Matrix Health Group News

Winter, 2016

Volume 11
Issue 1

A quarterly publication

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

Matrix Health

MEDEX BIOCARE

FACTORRx SUPPORT NETWORK

HOMECARE FOR THE CURE

Matrix Heath Group in San Diego!
Hemophilia Association of San Diego County's
Third Annual San Diego Walk
(Front to back) Dylan, Trevor, Jordan and Kelsey

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Matrix Health Group

Dedicated to Making a Difference!

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Matrix Health Group News

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

The purpose of *Matrix Health Group News* is to provide an opportunity to connect with others by providing information such as current news, upcoming events, educational matters, personal stories, and a variety of opinions and views on topics of interest to the bleeding disorder community.

The information and opinions printed in this newsletter do not necessarily reflect the views and opinions of the partners, employees, others associated with *Matrix Health Group News* or that of Matrix Health Group.

Health related topics found in *Matrix Health Group News* are for informational use only and are not intended to take the place of treatment or medical advice provided by your health care professionals or hemophilia treatment center. Please consult with your health care professionals when medical questions arise.

Mission and Vision

The **MISSION** of Matrix Health Group is to provide individualized, focused services to people with bleeding disorders nationwide.

Our **VISION** is to enhance the lives of those we are privileged to serve by providing the best pharmacy and support services possible.

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

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

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

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

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

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

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Like us on Facebook!

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

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

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

A Note from the Editor

Dear Readers,

Happy New Year! All of us at Matrix Health Group are very pleased to start a new year of service to the bleeding disorder community. While our family has grown considerably, our commitment to providing exceptional and individualized care has not changed. With our Guiding Principles of Integrity, Compassion, Dedication, Enrichment and Enthusiasm as our compass we work hard every day to fulfill our Vision and Mission. We are proud of the organization we have grown to become and will continue to work tirelessly to meet our goal of helping those we serve achieve better health. If you are not already one of our valued patients, I encourage you to consider our services. We will not disappoint!

In this first edition of 2016 we are pleased to share with you the winners of our 2015 Memorial Scholarship Fund. We take a look at the importance of assigning chores to children of all ages (with or without a bleeding disorder!) and discuss how to avoid fatigue when it comes to providing care for others.

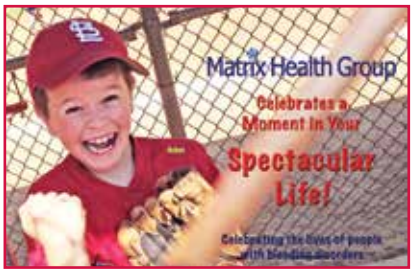
On another note, we are currently collecting stories from siblings - adults and children - of people with bleeding disorders. If you or your child without a bleeding disorder has a story to share about the challenges and joys of what life has been like, please consider sending it along with photos to us at maria.vetter@matrixhealthgroup.com.

Wishing you all a healthy and happy 2016!

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

A Moment in Your Spectacular Life!

2016 Calendar



Now Available!

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

877-337-3002

maria.vetter@matrixhealthgroup.com

Contact us today to receive your complimentary calendar.

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!

TRICARE APPROVED!

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

We look forward to hearing from you!

We offer:

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

Matrix Health Group Proudly Announces
2015 Memorial Scholarship Winners

Matrix Health Group offers nine $1000 scholarships assisting individuals affected by bleeding disorders seeking higher education. These scholarships honor the memory of several individuals who touched the bleeding disorder community in unique ways. In addition to honoring the memory of these remarkable people, this scholarship program aligns with the commitment Matrix Health Group holds to Enrichment, one of five Guiding Principles forming the backbone of our company value system.

We are thrilled to announce this year's scholarship winners! We received a tremendous amount of very qualified applications and our third party committee informed us it was very difficult to choose the award recipients. Without further ado we proudly present our winners!

Taha Ahmed
Tim Kennedy Memorial Scholarship

Taha Ahmed is a man with a vision, "I have high hopes for my future in the next few years of my life and I am ready and able to do what is necessary to achieve my dreams." Having hemophilia is not getting in the way of those dreams. When Taha receives his degree in Electrical and Computer Engineering he plans to attend graduate school pursuing a doctorate in engineering with ultimate aspirations to land a position with tech giant Apple as a Licensed Professional Engineer. Taha has served as a camp counselor at a bleeding disorder summer camp since 2010 and enjoys computer building and repair in his spare time. Congratulations Taha!

Alex Cornell
Ron Niederman Memorial Scholarship

Having a brother with severe hemophilia, Alex grew up as no stranger to medical supplies, trips to the hospital and other experiences common for families with a child who has hemophilia. This, coupled with a desire to help people encouraged Alex to pursue a degree in Biomedical Laboratory Science. Alex notes, "I've always wanted to help people in some sort of way and through academia, I have found my analytical skills would be a big contribution…there is nothing more important than a person's health."
Congratulations Alex!

Nathanial Cornell
Tim Kennedy Memorial Scholarship

Nathan does not let the challenges hemophilia has brought him get in the way of his ambitions. He shares, "I have gone through my fair share of hardships and as a result, I am a stronger, kinder, more motivated individual than I otherwise would have been." Currently in his sophomore year, Nathan plans to pursue a major in both Computer Aided Drafting and Design and Welding Technology. He is highly regarded by friends and colleagues alike.
Congratulations Nathanial!

Haylee Horn
Millie Gonzalez Memorial Scholarship

Haylee admits, "One of the hardest challenges I struggle with is the feeling of alienation that comes with having a chronic illness." Though life with Dense Granule Storage Pool disease, a rare bleeding disorder, has been challenging, Haylee found an outlet through art. Her passion for ceramics in particular has inspired her to pursue a degree in Ceramic Art with a minor in Business at Anderson University. Haylee actively volunteers in the bleeding disorder community, is involved with her church and has demonstrated great academic success.
Congratulations Haylee!

Malia Jackson
Millie Gonzalez Memorial Scholarship

"I was always afraid of those thin tiny needles with blue plastic wings on them. I feared the pain they brought when they penetrated my skin," Malia recalls of her first experiences with butterfly needles. She recollects, "I didn't understand why doctors called them butterflies, a name so pleasant if they only brought pain." Having von Willebrand Disease, Malia eventually learned to overcome her fear and understand the importance of the infusions in helping her maintain health. Her experience also awoke a desire to help others realize better health and today she is pursuing a nursing degree at the University of Colorado. In her spare time, Malia volunteers with the Easter Seals helping children overcome their fear of needles. She remarks, "I understand how scary and painful this all can be, but I try to teach the children that in the end it's just a butterfly, and butterflies are beautiful." Congratulations Malia!

Angela Kessler
Mark Coats Memorial Scholarship Winner

Angela's diagnosis of von Willebrand Disease has influenced her life and career choices in a number of ways. Currently pursuing a Clinical Laboratory Science degree (with a double minor in Chemistry and Spanish), she acknowledges, "At times it has taken a very high toll…although there have been significant adversities associated with my bleeding disorder, it has affected me in positive ways as well." From volunteering over 600 hours for agencies primarily supporting the bleeding disorders community, to her decision to pursue a career as a clinical lab scientist, Angela shares, "I hope one day to contribute to a medical advancement that will benefit the bleeding disorders community." Congratulations Angela!

Perseus Patel
Joe Holibaugh Memorial Scholarship

"I had forgotten how it felt to stand, forgotten the excitement of left foot-right foot, heel-then-toe. I was a ten year old boy being carried in my mother's arms," Perseus recalls of a rough childhood living with severe hemophilia and inhibitors in India. After moving to the United States Perseus fortunately received access to care that allowed him to walk again. He recalls, "These early emotional adversities forged my devotion to serve children and families." Perseus has gone on to achieve great academic success. He is currently pursuing a Medial Doctorate specializing in Hematology. His extensive volunteer work includes much experience serving the bleeding disorders community, including founding a camp program for children with hemophilia in India. Congratulations Perseus!

Evan Poole
Joe Holibaugh Memorial Scholarship

Now in his junior year pursuing a Mechanical Engineering degree, Evan, who has hemophilia B, boasts an impressive list of accomplishments. From academic achievements to tenure with the National Hemophilia Foundation's National Youth Leadership Institute program to fundraising efforts and work as president and founding member of "Engineers Without Borders," Evan is always looking for ways to pay it forward. He affirms, "I aspire to make the world a better place by improving the quality of life for others. I will do this through a career in mechanical engineering." Congratulations Evan!

Sachin Rudraraju
Mike Hylton Memorial Scholarship

"Passion and dedication toward a specific goal can open up countless doors," Sachin, winner of the Mike Hylton Memorial Scholarship shares. In his early twenties, Sachin has already opened doors those twice his age may never even touch. His resume boasts incredible academic achievement and impressive work as a researcher, design engineer and programmer. He holds a host of awards for his numerous achievements and in 2016 will graduate with a degree in Computational Biology and a Minor in Computer Science. The Ohio native attends Cornell University and has not once allowed hemophilia to prevent him from pursuing his ambitions. Congratulations Sachin!

All of us at Matrix Health Group wish you the very best in your continued success. Your example is an inspiration to the bleeding disorder community and embodies the values we seek to honor with our memorial scholarships. Congratulations to all of our scholarship recipients!

The Value of Chores

By: Sarah Henderson

As parents of children with bleeding disorders, we always try to treat each child as normally as possible. Add a chronic health condition and common parenting struggles become more complicated, one difficulty in particular being chores. This is especially problematic when you have a child who is frequently on bedrest or trying to keep a bleeding joint elevated.

It is important for children to have chores because chores are the foundation for many important concepts needed to grow into successful, happy adults. Chores help children develop self-worth because they are learning how to be an important part of the family unit and something bigger and more significant than just themselves. Children with chores tend to grow into adults with better coping skills… we know this is especially important when dealing with a bleeding disorder since they will need better coping skills than most to navigate life. Learning how to manage a bleeding disorder and other necessary daily tasks will make them more ready for independence in adulthood.

The Washington Times reports that, "Marty Rossmann of the University of Mississippi used data collected over 25 years starting in 1967, to discern whether asking children to help with household chores starting at age 3 or 4 was instrumental in predicting a child's success in their mid-20's. Chores, she determined, instilled in children the importance of contributing to the family unit and gave them a sense of empathy as adults. Those who had done chores as young

children were more likely to be well-adjusted, have better relationships with friends and family, and be more successful in their careers."

