

**Winter  
2014**

**Volume 9  
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...

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Annual Meeting**

**Making Sense  
of the ACA**

**Burden to Blessing**

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**Furry Friend  
Photo Request**

**Talk Radio**

## Matrix Health at our Nation's Capital



Team Matrix and Team Harley Heroes join forces in  
Washington D.C. to *Make a Difference!*  
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## Mission and Vision Statement

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.

## Matrix Health News

Winter 2014  
Volume 9, Issue 1

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Maria Santucci Vetter

Editor: Susan Moore  
Editor: Justin Lindhorst

The purpose of **Matrix Health News** is to provide an opportunity to connect with others in the bleeding disorders community by providing information such as current news within the community, 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 News** or that of Matrix Health Group.

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## 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 pictures, 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.

<https://www.facebook.com/pages/Matrix-Health-Group/140849859422348>

## A Note from the Editor

Dear Readers,

A New Year has begun! Welcome to the first 2014 edition of Matrix Health News! Looking over past editions dating back to 2006 – it's amazing to see how far we have come. Our readership has increased exponentially as our vision of providing an inspiring, easy-to-read newsletter has remained the same. Looking through these past editions it is inspiring to see how we have moved forward together as a community. So much has happened since that first edition – from the elimination of lifetime caps and pre-existing conditions to the promise and hope of new treatments and advancements that continue to make living life with a bleeding disorder much more manageable than it was in the past.

As we set forth together during this New Year, let us not forget the importance of our community as the stories and experiences we share help light and shape our paths together. Matrix Health News will continue to provide a venue for doing just that. 🌟

All the best,

*Maria*

Maria Santucci Vetter  
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### Matrix Health Group

is pleased to announce

## A Moment in Your Spectacular Life!



## 2014 Calendar

Our calendar highlights a fantastic collection of photos depicting the *spectacular* moments in the lives of people with bleeding disorders!

Just contact the Matrix Health Group Care Coordinator nearest you to receive your free calendar.

Please see page two for a list of Coordinators.

Available only 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!



**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 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*

# A Brief Recap: 65<sup>TH</sup> NHF's ANNUAL MEETING



By Ben Martin

Thousands of members of the bleeding disorders community spent a weekend at the *Happiest Place on Earth* in October, as the National Hemophilia Foundation's 65th Annual Meeting took place in Anaheim, California. Meetings such as this have always served two purposes for me, and this was no exception. First is the amazing opportunity to network with people from all over the country with whom I share so much in common, having a bleeding disorder myself. Spending time with my counterparts from other chapters always yields new ideas and opportunities that help make me better at what I have dedicated my life to.

A unique opportunity to meet someone new at this year's meeting was the presence of Alex Borstein, the comedienne who voices several characters on the animated show *Family Guy*, who just happens to be a carrier of hemophilia. Infused with her sharp brand of humor, Borstein had the crowd rolling throughout her speech during the event's opening session as she shared her experiences with hemophilia.

Also present at the event was Los Angeles Angels' pitcher C.J. Wilson. While spending the evening signing autographs at Disney's ESPN Zone, C.J. was too busy to watch his rivals play ball in the MLB playoffs, all being shown on the big screens!

Much of the weekend was spent fulfilling the second purpose of the meeting, attending the educational breakout sessions over three days. Topics this year were especially exciting, as we

learned of the many changes on the horizon for our community.

This year's theme, *United in Progress*, reflected on subjects drawing the biggest crowds: updates on what to expect from the Affordable Care Act and exciting news on clotting products getting ready to hit the market. The new health insurance regulations are sure to change the experience people with bleeding disorders have as they interact with their health insurance companies, and these sessions generated countless questions from consumers anxious to take advantage of new healthcare opportunities.

Also popular with consumers were the many sessions covering new, longer-lasting factor products currently undergoing clinical trials. The hope of being able to reduce the frequency of infusions generated a buzz, knowing this advancement in technology will help all gain more independence and flexibility in life.

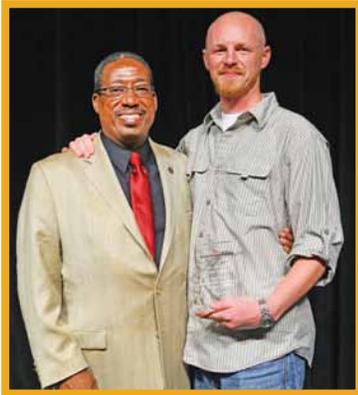
The meeting closed with a bang, as participants were given passes to Disneyland and were free to roam the park to their heart's content. Mickey Mouse was

sighted, rides were enjoyed and new friends were made.

While this year featured magical kingdoms and cartoons come to life, next year's annual meeting will bring participants to national monuments and roaming politicians, as NHF will gather in Washington, D.C. in September. See you there! 🇺🇸



All smiles at the Matrix Health Group booth!  
(left to right) Maria Santucci Vetter, Barry Haarde, Eva Kraemer, Justin Lindhorst and Marina Vera.



Val Bias, NHF CEO presents Ben Martin his award.

Winning an award at *NHF's Official Annual Meeting and Awards Luncheon* is a pretty big (okay - really big) deal. That's why we are exceptionally proud of Ben Martin who received the *Award of Excellence, Chapter Recognition* for volunteers who have made an outstanding contribution to their local NHF chapter.

Members of his local bleeding disorders community nominated Ben for this award. Though he was very pleasantly surprised, those who know him well were not. Ben has worked very hard for his chapter and is heavily involved with many activities including summer camp.

Additionally last December, the Hemophilia Foundation of Northern California awarded Ben the *Sue Anderson Community Member of the Year*. Congratulations Ben!

Thanks to everyone who stopped by the Matrix Health Group booth during the meeting! Collecting a copy of the anticipated 2014 "Spectacular Life" calendar, pausing for photographs with well-known community athlete and independent fundraiser at large, Barry Haarde, learning about and participating in a fundraiser for *Save One Life*, partaking in a raffle for a new bicycle or just kicking back enjoying the tunes and video slide show of all the photos collected for the calendar, there was plenty to do at our booth. We would like to welcome each of our new readers who signed up for Matrix Health News during the conference. As promised, we have donated five dollars to *Save One Life* for each new subscriber to our publication.



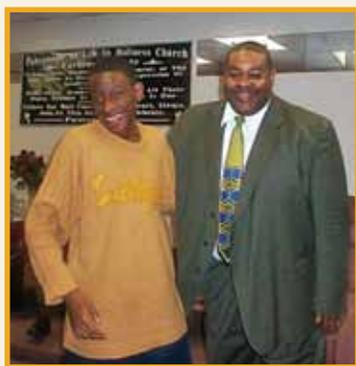
Congratulations are also in order for Beth S. from Maine - winner of the bicycle raffle! Thanks again to all who came by! 🚲



# Understanding the Importance of Remembrance and Celebration Sessions

By Greg McClure, MA, MS, LSW

Many years ago when I became a social worker in the field of hemophilia, I had a unique relationship with this community. I was the father of two sons with hemophilia and had served on the board of directors for my local hemophilia organization. From 1998 to 2005, I was employed by the Bleeding Disorder Alliance Illinois as a social worker to provide services to adult patients at Michael Reese and Northwestern Memorial hospitals in Chicago as well as the unserved and underserved families of our community.



Marcus and his dad, Greg

My youngest son Marcus had started attending camp and began to establish some great relationships with others in his own age group. He was particularly fond of one counselor, Tim Kennedy. Tim always expressed a strong concern about his family when we met at clinic. Because of Tim's mentorship, Marcus became a junior, then a senior camp counselor.



Tim Kennedy and Diane McClure

The advent of HIV/HEP C seemed to put our entire community in the closet, especially after the incidents surrounding Ricky Ray and Ryan White. I attended over 20 funerals during this time. I had grown to respect and love these young men and their families during the clinical encounters we shared. These familial connections exist today.

Remembrance and Celebration Sessions have been held at the annual meetings of the Hemophilia Federation of America and National Hemophilia Foundation for many years now. Through the years, I continuously reflect on the families and remember

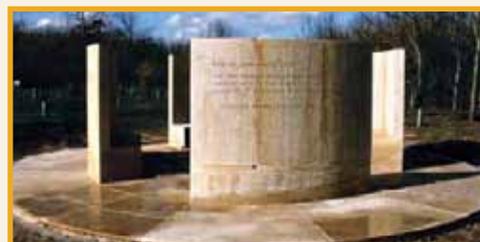
the pain and the joy expressed by those who had lost loved ones.

