Highlights in This Issue...

Dinner with Jeanne

NHF Hosts 64th Annual Meeting

The Value of Community

Bleeding Community Resources

Advice for Young Self-Infusers

Cause for Applause
The MISSION of FFP, LLC, d.b.a., Matrix Health 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.

In order to do this, the Matrix Health Care Team follows each person’s prescription needs, monitors their progress, communicates with their physician and other health care providers, as well as coordinators with their insurance company in order to ensure the payment of benefits and stay informed of national and state programs that may provide further benefits.

The purpose of Matrix Health News is to provide an opportunity to connect with others in the hemophilia community, upcoming events, information such as: current news in the hemophilia community by providing the best pharmacy and support company in order to ensure the payment of benefits and stay informed of national and state programs that may provide further benefits.
Attention Tri-Care Patients:

Matrix Health is a specialty pharmacy devoted to caring for those with bleeding disorders. We are dedicated, determined, and committed to personalizing 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, our goal is to make your life easier! 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 - 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.

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

We look forward to hearing from you!

A Note from the Editor

Dear Readers,

Happy New Year! The beginning of a new year has an especially invigorating effect on me. It is an ideal time to reflect on what I have accomplished and encourages me to set new goals! Take a few minutes to reflect on all you have done and learned over the past year, and give some thought on how you can make 2013 even better.

As we at Matrix Health News welcome the new year, we wish to thank our many readers and contributors to our newsletter. We appreciate your feedback, comments and insight. Your ideas help us to provide a publication specifically dedicated to enriching the lives of people with bleeding disorders. We look forward to sharing with you many more articles and stories, which you will hopefully find interesting, helpful and inspiring. Please continue to share your ideas so that we can improve in honoring our quest to “Making a Difference” in your life.

We wish you all a wonderful 2013 filled with good health, peacefulness and abundant happiness!

Sincerely,

Maria Santucci Vetter
Editor-in-Chief
Matrix Health News

Matrix Health
is pleased to announce

A Moment in Your Spectacular Life!

2013 Calendar!

Debuting at NHF’s Annual Meeting in Orlando, the community’s response to our 2013 A Moment in Your Spectacular Life calendar was phenomenal! Our calendar highlights a fantastic collection of photos depicting the spectacular moments in the lives of people with bleeding disorders! If you would like to receive a free calendar, just contact the Matrix Health Care Coordinator nearest you.

Remember to set aside your favorite photo for the 2014 A Moment in Your Spectacular Life calendar! Ask your Care Coordinator how to participate!

Please see page two for a list of Care Coordinators.
(Calendars available only while supply lasts)
An Evening with Jeanne Ginder-White

By Susan Moore

It was a quiet and peaceful evening on the main thoroughfare, deep in the rural village of Morristown, Indiana the night we all met. Five of us shared a quiet, intimate meal at the Kopper Kettle, a quaint and charming restaurant where the old-fashioned décor was enchanting and delightful. Our special guest was Jeanne White-Ginder, mother of Ryan White. Joining us was Michael Perigo of Hemophilia of Indiana, Rania Salem of southern Ohio, Dan Holibaugh and myself, both from northern Ohio. Our dinner was a precious occasion as we enjoyed continuous conversation and wonderful companionship while the hours took flight.

The restaurant choice came about while Mike and Jeanne were traveling together in 2011, stopping to eat at the Kopper Kettle. Always thinking of the chapter and planning ahead for the 2012 Hearts Gala, Michael asked the restaurant manager if he would consider donating a gift certificate. His request was politely declined. Witnessing this exchange, Jeanne winked at Mike as she stepped up, introduced herself to the manager, revealing to him that a donated gift certificate would mean so much to her. The manager immediately reversed his decision and offered a generous gift certificate - Dinner for Four!

Months later as a guest at the 2012 Hearts Gala, Jeanne had a wonderful live auction package idea and suggested she be auctioned off along with the Dinner-for-Four as “An Evening at The Kopper Kettle.” Rania Salem from Matrix Health was the winning bidder, and graciously invited the rest of us to join her and Jeanne!

Even after spending much time with a host of celebrities, most notably Oprah, Elton John and Michael Jackson, Jeanne is as down-to-earth as can be. She recounted several personal family stories of Ryan, his sister Andrea, and their friends and neighbors. We compared the usual stories of stints in the emergency room, injuries our boys endured and butting heads with school officials, insurance payers and others involved in our child-raising adventures.

On a somber note, Jeanne dealt with a much graver issue than Rania or I have, but one shared by Dan as well – that of losing sons affected by HIV. Her courage in giving Ryan the freedom to become a public figure served to better our entire community, by generating a much-needed awareness, and the impact of that will be with us for generations to come. Our community is indeed grateful for her open mind and sharing heart.

Much too soon it was time for us to depart, returning to our homes in the serenity of darkness. On the long drive home, I reflected upon our evening’s conversation and how so much has changed within the bleeding disorders community, realizing once again how much Jeanne and Ryan have given. Our dinner with Jeanne was a heart-warming experience that each of us will always cherish.

www.matrixhealthgroup.com
For three days every year members of the bleeding disorder community gather en masse to network, participate in educational sessions, learn the latest in industry news and also to simply enjoy the company and camaraderie surrounded by others who know and understand their challenges. The 2012 Annual Meeting of the National Hemophilia Foundation continued this tradition from November 8 to 11 in beautiful Orlando, Florida, as the community gathered once again to join in the meeting theme of *Mapping our Future*. Executive Director Val Bias commented, “We are active participants in the daily planning and execution of our lives… we create a map of sorts, leading toward a desired end – a path forward…my wish is that everyone will take away something to help you in mapping a future of hope and prosperity for yourself and our community.”