There are many chores that kids can help with while resting and/or elevating during a bleeding episode. Chores need to be age appropriate, but there are many things kids can help with, even while on bed rest:

1. Folding washcloths or hand towels
2. Matching and folding socks
3. Sorting silverware
4. Helping with menu planning and composing a grocery list
5. Helping younger siblings with homework

Be creative with any tasks that need done; take the time to figure out what chores can be handled by your child and incorporate him or her into family chore day or daily tasks. Depending on their bleeding tendencies, they may not be able to make a significant impact on the family workload, but the important thing is they stay involved and have a chance to make a meaningful contribution.

In a Love and Logic parenting book, *The Pearls of Love and Logic for Parents and Teachers* by Jim Fay and Foster Cline, M.D. we read, "Chores are the foundation of responsibility and self-esteem." They also offer three guidelines for assigning chores to children:

1. When children are small, they enjoy doing things together. Make chores fun!
2. Base chores on the maturity of your child
3. The secret of happiness with your child around chores is to use consequences without anger

There are many fun and innovative ways to get kids involved in chores and gain independence in doing them. There are lots of appealing chore charts that can be visual aids for kids to see what they need to do each day or week. It is imperative children learn that as part of a family, they need to work together and help keep a household running for the sake of others. Keep in mind though, a child who is always paid for doing what should be his or her share of the workload can become entitled and in turn, be robbed of the self-worth that can be learned.

Children who start helping at a young age by following mom or dad around the house doing things like wiping windows or sweeping, whether they are actually helpful or not, are learning to contribute and feel proud of themselves. By the time they are a little older and can actually handle chores around the house by themselves, they will know how to do the task and are less likely to argue because they have learned from an early age that everyone pitches in.

Chores also give kids a chance to see how much work is involved in running a household. This helps make them more appreciative of things done for them, and more likely to clean up after themselves without being instructed.

Having chores can also give children an advance in school and social settings. Pamela Mako, a teacher of 25 years states, "As an elementary school special education teacher, I have noticed students who have chores at home appear to be more successful in school. They tend to be hard workers, get their homework in, participate in extracurricular activities and overall have good character. Learning good work ethic is taught in part by having responsibility such as chores. Parents do not miss this teaching opportunity."

The following chore outline provides a rough guideline as to what ages certain tasks would be appropriate. If the idea of assigning chores in your family is a new concept, start by assigning simple tasks and adding more when your child is ready. Keep in mind that children develop differently physically and mentally, and some children may be able to handle certain

tasks better than others. Most importantly, stay consistent, follow through and set your child up for success with lots of praise. It is more important that the chore be done, rather than be done perfectly. Tasks should be routine and scheduled into their day.

Chores play a big part in helping children learn responsibility and work ethic. With or without a bleeding disorder. appropriate chores can and should be found for children of all ages. The lessons learned appear to have a positive effect well beyond childhood. What are you waiting for? Help your child learn some valuable life lessons and finally get that bookshelf organized!

2-4 year olds

- Help put away toys
- Help dust
- Put napkins on table
- Help put laundry in hamper
- Help feed pet

4-7 year olds

At this age, children should be considered helpers. As the child grows more mature, they can begin to handle these tasks independently.

- Help make bed
- Put away toys
- Help put away groceries
- Help set and clear the table
- Help put dishes in dishwasher
- Help wipe up messes
- Help feed pets
- Water house plants
- Dust
- Put laundry in hamper
- Help with yard work - rake with child's rake, plant flowers, water the garden, etc.

8-10 year olds

- Make bed
- Clean room with direction
- Water house plants
- Help make dinner
- Set and clear the table
- Help load and empty dishwasher/wash dishes
- Feed and help care for pets
- Dust
- Sweep
- Vacuum
- Put laundry in hamper
- Help with yard work - rake, plant flowers, water the garden, pull weeds, etc.
- Help wash the car

11 year olds and older

- Keep bedroom tidy and make own bed
- Carry in and put away groceries
- Set and clear the table
- Help make dinner
- Make small meals on own
- Load and empty dishwasher/wash dishes
- Clean the kitchen
- Mop the floor
- Clean a room with direction
- Clean the bathroom with direction
- Be responsible for the pets
- Dust
- Sweep
- Vacuum
- Collect and sort laundry, eventually start doing own laundry
- Yard work including mowing the lawn
- Shovel snow
- Collect and take out the trash
- Wash the car

Answers to puzzles featured on page 31.

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

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

what to do if you have the flu

By Nanette Vaughn, RN

On average, 5 to 20% of people are afflicted with the flu any given year in the United States. Especially for people who are high risk, having the flu can be serious and even life threatening. Approximately 200,000 are hospitalized and 36,000 do not survive. Flu season tends to begin as early as October and can run as late as May, with the typical peak season being in January through February.

Most healthy adults don't need medical treatment for the flu. However, if you feel you may have it, you should drink plenty of fluids, avoid contact with others, wash your hands frequently and get plenty of sleep. You should stay home for 24 hours after your fever is gone. And yes, chicken soup does help. Some scientists believe it has anti-inflammatory properties. As an added bonus to help thin mucous, try adding pepper or curry powder to your soup.

Other helpful spices include: ginger, which helps your body make a protein called interferon that fights viral infections, and chili peppers, which have an antioxidant and the heat can help unclog your sinuses.

Warm or cool mist vaporizers are equally effective and can help ease congestion; although if there are children in the household, a cool mist unit would be safer. With any vaporizer, remember to wipe it down daily with a solution of 9 parts water and 1 part bleach. This will prevent the growth of bacteria and mold. Some people benefit from saline nasal rinses. Sleeping with your head elevated may also be helpful. We all know there are multiple over the counter medications to treat flu-like symptoms. Keep in mind, those with a bleeding disorder should avoid products that contain aspirin or other ingredients which may cause bleeding. If you are unsure about what you can take, always check with your doctor or consult with a pharmacist for guidance.

If your symptoms are severe, or you are in the high risk group for flu complications - children under 5, adults over 65, pregnant, have congestive heart failure, any lung disease, diabetes or are immune compromised - your doctor may want to treat you with an antiviral medication. The most commonly prescribed are Tamiflu or Relenza. These drugs are most beneficial if given within 48 hours of onset of symptoms. They can shorten your illness by a day or two; but more importantly, they can help prevent complications such as pneumonia, bronchitis, sinus and ear infections. If a person has an underlying health concern, for example asthma or a heart condition, having the flu can worsen the problem.

Some physicians will want to run a rapid influenza diagnostic test, which requires a nasal or throat swab. Results take only 15-30 minutes, but false negative results are common. Viral cultures, also obtained by swab, are more accurate, but can take 60 minutes up to a 8 hours to determine the results. Important to note, you don't have to have a positive flu test to be prescribed an antiviral. Your doctor will make that decision with you based on the severity of your symptoms and your underlying risk factors for complications.

The following guides can give you an idea of your symptoms and when best to seek medical treatment.

SYMPTOMS	FLU	COLD
Onset of symptoms	Abrupt; usually multiple symptoms	Gradual; often starts with 1 symptom
Fever	Usual; for 3-4 days (100°-102°)	Rare; usually lower grade temp
Aches	Usual; often severe	Sometimes; milder
Chills	Common	Uncommon
Fatigue/Weak	Usual; can last up to 3 weeks	Sometimes; for a couple days
Sneezing	Sometimes	Common
Stuffy Nose	Sometimes	Common
Sore Throat	Sometimes	Common
Chest Discomfort	Common; can be severe	Sometimes; mild/moderate
Cough	Common; can be severe	Sometimes; mild/moderate hacking cough
Headache	Common	Sometimes
Vomiting/Diarrhea	Sometimes; more common in children	None

Severe Warning Signs Necessitating Treatment

Adults:

- Labored breathing or shortness of breath
- Pain or pressure in chest or abdomen
- Sudden dizziness
- Confusion
- Severe or persistent vomiting
- Symptoms that improve, then return with fever and worsening cough; could indicate pneumonia

Children:

- Labored fast breathing
- Bluish skin color
- Fever with rash
- Not drinking fluids
- Not waking up or interacting
- Inconsolable

Infants:

- No tears when crying or significant reduction in wet diapers (signs of dehydration)
- If symptoms improve then return with fever and worse cough, could indicate pneumonia

References: CDC website, WebMD, Medscape, Mayo Clinic websites.

Matrix Health Group

The Health Advocate

Costs of Improved Care

Paul R. Brayshaw, M.P.H.
Director of Healthcare Advocacy and Programs
Factor Support Network,
a Matrix Health Group Company
Regional Care Coordinator, Mid-Atlantic Region

Having a bleeding disorder means I have one of the most expensive chronic conditions to treat. Most of this cost is related to clotting factor replacement therapy (FRT) for the treatment of hemophilia. In 2006, I nearly reached a lifetime insurance cap after three years on a commercial policy following a secondary prophylaxis regimen to manage my condition. Over the last ten years and to preserve my joints and mobility, I have embraced a prescribed twice weekly, prophylaxis regimen. Adhering to this regimen has increased my healthcare costs nearly three times during this period. Although my cost of care has increased three-fold, I have experienced less bleeding episodes, avoided costly hospitalizations and experienced a better quality of life as a direct result of this therapy. I am writing to share my experience, discuss the importance of factor replacement therapy, share my concern with the increased costs of therapy, and offer my encouragement for the bleeding disorders community to embrace the opportunity and responsibility to improve personal health and positively impact health care spending.

The availability of clotting factor concentrates in the last fifty years and FRT has transformed care for people with hemophilia and bleeding disorders, allowing them to enjoy a 'normalized life.' Children and young adults are participating in more physical activities and engaging in sports more competitively as a result of prophylaxis. The long-term benefits of prophylaxis include reduced hospitalizations, fewer joint replacements and lower morbidity and mortality. To preserve physical health and wellness, maintaining access and adhering to FRT during the working years and into retirement is critical. However, the short term costs of care seem to negatively dominate the discussion as more people embrace prophylaxis in their lives.

Proper medical management and health care decisions involving my condition has meant discussions and consultation between a comprehensive clinical team of doctors, nurses, other caregivers, family and me. Growing up in Colorado meant downhill skiing as soon as the snow landed. Carving the slopes on skis was an activity my family enjoyed together, and to participate in this activity, I stubbornly accepted the extra time needed to infuse a dozen bottles of factor to be adequately protected. The added risks of participating in this hobby were worth the time burden and personal costs.

At the time and in those early days of FRT, I did not give much consideration to the increased societal costs associated with greater utilization. Fortunately I benefited physically as an early adopter of secondary FRT prophylaxis with all my body parts, original and intact. By staying physically active and keeping myself protected with maintaining my regimen, the short term increased cost were balanced with long term savings created by avoiding repeated bleeding episodes, hospitalizations and surgeries.