In subsequent years, Marcus (2007), my wife Diane (2011), and family friend Tim Kennedy (2011) were lost to me. These three will always be remembered for the friendships, advice and discussions they contributed to our community without regard to the entities that they represented. Often I am asked if the Remembrance and Celebration Ceremony is specifically for those who have been impacted by the HIV/HEP C virus - it encompasses all families with bleeding disorders.

When we come together at these annual meetings, it is a time to share our stories and reminisce about those who have shared a special place in our lives. I thank God for giving me the opportunity to have these people in my life with precious memories and thoughts from each of them. I hold no constraints on family members regarding the remembrance and celebration of our loved ones; they may have been caregivers, researchers or extended family members.

In the earlier sessions, it was difficult for some to withhold their anger and frustration. It was understandable; however, as we move forward I do ask that participants in the ceremony not make political statements.

For those that may not be aware, the Committee of Ten Thousand has been working on a memorial to honor all those who have passed away from HIV/Hep C infection. My hope and prayer is that as a close-knit community, we can support their efforts at memorializing our brothers and sisters, and continue to come together in love and memory of all those we have lost. ☸



Rendition of proposed Living Memorial. For more information or to make a donation, please visit [www.cott1.org](http://www.cott1.org)

## Making Sense of the ACA

By Susan Moore

**T**he Patient Protection and Affordable Care Act (ACA) also known as *ObamaCare* was passed by Congress in 2010 and has now taken effect. What does this mean for everyone? Millions of previously uninsured Americans will now have access to low-cost healthcare.

Although this is a hot-topic issue creating questions and confusion, the ACA is meant to make life easier for many Americans. Several provisions have previously rolled out, such as eliminating out-of-pocket expenses for annual check-ups, allowing young adults to remain covered on their parent's plans until they turn 26 and eliminating pre-existing conditions for children and, as of January 1, 2014, for adults as well. Some of the intentions of the ACA are to:

- Decrease the cost of healthcare coverage for many Americans
- Eliminate lifetime caps
- Increase preventative care and prescription benefits
- Make primary care physicians and specialty doctors accessible to more Americans
- Expand insurance plans to include essential health benefits such as
  - Emergency room services
  - Prescriptions
  - Doctor office visits
  - Hospital admissions
  - Mental health care

The most sweeping reform that began January 1, 2014 is the *Individual Mandate*. This part of the law requires most Americans to have some form of healthcare coverage. If uninsured, the ACA requires individuals to purchase coverage that meets basic minimum standards or pay a penalty fee of 1% of taxable income or \$95, whichever is higher. The penalty for uncovered children under 18 years old is half that of adults. The fee will increase in 2015 to 2% or \$325, and again in 2016 to 2.5% or \$695. This penalty, called the *Individual Responsibility Payment* will be assessed when income taxes are filed. An exemption may be available based on qualifying circumstances. Paying the penalty does not mean a person is then insured.

States have set up *Exchanges* and the federal government established *The Marketplace*, a compilation all state exchanges to help in shopping for qualifying insurance plans. These allow buyers to compare costs, levels of coverage, apply for financial assistance and more.

When applying for coverage through *The Marketplace*, eligibility for various cost-saving subsidies based on income can be determine. As the ACA has rolled out, several changes and additions have been made to the various hardship exemption rules.

Open enrollment began October 1, 2013 with many glitches and problems associated with the website; however, the site is expected to be fully operational in the near future. It is advisable to go online after 9 pm during the week, after 12 pm on Saturday and all day Sunday to avoid high-traffic times.

Those who have successfully enrolled and paid their premium before December 23, 2013 have health insurance coverage beginning January 1, 2014. Open enrollment ends on March 31, 2014, after which one can enroll for 2014 coverage only if a qualifying event has occurred, such as a birth, job loss or a divorce.

There are four ways in which coverage can be apply:

1. Paper application: Download and print the form; complete the information and mail it in
2. Online application: [www.healthcare.gov/how-do-i-apply-for-marketplace-coverage/](http://www.healthcare.gov/how-do-i-apply-for-marketplace-coverage/)
3. Phone application: call 1-800-318-2596 or TTY 1-800-889-4325 – available 24/7
4. Apply with personal assistance: go to <https://localhelp.healthcare.gov/> and type in your zip code; multiple free resources will be listed by name, address, website and phone number.

If you find it difficult to navigate the system and still need help in searching for a suitable insurance policy for you and your family, please give your Matrix Health Care Coordinator a call. We are here to help in any way we can. A complete listing of Care Coordinators can be found on page two. 📞

Source: [www.healthcare.gov](http://www.healthcare.gov)



## From Burden to Blessing

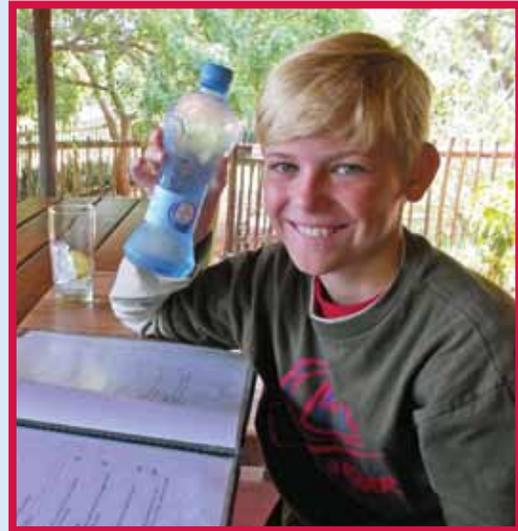
By Christian H.

Hi, I'm 12 year-old Christian and I'm going to share my experience with severe hemophilia A. I admit, when I was younger, I hated hemophilia, but now I see it not as a disadvantage but as an advantage. I wouldn't be the person I am today without it. Sometimes, when I was younger, I'd get joint bleeds and be stuck on the couch for a week. I would watch my siblings run around like free roaming chickens and feel trapped because I didn't know anyone else like me. Once I got into the community of people with hemophilia, I was able to find others who shared the same experiences as me and they understood how I felt.

When I was nine, I went to Camp Boggy Creek, a camp for kids with bleeding disorders. There I met some boys who inspired me to start self-infusing. Before this it was just my mom who infused me, but my dad started practicing on me too and soon felt comfortable with it. Before my dad learned, I couldn't travel with him. Last year, he took me to South Africa to visit his family. After this experience, I determined that I was going to rise up and fight hemophilia and never let it hold me back from life's experiences again. We worked with my hemophilia treatment center to find a dose and schedule that helped me virtually



Christian with his family: mom Jennifer, dad Henk, sister Sarah and younger brother Ryan.



eliminate all bleeds. I loved the freedom I was finding! I used to hate having hemophilia, but then I realized hemophilia is a part of who I am and I am not about to hate a part of myself!

Hemophilia is no longer something that holds me back, but something that gives me confidence. If I can conquer this, I can conquer anything! One of the times that my skill of self-infusing really came in handy was when my parents were out for the evening and we had a sitter at the house. I was getting into my bunk bed and hit my head on the ladder so hard that I felt I had an intracranial bleed. I immediately went to my factor cabinet and mixed my factor. Then I pushed the needle into my vein, but I thought I had missed, since I had no blood return. When I thought I was going to have to take the needle out, I said to myself, "Persevere and just push a tiny bit more." Thankfully, I got a blood return and was able to infuse! It was then I realized that I had single-handedly stopped an intracranial bleed! After that day, I concluded that my fear of hemophilia was no longer a part of me and that hemophilia was something I would embrace in the future.

Sticking to my prophylaxis dosing schedule has allowed me to enjoy activities like competing on my cross-country team, jumping on the trampoline and riding my dirt bike. I experience very few bleeds now. My advice to other kids with hemophilia would be to learn to self-infuse, stick to a strict prophylaxis dosing schedule and above all, never give up. No matter how hard hemophilia is for you right now, rise up and fight this disease! Don't let it beat you and get you discouraged. You can live a great life! I've met such wonderful people who care, and have gained so much perseverance and determination because of the challenges I've had to overcome. What started out as a burden has now become a blessing. 

# Rich Pezzillo



*"Ain't Nothin' Gonna Break My Stride* is how the song goes by Matthew Wilder and that is how I choose to live my life. Hemophilia will never break my stride or prevent me from doing what I want to do, from becoming who I want to become or stopping me from going where I want to go."

