Matrix Health Group NEWS

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DEDICATED TO MAKING A DIFFERENCE

> **What lies behind you and what lies in front of you, pales in comparison to what lies inside of you.**
>
> — Ralph Waldo Emerson

SUMMER 2017

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MISSION + 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.

FINE PRINT

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

The purpose of Matrix Health Group News is to provide 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 disorders 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.

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A NOTE FROM THE EDITOR

Dear Readers:

By the time this newsletter is in your mailbox, summer will be in full swing! Though parts of our glorious country enjoy summery weather all year long, I cherish these long days of sunshine and warmth. Many children in our community eagerly await these summer days as they head to bleeding disorders camp. When they return home with sun-kissed faces and 'interesting' arts and crafts projects, undoubtedly they will share their stories of adventures and friendships. We encourage you to have your child write down their thoughts and memories. Please consider sending these stories to us so we may share them with our readers in a future issue of our newsletter.

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

Beginning with this issue, we introduce a new feature titled *Spotlight on Research*. Our own Diane Horbacz, Research and Education Development Specialist, will lead this quarterly segment keeping focus on the latest initiatives changing treatment paradigms for bleeding disorders.

Our newsletter continues to grow with more and more pages added every quarter. Personal stories, advocacy, education and more - we have it all! Though your days may be busy, steal a moment to relax, pour yourself a nice tall glass of iced tea, read our summer issue and enjoy!

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- Multifaceted team approach promoting adherence to treatment plans, resulting in positive health outcomes
- Informative quarterly newsletter, MATRIX HEALTH GROUP NEWS

WASHINGTON DAYS

BY PAUL BRAYSHAW AND DAVE BURGESON

A group of our friends and neighbors visited Congress to represent the bleeding disorders community as participants in the National Hemophilia Foundation's annual advocacy efforts, ***Washington Days***. Nearly 500 individuals from 46 states and Puerto Rico arrived Wednesday, April 8th in Washington D.C. to educate and encourage lawmakers to support issues essential to the health of our community members.

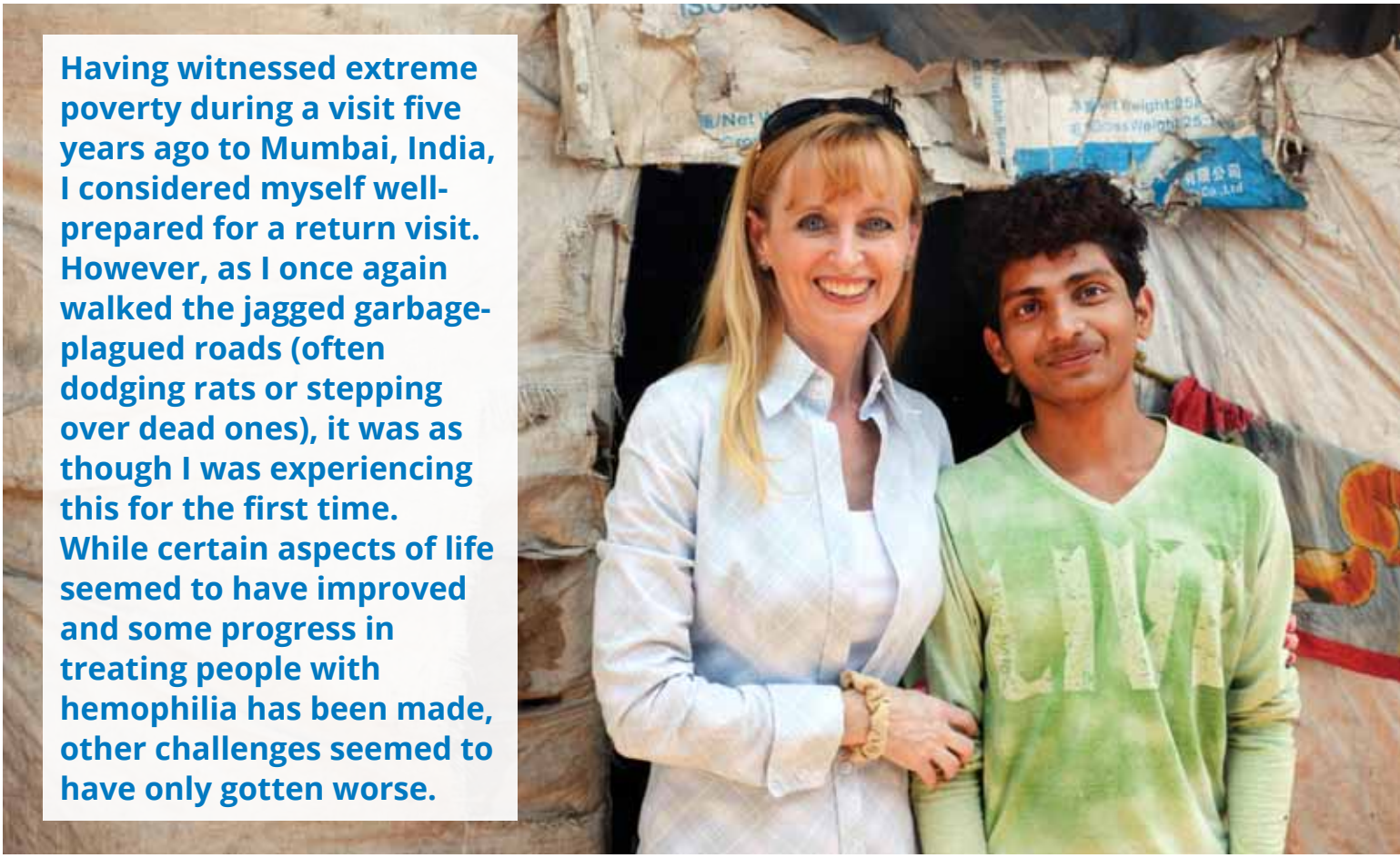
NHF WD focused on three specific issues including, support to maintain the elimination of lifetime and annual limits/caps on essential health benefits, support to maintain the federal requirements for essential health benefits, and support to ensure Medicaid eligibility for all individuals meeting poverty level standards.

According to NHF Washington Days materials, 55% of our community is insured by private insurance plans. Due to the legislative requirements of the Affordable Care Act (ACA), these plans must maintain certain provisions to protect individuals against financial loss. Additionally due to the ACA, private insurance plans are required to maintain essential health benefits. As part of the NHF Washington Days event, advocates sought to ensure these policies be supported throughout the legislative attempts to repeal and replace the ACA.

Regarding access to Medicaid, the ACA authorized states to expand eligibility to all individuals with incomes lower than 133% of the federal poverty limit. The expansion of Medicaid allowed parents, and childless men and women above the age of 19 to gain insurance in 32 states. Proposals to repeal this added coverage may take effect in 2020, and would seriously undermine the ability of these people to maintain health insurance coverage.

The theme of NHF Washington Days was enriched by the *Red Tie Challenge*, created to raise awareness for inherited bleeding disorders, as well as in support of Bleeding Disorders Awareness Month. Per the information available at redtiechallenge.org, "the tie is a symbol of the blood ties that bind over 3 million Americans together." This movement has created an excitement that continues to generate throughout the United States, and the world.

