Matrix Health Group News

Fall 2016

Volume 11
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 BIOCARE

FACTOR Rx
SUPPORT NETWORK

The Illinois Golf Dream Team!
Matt, Jim, Jim and John take to the links!
BDAI Annual Driving fore Hemophilia Golf Fundraiser
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Matrix Health Group

Dedicated to Making a Difference!

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Matrix Health Group News

Fall 2016 - Volume 11, 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.

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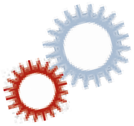


THE HEALTH ADVOCATE:

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.fb.com/matrixhealthgroup

A Note from the Editor

Dear Readers,

Welcome! The first issue of Matrix Health News appeared in July 2006. From that issue to this one, our 42nd, we have published over 300 articles (excluding short notes and letters) on a quarterly schedule.

We founded this publication with the goal of "educating, empowering and enriching the lives of individuals and families living with hemophilia, vWD and other bleeding disorders." We continue to provide our publication to all parties from patients and their families, to manufacturers, treatment centers, chapters, foundations and other organizations with an interest in bleeding disorders. Notably, we continue to do so with no outside advertising and at no costs to our readers.

We feel the sharing of bleeding disorder information and personal stories from those living with a bleeding disorder can benefit our community as a whole whether the reader is affected or in the role of supporting affected individuals and families.

Our work in producing *Matrix Health Group News* is a personal source of pride. With the completion of each issue, my small team of devoted editors and I wonder how we will fill the next. Yet, the variety of topics and suggestions from our readers proves to be endless. Please keep your comments, ideas and suggestions coming. We truly appreciate hearing from our community members!

We especially hope you continue to enjoy *Matrix Health Group News*!

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

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:
877-337-3002
by email:
info@matrixhealthgroup.com
or visit our website:
www.matrixhealthgroup.com

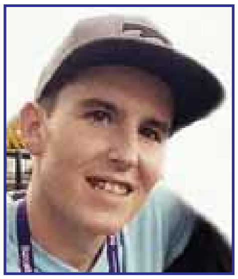
- Experienced, compassionate Care Coordination Team with a personal contact assigned to each patient for pharmacy, reimbursement and support services
- Professional Pharmacy Team with extensive knowledge of bleeding disorders available 24 hours a day, 7 days a week
- Pharmacies in Florida, Tennessee, California, New Jersey, and Illinois - our services span across the nation
- 24-hour standard delivery; emergency shipments as 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*

It is with tremendous sorrow we mourn the recent loss of several bleeding disorder community members. Each made their mark on the community in unique ways, and all will be deeply missed.

In Loving Memory

Raymond Winn *March 28, 1991—July 24, 2016*

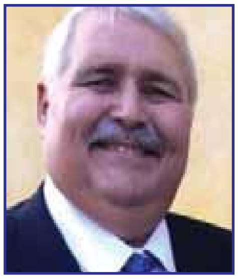
Ray was a young man with a huge heart. He had an adventurous and kind spirit, and greatly enjoyed spending time with friends and family, riding horses and enjoying the great outdoors. Two quotes often used by Ray were, "Cowboy up!" and "Live life to it's fullest." In June, Ray was in an accident that contributed to his untimely passing one month later. Ray is survived by loving parents Toby and Marilyn, five siblings and many friends and fellow community members who will miss him dearly. His father Toby shares, "Ray was always helping, giving or making people laugh. He placed others before himself. Ray's giving spirit lives on as many of his organs were donated. There are several families who will keep their loved one longer because of my son. I miss him immensely, but the fact that even now he continues to give makes me so proud to be Ray's dad. I must also thank everyone in the hemophilia community who helped our family during this difficult time. There are too many wonderful people and organizations to name, just know we are deeply grateful for the care and support we received."



Matthew Stinger *May 17, 1983—August 15, 2016*

We are saddened to hear of the passing of Matthew Stinger, a much loved member of the bleeding disorder community. Matthew passed away suddenly at the age of 33. The son of Susanne and the late Arthur Stinger, he was born in Abington, Pennsylvania. Matt held bachelor degrees in Psychology and Nursing from Seton Hall University and from 2006-2011, worked as a registered nurse in the pediatric emergency room at Children's Hospital of Philadelphia. Matt then worked as an RN/Hemophilia Resource Specialist for a specialty pharmacy serving the needs of patients within the bleeding disorders community. Matt was very involved with The Double H Ranch Camp both as a camp attendee and a counselor. Donations in Matthew's name may be sent to The Double H Ranch Camp, 97 Hidden Valley Road; Lake Luzerne, New York 12846.

Rest in Peace, Matthew. You will be greatly missed.



Ellis Sulser *October 6, 1961—July 29, 2016*

For those who did not know him personally, Ellis Sulser was a gentle giant, a teddy bear-like man who managed to defy medical odds throughout his life. With his passing, the world lost a global citizen and peaceful warrior. As someone who knew him as a friend, I lost a blood brother, mentor, a former employer and colleague, and partner in improving access to health care for people with bleeding disorders.

Ellis was involved in numerous, vital roles throughout his life and career. He helped organize and enroll a group of high school-aged advocates in the effort to introduce, enact and obtain funding for the Ricky Ray Relief Fund Act in the late 1990s. He was actively engaged in his church and deeply loved by his wife, Linda Leigh, and numerous springer spaniels. His friendships spanned the U.S. and the world as he relocated across the country, especially during his career as a co-founder and president of Factor Support Network. Following his retirement in 2013, he relocated to Virginia and later to Florida to be near family and friends, and closer to a daily fishing routine. While his health challenges persisted, Ellis always had a zest for life and tenderness that preceded any encounter. He was so very generous with his time and resources, and hospitable to all those he welcomed into his home. Ellis also craved fishing (and catching) and planned to spend more time in his newly built fishing boat.

The life and memory of Ellis will be a celebrated part of all those who knew him, and the examples of decency and dedication bestowed on those people whose lives he impacted. Rest in peace, Mr. Sulser!

~ Paul Brayshaw

Matrix Health Group

ANNOUNCES THE 2016 MEMORIAL SCHOLARSHIP RECIPIENTS!

Matrix Health Group offers nine $1,000 scholarships assisting individuals with bleeding disorders seeking higher education. These scholarships honor the memory of several people who touched the bleeding disorder community in unique ways. In addition to honoring the memory of these remarkable people, the scholarship program aligns with the value we place in *Enrichment*, one of our five Guiding Principles forming the backbone of our company value system.

It is with great pleasure we announce the recipients of our 2016 Memorial Scholarship Program! We received a record number of applications this year, and our independent scholarship committee reported the selection process was quite difficult. Thank you to everyone who applied and we wish you great success in your bright futures!

Congratulations to our 2016 Scholarship Recipients!

Stephen Lambert *Joe Holibaugh Memorial Scholarship*

Stephen is in his third year at George Mason University. Majoring in Government and International Politics, Global Affairs, and History, Stephen is also pursuing minor degrees in Conflict Resolution and Arabic. He has big plans for the future and aspires to work in either the government or nonprofit sector to create scalable safe water projects. Living with hemophilia, juggling three majors and two minors, Stephen still finds time to enjoy hobbies of swimming, diving, rafting, kayaking, rock climbing, volunteering and more! Congratulations Stephen!

Elizabeth VanSant *Joe Holibaugh Memorial Scholarship*

Elizabeth has a strong love for music. Living with severe hemophilia B, she used music as a way to cope with the challenges of life with a bleeding disorder. She recalls, “Whenever I was having trouble with learning how to infuse, I always turned to music to help ease my anxiety.” When she enrolled at the University of Kansas, she knew her degree had to involve music. Now in her third year of a Music Therapy program, Elizabeth is looking forward to applying the skills she has gained to help others realize the soothing, healing power of music. Congratulations Elizabeth!

Calvin Dutcher *Tim Kennedy Memorial Scholarship*

“My motivation to pursue a higher education comes from the love of learning in hopes of making an impact through service to organizations and communities,” Calvin explains. Currently attending Texas Christian University, Calvin is pursuing a Political Science major, with minors in Psychology of Leadership and Economics. Once he completes undergraduate studies, he plans on attending law school with a focus on health law. Having hemophilia has definitely influenced Calvin’s future career plans. He shares, “Healthcare law is important to me because of my hemophilia and the individuals that have helped me through my struggles and challenges. I would love to impact policy and represent the bleeding disorder community through legislation and execution of healthcare policies.” Congratulations Calvin!

Justin Horbacz *Tim Kennedy Memorial Scholarship*

Justin has a positive mindset and ambitious outlook that has served him well. He shares, "Dealing with painful bleeds, facing anxieties over port surgeries, and overcoming trepidation over learning to self-infuse all shaped the person I have become today. I do not view these as negative incidents in my life. These were challenges I was able to overcome that have made me stronger." Pursuing a Biology major at the University of Florida, Justin plans to study medicine and hopes to become a pediatric hematologist. Justin boasts a wide variety of hobbies, accomplishments and extracurricular activities. He recently raised over $10,000 for a hemophilia summer camp program. Congratulations Justin!

Cameron Dutcher *Mike Hylton Memorial Scholarship*

Cameron is a freshman at California State University. As an avid collegiate baseball player, Cameron is pursuing a degree in Business Administration – Sports Management and Marketing. Having hemophilia and actively pursuing athletics has been an obstacle but Cameron shares that it has also helped him in many ways. After college Cameron would like to become a player agent for professional athletes or a recruiting coach for college players. He would also like to remain involved in the bleeding disorders community encouraging others to "Stay physically strong to prevent injury and giving confidence that they too can do anything they set their mind to." Congratulations Cameron!

Zackary Swisher *Ron Neiderman Memorial Scholarship*

"I never wanted hemophilia to ever be, or become, the biggest controlling factor in my life. I always told myself that I wouldn't let it affect enjoying all different types of activities, but rather it only affected how I participated in them at most," Zackary Swisher shares. He continues, "Having severe hemophilia, I never really participated in many sports and instead focused more on doing well academically." Currently enrolled at Kettering University in Mechanical Engineering, Zackary hopes to apply what he learns as an engineer to his love for automobiles. Zackary explains, "All of my hobbies revolve around automobiles. I enjoy repairing, improving and learning new things about them." Congratulations Zackary!

Courtney Decker *Millie Gonzalez Memorial Scholarship*

With no family history, Courtney's diagnosis with type 1 vWD at the age of 10 was quite unexpected. Though Courtney was initially shocked, she recalls, "After walking out of the examination room, I realized my situation could be much worse. I saw other children sitting in wheelchairs around the waiting area with masks and no hair. Despite their grave illnesses, those children had smiles on their faces." This experience greatly influenced Courtney, and led her to pursue volunteer activities with children. With a list of awards, recognition and numerous volunteer activities, Courtney is beginning her collegiate career studying Business at the University of North Carolina. Congratulations Courtney!

Danica Topham *Millie Gonzalez Memorial Scholarship*

Danica is a sophomore studying Political Science at Brigham Young University. Danica has not been slowed by her vWD diagnosis. She boasts a 4.0 GPA and has received awards including the Yale Club of Nevada Outstanding Scholar Award, Young Womanhood Recognition and the United States Achievement Academy Yearbook for English. She is active in her local community and has consistently been described as "Smiley, positive and contagiously happy." Her positive demeanor is described well as she explains, "Everyone has had trials. Everyone has their stories. Everyone deserves to see a smile." Congratulations Danica!

Matthew Buske *Mark Coats Memorial Scholarship*

"Hemophilia has been a stepping stone more often than a stumbling block in my life," asserts Matthew. Matthew has learned how to manage the challenges having a bleeding disorder presents in order to meet and surpass his goals. An active basketball player, learning to prophylactically infuse himself granted Matthew the independence to make the varsity team in high school. Currently enrolled at the University of Missouri pursuing a degree in business with an emphasis in non-profit management, Matthew hopes to give back to the bleeding disorder community after graduation. Congratulations Matthew!

