, Protective Gear for Sports, Distraction Techniques and Coping with Home Infusions, Platelet Disorders, Period Problems in Women: Non-Hormonal Fixes and Sports Snacks.*

Following the education sessions of the conference, all were set loose to play in the Kalahari Resort - a truly impressive place. It is said the Wisconsin



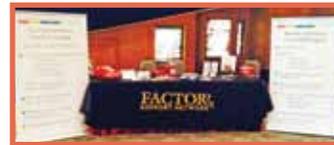
Bryce and Takoda visit the Homecare for the Cure booth.

winters are so cold that when you milk a cow, you get ice cream and so in search of fun, someone had the great idea to build the resort like an indoor city! The facility includes an indoor waterpark, pools, Jacuzzis, arcades, a ropes course, go-cart track, a bowling alley, restaurants and even a 12-screen movie theater. Fun was had by kids of all ages and was quite a treat for the conference attendees!

Nevada

Kelly Gonzalez

The Nevada Chapter of the National Hemophilia Foundation hosted its annual **Northern Nevada Family Education Weekend** event on June 13-14th at the Elko Convention Center in beautiful Elko. For families and caregivers whose loved ones have a bleeding disorder, the event was an opportunity to gain access to information, become empowered and have a little fun.



Adults from more than 20 families attended seminars led by guest speakers including Amber Federizo from the Nevada HTC who presented *How Not to Marry Your Mother*; Ian Corona from Biogen on *Cracking the Code*; financial analyst Danny Gillins from Raymond James Financial Services, Inc. on *Basics of Retirement Planning and Investing*; and Jeanette Cesta sponsored by Octapharma facilitated *To Tell or Not to Tell*, a discussion on disclosure of one's bleeding disorder. The children, supervised by adult volunteers and the N.H.F. Leaders in Training, participated in a fun-filled weekend which found them enjoying a water park and exciting carnival.

A BIG "thank you" goes out to the team at the NHF Nevada Chapter, the HTC and all the people who made this event possible!

Illinois

Eva Kraemer

Had one checked the weather we should have seen torrential downpours during the **Driving fore Hemophilia**, Bleeding Disorder Alliance Illinois' (BDAI) 18th Annual Golf Fundraiser on June 16th. Happily for the competitors in the foursomes, the clouds gave way to sunshine and spirited camaraderie at the Ruffled Feathers Golf Course in Lemont.

While fundraising for the Illinois bleeding disorder community, BDAI's Executive Director Bob Robinson, staff and volunteers ensured

a cheerful round of golf was had by all. Lady and gentleman golfers enjoyed plenty of challenges, contests, games, drinks and snacks along the way.



Fabulous Foursome!
Matt McGrath, Jim M., John S. and Jim M.

The picturesque day fueled everyone's good will for this necessary cause, benefiting children and adults with inherited bleeding disorders. Matrix Health Group sponsored an illustrious foursome and their addition only contributed to the success of the day.

Washington DC

Carri Nease

Navigated by Hemophilia Federation of America, patients and families came together in our Nation's Capital for HFA's **Patient Fly-In and 2nd Annual Congressional Reception** to speak with our Senators and Congressmen, asking for support of the Patient's Access to Treatment Act (PATA). We specifically covered the dire consequences of specialty tier drug programs and the current move of insurers shifting the burden of prescription drug costs to patients, often foregoing the traditional copay model and instead, demanding patients pay a percentage of the costs by way of a coinsurance, ranging anywhere from 20% to over 50%.

Also discussed with our legislators was the need to close a loophole allowing insurers to refuse 3rd party payment of insurance premiums (PSI, Kidney



Tyin and his mom Carri visiting the office of U.S. Senator Barbara Mikulski of Maryland.

Foundation, Cancer Foundations) when not from the specified groups listed in the ACA, (State and Federal Governments, The Ricky Ray Relief Fund). This loophole allowed insurers to refuse payments for health insurance premiums from charitable organizations and patient assistance programs, thus making the health insurance unaffordable for many families with chronic and life threatening diseases and disorders, causing defaults on premiums and lapses in coverage.

Meeting directly with lawmakers is a vital aspect in making sure the needs of the bleeding disorder community are heard and considered. We applaud the HFA and their ongoing efforts to identify and address key legislative issues for the bleeding disorder community. It was an honor to attend the event and I hope to do so again next year!