If you have not taken the Red Tie Challenge, please take a moment and get tied!



Having witnessed extreme poverty during a visit five years ago to Mumbai, India, I considered myself well-prepared for a return visit. However, as I once again walked the jagged garbage-plagued roads (often dodging rats or stepping over dead ones), it was as though I was experiencing this for the first time. While certain aspects of life seemed to have improved and some progress in treating people with hemophilia has been made, other challenges seemed to have only gotten worse.

ATTITUDE OF GRATITUDE: A Higher Hemophilia Perspective

BY DIANE HORBACZ

OUR JOURNEY BEGINS

In April 2017, my husband Gary, 15-year-old daughter Erin and I traveled to Mumbai to visit children we sponsor through Save One Life (SOL). In temperatures exceeding 100 degrees, we journeyed to 8 homes located in the neighborhood slums of Dadar, Parel, Bandra, Jarimari, Andheri and Goregaon, listening to stories of the challenges families face living with hemophilia. With limited or no access to factor as well as impoverished living conditions, young children with untreated bleeds are afflicted with knees the size of grapefruit and crippled by the time they reach their teens.

In addition to home visits, we spent time at King Edward Memorial Hospital speaking with patients, medical professionals, the Indian Council of Medical Research and an assembly with over 30 SOL beneficiaries. We were educated on how homeopathic medicine is being used to treat and prevent bleeds in the absence of factor and how premarital carrier testing is conducted as part of a spousal matching/selection process. We discovered how education is offered only until the 8th grade at which point one must pay for additional formal schooling. We also learned how the financial support children receive through SOL enable many children to receive an education beyond 8th grade, and for some, even through college.

Accompanying our family on these visits were individuals from the Haemophilia Society, Mumbai Chapter (HSMC). Familiar with the vital role HSMC

serves in supporting individuals with hemophilia from our first trip to Mumbai, we began to explore the complex legal, healthcare, federal and state governmental obstacles, which at times hinder efforts to effectively care for the hemophilia population. The seemingly insurmountable hurdles faced by this community kept my husband and I awake at night searching for solutions and ways to help. While our 2012 trip served to match sponsors with children, our 2017 trip enabled us to learn even more about the challenges and complications individuals with hemophilia face daily, and plan for future support.

To learn more about *Matthew's Mission:*

www.fb.com/matthewsolmission/

THE TRUE BENEFICIARY

While I am hopeful that our visit may have positively impacted the lives of families in Mumbai along with a promise of continued support, it turns out that my family perhaps was the primary beneficiary of these mission trips. The experience of travelling through poverty and squalid living conditions were somehow not the lasting memories of our trip. Rather, we were most struck by the sense of resiliency, hope and thankfulness among even the poorest and most desperate families.

The people of Mumbai shattered my pre-conceived notions that these families would exhibit a sense of hopelessness, defeat and sadness. Their inner strength and optimism helped drown out the potentially depressing aspects of

their lives and were utterly inspirational. My experiences in Mumbai forced me to re-examine my sense of entitlement to the "luxuries" we are used to living with hemophilia in the states: a refrigerator with factor, access to some of the best doctors in the world, healthcare coverage that ensures continued access to expensive treatments, and the expectation of further improvement of my sons' lives through cutting-edge research and development.

Armed with a better appreciation of things we take for granted living in one of the wealthiest countries in the world, I plan to share my renewed sense of gratitude with the hemophilia community in the U.S. to help families cope with their challenges through a new educational program entitled, ***An Attitude of Gratitude***. My two primary goals are to 1.) help provide an understanding of the stark differences of living with hemophilia in the U.S. versus in developing countries and 2.) use this understanding to help redirect negative energy (i.e., rebellious activity, teenagers refusing to infuse, feelings of inadequacy, self-pity) into a more positive energy, resulting in more constructive outcomes.

For now, here are a few of the more inspiring moments we encountered during our week in Mumbai:

Eagerness and enthusiasm of a young child with a swollen knee that was at least 3 times its normal diameter. No complaints, no tears - just a request for the physician to speed the drip of factor so he could more quickly join the SOL family gathering sponsored by the Haemophilia Society, Mumbai Chapter

Genuine warmth and generosity as we visited one of the poorest families we had encountered who encouraged us to enjoy homemade bread and offered us bottles of cola that were clearly luxuries

Thankfulness and smiles of a poor family after we offered gifts of small stuffed animals to the young daughters

Intense focus on education and pride in the children's voices as they proclaimed their school grades

Strength of a mother who explained her son with hemophilia was recently expelled from school given his inability to communicate due to the added diagnosis of autism

Fortitude of a father whose child had been hospitalized for over a month for treatment of an infection following knee replacement surgery

My experiences in Mumbai have gone well beyond a mission trip meant to help those less fortunate. My travels have unexpectedly helped me better understand and appreciate the benefits of living in a developed country, particularly with a life-threatening health condition. I want to share these experiences in the hope they may help other families in the U.S. as they continue to face the challenges posed by hemophilia.

AN ATTITUDE OF GRATITUDE

Over the past decade, science has shown the practice of gratitude can be transformational in a person's life. Help your child develop more grateful, purposeful thinking as a way to cope with the many psychosocial issues related to living with a bleeding disorder. This inspiring presentation and guided discussion explores our mission as parents to help our children develop a sense of well-being.

For information on how to bring this presentation to your community, please contact:

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or call Matrix Health Group Corporate Office at toll free: 1-877-337-3002

MY LIFE WITH WEEBLE AND G-GIRL

BY ROBIN LAWRENCE

One of my philosophies in life is that instead of making excuses about why I've failed at something, I'm going to share a story of how, against all odds, I've succeeded.

I share this and other beliefs with my children every single day...well, I guess they aren't technically my children...at least it didn't start out that way, but let me share my story.

Never able to have children of my own, I'd always felt like a part of me was missing. I've yearned to have an infant to embrace, and tell them from the very start that they are precious and important simply because they exist. I longed for a tender heart to shape and mold into a strong, beautiful person, but that wasn't to be.

When we received a call that a tween brother and sister had suffered a tragic event in their lives and needed a home, I knew right away they were supposed to come live with us. It took a little longer for my husband to reach the same conclusion, but eventually he did. If not us, who? If not now, when? If not here, where?

Even when you do it right, being a parent to any child will still wear you down and tire you out, but many can agree that raising a child or children with special needs is exhausting! As if being born with hemophilia were not enough, these children had also dealt with a lot of loss in their short lives. What that looks like in the life of a child is constant confusion, an inability to remember anything, fear of abandonment, fear of more loss, fear of failing, fear of success. They doubt themselves and doubt everyone else. I sometimes wonder if there will come a day they won't be waiting for the other shoe to drop, and won't be waiting for us to disappoint them just like everyone else has.

Soon after becoming part of our family, I decided to give my kids new identities. I told my new son about some toys I had growing up, and one in particular - the *weeble*. You could drop, poke or hold the weeble down, but they would always get right back up. And so a nickname was born, "Weeble" represented my child who would not be held down.

I told my new daughter I saw such greatness in her, and wanted her to realize how strong and capable she is. I made up a tale about her life. In it, she was born and raised as a normal girl, but after something happened to her when she was 12, she met someone who told her the truth about her real identity - she's actually the super hero, "G-Girl!"