2016
NHF Recap

NHF's
68TH
ANNUAL MEETING
A BRIGHTER
FUTURE TOGETHER
JULY 21-23, 2016 • ORLANDO, FL

By Terry Stone

Hosting a national conference is a monumental feat. Although when it's your 68th meeting, the National Hemophilia Foundation knew just how to make it shine. Bleeding disorder community members received a warm (very warm) welcome at the venue for the 2016 annual meeting at the Gaylord Palms Hotel in sunny Orlando, Florida. The meeting was held July 21-23 and NHF did not need to wave a magic wand from Mr. Ollivander's shop in Diagon Alley to make it magical. They did, however, rely on a parade of whimsical and fun spirited staff to plan and execute one of the most richly diverse conferences to date. And as luck and great timing would have it, the World Federation of Hemophilia joined NHF, hosting their World Congress in a first ever back-to-back set of conferences. This allowed a unique opportunity to blend our worlds, meet new friends, and experience a worldwide sense of community.

It was the grandest reunion you've ever seen, hosted by the grandest hotel in the region, welcoming the grandest community members, at one of the grandest times in history for patients with bleeding disorders. The future is bright, and what better place to come together to learn and see what the future holds than the sunshine state of Florida. The news is bright so put on your coolest shades and read on to learn all about this year's national conference.

Keeping with tradition, NHF's CEO Val Bias extended a warm and heartfelt welcome to all. He reminded members of darker days only to deepen the understanding that from our challenges come solidarity and growth. Together we advocate for better treatments, compassionate understanding, and choice! He introduced several community superheroes that made their mark and helped foster awareness and sensitivity. They were brave at a time when they were dealing with so much. One of such was Louise Ray, whose son Ricky was the inspiration for the Ricky Ray Hemophilia Relief Fund Act that compensated families whose loved ones inadvertently infused tainted blood. Their brave voices made a difference. Jeanne White Ginder, mother of Ryan White who just tried so hard to live a normal life after contracting HIV/AIDS from contaminated factor. He put a face to the struggle and his legacy lives on as the Ryan White CARES Act serves thousands of people each year. Together, Ryan and his mother made a difference, and Jeanne continues to make a difference. Finally, our newest little superhero Max Levy, a.k.a. Iron Max, who made his NHF debut. Max gained national attention when Marvel turned him in to a comic superhero! What an amazing little hero at just the ripe old age of 5! He is the face of hemophilia today, and oh what an adorable face it is!

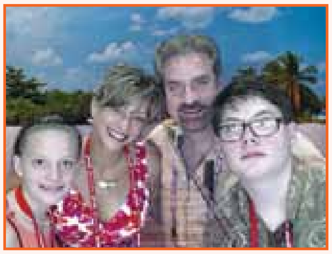
As Val explained, it's because of these reluctant heroes…. every day folks who were dealt a difficult diagnosis yet made a difference so that we now see the dawn of a new revolution of sorts. Innovative new drugs, genotyping to learn more which may fuel more personalized therapy and a better understanding deeper within the diagnosis, and new therapies that may offer treatment alternatives so different than what is available now. Times….they are changing! That means great news and a better future, or as the theme

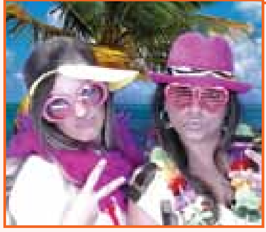
Booth Visitors Bring the Smiles!



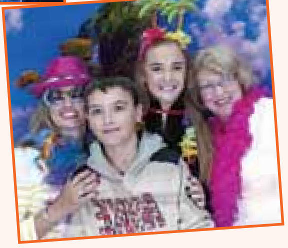

From Sunny Beaches...







To Underwater Shark Attacks!



Photo Booth Fun for Everyone!








of this year's conference suggests; "A Brighter Future Together!"

After a motivating opening session and interactive exhibit hall where families enjoyed being united, there were plenty of opportunities for branching off and exploring sessions designed for different groups. To kick off the conference, family receptions for Factor FVIII, Inhibitors, vWD, and Teens were great icebreakers for new families and seasoned veterans. Sometimes you just need to hang with your peeps, others just like you! Rap sessions were wildly popular. Whether you were the CEO of your family (women), too cool for school and want to rule the world (Teen Track), or an old timer with seasoned joints (Inner Geezer); there was a circle of friends for you to share with.

Winner of the iPad Raffle,
Shannon B. of North Carolina!

On the medical news front, advances in the treatment of Hepatitis C (HCV) for those affected were discussed in the chronic HCV update: *From Infection to Cure*. No longer must a patient endure 48 weeks of ribavirin/interferon or other therapies that were grueling to get through. New FDA approved once-daily pills can produce sustained viral response in about 24 weeks that is not difficult to manage. Good news didn't stop there as manufacturers introduced and educated patients on a variety of new products and longer lasting therapies during *Industry Symposiums*.

There was a variety of topics explored that touched on community hot topics and interests like *Hidden Bleeds-Understanding Microbleeds* - those bleeds you may not fully feel, but are important to be aware of; *Pain in the Bleeding Disorders Community: A Call to Action* to help form future recommendations for the medical community; vWD workshops to ensure this group within our community has equal time and attention to their specialized needs; and new initiatives to better diagnose and treat women bleeders. Yes, women bleed too!

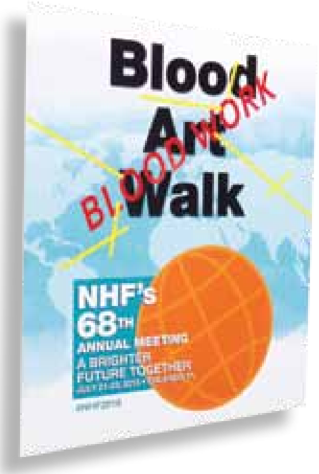
With so many medical updates, it's important to know that NHF also offered a very diverse selection of supportive topics to help with managing, living with, and caring for this journey we share. *Caregiver Fatigue, an exploration of Mind, Body, Meditation*, *Dad and Daughters*; making healthy choices, various sessions on advocacy, financial planning, music therapy, and the list goes on and on. All sessions were recorded and are available to order. Contact NHF for more information.

Winner of the Apple Watch Raffle,
Isaiah R. of Minnesotta!

As this community evolves, the importance of never forgetting where we came from and whose struggles and strength were the vehicles that carried us into our bright future; a special *Remembrance and Celebration of Life* was held Friday afternoon. Some came to honor the memory of a friend, family member or loved one. Others came simply to fellowship and share their gratitude for those brave advocates whose voices helped their affected loved ones to live well now. Never forget….NEVER forget!

It was a busy few days of trending topic education, product updates, medical news, networking gone crazy, and a wonderful celebration of past, present, and future. The final night was a block party like no other at Universal CityWalk. Sponsored by Biogen, special access was provided to experience a real life block party with great food and an uncontrollable desire to dance to the jams of Latin beats, Irish jigs and Jamaican vibes. It was a fitting celebration just as any family reunion would have! After a dancing dinner, all access to the park was granted. It was a real treat with many Harry Potter fans heading straight to Diagon Alley for a magical experience.

As the conference came to a close, it was clear that this community of savvy, educated, inspired blood brothers and sisters and all those who care for and about them will continue to share their journey, use their voice for the betterment of all, and lead not follow to ensure a brighter future together!

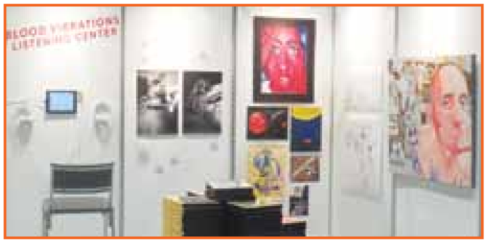


For the third year in a row, you may have seen or heard original artworks and music at National Hemophilia Foundation's Annual Meeting. This exhibition of creative individuals from the bleeding disorder community is named ***Blood Work*** and is a program of FOLX (http://folxfolx.org).

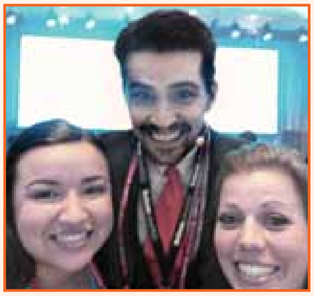
Every person who submitted to this year's Blood Work exhibition should be proud of their achievement and participation. For example, Kathy Seward MacKay's photography series, *Dying in Vein*, provided an acute reminder of the adversity our community faced in the 1980s with images that are both harrowing and tender. Other surprises this year included oversize reproductions of doodles and letters created by Ryan White. From the always impressively produced and hilarious work of Patrick James Lynch's *Stop The Bleeding* series to the swine-spired superhero character studies by Quinn Packard; it was a beautiful show!

FOLX aims to promote the inclusion, visibility and empowerment of people from diverse backgrounds within the bleeding disorders community. FOLX wishes to support additional versions of success from arts and music to activism and ingenuity. This recognition is important in remaining diligently inclusive of individualized approaches to living with a bleeding disorder.

We at Matrix Health Group were proud to sponsor the efforts of Justin Levesque and Philip Smith, founders of FOLX and the *Bloodwork* exhibit!



Thursday night closed with excitement as Jacey Gonzalez, daughter of our very own Kelly Gonzalez, Regional Care Coordinator - Nevada, received an *Impact Award* for advocacy in the bleeding disorder community! The Impact Awards, hosted by Patrick James Lynch and Believe LTD, and sponsored by Shire, celebrated success stories of youth from around the nation. Sixteen young adults who have made an "impact" were celebrated at this wonderful, comical celebration. We are so proud of Jacey and the other award winners for their hard work and efforts to advocate on behalf of our community!



WFH 2016
WORLD
CONGRESS
Orlando, USA · July 24-28

THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY

The XXXII International Congress of World Federation of Hemophilia (WFH) recently concluded in Orlando, Florida, with more than 6,000 attendees from over 125 countries. WFH 2016 World Congress followed the National Hemophilia Foundation's (NHF) 68th Annual Meeting, and was the first meeting in over 25 years in the United States.

Rania Salem, Jeff Johnson, Sean Hubbert and Paul Brayshaw attended this meeting on behalf of Matrix Health Group. "The opportunity to be in attendance to attend sessions and to engage with other stakeholders regarding care delivery and health outcomes, specifically the state of the art in nursing care, dental health, and community based approaches to self-care is so critical to be impactful in the lives of patients," said Paul Brayshaw.

According to the WFH Congress website, "Attendees of the WFH 2016 Congress include hematologists, pediatricians, orthopedic surgeons, physiatrists, physiotherapists, dentists, nurses, social workers, psychologists, geneticists, laboratory technicians, researchers, and scientists, who, together, represent the comprehensive care team for people with bleeding disorders. Presentations, workshops, symposia, and exhibits featured the latest trends in research and treatment for hemophilia and other inherited bleeding disorders."

To help coordinate planning for the meeting and to achieve the meeting objectives, the NHF and WFH sought a shared vision of *Treatment for All for over 50 years*. As part of this commitment, sessions were devoted to all aspects of patient care, in particular sessions on healthcare data, models of patient partnerships in healthcare, and dental care. The overarching theme of *Treatment for All* was greatly reinforced by the experience of meeting clinicians and community members from around the world.

For one attendee, Mr. Mukesh Garodia, an executive member of the Hemophilia Federation of India, the World Congress 2016, was his fourth. "It has become bigger and better each time with new innovations being presented in medical and psycho-social aspects along with youth sessions," said Mr. Garodia who represented his country in the General Assembly. Mr. Garodia joined other leaders from different parts of the world to establish policies and recommit to the needs of the national member organizations, the official representatives of WFH-member countries. "My greatest takeaway from the 2016 Congress was the Women's Booth, a project that I had the distinction of being a part of with women leaders from different countries. Hemophilia is still predominantly known as a 'male disorder' and the booth highlighted how bleeding disorders affect women and the difficulty these women face in a male-oriented medical field."

Shared experiences and insights from the meetings were a stark reminder of the benefits people with bleeding disorders enjoy while living in more developed countries. Whereas discussions among participants from the U.S. and other first-world countries often involved new developing therapies and trials, working within the system to tailor care to one's personal needs, and strategies for complimentary care. Discussions with attendees from less fortunate regions tended to center on topics such as how to care for joints after prolonged bleeding due to absence of factor, dealing with chronic pain without access to pharmaceutical therapies, and so on. According to WFH materials, "75 percent of people with bleeding disorders lack access to factor."