The event held many educational and breakout sessions for consumers, NHF chapter staff and medical professionals who treat bleeding disorders. Topics ranged from hemophilia and vWD basics to body art, women’s issues, pain management, support for siblings and much more. From the myriad of educational sessions, to the information on hand in the exhibit hall, coupled with the fun social activities that went
Throughout the weekend, participants found multiple tools in helping themselves and the community plot a promising path forward.

Matrix Health Group continued their support of the National Hemophilia Foundation this year. Our booth was a welcome and fun pit stop as participants blazed a trail across their “road map.” Matrix Health Group staff was on hand to provide information and share some fantastic giveaways with the visitors to the exhibit hall. Early in the summer, we asked our readers to submit photos depicting fun, memorable and spectacular moments in their lives. With the debut of the 2013 A Moment in Your Spectacular Life calendar we shared these moments with the community, showcasing that even with a bleeding disorder life is grand. In addition to the calendar, the booth featured a video slideshow of each picture submitted for the calendar. Participants truly enjoyed seeing their pictures flash across the screen!

The calendar and video served as an important reminder for those mapping their future that though we may face challenges, with a positive attitude, strong support team and commitment to therapy adherence and other health measures, we can achieve great accomplishments.

For the 64th year running, the National Hemophilia Foundation helped provide the tools for the bleeding disorders community to identify, meet and overcome obstacles. It is through such gatherings that we are able to come together, learn from each other and move forward together. We are proud to continue sponsorship of such events and look forward to future involvement as together we chart a path on our collective map to a healthy and hopeful future for all individuals living with a bleeding disorder.
Can you imagine a time when whole blood and plasma were the choice treatments for treating hemophilia – and as a patient you were responsible for replenishing the donated blood supply your therapy used?

Can you imagine having to approach friends, family and often extended friends and family with continuous pleas to donate blood so you or your loved one could receive treatment?

Can you imagine life without access to safe and efficacious products, little or no hemophilia treatment centers, support network of peers, or other community resources we are privy to today?
Though it may be hard for many of us to imagine, such was the harsh reality individuals and families raising a child with a bleeding disorder had to face in the not so distant past.

My grandparents were part of that group as they fought to meet the needs of their son living with severe hemophilia in a suburb of Cincinnati where at the time local support was almost nonexistent. Knowing there had to be others in the same boat, they set out to build a community where there was none. After a lot of hard work and with the devotion of many hours, a small network of individuals and families affected by bleeding disorders formed. Together, they began collectively working to help meet the common needs of the newly established local community.

They organized blood drives at businesses and college campuses, and formed a blood bank. The members of the chapter could depend upon the blood bank when treatment was needed. This provided some relief from painful bleeding episodes and lessened the need to constantly burden friends and family for donations of blood.

The group took trips to the statehouse to advocate for treatment and teach elected officials about the challenges faced by those living with bleeding disorders. They placed ads in the paper reaching out to other families, and held one of the first local meetings that brought together community members and medical professionals. Time and effort paid off and soon Cincinnati had a network of individuals dedicated to bettering the lives of people living with bleeding disorders.

From the efforts of those that laid the foundations, to the continual work being done today, our community is now strong and brimming with resources to help make life a little easier. Have you considered how being a part of this community has helped you or your loved one deal with or better manage this condition? Take a moment to reflect how our community’s collective efforts have directly affected and vastly improved the way we live our lives.

So what are the benefits of belonging to a strong community? Perhaps the value is best seen when there is an inherent lack thereof. According to the California Healthcare Foundation, “Studies show that without sustained support, many adults [with chronic conditions] will not succeed in managing their conditions well, leading to worse health outcomes.” Luckily, the resources in our community provide that sustained support for those that seek it. Being a part of a group also helps combat feelings of isolation. Hemophilia and von Willebrand Disease are rare conditions. Chances are your neighbor, co-worker, even the local emergency room doctor know very little about your bleeding disorder. In the past, many individuals felt isolated and alone in dealing with their condition. Today, our community has created a strong network of peer support groups, and those feelings of isolation are becoming less.

Additionally, the collective experience and sharing of information between these groups can help to improve the way we understand and manage our bleeding disorder. The California Healthcare Foundation goes on to note, “Interventions that mobilize and build on peer support are proving to be both effective and inexpensive and are therefore an ideal way for health systems to help their patients manage chronic conditions.”

In this community, one has access to a vast network of peer support. There are groups that address every subset of our population. From support groups and programs for dads, moms, women with bleeding disorders, blood brotherhoods, sisterhoods, groups for siblings, social media groups, camps for youth and adults with bleeding disorders, and everything in-between, there is opportunity for us to tap into one of these groups and learn from each other.

Research has shown that our group interaction directly correlates to better health outcomes. Peers for Progress reports, “Studies have found that social support decreases morbidity and mortality rates, reduces health care service use, increases life expectancy, self-efficacy, knowledge of a disease or conditions and self-reported health status and better self-care skills, including improved medication adherence. Additionally, providers
of social support report less depression, heightened self-esteem and improved quality of life.” These studies are a direct testament to the strength that we gain from the community we’ve formed.

In addition to our system of social support, the advocacy efforts of our community over the years have directly impacted the quality of care we all receive today. Even with the gravity of the situation those with bleeding disorders faced during the 1980s when the products used to treat hemophilia were contaminated with HIV and hepatitis, our community banded together and led the charge demanding a safer blood supply and retribution for the victims of those affected. From their efforts came watchdog groups who to this day keep vigil over our nation’s blood supply and hemophilia clotting products.