Ohio

Rania Salem

On June 19-21, family and friends of the Southwestern Ohio Hemophilia Foundation (SWOHF) gathered for the 22st anniversary **Family Fest Summer Fun Weekend**. After first checking into the Higher Ground Retreat Center in West Harrison, families headed to the main hall to meet with industry representatives. While adults discussed products and services, little ones took time for arts and crafts. Everyone then gathered for a delicious barbeque dinner, something we look forward to every year. This time together is precious – we meet with old friends and make new ones as the weekend festivities kick off. SOHF also holds its annual Bouncing for Bucks fundraising campaign. This is a hugely popular getaway for families in Dayton and surrounding areas. Thanks to Amy Berlean, Executive Director, and all those who work so hard to put together this great weekend event.



Virginia

Terry Stone and Paul Brayshaw

The Virginia Hemophilia Foundation (VHF) continues to break records as they welcomed more than 140 community members and industry friends to their **Statewide Annual Educational Meeting** over the weekend of June 19-20 in the tranquil southern city of Suffolk. Traditionally the meeting is a heartwarming reunion for VHF families, but this year welcomed even more families than usual. Some are new to the community, while others are members, but have not



been able to participate in the past. The turnout was an impressive showing which is a testament to the great outreach and planning VHF does to ensure members have every opportunity to join in and get active with the chapter. Prior to the event members had the opportunity to purchase chapter tee shirts that read, "Virginia is for Bleeders." This campaign has been a huge success; not only to raise awareness and funds for the chapter's initiatives, but also to show community pride! Many attendees wore their shirts during the meeting.



Held at the Hilton Garden Inn along a beautiful riverfront park, attendees who came in Friday evening were treated to a family dinner followed by time to enjoy

a waterfront stroll behind the hotel and listen to a live concert as part of the hotel's TGIF concert series.

Saturday morning began with a buffet breakfast and then moved swiftly to the events of the day. Industry sponsors were set up along the perimeters of the conference room and were ready to greet VHF members as they arrived.



Two cuties! Graham and Porter getting ready to have fun in the kid's program

The program began with a welcome from Executive Director Kelly Waters, followed by chapter business duties and then straight in to the program. Novo Nordisk provided the opening speaker who presented *HERO: Strength in Numbers* program followed by news on the *Advanced Therapies for Bleeding Disorders and the Impact to Patients* sponsored by CSL Behring. Break-out sessions were immensely popular, which made it hard to choose from. Topics included a session for women and a discussion on *Work-Life Balance, a Dads in Action RAP Session* with guys who know what it's like to have a bleeding disorder in the family, and the last was an *Advocacy Behind the Scenes: Fair Co-Pay VA 2015* talk. The meeting wrapped up with an inspiring presentation sponsored by Pfizer that reminded us of the benefits when we *Step it Up* and be more active with hemophilia!

The VHF kids had plans all their own as they boarded buses and were transported to a day of fun and friendship at the YMCA Camp Arrowhead. Matrix Health Group/Factor Support Network were honored to be an industry sponsor for this event. Throughout

the day, we enjoyed visiting with fellow community members and sharing news on our many programs and services, and how we strive to *make a difference*. Congratulations to VHF for another wonderful event; we wish new president Murai West and her board continuing great success.

Ohio

Enrique Morey

On Saturday, June 27th, families and friends of the Tri-State Bleeding Disorders Foundation gathered for yet another fun filled **Family Education Day at Coney Island** in Cincinnati.

Everyone gathered for a picnic style lunch, met with vendors who service the bleeding disorders community, and spent time with old and new friends. Then it was time for some fun in the sun as families enjoyed the wave pool while others had fun on the rides of the park. A big thanks to Lisa Raterman, Executive Director, and Helen Lamping, Assistant Executive Director, who never fail to bring a great time!



California

Heather Messerly

Overlooking Downtown's Disney District, *Ralph Brennan's Jazz Kitchen* in Anaheim was the place to be on July 9th when Novo Nordisk and Factor Support Network joined forces to present a **HERO Educational Dinner**. This event was for teens and preteens with bleeding disorders, as well as their siblings and families. It was an evening to discuss what it is like to live with a bleeding disorder - not what to do when you have a bleed, but how a bleeding disorder may affect the entire family and everyday life. We discussed how it might affect school, sports, dating, social life, etc. Guest speaker, Jennifer Donkin, CNP from Children's Hospital



Jennifer Donkin, guest speaker with Heather Messerly.



Event hosts, Heather Messerly and Jack Ratelle, Hemophilia Community Specialist from Novo Nordisk.