In the session, *Show me the Data! Challenges and Opportunities in Data Collection*, panelists described effective and efficient data collection throughout the world. "There is no one-size-fits-all approach in data collection…; quality data needs to be trustworthy, appropriate, understandable and powerful," said

Alfonso Lorio, MD, PhD, FRCP(C), Associate Professor, Department of Clinical Epidemiology and Biostatistics, McMaster University, Canada. With a small patient population and extraordinary individual costs, data will continue to play a critical role in health care delivery and reimbursement for people with bleeding disorders. "There is no perfect data, but there are sources for collecting the best data possible, including the WFH Annual Global Survey," said one panelist. The 2015 Annual Global Survey, which may provide an effective advocacy tool, will be released in October and can be viewed at www.wfh.org/GlobalSurvey.


Mr. Alain Weill, WFH President

The *Models of Patient Partnerships in Healthcare* session focused on successful partnerships between patients, families and healthcare professionals. With effective coordination and communication, the health outcome of the patient is optimized. Three core principles involving health sciences teaching, healthcare research and care provision help establish the foundation for patient partner relationships to achieve the greatest health outcome.

No matter where we live, hemophilia is a lifelong challenge for individuals and families affected by the disorder. Being an American with access to the U.S. healthcare system helps to enable patients the greatest opportunity to lead a normalized life in the land of liberty. "As a person with hemophilia who is accustomed to the consumer-focused atmosphere at our national events, it was almost overwhelming to shift over to the higher level presentation of bleeding disorder treatments and therapies being presented in the hall at World Congress," said Jeff Johnson. The more we can connect with others and encourage the communication across borders, the more we can make sure that expertise and current approaches to care get to those who need them most. The biggest goal is getting factor to everyone who needs it, but it doesn't stop there. We need to reach out however we are able and improve overall quality of care, and quality of life, in whatever way we can. The more we can encourage the free flow of ideas and sharing of information, the better we can look out for our fellow bleeders around the globe."

After attending her first World Congress, Rania Salem, RN, felt exceedingly fortunate, "My profound reaction following the meeting was one of feeling blessed - blessed to live in a time and place with the best care in the world, blessed to know the practices and procedures of the U.S. have led the path to optimal health outcomes. Blessed that my son with severe hemophilia is able to grow up with his disorder minimally impacting his life, thanks to the care rendered by treatment centers, physicians and unconstrained access to clotting factor. It's hard to imagine the burden of a bleeding disorder with the lack of care for those living in countries struggling with poverty, inaccessible roadways or necessities like clean water. We truly are blessed in our country; the fact is, our children with a bleeding disorder can live relatively ordinary lives."

Also attending her first World Congress, Sean Hubbert relates, "It was eye-opening in that I learned how fortunate we are to have access to care. I met a Pakistani family with 10 and 3 year-old children, both factor IX deficient. They have suffered massive joint damage, and the 10 year-old is not even able to walk – his parents have to carry him everywhere as they don't have access to a wheelchair."

To help improve access to medication and treatment the WFH Humanitarian Aid Program was created. Between 2016 and 2020, the program will seek to provide a dependable supply of 500 million units of factor to improve diagnosis, training and other interventions.

Other ways to help improve *Treatment for All* involve working with local clinics and non-profits in the U.S. to gather excess medications and ancillary supplies for donation. If you have switched products or for other reason have non-expired factor product on hand, please consider donating to an organization such as Project Share (www.kelleycom.com/projectshare/), whose mission is focused on, "Encouraging the hemophilia community in developed countries to donate unwanted factor to developing countries, with the following goals: Attracting underserved patients to treatment centers; supporting camps, surgeries and physical therapy; establishing independent hemophilia care; alleviating suffering and saving lives.

The WFH global meeting takes place every other year - the next meeting is planned for Glasgow, United Kingdom May 20-24, 2018. For those of us who had the opportunity to attend the 2016 meeting in Orlando, we are grateful for the experience, the information and especially the people we met. Together, we can *make a difference* and obtain treatment for all!

Making a Difference!

Curt Krouse

Executive Director,
Eastern Pennsylvania Chapter of the NHF

Curt Krouse, Executive Director of the Eastern Pennsylvania Chapter of the NHF (EPC), and his dedicated staff are working hard to provide top-notch support services to those individuals and families within the bleeding disorders community. Recently I had the pleasure of sitting down with Curt for an in-depth conversation. Getting together at the chapter's new office in Springfield, Pennsylvania, our conversation covered an array of interesting topics, thoughts and opinions. Read on to learn more about Curt Krouse, and how he and the Eastern Pennsylvania Chapter are making a difference in the bleeding disorder community!

Interview by Tina McMullen

T: What attracted you to the world of non-profit?

C: Having hemophilia gave me a natural interest in pursuing a position with a non-profit organization. In addition, I wanted to help keep the Eastern Pennsylvania Chapter active, vital and growing within the community.

T: How long have you been Executive Director of the EPC and can you give me a little background information on yourself?

C: I started with the chapter in January of 2014. My previous position was in college sports marketing. My family's involvement with the bleeding disorders community played an important part in my consideration of the executive director position.

T: What are some of your more interesting responsibilities?

C: I enjoy working with patients, hemophilia treatment centers and manufacturers. It is a priority of ours to connect with new people while maintaining the relationships we already have.

T: How large is your territory?

C: Our territory covers 41 of the 67 counties in Pennsylvania. It includes six hemophilia treatment centers, and we represent and serve approximately 2,000 bleeding disorders patients.

T: How does the chapter help patients and their families cope, adjust and otherwise live with their bleeding disorder?

C: There are a number of ways…by working closely with the HTCs, bringing families together for social interaction and education, and helping patients who need medical alerts and comfy caps. We also help in emergency financial situations. Additionally, we focus on advocacy efforts to ensure access to care for our members.

T: Since your arrival in early 2014, what changes has your presence brought to the chapter?

C: First, I looked at our mission and contemplated how to align our marketing and programming. We have patients spread out over a large area, but we were called the Delaware Valley Chapter. I changed the name to Eastern Pennsylvania and created a new plan to bring programs to families who are unable to travel to the Philadelphia area.

T: What are your goals for the future of the chapter?

C: We are now truly a chapter of outreach. Our goal is to help those in need and continue to connect with newly diagnosed families. Providing education and support can help alleviate many of the initials fears and concerns a family may have.

T: What do you feel are the biggest social issues facing people with bleeding disorders?

C: It depends on the age. Older people with bleeding disorders may have psychosocial issues having grown in an era of "bad blood." At any age though, it is tough to not always be able to do what you want to do. We all just want to be "normal." In my opinion, treatment of mental and emotional issues is often swept under the rug.

T: Does your chapter have any new ventures planned on the horizon?

C: From an educational standpoint, everything is changing. In addition to providing programs for men, we want to focus more on women with bleeding disorders and carriers. We are also forming a new teen group to educate and engage our young adults.

T: What kind of resources does the chapter provide for the community?

C: The chapter helps provide many resources from patient services programs, educational; scholarships, a men's group, and advocacy programs, just to name a few.

T: How do you feel you are "Making a Difference"?

C: We are encouraging our community to feel more empowered, and to have a greater say in what we are doing and the direction we are heading. We are also strengthening our relations with HTCs and industry partners.

T: What is your favorite part of the job?

C: My favorite part of the job is knowing I am helping to make sure the needs of our bleeding disorder community are being met. I also enjoy the relationship with our corporate partners and HTCs. Working together with our corporate partners and HTCs benefits the patients.

T: As executive director, what has been your biggest accomplishment?

C: I feel my biggest accomplishment has been charting a new course for the chapter and expanding our *County Captains*, which I believe is unique to the Eastern Pennsylvania Chapter. County Captains are volunteer representatives in place to champion our goal of growing a larger and more connected hemophilia and von Willebrand community. Captains are available to members as a resource to meet other families and develop new events in each area.

T: Where are you from originally?

C: Penn Valley, Pennsylvania. My incredible parents still live in the house where I grew up with my three loving, older brothers. I owe everything to them. Because of their love and care, I'm able to lead a normal life.

T: If you had to name an all-time favorite movie, what would it be and why?

C: My favorite movie is Rocky. It is the story of perseverance, strength and never giving up, much like the resilient people in our community.

T: What is your favorite spare time activity?

C: Being with my wife, Laurie, and our children, Carter and Ryan.

T: How has having hemophilia influenced your life?

C: As a youngster, I had bitterness and anger, but as I grew older, I learned to embrace it. Being part of such an amazing community has greatly influenced my life. I am truly blessed.

T: Your devotion and commitment to the bleeding disorder community is clearly evident, but where does that dedication come from?

C: My dedication comes from understanding and having empathy for the families dealing with all that comes with a bleeding disorder. My dad became involved with the chapter in the 1970s. Growing up and seeing how my parents helped families in this community was inspirational.

T: Is there anything else you want our readers do know about you?

C: I am proud and honored to serve our community as Executive Director. Having the opportunity to support and help people in the bleeding disorder community is a privilege that I treasure.

In closing, being a member of this community, I have personally seen firsthand how Curt and the Eastern Pennsylvania Chapter have assisted and supported our community. When dealing with all that comes from having a bleeding disorder, having a support system is crucial to experiencing positive health outcomes. Thank you, Curt Krouse and to the Eastern Pennsylvania Chapter staff for all you have done and continue to do in *Making a Difference* in our community. You are immensely appreciated and valued!

By Anne Cook, soon-to-be Dague

An Unexpected Future

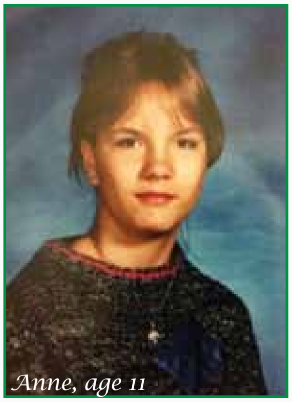
Hemophilia is something I never expected to touch my life in such a profound way. Sure I had heard about it, but never really understood exactly what it meant. "Oh, paper cuts are dangerous," was my mindset before I met my fiancée two years ago.

When I met Mike Dague, he told me he had hemophilia. Honestly, I was confused. When he told me he had HIV and hepatitis C, my only question was, "How long do you have left?"

Diagnosed at just 11 years-old, he was infected with HIV and hepatitis C when blood products were tainted in the 1980s. At the time, doctors handed his parents his death sentence. His world was crashing down as coincidently, mine was as well. A little over 1000 miles away in Miami Beach, I was living with the same shame and secrecy Mike was. My mother contracted HIV from a blood transfusion; however, we were living in the spotlight, whereas Mike could remain somewhat anonymous.

My mother and I were splashed across the Miami Herald like a freak sideshow - "Straight, non-IV drug using mother searches for a family for her daughter before she dies." This was in 1988, when Mike and I were both 11 years-old and had no idea what lay ahead in respect to our futures, or if we even had futures. I was constantly tested for HIV, avoided by EMTs in their hazmat suits taking my mother to Jackson Memorial Hospital in Miami. My mother died a year after she was diagnosed with this mysterious disease. This is why I asked Mike how long he had left. For me, HIV meant death.

Mike, age 8



Anne, age 11

While I was living through my nightmare, Mike was making his 4 am trips to the hospital for cryoprecipitate treatments - the very lifesaving medicine that gave him his "death sentence." Not something offered in the smaller community hospital near where they lived, Mike's father, Jack, would drive him to Louisville, Kentucky for his treatments. While making these long trips, Mike developed a love for semi-trucks, so his dad bought a CB for Mike to communicate with truckers. This was also the beginning of his love of classic rock. These were the only highlights he had on these trips to the hospital. After arriving home, Jack would go to work and Mike to school, even though they had been up since 3 am. Once home treatment became available, his father began giving Mike his treatments.

Mike's mom Shirley, told me about his childhood years of severe joint bleeds and going to school in slings, where he was taunted for bruises and limps.

Shirley and Jack both felt helpless, not knowing how to help their son. Unfortunately, they shut down and didn't speak much about his health. If they could somehow detach themselves from hemophilia and HIV, maybe it would be easier for them when they would eventually have to live without him. Thirty years later, they now realize they cut the quality of their lives short by living with anticipated grief.

In the summer of 1983, Mike's parents found a summer camp for kids with bleeding disorders called Camp Courage. This was a place where Mike could be Mike, without shame or fear of being a hemophiliac or, in later years, without the stigma of HIV and hepatitis C. He looked forward to it every year and planned for camp throughout the year. He would make lists of what to do, who to bunk with and pranks to play. He would make lists of movies and shows he wanted his mom to record on the VCR while he was gone. Mike developed a love of movies during the times he was ill or down with bleeds. It was an escape for him - a well-deserved escape.