Their efforts eventually led to government legislation with the Ryan White Care Act - the largest federally funded program for individuals living with HIV/AIDS in the country. Also, the Ricky Ray Hemophilia Relief Fund Act provided compensation for individuals with hemophilia who were exposed to HIV. Today it is through our ongoing efforts on a local and federal level that we have assisted in preserving federal funding for hemophilia treatment centers and government programs that help individuals with bleeding disorders receive the care and medication that allow us to live a healthy life. Recently, our voices were heard loud and clear as Congress worked to pass the Affordable Care Act, which finally dispelled lifetime caps and pre-existing conditions, both obstacles that impeded our ability to find and maintain adequate healthcare coverage.

Further, we also have access to a vast library of publications and programs that help teach, inspire, enrich, educate and elevate all of us in the community. From the guidelines issued by the Medical and Scientific Advisory Council (MASAC), to the wellness programs such as the National Hemophilia Foundation’s (NHF) “Steps for Living,” and the Hemophilia Federation of America’s (HFA) newly unveiled “Fit Factor,” to the vast library of publications offered through NHF’s HANDI and other organizations such as LA Kelley Communications, we have the ability to arm ourselves with the knowledge to live as healthily as we possibly can.

The list continues... We are supported by organizations such as Patient Services Incorporated (PSI) when the financial burden of healthcare premiums for our condition becomes too great. We have access to programs such as HFA’s “Helping Hands,” which has provided thousands of dollars of financial aid for members of our community struggling with medical and other payments. There are numerous scholarships available for community members pursuing higher education. This is all on top of a vast web of local chapters who offer an array of programs and services aimed at helping the community; and this is only the tip of the iceberg! The list of organizations and resources available to this community would fill the pages of this entire newsletter, and then some!

It’s easy to forget among all the hustle and bustle of our local and national meetings just how blessed we truly are to have the community we do. As we gather at often-impressive venues with delicious food and an abundance of activities, I think some may lose sight of the true importance why we must remain together. Some forget or do not realize the extent of the struggles our community has faced to bring us to this day. Others might not be aware there are groups of people living with chronic conditions who do not have the benefits of a strong community as we do.

So as we begin a new year, I propose a challenge for all of us: take some time to reflect on how this community has affected you, your family or your loved one with a bleeding disorder. What have you learned? What can you share? What tools have you gleaned from this community to help you live better, healthier and stronger? How can you grow through community interaction while helping others grow along the way?

Today, my grandparents marvel at the abundant resources available to the bleeding disorder community. Sifting through old pictures, newspaper articles and letters pleading for blood donations, I’m amazed at how far our community has come. From my experiences as a child at camp where I first met others with a bleeding disorder,
to all the hard work of the medical professionals, various nonprofit organizations and the safe, effective factor products we have today, the mark this community has left on my life is plainly visible. But the greatest impact for me has been meeting the remarkable group of individuals that make up this community. Their stories inspire me, their experiences teach me, and the collective wisdom we share guides me to pursue the best for not just myself, but for all who walk this path with me.

Sources:
http://peersforprogress.org/learn-about-peer-support/science-behind-peer-support

Community Resources

AIDSinfo - A Service of the U.S. Dept. of Health and Human Services
Offering information on HIV/AIDS treatment, prevention and research
www.aidsinfo.nih.gov
800-448-0440 toll free
Email: ContactUs@aidsinfo.nih.gov

Bleeding Disorders Legal Hotline
Free and confidential legal information regarding health insurance, workplace and school
800-520-6154 toll free

CDC - Centers for Disease Control and Prevention
24/7: Saving Lives, Protecting People
A current list of hemophilia treatment centers can be found on this website
www.cdc.gov
800-232-4636 toll free
Email: cdcinfo@cdc.gov

Coalition for Hemophilia B, Inc.
Making quality of life the focal point of treatment for individuals with hemophilia
www.coalitionforhemophiliab.org
212-520-8272
Email: hemob@ix.netcom.com

COTT - Committee of Ten Thousand
A grass-roots, advocacy, support and policy organization serving the hemophilia and larger bleeding disorders communities
www.cott1.org
202-543-0988; 800-488-2688 toll free
Email: cott-dc@earthlink.net

HFA - Hemophilia Federation of America
A national nonprofit organization that assists and advocates for the bleeding disorders community
www.hemophiliafed.org
800-230-9797 toll free
Email: info@hemophiliafed.org

Hepatitis C Support Project
Providing unbiased information, support, and advocacy to all communities affected by HCV and HIV/HCV coinfection, including medical providers
www.hcvadvocate.org
Email: alanfranciscus@hcvadvocate.org

Hepatitis Foundation International
Promoting liver wellness, healthy lifestyles and health education
www.hepfi.org
301-622-4200
800-891-0707 toll free
Email: hfi@comcast.net

Inalex Communications
Where people can embrace, learn, and share insight, support, and practical advice on families, relationships and lives
www.inalex.com
201-493-1399; 866-802-0304 toll free
Email: jce-caronna@inalex.com

LA Kelley Communications
Education, innovation compassion for chronic disorders
www.kelleycom.com
978-352-7657; 800-249-7977 toll free
Email: info@kelleycom.com

NATAP - National AIDS Treatment Advocacy Program
Educating about HIV and Hepatitis treatments and advocating for people living with HIV/AIDS and HCV
www.natap.org
212-219-0106; 888-26-NATAP toll free
Email: info@natap.org

Patient Notification System
Providing information on plasma-derived and recombinant analog therapy withdrawals and recalls
www.patientnotificationsystem.org
888-UPDATE U toll free

PSI - Patient Services, Inc.
Supporting people with expensive chronic illnesses and conditions through locating solutions with health insurance and assisting with premiums and prescription co-payments
www.uneedpsi.org
800-366-7741 toll free
Email: uneedpsi@uneedpsi.org

PDSA - Platelet Disorder Support Association
Enhancing the lives of people with ITP and other platelet disorders through education, advocacy, research, support and communication
www.pdsa.org
301-770-6636; 877-528-3538 toll free
Email: pdsa@pdsa.org

WFH - World Federation of Hemophilia
Providing global leadership to improve and sustain care for people with inherited bleeding disorders
www.wfh.org 514-875-7944
Email: wfh@wfh.org

WFH - USA
The friend-raising and fundraising arm of the World Federation of Hemophilia in the U.S.A.
www.wfhusa.org 877-417-7944 toll free
Email: info@wfhusa.org
Texas
Tammy Davenport
During the weekend of August 10, 2012, The Lone Star Chapter of NHF along with the Texas Central Hemophilia Association held their Annual Texas Bleeding Disorder Conference in the beautiful hill country of San Antonio. With a backdrop of canyons and nature’s beauty, The Westin La Cantera Hill Country Resort was the ideal location for such a gathering. Approximately 1,000 consumers and industry representatives from across the state attended the conference.