Rich Pezzillo, Jr. is a young adult who already could have a biography more compelling than most. Rich was diagnosed at age four with moderate hemophilia A when his younger brother, Anthony, who is two years younger, had his tonsils out.

"Growing up I knew that I had a bleeding problem and bruised easily, but it really didn't affect me that much," he recalls. "I played t-ball when I was younger and remember getting hit in the head during one of the practices. I was fine, but had to be taken to the hospital just to be checked out. After that incident my parents took me out of t-ball and told me that I couldn't play sports."

Throughout his childhood, Rich developed a passion for the outdoors, weather (which he studied in college) and growing his own garden on the side of his parent's house in North Providence, Rhode Island.

"In the summer while my friends were out playing sports, you could almost always find me in the garden I designed and planted. By the end of the summer we would have enough food to feed a small town."

Although like most living with a chronic condition, Rich tried hard to do whatever it took to be like everyone else and not let this bleeding disorder control his life.

"Growing up, I had it easy; very few muscle bleeds, no joint bleeds and I missed very little school because of hemophilia."

However, when he was 18 it all changed. During a routine annual cleaning at the dentist, he was told that he needed all four of his wisdom teeth taken out, a common procedure that many young adults have. At the time, Rich was not being followed at a hemophilia treatment center.

"It didn't cross my mind or come up in conversation with my parents. I had so little problems with hemophilia that we didn't think this was going to cause an issue. Boy, was I wrong."

Three days after the surgery, all four of the surgical sites started oozing blood. After a day of bleeding, Rich's parents decided to take him back to the dentist who re-stitched the four sites. A day later, the sites continued to bleed and at this time Rich was admitted into the hospital where he was administered over 40,000 units of Factor VIII.

Eventually the bleeding stopped and Rich went off to college to pursue his dream of becoming a meteorologist. Just a few months into his college career, Rich's life came to an immediate halt when he developed two massive muscle bleeds at the same time in his right quad and left hip. The volume of blood nearly caused severe nerve damage, and bound him to a wheelchair and crutches for over a year. Doctors discovered Rich had developed a high-titer inhibitor.

"Being confined to a wheelchair for close to a year and being told by doctors that I would never walk again gave me a lot of time to think, to cry and to pray - it changed my life forever."

Rich's tenacity during these difficult years proved he would refuse to take "no" for an answer. Every roadblock he faced made Rich eager and driven to find a new alternative or method of treatment. Rich and his

# Dedicated to Making a Difference!

## Interview by Justin Lindhorst

family knew this road was not going to be an easy one, but they chose to fight.

"My mantra became, '10% is what happens to you, while the remaining 90% is your attitude.'"

After a failed attempt at immune tolerance therapy (ITT) for five years, four PICC lines, three central ports, developing a clot in his chest around the port, a year in a wheelchair and having to take three years off from college due to his health, Rich continued to fight.

"During this time, I began to hate my life as an early-20-something year old, and was as depressed as a person could get over the unfairness—the "why-ME-ness"—of it all. I fell into a depression as deep as an abyss. Even though I was depressed, I told myself that I was going to continue to fight and never give up."

With the support of his family and friends, Rich began to accept having hemophilia as a part of his life. It didn't define him; it was just a part of his story and journey. Eventually, Rich found a treatment to suppress the inhibitor that worked for him. It was during this time that he became the first college graduate of his family. Although it took him an extra couple of years to earn his diploma, Rich now says that he wouldn't go back and change a thing.

"If someone gave me a magic wand and told me it would take away my hemophilia and all the problems I have faced and will face in the future, would I use it? My answer would be, 'no.' I would not be who I am if it wasn't for having hemophilia. It has given me the tools to become someone I am proud of. In many ways, I don't know who I would be without it.



Rich became involved in NHF's National Youth Leadership Institute (NYLI) and eventually co-chair of the entire program. Like many patients who have a bleeding disorder, he emphasizes the importance of community and getting involved.

"There may not be a medical cure for hemophilia, but in my opinion, the cure is community. Having people to support, love and empathize with you is half the battle."

As many of us know, when times are tough, life has a way of opening doors. During an NHF Washington Days meeting with United States Senator Sheldon Whitehouse from his home state of Rhode Island, Rich showed a legislative aide a copy of one of his insurance explanation of benefits (EOB). This particular EOB indicated that for one month, he had been prescribed an astonishing \$1.5 million of factor. The meeting left



Rich presents at a Hemophilia Federation of America meeting

a significant impact on the staffer and would eventually have a huge impact on Rich.

Months later, Rich was in the hospital yet again, and was feeling very down about his health and quality of life. Out of the blue, he received a call from a staffer at Senator Whitehouse's office asking if they could use his story for a speech the Senator would be giving on the floor of the U.S. Senate to promote more funding for health care. The call brightened Rich's day! Rich watched the speech live on C-SPAN and was able to hear his story being told on the Senate floor. Senator Whitehouse even had a life-sized picture of Rich to go along with the speech.

Rich stayed in touch with the Senator's office and continued to participate in Washington Days as a voice for the bleeding disorder community. Upon his college graduation, Rich was offered an internship in Senator Whitehouse's office. Although this is not what Rich went to school for, he knew that he had to take advantage of this incredible opportunity.

"I could not believe I was going to move to Washington D.C. and work on Capitol Hill for someone I admired and respected. I had to pinch myself many times to make sure I wasn't dreaming."

After the six month internship was completed, Rich was offered a full-time position as the Senator's press assistant. He remained on the Hill for over four years and worked his way up, earning the title of Deputy Press Secretary. During his time in D.C. Rich's health continued to improve dramatically.

"Working on Capitol Hill taught me more than a textbook or college professor. I am forever grateful and blessed for the opportunity, and for the growth I experienced professionally, emotionally and personally."

In 2012 Rich left the Senator's office to pursue a position as Communications Manager with the Hemophilia Federation of America (HFA).

"Not many people can say they love their job, but I truly do! HFA is an incredible organization and I feel very fortunate to be a part of it. Working for a group you believe in with your entire heart is an incredible feeling."



As you follow HFA on social media, Rich is the face behind it. He also manages their quarterly newsletter *Dateline Federation*, all marketing materials and campaigns, and website content. Additionally, he assists the staff with new initiatives to serve the ever-evolving needs of the bleeding disorders community.

Rich has now lived in Washington, D.C. for five-and-a-half years. His health has improved so much he began running as a hobby. With great satisfaction Rich is proud to share he has achieved a life-long dream of having run five half marathons and one full marathon. As much fun as he is having in D.C., eventually Rich would like to move back to New England to be closer to his family.

Through all the adversities he has faced, Rich understands that some days will be tougher than others. Each new day may bring unforeseen and challenging obstacles for all of us to face.

"It took lying in a hospital bed and sitting in a wheelchair for months to realize I am going to take what I have been given, accept it, deal with it, live with it and make the best out of it. As I look back at all I have gone through, I can truly say life is, by far, the greatest gift of all." 



The Pezzillo brothers, then and now.

# Join Us in Paying Tribute to Our Furry Friends!



*Rocchetta*

## **Maria Santucci Vetter**

Anyone who has a pet can attest to the many positive benefits of owning one - namely their unconditional love, compassion and company. For the past 16 years, I've had a little ball of fur constantly parked at my feet. My little "Rocchetta" has been a faithful and protective companion. These days she is aging quickly; her vision and hearing are all but gone, and her old bones don't move as quickly as they once did. When her time comes, we will grieve deeply, but will take comfort in knowing we have given her a happy life. She has needed us as much as we have needed her; she has, without a doubt, made our lives all the better and we will forever be thankful for having had her.

There is something about an animal a person can't always get from another person. There is never any judgment or fault; never probing questions or blame. Pets don't offer advice or try to fix things; they are just there, ready with their love and affection, and they have an uncanny way of knowing when we need them most.

When my kids roughhoused, Rocchetta would frantically bark until I came to separate the troublemakers. When dinner was served with an item that didn't agree with someone's palate, it was interesting to see how it quickly it managed to disappear from the picky eater's plate. When one of my kids was grounded, she kept him or her company providing an ear for the unfairness of it all, and when someone didn't feel well or had a bleed, she was right there diminishing the pain with her compassion. She was undoubtedly instrumental in shortening those bleeding episodes and providing something to think about rather than the swollen joint.