There are these kids who stole my heart, they call me "Mom"

We began adjusting to life as a foursome. Weeble complained frequently about pain in his joints and back. We took him to a new hematologist who quickly determined he was not receiving anywhere near the correct amount of factor. He was experiencing micro-bleeds and various other bleeding episodes throughout his body. It didn't help at all that his 5'6" frame was carrying 238 lbs.

The doctor increased his factor dose, and we increased his activity. Since he'd never done any sort of exercise, we needed to start off slowly, but there is no 'slowly' with this boy. He was already feeling so much better about himself that he wanted to try everything NOW.

One day, he borrowed my 2-pound weighted hula-hoop and in no time had a huge hematoma wrapped around his abdomen. When he came waddling down the driveway like an old penguin, I packed him up and headed to the emergency room. That earned us three nights in the hospital.

Ten days later, we were back in the ER to address what had become a bleed in the intercostal space between his lung and ribcage for an additional three-day, two night, all-inclusive stay in the hospital.

Weeble's hematologist became more assertive with the treatment plan. As this particular bleed grew smaller and smaller, and as our son weighed less and less on the bathroom scale, we've enjoyed fewer and fewer such bleeding episodes.

As a symptomatic carrier, G-Girl seems to bruise if we even look at her wrong! She sometimes looks as though she's been mistaken for a piñata! Lengthy, heavy, and irregular menstrual cycles have been her norm. Currently, we are carefully documenting her cycles as well as the frequent bruises in order to give her hematologist detailed information at her next visit so he can provide a treatment plan recommendation.

As they began the school year, their previous transcripts told a tale of D's and F's, ADHD and aggression. So we began intensive tutoring, both at home and at school. Reminders posted on mirrors, tucked in drawers and pinned in closets - sprinkled with lots of tears and lots of laughter - helped our kids stay on track.

I tell them they aren't like all the other kids. They're so much better because they're largely self-made. They often hear, "You were given this life because you're strong enough to live it."

The two have worked so hard every single day since coming into our home. Some weeks it seemed like we'd never get done with homework, working until bedtime every night. We are still playing catch up from years of missed opportunities, teaching them the basics and the fundamentals I just assumed every child knew by now.

Once they realized we weren't going to laugh at them for not already knowing everything, and that their new teachers did want them to do well, I watched lights come on in both of their brains. Soon Weeble and G-Girl were earning grades that would make any parent proud. The girl and the boy who used to earn D's and F's? Gone. G-Girl is now earning A's and B's...hard-fought, all. She wants to wait to choose the job she's going to have for the rest of her life (we still have time, little girl!). For now, she's excited to be turning in her homework every day, and plans to cheer next year.

She has a beautiful singing voice and can draw/paint anything.

This past school year she received a Good Citizen Award, which is received by the student who best exhibits respectfulness, kindness, politeness, and more. Her teacher shared that he couldn't think of a better choice than G-Girl with her happy smile and wonderful attitude.

Weeble is also earning A's and B's. In fact, he's enrolled in Honors Math when he begins his first year of high school in the fall. I've never seen a boy who's so quick to figure out designs and schematics. He wants to be an architect or an engineer. I tell him he can become anything he sets his mind to. Oh, and that bathroom scale? When Weeble jumps on now, it reads 75 pounds less than the first time he climbed on. His self-esteem is soaring, just as it should be!

Daily notes tucked into their lunch bags are there to encourage and remind them that we love them. It's been funny to watch the transition of their friends who at first, told them they were too old to get notes in their lunches. They still get a note every day and now their friends tell them often how they wish their moms would put notes in their lunch bags, too. They shared with me one of their favorite notes has been, "Be the nice one. Be the smart one. Be the kind one. Be the real one. Be perfectly YOU! I love you, Mom."

Kinda trendy, kinda quirky, kinda popular, serious about learning all the things they missed for so many years of their lives... that's my Weeble and G-Girl. They aren't like all the other kids – and that's just fine with me! I believe the sky's the limit for our family of four. It's amazing what can happen when you just add love.

The hemophilia community is a very passionate group. One could say there is fire in their hearts and hope in their souls. And that fire and hope ignited at the HFA Symposium in Providence, Rhode Island on April 6th-9th. We were welcomed by the mayor of Providence, Jorge Elorza, and the city, whose downtown buildings were dramatically lit with red lights at night in our honor.

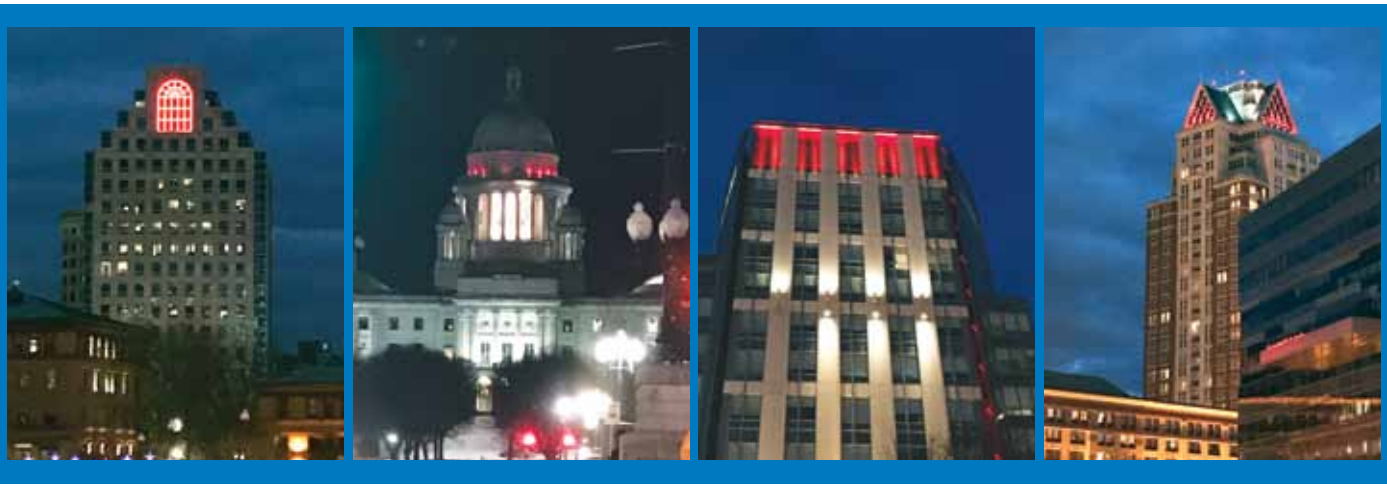
HOPE IGNITES

An HFA Recap

BY RICHARD VOGEL, PAUL BRAYSHAW, FELIX GARCIA, CHERYL ASHMORE AND CHRISTOPHER TEMPLIN

HFA has come a long way from its humble beginnings in 1994, but much of whom HFA is has stood the test of time. Originating as an outgrowth of COTT (The Committee of Ten Thousand), it was recognized that COTT represented those who were infected with HIV, but there were other young families not affected who needed support, advocacy and education. Ricky Ray legislation was just being introduced and HFA added their support in getting it passed and later funded. To celebrate community and provide outreach, HFA started to host national symposium meetings to bring the community together.

