Winter 2015

Volume 10
Issue 1

A quarterly publication
Dedicated to Making a Difference
by educating, empowering and enriching the lives of families living with hemophilia, vWD and other bleeding disorders

Matrix Health News

a publication of

Matrix Health Group

Dedicated to Making a Difference
in the Lives of People with Hemophilia, vWD and other Bleeding Disorders

Highlights in this Issue...

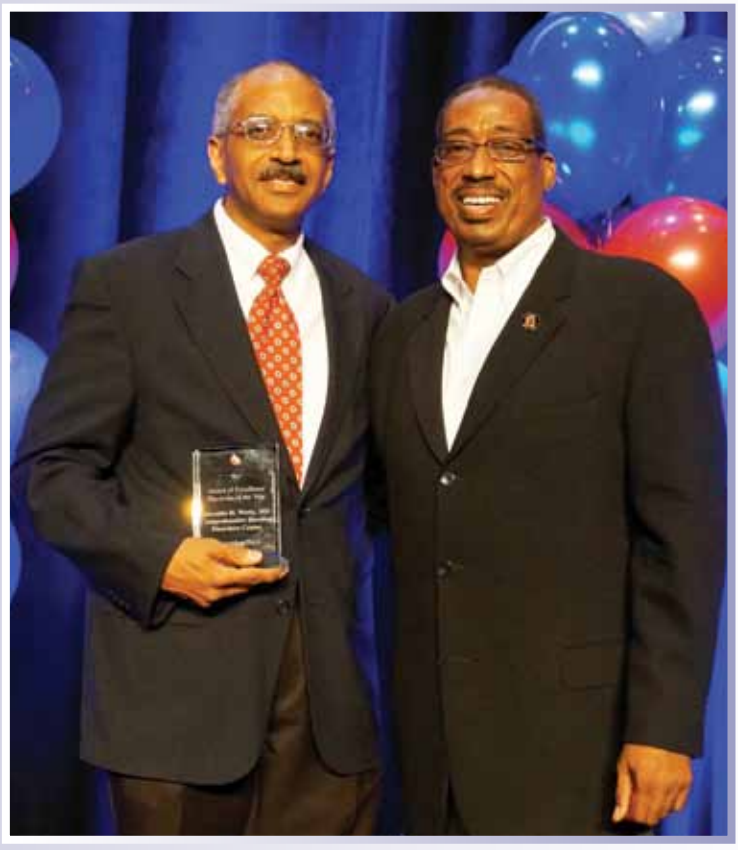
Important Announcement!

2014 NHF Recap

NOHF Fall Festival

NHF's Physician of the Year

The Health Advocate



Dr. Osvaldo Wesly
NHF's *Physician of the Year*
with NHF CEO Val Bias (right)
Story on page 10

Matrix Health Group

Dedicated to Making a Difference!

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Matrix Health News

Winter 2015 - Volume 10, Issue 1

Editor-in-Chief: Maria Santucci Vetter
Editors: Susan Moore and Justin Lindhorst

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

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

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

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

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

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

CONTENTS

A Note from the Editor . . . page 4

FACTOR Rx SUPPORT NETWORK *A Special Announcement!* . . . page 5

NHF 2014 Recap . . . page 6

NO HF **Northern Ohio Hemophilia Federation**
Family Fall Fest . . . page 9

Physician of the Year! *Osvaldo Wesly, MD* . . . page 10

Our Welcome to the World of Hemophilia . . . page 12

THE HEALTH ADVOCATE . . . page 14

Matrix on the Move! **Upcoming Events** . . . page 26

Time for FUN! . . . page 27

Like us on Facebook!

Visit us today to learn more about our specialty pharmacy and support services, read popular articles from ***Matrix Health News***, view photos, learn about our upcoming events and find information on the bleeding disorders community.

"Like" our page to see how we are ***Dedicated to Making a Difference*** in the lives of individuals with hemophilia, vWD and other bleeding disorders!

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

A Note from the Editor

Dear Readers,

Happy New Year! We at Matrix Health Group hope 2015 is off to a good start for you, your family and friends, and we wish you good health, prosperity and joy in the New Year.

Matrix Health Group is *Dedicated to Making a Difference* in the lives of individuals with bleeding disorders and other chronic health conditions. Our "Making a Difference" segment highlights community members, medical professionals and organizations who make a positive impact for those living with hemophilia and von Willebrand Disease. Our cover story focuses on Dr. Osvaldo Wesly and his work at the Comprehensive Bleeding Disorders Center (CBDC) headquartered in Peoria, Illinois. Please read about his dedication to the community on page 10.

We are excited to introduce a new feature of our newsletter titled *The Health Advocate*. Paul Brayshaw, Director of Healthcare Advocacy and Programs will highlight the current advocacy efforts underfoot in the bleeding disorders community. Our needs cannot be met unless they are heard and we look forward to providing a venue for that voice. As a community we should seek to connect and expand our advocacy efforts, Matrix Health Group looks forward to playing a role in that process.

May 2015 prove to be a fulfilling, wonderful year for each and every one of our community members!

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

Now Available!

2015
Spectacular Life!
Calendar

Packed with tons of photos of community members, our calendar highlights just how amazing life can be, even with a bleeding disorder!

Call, send an email or visit our website to request your complimentary calendar before they are all gone!

877-337-3002
info@matrixhealthgroup.com
www.matrixhealthgroup.com

Available while supply lasts

Attention TRICARE Patients

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

TRICARE APPROVED!

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

We look forward to hearing from you!

We offer:

- Experienced, compassionate Care Coordination Team with a personal contact assigned to you for your pharmacy, reimbursement and support services
- Specialized, knowledgeable Pharmacy Staff with a comprehensive line of factor products and complementary supplies
- Located in Weston, Florida and Bartlett, Tennessee - our services reach across the nation
- 24-hour delivery with emergency same-day shipments available
- Interactive physician relationships providing you with custom treatment plans
- Specialty team of Reimbursement Facilitators dedicated to assist you with private and government insurance reimbursement needs
- Informative quarterly newsletter, *Matrix Health News*

Matrix Health Group

A Special Announcement

Our family is growing!

FACTORRx SUPPORT NETWORK

Our model of care is centered on fostering the health and wellbeing of each individual we are privileged to serve. In order to provide the very best for our patients, Matrix Health Group has been expanding through acquiring specialty pharmacies with similar values and a focus on high-touch, patient centered care. Our 2011 acquisition of Medex BioCare near Memphis, Tennessee was the first step in this process and we are pleased to share with you exciting news about our most recent acquisition of Factor Support Network in Camarillo, California.

Factor Support Network was founded in 1994 and offers nationwide pharmacy and support services aimed at improving patient outcomes. Their accredited pharmacy, comprehensive advocacy and educational services makes this is an organization we are very proud to partner with. Matrix Health Group Chief Executive Officer Bruce Greenberg affirms, "We are extremely excited to welcome the wonderful people at Factor Support Network into the Matrix Health Group family. We have the utmost respect for the company and this acquisition allows us to better serve the bleeding disorder community with a common philosophy, and now expanded ability."

Factor Support Network President Terry Rice notes, "We have always been about empowering patients to achieve their highest quality of life. This has been our mission for the past 20 years and it is important that this mission continue. Matrix Health Group shares these values and our combined efforts will enhance our ability to meet and exceed the diverse needs of those we serve. We are excited and pleased to move forward together with the united purpose and resolve to *make a difference*."

This partnership expands the national footprint of Matrix Health Group and more importantly, allows our organization to bring a model with proven positive health outcomes to more individuals. By maintaining our commitment to the communities we serve and utilizing our Guiding Principles of Integrity, Dedication, Compassion, Enthusiasm and Enrichment as a compass, Matrix Health Group will continue our efforts to provide the very best in pharmacy and support services for the bleeding disorders community.

NHF 2014 RECAP

History comes full circle as NHF's 2014 Conference welcomes attendees to our Nation's Capital where our voices make change.

By Terry Stone and Eva Kraemer

The sun was shining brightly on a colorful fall day as if to warmly welcome the NHF and all attendees from near and far to America's Hometown, Washington DC. Many of us have walked the halls of Capital Hill advocating for the needs of this community. For others the NHF meeting provided the perfect opportunity to pay their first visit to "America's Hometown." Yes, we are here often, and this is hometown to us all who have come to make change.