Los Angeles, was interesting, lively and interactively involved the entire audience in the discussion. Everyone had a great time sharing an evening of learning, socializing and knowing you're not alone while enjoying a great meal together.

Illinois

Eva Kraemer

Who would have thought that diet could influence hemophilia? That is precisely what was discussed at Bleeding Disorder Alliance Illinois (BDIAI) and Emergent BioSolution's program, **Rebuilding the Body with Diet - Nutrition Framework for People with Hemophilia** on July 9th at Seasons 52 Restaurant in Schaumburg. The presenters interactively discussed how balancing vitamins, carbohydrates, fats and proteins all play a part in keeping the body healthy while providing it the ability to recover and rebuild after injury.

The concept of "super foods" was introduced as eating certain foods that may assist the body and mind to work to at optimal levels of functioning. Incorporating certain combinations of these super foods such as beans, dark green veggies, citrus fruit, sweet potatoes, avocados, berries, tomatoes, Omega 3 fatty acids from salmon, whole grains and nuts may be just the



Enjoying Seasons 52 together!
Cammie N., Gisele M.,
Eva Kraemer and Murali P.

ticket to optimizing one's health and overall well-being. The program was quite valuable and all those who participated gleaned some useful information as we decided, "Why wait until tomorrow to get started and see what positive outcomes we will have?"

Iowa

Erick Johnson, Jill Johnson and Karl Score

During July 10-11, Hemophilia of Iowa held their **Annual Education Weekend** at the Cedar Rapids Marriott in Cedar Rapids. Families affected by hemophilia from all over the state attended to take advantage of the educational opportunity. The event kicked off with dinner and an ice cream social. The next day, the available sessions were designed to help families navigate the maze of hemophilia issues. Many topics were covered such as *Hitting a Homerun at*

your Clinic Visit, Dads in Action: Dad is an Action Verb and Partnering with Your School. There was also an especially interesting timeline exhibit entitled *Historical Journey of Bleeding Disorders Over the Last 60 Years*, which was very well produced and contained many photos and little-known facts about bleeding disorders.



The event was well attended and on behalf of Homecare for the Cure, a Matrix Health Group Company, we were excited to help people learn more about research to cure hemophilia.

Florida

Juan Bruno de la Fuente

Florida Hemophilia Association (FHA) held its **32nd Annual Family Education Symposium** on July 16-19. Held at the Nuevo Hotel in beautiful West Palm Beach, this central location allowed a larger assembly. The weekend began with a vendor meet-and-greet cocktail reception and the exhibitors were available throughout the event to answer questions about their products and services.



The FHA symposium provided a number of topics important to the bleeding disorder community, including legislative updates, new treatments and gene therapies, to ways of coping with a bleeding disorder. The rap sessions proved to be most enlightening and informative. Highly regarded speakers included Joanna A. Davis, MD, Medical Director of the Pediatric

HTC, University of Miami; Robert F Sidonio, Jr., MD, MSc, Associate Professor of Pediatrics, Division of Hematology/Oncology and Associate Director of Hemostasis and Thrombosis at the Aflac Cancer and Blood Disorders Center of Atlanta/



Spiderman shows off his spidey skills.

Emory University; and Christopher E. Walsh, MD, PHD, Associate Professor and Director of the Hemophilia Program at the Icahn School of Medicine at Mount Sinai in New York. Each provided valuable information as to therapies and treatment regimens and allowed participation and questions from the audience



The last evening provided much enjoyment with the *Superhero for a Night* theme. Face painting and music welcomed everyone as many came dressed as their favorite superhero. The party provided a perfect opportunity for everyone to get to know each other better and share the many stories of our community.

With this wonderful event, FHA brought together our Florida community to discover the latest in bleeding disorder news and trends. Kudos to the Family Education Planning Committee - Debbi Adamkin, Executive Director, and her team, Chelsey Adamkin, Jeanette Cesta, Julie Cesta, Bobby Monahan, Valerie Mooney and Ed Moore.

Maryland

Paul Brayshaw and Terry Stone

The early morning silence of the Quiet Waters Park in Annapolis can give a peaceful solace to those who journey through its beautiful backdrop of lush tree-lines and winding paths. It is here as the sun rose to meet the day that more than 150 runners, walkers, and volunteers joined together to embrace the beauty and offer their support for the Hemophilia Foundation of Maryland's **Annual Race to Stop the Bleeding** Saturday, July 18th.