Melanie Gable, a motivational speaker from Colleyville, Texas was the key speaker of the conference. Melanie shared a tragic, but very inspirational story: While out jogging in June of 1995, she was the victim of a random attack of violence. She was run over by a man in his truck who then attempted to kidnap her. She was thankfully rescued by a man who heard her screams.

After suffering severe internal injuries and many broken bones, Melanie fought to regain her life and despite the odds, has gone on to live a fully functional and inspiring life. In addition to being a guest on several talk shows such as The Oprah Show, Melanie’s story has been published in numerous magazines. After listening to her unbelievable story, many of the attendees wanted to spend additional time with Melanie, so Matrix Health sponsored a reception where those who wished could visit with her in a more intimate setting. At the reception, Melanie answered more questions about her experience, her willingness to forgive her attacker and about her faith, which gave her the strength to get through her ordeal. Despite this tragic experience, Melanie holds firm to the belief that the world is full of good people who are genuinely willing to help others.

Conference breakout sessions were also part of the meeting and covered educational topics such as Women with Bleeding Disorders, Blood Brotherhood, von Willebrand Disease and a session shared in Spanish for the Hispanic attendees. Michelle Rice, Policy Director of the National Hemophilia Foundation, gave an extremely informative presentation on Being a Responsible Consumer. She covered the legalities and ethical guidelines that homecare and manufacturing companies are required to follow. On an interesting note, she explained that when a company representative turns down a specific request by a consumer, it does not mean they do not want to help, just that they are not legally able to do so. This policy is for the protection of the company as well as the patient.

The weekend wrapped up with everyone parting ways and heading back to their respective areas of the great state of Texas. With so much information for the entire family, the Annual Texas Bleeding Disorder Conference was a grand success. And like everything in Texas, everyone is looking forward to doing it again next year, just BIGGER.
Kentucky
Rania Salem
The Kentucky Hemophilia Foundation (KHF) held its Annual Meeting at the Seelbach Hotel in Downtown Louisville on August 25, 2012. This event is a major educational forum for the Kentucky bleeding disorders community. Patients and their families started the morning visiting with the numerous pharmaceutical and homecare representatives who were also available throughout the day to support the community and answer questions about their products and services. When it was time for the adults to head off for the educational sessions, the children were kept entertained with fun-filled childcare programs, which included breakfast, arts and crafts, and an assortment of games.

As the adults enjoyed a breakfast of their own, guest speaker Don Stevens, Psy.D kicked off the meeting with the first educational session entitled Building Resiliency in Your Child and Your Family. Following his presentation, breakout sessions were held covering topics such as Self-Defense Program for Women and Girls by Sensei Nancy Cutrell of Evansville ChunJiDo Academy; Meditation for Chronic Pain & Stress Management by Diane Dimon, Dr.RS of Matters of the Mind (sponsored by CSL Behring); and Health Care Reform by Kim Jones, RN, Group Manager of Reimbursement for Baxter BioScience Department of Healthcare Economics.

While the guests enjoyed lunch, the Kentucky Hemophilia Foundation board members gave presentations of their annual update, financial report, board elections, recognition awards and door prize winners. In conclusion, guests headed to a local company called Glassworks, which is a one-of-a-kind facility dedicated to the art of making glass. A big thank you to KHF for a fun-filled educational day!

Illinois
Lisa Miller and Eva Kraemer
The night was full of camaraderie on August 27, 2012 at the Crown Plaza-Metro in downtown Chicago as the Board of Directors hosted the Bleeding Disorders Alliance Illinois (BDAI) 2012 Annual Meeting and Awards Dinner. Guests of all ages feasted upon a decadent buffet while Board President Bill Eftax reported on the status of the organization. With Executive Director Bob Robinson moderating, a panel discussion took place to review how BDAI serves people in the bleeding disorder community from the perspective of mothers, Latinos and blood brothers.

Awards were graciously accepted for the following contributions: Outstanding Healthcare Service Contribution recipient Dr. Ruth Seeler was recognized for her dedication of more than 40 years as she fondly recounted the many faces that passed through camp. Outstanding Volunteer recipient Elizabeth Fung, former social worker at Lurie Children’s Hospital HTC for more than 30 years, thanked all those in the community who had touched her life, observing that her time as a social worker helped her grow both personally and professionally. Outstanding Support of Camp Warren Jyrch was proudly presented to Jim Hurster for camp would not be the same without his afternoon of tie-dying with the campers! Additionally, the family of Bradley Krueger presented the Bradley Krueger Scholarship recipients for the 2012-2013 school year.

The evening was not without surprise when it was announced that Rocky Williams, well-known to many in the community, had accepted the new Education and Outreach Coordinator position at BDAI. As anticipated, the Annual Meeting and Awards Dinner proved to be a very enjoyable event.