There are a number of items further complicating the issue. With new and advanced products being developed, the promise of better health outcomes is associated with increased costs. However, when

modest enhancements are not sufficiently reflected in improved health outcomes, the innovations seem to have less of an impact on the gap between a 'normalized life,' and the impact of increased costs generating scrutiny from insurance companies and potentially creating barriers for treatment adherence. It is difficult to adhere to a prescribed therapy regimen when out of pockets costs are prohibitively expensive.

Fortunately the majority of FRT manufacturers are offering financial assistance programs to remove this burden, though there are many in our community who are unaware or under-utilizing these programs. Further, as a community we must consider some difficult questions. What responsibility should we as patients, consider when the increased costs of prophylaxis are being utilized for higher risks activities instead of, or in addition to, minimizing risks to ensure long-term physical health? How does the consumer contain health costs when the best evidence for long-term health is lifelong adherence to a FRT prophylaxis regimen? Are disease management, monitoring and utilization of clotting factor concentrates the responsibility of a consumer?

Preventing accidents or injuries by avoiding excessive risks, and adherence to a prophylactic FRT regimen may be the best advice. Yet the increased costs associated with FRT prophylaxis has positioned all people with bleeding disorders and other rare, chronic conditions in a critical dilemma. How do we make lifestyle choices that may increase risk and overall healthcare costs? The cost of care for people with bleeding disorders has generated increased attention by insurance companies, policymakers and other stakeholders. Legislation has been introduced in Washington and in state capitols across the country to respond to these increased costs.

As a community, we should recognize the attention our cost of care generates from various stakeholders. The resources and money involved in managing this condition have made us highly sought after commodities by manufacturers seeking new patients for their factor replacement therapies in addition to homecare companies and HTC 340B programs distributing these products.

The resources allocated to treat bleeding disorders have resulted in insurance companies viewing us as a catastrophic cost. Hemophilia treatment centers assess us as a 340B lifeline, as well as a data repository ripe for study. Pharmacy benefit management companies view bleeding disorders like any other disease, and seek to manage per patient cost. Understanding the role these entities and others play in our health care consumption make us savvier, better-educated healthcare consumers.

As individuals, we are ultimately responsible for how we live our lives and how we consume healthcare services. Maintaining a prophylaxis regimen has improved my quality of life and kept me healthy. I hope my most enjoyable years get better with age. I am blessed with a loving wife, two healthy young boys, and a good paying job with comprehensive health benefits. Because I love what I do in my career, work life is great. I also recognize being employed and working provides for many essential life needs, especially health insurance. With quality employer-based health benefits, I am able to maintain the most efficient access to health care while I enjoy the broadest opportunities for my pursuits of happiness. Such opportunities should be available for all members of the bleeding disorder community and controlling cost should not come at the expense of the proven positive health outcomes FRT provides.

It is up to us to understand and continue to vocalize the importance of FRT as more attention is given to the costs associated with managing a bleeding disorder. We must also remember our own responsibility as healthcare consumers. By avoiding excessive risks in daily life and properly adhering to prescribed factor replacement therapy regimen, our community has the opportunity to improve personal health outcomes while having a positive impact on the costs of care as responsible, albeit costly, health care consumers.

Overcoming Parent Burnout

By Robbi Blume
Nebraska Foster and Adoptive Parent Association Resource Family Consultant-Northern Area

Parenting can be a tough job. In order to work with our children, it is important to remember to take care of ourselves first. This is often easier said than done. Burnout is a common psychological problem that affects people of all ages, but is most common in "helping" positions such as nurses, caregivers, teachers and parents. These people tend to sacrifice themselves for others and often end up being burned out – exhausted, listless and unable to cope. Burnout is a condition that derives from stress and poor stress management. It occurs over a period of time, usually months, and can lead to physical and mental exhaustion.

As parents and caregivers we often struggle to fit all the things we need to do into our available time. We sometimes find it difficult to deal with the emotional involvement it takes to care for another human being. It becomes difficult to see the tangible results and appreciation for all our efforts.

A helping professional or parent must often keep their own feelings inside to provide for the best interest of the person or child they are trying to help. A primary stressor for caregivers is the demand to take on other people's pain, anger and hostility. Many negative feelings of the child may be directed toward the parent as they are a safe target.

We have to perform a juggling act each day, balancing our needs, our spouse's needs and the needs of our children. It is not surprising that with so much to deal with on a daily basis, we often find ourselves going into survival mode, finding ways to distance and protect ourselves from too many demands even though this behavior can decrease our effectiveness as caregivers.

The risk of burnout increases when parents:

- Lack support
- Feel powerless
- Are perfectionists
- Are workaholics

Some of the symptoms of burnout include:

- Fatigue
- Health failure (e.g. headaches and stomach aches, back pain)
- Feelings of sadness and anger
- Appetite changes
- Depression or lack of interest in everyday activities that were once enjoyed
- Feeling like running away
- Feeling trapped or hopeless

Awareness is key to preventing burnout. Even if you don't fit in any of the common categories, a busy lifestyle with little support is enough to trigger burnout. Try making a few of these simple changes to keep burnout at bay:

- Learn to relax
- Keep a journal
- Get enough sleep
- Eat well
- Be physically active
- Express yourself
- Laugh everyday
- Let someone take care of you
- Develop and maintain a social support system (friends, neighbors, co-workers, church family)
- Use respite care

Sometimes parents need a temporary break from care giving so they can come back refreshed and ready to provide good care again, which makes respite care a valuable tool for families. By respite, I don't mean dropping your child off with strangers who don't understand his or her medical or behavioral needs. I mean finding activities within your community that the child may attend for short periods of time such as story time at the library, 4H club meetings or church youth group.

It can be as simple as hiring someone to come into your home to play a game or do an activity with your

child while you take a bath – yes, by yourself – or make a phone call. Plan this in advance so you can look forward to the break. Periodic respite enhances the quality of care we provide as parents. Commit to "self care" and make a plan. From now on, I will make time to take care of myself by doing the following:

Once a day:

_____

_____

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_____

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_____

Once a week:

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Once a month:

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_____

Check up on yourself by asking:

- When was the last time I had a really good laugh?
- How often do I eat breakfast?
- How often do I connect with other parents?
- How often do I connect with friends?
- When was my last date night?
- When did I last read something for fun?

You deserve to be cared for just as you care for others. Whether raising a family or working in a "helping profession," employing a few techniques to keep burnout at bay is essential to your wellbeing and ultimately the wellbeing of those you are caring for. As we begin a new year, commit to providing yourself the same level of care and support you provide others. Only good can come of it!

Brandywine Valley Hemophilia Foundation Annual Celebration

Board Members Jill Abrams and Gail Vannicola with Biogen's CoRe Manager Christine Rowe (center)

With limited seating, 64 lucky guests attended the Brandywine Valley Hemophilia Foundation's Holiday Luncheon where fun activities ensued! Held at Longwood Gardens in Kennett Square, Pennsylvania, guests enjoyed a tasty meal and a walk through the gardens where a half-million twinkling lights illuminate the way. No holiday party is complete without the arrival of Santa who led our guests in carols, handed out gifts and selected names for our lucky raffle prize winners.

Chapter President Gail Vannicola shares, "We are thankful for our sponsors, Baxalta and Biogen, our board members, chapter volunteers and community members for making this such a fun event! Next year, we hope to hold this annual event at a larger venue so we can share this jubilant holiday celebration with even more friends!"

Volunteers Linda Wallace, Agness Ann Mathis, Gail Vannicola and Jill Abrams work hard to make the organization a success

Kevin and Mom Melissa visit with Baxalta's Tom Wallace and Board Member Chris Ramsey

Luke knows you're never too old to receive a gift from Santa, with mom Gail.

Matrix on the Move

Tennessee

Stephen Lawrence, David Tignor, Robin Lawrence

Aaron, Christy and Robin line up with smiles!

Grandpa Roger shows off his little 6-month old Kendra

Families from the Tri-Cities area were invited to share an evening of good food and great company, as Pfizer and Matrix Health Group held an ***educational event*** at Peerless Restaurant in Johnson City on August 29th. The families at this event had the opportunity to hear Nayan Heath, BSN, RN, Nurse Educator Specialist, speak on how to engage people from all walks of life in *Constructive Conversations*. This provided for constructive conversations indeed, as all present were encouraged to share in this very animated presentation.

Nevada

Kelly Gonzalez

Ready to Walk!

On September 12th nearly 200 patients, friends and family gathered at Virginia Lake Park in Reno to support the Northern Nevada ***NHF Walk***. The two-part event, Northern Nevada on September 12th and Southern Nevada on September 26th, raised nearly $62,000! Factor Support Network in conjunction with the HTC of Nevada hosted a booth and participated with a walk team as well. Funds raised at this annual event benefit Nevada's bleeding disorder community.

Kelly Gonzalez with HTC staff, Ariana and Jennifer.

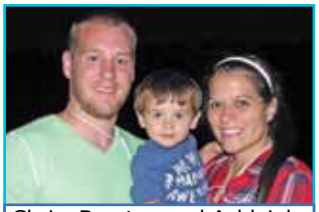
Amber and Erin Nurse Practitioners

Tennessee

Shannon Cassada and Cyndy Coors

Matrix Health Group and CSL Behring hosted an ***educational dinner*** on September 15th on the Southern Belle Riverboat Dinner Cruise in beautiful Chattanooga. Over 60 people attended this dinner and enjoyed an evening cruising the Tennessee River and listening to CSL Behring's Common Factors Advocate, Lori Kunkel, speak on the *ABC's (A-Advocate, B-Believe, C-Create)* for yourself or your loved one with a bleeding disorder. Lori discussed how to be empowered and help educate emergency room staff and school personnel. She adamantly shared with everyone, "Your diagnosis of a bleeding disorder does not define who you are!"

Shannon Cassada speaks to the group.



Chris, Braxton and Ashleigh.

Todd Grayson, Sales Manager-Coagulation at CSL Behring offered information about CSL's products and resources available to the bleeding disorders community, and Shannon Cassada shared the services provided by Matrix Health Group. After dinner, families were invited to stroll around the riverboat and enjoy spending social time together as the Southern Belle returned to dock.

Happy Family!

Robin Lawrence, David Tignor, Shannon Cassada, Cyndy Coors with Lori Kunkel and CSL's Todd Grayson.

California

Marina Vera

Daniel challenges Luke Skywalker to a sword flight.