Growing in popularity, this family-friendly race has quickly become the chapter's largest and most critical fundraising event. Never short of volunteers, helpers were ready to offer a warm welcome as registration was completed and power fuel was grabbed at the snack table. Industry sponsors were on hand to show their support and to treat everyone to some useful give-a-ways for their coveted goodie bags.



After sneakers were tied and hair pulled back, it was time. Ready, set, GO! The trail filled quickly as walkers, runners, and joggers navigated their way through the park

following the path's winding turns, knowing that with every step they were doing their part to make a difference for the families of HFM! As the end of their journey neared, a refreshing wind carried the tantalizing scent of sizzling burgers on the grill while familiar sounds of laughter among old friends promised a welcome rest ahead with good food, great friends and another wonderful event. Many thanks to Emma Miller, Executive Director, Jamie Edwards, Chapter Administrator and their army of loyal volunteers, industry reps, community members and the folks that love them! Keep your sneakers close, next year's event will be here before you know it!



Illinois

Eva Kraemer

The Bleeding Disorders Alliance Illinois (BDAI) Annual Walk is just around the corner. To help kick off the event, Novo Nordisk and BDAI treated families to information and a fun-filled afternoon at Brookfield Zoo in Brookfield on July 19th. For many, the **Walk Kickoff** was a review as this will be the sixth year that BDAI hosts the Walk; but for others, team formation and fundraising ideas were discussed. The pavilion at the zoo was a great venue to inspire everyone. Team Matrix will be ready for September 12th!



BDAI Walkers! Murali, Sridevi M, Eva Kraemer, Sreeni and Hemalettha

Kentucky

Justin Lindhorst and Rania Salem

During the week of July 19-23, we added another knot in our "camp counselor" belt with one more successful year at the Kentucky Hemophilia Foundation's **Camp Discovery**, in Louisville. Ursela Kamala, Executive Director and Paula Bias, Camp Director, along with the Camp Committee provided an unforgettable year, balancing learning and fun for over 30 children affected by a bleeding disorder.



Long time camper Mason notes, "This past summer



at Camp Discovery was my 9th year. Through my time at camp, I've grown as an individual with a bleeding disorder and a leader in the community. I began as a young, shy camper who was terrified of needles. A few camps later, I was self-

infusing and in recent years, I've been progressing into the counselor role. I've had the amazing opportunity to educate others on managing their bleeding disorders. Of course, I can't forget to mention all the people I've met and the great times I've had at Camp Discovery!"

By combining traditional camp activities with engaging educational sessions, Camp Discovery provides Kentucky's youth a phenomenal opportunity to build friendships, make memories and acquire the skills to more effectively manage their condition. Testimonies like Mason's give proof to the positive outcomes of participating in hemophilia camp!

Ohio

Susan Moore

The **25th Annual NOHF Golf Outing** was held July 20th at the prestigious and challenging Shaker Heights Country Club in Shaker Heights where 125 golfers played in breezy, warm and sunny weather! This golf outing funds the Matteo Memorial Fund, honoring the lives of Ron and Tim Matteo. NOHF is one of the oldest chapters around, and they are delighted to let everyone know that all proceeds from the golf outing go directly back to the community in the form of camp and educational scholarships, Medic Alert memberships, emergency financial assistance and to support research.



Dawn Evans, Tanya Ricchi and Randy Clites

The 9th hole of the course was the most fun – players gambled on being able to make their ball reach the green from the tee. If the ball made it to the green they got their money back – if not, their gamble became a donation. Golfers were entertained by two dancers performing a happy dance when the ball made it to the green, and a big thumbs down when the ball landed elsewhere. A continental breakfast, boxed lunch

and scrumptious dinner was provided for the golfers, who raised nearly \$50,000! Following golf, awards and trophies for the high achievers were announced at dinner where participants could also bid on the live and silent auction items.

Congratulations to our wonderful staff at NOHF for yet another successful fundraiser!

Illinois

Eva Kraemer

The Bleeding Disorders Alliance (BDAI) and Baxalta went back to basics with **Hello Talk: My Factor: My Body**, presented by Suzi Greer at RAM Restaurant & Brewery in Chicago on July 21st. It's always a good idea to refresh

our memory, see what we know and what we've yet to learn as we participated in a discussion with an overview in hemophilia, treatment options and understanding how factor

works. We also learned how factor dosing and schedule is selected based on the type of factor deficiency, severity, location and extent of bleeding, patient clinical condition and patient age and weight. We enjoyed a lot of dialogue and were glad for this refresher. Thanks to BDAI and Baxalta!