Illinois
Eva Kraemer and Lisa Miller
When we envision a perfect September day, we often think sunny with a hint of a breeze, pleasant; a sweater or jacket may be necessary, but wearing shorts stills feel good because we’re not quite ready to let go of summer. This is exactly the kind of day that was enjoyed by all who attended the 2012 Annual Matrix Health/Bayer Family Picnic on Saturday, September 8th at Twin Lake Recreational Area in Palatine, Illinois.

More than 65 bleeding disorder community members from around the Chicago-land area enjoyed a fun-filled, relaxing
afternoon. The options to enjoy the camaraderie as well as relish the day were endless: paddle boating, fishing, Nerf football, Frisbee, bocce ball and a feast of delectable dishes to satisfy everyone’s appetites.

With educational information to share, Bob Johnson, social worker at Stroger of Cook County Hospital’s Hemophilia Treatment Center, reminded everyone of the importance of keeping an infusion log and explained some of the available Internet and cell phone applications. Dare it be stated that after talking with those who attended, the 2013 picnic will be marked on many more calendars around the area!

Illinois
Eva Kraemer and Lisa Miller
More than 600 walkers were greeted by an extraordinary sunny, late-summer morning as Bleeding Disorder Alliance Illinois (BDAI) kicked off its 3rd Annual Hemophilia Walk in downtown Chicago on September 15, 2012. Diversey Harbor, located on beautiful Lake Michigan was our scenic backdrop as we walked to promote awareness and friendship. This year was especially meaningful to Matrix Health and to those who walked with us as it was dedicated in loving memory to our own Tim Kennedy. Tim’s family appropriately chose the team name Tour de Tim and we donned team shirts with images of Tim and his two young sons, Danny and Kyle. Matrix Health is a proud sponsor of this event, and Tour de Tim was one of the top five fundraising teams, while our famed Matrix Health Region Manager and Team Captain, Lisa Miller, was one of the top three fundraising individuals, three straight years running.

BDAI is dedicated to improving the quality of life for persons affected by hemophilia and other inherited bleeding disorders through advocacy, consumer services, education and research. This fundraising event allows everyone an opportunity to get together to support the Illinois bleeding disorder community. This special occasion brings many of us together and we all look forward to participating in Hemophilia Walk 2013!

Kentucky
Rania Salem
It was that time of year to enjoy a crisp fall day at the annual Kentucky Hemophilia Foundation’s (KHF) Family Zoo Day in Louisville, Kentucky. On September 29, 2012, guests spent the day strolling and viewing the lions and bears, leisurely wandering through the lush botanical gardens and spending time with family and friends.

The Kentucky bleeding disorders community excitedly looks forward to this fun event every year and this
year, the day did not disappoint! Much fun was had while folks visited with friends, old and new. Adults and children alike were presented with the chance to make acquaintances with the furry, slithery and slimy types as the zoo keepers brought out live animals for an up close experience. After a delicious, picnic style lunch, the children all gathered for fun carnival games and chances to win some really cool prizes.

Many thanks to Ursela Lacer, Executive Director, her staff and many volunteers who never fail to please! Matrix Health is grateful for the opportunity to sponsor such a great event for the Kentucky bleeding disorders community and we very much look forward to it again next year!

Illinois
Eva Kraemer
October is Hispanic Heritage Month and on October 6, 2012, the Latino bleeding disorder community in the Chicagoland area celebrated their roots in a unique and appropriate location - the National Museum of Mexican Art. Located in the heart of Pilsen, a well-known Mexican neighborhood within Chicago, the Bleeding Disorder Alliance Illinois hosted Celebrating Hispanic Heritage, an educational program covering dental care and the importance of getting regular check-ups to upwards of 75 enthusiastic participants.

All enjoyed a delicious spread of Mexican fare while a deejay entertained and energized the crowd with lots of great Salsa, Merengue and Bachata; no one could resist the urge to get out on the floor and dance! Some of the moms in the Latino bleeding disorder community went above and beyond to make confetti eggs or Cascarones. A tradition, usually celebrated at New Year’s Eve, was enjoyed by all as we were given eggs to then break on an unsuspecting victim's head, releasing a rainbow of confetti fun. Eva Kraemer García was honored to be with the Latino community to celebrate one another.

Idaho
Liselle Easto
Eastern Idaho hemophilia community members were invited to attend the Annual Family Conference (AFC) on October 12, 2012 at the Legacy Flight Museum in Rexburg, Idaho. The AFC started with a warm welcome from Chad Stevens, Chapter President of the Snake River Hemophilia and Bleeding Disorders Association.

Following Chad, Zac Walker, Camp Director of the Idaho Chapter National Hemophilia Foundation gave a presentation about the family camp held in late June and the benefits gained for the families that attended. Taryn Margrini, Executive Director of the Idaho Chapter introduced herself to the Snake River Bleeding Disorders attendees and discussed her plans for the Idaho community.

The new HTC nurse at the Idaho Hemophilia Treatment Center, Kara Gardner, introduced herself and stated her mission for improving the treatment and care of the bleeding disorder community in Idaho. A fascinating physics presentation was made by students of Brigham Young University Idaho who demonstrated examples of the conductivity of static electricity and weight distribution.
After the presentations, attendees were treated to a delicious prime rib and chicken dinner. Guests also had the chance to visit vendor booths and network with other members of the community. After dinner, Novo Nordisk offered an interesting discussion on the origin of bleeding disorders and the effects of joint bleeds. In addition to the educational information, attendees were given ample time to explore some of the airplanes that have served our country on exhibit at the museum.