The bleeding disorders community is no stranger to Capital Hill. From the grass roots efforts that led to the passing of the Ricky Ray Hemophilia Fund Act signed into law in 1998, which provided help to those affected with HIV/Aids from contaminated blood products, to celebrating 20 years of Blood Safety thanks to the efforts, stories, and voices of so many. It is here in our Nation's Capital that we speak up, advocate for our needs, and it is here where together as a community we convened at the historic Marriott Wardman Park Hotel September 16–18th to unite, reconnect, celebrate our past accomplishments, and plan for the future, TOGETHER!

President Val Bias kicked off the conference with an inspiring message that reflected on the successes of the past while reminding us all that our work continues. Val shared that our mantra could be "Nothing about us, without us" and spoke about current initiatives like *The Comprehensive Care Sustainability Collaborative* (CCSC). Launched in July, this effort will bring payors and hemophilia treatment centers together to improve care and sustain the comprehensive care model that other patient groups have emulated.

Matrix Health Booth Team! Stephen Lawrence, Terry Stone, Maria Vetter, Justin Lindhorst and Eva Kraemer.

Also, his excitement was shared regarding the *My Life, Our Future Genotyping Initiative* that is moving full speed ahead with more than 1,500 people currently enrolled in the program. A partnership between NHF, the American Thrombosis and Hemostasis Network, Puget Sound Blood Center and Biogen Idec, their work has already discovered 68 new mutations. Participants can take a free blood test that enables them to learn more about their own specific mutation. Secondly, they also have the option to contribute their data and samples to a central repository. Once 5000 participants are reached, scientists will be able to apply for access to this information which could lead to improvements and care and continuing advancements. So whether you walk the halls of Capital Hill or participate in the current initiatives by being tested and sharing your data, everyone can move progress forward in their own way.

NHF always packs a full agenda for all those who are able to attend and this year was no exception. Thursday commenced with a reception for new families to meet and greet, and develop new relationships with other families as they begin on their life-long journey of learning and growing. Other programs included *Communicating with Your Provider about Pain*, *Fighting the Stigma of Disability*, *Hepatitis C Updates*, *Victory for Women: Women and Aging*, *Caregivers Roundtable*, *Ethical Dilemmas in Our Community*, *Siblings: How to Step Out of Their Shadow*, *We Are Family! African American Voices* and *vWD Family Celebration*.

Matrix Health Group

Matrix Health Group

Together Making a Difference!

FBI

There was an Afterglow Lounge at the end of the evening for families to network in a more relaxed environment, complete with snacks and beverages.

Artwork created by community members was proudly displayed.

Emily stops for a photo with her son, "The Man, The Legend," Barry Haarde.

Friday was another education-packed day; there were industry symposiums on *Being More Active with Hemophilia*, I*f It Matters to You, It Matters to Us*, which addressed scientific information and *Pain Management and Increasing Functional Ability for Patients with Hemophilia with Inhibitors*. More roundtable discussions were facilitated in English and Spanish about *Parent's Expectations after Diagnosis*, *Guilt: The Blame Game*, *Dad's Empowerment*, *Career, College and Beyond* and *It Must be True! I Saw it on the Internet*, *Expectations with Sports*, *Traveling* and *Relaxation Techniques During Infusions*. *Victory for Women* offered a session about women thriving with a bleeding disorder and Spanish speakers were able to participate in a session about music therapy for pain management.

The afternoon concluded with the presentation, *HIV and World Federation of Hemophilia Updates*. Friday also showcased Illinois' beloved Greg McClure, MA, MS, LSW, as he led the *Remembrance and Celebration of Life*, something he does every year to provide the community time to reflect upon and celebrate the lives of our loved ones, both living and departed.

Saturday, the last day of sessions, provided everyone with more symposiums highlighting success in the community and understanding prophylaxis treatment. Sessions also included *Ask the Experts: Inhibitors*, *Addressing Your Insurance Claims*, *Mindfulness*, *Support for School Issues*, *A Conversation about Creativity*, *Respect my Diversity*, *Disaster Preparedness*, *Healthy Cooking* and *Coping with Chronic Illness*. Saturday also featured the *Awards of Distinction and Excellence Luncheon*.

For those looking for a break from the educational sessions, there were fun and games and great information at the many exhibitor booths in the exhibition hall. The Matrix Heath Group team was at the ready to welcome all who stopped by for a visit. We had a terrific time visiting with folks while we watched our very talented caricaturist draw some "spot on" portraits. The Matrix cookbooks and spatulas were a real hit this year, and we raffled a *Bleed Recovery Basket* packed with things to make you feel better as you rest from a bleed. It was full of soothing items including a cozy blanket and a Kindle Fire with a gift card to name a few. Our lucky winner was the Yasmin P. family of New Jersey.

Evening events included a variety of options that moved people out of the hotel and into the city to see all that DC has to offer! Dinner at the Smithsonian's National Zoo Tiger Den was a roaring success! For those who might have been concerned that they might "be" dinner rather than *having* dinner at the zoo, there were industry dinners around town at some of Washington's best restaurants. The closing night event was out of this world…or at least you could see how they got there as families were treated to private access at the Smithsonian National Air and Space Museum.

So as the convention and biggest family reunion ever came to a close, it was evident that this gathering in the shadow of our national monuments and government halls was one to be remembered. As families packed for the trip home, promises were made to see one another soon, and that they will as Washington Days are just around the corner. To the Hill, and beyond! Nothing about us, without us!

Final Night Event began with a wonderful dinner...

and concluded with fun at the museum!

Northern Ohio Hemophilia Foundation

Family Fall Fest

By Dan Holibaugh

It's a sure bet to say that most everyone has been to meetings, conferences or symposiums that were not all that interesting and perhaps even a little boring. Well, not this time. A full house of attendees with high expectations had been looking forward to this year's Northern Ohio Hemophilia Foundation's (NOHF) *Family Fall Fest and Annual Meeting*, and they were not at all disappointed. Held the weekend of October 17-18, NOHF celebrated their 60th year as a chapter and it may well have been the very best annual meeting ever. This is one of the oldest and largest chapters in the country, serving 24 counties in the northeast quarter of the state.

Tanya Ricchi, Val Bias, Dr. Glenn Pierce and Randi Clites

Matrix' Dan Holibaugh and Susan Moore with Tanya Ricchi (center)

On this weekend in the Rock and Roll Hall of Fame city, rock stars such as Cleveland's own Dr. Glenn Pierce, NHF CEO Val Bias, HFA's Executive Director, Kim Haugstad and HFA Communications Director, Rich Pezzillo were live on stage and most definitely rocked the crowd. Friday evening began with a social hour, exhibits and raffle prizes being drawn. Following a warm welcome from Interim Executive Director Tanya Ricchi was a fabulous dinner and soon the official opening program was underway! The theme of the symposium centered on all that has happened within the bleeding disorders community throughout the last 60 years. Each of the three prestigious speakers walked us through their presentations using actual photographs of our community from newspapers and personal archives.

One of our young contemporary leaders Rich Pezzillo opened the sessions with an interactive look at our community's timeline. The evening wrapped up with breakout discussions on subjects such as *Women's Task Force*, *Dad's in Action*, *First Steps*, *Blood Brotherhood* and the *NOHF Board*. An ice cream social sponsored by HFA along with family swim time followed.

The programs began the following morning with Val Bias describing his role as NHF's CEO and the long road of personal experience and commitment to our community that brought him here. He spoke of finding a voice from within and learning the importance of advocating for the community.

Glenn Pierce MD, PhD. spoke next, accompanied by a slide show featuring his remarkable life. Born with severe hemophilia and brought up in the projects of Cleveland's west side by a single mom in the 50's was probably not what most of us would describe as a propitious launching into life. He did however thrive to become a revered scientist and has since dedicated his work to finding a cure for hemophilia.

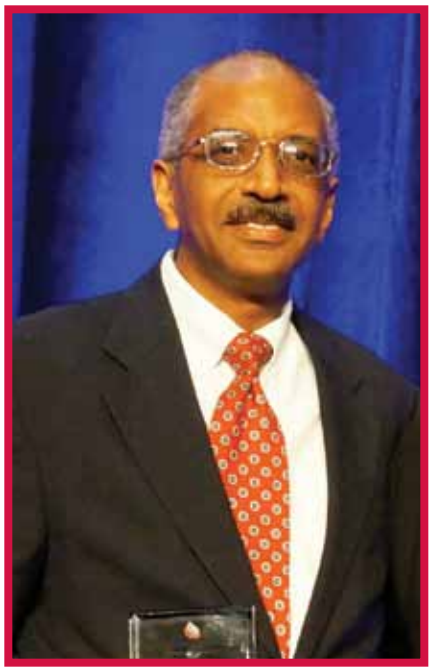
While datelining the last 60 years of the hemophilia population's struggles as well as advancements, all three speakers, Rich, Val and Dr. Pierce highlighted the most difficult times when we were losing loved ones to AIDS in the 80's and 90's. The speakers connected the dots, historically speaking, with reference to the different organizations such as COTT, MANN and WONN that worked together during the very difficult years of this crisis, and the leaders that rose to find answers and accountability to affect change. As we were reminded of the struggles of the past we were also encouraged to recognize the significant advances in care and safety that have been made in the last few decades. The teenagers in the audience were pointed out as being the next leaders in our midst and asked to become involved as they take the reins and move our community into the future.