Happy kids! Khalil, Kristian, Taryn and Xander visit with Eva Kraemer

Florida

Justin Lindhorst

The Florida Hemophilia Association hosted a phenomenal **Youth Leadership Retreat** July 30 to

August 1 in beautiful Key Largo. The weekend featured innovative programming designed to empower and inspire young adults to manage their condition and get involved with their community. With discussions on leadership, career planning, a lively debate on ethics and breakout sessions aimed at getting more youth involved, so much was covered over the course of the retreat. Even with a packed schedule there was still room for phenomenal team building fun "Florida Keys style" including stand-up paddle boarding, snorkeling, kayaking and even a catamaran ride!

During the final day, participants



were treated to the ultimate Florida Keys experience – a free-swim with dolphins. I was honored to volunteer with such a great group of future leaders in the bleeding disorders community. From the programming to the fantastic activities, the retreat provided memories, important life lessons and experiences not soon to be forgotten.

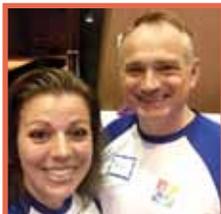
Nevada

Kelly Gonzalez, Terry Rice, Meredith Paige and Bonnie Culver

The Cure 4 The Kids Foundation, which benefits patients from the Nevada HTC and Nevada Children’s Specialty Center, hosted its annual **Bowl 4 The Kids** event on Saturday, August 1st at the Strike Zone Bowling Alley in busy Las Vegas. This event is designed to bring patients, parents, siblings and the philanthropic community together for both fun and fundraising. While more than 75 families and 450 people experienced the joy of bowling, face painting, creating balloon animals and build-a-bear, funds were raised to benefit patients.



Meredith Paige



Kelly Gonzalez and Terry Rice



Smiles all around! Jacey, Kelly Gonzalez, Stacey, Cage and Mason

The Matrix Health Group Family – Factor Support Network, Homecare for the Cure and Matrix Health – was proud to be a bronze sponsor for the families of Southern Nevada. We thank everyone for hosting such an important and beneficial event!

California

Gabriela Zamora

One of the largest events of the Hemophilia Foundation of Northern California, the 11th annual **Vines, Hops & Golf** was held August 9-10 at the beautiful Fairmont Sonoma Inn & Spa in Sonoma where we enjoyed the company of many wonderful people who support the foundation. On the evening of the 9th while savoring

a delicious dinner, everyone also experienced a wine and cheese pairing class. The silent auction held at the end of the evening proved to be a huge success.



The next morning brought 104 eager golfers to the greens of the Sonoma Golf Club for the tournament part of the event. Joining the golfers was talented golfer, 9 year-old Jaden D. Just recently, Jaden received an invitation from the Professional Golf Association in Chambers Bay, Washington to compete in a regional tournament. In an innovated way to fundraise for the chapter, Jaden was auctioned off to the highest bidder to golf with their foursome. He brought in \$1700!

The tournament greeted golfers with a bag full of goodies and a tasty boxed lunch. The event concluded with a wonderful dinner, silent auction and awards. Funds raised during the two-day event benefit the programs of HFNC. Special appreciation for all the community members and supporters who organized and carried out this memorable event!

Tennessee

Stephen Lawrence

Named in honor of 12 year-old Caleb Wood, **Pitchin’ for Caleb** has historically been a fun filled day of horseshoe pitching. This year however, those horses got to keep their shoes as they were replaced with corn hole boards and beanbags. Either way you do it, the competition is stiff and the atmosphere exciting!

As the heavenly aroma of smoked pork filled the air, participants stood in line to begin the day. Each entry fee included a delicious lunch of down-home Tennessee barbecue with all the fixin’s provided by grill masters Ronnie and Scotty Webb, and a t-shirt to commemorate the day.

Held at Centennial Park in Crossville, people traveled from near and far to join the festivities...one family



Horseshoe pitchin’ Caleb and Robin Lawrence

came all the way from Cape Cod, Massachusetts to join in the fun! The tournament supports the Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF). Since the first year of the annual competition, this event has raised more than \$65,000 for THBDF. The Wood family works tirelessly to raise community awareness

about bleeding disorders and about the importance of supporting the Tennessee chapter. Providing financial assistance to families and assisting kids attend summer camp are topics about which the Woods' are very passionate! A very special event by a very special family...this is a winning combination no matter how you pitch it!