The week spent at camp was priceless. He met lifelong friends at camp, who became his pen pals during the year. Sadly, every year, the number of friends would dwindle. Each year, one or more of his friends would not return to camp. HIV or complications of hemophilia were picking his friends off one by one. Month-to-month, year-to-year, he wondered who would be gone next, or if he would be the one missing from camp.

By 1988 when Mike was diagnosed with HIV, he had already lost 10 friends. Not wanting to deal with losing more friends, in 1992, he stopped attending camp. Mike lost more than 20 of his friends.

He continued to live in silence. Meanwhile, I moved to Kentucky in 1989; I too lived in silence as I avoided reporters for follow up stories about my mom. Eventually 19 years later, our silence would bring us together.

Fast forward....

In 2014, Mike and I met. We fell in love. Unlike previous relationships, we both had a true understanding of our foundations; however, our foundations were damaged. We found support, love and the necessary tools to repair that foundation, together. Mike proposed in May of 2015.
We have blended our family: Mike's 10 year-old son, Josh, and my almost 10 year-old son, Adin. Blending sounds easy, simply stirring. Our family blending was more like a Ninja Pro Blender without a lid, grinding up gravel on the highest setting. With hard work though, we have made it work.

Our boys are aware of hemophilia and we have educated them on a level they understand. Both Adin and Josh are very interested in genetics, though explaining mutations has been trying. We've tried to make the comparison to mutants in X-men, but they don't buy it. However, daddy's "boo-boo" shots are completely understood in their importance for Mike's health.

We continue to make this work - fixing our foundations. As a way to help Mike with his infusions, I obtained my phlebotomy certification and I've gotten pretty good! I can hit some veins he has previously been unable to use. When we first started dating, he was only treating once a week, now he is following prophy regimen and has seen a significant decrease in bleeds. We keep logs of his treatments; any pain he may be in and if it's a bleed or arthritic in nature. After living with a dislocated elbow and fractured radius for 6 years, he had a total elbow replacement in 2015. Mike never took care of himself as well as he should have. My goal now is to add to the quality of his life.

For many years, Mike worked in a large chain grocery center. He excelled at this job, but ignored the physical damage it was causing. The constant lifting, stooping and walking was continuing to damage his joints. We both realized this line of work was not healthy for him, so after his elbow replacement, I went back to work full time so Mike could leave his job. He now stays home to care for our boys and to continue to focus on his health.

Our life together is just like everyone else. We have our kids to care for, PTA meetings and parent-teacher conferences, as well as 3 dogs and 2 cats to chase. The only atypical thing in our lives is that we happen to have an extra refrigerator for factor and enough medical supplies to open a triage in our kitchen.

Mike and our boys are my most prized people on this earth. They are my inspiration and the reason I wanted to share our story. Mike is my motivation and the muse for my activist heart for hemophilia awareness. Mike is living a better and healthier life these days and together, our future is bright.

HFA Helping Hands

The Hemophilia Federation of America (HFA) ***Helping Hands*** program was established to help patients and families affected by a bleeding disorder alleviate financial hardships due to their condition. Helping Hands aids in providing basic living expenses like housing, utilities and transportation, as well as durable medical items (i.e. medical IDs, protective gear, braces, cooling/heating supplies, fitness support) for the care of bleeding disorders. If you have an inhibitor with a measurable titer and/or shortened half-life, the Helping Hands program is able to provide assistance for educational travel, medical travel, tutoring, and educational supplies.

In order to determine your eligibility for the *Helping Hands Emergency Expenses* program, you must be referred to the program by a health care provider once per year and are considered within two weeks. For other types of assistance, requests are considered within thirty days, and applications may be submitted directly. Once an application has been reviewed, HFA program coordinators will schedule a phone interview to discuss the request for assistance.

For additional information and to apply, please visit www.hemophiliafed.org/programs/helping-hands or contact HFA directly at 1-800-230-9797.

Helps Those in Need

Gears for Good Supports Helping Hands

The Helping Hands program must rely on generous donations and public support. To help ensure applicants are able to continue to rely on this program, HFA initiated a national community based, bike benefit/fundraiser, Gears for Good. 100% of all contributions raised with Gears for Good are used to fund HFA's Helping Hands program.

According to HFA fundraising materials, "The Gears for Good bike rides are examples of our enthusiasm for exercising to maintain healthy joints and muscles. This charity bike ride is HFA's only event-based fundraiser and it's a win-win for the bleeding disorders community as it combines physical activity with raising funds for HFA's assistance program, Helping Hands."

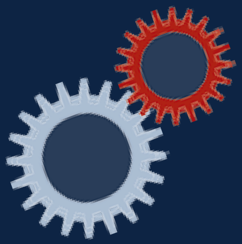
"HFA offers programs that directly impact the life of people living with a bleeding disorder. The funds raised through this charity bike ride will fund Helping Hands, a program that directly supports individuals in desperate temporary financial need in the community. Our Helping Hands program is truly something special and we're pleased and honored to have your help in supporting it."

For the last several years, Paul Brayshaw has participated in the ride to help support the efforts of HFA and the Helping Hands program. "The Helping Hands program offers a critical resource for patients and their families affected by bleeding disorders. The emergency funds available through the program offer precious support for community members with a dire need. As a person with severe hemophilia B, I am thrilled to ride my bike 156 miles for a great cause, as well as literally enjoy the benefits of healthy activity and health promotion," shares Paul.

If you would like to support Paul Brayshaw in his fundraising efforts or support Gears for Good in any way, please visit: give.hemophiliafed.org/site/TR?frid=1060&pg=entry.

Be a Virtual Rider!

Unable to ride, yet want to support Gears for Good? Become a ***Virtual Rider***! Virtual Riders set up their own personal fundraising page and begin raising funds to support Helping Hands.

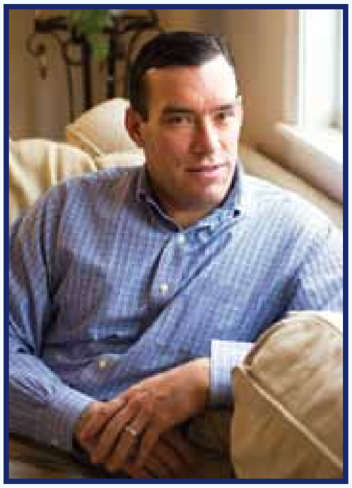


To learn more about how to become a Virtual Rider, please visit, www.hemophiliafed.org/programs/gears-for-good

Click on *Register as an Individual*, select *Join as a New Participant*; choose *Virtual Rider* in *Participation Options*, and begin the registration process.

Matrix Health Group

THE HEALTH ADVOCATE



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

THE UNAFFORDABLE CARE ACT AND MARKETPLACE ACCESS

By Paul Brayshaw

The Affordable Care Act (ACA) was passed by Congress and signed into law by President Obama on March 23, 2010. On June 28, 2012, the Supreme Court rendered a final decision to uphold the health care law. In its contemporary form, the ACA has had profound implications on the practice, delivery, and the real world experiences of patients in the health care setting. After six years of maturation and marinade, Obamacare is at a critical juncture for patients with bleeding disorders and other high cost conditions. At stake is the ongoing ability of people with specific conditions, such as bleeding disorders, to access health insurance through the ACA.

As a function of Executive Rulemaking, the Centers for Medicare and Medicaid Services (CMS) released an interim final rule in 2014 that excluded non-profit charities from the list of entities that can provide third party assistance for patients, allowing health plans to deny coverage to patients by rejecting the premium assistance provided by non-profit third parties. To help appease insurers and contain the exodus of health insurance companies from State Health Exchanges, CMS is granting authority to allow the insurance carriers to determine whether 3rd party payment of premiums are acceptable.

Whether or not the CMS purposefully or inadvertently created this dilemma, if people with chronic conditions are disabled, unemployed and unable to maintain health insurance outside of the workplace, a patient may have to forego health insurance due to excessive cost sharing. As a result, patients will shift care to hospitals and emergency room settings, where care is most disruptive for patients and least optimal for effective disease management.

Organizations like Patient Services Inc (PSI) were founded on the principle of helping patients maintain access to health insurance for the treatment of certain medical conditions. Patients who depend on programs offered by PSI have already been directly affected by this policy change. According to PSI and educational materials of the Marketplace Access Project (MAP), "insurance companies in 38 states are citing this rule to deny treatments and services for individuals living with chronic, rare and life-threatening illnesses who sometimes rely on non-profit premium assistance programs to help cover the high costs of simply maintaining their health insurance." Less extreme, but equally insidious are situations of underinsurance, where patients have to choose a less expensive plan, with a more restrictive network of doctors and without access to specialty care.

To help respond to this crisis, PSI has led efforts in Washington, D.C. seeking withdrawal and/or modification of the rule administratively, as well as through legislation, H.R. 3742, the Access to Marketplace Insurance Act. The bill in Congress seeks to carve out the ability of non-profit charities to provide premium assistance under current guidance.

Consider reaching out to your member of Congress, local elected officials, and the State Insurance Commissioner to express the critical importance of access to the ACA. The Marketplace Access Project at www.marketplaceaccess.org has also been established to provide patients and stakeholders a repository for information and updates to stay engaged.

Patients affected by chronic and life-threatening illness must consider the implications of these developments, and the impact on each of our lives. Regardless of your source of insurance, access to care will remain a critical part of living with a lifelong chronic condition.

HEALTH INSURANCE

OPEN ENROLLMENT

Open Enrollment season is upon us! This is an important time of year for all Americans, especially those with special health conditions. As you evaluate insurance plans it may also be wise to consider your current pharmacy provider. Are your needs being met? Are you receiving the level of care you deserve? Now is the time to consider changes.

The federal health insurance exchanges open on November 1st 2016 and will continue to enroll beneficiaries until December 15, 2016. If you feel your current plan is not meeting your needs or if you want to purchase coverage for the first time, this is your opportunity. When selecting a plan, it can be easy to become overwhelmed by what many consider a daunting process. Fortunately there are resources available to help navigate the often complex terrain of health insurance.

Matrix Health Group employs a team of experts who are well prepared to assist you identify coverage options, resources and potential adverse effects. Don't hesitate to reach out to the friendly professionals in our reimbursement department for assistance with public or private coverage concerns: 877-337-3002, ext.#3.

Additionally, both the National Hemophilia Foundation and the Hemophilia Federation of America offer great insurance resources. The "Personal Health Insurance Toolkit" from NHF offers a comprehensive guide to determine personal healthcare needs. From cost comparison worksheets to guidance on how to file appeals and grievances, this is an excellent tool. The Hemophilia Federation of America's Project CALLS (Creating Alternatives to Limiting and Lacking Services) seeks to identify trends in the insurance industry and build a case for change where reform is needed. Whether subjected to a lengthy prior-authorization process or forced to use a pharmacy not meeting your needs, the team at Project CALLS wants to hear from you. Included you will find links to both of these resources.

The entire team at Matrix Health Group is "Dedicated to Making a Difference" in the lives of those with hemophilia and other bleeding disorders. Our pharmacists have extensive knowledge of bleeding disorders, our team of care coordinators provide around-the-clock, personalized case management and our reimbursement specialists are ready to assist in all matters pertaining to insurance, public and private. With our team of experts, we are committed to providing care that complements your individual needs. For more information, visit us online at www.matrixhealthgroup.com. For a no-obligations eligibility-check, forward your current insurance information to: intake@matrixhealthgroup.com

FAMOHIO

Keeping Ohio Bleeding Disorder
Families Connected Since 1992

By Rania Salem and Shelia Biljes

Twenty-five years of excitement, education, networking – this is what FAMOHIO means to the families in Ohio with bleeding disorders. People gather to learn more about their disorder, how to manage everyday life and how to conquer all the problems a bleeding disorder brings. Financial, medical, insurance – you name it, if it is an issue, it is given attention.

The FAM in FAMOHIO relates to the **FAM**ily! All ages are included, from the youngest newborn to the eldest grandparent – there are hugs and learning for everyone. This event always begins on a Friday night and extends through Sunday morning; this year's took place August 5-7th at the Columbus Marriot Northwest. It says a lot when, in 25 years, no two years have been the same! Different speakers, educating on different topics, varied activities for adults as well as age-appropriate fun stuff for the kids to enjoy, and different themes to mirror the current issues of the year.