Dr. Jeffrey Hord from Akron Children's Hospital HTC presented next with a 101 synopsis of hemophilia and Dr. Alvin Schmaier from University Hospitals Case Medical Center gave an overview of von Willebrand Disease and treatments. A question and answer opportunity followed each session. After lunch, the weekend wrapped up with the NOHF Board business meeting and presentations of awards.

Matrix Health Group would like to thank Interim Executive Director Tanya Ricchi, Program and Advocacy Director, Randi Clites and LaChandra Oliver for developing a great event and bringing such notable speakers to the program. NOHF...60 years and going strong!

Osvaldo Wesly, MD

Physician of the Year!



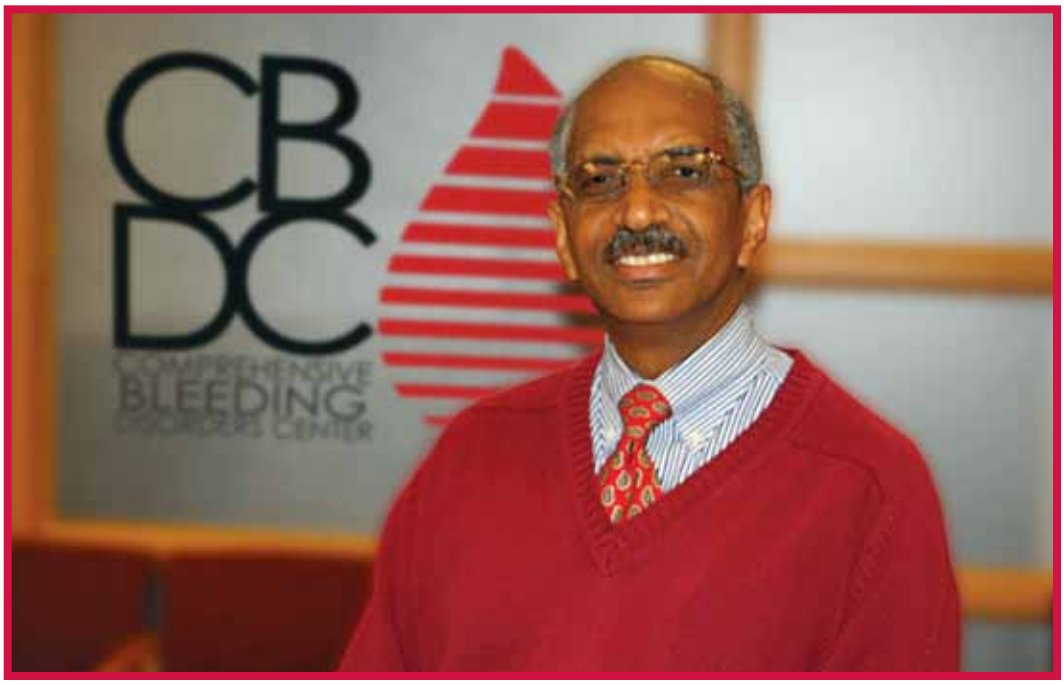
Dedicated to Making a Difference!

With over 25 years' experience with hemophilia and other blood disorders, Dr. Wesly has provided outstanding care for patients at the Comprehensive Bleeding Disorders Center (CBDC) since 2010. This year at the National Hemophilia Foundation's 66th annual meeting, Dr. Wesly received the 2014 "Physician of the Year" award. This distinctive honor is given to physicians who have influenced the lives of their patients through compassionate care, comprehensive knowledge of the latest treatments, and demonstrating a commitment to advocating for the needs of patients served.

"For Dr. Wesly to receive this award and be recognized at this level affirms all of the hard work and passion that he brings to the center," said CBDC's Executive Director, John Redington. "We are very privileged to have him as part of our organization. This man excels at everything he puts his mind to. Wesly's patients agree.

"Doctor Wesly and his team have had a major impact on me. He and his staff have always made me feel comfortable and have provided me solid medical and personal advice when it comes to setting and reaching my health and other goals," affirms Tony, a young man with severe hemophilia.

Left to right:
Tom Joseph, Outreach Coordinator; Ryan Hinnen, Marketing Coordinator; Dina Witter, Nurse Coordinator; Dr. Osvaldo Wesly, Medical Director; Kathy Kiefer, Executive Assistant; and John Redington, Executive Director



Carmen notes, "He sees us with such love. It's a sincere love. He attends to my son and grandson with such tenderness."

Michael states, "He cares. We have tons of hematologists in the state of Illinois. I can have any doctor do the blood work, but Dr. Wesly cares about me and that's what matters the most."

As a student, Dr. Wesly has studied at some of the most prestigious universities in the United States including the University of Wisconsin-Madison. He is multi-lingual with fluency in English, Spanish and Polish. As a research fellow, he studied under Dr. Howard Temin, a Nobel Prize winner. He also served as a clinical instructor while completing his genetic and immunology research at the University of Wisconsin - Madison. He was then accepted into the world-renowned Fred Hutchinson Cancer Research Center in Seattle, Washington where he trained under a second Nobel Prize recipient, Dr. E. Donnal Thomas.

Wesly has been involved in teaching medical students, residents and fellows throughout his career, was voted "Professor of the Year" at the Southern Illinois University School of Medicine and has been counted among the best oncologists in the state of Illinois by the American Cancer Society.

Outside of his medical career, Wesly is an avid reader, history buff, and enjoys staying up-to-date on worldwide news and events. He and his wife, Jadwiga (also a physician) have three children and call Springfield, Illinois their home.

Whether traveling to under-served areas in the state or providing expert medical advice to patients at the CBDC headquarters, Dr. Wesly is a man dedicated to his practice. His patients, co-workers and peers all agree that his experience, compassion and unwavering dedication sets him apart as a doctor and as a leader.

We recognize Dr. Wesly and his team for their hard work and commitment to *"Making a Difference"* in the bleeding disorder community. Congratulations on being awarded the 2014 National Hemophilia Foundation Physician of the Year!

Our Welcome to the World of Hemophilia

By Heather Messerly

February 28 is Rare Disease Day, and although I prefer to think of my son's hemophilia as a disorder rather than a disease, it is a great day to bring awareness to all those affected by rare conditions. Here is my son's story.

My beautiful son Trevor was born in Yigo, Guam, late in the evening of February 25, 2003. He was perfect and I couldn't wait to bring him home to meet his four siblings. I opted to have him circumcised, which would take place the following day, and then a couple hours later I would be able to bring him home.

The next day after his circumcision, I was dressing Trevor in a cute new outfit to bring him home, but as I changed his diaper I found it was covered in blood. I was sure the surgeon who performed the procedure had hit his dorsal artery and as I went to give the surgeon a piece of my mind, a hospital CODE RED was called for my son. Trevor was whisked away and taken into emergency surgery. He came back with his penis stitched and tightly wrapped. "Bring him back on Monday, we will remove his bandages and all will be fine," I was told. So I took my baby home.

After the weekend I took Trevor back to the hospital as instructed. The bandages were removed and he was still actively bleeding. Panic set in as the medical professionals and I all realized there was something seriously wrong, but I was told the medical center in Guam did not have the capabilities to diagnose or treat him. A medivac flight was arranged immediately – a chartered Air Force hospital jet from Okinawa would arrive the following morning to take Trevor and me to Tripler Hospital in Hawaii. All night the most amazing nurse sat with Trevor and applied pressure to the spot where he was bleeding. I sat by his side crying.

The following morning an ambulance arrived to take us to the jet. A medical team was traveling with us, including the surgeon who preformed the circumcision. Lights on and sirens wailing

through the streets of Guam, no stopping at the airport, straight to the runway where the plane was waiting. Trevor was put into a sort of incubator with tubes and alarms hooked up

all over him with a constant staff watching and checking on him. During the flight alarms began to ring, he had lost so much blood that his blood pressure and oxygen levels had dropped to dangerous levels. There was nothing anyone could do. I sat on the plane looking at my beautiful son while tears streamed down my face...and at that moment, I lost all faith.