The Hemophilia Foundation of Southern California sponsored their 7th Annual ***Hemophilia Beach Walk*** September 19th at the Crescent Bay Park in Santa Monica. Over 400 people signed up to share in the warm weather and camaraderie of the day. Families enjoyed mingling and taking pictures with characters from Star Wars including Darth Vader, Luke Skywalker, Master Yoda and Princess Leia. Well-known community rapper Isaiah Solis gave a live performance and, as always, there was plenty entertainment for the kids. Factor Support Network sponsored face painting while volunteers from Camp Painted Turtle sponsored an arts and crafts table. This year's walk proved to be another great event for the chapter!

Who's behind that painted face?

Florida

Peggy Gay

Chapter President,Fran Haynes is challenged to a balancing act.

CSL Behring and Hemophilia Foundation of Greater Florida presented ***Gettin' in the Game Program and Ropes Challenge Course*** with Tim Grams, CSL Getting in the Game athlete. Held September 19th at Tampa's University of South Florida Riverfront Park, this fun day was designed for children and young adults ages 12 to 21, and included fun-filled team building activities, lunch and a ropes course. Our day was filled with laughter as everyone worked together to implement team-building solutions as various tasks and problems were presented.

Maine

Cheryl Ashmore

A beautiful 75-degree, early autumn day in scenic mid-coast Maine brought approximately 100 hikers to the 3rd annual ***Hike 4 HAM*** fundraiser. Hemophilia Alliance of Maine (HAM) is a four-year-old organization experiencing a tremendous amount of growth. The fundraiser's informal motto is, "In Maine, we don't Walk, we Hike" and true to form, folks from all age groups hiked a moderately difficult 3 mile trail to the top of Mount Battie in Camden. Afterward, everyone enjoyed a delicious barbecue lunch while taking time to renew acquaintances and visit old friends. Homecare for the Cure, a Matrix Health Group Company was a proud sponsor of the hike.

Happy Hawk family!

Syrus enjoys the fantastic view.

Superhero family! Ryan, Lisa and Caroline

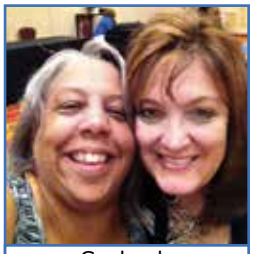
Alex, Daniel and Syrus hide in the shade.

Terry Stone and Paul Brayshaw welcome visitors to the booth.

Maryland

Terry Stone

Now that school bells are ringing and students small and tall have settled into their studies this fall, the topic of bullying and personal safety is undoubtedly on the minds of parents and educators alike. In keeping with the hot topics of the times, Hemophilia Foundation of Maryland welcomed its families to a ***Family Educational Dinner*** on September 19th at the BWI Airport Marriott to address the topic of bullying and shared some great tips on how to handle it.



Cool gals Stephanie and Terry take a selfie!

Many thanks to Baxalta and a host of industry supporters including Matrix Health Group and Factor Support Network for sponsoring this great event of learning, sharing and networking. Opportunities like this are so important to the community and it opens the door for families to gather. As the evening came to a close, Harvey Gates, Chapter President, invited several families to the podium to introduce themselves. Although not new to hemophilia, they were new to the chapter and other members. It's a wonderful testament that wherever you are in your journey of living with hemophilia, the chapter is, has been, and will always be there ready to support, connect and inspire you to live well with hemophilia.

Michigan

Bonnie Culver

Homecare For The Cure, a Matrix Health Group Company, had the pleasure of hosting an ***educational dinner*** with Lisa Wiles, Hemophilia Product Specialist at Emergent Biosolutions for families of Michigan's hemophilia community on September 22nd. Presented by Brian Rodgers, Hemophilia Nutrition Specialist, the topic for the evening was *Rebuilding the Body With Diet*. Brian says of the event, "While presenting this nutrition program, there were several great questions leading to

multiple open conversations on the benefits a healthy diet can have on people with and without hemophilia. We touched on topics ranging from the negative effects excess weight can have on joint health to vitamins and nutrients that affect coagulation and blood flow. The overall outcome of the presentation shed light on the multitude of benefits a healthy lifestyle can have on bleeding disorder care. By making small changes on the road to healthy living, we end up taking a giant leap in our well-being."

Guests asked many excellent questions and Brian was very thorough in his answers; he also had great take-aways for us including an informative meal chart, showing portion sizes for fruits, grains, vegetables, proteins and dairy. The chart can also be used as an aid to identify 'super foods' while grocery shopping.

At the Spartan Hall of Fame Café in East Lansing, our meals for the evening were altered to meet a healthy diet criteria. Featured items were Cajun Tilapia, Top Sirloin Steak, Tequila Lime Chicken, Penne Pomodoro, Hall of Fame Salad with Chicken or Salmon, and a fantastic low-fat Angel Food Cake topped with fresh berries for dessert. The meals were all absolutely fantastic and a great reminder that eating healthy does not mean the meal has to be expensive or tasteless.

South Carolina

Peggy Gay

Tristin enjoyes camp!

Hemophilia of South Carolina Chapter held their ***Family Camo Educational Weekend*** September 25th–27th. This fantastic event brought in approximately 55 families with over 185 people to the Ocean Creek Resort in Myrtle Beach.

Breakout sessions directed to specific age groups were offered to the families. Adults attended educational programs presented by Inalex on *Your Miracle, Your Life*, and *Getting off your Aspirations* by Barry Haarde. Teens and parents attended sessions on *Constructive Conversations* and *High Fives and Do Overs*. The sessions for families with children included *Expecting the Unexpected* and *Bullying Online and Offline*. These sessions had wonderful speakers that presented helpful information on bleeding disorders issues. Saturday was fun for all as families enjoyed *Jungle Safari Family Miniature Golf* and *Elvis is in the House*. On the beach, a castle building contest, "The Sand Art Castle Project," ensued among the families. The weekend wrap-up began at noon with a *Lunch Box on the Run* and free time on the beach. Everyone had a great time learning and socializing; thanks to Executive Director Sue Martin for all her hard work and dedication to our community!

West Virginia, Maryland, Virginia

Paul Brayshaw

Brothers Paul and William Brayshaw ride for a great cause.

September 25th-27th, for the fifth year in a row, the Hemophilia Federation of America hosted its ***Gears for Good Bike Benefit*** along the Chesapeake and Ohio Canal Towpath; a three-day, 156-mile ride to raise funds for HFA's Helping Hands Program. The ride began on Friday morning when riders were transported by van from Washington D.C. to begin the journey, then headed downstream 35 miles from Paw Paw, West Virginia through a 2000 foot brick tunnel. Day two kicked off in Hancock, Maryland with several tourist stops, including Fort Frederick, a military outpost, Antietem, a civil war battlefield, and 65 miles to Harper's Ferry, West Virginia, a national historic site. Day three started another 60-mile ride with a short walk along a railroad trestle and points of interest like the Great Falls of the Potomac River and Georgetown, D.C. Once arriving in Arlington, Virginia, the riders were welcomed to a barbecue picnic to conclude the journey. Unofficial estimates suggest the Gears for Good Bike benefit will have raised $100,000 for the Helping Hands Program.

Nebraska

Sarah Henderson

Team Matrix hit the road September 26th while attending the 7th annual ***Hemophilia Walk*** for the Nebraska Chapter. Located at the beautiful Chalco Hills Recreation Area in Omaha, the walk included a 1, 4 or 6 mile path. After completing the pleasant walk, the group enjoyed a tasty lunch catered by Olive Garden. Kids had a boisterous time playing in bouncy houses, having their faces painted and filling up on cotton candy! Team Matrix raised $1,447 of the over $35,000 raised by the walk. Congratulations to the chapter on hosting another successful event!

Andre, Megan and Cooper have fun at the zoo!

Wisconsin

Bonnie Culver

Hosted by the Hemophilia Foundation of Wisconsin at the Milwaukee County Zoo, over 500 Wisconsinites teamed up for a ***Hemophilia Walk*** with the National Hemophilia Foundation in an effort to raise dollars and awareness for the bleeding disorder community on September 26th.

The weather was amazing and we could not have asked for a better day! We started off early with participants gathering as team pictures were taken. After a short presentation, teams were off and walking! The Milwaukee County Zoo is a fabulous place to spend the day with friends and family, and the animals and staff are incredible.

Led by Megan M., team Bruise Brothers earned a first place trophy for raising the highest amount of donations at nearly $7000. The Great Lakes Hemophilia Foundation reports receiving over $80,000 in total contributions. All donations will help Wisconsin families by:

- Providing education to help people with bleeding disorders avoid debilitating complications and live longer, more active and healthier lives
- Conducting advocacy initiatives at local and national levels to help ensure access to medical care
- Building awareness of bleeding disorders to promote early diagnosis
- Advocating and creating awareness for blood safety
- Funding research toward better treatments and cures
- Building a supportive community among individuals and families
- Promoting choices that lead to optimal health and living life without limitations

Illinois

Eva Kraemer

Adam, Eva Kraemer and David

Bleeding Disorders Alliance Illinois and the Hemophilia Federation of America hosted an ***educational event*** at Pompei Restaurant in Chicago's Little Italy neighborhood on September 28th. A program titled *Been There, Done That -Transitioning Teens* was presented, followed by a round-table discussion covering several topics such as hemophilia treatment then and now, "bad blood," deciding whether to start prophylaxis and getting into a romantic relationship. The group was intimate and everyone felt comfortable and compelled to participate.

Pennsylvania

Tina McMullen

It was a cold, wet and windy day for the Eastern Pennsylvania Chapter's ***Annual 5k Run/Walk***, but that did not deter the 200 people in attendance from participating in *Celebrate Halloween with a Costume 5k Run/Walk* held in Collegeville Saturday, October 3rd. This year brought out some very creative costumes from a bumblebee to all kinds of princesses; even Elvis was in the house!

Vickie shares her story.

Vickie, mother of 4-year old Tommy who has severe hemophilia, gave a very moving and heartfelt speech. She touched upon what it is like to live with hemophilia and the importance of the chapter's fundraisers, and just how much they mean to her and her family.

Despite the bad weather, it turned out to be a truly wonderful day! Thanks to Curt Krouse, Executive Director, and his dedicated team for hosting this tremendous event. Curt presented Dr. Lacra Ivanciu of the Children's Hospital of Philadelphia with a $30,000 grant. Here's hoping for sunny skies and even more runners and walking teams next year!

Nevada

Kelly Gonzalez, Meredith Paige, Terry Rice and Holly Shaw

Nevada HTC Nurse Practitioner Amber Federizo and Kelly Gonzalez

Tiffany and Gabriele

Patients, parents, providers and philanthropists gathered October 9th at the Hard Rock Hotel in Las Vegas to celebrate and participate in the ***Annual Circus Couture***. Raising nearly $200,000, the event featured a fashion show, silent auction, live auction and an amazing performance by Cirque performers from the various shows in town.