Most of us know and appreciate the history of FAM: Way back in the height of the AIDS crises, six men who shared the diagnosis of hemophilia and AIDS gathered to discuss how they could best channel their energy to meet a positive goal that would benefit many. They firmly believed education was the key to ensuring a positive future for everyone affected by a bleeding disorder. Over the years, the Board has developed an award to honor each passing founder while recognizing the contributions and value of those carrying on their dream. Here are the 2016 recipients:

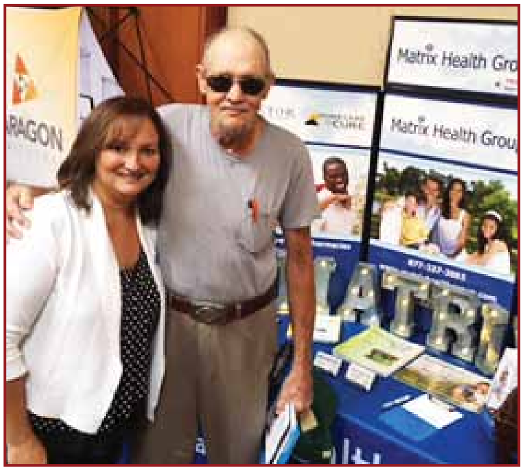
- The *Timothy Pryor Special Recognition* was awarded to Jodi Skinner for her countless hours and commitment to the community. Randi Clites, award nominator, states, "Her compassion for the community is contagious." She is a board member of her local Central Ohio Chapter of NHF, board member of FAMOHIO, member of the Ohio Bleeding Disorders Council, fundraiser, and volunteer. She never says no, and gives her heart and soul to this community.
- The *William Dennis Award* went to Jermaine Davis, not your average teenager. Because of his involvement in the bleeding disorders community, was chosen as a Nationwide Children's Hospital Ambassador. Invited to co-host a telethon with his local channel 10TV news anchor, Jerry Revish, Jermaine helped raise money for Children's Hospital. Jermaine is a dedicated advocate for the community, going to both State and National Advocacy days, speaking with Senators and Representatives to raise awareness for hemophilia.
- The *William Dennis Award* was also received by ProMedica Toledo Children's Hospital Northwest Ohio Hemophilia Treatment Center.

- The *Ira Gaffin Award* was given to Cindy Michael for her dedicated work at ProMedica Toledo Children's Hospital Northwest Ohio HTC since 1987. She is a member of Ohio Bleeding Disorders Council, recruiting families to advocate at Ohio's legislative outreach.
- Ohio's Senator Charleta B. Tavares (D-District 15) earned *The Thomas Burr Award* for her continued support and willingness to give a voice to our community, especially on a legislative level. She is a ranking member of the Finance, HHS, and Medicaid committees, to name just a few.

Friday night featured a *Celebration Room*, commemorating 25 years of FAMOHIO, a *Women's Comfort Room* and the annual *Fitness Walk*, with a trip to the ice cream truck to cap off the night.

After everyone enjoyed a Saturday morning breakfast symposium, the educational sessions began: *Foundation for Women and Girls with Bleeding Disorders*, *My Life Our Future*, *Bullying- Online and Offline* and *New Products in Hemophilia Care, What's in the Pipeline*. While adults learned from these topics, kids were treated to age appropriate sessions such as arts, crafts, swimming and quality time with Jim "Basketball" Jones. Jim is all about individuals developing and harnessing their inner strength and positive mindset to lead a more fulfilling life, holding more than 5000 assemblies and inspiring countless lives over the past 15 years. He believes we all learn over time and at our own pace, and as long as we never stop learning we will find our own success. We have to take ownership in our own effort, be willing to learn from others and believe in ourselves to realize our potential. Jim put these principles into action at an early age as he acquired the skills to overcome his own learning disability.

Saturday night closing brought everyone together for balloon benders, face painting, oversized games, caricature artists, visits from Star Wars Characters, music and fun at the photo booth.



Sunday morning wrap-up included breakfast with Chalk Artist, Matt Lewis. All too soon it was time to say goodbye. FAMOHIO has always been a place where friends catch up and new friends are made each year, forming lasting relationships with others who face the same challenges and obstacles.

Many thanks to the FAMOHIO Board, the planning committee, sponsors and the volunteers who make all this possible year after year.

Matrix on the Move!

Washington DC

Terry Stone and Paul Brayshaw

The Hemophilia Association of the Capital Area (HACA) hosted its 3rd annual ***Family Education Day*** on May 21st in Washington, D.C. at the Marriott Metro Center. This year's meeting made for a perfect trifecta, as HACA members convened in America's hometown among the monuments, memorials, and just a few blocks from the White House. Like they say in real estate: location, location, location! Centrally situated in the heart of the city, The Marriott Metro Center staff rolled out the welcome mat and greeted HACA members from across the National Capital Region.

Terry Stone (second from right) with HACA members at the chapter's annual education day.

The weather was brutal with gusting winds and rain, but that didn't stop our storm-hardy members from joining for a full afternoon of informative sessions. After all, this is not the first storm our community has had to push through, am I right? Hot topics including the latest on *Pain Management*, *Financial Finesse*, and *Communicating in the Workplace* were timely and informative. Children and teens had their own cool programming, including a Mad Science Show, a visit to the National Portrait Gallery, and a round of Jeopardy – bleeding disorders version. Not to mention time away from mom and dad… Priceless!

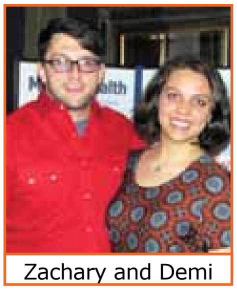
As the meeting wrapped up, Executive Director Brenda Bordelon thanked everyone for coming and was especially grateful to see veteran families visiting with the numerous families joining this HACA event for the first time. Tickets to the International Spy Museum were given to the families to enjoy after the meeting or on their own another day.

Way to go Brenda as well as the second half of HACA's dynamic duo, Krystina Tucker, for continuing to reach out and team up with our wonderful HTCs to make sure all patients know about the chapter and the wonderful benefits of getting involved! This was Brenda's first *Annual Education Meeting* as Executive Director. All of us at Matrix Health Group welcome you back to your HACA home and look forward to supporting many great events in the future!

Tennessee

Shannon Cassada, LeAnn Wilson, Stephen Lawrence, and David Tignor

Baxalta and Matrix Health Group partnered up May 26th to host a dinner and ***educational presentation*** at Calhoun's on the Tennessee River in Knoxville. April Morris, MSN, FNP gave a presentation on *Expecting the Unexpected: Emergencies Happen*. She discussed crucial information about emergency preparedness.



Zachary and Demi

Tyler and Madison

During and after the presentation, dinner guests shared stories and experiences that helped them during emergency situations. The conversation was eye opening and we all learned more about how to prepare for, and react to emergency situations.

Nevada

Kelly Gonzalez, Gaby Zamora and Holly Shaw

Red Rock Country Club in exciting Las Vegas was the place to be June 6th for the ***Annual Golf 4 the Kids Tournament***. Supporters of the rare disease and hemophilia communities gathered to enjoy a worthwhile cause. Surrounded by beautiful country club homes and a picturesque mountain background, the 36 foursomes began their day with a hardy breakfast and driving range practice. Play continued on 18 holes of the private mountain course. Factor Support teammates golfed with patients, health care providers and community supporters as over $60,000 was raised to benefit the Nevada Chapter.


Golfers,
Jose, Kelly and Joseph

Our day concluded with lunch served in the refreshing, air-conditioned clubhouse. With the goal of ensuring kids with bleeding disorders and other rare diseases have the chance to attend Camp Independent Firefly, fun items were raffled and items auctioned to generate the much needed funds. Thank you to all the supporters who made this day a huge success!

South Carolina

Peggy Gay

Hemophilia of South Carolina Chapter proudly hosted their ***43rd State Annual Meeting and Upstate Educational Day HELLO*** (Helping Embrace Life's Learning Opportunities) Conference during the weekend of June 10-11th.


Chapter President Lisa
Bordelon and Peggy Gay

Eager families arrived at the Embassy Suites Greenville Golf and Conference Center on Friday evening and were soon registered and participating in a fun ice breaker where everyone shared laughs while getting to know each other. While enjoying the buffet that followed, keynote speaker, Val Bias, CEO-NHF addressed the crowd and shared a presentation titled, *My Journey and Our Future*. Lisa Bordelon, Chapter President, then acknowledged and thanked the board members who were rotating off and introduced the new members. Special awards were acknowledged and the chapter's annual report was shared, which covered the year in review and the vision moving forward. Current updates on research affecting the bleeding disorder community wrapped up the evening.

Adventures began Saturday morning as children were whisked away for their programs. For the adults, education breakout sessions covering a variety of topics were available, such as *Women and Carriers with Tendencies Toward Bleeding*, *Positive Assertiveness*, *Braving Change on Core Conversations*, *Mastering Social Media*, *Advocacy*, *Relationships and Treatment/Educated Consumer*, just to name a few.

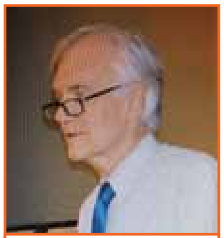
The sessions featured wonderful speakers who shared interesting and helpful information on bleeding disorder issues throughout the day. Dinner wrapped up the event with an outdoor patio BBQ and a fun time to mingle and share personal stories. A warm thank you to the South Carolina Chapter for hosting this exceptional and informative gathering.

Tennessee

Cyndy Coors, Shannon Cassada and Stephen Lawrence

The Tennessee Hemophilia and Bleeding Disorder Foundation's (THBDF) ***Bloodstrong Annual Meeting*** was held June 10-12th at the Chattanoogan Hotel in the heart of beautiful Chattanooga. Hugely successful, this event boasted the largest attendance and the best annual meeting yet!


Jeanne White-Ginder,
mother of Ryan White


Dr. Alan E. Kohrt,
father of
Dr. Holbrook Kohrt

Keynote speakers Jeanne White-Ginder, mother of Ryan White (1971-1990), and Alan E. Kohrt, Chief Medical Officer, Professor, Chair and father of Dr. Holbrook Kohrt (1977-2016), shared emotional and endearing family stories of their sons with hemophilia, and the tragic loss of the two amazing lives cut short. There wasn't a dry eye in the room! We felt privileged and honored to hear about their personal journeys and our hearts are forever with them.

Educational breakout sessions ensued with Dr. Meghann McManus and Dr. Manoo Bhakta of the Chattanooga HTC speaking respectively on *Bleeding Disorders 101* and *Hemophilia Care in the 21st Century*. A Grifols-sponsored presentation covered *Overview of Inhibitor Development and Management*, while a CSL Behring-sponsored session discussed *vWD as a Family*. Other available topics included *Financial Planning*, *You Are a Dad in Action*, *Navigating Medical Needs at School*, *Skills for Coping with Anxiety and Depression*, *Healthcare Coverage after the ACA*, and *Alternative Therapies for Pain*.

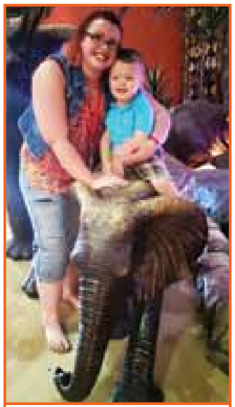
While parents attended sessions, children enjoyed a fun rock climbing experience, and visited Creative Discovery Museum and The Chattanooga Zoo at Warner Park. Our final night dinner was held on the Southern Belle Dinner Cruise Ship, allowing us a relaxing journey on the Tennessee River! This event was inspiring, with interesting and worthwhile educational information and time spent with our close-knit community members – we eagerly looking forward to the next THBDF meeting!

Wisconsin

Bonnie Culver and Eva Kraemer

Executive Director, Danielle Leitner-Baxter and the staff of The Great Lakes Hemophilia Foundation (GLHF) hosted its annual ***Wisconsin Bleeding Disorders Conference*** in Wisconsin Dells at the Kalahari Resort June 10-12th, for about 75 families.

The community kicked off the weekend with a special keynote address, facilitated by the one and only Patrick James Lynch. Well known for his web series titled *Stop the Bleeding*, he shared his personal story about living with severe hemophilia and observations on the community from his bleeding disorders-related work, domestically as well as internationally.