This year's 1,100+ attendees is dramatically different from the 70 or so at that first symposium; however, the purpose remains the same. The Symposium is a family meeting focused on advocacy, education and peer support for community members. HFA recognizes the importance of community coming together and from the first symposium, has provided many scholarships each year to families who would otherwise be financially unable to attend. This year, several hundred scholarships were provided, continuing that commitment to families.



Graham flashes a winning smile!

For the early birds, mornings began with rise and shine sessions including martial arts, yoga, Zumba, and a body workout and walk. There were even midnight yoga sessions for the night owls. For the rest of us, the days started with industry-sponsored breakfast and ended with industry-sponsored dinners. In between, the hours were jam packed with interesting and timely educational sessions.

In a morning breakout session ***Pain Management and Addiction***, the panel consisted of Chidi Ani, MD, Kristen Langdon, PhD, consumer David Tignor, and hemophilia mom Sonji Wilkes. Dr. Ani explained the difference between pain, acute and chronic. Acute pain is the body's normal response to pain, which comes on fast and resolves in a few weeks, whereas chronic pain is intractable and lasts for months. It includes spontaneous bleeding into joints, trauma and surgery, which leads to inflammation and pain. The objective is not necessarily to cure, but to make pain manageable through a multidisciplinary approach, which can include your primary care provider, hematologist, pain physician, social worker, psychologist, nurse and complementary medicines such as acupuncture and biofeedback.

David spoke about using music and outdoor recreation, such as fishing, to redirect his discomfort. Sonji discussed her young son's addiction to pain medication after a major bleed, and how his physician recommended stopping cold turkey. Not pleasant for anyone, especially a young child.

Along the lines of pain management, Samantha Carlson, LMSW OSW-C, ACHP-SW of the West Michigan Cancer Center & Institute for Blood Disorders presented an interesting session on Medical Marijuana and Bleeding Disorders. She discussed the possible benefits for bleeding disorder patients including neuropathic pain management, seizure disorders, HIV/AIDS weight loss issues, nausea and hepatitis symptoms.

Old Pals, Gerald and Rich

Mike and Rich - Represent!

Johnny of Puerto Rico

Genny, Johnny and John

HFA's Spanish Track in Review

"Si se puede" or "Yes we can," was the chant heard from the Spanish track attendees at this year's annual Symposium. Each session leader reiterated this important message within their presentations.

The Opening Session icebreaker led by Matrix' own Felix L. Garcia sent the audience on an emotional roller coaster as they got to know one another. The group began by sharing some of the scariest bleeding disorder moments in their lives, and how they persevered. To have the opportunity to verbalize the fear and their efforts in overcoming the obstacles led to igniting hope among the participants.

Men and women each had their own sessions within the Spanish track. This year was the first for this initiative, and the word is everyone was grateful for the opportunity to share with his or her own gender and inspire one another.

The final Spanish track session on Saturday proved to be the most moving. Stories were told of hardships from around our continent, from Latin America to the U.S. Tears were shed by all, followed by the kind of love and understanding commonly seen in our tight-knit community. Hope was certainly ignited that day, and bonds forged will last a lifetime.

The Spanish-speaking segment of our community truly appreciated the opportunity to learn and share in their native language, enhancing the feelings of being part of our family.

Two of the sessions devoted to insurance issues included federal issues: *Health Care Reform Update* and *State of the States, Legislation from Around the Nation*. Presentations were followed by panel discussions with various industry stakeholders, patient advocates, and HFA Government Relations staff.

On the federal level, discussions focused on what to expect from health reform and lessons learned from the passage of the ACA. On a state level, discussions dominated regarding Medicaid, step therapy legislation, protections if the ACA is repealed, and recommendations for organizations to provide assistance.

Katie Verb, JD Director, Policy and Government Relations HFA, led a presentation on insurance trends and provided a helpful overview of basic insurance terms. She described the difference between self-insured versus fully insured, the costs that count toward out-of-pocket expenses as well as those that don't. According to Katie, insurance trends involve many cost containment practices of insurance companies including increased utilization of prior authorizations, step therapy, formularies, preferred drug lists, balance billing, narrowing of provider networks, as well as mandating certain types of providers.

To help respond to critical gaps in insurance coverage, HFA relies on grassroots reporting to understand what is happening throughout the country. HFA's Project CALLs (Creating Alternatives to Limiting and Lacking Services) is a phone/internet-based survey. If you experience any disruption or delay in care, please consider sharing your experience at www.projectcall.org or send an email to projectcalls@hemophiliafed.org to learn more.

Always touching and meaningful at HFA Symposiums is when we take time to remember those we have lost. In the ***Remembrance Service: Lest We Forget*** session, the air of the packed room was thick with sentiment and sadness, often heartrending, yet celebratory. Each year, the list of the names scrolling on a screen, many with photos, continually grows longer and longer. With each new name, a story is lost and a family torn apart. With this session, we remember, pay tribute and celebrate the lives of those deeply loved and missed.

We lost a few very important leaders of our community this year - John Reed, Corey Dubin and Ellis Sulser can rest in peace knowing the time they spent away from their families was not wasted, nor in vain, as they have been tremendously inspirational to us all. Their legacy will forever carry on in every one they spoke with and taught our community's history, and how important it is to never forget our history. They taught us the art of being effective advocates, and to be proficient in maintaining our health and welfare by keeping advocacy always on the agenda. The absence of these great leaders from our world will forever be felt.

HFA is about community and remembrance, and this was evident at the final night event and WaterFire Ceremony. A Providence tradition, this stunning ceremonial lighting of bonfires at the tidal basin was a sight to behold. All HFA member organizations stood around the tidal basin in silence, holding state signs and reflecting on the past while looking forward to the future.

With the heady aroma of wood smoke and captivating music from around the world, you could feel hope igniting for the bleeding disorder community. A fitting way to end another great Hemophilia Federation of America Symposium!

The New England Hemophilia Association soared as the local chapter host of this year's HFA Symposium. The smoothly coordinated weekend showcased the versatility of the chapter staff and families. They welcomed the nation with open arms and a big hug, and ensured attendees got a terrific sense of our unique region.

Rich Pezzillo, ED of NEHA and alum of HFA, provided solid leadership and invented creative approaches to help make this symposium the most unique in years. NEHA spent months planning little pieces of fun to entertain attendees. Rich interpreted New England's interesting, but strangely difficult-to-mimic dialect. It was great fun to hear his words repeated many times from voices raised for a southern drawl or Midwest twang. We placed dancing aliens in the corridor on the way to the final night event and distributed "Wicked Strong Family" stickers that proved extremely popular.

Volunteers from all six states served by NEHA provided friendly faces and "concierge" services to attendees from all over the nation. New England folks also took turns volunteering in the rotunda, facilitating introductions that led to new friendships and lending a compassionate ear to anyone wanting to share.

The Hemophilia Alliance of Maine rented a bus and graciously transported people to Providence, some of whom had already driven a substantial distance to the pick-up spot. The bus stopped several times along the way, picking up old friends and new, celebratory on their way to an event, which was for many, their first exposure to a national bleeding disorders convention.