The Cirque performers and the Cure 4 The Kids Foundation started this event three years ago to benefit the local charity and for kids suffering from rare diseases including cancer, immune deficiency, hemophilia and many more. The charity states their mission is to, "Advance cures and means of prevention for pediatric catastrophic diseases through research and treatment, while providing access to quality medical care for the uninsured, under insured, and medically indigent children of Nevada with complex medical issues; through a charity care plan, education, research, and advocacy." What really matters is that all children can receive care through Children's Specialty Center and the Hemophilia Treatment Center of Las Vegas. Factor Support Network and Matrix Health Group proudly provided sponsorship to assist in this important mission.

We enjoyed the opportunity to reach out and network with this amazing community. A huge thank-you to the Cure 4 The Kids Foundation and Circus Couture for bringing us this wonderful opportunity to *Make a Difference*!

Factor Support representatives pose with a member of Circus Couture

Heather shows off her Walk medal.

California

Heather Mikel Messerly

A charming setting by the bay at Liberty Station in San Diego was the venue for the October 10th Hemophilia Association of San Diego County's ***Third Annual San Diego Walk***. The walk of over 100 participants surpassed the chapter's fundraising goal by $5000! It was a lot of fun to see so many families and friends at the event. Kids gathered at the games and face painting stations, and Chick-fil-A and Jamba Juice satisfied the hungry appetites. At the end of the 5k walk, volunteers handed out refreshing popsicles and other ice cream treats, which were greatly welcomed as this October day was an unusual scorcher!

Jordan, Kelsey, Heather, Dylan and Trevor

Idaho

Gaby Zamora

The Idaho Chapter of the National Hemophilia Foundation's 4th annual ***Hemophilia Walk*** took place in Boise's beautiful Ann Morrison Park October 10th. This event brings individuals, families and friends together to spread bleeding disorder awareness and raise funds to benefit the services provided by the chapter. Everyone was so excited for the walk to begin, whether it was the 1 or 3 mile path! Congratulations to *Top Individual Fundraiser*, Tshane Bell and *Top Team Fundraiser*, Kure for Keaton! Following the walk refreshments were available to all, and everyone had the opportunity to greet new Executive Director Barbara Fawcett. Welcome to our community Barbara!

St. Lukes HTC nurse, Kara Garner with Gaby Zamora

Idaho Chapter ED, Barbara Fawcett, NHF's Joseph Kleiber with Gaby Zamora.

Illinois

Eva Kraemer

Rosa, Sophia, Yardley, Felix, Alexis, Eva Kraemer, Cris and Liam

October recognizes "Celebrando el Mes de la Hispanidad" or ***Celebrating Hispanic Heritage Month***, which is a tribute to Hispanic/Latinos throughout the United States. Bleeding Disorders Alliance Illinois (BDAI) and Baxalta delivered an educational event for the Latino bleeding disorder community October 10th at the National Museum of Mexican Art. Nestled in Pilsen, a well-known Mexican neighborhood within Chicago, around 100 community members listened to a presentation about self-advocacy both in Spanish and English. Pedro Angel from Angel's Restaurant prepared a delectable meal with many different Mexican delights for all to relish as we reminisced about the culture and heritage being represented while learning advocacy tips.

Michigan

Bonnie Culver

Emergent's Lisa Wiles with Bonnie Culver

More than 125 high spirited, cheerful attendees gathered on the chilly morning of October 10th for Hemophilia Foundation of Michigan's ***Walkin' on the West Side*** in Grand Rapids, the first annual walk on the west side of the state. The walk began and ended at the Fifth Third Ball Park, home of the 2015 Midwest League Champions - the West Michigan Whitecaps. After donning their NHF Walk t-shirt, participants made their way along the bike path near the beautiful Grand River. Additional activities offered during the morning were Speed-Pitch and Pumpkin Decorating, as well as breakfast and lunch. Special shout outs go to the *Top Individual Fundraiser*, Rebecca Warner, and to *Top Team Fundraiser*, Team Emma J. This event raised $35,000, which is an awesome first year total!

Ohio

Joseph Opalka

Members of the Northern Ohio Hemophilia Foundation (NOHF) attended the ***Annual Sponsorship & Family Fall Fest*** at the Doubletree Hotel in Independence October 16th and 17th. It was my pleasure to see all the smiling faces as everyone arrived for an evening of meet-and-greet where they had an opportunity to walk the exhibit area and talk to company representatives staffing the industry booths. It was especially delightful to welcome new families in the crowd and witness how the excited children kept everyone smiling and on their toes. After a delicious dinner was served, Matrix Health

Group hosted an Ice Cream Social. With lots of special toppings to choose from - chocolate, nuts, gummy bears and sprinkles to name a few - the social was a huge hit for every age group!

Saturday was a busy day as adults and children attended several separate educational seminars. There were many presentations including a session by Betsy Hockey, University Hospitals Physical Therapist, who discussed safe sports and the benefits of having strong muscles and joints when living with a bleeding disorder. Also presenting was Tom Wetzel, Northeast Ohio suburban Police Lieutenant who spoke on providing a safer environment for our children by addressing Internet and public safety issues in our local communities. As adults were gaining wisdom, much to the thrill of the children, a mobile video game truck arrived to entertain them.

After closing words by Tanya Ricchi, NOHF Executive Director, everyone enjoyed a nice lunch and social time with new and old friends alike. Many thanks to everyone with NOHF for providing this wonderful event!

California

Heather Mikel Messerly

If you know swimming, you've heard about the Woollett Aquatic Center in Irvine. This was the venue of the 2014 USA National Swim Competition, which brought in nearly all the U.S. Olympic team swimmers. Factor Support Network teamed up with CSL Behring to host the first-ever ***Swimming for Health*** program Saturday, October 17th. We were lucky enough to have an entire pool just for our event – that's right, a pool swam by the likes of Michael Phelps and Ryan Lochte.

CSL's Brian Taylor, Manager Coagulation Products, recruited Tim Grams, who set five Division 1 swim records at University of Denver, to be the keynote speaker. He spoke about his experiences as a person with hemophilia and how swimming has helped him with his overall health and well-being. Collegiate swimmers Mikey and Manny Forbes were also invited as guest speakers. The brothers shared their family story of how four siblings have hemophilia and are collegiate swimmers. Tim's talk, plus the Forbes' stories stimulated much discussion among attendees.

Mikey then led the group in dry land exercises, explaining the importance of stretching before working out. On the deck, the three men and their friend Javier demonstrated a Medley relay - back, breast, fly and free - so the audience could see how all four strokes are executed. After the demonstrations, the swimmers got into the pool and worked one-on-one with the athletes to learn proper swim techniques, which was followed by free time in the pool.

Mikey Forbes, Manny Forbes, and Tim Grams, the health panel

Swimming for Health Mikey Forbes, Tim Grams, Heather Messerly, Brian Taylor and Manny Forbes

Brian shared with us, "This is a great program for bleeding disorder patients as it is designed to both inspire and educate patients to lead healthy lives through sports and fitness." Tim, Mikey and Manny led an amazing and entertaining discussion on swimming, exercise, not giving up, and treating your hemophilia while succeeding, which motivated the entire room. Hemophilia Alliance of Orange County Executive Director Michele Warner said of the event, "It was fun and informative, as well as inspiring!"

Since the event, Brian and I have received many compliments from everyone. We were applauded for coordinating such a fantastic and unique event that blended education and fun. We both feel the importance of exercise, especially swimming, is a topic that very much benefits members of the bleeding disorders community.

West Virginia

Tina McMullen and Eric Lambing

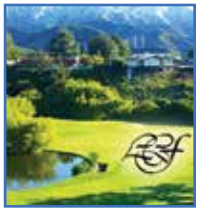
It was a brisk day in the beautiful mountains of West Virginia for the West Virginia Chapter of NHF's ***Inaugural Hemophilia Walk***. The event took place October 17th at the Waterfront Place Hotel in Morgantown. Cool weather did not deter families from participating in this event; more than 100 people celebrated the chapter's first walk. The day began with an exciting *Half Mile Kids Fun Run*, and then Mary Ann Ludwig, NHF VP for Resource Development, gave a motivational speech and the walkers were on their way! It was enormously encouraging to see so many families participate even though their little ones were all bundled up in strollers.

Tina McMullin and Patty visit together at the Factor Support booth.

Awards were given for *Top Fundraising Team* to Team War Machine from Charleston, while *Top Fundraising Individual* went to Chris Britton of Morgantown. Overall, the chapter's first walk raised nearly $30,000! Children and adults had a great time with entertainment from Scooter the Clown, fun balloons

and fantastic face painting. In fact, I believe there were just as many parents walking around with painted faces as there were children! Lunch was served and music provided by Rob Lightner and LaRon Carroll filled the air. It was a beautiful day and I'm sure the families and participants are all looking forward to this event next year. Congratulations to Amber Tichnell, Executive Director, and her many volunteers who did an amazing job organizing the event!

California



Marina Vera

The ***32nd Annual Golf and Tennis Tournament*** hosted by the Hemophilia Foundation of Southern California took place October 19th. For the first time ever the tournament was held at La Cañada Flintridge Country Club in La Cañada Flintridge, an area offering stunning mountain views. The 110 golfers and 10 tennis players were appreciative of the weather - just a bit on the cool side! This successful event raises funds to benefit Camp Brothers and Sisters at Painted Turtle. Participants ranged from community members to physicians, industry personnel and philanthropists. In addition to golf and tennis, the day included a delicious dinner of barbecue and prime rib, and a silent auction. It was fun to volunteer at this event and I look forward to helping again next year!

New York

Richard Vogel

Laughter was in the air at the National Hemophilia Foundation's 3rd annual ***What's So Bloody Funny?*** fundraising benefit. Held October 21st at the legendary Gotham Comedy Club in New York City, the show was attended by about 150 community members, industry representatives and others who had no connection to the bleeding disorders community. Actor, comedian,

Richard Vogel and Alex Borstein

writer and producer Alex Borstein, a long time friend to the bleeding disorders community and the voice of Lois Griffin on *Family Guy* and MADTV's *Ms. Swan*, emceed the event. Comedians included Marina Franklin, most recently in *Trainwreck*, John Early of NBC's *30 Rock*, Matteo Lane of MTV's *Joking Off* and Robert Kelly, who plays BamBam on *Sex & Drugs & Rock & Roll*. This was an evening of non-stop laughter, and Matrix Health Group was ecstatic to sponsor this successful event!

Illinois

Tracy, Jim, Jen and Kasey with Eva Kraemer (center).