Ohio
Susan Moore and Dan Holibaugh
Autumn is a beautiful time of year in northern Ohio and signals the yearly gathering of the Northern Ohio Hemophilia Foundation for their Annual Meeting on October 12-13, 2012. Held once more at the beautiful Embassy Suites in Independence, Ohio, all 145 consumers enjoyed another successful conference. The weekend was planned with diligence by the board and staff, and headed by the very capable Executive Director, Lynne Capretto and her team, Tanya Ricchi, LaChandra Oliver and Randi Clites. This year the focus was on wellness, an obvious theme of importance, given the mission statement of this wonderful chapter: “Our mission is to enhance the quality of life for people with genetic bleeding disorders and their families, through advocacy, education, research and other constituency services.”

Topics offered to adults were: Living with Hemophilia - Taking Care of Your Health as You Age, Keeping Joints Healthy with Early Treatment, Keep Moving, and Balancing Nutrition and Weight.

While adults were absorbed in their programs, the children were well taken care of: Infants through 5 year-olds were placed in a certified daycare program; 6 to 12 year-olds enjoyed a swim session and an educational and social event; teens were able to network and learn together with the theme Transitioning into Adulthood, going off-site for lunch and bowling. On Friday, kids of all ages were treated to a popcorn-filled movie night!

All were delighted to welcome Glenn Pierce back to the fold; Dr. Pierce was born and raised in northern Ohio and NOHF is his home chapter. As keynote speaker, his topic was New Research and Development in Hemophilia.

Much information was shared during the Saturday morning meeting: Kendra Adams was named Volunteer of the Year, and she and Patsy Carman joined the Board! Lynne received flowers from the children to recognize her service to our chapter, and although Frank and Dominic Piumno were unable to attend, they received the Shining Star Award for their dedication to our cause. Our Chapter is a great one, and we look forward to seeing everyone in 2013!

Idaho
Liselle Easto
In the pre-dawn hours of October 20, 2012, approximately 170 people gathered at Ann Morrison Park in Boise, Idaho to participate in the first annual 2012 Hemophilia Walk and Fall Festival. Among the attendees were 2013 Idaho pageant winners Mrs. Idaho America, Kaley Sparling; Mrs. Capital City, Heather Quisel, and Mrs. Idaho United States, Lisa Stoehr.

The enthusiastic crowd was greeted with a welcome from Taryn Magrini, Executive Director of the Idaho
Chapter National Hemophilia Foundation. After opening announcements, everyone was invited to take part in a Zumba warm up. Once warmed up, participants were able to walk either the one-mile or three-mile loop. At the finish line, cheerleaders from the local high schools presented participation medals to the walkers. Once across the finish line, folks had time to visit the manufacturer and homecare company booths, participate in activities such as pumpkin decorating, face painting, a bounce house, an obstacle course and enjoy the entertainment of a clown making balloon animal figures. The first ever Idaho Hemophilia Walk was a fantastic success!

Ohio
Rania Salem, Susan Moore and Dan Holibaugh
The Central Ohio Chapter of the National Hemophilia Foundation is dedicated to provide education, advocacy and support programs for those with bleeding and clotting disorders, and to drive innovations that lead to a better quality of life for consumers. On November 1, 2012, at the enormously popular Der Dutchman in Plain City, Ohio, people affected by a bleeding disorder enjoyed abundant food, time with old and new friends, and great conversations.

The LIFEBLOOD Awards were presented as follows:

For Inspiration - given to Janet Rider who became an awesome friend to Melissa Swartz during her son’s battle for life after having suffered a subdural hematoma. Complete strangers, now best friends thanks to the camaraderie the chapter brings to people.

For Volunteerism – went to Jodi Estep who joined multiple committees and the board of advisors, and spearheaded a new fundraiser that brought $17,000 to the chapter.

For Philanthropy – presented to the McDorman family for their longstanding support of the Hemophilia Walk, having raised $6,500 over the last 4 years.

For Corporate Philanthropy – given to Porter Wright, a Columbus-based law firm, for having invested more than $10,000 in the chapter over the past four years, and for their participation in the chapter’s planning committees and board of advisors.

The Lifetime Achievement Award went to Rick Sites, without whom the chapter would not exist. Few knew that while Rick was actively involved on the FAMOHI Board, he was also instrumental in gathering interested parties to form the Central Ohio Chapter of NHF.

Recognition was also given to Tom Allie for his continued work with his local Eagles Aerie. Through his activism, Tom presented the chapter with a check for $4000. Jim Wasserstrom, President of the Board, received recognition for the support he gives the Chapter – even offering office space. Rob Alexander, Executive Director of Central Ohio Chapter of NHF deserves credit for the notable meeting he put together that was enjoyed by nearly 175 consumers. Rob has done a magnificent job of redefining the activities and future of this Chapter. Thank you, Rob!

Florida
Dave Burgeson
The Florida Association of Pediatric Tumor Programs held their 35th Annual Seminar “Advances in Pediatric Hematology/Oncology” November 15-17, 2012 at the Hyatt Regency Grand Cypress Hotel in Orlando, Florida. Matrix Health is proud to sponsor this important educational gathering where nearly 300 doctors and pharmacy representatives as well as speakers and educators attended. Don Eslin, MD, was Seminar Medical Director and among the presenters was Christopher Walsh, MD whose Coagulation Detectives: Cases in Rare Bleeding Disorders was a highlight for those attendees most interested in the bleeding disorder community.

Illinois
Lisa Miller and Eva Kraemer
Back by popular demand, the Bleeding Disorder Alliance Illinois (BDAI) ushered in the holiday season by hosting the Wine Tasting Dinner and Auction at the Renaissance Schaumburg Hotel on November 16th, 2012. The mood was warm and inviting as the guests dined on a three-course meal. Each course was accompanied by an exquisite wine followed by a description of the
A dedicated family went above and beyond to put together two fundraising events raising awareness and charitable donations for the Tennessee Hemophilia Chapter, as well as St. Jude’s Children’s Hospital. Through these events, this remarkable family raised well over $1,200 for these tremendously worthy causes. **Rock Fest 2012** was held on August 18, 2012 at the Hollywood Lounge in Paris, Tennessee. Four featured bands rocked the crowd, including *Mindset Defect*, *3 Minutes to Live*, *Life Relentless* and *Clothes You Live In*.