The community coming together in an exuberant effort to assist and support HFA was a feel-good movement that left us inspired, recharged and grateful to expand our community to a national level. Thank you, HFA, for allowing us the honor to represent New England in a substantial way.

LEGISLATORS AID IN HEMOPHILIA AWARENESS PLAN

BY BRIAN GRAVES
CLEVELAND DAILY BANNER
POSTED APRIL 7, 2017
REPRINTED WITH PERMISSION

State legislators recently gathered with the Chris Cassada family to bring awareness to hemophilia, which two of the three Cassada sons face on a daily basis. From left, front row, are State Rep. Dan Howell, Teigan Cassada, Zander Cassada, Raleigh Cassada and State Sen. Mike Bell. Second row: State Rep. Kevin Brooks, Shannon Cassada, Chris Cassada. Back row: Sabrina Owens (aunt) and grandparents Tina and Russ Carmichael.

BANNER PHOTO, BRIAN GRAVES: **brian.graves@clevelandbanner.com**

Teigan and Raleigh Cassada are having to go through life with an incurable disease, but with treatments are able to carry on a normal life.

They are two of thousands who suffer from hemophilia, a bleeding disorder which prevents the blood from clotting correctly and can cause continual bleeding with injuries.

"The Cassadas came to our offices a few weeks ago to discuss Bleeding Disorder Awareness month," said state Sen. Mike Bell. "They told us about their two boys who are dealing with hemophilia and wanted us to help raise awareness about this disease and other bleeding disorders."

Bell said the Cassadas informed him the month of March is actually the official recognition month, but the local legislators still wanted to get out front to help with the cause.

"We got started too late to do a resolution for Tennessee this year, but we will do one next year," Bell said. "What we did now is prepare a proclamation from the state House and Senate with state Reps. Dan Howell and Kevin Brooks along with myself and state Sen. Todd Gardenhire."

Howell noted Chris Cassada is the president of the Tennessee Hemophilia and Bleeding Disorders Foundation.

"They are very active in this cause," Howell said. "They are a beautiful family and have an awesome story to tell, and it's important to see what they are personally trying to do to bring awareness to this issue and try to help others with a similar need."

Chris Cassada said son Teigan, who is now 11, was diagnosed at the age of 2 with Hemophilia IX Severe.

"When he was diagnosed, we knew nothing about it," Cassada said. "So, we started doing some research online and trying to find information — just trying to get knowledge of what we were dealing with and what we needed to do."

"At the time," he added, "we just felt like everything had fallen apart."

That was when the family was able to connect with the state organization.

"That was about eight years ago and started to connect with the community across the state," he said. "It has slowly evolved into us being more a part of the foundation."

The Cassadas then found their second son, Raleigh, diagnosed with the disease at birth.

"I was able to get on the board three years ago, served as vice president for East Tennessee, then was elected in December to be board chairman," he said. "This is something we're just trying to do not only as a family, but to help our community across the state and across the nation is to raise awareness for our community so more people know about it."

Cassada said hemophilia is a chronic illness "that does not go away."

"There is no cure," he added. "And, it's a very costly thing to deal with — one of the top three in the world as far as cost."

The boys get prophylactic treatments once a week when they are given factor concentrate, which infuses the patient's blood with clotting factor proteins.

When a person needs to use the factor, sterile water is put in the bottle with the powder and mixed. When the powder has dissolved, it is injected into a vein. People who must use factor often are taught to give it to themselves. They can treat themselves at home, school, work, or while traveling. They don't have to go to the hospital every time they start bleeding.

> **"We are just trying to raise awareness and get more people involved in our community and our chapter, which has 3,200 members across the state. We are a nonprofit and want people to know about us and that we are here."**
>
> **— CHRIS CASSADA**

Both Cassada boys, even at their young ages, are capable of giving the injections to themselves.

"It helps put their levels up where they can live a normal and healthy life, where they can be active and play sports," Cassada said.

"We are just trying to raise awareness and get more people involved in our community and our chapter, which has 3,200 members across the state," he said. "We are a nonprofit and want people to know about us and that we are here. The more awareness we do, the better it is for the families that have not found us yet, and it makes it easier for them to connect with us as well."

The website for the Tennessee Hemophilia and Bleeding disorders Foundation is www.thbdf.org.

SPOTLIGHT ON RESEARCH

BY DIANE HORBACZ
BIOMATRIX RESEARCH & EDUCATION
DEVELOPMENT SPECIALIST

The University of Florida (UF), located just two miles from downtown Gainesville, is a college campus comprised of nearly 50,000 students. Located on the northern end of campus is the Ben Hill Griffin Stadium, popularly known as the "The Swamp" and home of the Florida Gators. UF students, its alumni and sports fans are commonly referred to as the "Gator Nation." However, the 2,000-acre suburban campus, with its landscape of Spanish moss laced trees and bustling with students donned in a palette of orange and blue, is more than meets the eye. In the heart of campus, at UF Health, researchers are conducting studies related to the treatment of hemophilia, including gene therapy.

In 2011, UF researchers received grants totaling almost $4.7 million to develop therapies for improving the health and quality of life of individuals with hemophilia. Collaborative efforts between groups of physician and non-physician scientists have led to groundbreaking innovations with great promise for the future treatment of those with hemophilia. This spotlight on research focuses our attention on the efforts underway on the UF campus, including studies on new therapies for the treatment of hemophilia as well as advances in gene therapy as a potential cure.

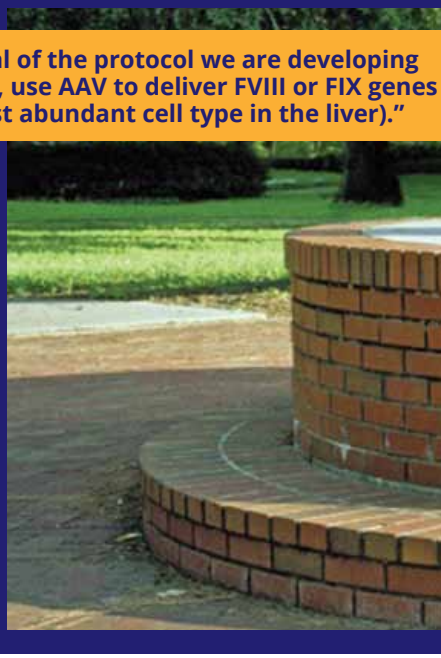
A FOCUS ON GENE THERAPY

Gene therapy requires a corrected gene (one with genetically modified DNA) and a method to deliver this new working gene into a human cell. Researchers at UF have focused on the use of viruses (vectors) as the preferred delivery mechanism given a virus' unique ability to both seek out and "infect" specific cells (liver cells for the treatment of hemophilia). The most frequently used vector is an adeno-associated virus (AAV) given its small size, the fact it elicits only a weak immune response and has never been shown to cause disease. Scientists engineer the AAV to ensure safe and efficient delivery of the new gene. The AAV is then injected into a specific tissue in the body where it delivers a copy of the functional gene directly into the nucleus of the targeted cell. Once inside the nucleus, the functional gene supports the production of the normal protein that was once deficient or missing, and corrects the underlying cause of the disease.