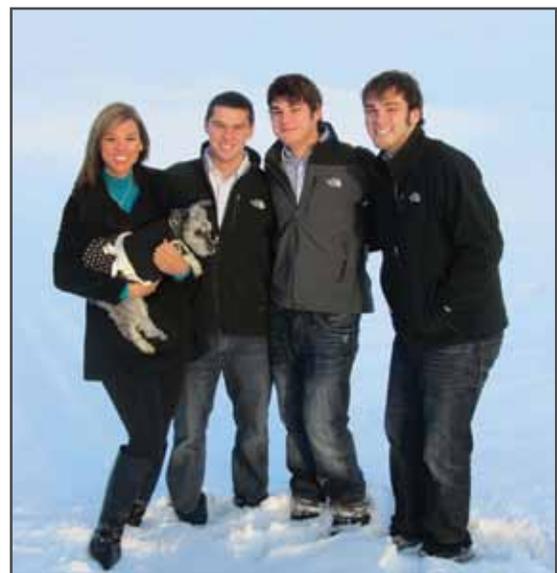
In an upcoming issue of our newsletter, we at Matrix Health Group would like to pay tribute to our faithful companions. We ask that you and/or your children submit stories and photos of you together with your much-loved pets. Please tell us about your furry friends and the joy they have given you. We would love to share your favorite stories and pictures with our readers. We look forward to hearing from you! 🐾

Please mail or email your stories and photos to:

**Maria Santucci Vetter**  
2202 Brownstone Court  
Champaign, IL 61822

[maria.vetter@matrixhealthgroup.com](mailto:maria.vetter@matrixhealthgroup.com)

(Please add "My Pet" to the subject line)



*Rocchetta with her sister and brothers*

# Talk Radio

By Terry Stone

When you get two hemophilia moms together, it is guaranteed there will not be a silent moment between them. Sharing stories of raising kids

with hemophilia: the early days, the traumatic moments, camp, the first time your child infused himself, and of course, every mom has an "ER visit" drama to talk about. Well, this is exactly what listeners heard as they tuned in to *The Radio Hotline* with Dennis Price Tuesday, Oct 15th from 8 – 9 pm on Fairfax Public Access Channel 37 in Northern Virginia.

Miriam Goldstein, President of the Hemophilia Association of the Capital Area (HACA), and radio host Dennis Price are neighbors. Dennis knows Miriam's children who both have severe hemophilia A. Through his friendship with the family he has an understanding of hemophilia, but wanted to learn more and thought it would be a great topic of discussion for his radio show. It was a welcomed opportunity to not only educate the community on hemophilia and bleeding disorders from a mother's viewpoint, but also to invite the community to join us for the inaugural NHF Walk for Hemophilia here in our Nation's Capital on October 26, 2013.

As co-chair of the D.C. walk, along with my daughter Michelle Stone-Stielper, I was excited to join Miriam on the radio. We hoped talking about our experiences of having children with a chronic condition would inspire listeners to want to learn more and support our walk. As we entered the home stretch leading up to the event, the chapter had almost hit their fundraising goal!

Miriam was one of the first moms I met at a holiday event when my son Matthew was just two months old. She was one of several mentor moms who helped me through those early years of caring for my son. I was the poster child of what NOT to be as a new hemophilia mom. I was terribly scared, didn't want anyone to hold my baby for fear of injury and had no shame in considering wrapping him up in bubble wrap to keep him safe. I figured there were three

things we shouldn't leave home without... diapers, formula and bubble wrap.



Thanks to the efforts of HACA and moms like Miriam, I was able to send those "black clouds" over me packing, and we all began our education. We started to network at various chapter events, and had empowering visits with Matthew's clinical team at Children's National Medical Center who helped us understand all of the medical information we needed to know. The moms I met made it real by giving us tips and so openly sharing their living-with-it-knowledge from the home front. Priceless!

Together Miriam and I explained what hemophilia and other bleeding disorders are. We shared the history of the darker days of contaminated blood supplies and shortages, and expressed our relief and happiness that those days are behind us. We explained through a strong community voice and grass roots efforts, there has been and continues to be great progress in care and advancements in treatment with new products in the pipeline.



Terry Stone

Miriam Goldstein

Living with hemophilia is similar to the weather. It's predictable and yet, it is not. Calm seas lend its way to turbulent, stormy and unpredictable days. Once the storm clears and the seas settle, there is tranquility and a much-needed period of smooth sailing, hopefully! Thanks to the efforts of many, those of us who navigate our way as we live with hemophilia are living beautifully normal lives. Public awareness beyond our community, as well as monumental fundraising efforts like the National Walks for Hemophilia all across the country are helping make this happen. To continue driving progress, every effort we can offer, whether it's supporting a walk in your community, volunteering your time or sharing your story on the radio, is *Making a Difference!* 🌀



## Illinois

### Eva Kraemer

The night was full of camaraderie as the Board of Directors hosted the 2013 Bleeding Disorders Alliance Illinois (BDAI) **Annual Meeting and Awards Dinner** on August 19th at the Crown Plaza Chicago Metro Downtown Hotel. The winds of change were blowing this year as Executive Director Bob Robinson thanked Board President Bill Eftax and Secretary Bruce Lerner for their six years of faithful service.

The change brings a familiar face to most of us - someone who has been extremely involved in the



Eva Kraemer, BDAI Board Vice-President Eric Sary and BDAI President Ramona Towner.

community, chaired the Walk for three years and whose smiling face cannot be mistaken - Ramona Towner will be the next BDAI Board President. We welcome her with great anticipation of things to come for the future of our organization.

Several awards were graciously accepted for categories such as *Outstanding Healthcare Service Contribution* going to Dr. Emily Czapek for her dedication and commitment to the bleeding disorder community, and to Eric Walkanoff for his *Outstanding Support of Camp Warren Jyrch*. *Outstanding Volunteer* went to a young member of the community and camper named Ryan who decided he could fundraise for the Walk on his own, and that's exactly what he did, standing out as one of the top fundraisers for 2013.

Additionally, the family of Bradley Krueger

announced the recipients of the Bradley Krueger Scholarship for 2013-2014 school year. Last, but not least, Communications Coordinator Alex Johnson was welcomed as the newest member of the BDAI staff.

## Florida

### Hector Heer, Chad Brown, Justin Lindhorst

The 2013 Florida Hemophilia Association (FHA) **Family Annual Meeting** was held at the Embassy Suites Hotel in West Palm Beach, Florida on September 6-8, 2013. It was a well-attended meeting with great speakers offering fantastic information. On the first evening manufacturers had the opportunity to talk with booth visitors about their company and products. Day two consisted of a series of presentations: Dr. Wynn led a discussion about raising the perfect patient and helping patients become comfortable with treatment center staff and doctors. He spoke on educating the patient, encouraging open discussion about bleeding disorders, fostering independence through childhood and keeping on track for the transition to adult care. Edward Kuebler, LCSW of the Gulf States Hemophilia and Thrombophilia Center, talked about juggling life with a bleeding disorder. Dawn Rotellini, Director of Chapter Development and Training from the National Hemophilia Foundation, spoke on how to be a good consumer.

As the adults and care providers absorbed exciting information from the meeting, the up-and-coming young leaders of the



FHA Executive Director Debbi Adamkin, NHF CEO Val Bias, and FHA Development Assistant Tory Gilliam.

community were engaged with their own break-out session. The session for young adults focused on three key elements: First, Chad Brown, retired athlete and Matrix Health Care Care Coordinator, presented his life story on being an athlete with severe hemophilia.



Second, Chris Maiorano, a personal trainer, discussed the importance of exercise and how to work within your limits. Chris presented a breakdown of different types of exercises, equipment and their proper use. The session was interactive, allowing the young adults to try out the different exercises with resistance bands. With young adults, you never know if they are really enjoying themselves, but you could see in the eyes of the young bucks and does that they had a blast in some of the exercise relays.



Last, but not least, Matrix Health Care Coordinator Justin Lindhorst spoke on the importance of a strong community and how they could have a positive effect on its future. Justin followed his points by leading the group in a variety of team-building challenges.

After a great day of education and networking the FHA showed their appreciation of the bleeding disorder community. With an elegant sit down dinner and a compassionate appreciation speech given by Executive Director Debbie Adamkin, rewards were handed out to volunteers involved with the success of the annual meeting. After the dinner and awards, everyone let loose on the dance floor with fantastic music. Thanks again to FHA and the hard-working volunteers for hosting a magnificent 2013 Annual Meeting!