Megan and Cooper take a photo break!

Community round table discussions were available to patients and families, leading into breakout sessions, including: *More than Deep Breath: Using Mindfulness to Help You and Your Kids with Medical Anxiety*, *Bleeding Disorders Advocacy 101*, *Q & A with Dr. Diamond*, *"Stop the Bleeding!" Activity Book Session*, *Long Acting Factors - Fact or Fiction*, *Healthy Cooking and Nutrition*. There was so much to be learned and shared; it was a delightful weekend and we were ecstatic to participate.

Florida

Hector Heer

Who doesn't love a fun, family picnic with a few of your best friends? The Foundation of Hope & Life USA's ***2nd Annual Picnic*** brought about many smiles for members of the bleeding disorders community in south Florida. The fantastic afternoon took place at the La Ventana de los Cielos where zoo-interaction, aqua-experience and equestrian activities benefit children with special needs.

Alba and Hector looking forward to cotton candy!

Hector Heer with Giovani and Guillermo

This event was well attended by the Florida hemophilia community. Organizers and participants expressed many thanks to those volunteers who made this event possible. The Foundation Hope and Life also received much appreciation for bringing bleeding disorder community friends and family together to share a good time, a delicious paella lunch, and feelings of brotherhood and support for one another.

Raffle time! Isabella chooses the winning ticket!

New Jersey

Richard Vogel

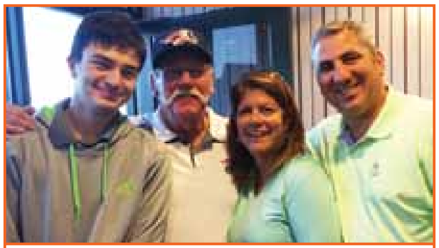
As the sold-out crowd sang along to Alice Cooper's "School's Out for Summer," the fireworks show was the end to a beautiful spring evening of education, fun and another win for the home team.

Father and daughter, Chris and Allison having fun at the game!

Mom and son, Milinda and Alex enjoy their time together

On the evening of June 17th, Emergent Biosciences and Matrix Health Group hosted an ***educational evening*** at the TD Bank Ballpark, home of the Somerset Patriots, a minor league ball team in New Jersey. The evening started with 25 community members milling around the private suite enjoying typical ballpark food - chips, salsa, peanuts and popcorn. As pre-game festivities began, we gathered and engaged in an educational conversation about fitness and health led by Kevin Harris, a community member, and Angela Forsyth, Physical Therapist. Both excellent speakers are part of the Emergent speaker bureau. The two worked in tandem explaining proper exercise techniques to minimize stress on joints. The big take away was only you know your body, so listen to it and know your limits.

Joe, Glenn and Rich - Jersey boys causing trouble



Christopher, Sparky Lyle, Lisa and Chris

After a few exercise demonstrations, the ballgame got underway as we all watched the Somerset Patriots beat the Southern Maryland Blue Crabs while munching away on burgers, hotdogs, chicken fingers and soft pretzels. At one point, the door to the suite opened and who should walk in but Yankee great, Sparky Lyle. You couldn't miss him with his signature handlebar mustache, made famous by helping the Yankees win World Series Championships in 1977 and 1978.

As always, we have a blast at these events here in Jersey, and some were lucky to leave with a Sparky Lyle autograph!

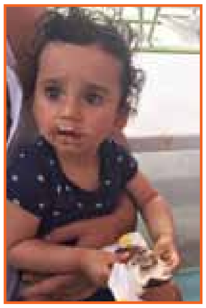
Nevada

Kelly Gonzalez

With over 200 patients and family members in attendance, the NHF Nevada's ***Spring Education Fest*** kicked off June 17th at the Circus Circus Hotel in Las Vegas with bleeding disorders community members socializing and visiting industry booths. Kelli Walters, NHF Nevada Executive Director continued the event by sharing chapter updates and goals for the next year. With a focus on advocacy and awareness of current topics in the bleeding disorder community including programs and products, education for the adults continued through lunch.

Meanwhile, the youth participated in fun activities with the chapter's newest teammate, Lupe Torres, Project Coordinator, and chapter volunteer, Jacey Kelley-Gonzalez.

The afternoon brought everyone together at the Wet'n'Wild Las Vegas Water Park to celebrate the annual *Renee Paper Picnic.* This special occasion is a way to honor and respect Renee, who was a tireless advocate in the Nevada community. Factor Support Network hosted an ice cream break to made sure the community members stayed cool, hydrated and, of course, had their fill of ice cream! Thank you to the NHF Nevada Chapter and industry and community sponsors who work together to make this educational event possible!



Virginia

Terry Stone and Paul Brayshaw

Nestled in the quaint historic town of Charlottesville just a few winding roads from Thomas Jefferson's beloved Monticello in the beautiful Piedmont Valley, the Virginia Hemophilia Foundation called all members near and far to gather for the chapter's ***Annual Meeting*** June 17-19th. Although Monticello was not far away and Thomas Jefferson was known as quite the gracious host, the meeting was held at the Doubletree Hotel, which was a lovely alternative. We are quite confident Jefferson would have approved! The weekend was rich with education, chapter business and the year in review, along with opportunities to dine together and delight in the news and events among members since last they convened.

On Friday night, families were welcomed with a hearty dinner followed by a rousing game of *Bleeding Disorders Jeopardy*! An early bedtime (for most) was observed with the new day just hours away. The sun welcomed everyone and the day kicked off with an early call for breakfast and a swift start to the full agenda ahead. All enjoyed timely and hot topics such as *Advocacy and Insurance*, *New Products: Here and On The Horizon*, *Women: Taking Care Of Themselves*, and a *Dad's in Action* discussion. In closing, a discussion on *Pain Management and Considerations for the Hemophilia Community* was presented by the one and only Christopher Walsh, MD, PhD, Hematology at Mount Sinai Hospital.

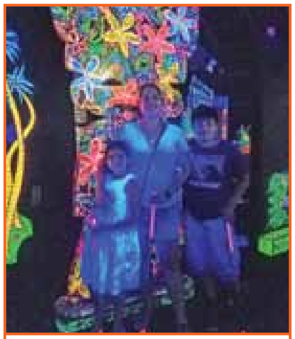
Dr Christopher Walsh and his groupies. You're so worthy Dr. W!

While the elders listened and learned, their young offspring delighted in a motor carriage ride for a short journey to Camp Holiday Trails for a day of fun and frivolities. Finally, and in usual fashion, many industry supporters were at the ready to share their news (hear ye, hear ye) and provide useful goodies and gadgets to all. Matrix Health Group was pleased to be a corporate supporter of this enriching annual meeting and family event. The Matrix Health water bottle was a huge hit and as Jefferson would prefer, it was a useful gift!

Illinois

Eva Kraemer

Bleeding Disorders Alliance Illinois (BDAI) and the Hemophilia Federation of America (HFA) hosted a ***Sports in Bleeding Disorders Educational Program*** at Putting Edge in Norridge June 18th for the Chicagoland bleeding disorder community. Competing with one another at an indoor, 18-hole, glow-in-the-dark mini golf course only added to the camaraderie and spirit of the afternoon. Afterward, we all enjoyed a presentation from Dads in Action's Todd Pittman, who elaborated on how to prepare when playing sports with a bleeding disorder and how to manage a bleed when and if they happen. Todd encouraged a lot of great interaction and I sure had a blast with the families as we golfed in the dark!



Ava, Adrienne and Jacob all aglow!

Brothers, Cortez and Cory having fun!

New Jersey

Richard Vogel


Golfer Perry Parker


Wrapped in red - Marissa, Rich and Laini

With a loud bang the shotgun signified the start of the ***37th Annual Dennis Keelty Memorial Golf Tournament*** on June 20th at the renowned Plainfield Country Club in Edison, home of the PGA Barclays Tournament. Named in memory of Dennis Keelty who passed away from complications of hemophilia, proceeds benefit the Hemophilia Association of New Jersey and will be dedicated to patient programs.

Twenty-six teams with over 100 golfers enjoyed a beautiful sunny, hot, first-day-of-summer on the links. Consisting of community members, pharmaceutical and specialty pharmacy representatives, and other interested business groups, the day started with a few golf clinics headed by professional golfer and community member, Perry Parker. Perry busily adjusted swings and doled out helpful tips to appreciative golfers. For those skillful, or maybe just lucky enough, three of the golf holes featured a vehicle to win with a hole-in-one. Chances included a Jaguar, Cadillac and a Volkswagen. I was positioned at the 14th hole to watch for a hole-in-one for the Cadillac. Some players came close, but no one was actually able to fill the cup in a single swing.

When the golfers were finished, scores were tallied and the 2 top scores from each foursome counted toward the team score. Prizes included golf rounds at various clubs in New Jersey, golf clubs, drivers and range-finder binoculars to calculate distance to the hole. Cocktails and hors d'oeuvres helped everyone unwind after the energy spent on the links. Then it was onto a satisfying dinner of carved filet of beef, turkey and pasta stations. Prizes were awarded during bananas foster and other desserts with a special award given to George and Richard Keelty, who founded this tournament and kept it going for the last 37 years. Quite a feat, indeed!

Illinois

Eva Kraemer


Thomas... cool, calm and ready to putt

The weather was the best anyone had seen in the last 19 years of hosting Bleeding Disorder Alliance Illinois' (BDAI) ***19th Annual Driving fore Hemophilia Golf Fundraiser*** June 21st. It was the topic of every foursomes' conversations as the absolutely pristine meteorological conditions at Ruffled Feathers Golf Course in Lemont, 25 miles west of Chicago, provided the perfect backdrop for this well-attended fundraiser. BDAI's Executive Director Bob Robinson, staff and volunteers provided 18 challenging holes of golf, and revelry was had by all as donations were made to help the Illinois bleeding disorder community. Lady and gentlemen golfers were treated to an abundance of challenges, contests, games, drinks and snacks as they made their way through the course. The picturesque day fueled everyone's good will for this necessary cause, benefiting children and adults with inherited bleeding disorders. Again, Matrix Health Group sponsored a legendary, dreamteam foursome and although the team didn't win a prize, they all had a wonderful day!

California

Marina Vera


Selfie time! ED Michelle Kim and Kelly Gonzalez


Marina (far right) with granddaughters, Alina, Angelina and Deanna

Hemophilia Foundation of Southern California hosted its ***8th Annual Bleeding Disorders Walk*** at Griffith Park, Crystal Springs-Pettigrew Picnic Area in Los Angeles June 25th. Over 450 enthusiastic attendees spent a day filled with fun and family activities for all to enjoy! Following registration and receiving an official walk t-shirt, families had plenty of time to visit vendor booths, a mobile petting zoo and enjoy a pony ride. Other activities included a roping contest, face painting, crazy hair, caricatures and balloon twisting. A fun photo booth was also available to pose with Woody, the colorful character from Toy Story.

After community member Morgan Stowers sang the National Anthem, Executive Director Michelle Kim began with opening remarks and the introduction of Dr. Nadia Ewing from the City of Hope HTC in Monrovia and Michael Franzsen, HFSC Board President. Next up was the announcement of awards for top fundraising team and best t-shirt design. The crowd was happy to share the moments of recognition with awardees. With the crowd's energy high, Michelle Kim gave the signal to start the Walk!

The sun was blazing and shade was in short supply for the 3-mile walk around the park. As walkers crossed the finish line, they were happy to receive their participation medals. They were even happier to see Shire-Baxalta's ice cream stand and Domino's Pizza! The alk participants were treated to a Trick Roping Performance as they relaxed and cooled down after the walk in heat of the day!

As Team Captain for the "FSN Blood Bandits," I arrived dressed as a cowgirl with my 3 granddaughters.

Kylie Brockett and Brooke Hopkins, employees of our Camarillo pharmacy, came with youngsters in strollers while Kelly Gonzalez, Regional Care Coordinator (RCC), her husband, son and a pair of twins drove all the way from Nevada to join in the fun. RCC Gabriela Griffin arrived from Lake View Terrace to round out our team. Thank you HFSC for another fun family event!

Ohio

Eric Lambing

June 25th was a beautiful day for a swim! The Tristate Bleeding Disorders Foundation hosted its annual ***Family Educational Day*** at Coney Island Waterpark in Cincinnati. The sky was blue and the sun was warm with temperatures reaching the high 80s. With over 100 people ready to have fun, the event began with a cook-out and an educational session, and everyone had the opportunity to meet the sponsors and learn all about the new and improved information. Spirits were high as the education wrapped up and everyone headed to the park to enjoy a day made perfect for rides and a dip in the pool. Thank you, TSBDF for hosting this favorite summertime event!