Eva Kraemer

Bleeding Disorder Alliance Illinois (BDAI) held its annual ***Autumnal Wine Dinner and Auction*** October 23rd for about 100 guests in Chicago. Champagne sponsor, Jim Hurster of CSL Behring brilliantly selected the Columbia Yacht Club as guests were mesmerized by Lake Michigan and the Chicago skyline reflecting off the water as the backdrop of the evening. Everyone feasted on a four-course meal with each course accompanied by an exquisitely paired wine. Many generous and talented guests donated their time and funds making baskets to be auctioned in support of BDAI to continue providing education to the Illinois bleeding disorder community. Thanks to CSL Behring, BDAI and all those who came out to make the evening a marvelous success!

Tennessee

Stephen Lawrence and Robin Lawrence

Rain, rain, go away! THBDF has come out to play! Held at the Park at Harlinsdale Farm in Franklin, the 2015 Tennessee Hemophilia and Bleeding Disorder Foundation's (THBDF) ***Fall Festival*** was a fun celebration of all things fall. Everyone enjoyed carnival games, hayrides, family photos, pumpkin painting, the children's costume contest, an inflatable slide and a visit from the Nashville Zoo's Wildlife on Wheels. Barbecue, hot dogs, chips, cookies and drinks were provided for all, along with an endless stream of popcorn and cotton candy. It was certainly a fun day for the families who dared to throw caution to the wind and dance in the rain!

Pongo and Cruella (aka Stephen and Robin Lawrence) greet visitors at the Matrix Health Group booth

Sam, Baby Haley Ann and Becca.

Washington D.C.

Terry Stone and Paul Brayshaw

The Nation's Capital is America's hometown where history is honored and memories are made. The Hemophilia Association of the Capital Area (HACA) welcomed their very own history makers for the D.C.

Hemophilia Walk
Saturday, October 24th. They came from all over - the tall and the small, the bleeders and greeters, the friends and family, the nurses and staff, and everyone had a blast!

Team Matrix-Harley Heroes strike a pose for multiple cameras, our very own paparazzi

Mother Nature really did her part. The sun was shining, the leaves were falling and the gentle autumn breeze blew through the columns of the majestic Lincoln Memorial. It seemed to inspire all who came to walk for HACA and raise much needed funds for the bleeding disorders community under the approving eyes of good ole' Abe!

Paul Brayshaw and his son Graham catch up with Nina and Kirstin

This was HACA's third annual walk. Matrix Health Group/ Factor Support Network's Director of Advocacy, Paul Brayshaw and his sister Dana Brayshaw served as co-chairs for this purpose-driven walk. United at the podium, they gave a warm welcome to the crowd, followed by presentations from Baxalta and HACA's Executive Director, Karen Krzmarzick. Team Matrix Harley Heroes gathered friends to walk with our team and we enjoyed doing our part to contribute. It was great to see walkers, joggers and doggie-human combos talking and walking along the national mall.

The walk followed the path of the reflecting pool shaded by grand oak trees and circled around one of the newer memorials in D.C., the World War II Memorial. We were honored to stop along the way to pay our respects to honor flight veterans there to see the memorial in honor of their service. The walk raised over $70,000 and HACA expressed their thanks to all the sponsors, local industry, volunteers, entertainment, and the many friends and family who joined together to make history and to "Make a Difference."

Florida

Peggy Gay

The Hemophilia Foundation of Greater Florida held its ***Inaugural Orlando Creepy Crawl 5k and Walk for Bleeding Disorders*** Sunday, October 25th. Held in Harbor Park at Lake Baldwin, walkers were encouraged to dress up for Halloween. Many participants wore fun and creative costumes, which gave way to suggesting a costume contest being implemented next year. Honorary Chair Matt Morgan kicked off the event with a short speech on why the walks are important, some facts on bleeding disorders and a quick thank you to all.

Creepy Crawl Walk

First Place Male and *First Place Overall* was Tony Segreto of Mount Dora, Florida, and *First Place Female* went to Louise Long of Orlando. The winners received pumpkin trophies and recognition during the award ceremony. The *Traveling Team* trophy was awarded to Team Mikey for raising $2,430 with team captain Mike Berkman, Jr. raising $2,200 of it himself. Team Dominic came in second with $2,285. Team Hunter was third with $1,375 and was also awarded the *Spirit Award* by having 31 people on their team and sporting some awesome custom t-shirts.

After the race, everyone visited the industry booths while enjoying coffee, drinks, fruit, snack bars, bagels and doughnuts. HFGF raised almost $40,000 to benefit the bleeding disorders community. See you soon at the 2nd annual *Orlando Creepy Crawl 5k and Walk for Bleeding Disorders* taking place October 30, 2016!

Michigan

Bonnie Culver

Homecare for the Cure, along with Lisa Wiles, Hemophilia Product Specialist at Emergent Biosolutions, hosted a ***dinner event*** October 27th in West Michigan at the lovely Sunnybrook Country Club and Banquet Center in Grandville.

All smiles! Cole, Eli, Nora and Weston

Kevin Harris, Consultant/Public Speaker at Emergent Biosolutions, presented *Rebuilding the Body with Diet*. Kevin was very thorough in his explanation of the components of food and how a good diet can help build a strong body. Many questions were asked and an interactive discussion ensued. Following the nutrition presentation we watched a video discussing the cure for hemophilia prepared by Homecare for the Cure. We learned about curative therapies and recent drug product breakthroughs. Homecare for the Cure is proud to donate to hemophilia research.

Maryland

Terry Stone and Paul Brayshaw

Goblins, witches and ninja...oh my! Learning, bonding and family...no lie! While trick-or-treaters all across the great state of Maryland ventured into the streets for good ole' fashion Halloween fun, the families of the Hemophilia Foundation of Maryland (HFM) united for a ***Family Weekend*** October 30th-31st at the Hyatt Regency Chesapeake Bay Resort in Cambridge. This was the eighth year for this popular weekend event. What makes it so coveted by the community? Well, you just really have to be there and experience it first-hand.

The weekend is chock-full of well-balanced seminars, social gatherings and great food. What's not to love? Checking in at the registration table gives you the feeling of walking in the front door of your family's house for a holiday visit. You feel all warm and fuzzy, there are hugs and help at every corner, and Momma Emma (aka Executive Director Emma Miller) and Sister Jamie Edwards (aka Chapter Administrator), are at hand to make you feel right at home while your every need is accommodated. Oh and let's not forgot Auntie Trish (aka Trish Underland, HTC nurse at John Hopkins) who was the resident baby snuggler and took amazing care of the littlest ones so parents could enjoy the meetings. The rest of the kids were in the experienced wild and wacky hands of an army of volunteers whose mission was to execute OPERATION FUN with music, arts and crafts, biking and canoeing.

Emma Miller (aka Glenda the good witch) and Terry Stone (aka The INFUSIONATOR) getting ready to welcome everyone to the carnival!

Paul Brayshaw and family at the *It's a Family Thing* Carnival.

Throughout the weekend we had seminars covering a variety of topics to interest all, no matter where the family was in their journey of living with a bleeding disorder. Breakout sessions were designed to feed the soul and the tummy. Ladies got in touch with their feelings on disclosures and sharing in social media while sipping wine and painting. Men retreated to a barbecue to grill some meat and talk shop or whatever men do with a barbeque, meat, and no ladies around. There was also Zumba, rap sessions, and Cola and Cookie meet-ups for teens. Oh, there was so much more, so much more!

Hats off to Emma, Jamie and the entire HFM community for making this chapter one of the most passionate and successful organizations across the country. If the number of hugs and thanks that came from the families as they said their good-byes was a measure of a successful event, then this event should win an award! But at the end of the day it's about and for the members, and that's why this chapter shines!

Ohio

Rania Salem

Friends and families of the Central Ohio Hemophilia Foundation of NHF gathered November 3rd for the ***Annual Dinner at Der Dutchmen***, a restaurant and bakery in Plain City, Ohio. This greatly anticipated event brings our tight knit community together to break bread, share experiences and enjoy each other's company over a delicious family style dinner. It's the time we look forward to hearing about the state of the chapter, updates from our industry sponsors, announcement of the top fundraiser of the Hemophilia Walk, and for the presentation of the LifeBLOOD 2015 awards.

Central Ohio Chapter LifeBlood Recipients

A special congratulations to Claudia Lupio, Nurse at Nationwide Children's Hospital on her retirement. She will be greatly missed by everyone whose life she has touched in the years of servicing the bleeding disorder community. Many thanks to the Central Ohio Hemophilia Foundation for hosting this favorite community event!

Jodi Skinner proudly holds her LifeBLOOD award at the Matrix booth.

Florida

Peggy Gay

The Hemophilia Foundation of Greater Florida (HFGF) held its Jacksonville 7th annual ***Turkey Clot Trot & 5k for Bleeding Disorders*** Saturday, November 7th in Nocatee. Boasting 192 participants, a total of 23 teams were represented. The *Male Open Winner* was 14 year-old Brice Mourow, and *Female Open Winner* was 11 year-old Reilly Barber. Top Fundraising Team went to Team Mason, raising over $4300. Team Mason's captain, Holly Wright won *Top Individual Fundraiser* by raising $3,272 all on her own, while Aaron's Clot Trotters won the *Spirit Award* by bringing 29 people to the event. Congratulations to all the winners! The event was a huge success as HFGF raised over $43,000, exceeding their goal of $40,000!

Turkey Clot Trot runners Jim, Lily and Luke

Idaho

Gaby Zamora

The beautiful Colonial Theater Willard Arts Center in Idaho Falls was the place to be November 7th for the Snake River Hemophilia Bleeding Disorders Association's ***Annual Family Conference***. Chad Stevens, Chapter President, was thrilled to see so many families attend

this conference. He recalled when the meeting was first hosted in 2004 and only one family was in attendance. That number has grown to 13 families!

Guest speakers Kara Gardner, RN, MSN, NP and Kyle Davis, PhD of St. Luke's Hemophilia Center in Boise addressed the families and caregivers over dinner. They offered their services to the families in Idaho Falls even though it is about four hours from Boise. I can tell you it is worth the drive; I personally had an issue come up earlier in the week, was treated by the St. Luke's team and can't express how grateful I was to receive their outstanding care! The afternoon featured Biogen speakers Aban Patel and Wendy Wolner who spoke on *Life-Skills: Express Yourself,* a session addressing emotions in daily interaction.

Thank you to Chad for diligently working to gather Idaho families together!

Tennessee

David Tignor

The warm, wet autumn morning of November 7th at Trinity Baptist Church in Jonesborough was the setting for the 8th annual ***Race for Ian***. This fun-run is a consumer-led fundraiser started by Michael and Sarah Bates on behalf of their son Ian. It takes a lot of hard work and dedication from the Bates family, and the many volunteers and financial sponsors to organize this meaningful event.