## Washington D.C.

### Eric Lambing

It's always a reunion of friends and family when Hemophilia Association of the Capital Area (HACA) members join together. The **Annual Educational Seminar** of the HACA was held Saturday, September 7, 2013 at the Springfield Hilton Hotel. The agenda was filled with news, educational sessions and time for catching up among friends.

Our very own Matrix Health Group Regional Care Coordinator Terry Stone, Co-Chair of the Hemophilia Walk, started the day's events with an inspiring message and a call for action to participate in the inaugural NHF walk here in our Nation's Capital. Many of the attendees had already committed to teams and were working hard to raise funds to help HACA reach their goal. For those that hadn't, an opportunity was available to sign up for a team during the meeting.



Terry Stone captures the crowd's attention.

The chapter welcomed Val Bias, NHF CEO and Dr. Marion Koerper, NHF Medical Advisor, who presented *My Life, Our*



HACA Executive Director Karen Krzmarzick and NHF's CEO Val Bias.

*Future*. This explained the new initiative regarding genotyping being rolled out by the founding partners of the program - NHF, Puget Sound Blood Center, American Thrombosis and Hemostasis Network (ATHN) and Biogen Idec. Other educational programs included sessions on mental health, leadership, vWD and an Affordable Care Act update. Teens participated in an advocacy program, *Raise Your Voice*, while the younger children learned about healthy snacks and the importance of being physically active.

The day wrapped up with the annual business meeting, election of new officers and board members, and concluded with a lovely luncheon and time to visit exhibitors for updates and great information. Another informative annual meeting came to a close with many attendees still visiting and making the most of their time together, as families tend to do!

## Illinois

### Eva Kraemer

For those who were up for music, open floor dancing, deliciously authentic Mexican food, raffles prizes and more, St. Pius Church in Pilsen - one of the most prominent Mexican neighborhoods in Chicago - was the place to be on September 9, 2013.



The Hispanic Bleeding Disorder Alliance drew happy people to its First Annual Fundraising Dance!

The Hispanic Bleeding Disorder Alliance, part of Illinois' Bleeding Disorder Alliance (BDAI) hosted its **First Annual Fundraising Dance**. The musical group, Los Orejones, entertained approximately 150 people. This fundraiser was a great example of collaboration and hard work by the exceptionally dedicated members of the Hispanic Bleeding Disorder Alliance, and Matrix Health Group was more than honored to support this event.

## Ohio

### Rania Salem

The **Third Annual Family Weekend Retreat** was shaken up just a bit. In previous years families were categorized by age and disorder specifics into seven different retreats. This year, all were combined into one huge family camp weekend with five lodges housing up to twenty people in each!



Rania Salem dares to soar thru the forest on a zipline!



Kathy and her family geared up and ready to go!

We enjoyed a wonderful weekend filled with camaraderie and education, including lots of time for fun and relaxation. Families had their choice of six excursions this year - ATV riding, canoeing, horseback riding, ziplining, skeet shooting or a guided nature trail hike through the breathtaking scenery of Hocking Hills. Of course no retreat is complete without tug-of-war, campfires, hot tubs, pool time and having



ATV Time - All helmets on!

meals together. Everyone also enjoyed time to "break it down" on the dance floor during the black light party and talent show. Most importantly, groups gathered in each lodge throughout the day to learn information on their bleeding disorder and discuss current, important hot topics. This is a very sought-after event for the Central Ohio Chapter of the National Hemophilia Foundation and we are already looking forward to seeing everyone in 2014!

## Illinois

### Eva Kraemer

The first day of autumn brought approximately 600 walkers to the Bleeding Disorder Alliance Illinois (BDAI) **4th Annual Hemophilia Walk** in downtown Chicago. For a change of pace, BDAI hosted the Walk at North Avenue Beach. It was a really good event that brought out so many wonderful people committed to the community. Matrix Health Group is a proud sponsor of this noteworthy event. Thanks to the dedication for her family and our bleeding disorder community, Matrix Health Region Manager Lisa Miller was captain of a top ten fundraising team four years running.



Ready and eager to walk!



TEAM MATRIX "Keepin' it Clottin'" at the finish!



Carl, Eva Kraemer and Lisa Miller along with Team Matrix cheerleader, Jim.

BDAI is dedicated to improving the quality of life for persons affected by hemophilia and other inherited bleeding disorders through advocacy, consumer services, education and research. This fundraising event allows everyone an opportunity to come together to support the Illinois bleeding disorder community, and we are all looking forward to participating in Hemophilia Walk 2014!

## Ohio

### Susan Moore

The Northern Ohio Hemophilia Foundation (NOHF) Women's Task Force sponsored a retreat for women and girls with bleeding disorders at the Epworth Retreat Center at Camp Asbury in Hiram, Ohio on September 21-22, 2013. We hiked through the woods to the mess hall for most of our meals, enjoying the rustic campgrounds as we walked. Meanwhile our cabin was equipped with full kitchen, bathrooms with showers and bunkrooms, with the best part being the huge, wonderful fireplace where we had a real fire and made S'mores. It was a time for learning, bonding and sharing, with no TV!

Following an icebreaker game that gave everyone the opportunity to know each other, we were treated to educational presentations. First up was *Matters of the Mind*, with Diane Dimon, Dr.RS, who taught everyone a few valuable relaxation techniques that can be used during the course of our busy days. Personally, I have been reaping the benefits of her presentation by using her suggested methods to fall asleep at night. Christine Jackovitz offered sound advice on improving our eating habits and provided samples of delicious fat-free cheese to demonstrate that fat-free can still be very tasty! Also present, Susan Hunter and Irene Boehlefeld, who spoke about bleeding disorders in women. Danielle Schwager led a rap session enjoyed by all – no topic was taboo.

The big plan was to enjoy an outdoor campfire after dinner on Saturday, but this group of city slickers went outside and ran right back in! Do you know how very DARK it gets in the woods? And do you know how creepy those night sounds are in the woods? We sure do! So now you know why we stayed inside with our indoor fire. Believe it or not, I had my first s'more ever, and boy, was it good! We played



Amanda and Janet



Tiffani making her s'more!



Christine enjoys her food demonstrations!



Delaney making her own treat!

card games – Skip Bo was my personal favorite – and Aggravation. Music played on the radio and a couple women showed off their best dance moves – pretty impressive I thought! Community members Debbie W. and Amanda M. prepared our final meal of the weekend. These ladies deserve a big round of applause for cooking for such a large crowd of hungry ladies!

At the end of the weekend everyone pitched in, put things away and in short time left the cabin in great shape. With good friends, even the clean-up proved to be fun! If your local chapter doesn't have a retreat for women, get involved – plan one soon!

## Tennessee

### Stephen Lawrence and David Tignor

Matrix Health Group and Pfizer hosted an **Educational Dinner** at the Copper Cellar in Knoxville, Tennessee on September 21, 2013. Pfizer's Nurse Educator Specialist, Daysi Fardales gave a presentation on *Exploring Mental Health in the Hemophilia Community*. She discussed many of the emotional issues such as ADHD, anxiety and depression that children, adolescents, adults and caregivers can experience when living or dealing with a bleeding disorder. Daysi also covered how to identify symptoms and different ways to treat the symptoms, which led to an open discussion where personal experiences were shared by the attendees. The presentation was very informative and well received by all.



Keitrus, Taylor and Shawn of Knoxville, TN.



Baby Brantley, Christa and Joe of Clinton, TN.

## Kentucky

### Rania Salem

Beautiful weather... check! Friends in abundance...check! Fun **Family Day at the Zoo**... check! Kentucky Hemophilia Foundation in full swing supporting the bleeding disorders community... check! Zoo goes from all over Kentucky look forward to this annual event at the Louisville Zoo – one of the most highly attended chapter events of the year! It's a time for families to meet with friends and industry vendors, and share a



meal with others who walk in their shoes. The kids enjoyed all the carnival-style games and meeting with furry and slithery little creatures brought out by the zookeepers while the adults were catching up with each other. A great time was had by all and we look forward to seeing everyone again next year. We thank Ursela Lacer, Executive Director and her wonderful assistant, Sandy Franklin for hosting such great events for our community.