In Hawaii, we were quickly escorted to an ambulance waiting on the runway and rushed to Tripler Hospital. As soon as we arrived, Trevor was taken away from me and I was told to sit and wait. I sat and waited, and cried some more, surprised there were any tears left. After what seemed like an eternity (but was actually about an hour and a half) a pediatric hematologist came to speak with me.

"Your son is stable now. He has severe hemophilia A. We have started factor replacement therapy and for the moment, the bleeding has subsided. Do you have any questions?" Yes, I had questions - where to begin! My first inexperienced question was, "Will he get AIDS?" and my second, "Can you fix him so he and I can go back to Guam to my other kids?" Obviously, I had a lot to learn about hemophilia. The doctor continued, "He lost a lot of blood and we have many tests to run to make sure there are no other complications. Plus, he will need to stay until we are sure the bleeding is under control. Would you like to see him?" Holding my baby in that moment was all I cared about. I held him tight, cried on him and told him I loved him. I spent the night with him in the neonatal intensive care unit (NICU), but I did not sleep. I stayed up all night looking at my amazing son, kissing and rubbing his head, and singing to him. Trevor spent the next week in the NICU then was transferred to the pediatric intensive care unit (PICU). Thankfully, he had no other complications.

So I was given my first welcome into the wonderful, crazy world of hemophilia. While that initial experience was nothing short of gut wrenching, as Trevor has grown so too has our experience in managing his condition. Having a bleeding disorder has not defined Trevor or his childhood. Though we may face bumps in the road from time to time, we have learned to adapt and address challenges as we face them. Along the way we have met amazing fellow community members and have found a second family among them. These people and our collective experience have become a part of who I am today - and I would not change that for anything.

Trevor (center) and his siblings,
Madison, Jordan, Alexis and Brandon

Matrix Health Group

The Health Advocate

Patient Focused Drug Development for Bleeding Disorders

Paul R. Brayshaw, M.P.H.
Director of Healthcare
Advocacy and Programs
Factor Support Network,
a division of Matrix Health Group
Client Services Representative,
Mid-Atlantic Region

In September the Federal Food and Drug Administration (FDA) hosted a public meeting on Patient Focused Drug Development for Hemophilia A, Hemophilia B, von Willebrand Disease and other Heritable Bleeding Disorders. The FDA is responsible for protecting the public health by assuring the safety, effectiveness, quality and security of human and veterinary drugs, vaccines and other biological products and medical devices. The meeting was an opportunity for patients and the public to meet with FDA officials to discuss the effect of bleeding disorders and to allow the agency to gather patients' perspectives on current approaches to treatments.

Specific questions provided to panelist prior to the meeting sought to gather real life patient data experiences regarding symptoms and aspects of the condition having the most significant impact on quality of life and how patients manage their bleeding disorder.

At the conclusion of the meeting, based on the testimony of community members, it was apparent that our genetic, chronic condition is the basis for many of our physical and mental health challenges. Joint damage and related pain, infections, prolonged and heavy bleeding during menstruation and fatigue were some experiences shared throughout the discussion. It was also clear that if patients and families affected by bleeding disorders successfully manage the condition and its symptoms, quality of life is greatly improved and complications can be significantly reduced.

This patient-centered meeting was an attempt by the FDA to gather insight into the lives of people with bleeding disorders, and its success will be clearer as future rules and regulations are implemented. The personal experiences of patients with bleeding

disorders may assist the Agency and encourage future communications focused on access to medications, therapies and delivery of care. However, until the Agency responds to the issues discussed at this first meeting, it will be difficult to gauge its real impact. Among rare diseases like hemophilia and other bleeding disorders, patients are fortunate to have therapeutic options to effectively treat their particular condition, and it is very important that we maintain access to these and new options as they become available.

Such meetings are very important and as a community we should always be on the lookout for opportunities to get involved and be heard. Our unique experiences provide a very important context for government agencies such as the FDA to consider during any regulatory decision-making regarding the bleeding disorders community. As we begin this new year make it a goal to involve yourself in some capacity with advocacy. Your voice, your story, your experience is invaluable information for decision makers who have the potential to affect all of us in the community. During a time when the spotlight is on healthcare reform we must take the opportunity to advocate for the needs of our community. Check in with your local chapter and their initiatives, bookmark the public policy/advocacy webpages of the Hemophilia Federation of America and the National Hemophilia Foundation and be sure to check back here with the Health Advocate quarterly.

About the Author

Paul Brayshaw graduated from The George Washington University School of Public Health in Washington D.C. in 2005, earning a Masters in Public Health. With a career spanning various roles in government and healthcare, Paul has been employed as a Legislative Assistant by the United States House of Representatives, and subsequently as a Program Analyst in the United States Department of Health & Human Services where he helped to administer compassionate payments to individuals who contracted HIV through contaminated plasma therapies, and their eligible family members and survivors. Currently, Paul is employed as the Director of Healthcare Advocacy at Factor Support Network, a division of Matrix Health Group. Residing in Northern Virginia with his wife and children; Paul also has severe hemophilia B.

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Matrix on the Move!

Idaho

Liselle Easto

On September 5th the Idaho Chapter of the NHF celebrated their 19th successful year of hosting the ***Blood, Sweat and Cheers Golf Tournament*** at the Boise Ranch Golf Course. Seventy golfers including patients from the bleeding disorder community, industry supporters and community leaders participated in this fun event, raising over $18,000 to support programs and services for people with bleeding disorders and their families in Idaho.

Ryan S., Shane B., Joe K. and Steve M. soak in a beautiful day of golf.

Tennessee

Stephen Lawrence

The ***15th Annual Royal Gala*** benefitting the Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF) was held on September 5th at the Loveless Café Barn in Nashville, Tennessee. The Royal Gala is the brainchild of Catherine van Eys, and it was under her able leadership that led to our very first Royal Gala years ago. Many of her friends and family served on that first committee and continue to support this wonderful event to this day. As the elegant evening began with the serving of hors d'oeuvres, the Master of Ceremonies Mr. Dave Nichols introduced John Jarratt, who provided beautiful piano music that filled the room. As John tickled the ivories, guests mingled and placed bids on a vast array of silent auction items. An invocation by Reverend Dr. J. Peter van Eys preceded a delicious meal and dinner entertainment by *The Jazz Alliance*.

THBDF Executive Director Amy Maddy, Robin Lawrence, Stephen Lawrence and THBDF President Suzie Harlan.

John Jarratt

The foundation took the opportunity to recognize members for their selfless work within the community, including Mavis Harrop, retired LCSW, Vanderbilt HTC. Executive Director Amy Maddy presented Mavis with the 2014 *Victoria's Cup Award*, an annual recognition for distinguished service and support to THBDF.

Everyone was gifted with the newly released book titled *The Cure for the Chronic Life.* Co-authored by breast cancer survivor and wife of NFL legend Brett Favre, Deanna Favre and Shane Stanford, a pastor who lives with hemophilia and HIV, this book discusses the importance of "overcoming the hopelessness that holds you back."

At the close of the silent auction, THBDF President, Suzie Harlan shared the story of her family and what it has been like to raise twin boys with severe hemophilia. Her story was followed by an exciting live auction and then it was time for the dance floor to fill up with those eager to move and groove to more big band music by *The Jazz Alliance*. All had a royal good time!

Virginia

Terry Stone

HACA moms enjoy gal time!

While husbands and sons watched football, the women of the Hemophilia Association of the Capital Area (HACA) quietly *passed* by their guys with little to no *interference*, and *touched down* at the home of Laura Shumway who hosted a relaxing ***Women's Day Out*** on September 7th in Reston, Virginia. It was a refreshing afternoon of amazing food and great conversation with a lovely group of women hanging out, sharing stories and just enjoying time together. The conversations varied from having babies with hemophilia, to safety tips, to body piercings and tattoos. Should you expect anything less than a spirited and jaw-dropping chat with hemophilia ladies? I think not!

After great snacks and a lively chat, the group enjoyed a tasty dinner of beef and chicken hot off the grill thanks to Laura's grill-daddy husband Dean! The event went well past the dedicated time, and yet it was still hard to break away. Many thanks to the Shumways for their hospitality, and to the attendees who missed the football game with their sweeties; the Redskins lost...again!