**Jammin’ for Jeremiah** was held on September 22, 2012. This fun event included live music, a silent auction, face painting, games for kids and a late summer meal of great-tasting hotdogs and juicy grilled burgers as well as delicious pizza.

A heartfelt THANK YOU goes out to the Quinn family for all their hard work in making these two events so successful. We are looking forward to the Second Annual Rock Fest and Jammin’ for Jeremiah to take place in 2013!

**Idaho**

**Liselle Easto**

On the morning of December 1, 2012, the NHF Idaho Chapter members gathered together for the **Annual Family Conference and Holiday Party** at the Hampton Inn Downtown in Boise, Idaho. Upon arrival, attendees were invited to partake of a continental breakfast and to visit vendor booths. After warm greetings from Taryn Magrini, Executive Director and
Leaving the Nest

Lynne Capretto has announced her retirement and is leaving her position as Executive Director of the Northern Ohio Hemophilia Foundation effective January 1st, 2013. Lynne came to us at a time when our chapter was in distress, membership in decline, running in the red and close to being dissolved. She was given the monumental task of turning our organization around in 12 months or the unthinkable would happen – our chapter would no longer exist. In the past ten years, new programs and initiatives have sprung up under her guiding hand, contributing to the success and strong growth of the chapter.

Lynne, thank you for your service and dedication to our community. We wish you and husband Rob the very best in the coming years, and hope to welcome you back to our events. Life at the chapter will not be the same without you - we will miss you!

South Carolina

Stephen Lawrence and Peggy Gay

Hemophilia of South Carolina Foundation held their 2012 Holiday Party, Annual Meeting and Educational Symposium on December 7-9 at the Landmark Resort in Myrtle Beach. There were over 230 in attendance for this year’s meeting. Guest Speakers included Michelle Rice, NHF Director of Public Policy, Sue Geraghty, RN; Lisa Greene, BS CCP; Jennifer Meldau, MSRN CPNP; and Pat “Big Dog” Torrey.

Several of the young and young-at-heart braved the cold Atlantic Ocean waters as they participated in the Annual Polar Bear Plunge, raising over $600 for the Foundation through this event.

Ohio

Rania Salem

On December 16, 2012, friends and families of the Central Ohio Chapter of National Hemophilia Foundation gathered for the 6th Annual Night at Wildlights at the Columbus Zoo in Ohio. With over 200 people in attendance, this is one of the most popular chapter events. Families gathered in the warm pavilion to meet new families, see old friends, and learn something new about their bleeding disorder. Vendors were on hand to welcome the families and provide information.

While the events are always so much fun, and the food is always so delicious, education is equally important. Every event brings about some very important topics to the bleeding disorders community. During this event, we learned of the importance of being an advocate for our children and loved ones with a lecture entitled Grassroots Advocacy: Hemophilia’s Voice in the Community. Rob Alexander, Executive Director, followed speaking of why one should be an advocate and the importance of standing up for our bleeding disorders community. He welcomed everyone to join him as we lobby at the state house in Columbus with the Ohio Bleeding Disorders Council, as well as lobbying Washington Days in D.C. in February.

After this very important lecture, it was time for families to cozy up and enjoy the amazing light display at the Columbus Zoo. What a marvelous way to end the year and to bring holiday cheer. Thanks Rob, we look forward to seeing everyone again in 2013!
My Advice to Young Self-Infusers

By Rick Starks

Hey All! Learning to self-infuse can be a challenge. Not that I have all the answers, but as a 58 year-old with severe hemophilia B who has been self-infusing for more than 40 years, I have lots of experience to share. While we all develop our own systems and techniques to help our infusions go a bit easier, I’d like to pass on some advice to you. Some of this was learned through the clinic while others from my own experience of infusing every other day. I’m not saying I’m an expert and you should always seek your doctor’s opinion, but here are some tips that have helped me along the way:

1. Use the smallest needle possible. I use a 25-gauge butterfly needle for my infusions. I believe the smaller the needle, the less trauma and scarring of the vein. Yes, it takes a little longer to infuse, but what’s another minute?

2. Become proficient infusing ambidextrously. I have learned to infuse using my right or left hand. This just gives you more options.

3. Rotate the veins you use. We all have our favorite veins, but constantly using the same ones will cause them to scar and they may become more difficult to infuse later in life.

4. Hydrate yourself by drinking plenty of fluids before you infuse. Soda pop and other caffeinated beverages dehydrate, so drink water, sports drinks, and fruit or vegetable juices. Veins that are well-hydrated become a bit easier to stick.

5. Relax! Don’t be in a rush. Whatever you have to do will still be there in ten minutes. Concentrate only on the task of getting that factor into your veins (I used to tell my kids I was “powering up”).

6. Try to view your infusion as if you’re infusing someone else. It helps distract you from your own pain and sometimes helps resolve that little bit of flinch that can happen.

7. Do not push down on the needle before or while you are removing it from your vein. Pushing down on the needle while it is still inserted can damage the vein.

8. When the infusion is done, use pressure! Just because the needle is out, the job isn’t done. Put full pressure on the infusion site for at least 30 seconds, then follow with less, but steady pressure for up to another 15 minutes afterwards. This helps reduce those little bruises at the infusion site.

9. On the days you infuse, make an effort to exercise. Push it a little harder on those days. I am a firm believer that the more fit you become, the less injuries you sustain.

10. You’re going to miss! It happens, we’re all human. Eventually, no matter how good you are, you’re going to miss the vein or it’s going to blow on you. It happens, accept it. Don’t doubt yourself, it happens to everyone sooner or later.