## Ohio

### Dan Holibaugh and Susan Moore

It isn't just us. We spoke with several people to get their opinion about the **2013 Family Fall Fest** held on October 11-12, and everyone felt the same. This weekend was loaded with fun and excitement! Was it because the dinner was better than ever? Or maybe it was the bigger-than-life presence of Pat "Big Dog" Torrey who gave the opening night workshop session? His very engaging and interactive presentation had everyone up on their feet. Many were especially interested as he spoke about the need for people to get out of their comfort zone because that is when we grow. Perhaps his energy struck a positive note, setting the tone for the whole weekend.



Amanda, Jim and Tracy strike a pose.



"Big Dog" Torrey

Break-out sessions included *Health Care Reform* with Mary Garvey of NHF presenting, *Ohio Overview of the Market Place* with Curtis Wourms of Enroll America and *Advocating in Health Care* presented by Danna Merrit. There were meetings for the *Women's Task Force* with Co-Chairs Amanda McCallum and Debbie Wisniewski, and *Dads in Action* with Co-Chairs Todd Pittman and Ray Volney.

There was also time for an ice cream social and an open family swim that ran until 11:00 Friday evening. Everyone had opportunities to ask questions and speak with the many sponsors that were there on Friday evening and again on Saturday morning.



Dan Holibaugh chats it up with Ray V.

The annual business meeting on Saturday announced the newly-elected board members. The awards ceremony named *Volunteer of the Year* went to McCallum Family. Amanda, Matt and son Dominick raised more than \$13,000 for this year's Walk in honor of their daughter Delaney. The *Shining Star Award* went to the remarkable Humberson Family. Karen and Brent generously funded the chapter's first annual swim program in 2012 and continued to support the program in 2013. Members elected Amanda McCallum and

Karen Humberson as their representatives on the chapter's Board of Directors.



Desiree and Delaney smile pretty for the camera!

Matrix would like to thank newly appointed Executive Director Janet Tooley, Assistant Director Tanya Ricchi and Advocacy Director Randi Clites for their extraordinary and incredible efforts for putting together such an awesome weekend!

## Idaho

### Liselle Easto

In the chilly early hours of October 12, 2013, family, friends and community members of the Idaho Chapter of NHF gathered at Ann Morrison Park in Boise, Idaho to participate in the **Second Annual Hemophilia Walk and Family Fall Festival**.



After registration participants warmed up to an energizing session of Zumba dance moves led by Petra Yoder before beginning the walk. Friends and family were soon on their way and enjoying every step! Participation in this walk helped raise awareness and funds for various chapter programs including Camp Red Sunshine. Following the walk, everyone was treated to a carnival-style Family Fall Festival, featuring an awesome magic show performed by Magic



Nick and his daughters take a moment to visit the Matrix booth.



It's Zumba time in Idaho!

Man, Brad Hatcher, delicious hotdogs from Stan's Char-Broiled Hotdogs and exciting games and prizes. Awards were given for top fundraisers and best t-shirt design. What a fun event for such a great cause!

## Illinois

### Eva Kraemer

Elegance and fine wine brought 90 superbly dressed guests to the Bleeding Disorder Alliance Illinois' (BDAI)



**Autumnal Wine Dinner and Auction** on October 18, 2013. Champagne sponsors CSL Behring and Novo Nordisk appropriately selected the Columbia Yacht Club as the venue, and guests delighted in the moonlight of Lake Michigan as illuminations from downtown Chicago danced and glistened off the water. Beneath a warm and cozy tent, guests enjoyed a three-course meal, each accompanied by an exquisite wine paring with a description, compliments to Jim Hurster of CSL Behring, a well-known connoisseur of fine wine.

The generous and talented guests donated their time and gift baskets to be auctioned in support of BDAI to continue providing education to the Illinois bleeding disorder community. Everyone delighted in the evening surrounded by many dedicated individuals for a good cause.



Lovely ladies hamming it up! Sarah C., Eva Kraemer and Ramona T.

## Texas

The Texas Central Hemophilia Association held its **Hemophilia Walk** for the Dallas/Fort Worth Area at the Lone Star Park in Grand Prairie, Texas. The Walk took place on the very chilly morning of October 19, 2013. With two choices, a one mile and a 5K, the walk wound around the area surrounding the park. Matrix Health Group sponsored a unique fundraiser in support of the walk; Regional Care Coordinator Tammy Davenport handmade



Tammy Davenport and her Aunt Edna.



Kathryn S. and Tammy Davenport show off one of Tammy's scented candles.

candles in a variety of holiday scents and took orders for weeks before the walk. One hundred percent of the proceeds went to support the chapter. Despite the windy and chilly weather, the event was well attended and very successful, raising over \$40,000. Everyone is looking forward to walking again next year!

## Ohio

### Dan Holibaugh and Susan Moore



Biogen Idec's Tricia Oppelt and Dan Holibaugh (center) encircled by a few of the dinner attendees.

Wednesday was a wonderful day in the neighborhood – the neighborhood of the Blue Canyon Kitchen in Twinsburg, Ohio that is! On October 23, 2013, Matrix Health Group hosted a dinner sponsored by Tricia Oppelt of Biogen Idec. Several bleeding disorder families enjoyed a scrumptious meal in a cozy, southwestern atmosphere while learning about the company whose president, Glenn Pierce, hails from northeastern Ohio.

## California

It was a beautiful Saturday in southern California on October 26, 2013, a perfect day for the premier **Hemophilia Walk** for the Hemophilia Association of San Diego County (HASDC) at Liberty Station. Being close to Halloween, the costume theme for this walk added to the fun! Following registration, continental breakfast, games and face painting, the 5K walk began at 10 am with nearly 200 participants. Afterward friends gathered to converse and connect. Present were those affected by bleeding disorders and their families, the staff from Rady Children's Hematology Clinic, friends, industry and chapter members. Pizza was available for



HASDC Walkers 2013!



Best Buds Trevor and Anthony.



those who worked up an appetite, raffle prizes, and recognition to the team who raised the most money. The walk was a great success for the San Diego chapter!

## Florida

### Hector Heer

Friends and families were among the walkers showing their support for the bleeding disorder community on October 26, 2013 at the **1st Annual Awareness Walk** of the Foundation Hope and Life USA. Organized by Ana Calero, Foundation President



Ana Calero, Alexis Carbonell, Lazaro Montejo and Hector Heer.

along with volunteers from the South Florida area, the Walk raised funds to lend assistance to families living with a bleeding disorder. Set in C.B. Smith Park in Pembroke Pines, the day was made even more interesting by the participants showing up in their Halloween costumes. The sponsors, supporters, walkers and volunteers who enjoyed this fun event advance the beneficial work done by the Hope and Life Foundation. Good things happen when many hands pitch in to help.

## Illinois

### Eva Kraemer

Hispanic Heritage Month is typically observed in October and the Latino bleeding disorder community celebrated their culture at the **National Museum of Mexican Art**, located in the heart of Pilsen - a well-known Mexican neighborhood within Chicago on Saturday, October 26, 2013. The Bleeding Disorder Alliance Illinois (DBAI) hosted a program stressing the importance of self-advocacy with approximately 75 eager participants. Everyone broke into small groups to discuss how to become a better self-advocate with your doctor, your treatment center or when speaking to legislators. Families learned from other families



Celebrating Hispanic Heritage!

about the importance of education and taking charge of your own healthcare to become

more confident and successful when advocating for yourself and your family.

more confident and successful when advocating for yourself and your family.

Especially during a celebration, much of Latino culture focuses on scrumptious food, exquisite conversation and in this case, magnificent Mexican dancers! This was a joyful event and as always, I was delighted to be welcomed as a member of the Latino bleeding disorder community.

## Washington D.C.

### Terry Stone

The Hemophilia Association of the Capital Area (HACA) hosted a **Walk for Hemophilia** like none other on a chilly Saturday morning, October 26, 2013 on the historic grounds of the Lincoln Memorial. Volunteers arrived to set up by the glow of the moon in the early morning hours. The dim and somber light illuminated the memorials and gave a feeling we were embarking on something special, making history of our own.

This was the inaugural walk here in our Nation's Capital. With the efforts of 54 teams, 479 walkers and 683 sponsors, our chapter exceeded several goals while raising more than \$82,000!



Terry Stone looks on as NHF CEO Val Bias addresses the walkers

Our dedicated community members worked hard to support the walk with their strong presence, and deserve huge THANKS!