AAV DEVELOPMENT ADVANCES

The University of Florida has the highest number of scientists working on AAV to transfer therapeutic genes and was the first to identify the life cycle of the AAV. Improved understanding and further scientific

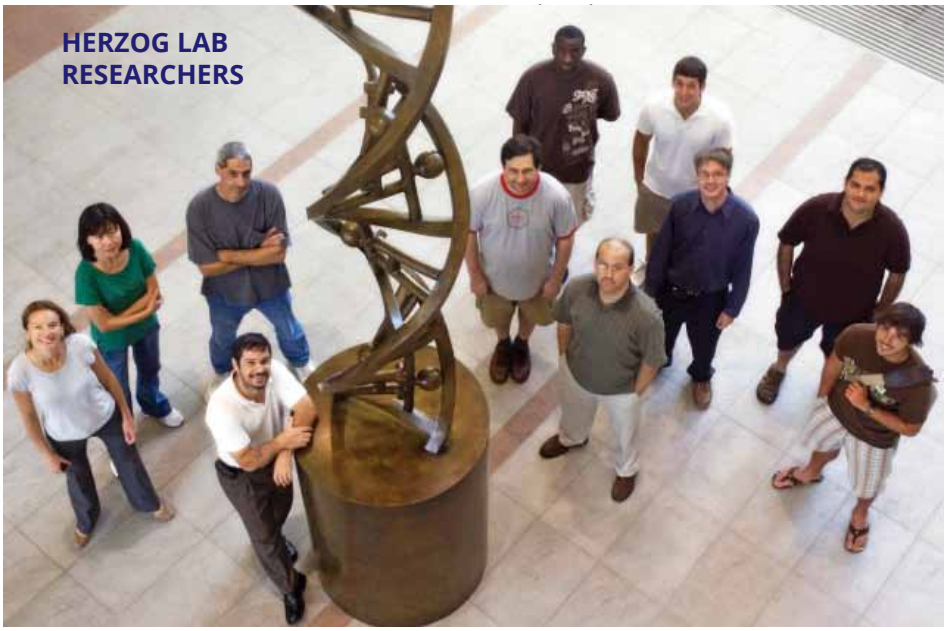
Roland Herzog: "All current clinical trials, and the goal of the protocol we are developing within our Division of Cellular and Molecular Therapy, use AAV to deliver FVIII or FIX genes to the liver (more specifically to hepatocytes, the most abundant cell type in the liver)."



development of AAV is rapidly bringing us closer to gene therapy becoming a reality.

Roland Herzog, Ph.D., Professor, Cellular and Molecular Therapy, Department of Pediatrics in the College of Medicine, is the principal investigator on several grants from the National Institute of Health and a co-investigator on grants from Bayer and Pfizer hemophilia programs. His lab's primary focus is on engineering recombinant adeno-associated viruses (AAV) to transfer a new functioning gene marked to restore the production of clotting factor. In clinical animal trials, mice and dogs have been successfully cured of hemophilia after effective execution of AAV gene delivery technology. In conjunction with other UF labs, the Herzog lab is now working on AAV development for human clinical trials.

Despite certain progress, one of the biggest challenges facing AAV gene delivery is making sure the immune system of an individual with hemophilia does not reject this new therapy. Therefore, in addition to ensuring successful delivery and expression of the new gene, scientists must find a way to eliminate the potential for a negative immune response.

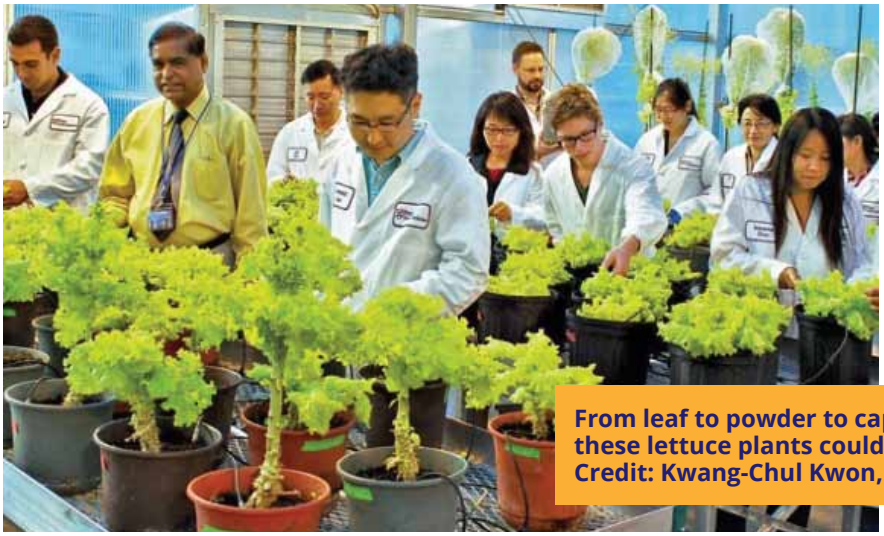


HERZOG LAB RESEARCHERS

INVESTIGATION OF IMMUNE TOLERANCE

The second focus of the Herzog Lab has been on finding ways to minimize/eliminate the possibility a patient's immune system rejects the virus used to deliver the functioning gene. With high hopes of achieving optimal response to gene therapy, researchers at UF have been exploring preemptive technologies that will enable immune tolerance. Success was achieved in 2013 when researchers Srivastava and Herzog developed immune-tolerant vectors capable of delivering a corrected gene without reports of inhibitor or adverse responses. This inventive therapy resulted in curing hemophilic mice in UF labs, and dogs at other universities. UF researchers are now working on the development of next generation vectors for gene therapy in human clinical trials.

Establishing immune tolerance to current factor replacement therapy is another focus of UF researchers. One promising approach is intended to eliminate negative immune responses to current hemophilia treatment, including inhibitors and allergic reactions.



From leaf to powder to capsule... Blood-clotting factors produced by these lettuce plants could eliminate the problem of immune rejection. Credit: Kwang-Chul Kwon, Jin Su & Henry Daniell, Univ. of Pennsylvania

LETTUCE IMPROVES IMMUNE TOLERANCE TO FACTOR THERAPY

What do hemophilia and a salad have in common? If your answer is "lettuce," you are correct! Taking a closer look at UF research, one of the most ingenious advances in scientific discovery taking place in the Herzog lab has been the ability to genetically engineer lettuce plants to contain clotting factor (protein). Scientists begin the bioengineering process by inserting a protein into an individual plant cell in a culture dish. From that single modified plant cell, a full plant is harvested in which every cell contains factor protein.

Dr. Herzog, in collaboration with University of Pennsylvania researchers, has proven that ingesting these protein-laced lettuce leaves significantly reduces inhibitor formation and severe allergic reaction to current factor therapy in mice and dogs. This approach is comparable to the practice of feeding peanuts to young children to reduce the likelihood of developing a life-threatening allergic reaction.

With the prospect of an oral remedy to prevent complications related to hemophilia therapy, this garden-fresh method being developed within UF laboratories has garnered much attention. As the next generations of immune-tolerant gene delivery vehicles are developed and methods to induce immune tolerance are determined, and as future therapies are further investigated, our spotlight on research at the University of Florida generates a green light for a brighter future for those living with hemophilia.