Ohio

Rania Salem

On September 12-14, members of the Central Ohio Hemophilia Foundation of NHF got together in the breathtaking Hocking Hills of Ohio for the ***4th Annual Family Weekend Retreat***. Families gathered at the Buffalo Lodging Company for three days of education, recreation and relaxation. Led by the Nationwide Children's HTC team, family members began with self-infusion training. It was very rewarding to witness members acquiring the tools to become independent infusers. Everyone then made way for fierce competition in the annual *Family Olympics*. A huge shout out to Joe Torrey of GutMonkey for putting on this amazing program that included games such as the ultimate egg carry, dizzy heads, balloon toss and a relay race.

Adventure followed the next day when everyone had the opportunity to select from several exciting options; the Dragon Fly Zip Line Adventure, exploring 12 miles of wooded trails on 400cc ATVs, skeet shooting from 50 different clay pigeons in 25 locations, or taking a guided nature hike from a volunteer naturalist. The fun did not end there - families geared up for the LipSync/Airband competition at the final night party. So much fun was filled into one spectacular weekend! A huge thank you goes to executive director Amanda Turner for her endless hours of organizing this amazing event. We look forward to it every year!

Illinois

Eva Kraemer

This late summer morning brought 500 walkers to the Bleeding Disorder Alliance Illinois (BDAI) ***5th Annual Hemophilia Walk*** in downtown Chicago on September 13. For the second year, BDAI hosted the Walk at North Avenue Beach, a most pleasant course winding through the Lincoln Park Zoo. Matrix Health Group, a proud sponsor of this event, is pleased to be one of the top 10 fundraising teams five years running, thanks to the dedication and efforts of our very own Lisa Miller. This fundraising event allows everyone an opportunity to gather in support of the Illinois bleeding disorder community. We look forward to BDAI Hemophilia Walk 2015!

Matrix representatives, Leo Poynton, Eva Kraemer, Lisa Miller and Matt McGrath

Texas

Tammy Davenport and Dave Burgeson

Sarah enjoys the sun.

As the weather began to change from the hot, humid dog days of summer to the only slightly cooler days of fall, local bleeding disorder community members were invited to a ***Matrix Health Group Pool Party*** on September 13. Held on the beautiful grounds of The Clubs of Kingwood, a number of families enjoyed a fun-filled day at the water park. We shared a wonderful lunch

Landon takes a big bite out of life!

with plenty of time to socialize while thoroughly enjoying this gorgeous day of fun in the sun.

Florida

Chad Brown

It's all about the kids! The Wingmen Foundation held the ***9th Annual Chippin' for Children Golf Tournament*** just outside Disney World at Champions Gate Links Golf Course on September 27th. In memory of his father, the tournament was started 9 years ago by Don Regan to benefit kids with bleeding disorders and cancer. Over the years of our association at the tournament, Don and I, both with hemophilia and a compassion to help others, decided to form the Wingman Foundation to "To support individuals and community members with chronic conditions through physical fitness, fitness education, advocacy, financial assistance of physical rehabilitation, and compassion." (www.wingmenfoundation.org) Today, proceeds from Chippin' for Children go to Wingmen Foundation's physical fitness and rehabilitation programs for chronic conditions like bleeding disorders and cancer.

The conditions for the day were overcast and rainy, which is a not unlike a typical Florida afternoon. This did not slow the enthusiasm of the 65 golfers. While registering for the day, participants had a chance to glimpse the raffle and auction items that were set up for the reception to follow the round of golf. The prizes, raffle and auction items included a brand new set of Titleist golf clubs, Pro-V golf balls, vacation trips and much more. Golfers warmed up on the range and enjoyed lunch provided by Johnny's Fillin' Station before the 1 o'clock shotgun scramble tournament. Luckily for golfers, it was a soft rain that fell on and off throughout the day, and we didn't get hit by the hard rains until the golfers were heading in. With just a little dry off time, everyone was ready to sit down for dinner and take part in the evening reception. Overall a fun and successful day was enjoyed by all!

Illinois

Eva Kraemer

Eva Kraemer with Iris C., Marcus R. and Greg McClure

Greg McClure, former social worker at RUSH University Medical Center HTC and founder of the Marcus McClure Big Dreams Foundation along with Bayer, hosted an ***educational program*** on Friday, October 3rd at Francesca's on 95th Restaurant in Oak Lawn, Illinois. Greg's presentation focused on living with hemophilia as it pertains to infants and children up to age 5. About 30 Illinois bleeding disorders community members attended. The welcoming environment as well as the expertise with which the program was presented set a perfect stage for discussion. Many new families were able to not only learn from the presenter, but also from the seasoned veteran families who raised healthy and happy infants to adulthood. I was honored to be invited and take part of a relevant program surrounded by warm and wonderful people.

South Carolina

Peggy Gay

Two families enjoy the sun: (back) Tuere, Jameelah, Nhi-Khanh, (front) Eli and Peyton.

Hemophilia of South Carolina held their ***Keeping It Coastal Family Camp Educational Weekend*** October 3-5. More than 60 families with a total of 212 registered guests arrived at the Ocean Creek Resort and Conference Center in Myrtle Beach, South Carolina.

Sue Martin Chapter President opened with welcome remarks and acknowledgements, then presented the *We are Drawn Together- Video of 65 Years of Leadership and Legacy on the Hemophilia Chapter History and Missions*. Dinner, followed by a *Family and Friends Movie and Games Night* was appreciated by all.

A refreshing early morning beach walk gave our Saturday a jump start! Breakfast and educational segments followed. Informative and interesting speakers highlighted each session and breakout gathering. Topics included *A Day of Discovery and Development* by Inalex Communications, and for teens and parents, *Ignition Transition*, *Partnering With Your School* and *Deciding If You're Camp Ready*. After posing for a group photograph, dinner started with the presentation *Hero:*

Strength in Numbers sponsored by Novo Nordisk. Entertainment and a talent show followed with lots of fun for everyone!

Virginia

Terry Stone

Taylor bowls with her litttle baby Owen!

Everyone loves camp! To ensure funding for all bleeding disorder children who dream of going to camp and having that "free to be me" experience in the state of Virginia, the Virginia Hemophilia Foundation held its ***2nd Annual Bowling for Bleeding Disorders*** event in Richmond and Virginia Beach simultaneously on Saturday, October 4th. Each location welcomed more than 70 participants ready to throw some strikes for our kids!

Bowlers enjoyed pizza, drinks and sweets during their two-game afternoon event. Door prizes added to the fun and winners were treated to great prizes. Some team names were in honor of a loved one with a bleeding disorder, while others were just showing support. Scores were good, but not as high as the spirits of the bowlers who had a fantastic day with family and friends. Collectively more than $31,000 was raised and will be put to good use next summer as excited and deserving kids prepare for Camp Youngblood at the beautiful Camp Holiday Trails in Charlottesville, Virginia.

Idaho

Liselle Easto

Eager members of the National Hemophilia Foundation-Idaho Chapter gathered for their ***Annual Walk*** to support hemophilia on the morning of October 11th. Following registration, attendees had the opportunity to greet each other, visit the vendor booths and participate in a warm up session before walking the loop. Among the walkers was actress, writer, producer and comedian Alex Borstein, aka "Lois Griffin" from television's *Family Guy*. Alex is a carrier of hemophilia and her brother has moderate hemophilia, giving her a personal connection to the community.

When the last walker crossed the finish line, everyone was treated to pizza and the opportunity to meet Alex and receive an autographed photo. A magic show and games were next on the agenda, and last but not least, Executive Director Taryn Magrini and Alex presented awards to the fundraising winners. All had a wonderful time!

Kentucky

Justin Lindhorst

On October 11th 43 teams with 260 walkers assembled at the historic Wetherby park in Louisville Kentucky for the Kentucky Hemophilia Foundation's (KHF) first ever ***Hemophilia Walk***! Participants gathered, donned their t-shirts and hit the track that runs through the beautiful park. Through the help of all the generous donors, the chapter was able to raise $35,000! Congratulations to the top three fundraising teams: Team Brody, Team Wipperman and Carter's Crew. Top individual fundraisers were Jamie B., Brody V. and Amy P. Matrix Health Group was a proud sponsor, and I was pleased to have the opportunity to participate in the inaugural hemophilia walk for KHF! Hats off to Executive Director Ursela Kamala, her hard working Board of Directors, and the many walkers and volunteers who made this event a success. Job well done!

California

Marina Vera

Marina Vera visits with young walkers.