HACA Walk check presentation

NHF President Val Bias presented chapter leaders, Karen Krzmarzick and Brenda Bordelon, and Walk co-chairs Michelle Stone-Stielper and myself with a bonus check for \$10,000 for exceeding their original goal.



Laura poses with Eric Lambing - both proud walkers on the Matrix Health Team

As darkness faded and warm sun blanketed the National Mall, there were many activities to keep attendees



Chapter Administrator Brenda Bordelon and Walk Co-Chair Michelle Stone-Stielper



Ole!



Eric Lambing joined the D.C. fun!

busy before the walk. There was Zumba, face painting and tattoos, a caricaturist, great music as well as the vendors with great treats for all ages. After the morning fun, Michelle and I gave the crowd a warm welcome, followed by a great inspiring speech from Val Bias, and a thank you from Alison Raymond, Territory Manager and Melissa Taylor, Inhibitor Specialist of the Walk's supporting sponsor, Baxter.

Families and teams united for the 10 am Walk for Hemophilia, which began along the beautiful oak-lined pathway around the reflecting pool at the Lincoln Memorial, passing the World War II Memorial, stopping only briefly to honor and allow a group of veterans to cross our path and enter the memorial. It was moving; certainly it was a moment, and a time to contemplate on the importance of honoring those who have made a difference. This monumental NHF Walk event, especially here in the Nation's Capital, was one of those "bucket list" moments. Making our history on the grounds where we honor our nation's achievements is something special, and we'll do it again next year!

## Florida Hector Heer



Everyone wants to know more about the many exciting advances we've been hearing about for years. Several products for factor replacement therapy "in the pipeline" and new research efforts may yield results leading to better treatments, and perhaps, eventually to a cure. This growing interest was the reason we at Matrix Health Group invited several families to learn about the **Genotyping Project** from Liliana Gomez, Community Relations Manager at Biogen-Idec.

Genotyping is leading to a greater understanding of bleeding disorders and solutions in dealing with the difficulties of treatment. Research is going on in a number of centers around the country and even overseas. The attendees were grateful for the

opportunity to learn about coming improvements for our population. The meeting was held on October 27, 2013 at the Brio Tuscan Grille restaurant in Hallandale, Florida.

## Tennessee David Tignor

It was a beautiful fall morning on November 2, 2013 for the **6th Annual Race for Ian 5K & 1 Mile Fun-Run**, a consumer-led fundraiser held at Trinity Baptist Church in Jonesborough, Tennessee. Ian is a bright, adorable 6 year-old living with severe hemophilia. His parents, Michael and Sarah, as well as other dedicated volunteers help organize this worthy event with proceeds going to St. Jude Children's Research Hospital and the Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF).



Ian's Family  
Isaac, Michael and Sarah  
stand behind  
Israel and Ian



On your mark, get set...

Following the race a slide show was presented of Ian's highs and lows of living with hemophilia, which further exemplified the importance of raising money for this cause. Awards were given out for several different categories of the race and door prizes were drawn for participants. Matrix Health Group was a proud sponsor for this meaningful and fun event, and we look forward to participating in next year's 7th Annual Race for Ian!

## Ohio Dan Holibaugh and Susan Moore

Central Ohio does it again! The folks at the Columbus Chapter must anxiously await their **Annual Meeting** that occurs mid-autumn each year at the famous Der Dutchman Restaurant in Plain City, Ohio. The attendance is always overwhelming and this November's meeting was no exception





An Ohio family visits with Rania Salem (far right) at the Matrix Health Group booth.

with over 200 greeting the speakers and sponsors. Prepared by Amish cooks and served family style, dinner is always fabulous and included a variety of homemade pies. This meeting is always



Rania Salem poses with Jennifer Cox

hosted on a weekday, never Saturday, and we believe we know why. To have the meeting on a Saturday could probably affect the attendance due to the Ohio State Buckeyes games that occur each Saturday in this football-crazed city.

The meeting of the Central Ohio Chapter of the National Hemophilia Foundation was a resounding success for everyone involved. Vendors giving financial support were pleased with the turnout, and the friendliness and interaction of consumers. Children were ecstatic reconnecting with friends while making new pals. Parents and grandparents welcomed the opportunity to share a meal with family and friends, and at the prospect of winning the many raffles that were drawn.

Every year the chapter gives special recognition to its outstanding members. The recipients receive beautiful trophies that have such significance in their design. This year the awards were as follows:

*Lifeblood Award for Volunteerism* was bestowed to Kathy Stewart. Her husband, Jeff and three of their children, Nelson, Mark and Vanessa were present to receive her award posthumously. Tragically, Kathy lost her life in a car crash last March 31st. Kathy was a giving person who not only tirelessly devoted her life to raising awareness and advocating for the bleeding disorders community, but to other charities as well.

*Lifeblood Award for Philanthropy* went to Paul and Amber Hemingway and family for their efforts in going above and beyond the call of duty in organizing the Blood Run 5K event, resulting in more than \$10,000 being raised. Working together, the Hemingway family made a difference!

*Lifeblood Award for Advocacy* was given to Erin

Groff for her trips to the Ohio Statehouse Days with notebooks full of insurance documents. She was so persuasive in her lobbying, a video was made to present to supporters of this Chapter, and went viral on YouTube! Erin and husband are raising a son, Ben.

*Lifeblood Award for Community Development* went to Kathy Chesser. Kathy has been instrumental in networking and raising awareness of vWD and Ehler-Danlos, holding monthly meetings in her home while reaching out through every avenue she can to learn more and share more.

*Lifeblood Award for Lifetime Achievement*, presented by Val Bias, CEO of NHF, was given to Jim Wasserstrom. Jim has dedicated his time and efforts to the growth and success of the Central Ohio Chapter. With Jim's leadership and guidance, this chapter grew from a fledgling, volunteer-based chapter, being run out of Kathy Stewart's basement, to a self-standing, staffed organization with its own office. Central Ohio was the first chapter to receive grant money from NHF, the first chapter to partner with NHF, and the first chapter to balance its books with a positive balance. Without Jim's leadership and guidance, this likely would not have happened.



Jim Wasserstrom receives the Lifeblood Award for lifetime achievement from Val Bias, NHF CEO!

Congratulations to each of the Lifeblood Award recipients! The atmosphere is always friendly and Matrix Health Group is looking forward to 2014 to see what the new executive director of Central Ohio Chapter of NHF will have in store!

## Florida

### Dave Burgeson

The Florida Association of Pediatric Tumor Programs, Inc. (FAPTP) provided a packed program for nurses, social workers and other health care professionals from around the country at the **36th Annual Advances in Pediatric Hematology/Oncology Seminar** held November 7-9, 2013. The meeting and events were held at the Sheraton Sand Key Resort on the beach in Clearwater, Florida. Brian Calkins, FAPTP Program Director and his staff provided events, meals, rooms and very smooth sailing for the 300 or so attendees, presenters and sponsors. In these settings, learning and participating in the educational presentations is a breeze.



Peggy Gay at the Matrix Health Group booth.

The seminar kicked off with a pre-conference bleeding disorder roundtable discussion sponsored by the

Hemophilia Foundation of Greater Florida and FAPTP titled, *Unusual or Challenging Coagulation Patients*. Joanna A. Davis, MD of Miami, Florida and Cynthia Gauger, MD of Jacksonville, Florida chaired the panel as several interesting case studies were shared and discussed. This panel discussion with case studies was included in the seminar for the first time this year and was well received.

Presentations on Thursday focused primarily on bleeding disorders and included a presentation by Carla Duff, CPNP, MSN, CCRP on *SCIG in the Hematology/Oncology Patient* and *Chicken Soup for the Nurse's Soul* by the author, LeAnn Thieman, LPN, CAP, CPAE. A special highlight was the barbecue dinner followed by dancing with a poolside deejay Thursday evening. Education continued through Saturday midday with Patricia Swasey, RN, MAN, CPON of Lantana, Florida presenting *Compassion Fatigue* to close out this year's excellent program.

### Florida Hector Heer

An interested crowd of seventy attended Biogen Idec's meeting on November 8, 2013 to hear the latest regarding the company's plans for the bleeding disorder community. Liliana Gomez, Community Relations Manager at Biogen Idec spoke, stressing the commitment to the community that Biogen plans to provide as they work toward the introduction of new factor replacement product. The Foundation of Hope and Life participated in hosting this educational evening.