And the race is on!

The rain stopped just before the race started and did not hinder participants. A warm and wonderful display of sportsmanship was exhibited as each 5k runner crossed the finish line. Those that crossed the finish line went out to the road to applaud, cheer and encourage the others.

Once everyone had the chance to catch their breath and replenish with snacks and drinks, awards were announced. Following the awards, Michael Bates described their personal hemophilia journey, the cost of treatment and how the past year has been a great one for Ian. A slide show presentation highlighting last year's race and what the family's life was like in the past compared to this exceptional year.
This event brings people together for a worthy cause - gaining hemophilia awareness while raising money to benefit the Tennessee Hemophilia and Bleeding Disorders Foundation and St. Jude Children's Research Hospital. Matrix Health Group is proud to support this marvelous endeavor!

Stephen heading to the finish line!

Daniel and Chris

Spring and AJ Francis

Cassandra receives instructions from Becki Berkowitz, RN

Nevada

Kelly Gonzalez

A small group of patients and their primary support person met November 10th for an ***infusion clinic and catered dinner***. Hosted by Factor Support Network (FSN) and the Hemophilia Treatment Center of Nevada, the topic of the day was home infusion techniques. FSN provided dinner and a brief overview of the benefits and freedoms offered by home infusion, while Becki Berkowitz, R.N., OCN - Hemophilia Nurse Coordinator at the HTC presented on safety and procedure for infusions.

Following the presentations, everyone had the opportunity to practice infusing with a Bayer *BayCuff™ Self-Infusion Training System*. The training system consists of a cuff that attaches to your hand or arm with Velcro straps and has tubes simulating veins, allowing you to practice self-infusion with real needles, but not actually having to put the needle into your own vein. Becki then worked one-on-one with each patient and their partner to help them become more comfortable and confident with the infusion technique. Congratulations to everyone who ambitiously took this first important step to learn and increase their comfort with the infusion procedure!

Pennsylvania

Tina McMullen

It was a brisk and windy day for the Eastern Pennsylvania Chapter of NHF's ***Turkey Trot 5k Run/Walk*** held in Lancaster Saturday, November 14th. The weather did not deter 150 devoted people from participating. The day began with everyone having the opportunity to visit a variety of industry vendors under the exhibit tent. It was then time for the half-mile kid run led by

EPC Turkey aka Kate Kiley

the official turkey mascot, Kate Kiley. Once the children completed their run, the 5k participants took their mark.

In addition to walking and running, the day included a live deejay, face painting for the kids and plenty of refreshments. Awards were given in various categories with the top finisher receiving a frozen turkey. Runners did not go home empty handed; everyone received a medal for completing the race. Due to the hard work and dedication of Curt Krouse, Executive Director and his staff, Fae Ehsan and Lindsay Frei, this event continues to grow year after year!

Kelly Gonzalez, Dr. Bernstein and Joseph Gonzalez stop to exchange a hug and take a picture during the holiday party!

A bonding moment... Maddie Lynn, daycamp attendee, with Jesse, supervisor/day counselor.

Nevada

Kelly Gonzalez

In the quaint city of Henderson, ***Fall Family Education Day*** was hosted by the Nevada Chapter of NHF on November 21st. Attended by over 200 members of the Nevada community, the event provided educational sessions to brief patients about insurance rights, regulations and how to be an informed consumer. As a patient, a mother of a child with a bleeding disorder and a patient advocate, I was honored to join Laurie Kelley of LA Kelley Communications and Michelle Rice, NHF Advocacy and Stakeholder Relations, as a *Pulse On The Road* guest speaker.

Following the educational sessions, a holiday party ensued where families celebrated life, exchanged good will and enjoyed each other's company. A surprise visit from a very special resident of the North Pole delighted everyone! Thank you to the Nevada Chapter for organizing this terrific event!

Maria Vargas, Kelly Gonzalez and Jennifer Roberts team up to show consumers the benefits of the 340B program services through FSN.

New York

Richard Vogel

India House, NY

The weekend of November 21st-22nd was a big one for the New York City Hemophilia Chapter (NYCHC). Starting with a ***Gala*** on the 21st and ending with the arrival of Santa Claus at the ***Education Day*** on the 22nd, a great time was had by friends and families of the bleeding disorders community!

The Gala was held at the historic India House in lower Manhattan. The name, "India House," was chosen as a symbol to the Indies, believed to epitomize the rare and exotic, while also paying homage to the Dutch West India Company, Manhattan's first colonizers. India House has a long and distinguished heritage tied into the formation of lower Manhattan as well as the history of business and commerce of New York and was the perfect spot to start off the weekend.

Rich Vogel with Glenn Mones, NYVHC Executive Director

In its 7th year, this marquee event for NYCHC has generated over a quarter of a million dollars and this year, the Gala honored the Giannola Family with the *2015 Award of Distinction* for their chapter fundraising efforts. Their team, Vincenzo's Entourage, consistently finishes as one of the top fundraising teams not just in NYC, but also across the entire country. Another member, Ramona Shih was presented with the Susan Galligan *Volunteer of the Year Award*. These individuals embody the spirit of NYCHC with their motivation and personal involvement, and through their efforts have raised tens of thousands of dollars for education, advocacy and research.

The evening started with cocktails and hors d'oeuvres, followed by a sit down dinner of surf and turf, salmon and chicken. The awards were followed by raffled items including sports memorabilia, sporting event tickets, restaurant dinners and even a bicycle.

The following day, NYCHC held their educational day and holiday celebration at the Crowne Plaza in Times Square. The day began with an infusion party and breakfast. Plenty of time was afforded to visit and talk with industry and specialty pharmacies before the educational workshops began. There were sessions for everyone - whether a family was new to the bleeding disorders community or an old timer like myself, no matter how old you are, there is always something to learn from this community.

An informative session on *New Directions in Treatment* was led by three well know doctors in the bleeding disorder community - Drs. Christopher Walsh, Catherine McGuinn and Suchitra Acharya. Seems like great new therapies are on the horizon!

After a working lunch, afternoon workshops continued. Excitement was in the air and you could feel the electricity in the room as the education day came to an end and the holiday celebration began with the arrival of Santa Claus! Gifts for the children and entertainers from Cirque-tacular added to the festivities.

All in all, it was a very successful weekend for NYCHC and the nearly 400 attendees to the event. Matrix Health Group was honored to be a sponsor of NYCHC's gala and the bleeding disorders community at large. I'm glad I was there!

Zoe and Jayden pose for a holiday photo with mom Jessica and Marina Vera

California

Marina Vera

We happily gathered at Dave and Busters in the City of Orange on December 5th to celebrate the holiday season. Hosted by the Hemophilia Foundation of Southern California, nearly 200 guests were treated to a ***Holiday Celebration***, including a delicious lunch and a spectacular time! Children enjoyed themselves making ornaments and decorating ginger bread cookies at the arts-and-crafts table sponsored by Factor Support Network. Community member Isaiah led a very joyful session of Christmas carol singing marking the arrival of Santa Claus who provided gifts for the excited children. Thank you to Biogen for sponsoring the lunch and an especially warm thank you to the chapter for hosting this fun event every year!

Ornament time!

Maine

Cheryl Ashmore and Brad Nolan

The Hemophilia Alliance of Maine (HAM) held their ***Winterfest*** at the iconic Samoset Resort on the ocean in Rockport December 5th. Maine is a rural state with members spread far and wide, but everyone makes a special effort to get to this fantastic family event to spend time with friends and greet new faces in the bleeding disorders community. Saturday morning began with a *Stick and Swim* sponsored by Homecare for the Cure. Several nurses and volunteer "pincushions" were on hand to coach, cheer and lend a hand or arm during this teaching session for self-infusion. Those who successfully accessed a vein received an award and an LL Bean backpack - red, of course! Afterward, both kids and adults enjoyed time in the pool. The ocean views were breathtaking - enough so that many took time to explore the coast by hiking out the mile-long granite breakwater.

Cheryl Ashmore visits with David, Tracey and baby Sophia

Zander learns to infuse!

Following numerous motivating educational sessions and a rousing game of Jeopardy with 6 teams competing, we had a jolly visit from Santa! Each child received a gift – even HAM's youngest member, 6 week-old Sophia. The Board and Staff of HAM are dynamic, engaged and involved, and outdid themselves with the planning and execution of Winterfest. We at Homecare for the Cure were pleased to be sponsors for this special holiday celebration!

Maribella and Sonia (back) share big holiday smiles with Derek, Adam & Lacie!

South Carolina

Peggy Gay

Representing 42 families, 182 guests attended Hemophilia of South Carolina's ***Year-End Meeting and Holiday Celebration*** at the Embassy Suites Hotel in Columbia. The festive evening included an informational program along with appetizers, dinner buffet and time to visit with industry representatives at their exhibit booths. Keeping them busily entertained, the children enjoyed craft projects such as creating their own holiday stockings and activity books. The younger children participated in a fun HSC tradition of searching for "Jingles" Elf on the Shelf. Of course, the evening wasn't complete without the highly anticipated arrival of Santa Claus, who delighted the children with gifts. This event is a fabulous way to end the year while looking forward to a prosperous and happy New Year!

Illinois

Eva Kraemer and Lisa Miller

Matrix Health Group and Biogen provided an ***informational dinner*** for the local bleeding disorder community December 9th at the Clubhouse

Together for the holidays!
(back row) Cory, Tony Vetter, Danny, Lisa Miller and John; (front) Shari, Cortez, Cory and Kathi.

Restaurant in Oak Brook. The atmosphere was cozy as an intimate group gathered together to hear Tony Vetter, Community Relations Manager, as he elaborated upon Biogen's prolonged half-life product for individuals with Factor VIII deficiency. There was a healthy exchange of questions and answers, which enhanced everyone's knowledge about available products. The room was filled with good cheer and we were happy to have been a part of the evening.

California

Marina Vera

Marina Vera with Bayer's Sylvia Vega.

One of several ***Holiday Parties*** hosted by the Hemophilia Foundation of Southern California, this joyful event took place at Dave and Busters near the Santa Monica Promenade December 12th. The setting was festively decorated with a huge Christmas tree and beautiful decorations. As families arrived they were greeted and directed to one of two areas – one for an educational presentation in English by Bob Miller, former Clinical Coordinator for the Hemostasis and Thrombosis Center at Children's Hospital Los Angeles, while in the other, Bayer Community Relations Specialist, Sylvia Vega presented in Spanish. In each room, children were absorbed in creating ornaments and decorating cookies at the arts-and-crafts table sponsored by Factor Support Network

Executive Director Michelle Kim finds out if she's been naughty or nice

At the conclusion of the presentations, the rooms were combined so everyone could enjoy the Bayer-sponsored lunch together. Shortly thereafter with a loud, "Ho Ho Ho!" someone special arrived wearing a glorious outfit of red and white. Everyone was so happy to visit and share wish lists with Santa! Thank you to HFSC for helping make this season even more special!