The October 18th Hemophilia Foundation of Southern California (HFSC) ***Walk*** started off perfectly with a cool ocean breeze. While families, many dressed in Halloween costumes, excitedly waited for the walk to begin on this 'boo-tiful' day, they trick or treated at the vendor's booths. Our Matrix Health Group booth was the designated Refuel Station, offering a variety of snacks to participants.

There were fun activities for kids to enjoy like face painting and arts and crafts sponsored by the Painted Turtle Staff. When the walk was completed, lunch was served and awards presented for

Top Funding Team, Top Individual Fundraiser, Most Creative T-Shirt Design, Best Halloween Costume and more.

HFSC surpassed their fundraising goal this year by raising more than $52,000. The proceeds will help sponsor chapter programs such as summer camp, family retreat, emergency assistance and scholarships.

West Virginia

Dan Holibaugh and Susan Moore

West Virginia has a brand new Chapter (WVNHF) and they celebrated their debut with two ***Open House*** events in Charleston and Morgantown respectively. The newly NHF appointed executive director, Amber Tichnell is at the helm with the help of Board president Chris Britton and his wife Heather who is tremendously involved as well.

October 19th marked the initial Open House held in Charleston, the state capitol, at the beautiful downtown Marriott Town Center Hotel. Live music and a buffet of delectable food graced the event as consumers had the opportunity to meet with Amber, Chris and Heather as well as the industry sponsors at their booths. While face painting and pottery crafts were offered to the children by volunteers, the adults, including the mayor of Charleston, had the pleasure of attending educational break-out sessions, *Collaborating in Care: Communications With Your Provider About Pain* and *Medical Mayhem*.

Summer and Thomas visit the Matrix Health Group booth.

The following Sunday, October 26th, the Chapter hosted another highly attended event at the Riverside Hotel in downtown Morgantown. Again the attendees were treated to live music and a buffet while they met with chapter staff, board members, industry sponsors and others from the community. Available breakout sessions included *Collaborating in Care: Communicating with Your Provider About Pain* and a question and answer session with Dr. Basu, the new director of the Morgantown HTC.

Special thanks to Donna Arden, RN from CAMC HTC and Lynn Ohgren, RN WV Department of Health for attending the Charleston event and Dawn Rotellini from NHF, Dr. Basu, Dr. Ophelia Combatant and Anita Graham, LISW all from UVW Ruby Memorial HTC for attending the Morgantown event. We at Matrix Health Group wish the WVNHF all the best in the coming years!

Illinois

Eva Kraemer and Lisa Miller

Pretty ladies - Eva Kraemer with Gina W. and Ramona T.

Elegance and fine wine brought over 90 superbly dressed guests to the Bleeding Disorder Alliance Illinois' (BDAI) ***Autumnal Wine Dinner and Auction*** on October 24th in Chicago. Champagne sponsor CSL Behring delightfully selected the Columbia Yacht Club where guests were bedazzled by Lake Michigan, as illuminations from downtown Chicago glistened off the water. From beneath the covered stern of the *MV Abegweit*, guests enjoyed a four-course meal with each course accompanied by an exquisite wine pairing.

Eva Kraemer, Kathi and Carl D. and Lisa Miller enjoy the event

Many talented and generous guests donated their time and money making baskets to be auctioned in support of BDAI to continue providing education to the Illinois bleeding disorder community. Thanks to CSL Behring, BDAI and all those who came out to make the evening a success.

Maryland

Terry Stone

"It's A Family Thing!" And so it was as families of the Hemophilia Foundation of Maryland came together October 24-26th for the ***Family Education Weekend Retreat*** at the bayside Hyatt Regency Chesapeake Bay to share in a marathon of events that attendees are still talking about. Maryland may be a small state, but the chapter makes sure that members are living large during this immensely popular event each year. It continues to grow and with the hard work of Emma Miller-Clark, Executive Director and Jamie Edwards, Chapter Administrator to secure funding, the weekend agenda continues to evolve with current and timely topics for the educational

sessions while creating fun and relaxing networking activities of interest to all ages.

Factor Support Network's Paul Brayshaw with one really cool dude, Vaughn Ripley.

Families arrived Friday afternoon with free time to settle in and enjoy the hotel amenities. After a group welcome dinner and a "get to know you" networking game, the men retreated to a gentlemen-only card game. The ladies and children enjoyed the pool, a movie and other games of leisure. Saturday's early risers could try their hand (and feet, legs and back) at yoga while others gave fishing at the pier a whirl. Sessions for the day included a myriad of topics and treasured time together. From talking about encouraging self-infusion and one man's journey of living with hemophilia, to sessions on mind, body and relaxation, and updates on factor with a longer half-life to name a few; the day was filled to the brim with fun. Men's grilling party, absolutely! Tea for the ladies, you can count on it! Kids having a blast…without a doubt!

Saturday evening was highly anticipated as the theme of the gathering was *Carnival Night*. Kids were encouraged to wear their Halloween costumes and join the fun by testing their skills on the many games that industry supporters happily manned for their enjoyment. What wasn't expected, however, was the amazing talent that came forward during Camp Academy's Talent Show by the kids, which brought down the house! They practiced during the day, and it sure paid off. From dancing and singing to telling jokes and acts of all kinds, the kids of HFM really put on a fantastic performance for their parents. If that weren't enough, the kids honored Emma with a birthday surprise by walking into the conference room single file, each holding a rose and balloon, and surrounded her with love, hugs, and special treasures in honor of her special day. There was not a dry eye to be seen for miles!

Sunday's early risers could try fishing once again, after which a hearty breakfast was served. Advocacy and remembrance were the topics on the agenda for the final day. After an advocacy report, HFA's Rich Pezillo and Sonja Wilkes presented a history and remembrance session. It was a moving historical journey from the early and darker days of life with hemophilia to where we are now as a community. It honored our heroes, both the medical trailblazers and those affected in the spotlight whose stories of struggle and scrutiny put a national spotlight on this community and who then embraced the opportunity to advocate for change in care, compassion, and understanding.

As the weekend came to a close, it was quite clear this event was one not to miss. Truly it was a magical weekend for all who attended. Notes for next year…sign up early, volunteer to help out to keep the magic going, and get an agent for the chapter kids because they are all so talented!

Illinois

Eva Kraemer

Hispanic Heritage Month is celebrated in October; the Bleeding Disorders Alliance Illinois (BDAI) and Baxter provided an ***educational event*** for our Latino bleeding disorder community on October 25th. Approximately 60 community members attended the event at the National Museum of Mexican Art located in Chicago. Presenter Richard Rutschman talked about the importance of being both self-reliant and working together to get things done.

It was a beautiful way to celebrate the richness of the Hispanic culture. The group was treated to traditional dances from throughout Mexico by Back of the Yards Neighborhood Council (BYNC) Ballet Folklorico, an award winning Mexican Folkloric dance troupe. The evening allowed guests to remember their roots, and although I am not of Hispanic decent, I was treated as if I were.

Virginia

Terry Stone

As the dawn gave way to beaming rays of sunshine, the Hemophilia Association of the Capital Area (HACA) couldn't have imagined a more beautiful fall day to hold its second annual ***NHF Walk for Hemophilia*** on the grounds of the Lincoln Memorial on October 25th. The air was crisp and the wind ever so gentle as volunteers

hustled to set up tables and mark the way with signage to prepare for hundreds of walkers who plan to show their support and honor those they care for who live with a bleeding disorder. And for those who are no longer here but whose legacy continues with a new generation. This year's co-chairs, sisters Stephanie Phillips and Chrissy Kulenguski led fund raising efforts to honor their father who lived life fully with hemophilia and served the chapter for years.

Happy D.C. Walkers!

There were so many great walk teams this year with creative names and designer shirts. Team Harley Heroes – Matrix Health Group rolled in to show their support and was honored to receive the award for the most money raised by a home care company. The day started with a variety of activities for all ages. Zumba and face painting were very popular, and the deejay fed the walkers' spirits with great tunes and served as the emcee for the morning.

Groups of walkers made their way to the starting flag where the walk began promptly at 10:00 am. Walkers were treated to a beautiful view among oak trees lining the pathway along the reflecting pool and within the watchful eye of the Lincoln statue. The path made a turn around the World War II Memorial, offering a quiet solace with water fountains that honors those who served from every state. As walkers continued toward the end of the path they were greeted by cheering fans with a keepsake medal and goodie bags generously provided by the many industry sponsors of the event including Matrix Heath Group! This year's event exceeded its goal raising more than $70,000!