Illinois

Eva Kraemer

The Bleeding Disorders Alliance Illinois (BDAI) and Novo Nordisk provided an **Educational Program** for the Spanish-speaking bleeding disorder community on August 20th at Seasons 52 Restaurant in downtown Chicago. Claudio Sandoval, MD, elaborated the genetic condition, with hemophilia found on the X chromosome, coming either from a father with hemophilia or a mother who is a carrier. When a child is first diagnosed, it's normal to feel the impact.



Eva Kraemer, Isabel and Agustin

Some tips to remember are: look for a therapist, support group or social worker, find other parents in the bleeding disorder community through the local chapter, ask for help and support from family members and friends, take care of yourself as a caregiver and share responsibilities with each family member. Having the presentation in Spanish, facilitated by a doctor is tremendously valuable and I appreciated the opportunity to be with the Spanish-speakers in the community.

Illinois

Eva Kraemer

The Board of Directors and Executive Director Bob Robinson hosted the 2015 Bleeding Disorders Alliance Illinois (BDAI) **Annual Meeting and Awards Dinner** on August 24th at the William Tell Holiday Inn in Countryside. This year's meeting was like no other as we welcomed Jeannie White Ginder, mother of widely known and inspirational, Ryan White. There was not a dry eye in the audience as she spoke of her son's journey with hemophilia and HIV and how he dedicated himself to HIV/AIDS outreach and education. We were truly inspired by her words and her son's contributions to the community.



Jeannie White Ginder



Looking fine! Eva Kraemer, Tom K. and Lisa Miller

Board President Ramona Towner gave a report on the state of the organization, touching on upcoming endeavors and announcing the 2015 recognition

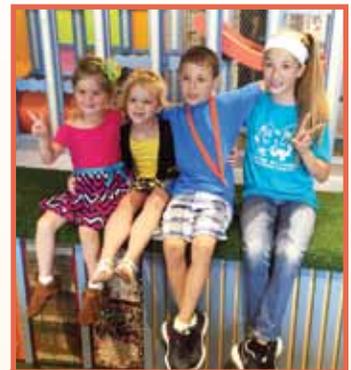
awards. Accolades were graciously accepted for the following contributions: The *Cibula Award* for Outstanding Volunteers was awarded to Tony Buccini; *Outstanding Healthcare Service Contribution* to John Urgo, RN at RUSH University Medical Center; and *Outstanding Support to Camp Warren Jyrch* to John Thorson. The family of Bradley Krueger presented the Bradley Krueger Scholarship to six recipients for 2015/2016 school year.

We will meet again at the 6th Annual Hemophilia Walk on September 12th at North Avenue Beach in Chicago.

Kentucky

Rania Salem

On August 29th, families and friends of the Kentucky Hemophilia Foundation gathered for their **Annual Meeting**, held at the beautiful Seelbach Hilton Hotel in the heart of downtown Louisville. The annual meeting is a half-day event bursting with education and full of interesting activities. Children were eagerly checked into groups for action-packed fun, while parents got to enjoy a day of learning and camaraderie together.



Kids having fun!

The day kicked off with a delicious breakfast while learning about genotyping with the program, *My Life, Our Future*. Two breakout sessions were then offered, *Bullying Online and Offline*, which covered sensitive issues surrounding bullying and how to understand and diffuse the situation, or *Mindful Eating*, highlighting skills to lose weight with peace, pleasure and purpose. It was an introduction to mind-body skills which patients and caregivers can use to improve their relationship to food, eating and their bodies.

Too soon it was time for everyone to come together for the Walk Kick-Off luncheon. This

rally recognized teams in the lead and encouraged others to step up their game in fundraising for the October 10th walk. The meeting continued with the election of new officers, recognizing past officers and getting an annual report of the chapter. When the meeting adjourned families headed over to the Kentucky Science Center to enjoy the rest of the day with other families. Thanks to the Kentucky Chapter for a day of excitement & learning!

Illinois

Eva Kraemer

A rainy start to the morning could not stop the 500 devoted participants from joining the 6th Annual Bleeding Disorder Alliance Illinois (BDAI) **Hemophilia Walk** in downtown Chicago on September 12th. BDAI hosted the Walk at North Avenue Beach for the third year running, winding through picturesque Lincoln Park Zoo. Matrix Health Group, a proud sponsor of this event, is pleased to be one of the top 10 fundraising teams for the sixth year, thanks to the dedication of Team Matrix led by our very own Lisa Miller.



Keepin' it Clottin' - Team Matrix!