These are just some things I’ve learned over the years. I used to think of infusing as a chore, something that was going to take time from my day. Now, it has just become a part of life. I might not look forward to it, but it is something necessary to keep me active and going.

Now go out and have a good life! I am!

About the Author:
Rick Starks and his wife of 25 years, Leslie, reside in rural southwest Nebraska and are the proud parents of four sons and a daughter ages 20 to 35. In addition to offering his advice to young self-infusers, Rick also volunteers as Crew Captain on a local EMS squad.

*Always seek the advice of your healthcare providers when making medical decisions.
Upcoming Events

February 12, 2013  Ohio
Amish Quilting Party!
We are sewing a quilt to benefit Northern Ohio Hemophilia Foundation. The finished quilt is to be auctioned off at the NOHF’s Black and Blue Ball on April 13th. A delicious lunch will be served. Join us! Beachy’s Chalet; Sugarcreek, OH
Contact: Susan Moore 330-472-2289

February 27 - March 1, 2013
Washington DC

March 2, 2013  Illinois
Bleeding Disorders Alliance Illinois
312-427-1495, www.bdai.org
Annual Spring Gala
Chicago Marriott O’Hare; Chicago, IL
Contact: Lisa Miller 630-698-8775 or Eva Kraemer García 608-852-3777 (Habla español)

March 16, 2013  Texas
Texas Central Hemophilia Association
972-386-3865, www.texcen.org
Denim and Diamonds Gala
Join us for a night of casino, dining, and live and silent auctions!
Dallas, TX
Contact: Tammy Davenport 936-524-4907

March 22-23, 2013  New York
The Coalition for Hemophilia B
212-520-8272
www.coalitionforhemophiliaab.com
March 22
6th Annual Fundraising Dinner
Water’s Edge Restaurant
Long Island City, NY
March 23
7th Annual Symposium
Grand Hyatt New York Hotel, NY
Contact: Maria Vetter 212-840-1033

April 12, 2013  Ohio
Northern Ohio Hemophilia Foundation
216-834-0051, www.nohf.org
Chairs: Tanya Ricchi & Lisa Margolis
Black and Blue Ball
Enjoy an elegant evening full of fun, food, spirits, music and auction activity!
Ritz-Carlton; Cleveland, OH
Contact: Susan Moore 330-472-2289 or Dan Holibaugh 330-904-6294

April 20-21, 2013  Illinois
Bleeding Disorders Alliance Illinois
312-427-1495, www.bdai.org
Statewide Fun & Education Weekend
Schaumburg Hyatt Regency
Schaumburg, IL
Contact: Lisa Miller 630-698-8775 or Eva Kraemer García 608-852-3777 (Habla español)

April 20, 2013  Florida
Matrix Health and CSL Behring in collaboration with the CJ Wilson’s Children’s Charities host the Par 4 Cure Golf Tournament
Bonaventure Country Club
Weston, FL
Contact: Hector Heer 954-940-1248 (Habla español)

May 4 2013  Florida
Florida Hemophilia Association
305-235-0717; www.floridahemophilia.org
3rd Annual Walk in the Jungle
Jungle Island; Miami, FL
Contact: Hector Heer 954-940-1248 (Habla español)

April 17
World Hemophilia Day!

April 20, 2013
Matrix Health and CSL Behring in collaboration with the CJ Wilson’s Children’s Charities host the Par 4 Cure Golf Tournament
Bonaventure Country Club
Weston, FL
Contact: Hector Heer 954-940-1248 (Habla español)
or Kelly Champagne 850-658-2952

Solutions to puzzles on page 22
Hi Kids!

Over the holidays, Michael received a brand new bike! Michael has a bleeding disorder, but even if he didn’t, he knows that bicycle safety is very important. When riding your bike, always wear a helmet so that your head is protected in case you fall and hit your head. Wearing a helmet can help protect you from having a bleed in your brain, which can be very dangerous.

Today, Michael is going to pick out a cool new helmet to wear when he rides his new bike. There are so many choices, but he wants one that is different from the rest. Can you help Michael find the helmet that does NOT have one that is an exact match?

Answers to the puzzles can be found on page 21. Have FUN!
Cause for Applause!
At Matrix Health, we are dedicated to MAKING A DIFFERENCE!

If you received outstanding service from a member of our staff, please take a moment to complete the following recognition form. With your permission, your comments will be shared with our employee who will receive a special thank you on your behalf.

It is our MISSION 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.

Your Name _____________________________________ Date of Service____________________________
Your Phone # ___________________________________ Email ___________________________________
Matrix Health employee(s) you wish to recognize: _______________________________________________
_______________________________________________________________________________________

In what manner did our employee(s) provide outstanding service or make a difference in your life? Please be specific and provide as much detail as possible (continue on an additional page if necessary).

May we use your name and story as part of our internal company communications or our external marketing efforts (such as company website, newsletter, etc.)?

Internal Communications □ Yes □ No  External Marketing □ Yes □ No

Thank you for recognizing our dedication to MAKING A DIFFERENCE! We sincerely appreciate the time you took to acknowledge one (or more!) of our wonderful employees!

Please mail, e-mail or fax this form to: Questions? Please call:
Matrix Health 954-385-7322
3300 Corporate Avenue, Suite 104 877-337-3002 (toll free)
Weston, Florida 33331
954-385-7324 (fax)
feedback@matrixhealthgroup.com Visit our website!

www.matrixhealthgroup.com

Visit our website!
www.matrixhealthgroup.com
Our **Mission** and **Vision** are realized through the value we place in our five guiding principles. These values represent our commitment to our employees, patients, and the community, driving our organization to excellence.

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

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

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

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

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

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**Matrix Health News**

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

Just complete this form and mail to:

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Weston, Florida 33331

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

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