For HACA and all of the supporters of this great event, it somehow gives us our "moment" in OUR history. We come to our Nation's Capital, with our signs, our shirts and our families, and we share, educate and advocate. It's what this community is known for and will continue to do. See you next year, we'll be hanging out with Lincoln on October 24, 2015!

Tennessee

David Tignor

Israel catching snow.

Snow fell, blanketing the ground at the Trinity Baptist Church in Jonesborough, Tennessee during the crisp morning of November 1st. This did not stop dedicated individuals from participating in the ***7th Annual Race for Ian 5k Run***. Race for Ian is a consumer-led fundraiser where the proceeds of the race go to the Tennessee Hemophilia and Bleeding Disorders Foundation and St. Jude Children's Research Hospital. Participants could choose to run 5k or the 1-mile fun run.

After completing the race, runners were offered refreshments with time to view a slideshow highlighting past years' races. The presentation also reflected upon some of the struggles experienced by Ian and his family. An award ceremony followed with prizes for various categories of the race and door prize winners announced.

This event not only raises funds for the community and research, but also helps bring about an awareness of bleeding disorders. Matrix Health Group is proud to help support this important cause.

Tennessee

Shannon Cassada and Stephen Lawrence

Members of the Tennessee Hemophilia and Bleeding Disorder Foundation

(THBDF), along with industry partners gathered together on November 3rd for the annual ***Music City Golf Tournament*** at Westhaven Golf Course in Franklin, Tennessee. It was a beautiful day for golf! The team from Cleveland Custom Pallets sponsored by Tom Cassada tied for first place with CSL's team. After a challenging tiebreaker, first place went to CSL.

After the rounds of golf were over everyone gathered in the clubhouse for a wonderful barbeque dinner and bidding on silent auction items. Pete Dyson, an athlete with hemophilia and a speaker for CSL addressed the group on his experiences with sports. He played, baseball, basketball and golf and today, is a high school basketball coach.

Ian offers a factor vial show-and-tell.

When children attend the THBDF Camp Freedom, a beautifully decorated stick is awarded to them when they show bravery and infuse themselves for the first time. This is a highly coveted award and not everyone earns one. This year the golf committee thought it would be neat idea to live-auction one off. It went for a high bid of $700, with another donor matching the same amount. Both generous donations went to fund Camp Freedom for 2015. What an exciting way to end the day! The tournament proved a great success with moneys raised to fund special opportunities for THBDF families and children throughout the year.

Ohio

Susan Moore and Rania Salem

On November 5th friends and families of the Central Ohio Chapter of NHF gathered for their ***Annual Dinner Meeting*** at Der Dutchmen Restaurant in Plain City, Ohio. Families had time to visit vendors and entered incredible raffle drawings, which included Disney World tickets, gym memberships, hot air balloon ride, one-of-a-kind cornhole set and so much more.

In addition to the delectable family style dinner everyone always looks forward to, it is also the time we hear about the state of the chapter, receive sponsor updates, announcement of the top fundraiser of the Hemophilia Walk, and learn who won the LifeBLOOD 2014 Awards.

Congratulations to the following winners:

- *Volunteerism:* The Frank Gao Family
- *HTC Hero:* Leslie Witkoff of Ohio State University
- *HTC Hero:* Charmaine Beiga of Nationwide Children's Hospital
- *Philanthropy:* Sean Gilmer
- *Lifetime Achievement:* Dr. Bryce Kerlin
- *Advocacy:* Jermaine Davis
- *Community Development:* Michelle McDorman

Of special interest were the results of this year's hemophilia walk. Highly successful with 41 teams and over 300 walkers, the event raised an outstanding $45,000! Special congratulations go to top fundraising team Will's Warriors, who raised more than $5000. Sean G. and Meagan S. each won the drawing of a new iPad for raising over $1000. A special thank you to the Walk Chair, Michelle McDorman for a job well done!

Tennessee

Stephen Lawrence and David Tignor

Bayer and Matrix Health Group hosted an educational dinner at Dave & Buster's in Nashville, Tennessee on November 10th. Shelley Moore, RN, BS presented *Hemophilia 101 – Back to the Basics and Your Best Health*.

Shelly demonstrates strength training with Brett.

Shelley discussed the importance of making healthy choices and emphasized how these choices can often be challenging this time of the year in the midst of the holidays. She

Brock vs Francis - The race is on!

Frances concentrates on a win.

then discussed the importance of exercising and strength training and brought the audience to their feet with an interactive demonstration. Shelley explained how exercising strengthens your joints, muscles, bones and promotes vascular health. After the presentation, the families enjoyed fellowship and fun.

Illinois

Eva Kraemer

Resilience was the topic at the Bleeding Disorder Alliance Illinois (BDAI) and Biogen Idec's ***educational dinner*** on November 11th at Connie's Pizza in Chicago, Illinois. Vicki Oberkrom, Community Relations Manager for Biogen spoke to an enthusiastic crowd about how keeping a positive attitude in the face of change helps people adapt to difficult or unfamiliar circumstances.

Cory, Nichelle, Chris and Kelly pose with Eva Kraemer (far right).

Also discussed was the importance of fostering resilience within the family, community and school, which encourages connectedness and a sense of belonging. Vicki offered keys for developing a resilient mind-set such as finding activities that support a positive perspective or rewriting a negative script that has been playing in our minds. All in all, this topic promoted a lively discussion and led to a successful and enjoyable evening.

Michigan

Bonnie Culver

On Tuesday November 11th I had the pleasure of attending an ***educational dinner*** sponsored by the Hemophilia Foundation of Michigan and Novo Nordisk. Presenter Audrey Taylor, RN, MSN, FNP, BC, NP from the Indiana Hemophilia and Thrombosis Center in Indianapolis was very energetic and wonderful at involving the audience in her presentation. The topic entitled *HERO: Strength in Numbers* explores the psychosocial issues in hemophilia, the different views on sports and activities, and paying it forward - how to be a HERO to others with hemophilia.

Jamil J. and his children have a great time at the educational dinner.

Recently more than 1200 people took part in the HERO (Hemophilia Experiences, Results and Opportunities) study. They were asked how hemophilia has impacted their lives, both good and bad. But how can those experiences help us? During this presentation we learned ways to turn these experience into new ideas to help change the perception of hemophilia.

As a small group we bonded well, with a variety of diagnosis and experiences we were able to provide much needed support and advocacy to one another. A warm thank you to Novo Nordisk and the Hemophilia Foundation of Michigan for a wonderful fun-filled evening with great company and wonderful food from Maggiano's Little Italy in Troy, Michigan.

Tennessee

David Tignor

Matrix Health Group and Pfizer hosted a ***Certified Nurse Educator Program*** at Peerless Restaurant in Knoxville on November 15th. Hemophilia Specialty Manager Andrew Berkowitz presented information about Pfizer resources and products for our community while Nurse Educator Specialist Daysi Fardales gave a presentation on *Exploring Emotional Well-Being in the Hemophilia Community*.

Josh, Brantley and Emma with David Tignor

Daysi discussed a few topics affecting many children, adults and caregivers in the hemophilia community such as stress, anxiety, depression and Attention Deficit Hyperactivity Disorder. She spoke

about possible causes, prevention and treatment options for their issues. This information led to open discussions of what some have had to deal with, what they have done to alleviate these issues, and other alternatives they have learned either through their local hemophilia treatment center or other medical professionals. Following the program, attendees enjoyed time with one another while continuing the discussions inspired by the presentation.

Brantley and Stephanie

Florida

Hector Heer

The Florida Hemophilia Association hosted their ***25th Annual Swing for the Kids Golf Tournament*** at Lago Mar Country Club in Plantation, Florida on November 17th. Check in was at 10:30 a.m. and warm up practice continued until noon when true golfing commenced. The day of camaraderie and sportsmanship was finalized with a delicious dinner banquet and award ceremony. The fun-filled, successful day concluded with a silent auction and raffle prizes. Everyone in attendance is eagerly awaiting next year's Swing for the Kids event!

(Left to right) Leslie C. and David D. with Matrix' Chad Brown and Joe Ziegler

Ohio/Kentucky

Rania Salem

On December 2nd friends and families of the Tri-State Bleeding Disorder Foundation gathered at New Riff Distilling in Newport, Kentucky for the chapter's ***Annual Meeting and Ask the Doc*** event. As this was our chapter's final event of 2014, it was a time to reflect on the year and to look forward to the future of the chapter as board president Dan Ferguson gave an update on the past year and announced upcoming events. Following a delicious meal at the swanky distillery, it was time for the doctors to take the stage. Dr. Tarango, Hematologist-Cincinnati Children's Hospital Medical Center and Dr. Palascak, Hematologist-University Hospital were on hand to answer questions from community members. We were all enlightened by the doctors' observations regarding treatment advances on the horizon along with their views on topics such as ports, antibiotics and dental work, genetic testing and gene therapy studies. We were grateful for their time and expertise and thankful to the chapter for putting together this wonderful evening. We look forward to seeing everyone in 2015.