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AUTHOR'S NOTE:

During my recent visit to the University of Florida, I was struck by the degree of school pride exhibited around campus where everyone (and everything) is emblazoned in the school's colors. It's said that UF students "bleed" orange and blue and that the school becomes part of the alumni's DNA. Upon closer inspection, it turns out that these metaphors also take on a very literal meaning thanks to UF's extensive hemophilia research efforts.

The University of Florida is recognized as one of the premiere research schools in the country with a research and development budget of nearly $750 million in 2016. Fortunately for the hemophilia community, research scientists are tackling bleeding disorders by employing cutting-edge technologies on-campus with the goal of improving the quality of life of those living with hemophilia. During my visit, I saw DNA technologies being fashioned to improve current therapies as well as advances in gene therapy bringing us closer to a cure for hemophilia. My visit with researchers at UF has made this Spotlight on Research possible and has taught me the University of Florida is truly "One Gator Nation, Under Research, With Advances in Therapy for All."

RESEARCH AT UNIVERSITY OF FLORIDA: A STUDENT'S PERSPECTIVE

BY JUSTIN HORBACZ

Currently a sophomore at the University of Florida (UF), I am majoring in Health Science. As a student with severe hemophilia, I was introduced to the hematology team at UF Health Shands Hospital early in my freshman year. Since then, I've been fortunate to establish a network of remarkable scientists and learn about incredible research related to the treatment of hemophilia and gene therapy. There are so many opportunities to learn about hemophilia at UF - I feel like a kid in a candy store!

I've had conversations regarding the safety and efficacy of using polyethylene glycol (PEG) as a means of increasing how long factor lasts in the body with Dr. Tun Wynn, Assistant Professor and Director of the Pediatric Hemophilia Treatment Center. I've also had conversations about another exciting technology using a bypassing agent to control bleeding. Dr. Anita Rajasekhar, Director of Adult Hematology and Assistant Professor, is conducting an ACE910 study with a patient on prophylaxis as well as with patients who treat on demand.

The scientific advances of extended half-life clotting factors and bypassing agents not only represent a more convenient method of treatment, but will also serve to reduce bleeds and prevent joint damage. I have learned these new therapies are considered "bridge therapies," intended for short-term use until gene therapy becomes available in the near future.

Most exciting to me is the work being done in the lab of Dr. Roland Herzog. His research centers on gene therapy and immunogenicity to ensure tolerance to future therapies, and the development of an oral treatment using concentrated, freeze-dried lettuce leaves, which have been genetically engineered to produce factor to induce immune tolerance.

Dr. Tung Wynn of UF and Justin Horbacz at the 6th Annual Gator Clot Trot 5k and Fun Walk in support of the Hemophilia Foundation of Greater Florida.

The research team at University of Florida so generously dedicates their time and talents to making my future better, and I am thankful! Now is an exciting time - from increased half-life products to new technologies being created to control bleeding. Changes in the healthcare landscape are underway for our generation of people with hemophilia!

Dr. Brad Hoffman, UF Assistant Professor of Pediatrics, performing sterile tissue culture work.

Paul R. Brayshaw, M.P.H.

Director of
Healthcare Advocacy and Programs
Matrix Health Group

THE HEALTH ADVOCATE

AMERICAN HEALTH CARE ACT

It seems like yesterday when President Obama visited my backyard in Falls Church, Virginia. The President, Secretary Sebelius with the Department of Health and Human Services, locally elected officials and patient advocates gathered on my patio to highlight critical protections of the Affordable Care Act (ACA) going into effect that day. As a result of nearly exhausting my lifetime health insurance cap of $1 million in 2006 (or 3 years on an individual health insurance plan in Virginia with severe hemophilia), I sought any solution possible to get the health insurance needed to cover the cost of insurance coverage to pay for the treatment of severe hemophilia B. While my employer eventually offered me a group health policy, I considered changing jobs, moving states and/or trying to qualify for disability. While my experience was one example of an unmet medical need, I survived the ordeal and enjoyed an hour with the President of the United States.

At the time of the backyard visit, I was finally free from threats to my health insurance coverage, as well as many other Americans with high cost, preexisting conditions similarly affected. Over the next 6 years, the ACA expanded coverage for approximately 20 million Americans. Then in November 2016, the election of President Donald Trump initiated the repeal of the ACA.

After nearly 2 months of negotiations and compromise to overhaul the ACA, the United States House of Representatives passed the American Health Care Act (AHCA) May 4th to replace Obamacare.

As originally introduced, the legislation will modify ACA requirements that health plans cover preexisting conditions, guarantee availability and renewability of coverage, cover adult children up to age 26, and cap out-of-pocket expenditures. It also allows states to apply for waivers allowing insurers to charge people with ongoing health conditions a higher rate if there is a gap in coverage, and if a there is a state high-risk pool available. Furthermore, the legislation enables states to redefine the “essential benefits” that must be covered by insurance. The ACA required those

benefits to be comprehensive - including mental health care, addiction counseling, hospital care, and pediatric care. Under the AHCA, states could allow insurers to craft far narrower plans.

The final AHCA as passed, combined the original bill with all the subsequent amendments, eliminates the taxes and tax increases imposed by the ACA, and removes the individual and employer mandate penalties.

AHCA also phases out enhanced funding for the Medicaid expansions, imposes either a block grant or per capita caps on Medicaid, cutting $880 billion over 10 years from Medicaid, which covers low-income and disabled people. Age rating ratios are increased from 1-to-3 to 1-to-5 in the individual and small group market, and allows states to go higher by waiver, as well as permits states to waive the ACA's essential health benefit requirements. It allows insurers to charge significantly more to customers with preexisting conditions if they fail to maintain continuous coverage and imposes a penalty on those who do not maintain continuous coverage.

While AHCA creates a fund of $138 billion to assist states in dealing with high-cost consumers, the legislation ends the ACA's means tested (i.e. financial capacity or ability to pay) subsidies as of 2020 and substitutes them for age-adjusted fixed-dollar tax credits.

The bill now moves to the Senate where it faces a very uncertain future. The Republicans can afford to lose, at most, two votes in the Senate, and both conservative and moderate Republicans have concerns about the legislation. Moderate Senators have already insisted on reversing some of the Medicaid cuts, as well as how AHCA would cap Medicaid spending while limiting the stability for people newly eligible for the program in the last few years. However, restoring some of the Medicaid spending could jeopardize support for the $150 billion in savings over the next decade among conservatives who want to slash federal programs.

Approximately 20 Senators live in states with Medicaid expansion. To pass AHCA without Democratic support, the legislation must meet strict budget reconciliation rules, and many of the provisions do not comply because they do not affect spending directly, as required under special budget rules that allow for a simple majority of 51 Senators.

Without the assurance of protections for people with preexisting, high-cost medical conditions, the AHCA would dramatically disrupt health care delivery in every state it is signed into law. For patients whom must face these reductions, it is critical to stay engaged and contact your members of Congress, and state and local officials to let them know what it means when medications and care are not readily available, and without any delays due to administrative processing (i.e. prior authorizations).

Now is the time for the bleeding disorders community to get involved and let legislators know how this bill will impact people with chronic health conditions. Reach out to your representative today!

MATRIX ON THE MOVE!