BDAI is dedicated to improving the quality of life for persons affected by hemophilia and other inherited bleeding disorders through advocacy, consumer services, education, and research. This fundraising event allows everyone an opportunity to get together to support the Illinois bleeding disorder community. This brings so many of us in together, making this fundraiser successful on all levels.

Illinois

Eva Kraemer

Bullying Online & Offline: What Caregivers and Parents Need to Know

was presented by the Bleeding Disorders Alliance Illinois (BDAI) and Baxalta at Pompei in Chicago's Little Italy neighborhood on September 2nd. Adults and adolescents each had their own track. Bullying was defined as "any unwanted aggressive behavior that is repeated or has the potential to be repeated that causes harm." In the past, bullying was more one-on-one-at school or in the neighborhood; however, in age of the Internet and social media, cyberbullying has arisen, allowing bullying to include more people.



Eva Kraemer, Osvaldo, Marisol, Baldo (in front) Ubaldo and Aldo.

Discussion was generated around who bullies, who gets bullied, effects of bullying, how to tell if your child is being harassed and skills to responding to bullying. Helping a child overcome bullying can be accomplished by open communication between child and parent/caregiver. Peers are the first line of defense; encouraging friendships are important. Help your child to be assertive by keeping his or her head up and shoulders squared; this may require practice between child and parent/caregiver to develop confidence. There are many responses a parent/caregiver may have to a child's admission to being bullying whether on or offline, but one of the more important take-aways from the evening was "do not ignore and do not blame." This was a really important topic and I was so glad I was able to be a part of the discussion. 🍷

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

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

Answer to puzzles on page 35

Reference: <http://www.cdc.gov/motorvehichlesafety/bicycle/index.html>

- helmet
- important
- hemophilia
- bleeding
- million
- emergency
- injury
- avoid
- cool
- ride



Upcoming Events

Oct. 10, 2015 California

Hemophilia Assoc. of San Diego County
619-325-357, hasdc.org
HASDC Annual Walk
NTC Park; San Diego, CA
Contact: Heather Messerly
619-787-0916

Oct. 10, 2015 Idaho

Idaho Chapter of the National Hemophilia Foundation
208-344-4476, idahoblood.org
Annual Walk
Ann Morrison Park
Old Tymer Shelter
Boise, ID
Contact: Gaby Zamora
925-234 2451 Habla español

Oct. 10, 2015 Kentucky

Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
Kentucky NHF Annual Walk
Wetherby Park
Middletown, KY
Contact: Rania Salem 513-470-5500

Oct. 16-17, 2015 Ohio

Northern Ohio Hemophilia Foundation
216-834-0051, nohf.org
Annual Sponsorship & Family Fall Fest
Doubletree Hotel; Independence, OH
Contact: Rania Salem 513-470-5500 or Eric Lambing 513-607-2033

Oct. 17, 2015 North Carolina

Hemophilia of North Carolina
800-990-5557
hemophilia-nc.org
HNC NHF Walk
Lake Crabtree; Morrisville, NC
Contact: Brad Nolan 704-806-0970

Oct. 19, 2015 California

Hemophilia Foundation of Southern California
323-525-0440, hemosocal.org
Golf and Tennis Tournament Fundraiser
La Canada Country Club
Tarzana, CA
Contact: Marina Vera 323-252-8682

Oct. 23, 2015 Illinois

Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Autumn Wine Auction and Dinner
Columbia Yacht Club
Chicago, IL
Contact: Eva Kraemer
608-852-3777 Habla español

Oct. 24, 2015 Tennessee

Tennessee Hemophilia and Bleeding Disorder Foundation
888-703-3269, thbdf.org
Fall Festival
The Park at Harlinsdale Farm
Franklin, TN
Contact: Shannon Cassada
423-241-9356

Oct. 24, 2015 Washington DC

Hemophilia Assoc. of the Capital Area
703-352-7641, hacacares.org
Hemophilia Walk
National Mall; Washington DC
Contact: Paul Brayshaw 202-271-4252 or Terry Stone 703-795-6269

Oct. 30-Nov. 1, 2015 Maryland

Hemophilia Foundation of Maryland
410-661-2307
hfmonline.org
Family Weekend
Hyatt Chesapeake Bay
Cambridge, MD
Contact: Paul Brayshaw 202-271-4252 or Terry Stone 703-795-6269

October 31, 2015 Virginia

Virginia Hemophilia Foundation
804-740-8643
vahemophilia.org
Trick or Trot 5K Monster Dash
Robious Landing Park
Midlothian, VA
Contact: Terry Stone 703-795-6269