Florida

Chad Brown

The ***2014 Reindeer Clot Trot*** hosted by the Hemophilia Foundation of Greater Florida (HFGF) on December 6 in Orlando was once again a sleigh ride of a time! Due to the growing numbers of participants, the walk location was moved to its new location at Baldwin Park in Orlando. Baldwin Park offers longer walking paths and lived up to the hype, and felt like home with all the friends and community family gathered together.

Chad Brown with his son Dash and Allison Sullivan HFGF's Special Events Coordinator.

With over 200 happy people in attendance there was no shortage of festive spirit, not only for the upcoming holidays but the huge success of everyone involved in raising more than $42,000 for HFGF. Funds will go toward HFGF's programming and to send kids to summer camp. For me personally, this year's walk was very special; after missing last year's event due to the birth of my son, he joined us on his first walk. In short, it was fun to show off Dash to so many of my community friends. I look forward to teaching him about his dad's disorder, and whom these fundraisers benefit. We at Matrix want to extend our appreciation to the HFGF staff and volunteers for a fantastic walk. It was an honor and pleasure to provide Subway sandwiches for the walkers and staff during the event. See you next year!

Event volunteer Bobby Monahan with Chad Brown

Upcoming Events

January 31, 2015 Maryland
Hemophilia Foundation of Maryland
410-661-2307, hfmonline.org
HFM Annual Meeting
BWI Marriott; Linthium Heights, MD
Contact: Terry Stone 703-795-6269

February 7, 2015 California
Hemophilia Found. of South California
323 525-0440, hemosocal.org
CA Health Advocacy Reform Forum
San Gabriel Mission; San Gabriel, CA
Contact: Marina Vera 323-252-8682

February 21, 2015 Ohio
Tristate Bleeding Disorder Foundation
513-961-4366, tsbdf.com
Family Fitness Education Day
University of Cincinnati; Cincinnati, OH
Contact: Rania Salem 513-470-5500

February 25, 2015 Ohio
Northern Ohio Hemophilia Foundation
216-834-0051, nohf.org
NOHF Quilting Party
Beachy's Chalet; Sugarcreek, OH
Contact: Susan Moore 330-472-2289

WASHINGTON DAYS **National Event!**

February 25-27, 2015 Washington DC
National Hemophilia Foundation
800-424-2634, hemophilia.org
NHF Washington Days
Crystal Gateway Marriott
Arlington, VA
Contact: Terry Stone 703-795-6269
or Dave Burgeson 239-784-4565

March 14, 2015 California
Hemophilia Found. of North. California
510-658-3324, hemofoundation.org
Annual Family Education Day
Children's Hospital Oakland
Oakland, CA
Contact: Bobby Wiseman
415-726-6187

March 14, 2015 Illinois
Bleeding Disorders Alliance Illinois
312-427-1495, hfi-il.org.org
Swing into Spring Gala
The Carlisle; Lombard, IL
Contact: Eva Kraemer 608-852-3777

March 20, 2015 Ohio
Central Ohio Chapter of the NHF
614-429-2120, nhfcentralohio.org
Chapter Open House
Super Games; Worthington, OH
Contact: Rania Salem 513-470-5500

March 21, 2015 California
Hemophilia Assoc. of San Diego Cnty.
619-325-3570, hasdc.org
Annual Meeting Family Info Day
San Diego Zoo Safari Park
Escondido, CA
Contact: Heather Messerly 619-787-0916

SAVE THE DATE SYMPOSIUM **National Event!**

March 26-28, 2015 Missouri
Hemophilia Federation of America
800-230-9797, hemophiliafed.org
HFA Annual Symposium 2015
Hyatt Regency - St. Louis at the Arch
St. Louis, MO
Contact: Eva Kraemer 608-852-3777

March 27, 2015 Florida
Foundation Hope & Life
786-374-6143, fhlusa.org
Annual Meeting
Bonaventure Country Club; Weston, FL
Contact: Hector Heer 954-940-1248

April 10, 2015 Ohio
Northern Ohio Hemophilia Foundation
216-834-0051, nohf.org
NOHF Black & Blue Ball
Downtown Ritz-Carlton
Cleveland, OH
Contact: Susan Moore 330-472-2289

April 10-12, 2015 Illinois
Bleeding Disorders Alliance Illinois
312-427-1495, hfi-il.org
Statewide Education and Fun Weekend
Chicago Marriott O'Hare
Chicago, IL
Contact: Eva Kraemer 608-852-3777

April 17-19, 2015 Michigan
Hemophilia Foundation of Michigan
800-482-3041, HFMich.org
SpringFest
Bavarian Inn
Frankenmuth, MI
Contact: Bonnie Culver 517-525-4152

April 27, 2015 Tennessee
Tennessee Hemophilia and Bleeding Disorder Foundation, 888-703-3269, thbdf.org
Music City Golf
Westhaven Golf Club; Franklin, TN
Contact: Shannon Cassada
423-241-9356

8th Annual Great Lakes Inhibitor Support Network
February 27 - March 1, 2015

GLISN is looking for adult and pediatric patients currently or previously affected by hemophilia inhibitors and their immediate families residing in Michigan, Indiana, Western Pennsylvania and Ohio to attend an exciting weekend event at the Kalahari Resort & Conventions in Sandusky, Ohio. The goal of the weekend is to encourage and empower families with valuable information regarding the challenges of hemophilia and dealing with an inhibitor. The weekend includes resort accommodations, waterpark tickets, meals, travel reimbursement, program content and material.

For information call the Northern Ohio Hemophilia Foundation 1-800-554-HEMO

Answers to puzzles on page 27

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

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

1) d. 13 — Clotting factors
2) d. 20,000 — People in U.S. with hemophilia
3) c. 400 — Born with hemophilia each year
4) d. 16,000 — Factor 8s in the U.S.
5) d. 60% — % of Factor 8 with severe
6) a. 4,000 — Factor 9s in the U.S.
7) d. 60% — % of Factor 9 with severe
8) a. 33% — Families with no history
9) d. 1.4 million — People in U.S. with vWD
10) a. 1 in 100 — Odds of having vWD
11) b. April 17 — World Hemophilia Day

References: www.hemophilia.org
www.cdc.gov/ncbddd/hemophilia/data.html

Time for FUN!

Hi Kids! Welcome to *Hemophilia in the Numbers!* Test your knowledge to see how many answers you may know! Answers are on page 27.

1) A person's body has how many clotting factors?
a. 8 b. 9 c. 11 d. 13

2) About how many people in the U.S. have hemophilia?
a. 8,775 b. 11,500
c. 16,000 d. 20,000

3) Each year, around how many babies in the U.S. are born with hemophilia?
a. 50 b. 200 c. 400 d. 800

4) Roughly how many people in the U.S. have Factor 8 deficiency?
a. 2,000 b. 7,000
c. 12,000 d. 16,000

5) Approximately what percentage of patients with hemophilia A are considered severe?
a. 10% b. 25% c. 40% d. 60%

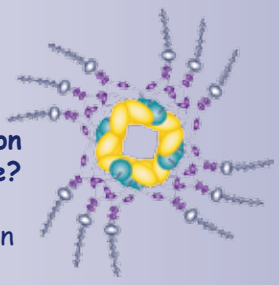
6) About how many people in the U.S. have Factor 9 deficiency?
a. 4,000 b. 8,000
c. 13,000 d. 18,000

7) Approximately what percentage of patients with hemophilia B are considered severe?
a 10% b. 25% c. 40% d. 60%

References: www.hemophilia.org; www.cdc.gov/ncbddd/hemophilia/data.html

8) What percentage of babies with hemophilia have NO family history of the disorder?
a. 33% b. 50%
c. 75% d. 100%

9) Around how many people in the U.S. have von Willebrand Disease?
a. 25,000 b. 100,000
c. 800,000 d. 1.4 million



10) What are the odds of a person having von Willebrand Disease?
a. 1 in 100 b. 1 in 1000
c. 1 in 10,000 d. 1 in a million

11) *World Hemophilia Day* is celebrated on which day?
a. March 13 b. April 17
c. July 9 d. October 2

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

SuDoku!

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

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

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