Cortez, Shari, Eva Kraemer, Cory, Genny and little Johnny visit with Santa.

Illinois

Eva Kraemer

The Bleeding Disorder Alliance Illinois (BDAI) celebrated their annual ***Holiday Party*** Saturday, December 12th, at the William Tell Holiday Inn in Countryside. Community members, family and friends created homemade ornaments and decorated cookies to their tummies' delight! Santa made a special appearance to spread cheer to children of all ages, sitting for keepsake photos to be cherished for years to come.

A buffet meal was served in the dining room while a fire burned at the hearth and in our hearts as guests feasted and made merry. I was jubilant to have been able to spend time with families, sharing stories from the year gone by while looking forward to a very happy and healthy 2016.

Illinois

Eva Kraemer

(back) Eva Kraemer with Nancy, Emma, Odilon, (middle row) Daniel, Adriana and Omar hamming it up in front.

The Blood Bond Bleeding Disorders Network (BBBDN) celebrated its first annual ***Holiday Party*** on December 18th, at the Ray and Joan Kroc Corps Community Center in Chicago. BBBDN is a grassroots, 501(c)(3) organization created to support the bleeding disorder community. It exists to improve the lives of people with bleeding disorders and believes that with the proper support and resources, its members have the potential to be defined not by their conditions, but by their contributions to the world.

Approximately 65 community members' family and friends gathered together to reminisce about the year gone by as the children delighted in the gifts received by Santa. Good food and drink always foster good will among everyone as the atmosphere gave way to giving and sharing. There was much to be thankful for and I was delighted to be invited.

California

Marina Vera

Patricia enjoys the beautiful tree with her grandson.

Hemophilia Foundation of Southern California (HFSC) hosted several holiday parties this year and they have all been so much fun! Dave and Busters in Ontario December 19th was completely packed with merry members of the bleeding disorder community for this annual event. The guest speaker Bob Miller, now retired, had been the Clinical Coordinator for the Hemostasis and Thrombosis Center at Children's Hospital Los Angeles for over 30 years. While he spoke to parents about the benefits of healthy exercise, the kids busily created ornaments and decorated ginger bread cookies at the arts-and-crafts table sponsored by Factor Support Network. Older kids were provided with a play card to enjoy the D&B video games after the party, and toddlers received a gift card by Santa, who of course, was the most anticipated highlight of the party! Many joyful thanks to HFSC!

Upcoming Events

January 29, 2016 California
California Chronic Care Coalition
916-444-1985, www.chroniccareca.org
Patient Education Day
Masonic Temple; Sacramento
Contact: Sean Hubbert 916-296-9066

January 31, 2016 New Jersey
Matrix Health Group and Emergent Sponsored Educational Dinner
Don Pepe's, Newark
Contact: Richard Vogel 732-991-7373

February 6, 2016 Maryland
Hemophilia Foundation of Maryland
410-661-2307; www.hfmonline.org
Annual Meeting
The Four Seasons Hotel, Baltimore
Contact: Paul Brayshaw 202-271-4252 or Terry Stone 703-795-6269

February 6, 2016 Nevada
NHF Nevada, 702-564-4368, hfnv.org
Education Day
Renaissance Hotel; Las Vegas
Contact: Kelly Gonzalez 702-858-2525

February 6-7, 2016 Ohio
Tristate Bleeding Disorder Foundation
513-961-4366, www.tsbdf.com
Family Education Conference
Great Wolf Lodge; Cincinnati
Contact: Rania Salem 513-470-5500

February 13, 2016 California
Hemophilia Foundation of No.California
510-658-3324, hemofoundation.org
12th Annual Community Crab Feed,
Colombo Club; Oakland
Contact: Gaby Zamora 925-234-2451
Habla español

February 16, 2016 Ohio
Northern Ohio Hemophilia Foundation
216-834-0051, www.nohf.org
NOHF Quilting Party
Der Dutchman, Walnut Creek
Contact: Susan Moore 330-472-2289

February 19, 2016 Nevada
NHF Nevada, 702-564-4368, hfnv.org
Winter Wine Fest & Silent Auction
Tivoli Village; Las Vegas
Contact: Kelly Gonzalez 702-858-2525

February 20, 2016 California
Hemophilia Foundation of So. California
626-765-6656, hemosocal.org
CA Health Advocacy Reform Forum
Pickwick Gardens; Burbank
Contact: Marina Vera 323-252-8682
Habla español

February 20, 2016 California
Central California Hemophilia Found.
916-734-3461, www.cchfsac.org
Surf and Turf 2016
Elks Lodge; Sacramento
Contact: Sean Hubbert 916-296-9066

February 27, 2016 Pennsylvania
Eastern Pennsylvania Chapter of NHF
215-393-3611, hemophiliasupport.org
Bowling for Fun
Thunderbird Lanes; Philadelphia
Contact: Tina McMullen 805-233-5037

National Event!

February 24-26, 2016 Washington DC
National Hemophilia Foundation
800-424-2634, www.hemophilia.org
NHF Washington Days
Crystal Gateway Marriott; Arlington
Contact: Dave Burgeson 239-784-4565 or Paul Brayshaw 202-271-4252

March 12, 2016 Illinois
Bleeding Disorders Alliance Illinois
312-427-1495, hfi-il.org.org
Spring Gala
Holiday Inn; Countryside
Contact: Eva Kraemer 608-852-3777
Habla español

March 19, 2016 California
Hemophilia Foundation of No. California
510-658-3324, hemofoundation.org
Annual Family Education Day
Oakland
Contact: Gaby Zamora 925-234-2451
Habla español

March 4, 2016 Ohio
Central Ohio Chapter of the NHF
614-429-2120, nhfcentralohio.org
Chapter Open House
Super Games; Worthington
Contact: Rania Salem 513-470-5500

March 5, 2016 Virginia
Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Bowling for Bleeders Fundraiser
AMF Sunset Lanes; Richmond and AMF Chesapeake Lanes; Chesapeake
Contact Terry Stone 703-795-6269

March 11-13, 2016 Nevada
NHF Nevada, 702-564-4368, hfnv.org
Hispanic PEP Event
Las Vegas
Contact: Kelly Gonzalez 702-858-2525

March 19, 2016 California
Hemophilia Assoc. of San Diego County
619-325-3570, hasdc.org
Annual Meeting/Family Information Day
Zoo Safari Park; San Diego
Contact: Heather Messerly 619-787-0916 or Gabriela Griffin 626 278-7143
Habla español

National Event!

March 31-April 2, 2016 Nevada
Hemophilia Federation of America
800-230-9797, www.hemophiliafed.org
HFA Annual Symposium
JW Marriott Las Vegas Resort & Spa; Las Vegas
Contact: Kelly Gonzalez 702-858-2525

April 8-9, 2016 Illinois
Bleeding Disorders Alliance Illinois
312-427-1495, www.hfi-il.org
Statewide Education & Fun Weekend
Pere Marquette Marriott; Peoria
Contact: Eva Kraemer 608-852-3777
Habla español

April 15-17, 2016 Michigan
Hemophilia Foundation of Michigan
800-482-3041, HFMich.org
SpringFest, Bavarian Inn; Frankenmuth
Contact: Bonnie Culver 517-525-4152

April 17, 2016 Pennsylvania
Brandywine Valley Chapter
610-863-7334, brandywinehemophilia.org
Big Red Run 5k Run/Walk
Ridley Creek State Park; Media
Contact: Tina McMullen 805-233-5037

April 25, 2016 New Jersey
Hemophilia Association of New Jersey
732-249-6000 www.hanj.org
20th Gourmet Dinner & Wine Tasting
Il Carpriccio, Whippany
Contact Richard Vogel 732-991-7373

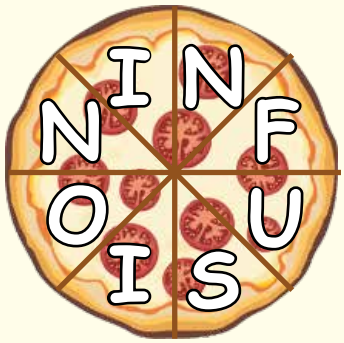
April 25, 2016 Tennessee
Tennessee Hemophilia and Bleeding Disorder Foundation
888-703-3269, thbdf.org
Music City Golf
Westhaven Golf Club; Franklin
Contact: Shannon Cassada 423-241-9356

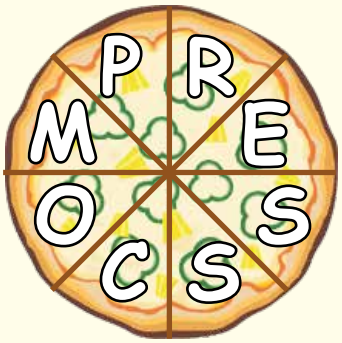
April 29, 2016 Ohio
Northern Ohio Hemophilia Foundation
216-834-0051, www.nohf.org
Black & Blue Ball
Downtown Ritz-Carlton; Cleveland
Contact: Shelia Biljes 440-813-1626

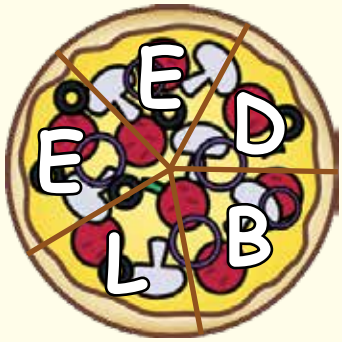
Time for FUN!

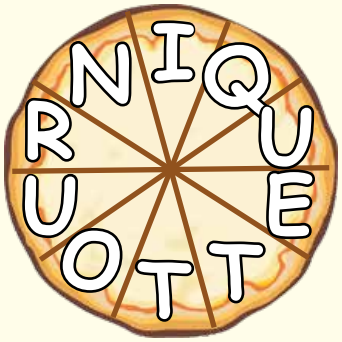
Hi Kids!

Each of these delicious pizzas are cut into slices. On every slice is one letter of a word common to bleeding disorder "vocabulary." Find the first letter of the word and follow around the pizza to read the word. Some of the words read clockwise, but some read counterclockwise. The pepperoni pizza has the first letter highlighted for you. When you're finished, try the Soduko puzzles. Answers are on page 9.









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

SuDoku!

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

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

Matrix Health Group News

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