Nov. 3, 2015 Ohio

Central Ohio Chapter of NHF
614-985-3752
nhfcentralohio.org
Der Dutchman Annual Dinner
Der Dutchman Restaurant
Plain City, OH
Contact: Rania Salem 513-470-5500

Nov. 7, 2015 Idaho

Snake River Hemophilia Bleeding Disorders Association
208-351-4785
Annual Family Conference
Location TBD
Idaho Falls, ID
Contact: Gaby Zamora
925-234-2451 Habla español

Nov. 7, 2015 Tennessee

Tennessee Hemophilia and Bleeding Disorder Foundation
888-703-3269, thbdf.org
Race for Ian
Trinity Baptist Church
Jonesborough, TN
Contact: David Tignor 615-841-4133

Nov. 16, 2015 Florida

Florida Hemophilia Association
305-235-0717
floridahemophilia.org
Swing for the Kids
Lago Mar Country Club
Fort Lauderdale, FL
Contact: Hector Heer 954-940-1248
Habla español

Dec. 5, 2015 Louisiana

Louisiana Hemophilia Foundation
225-291-1675, lahemo.org
LHF Annual Meeting
Crown Plaza Hotel
Baton Rouge, LA
Contact: Brad Nolan 704-806-0970

Dec. 5, 2015 South Carolina

Hemophilia of South Carolina
864-350-9941
hemophiliaofsouthcarolina.net
Year-End Meeting & Holiday Celebration
Embassy Suites Hotel
Columbia, SC
Contact: Peggy Gay 864-275-0246

Dec. 12, 2015 Illinois

Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Holiday Party
William Tell Holiday Inn
Countryside, IL
Contact: Eva Kraemer
608-852-3777 Habla español

Time for FUN!

Hi Kids! Read the story below and see if you can fill in the correct words. Choose from the words in the Word Box. When you're finished, try the Sudoku puzzles. Answers are on page 33.



"Michael, I'm not going to say it again! Either put your _____ on your head or put your bike away," his mother called out.

WORD BOX
 important emergency
 avoid million
 bleeding injury
 cool helmet
 ride hemophilia

"My mom think it's so _____ to wear a helmet whenever I ride my bike or my scooter. Just because I have hemophilia, she thinks I'm going to get hurt," Michael complained to his friend Josh.

Josh answered, "I'm sure it's not because of your _____. My parents make me wear one too and I don't have a _____ disorder. My uncle is a doctor and he told me every year in the U. S., about half a _____ people go to hospital _____ rooms because of bike accidents. He said more than half of those accidents happen to kids our age."

"My mom told me that too. I guess my having hemophilia would make any _____ even worse."

"Yeah, and accidents happen all the time. Our parents know that and just want to help us _____ bad stuff from happening," Josh answered.

"I get it, but I don't think wearing helmets makes us look very _____," Michael said.

"Well, I think being safe is what makes us cool. Plus, if we don't wear them, we don't get to _____, and I want to ride!"

| | | | | | | |
|---|---|---|---|---|---|---|
| 2 | 8 | | | | 3 | 9 |
| | | 3 | | 9 | 1 | |
| | | 8 | 1 | | 7 | |
| | 2 | 9 | 6 | | | |
| 1 | 6 | | | | 8 | 2 |
| | | 9 | 2 | 6 | 5 | |
| 7 | | 3 | 6 | | | |
| | 1 | 7 | | 8 | | |
| 8 | | | 1 | | 7 | 3 |

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

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

Matrix Health Group News

a publication of
Matrix Health Group
Dedicated to Making a Difference!!



Sign Up

To Receive Our Newsletter!

Matrix Health Group News

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

Just complete this form and mail to:

Matrix Health Group
3300 Corporate Avenue
Suite 104
Weston, Florida 33331

Sign up on our website at:
www.matrixhealthgroup.com

or call us toll free:
877-337-3002

Sign Me Up To Receive Matrix Health Group News

Name: _____

Organization: _____

Address: _____

City: _____

State: _____ Zip Code: _____

Daytime Phone: _____

Evening Phone: _____

E-mail Address: _____

Matrix Health Group values your privacy. We are committed to keeping your private information secure and confidential. We take your privacy very seriously by complying fully with HIPAA regulations and employing a team of IT experts whose job is to keep our data safe and secure. Our mailing list is private and will never be sold or shared with a third party. If you have any questions or would like to review our Privacy Policy, please contact our corporate office.