Nevada

Kelly Gonzalez


With guidance from Nurse Becki, Carol looks for a vein in Gig's arm

July 5th over a dozen patients gathered at the HTC of Nevada to enjoy a talk about ***Independence in Self-infusion***, a catered dinner, and to practice infusion techniques under the watchful guidance and supervision of Becki Berkowitz, RN. Self-infusing is an important part of gaining independence when living with a bleeding disorder, and we are proud to be part of helping our wonderful community members gain confidence and experience independence!

California

Cindy Picos

Marking the 2nd year for this growing event, ***Family Camp Weekend*** held July 8-10th was a huge success for the Central California Hemophilia Foundation. With more than 100 participants, attendance has tripled under the direction of Program Director and Chapter Vice President, Sean Hubbert. The event began on Friday afternoon as families checked into the dorms on the campus of the California State University Maritime Academy in Vallejo. Included in the fun-filled weekend were activities such as swim therapy, family circus acts, ice breaking exercises, games, movies and more! Opportunities were available to learn how to infuse and the highlight of camp was when a father, surrounded by cheering fans, learned how to infuse. There were many opportunities for bonding and many new friendships were formed. Participants completed a survey at the conclusion and the most popular comment was, "we want more time at Family Camp!" Thank you Sean Hubbert for organizing this event!

Nevada

Kelly Gonzalez

The beautiful Grand Sierra Resort was a prefect venue to start the ***Reno Education Day*** with the local chapter and our amazing bleeding disorder families July 9th! After family fun the children and adults separated as the nearly 60 kids were treated to games, painting and cooking. Meanwhile the adults received education on health and well-being, and had the opportunity to practice stretching, exercising and relaxation techniques.

After a healthy lunch and time to interact with industry reps everyone was off to the water park for an afternoon of wet and wild fun! We are so grateful to be able to network and make friends with our community members. Thank you to NHF Nevada for giving our families this event!

Nevada

Kelly Gonzalez

The Couples Bleeding Disorder Workshop and Retreat provided a wonderful opportunity for couples dealing with bleeding disorders as either patients or parents, to connect or reconnect with each other. In this workshop, held July 16th at the Hilton Grand Garden Inn, couples were able to express their stressors, hopes and goals to both the group and their partner. The group goal was to have a clearer vision for each couple, moving forward.

The program was hosted by Shire-Baxalta and supported by the Nevada Chapter of the National Hemophilia Foundation and the Hemophilia Treatment Center of Nevada. Following the retreat, couples dined, relaxed and had a wonderful "stay-cation" in Henderson, Nevada!

Nevada

Kelly Gonzalez

The much anticipated ***Bowl 4 The Kids*** fundraising event went off without a hitch July 30th as nearly 300 bowlers joined to fill 74 lanes at the Strike Zone Bowling Alley in Henderson, while raising money for *Cure 4 The Kids*. This non-profit organization raises funds for the treatment of the rare disease community, including Children's Specialty Center of Nevada and the Hemophilia Treatment Centers of Nevada. In addition to bowling, the families shared pizza, enjoyed a silent auction, welcomed treats and surprise visits from mascots and characters from all over the city! Factor Support Network proudly supports the cause as well as our rare disease community families! Thank you to everyone that worked to host such a fantastic event!

Kentucky

David Tignor

Happy ladies, smiling faces! Mary and Laci

The Kentucky Hemophilia Foundation ***Family Event Annual Meeting*** took place August 6th at the Louisville Hyatt Regency. Ursela Kamala, Executive Director extended a warm welcome, presented the KHF Annual report and recognized outstanding community volunteers. In addition to time for visiting industry exhibits, educational sessions were available on topics such as *Bullying Online and Offline*, *Spotlight on the Unaffected Sibling*, and *Genetics and von Willebrand Disease*. Jesse Shrader, CSL *Gettin' in the Game* athlete, also held a session called *Fastball Sports Talk,* a discussion on playing sports with a bleeding disorder.

Winding down the fullday, families were treated to dinner and a baseball game at Louisville Slugger Field to watch the Louisville Bats go for the win 2-1 against the Columbus Clippers. Matrix Health Group is happy to be a financial supporter of the KHF Family Event.

California

Cindy Picos

Jacob, Esma and Daddy Mike visiting with 6 Flags characters

Heather and Abraham stop to say hello!

The Central California Hemophilia Foundation (CCHF) sponsored an ***Education Weekend*** August 6-7th at the Sacramento Hilton Hotel drawing over 200 guests. The event featured educational sessions including *Living Fit with Hemophilia* by Bayer, *Life Skills* by Biogen, *How to Communicate with your Child's School* by Novo Nordisk, *Transition for Teens* by UC Davis HTC and *Bullying* by Shire-Baxalta. The busy day ended with a family style dinner co-hosted by Shire-Baxalta and Emergent, and everyone received tickets for Six Flags Magic Kingdom the following day. Along with manufacturers, the local HTC and home health companies, we proudly sponsored a booth at this important event.

Thank you to CCHF President Bonnie Leidheisl, Program Director and Vice President, Sean Hubbert, Board Directors, Gwen Welsch and Muriel Herr, and all the volunteers for their tireless work in organizing this fantastic event!

California

Gabriela Zamora, Kelly Gonzalez and Sid Ramirez

Hemophilia Foundation of Northern California held its ***12th Annual Hemophilia Heritage Vines, Hops & Golf Event*** August 7-8th. A fantastic dinner and silent auction was held at the Fairmont Sonoma Mission Inn & Spa. In addition to an enjoyable and informative wine and cheese pairing, guests could also bid on an array of remarkable auction items.

Kelly Gonzalez, Sid Ramirez and Gaby Zamora - Represent!

The following day found over 110 eager golfers at the scenic Sonoma Golf Club. After enjoying a quick boxed lunch, the rounds began. Joining one lucky team was 10 year-old Jaden D., who was auctioned to the highest bidder for play in their foursome. Jaden is one of our country's top junior golfers and his family are members of our community. As play wrapped up, everyone gathered for a delicious dinner, award announcements and another silent auction featuring sports-related memorabilia such as a basketball signed by Bill Walton, retired basketball player and television sportscaster. As with the auction the night before, all proceeds benefit HFNC programs. It was a blast spending the day with and community members. Many thanks to all the fantastic people who sponsored and volunteered to help make this event successful every year.

California

Sean Hubbert

Accomplished Riders! Aaron, Nate and Brad

The ***15th Annual California Coastal Ride for Hemophilia*** was held August 13-20th. Participating in this amazing 7-day event were 21 dedicated riders who covered more than 600 gorgeous miles along the scenic Highway 1 California coastline from San Francisco to San Diego. This is one of the largest fundraising efforts for the Hemophilia Council of California. An extra special thank you to all the wonderful riders!


Sean Hubbert supports the riders!

New Jersey

Richard Vogel

A group of blood brothers from the tri state area gathered for a ***BBQ and Pool Party*** Sunday, August 14th. We have been doing this for a few years and this year, the weather was perfect - hot and sunny.

The menu is seasonal and fresh, so on Saturday, I took out my Big Chief smoker, cooked a side of salmon and served it cold with a sauce of sour cream, fresh cucumbers and dill. We started the day with the salmon, steamed shrimp and heirloom tomato salad with fresh mozzarella. With some poolside fun, we worked up our appetites and went back for grilled steaks, lobster mac n cheese (a crowd favorite), corn and refreshing watermelon to wrap up the meal.

This is a great way for us to stay in touch during the summer months. We are able to discuss issues in a free forum. Though our group ranges from guys in their mid-20's to mid-70's, our issues, complaints and successes are all the same, and we are constantly learning from each other.

Virginia

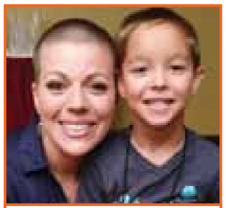
Paul Brayshaw and Terry Stone

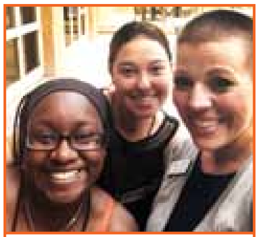
After a multi-year hiatus, the Hemophilia Association of the Capital Area (HACA) reinstated ***Annual Summer Picnic*** and hosted its return August 14th at Lake Accotink Park in North Springfield. Surrounded by old friends and new families, we enjoyed the sweltering heat and an occasional downpour of rain with putt-putt golf, carousel rides, and other fun and games. As a reminder of good times, HACA Chapter Staff compiled an amazing display of photos that captured the fun from prior picnics. We hope this classic event continues next year as a means to bolster membership and foster community relationships.

Arizona

Kelly Gonzalez, Gaby Zamora, Terry Rice and Felix Garcia


Go Team! Felix, Terry, Gaby and Kelly


All Smiles! Kelly and Aaden


Friends all together! Erica, Sarah and Kelly

Excitement surrounded our team as we mingled with the bleeding disorder community August 19th for the Arizona Hemophilia Association ***Annual Statewide Meeting*** at the Hilton Phoenix/Mesa. Preparing to present our company and our high touch service model in 5 repeated sessions was something the four of us eagerly anticipated. As patients ourselves, and knowing many within the community only made us even more excited to visit with everyone!

The presentations and breakout sessions on Friday and Saturday were filled with information, communication, and even some laughter and fun! Though the weather was a little uncooperative, families found themselves enjoying time together at the local water park on Saturday night.

The weekend concluded Sunday morning with breakfast and sessions before everyone headed home filled with renewed energy and enthusiasm to continue participating in Arizona community events. We appreciate the Arizona Hemophilia Association inviting us to the community and delighted the members welcomed us so graciously!

Delaware

August 27th was an extraordinary day for the Brandywine Valley Hemophilia Foundation. During a ***Golf Clinic*** at Fieldstone Golf Club, we had a surprise visit from VP Joe Biden! He wanted to meet our kids and then led a private tour of Air Force 2. It was an awesome day for everyone!

Answers to puzzles on page 35

1.) False
2.) True
3.) False
4.) False
5.) True
6.) True
7.) False
8.) False
9.) False
10.) True

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

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

Upcoming Events

Oct. 13, 2016 Nevada
Factor Support Network and HTC NV
702-732-1956, factorsupportnetwork.com
Infusion Clinic -HTC Clinic; Reno
Contact: Kelly Gonzalez 702-858-2525

Oct. 14, 2016 Tennessee
TN Hemophilia & Bleeding Disorder Found
615-900-1486, thbdf.org
Royal Gala, Loveless Barn; Nashville
Contact: THBDF 615-900-1486

Oct. 15, 2016 Idaho
Snake River Hemophilia Bleeding Disorders Association, 208-351-4785
Annual Family Conference
Colonial Theater; Idaho Falls
Contact: Gaby Zamora 925-234-2451

Oct. 15, 2016 North Carolina
Hemophilia of North Carolina
800-990-5557, hemophilia-nc.org
NHF Walk
Lake Crabtree County Park; Morrisville
Contact: Peggy Gay 864-275-0246

Oct. 15, 2016 Oregon
Hemophilia Foundation of Oregon
541-753-0730, hemophiliaoregon.org
Insurance Summit
Crowne Plaza; Lake Oswego
Contact: Jeff Johnson 360-553-6402

Oct. 15, 2016 West Virginia
West Virginia Chapter of NHF
681-212-9255, wvnhf.org
Hemophilia Walk
Waterfront Place Hotel; Morgantown
Contact: Tina McMullen 484-942-4457

Oct. 16, 2016 Indiana
Hemophilia of Indiana
317-570-0039, hoii.org
Mystery Bus Tour
Indianapolis
Contact: Enrique Morey 317-999-7912

Oct. 17, 2016 California
Hemophilia Foundation of Southern CA
323-525-0440, hemosocal.org
33rd Annual Golf & Tennis Tournament
La Canada Flintridge Country Club; LaCanada
Contact: Marina Vera 323-252-8682

Oct. 21, 2016 Illinois
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Autumn Wine Auction and Dinner
Columbia Yacht Club; Chicago
Contact: Eva Kraemer 608-852-3777