Liliana Gomez with Hector Heer and Ana Calero

THBDF 3rd Annual Walk for Hemophilia

*"Don't walk behind me; I may not lead. Do*



A sunny, crisp Saturday dawned at Harlinsdale Farm in Franklin, Tennessee on November 9th. This was the destination for the gathering of many friends and family members of the hemophilia community in attendance for the Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF) **Third Annual Walk for Hemophilia**. Our chapter partnered with the National Hemophilia Foundation to raise funds and awareness for hemophilia.

The Matrix Health Group team in Tennessee – Shannon Cassada, Cyndy Coors, Stephen and Robin Lawrence, and Paul Touchton worked to create our own Walk team called *The Blood Commanders*. Last year we decided to have a team to mirror the ever so popular Duck Commanders. First we enlisted the help of Gabriel King, talented uncle of two boys with hemophilia, and key in the design and creation of our logo and t-shirts. Next we began to build our team.

On the day of the Walk, an army of blaze-orange shirts showed up and took over the crowd. Orange was everywhere you looked! With over 60 people on the team, Paul Touchton was heard to say, "What a sight it was to drive up to the venue and see those bright orange shirts on about one out of every three people attending! It is symbolic of the hard work that the families of Way, Bates and Cassada put into getting the message out, convincing people to either walk, contribute, or do both on this spectacular day!"



Abstract Canvas

*"Don't walk behind me; I may not lead. Do*

*Don't walk in front of me; I may not follow. Just walk beside me and be my friend."*

*Shannon Cassada*

# Matrix Health Group

## and the Blood Commanders



**By Shannon Cassada**

The Blood Commanders worked hard to earn funds for this worthy cause. It proved to be a record-breaking year for us as we raised \$5765! Our team came together with various, inventive ways to raise money for this event. One family held a Hemophilia Walk-A-Thon at their child's school and asked each student donate at least \$1 to participate. Another family's school hosted a dress-down day for the teachers to raise funds for the Walk. Pam Way and Tanya Bates held a silent auction on Facebook, bringing in over \$1500! Others simply went to friends, family and local businesses, and asked for donations.

Even our team held its own competition. The team member to raise the most money won tickets to the Creative Discovery Children's Museum in Chattanooga. Raising \$1600 all on her own, the winner was Tina Carmichael, a lovely grandmother of two boys with hemophilia. The team also held a Duck Commander look-alike contest with many showing up in camouflage - some even sported long hair and beards! It was all in good fun and for a great cause!

Under the starting banner, the atmosphere

was surreal. Many of the walkers had never participated in this event before and many were not directly affected by a bleeding disorder, but they set out to support the ones who were. From teachers, church workers and friends, to moms, dads, brothers, sisters, aunts, uncles, grandparents, great grandparents, cousins, children, grandchildren and even great aunts and uncles were walking to support someone they care about.

With a banner in hand listing the names of her grandchildren with hemophilia, a grandmother attended the Walk for the first time. As she left the starting point, the moment overwhelmed her and her eyes filled with tears. She felt so proud to be walking in support of her grandchildren.

The Walk brings together wonderful, caring people and moments like this bring home the importance of hosting these types of events. We thank THBDF's executive director, Mary Hord for her dedication and leadership. The Matrix Health Group team would like to thank all the members of the Blood Commanders for their support and we look forward to joining next year to once again break our fundraising record! 



THBDF 3rd Annual Walk for Hemophilia

*Don't walk in front of me; I may not follow. Just walk beside me and be my friend."*

# Upcoming Events

**February 4, 2014 Ohio**  
**Annual Amish Quilting Party**  
 sponsored by Matrix Health Group to benefit Northern Ohio Hemophilia Foundation. A crib quilt and couch throw will be auctioned at the NOHF's Black and Blue Ball in April.  
 Beachy's Chalet; Sugarcreek, OH  
 Contact: Susan Moore  
 330-472-2289

**February 7, 2014 Florida**  
 Foundation Hope & Life with the collaboration of Matrix Health  
 786-374-6143, www.fhflusa.org  
**First Annual Golf Tournament**  
 Bonaventure Country Club  
 Weston, FL  
 Contact: Hector Heer  
 954-940-1248 (Habla español)

**February 26-28, 2014**  
**Washington D.C.**



National Hemophilia Foundation  
 212-328-3700  
 www.hemophilia.org  
**NHF Washington Days**  
 Contact: Dave Burgeson  
 239-784-4565 or  
 Terry Stone 703-795-6269

**March 1, 2014 Illinois**  
 Bleeding Disorders Alliance Illinois  
 312-427-1495, www.bdai.org  
**Annual Spring Gala**  
 Chicago Marriott O'Hare  
 Chicago, IL  
 Contact: Eva Kraemer  
 608-852-3777 (Habla español)

**March 13, 2014 California**  
 Hemophilia Association of San Diego County  
 619-325-3570, www.hasdc.org  
**Annual Meeting and Family Information Day**  
 Safari Park; San Diego Wild Animal Park; Escondido, CA  
 Contact: Bobby Wiseman  
 415-726-6187

**March 15, 2014 California**  
 Hemophilia Foundation of Northern California  
 510-658-3324  
 hemofoundation.org  
**Annual Family Education Day**  
 Four Points Sheraton  
 Pleasanton, CA  
 Contact: Bobby Wiseman  
 415-726-6187



**National Event!**

**March 27-29, 2014**  
**Tampa, Florida**  
 Hemophilia Federation of America  
 800-230-9797  
 www.hemophiliafed.org  
**Symposium 2014**  
 Tampa Marriott Waterside Hotel and Marina  
 Contact: Dave Burgeson  
 239-784-4565

**April 11, 2014 Ohio**  
 Northern Ohio Hemophilia Foundation  
 216-834-0051, www.nohf.org  
**Black & Blue Ball** – Masquerade!  
 Ritz-Carlton; Cleveland, OH  
 Contact: Susan Moore 330-472-2289  
 or Dan Holibaugh 330-904-6294

**April 12-13, 2014 Illinois**  
 Bleeding Disorders Alliance Illinois  
 312-427-1495, www.bdai.org  
**Statewide Fun & Education Weekend**  
 Rockford Clock Tower Resort  
 Rockford, Illinois  
 Contact: Eva Kraemer  
 608-852-3777 (Habla español)

**April 21, 2014 Tennessee**  
 Tennessee Hemophilia and Bleeding Disorder Foundation  
 888-703-3269, www.thbdf.org  
 Music City Golf Tournament  
 West Haven Golf Course  
 Franklin, TN  
 Contact: Shannon Cassada  
 423-241-9356

**April 26, 2014 Texas**  
 Texas Central Hemophilia Assoc.  
 972-386-3865, www.texcen.org  
 Denim & Diamonds Gala  
 Join us for a night of casino, dining, along with exciting live and silent auctions.  
 Austin Ranch; Grapevine, TX  
 Contact: Tammy Davenport  
 936-524-4907

## Answers to the puzzles on Page 27

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

- Do The Five!**
1. Get an annual comprehensive checkup at a hemophilia treatment center
  2. Get vaccinated Hepatitis A and B are preventable
  3. Treat bleeds early and adequately
  4. Exercise and maintain a healthy weight to protect your joints
  5. Get tested regularly for blood borne infections

For more information about **Do The Five!** visit:  
[www.hemophilia.org/NHFWeb/MainPggs/MainNHF.aspx?menuid=125&contentid=139](http://www.hemophilia.org/NHFWeb/MainPggs/MainNHF.aspx?menuid=125&contentid=139)

# Time for FUN!

Hi Kids!

Using the secret code, translate this important "National Prevention Program" message from the National Hemophilia Foundation. Stay healthy! 🐱💧🦋🚗🦋📞🚗🦋🦋!

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

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# Matrix Health News



Our **Vision** and **Mission** 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.

## Sign Up

To Receive Our Newsletter!

### Matrix Health News

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

Just complete this form and mail to:

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

Sign up on our website at:  
[www.matrixhealthgroup.com](http://www.matrixhealthgroup.com)

or call us toll free:  
**877-337-3002**

## Sign Me Up To Receive Matrix Health News!

Name \_\_\_\_\_

Organization \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_ Zip Code \_\_\_\_\_

Daytime Phone \_\_\_\_\_

Evening Phone \_\_\_\_\_

E-mail Address: \_\_\_\_\_

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