Oct. 21, 2016 Oregon
Hemophilia Foundation of Oregon
541-753-0730, hemophiliaoregon.org
Shooting for the Stars Benefit Auction
Multonomah Athletic Club; Portland
Contact: Jeff Johnson 360-553-6402

Oct. 21-23, 2016 Maryland
Hemophilia Foundation of Maryland
410-661-2307, hfmonline.org
Family Weekend
Hyatt Chesapeake Bay
Cambridge
Contact: Paul Brayshaw 202-271-4252
or Terry Stone 703-795-6269

Oct. 22, 2016 Ohio
Tri State Bleeding Disorder Foundation
513-961-4366, tsbdf.com
Family Day at Cincinnati Zoo
Contact: Rania Salem 513-470-5500

Oct. 22, 2016 Tennessee
TN Hemophilia & Bleeding Disorder Found.
615-900-1486, thbdf.org
Fall Festival
The Park at Harlinsdale Farm; Franklin
Contact: THBDF 615-900-1486

Oct. 22, 2016 Washington DC
Hemophilia Assoc. of the Capital Area
703-352-7641, hacacares.org
Hemophilia Walk; National Mall
Contact: Paul Brayshaw 202-271-4252
or Terry Stone 703-795-6269

Oct. 29, 2016 New York
Bleeding Disorders Association of Northeastern New York
518-729-3577, bdaneny.org
BDANENY Annual Meeting
Great Escape Lodge and Water Park; Queensbury
Contact: Tina McMullen 484-942-4457

Oct. 29, 2016 Virginia
Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Trick or Trot 5K Monster Dash
Robious Landing Park; Midlothian
Contact: Terry Stone 703-795-6269

Oct. 29, 2016 Washington
Bleeding Disorders Found. of Washington
206-533-1660, bdfwa.org
Bloody Fun Run
Green Lake Park; Seattle
Contact: Jeff Johnson 360-553-6402

Oct. 29-30, 2016 Vermont
New England Hemophilia Association
781-326-7645,
newenglandhemophilia.org
Fallfest
Hilton Burlington; Burlington
Contact: Cheryl Ashmore 207-479-0288

Nov. 4-5, 2016 Ohio
Northern Ohio Hemophilia Foundation
216-834-0051, nohf.org
Annual Sponsorship and Family Fall Fest
Doubletree Hotel; Independence
Contact: Shelia Biljes 440-813-1626

Nov. 5, 2016 Tennessee
TN Hemophilia & Bleeding Disorder Found.
615-900-1486, thbdf.org
Race for Ian
Trinity Baptist Church; Jonesborough
Contact: THBDF 615-900-1486

Nov. 5, 2016 West Virginia
West Virginia Chapter of NHF
681-212-9255, wvnhf.org
Annual Meeting
Stonewall Resort; Roanoke
Contact: Tina McMullen 484-942-4457

Nov. 6, 2016 Arizona
Arizona Hemophilia Association
602-955-3947, arizonahemophilia.org
Arizona Hemophilia Walk
Phoenix Zoo; Phoenix
Contact: Kelly Gonzalez 702-858-2525

Nov. 6, 2016 Illinois
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Celebrating Hispanic Heritage Month
Nat. Museum of Mexican Art; Chicago
Contact: Eva Kraemer 608-852-3777

Nov. 9, 2016 Ohio
Central Ohio Chapter of NHF
614-985-3752, nhfcentralohio.org
Der Dutchman Annual Dinner
Der Dutchman Restaurant; Plain City
Contact: Rania Salem 513-470-5500 or Shelia Biljes 440-813-1626

Nov. 9, 2016 Ohio
TriState Bleeding Disorder Foundation
513-961-4366, tsbdf.com
Annual Meeting- Ask the Docs
The Phoenix; Cincinnati
Contact: Rania Salem 513-470-5500

Nov. 11-13, 2016 Tennessee
TN Hemophilia & Bleeding Disorder Found.
615-900-1486, thbdf.org
Teen Summit
Brandon Spring Group Center; Dover
Contact: THBDF 615-900-1486

Nov. 12, 2016 Pennsylvania
Eastern Pennsylvania Chapter of NHF
484-445-4282, hemophiliasupport.org
Turkey Trot 5K Run/Walk
Calvary Church; Lancaster
Contact: Tina McMullen 484-942-4457

Nov. 14, 2016 Florida
Florida Hemophilia Association
305-235-0717, floridahemophilia.org
Swing for the Kids
Lago Mar Country Club; Ft. Lauderdale
Contact: Hector Heer 954-940-1248

Nov. 17, 2016 Nevada
Factor Support Network and HTC NV
702-732-1956, factorsupportnetwork.com
Infusion Clinic
HTC 6th Fl.; Las Vegas
Contact: Kelly Gonzalez 702-858-2525

Nov. 17-19, 2016 Florida
FL Assoc. of Pediatric Tumor Programs
813-396-9528, faptp.epi.usf.edu
39th Annual Advances in Pediatric Hematology/Oncology
Hyatt Regency Grand Cypress; Orlando
Contact: Dave Burgeson 239-784-4565

Nov. 19, 2016 Nevada
NHF Nevada Chapter
702-564-4368, hfnv.org
Annual Meeting
City of Henderson Convention Center
Contact: Kelly Gonzalez 702-858-2525

Nov. 24, 2016 Indiana
Hemophilia of Indiana
317-570-0039, hoii.org
Thanksgiving Day Run
Dillon Park; Noblesville
Contact: Enrique Morey 317-999-7912

Dec. 1, 2016 Arizona
Arizona Hemophilia Association
602-955-3947, arizonahemophilia.org
Arizona Golf Tournament
Ocotillo Golf Club; Chandler
Contact: Kelly Gonzalez 702-858-2525

Dec. 3, 2016 California
Central CA Hemophilia Foundation
916-296-9066, cchfsac.org
CCHF Annual Holiday Event
Gibbons Park; Sacramento
Contact: Sean Hubbert 916-296-9066

Dec. 3, 2016 South Carolina
Hemophilia of South Carolina
864-350-9941, hemophiliaofsouthcarolina.net
Year-End Meeting & Holiday Celebration
Embassy Suites Hotel; Columbia
Contact: Peggy Gay 864-275-0246

Dec. 3-4, 2016 Maine
Hemophilia Alliance of Maine
207-312-4448, mainehemophilia.org
Winterfest
Samoset Resort; Rockland
Contact: Cheryl Ashmore 207-479-0288

Dec. 4, 2016 Ohio
Northern Ohio Hemophilia Foundation
216-834-0051, nohf.org
NOHF Holiday Event
Cleveland Aquarium; Cleveland
Contact: Shelia Biljes 440-813-1626

Dec. 4-5, 2016 Louisiana
Louisiana Hemophilia Foundation
225-291-1675, lahemo.org
LHF Annual Meeting
Crown Plaza Hotel; Baton Rouge
Contact: Brad Nolan 704-806-0970

Dec. 7, 2016 Nevada
NHF Nevada Chapter
702-564-4368, hfnv.org
Elko Family Day & Winter Celebration, Hilton Garden Inn; Elko
Contact: Kelly Gonzalez 702-858-2525

Dec. 8, 2016 Nevada
NHF, Nevada Chapter
702-564-4368; hfnv.org
Reno Family Day and Winter Celebration
Katherine Dunn Elementary School
Sparks
Contact: Kelly Gonzalez 702-858-2525

Dec. 9, 2016 Idaho
Idaho Chapter of NHF
208-351-4785, Idahoblood.org
Annual Family Conference
Wahooz Family Fun Zone; Meridian
Contact: Gaby Zamora 925-234-2451

Dec. 10, 2016 California
Hemophilia Foundation of Southern CA
323-525-0440, hemosocal.org
Snowflake Festival
Hotel Maya; Long Beach
Contact: Marina Vera 323-252-8682

Dec. 10, 2016 Illinois
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Holiday Party
William Tell Holiday Inn; Countryside
Contact: Eva Kraemer 608-852-3777

Dec. 11, 2016 Kentucky
Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
Holiday/Year-End Family Event
American Legion Highland Post
Louisville
Contact: Rania Salem 513-470-5500

Dec.18-19, 2016 California
Hemophilia Alliance of Orange County
310-415-2390, haoc.org
HAOC Holiday Party
Hotel Irvine; Irvine
Contact: Heather Messerly 619-787-0916

Dec. 23, 2016 Indiana
Hemophilia of Indiana
317-570-0039, hoii.org
Holiday Party
Madison County Shrine Club
Anderson
Contact: Enrique Morey 317-999-7912

Hitting a Home Run
Staying Active with Hemophilia

Interview by Justin Lindhorst

“RUN – RUN – RUN – RUN!” the base coach shouted as Nicholas rounded third and headed for home. Crossing home plate, his teammates and supporters in the stands let out a hearty cheer. A few months later, I still remember his grin as he exchanged high fives with teammates in the dugout. Nicholas is six years old and has severe hemophilia A. For people with hemophilia, staying active is an important part of strengthening joints and muscles to help prevent bleeding episodes.

One way Nicholas stays active is through participating in his local T-ball league. Mom Veronica shares, “Nicholas started watching baseball around the age of 2. He always loved throwing a ball.” Though she had some initial concerns, Veronica decided to get him involved in T-ball. She explains, “I want Nicholas to grow up being aware he has a condition that needs to be accounted for, but don’t want it to stop him from trying new things. I definitely don’t want him to be defined by his bleeding disorder. Although that’s easier to say than do. I’ll never forget his first practice. I was so filled with fear…for a moment I could not believe I willingly signed him up. It was all worth it in the end when he rushed over after practice and exclaimed, ‘Did you see me mom? I did it! I’m just like the other kids!’”

After an exciting game on an unusually cool summer day, I had the opportunity to talk to Nicholas a bit about playing T-ball. He was very expressive about his involvement and wanted to share some of his experience with other members of the bleeding disorders community. Check out our conversation below!

J: What is your favorite part about playing T-ball?

N: EVERYTHING! I really like hitting the ball.

J: How do you stay safe while you play T-ball?

N: Well, you really have to watch the ball. You have to pay attention. Take your factor.

J: What have you learned from playing T-ball?

N: To always pay attention and always watch the ball. How to play with other kids and listen to the coach.

J: What advice would you give to other kids with bleeding disorders who want to play T-ball?

N: Always be careful. Make sure to tell your coach about hemophilia. Always be safe (I was asked to write that 100 times, but hopefully just once gets the point across).

J: How long have you played t-ball?

N: 3-years

J: What’s your favorite position to play?

N: First base because everyone throws the ball at you.

J: Who is your favorite baseball team and favorite baseball player?

N: The Angels. Mark Trumbo!

Nicholas definitely enjoys his T-ball. For Nicholas, the game is not just a way to make friends or learn the importance of teamwork and develop good hand-eye coordination, but also a way to strengthen joints and muscles to prevent bleeding episodes. When I asked Nicholas what he looks forward to the most about continuing T-ball he immediately and eagerly shared, “When the coach starts pitching us the ball!” Adhering to his prophylactic regimen and backed up by a strong support network consisting of his mom, extended family, HTC and homecare company, Nicholas will be sure to hit it out of the park!

Hi Kids!

Time for Fun!

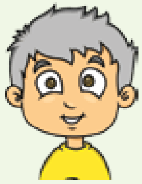
True or False? Fact or Fiction? Truth or Myth?

Have you heard some ideas about bleeding disorders that you know are not true? Some myths about bleeding disorders are often funny when you know the truth. See if you can identify which of the following statements are true and which are false. Mark a "T" for True and an "F" for False on each of the statements below. Answers are on page 31.

___ 1.) All people with hemophilia come from royal families and are related to Queen Victoria.

___ 2. Although most people with hemophilia are boys, girls can have hemophilia too.

___ 3.) Hemophilia goes away 3 days after your 23th birthday.



___ 4.) Having a bleeding disorder will turn your hair grey.

___ 5.) Von Willebrand disease is a lot more common than hemophilia.

___ 6.) Kids with a bleeding disorder can play many sports if they take proper precautions.

___ 7.) Drinking lots of orange juice and eating sour lemons will control bleeding.

___ 8.) A paper cut is the worst kind of bleed ever.

___ 9.) Wearing big, dark sunglasses helps find the vein when self infusing.

___ 10. With proper medical care and treatment, most people with a bleeding disorder can live a long, happy life.

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

SuDoku!

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

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

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