WISCONSIN

Eva Kraemer

Great Lakes Hemophilia Foundation (GLHF) hosted its annual ***Milwaukee's Best Bloody 2017*** fundraiser at the Italian Community Center March 5th. The turnout of people excitedly showing their support for individuals with bleeding disorders and for an afternoon of Bloody Mary tasting was astounding. Bartenders representing 16 bars came out to vie for The Best Bloody Mary recipe award. We all sampled and sampled…and sampled, to cast our vote. *Best Over All Bloody Mary* was awarded to Steny's Tavern and Grill, while The Loaded State took the *Most Like a Meal* award. The event buzzed with good cheer and merriment, all to benefit GLHF so they can continue to provide services to the Wisconsin bleeding disorder community. Matrix Health Group was honored to have participated.

OHIO

Shelia Biljes

Studies show that laughter truly is the best medicine. A good hearty laugh will increase immune cells and infection-fighting antibodies, improving your ability to fight disease. Laughter increases endorphins in the brain that help us deal with stress and even relieve pain naturally. It also reduces cortisol, a hormone that causes stress symptoms. Most people do not realize how little they laugh during any given day. The stresses of work, school, parenting and family are enough; add in the stress of a bleeding disorder and we can find ourselves standing on the edge.

Lori Kunkle demonstrates a glass filling with "stress."

Matrix Health Group and CSL Behring teamed up March 17th at the Canton Memorial Civic Center to hold a night of laughter and anti-stress education. Lori Kunkel, a speaker for CSL, presented ***Laughing Thru Stress*** and shared her thoughts on raising boys with hemophilia, and you can't help but laugh as you find yourself relating to her story.

As Lori poured water into a glass representing everyday life, she stated, "With every stress we encounter, we fill up our glass more. We cannot stop the stress, but we can find humor and a positive attitude to get us thru it." Lori draws on her own humor to help her as her three sons enter college and the working world.

Joe Kennedy, a professional clown and magician from Oakland, Maryland, uses humor to help raise money for children's hospitals. He entertains children with medical needs and those in struggling situations. Joe's father and nephew live with hemophilia B, so he understands the need to laugh and find humor in

Blake and Brooklynn

Alayna

Aubree

Cameron

Jordan and Kayla enjoy the show!

tough times. His combination of magic and comedy can supply enough belly laughs to keep one's immune system up for a week!

As a 16 year-old clown and magician-in-training, Blake performs as Joe's sidekick. He has many talents including riding a unicycle and bending phenomenal balloon animals, and has been a part of Northern Ohio Hemophilia Foundation's entertainment for years. Blake encourages laughter and fun in children trying to heal.

The event was a huge success with over 110 attendees. After dinner and Lori's presentation, everyone enjoyed a real circus complete with elephants, trapeze artists, more clowns, and even more laughter. Although our specialty is hemophilia-clotting products and other specialty medicines, Matrix Health Group was happy to provide the medicine of laughter for this special audience!

CALIFORNIA

Heather Messerly and Gaby Griffin

Participants enjoyed an absolutely perfect day in Southern California Saturday, March 18th as the Hemophilia Association of San Diego County (HASDC) hosted their ***Family Education Day***. Approximately 200 people arrived to learn and have fun at this annual event held at the San Diego Zoo. Individuals and families took the opportunity to visit industry booths, including Factor Support's where families could create their own emergency identification card, something very handy to have in your wallet or purse!

Community members then took part in education, first hearing from Dr. Courtney Thornburg, Medical Director of the Hemophilia and Thrombosis Treatment Center at Rady Children's Hospital-San Diego who spoke about maintaining a healthy heart. Lena Volland, Physical Therapy Specialist, discussed programs at the University of California, San Diego, that promote the benefits of physical health.

Terri Cowger Hill, Legislative Advocate with the Hemophilia Council of CA (HCC), discussed the importance of community involvement. Dr. Tina Beck, DDS, MS, of Southern California Periodontics & Implantology offered information on the importance of oral health for those with bleeding disorders. Maria

Community member Laura E. with Gaby Griffin and Heather Messerly.

Santaella, RN-BC, with NHF's Nursing Working Group, addressed a few measures that can be taken to prevent joint damage. Finally Nooshin Kosar, HASDC Executive Director, discussed the chapter's upcoming community events and the importance of summer camp for children affected by bleeding disorders.

After the educational portion of the event wrapped up, community members had lunch and time to again visit the industry booths and tour the zoo for the rest of the day. This awesome event combined education, friendship and fun!

ILLINOIS

Eva Kraemer

With mint juleps in hand, the Bleeding Disorder Alliance Illinois (BDAI) hosted their 28th annual gala, ***A Night at the Races*** March 18th at William Tell Holiday in Countryside. Colorful hats of all shapes and sizes danced about the banquet hall as the Illinois bleeding

Eva Kraemer (second from left) is joined by gala goers dressed to the nines!

Looking sharp!
Aptevo Therapeutics' John Thorson with Jim S.

disorder community placed bets on the horses.

Fabulous live auction prizes included a Chicago weekend, a package for four to play golf at a local golf course, sailing on Lake Michigan, and many more. Bob Robinson and the staff at BDAI provided a spectacular evening in support of children and adults with bleeding disorders, and this filly was happy to participate in such a great cause!

ARIZONA

Kelly Gonzalez

My Nana's Best Tasting Salsa Challenge provided the perfectly delicious opportunity to build relationships through food and fun in the bleeding disorders community March 24th and 25th in Phoenix. My Nana's Best Salsa Challenge brings everyone together to enjoy festivities while supporting the Arizona Hemophilia Association. This 33rd annual competition showcases over one hundred freshly-made salsas and professional "chefs" compete for the judges' votes while attendees enjoy all the chips and salsa they can eat! The Salsa Challenge proudly includes restaurants, businesses and individuals competing to make the best tasting salsa in their category.

Patient Care Specialist, Sid Ramirez joined us from Northern California to master the salsa. Sid created 18 different recipes before narrowing down to the one our team entered in the contest. His hard work and creativity paid off as we won THIRD PLACE! We are so proud of him and grateful to AHA for letting us participate. This tasty event raised nearly $70k for the AHA! Such a delightful event!

Sid Ramírez (left) and the Gonzalez family, Ruben, Dominic, Kelly and Jacey staff the Factor Support booth.

NEW JERSEY

Diane Horbacz

Just a hop, skip and a jump from the Seaside Boardwalk, families gathered March 25th at the Clarion Hotel & Conference Center in Toms River for Hemophilia Association of New Jersey's (HANJ) ***Spring Educational Symposium***. Along with a delicious brunch, an empowering presentation was delivered by Sonji Wilkes, Marketing & Communications Manager at Hemophilia Federation of America, titled *Adversity, Challenge, Not a Problem*.

Although crabs and starfish were down the road at the beach, kids at the event learned why crabs have blue blood, how starfish have a water vascular system (no blood) and how humans have the most amazing blood. As an Education Specialist, I enjoyed leading a cool presentation of *Fun Blood*, where kids put their hands in 12 pints of fabricated 'plasma' and explored components of blood as they were guided through a series of hands-on science activities.

Thank you to HANJ for making this event possible!

OHIO

Shelia Biljes

Everyone has artistic ability at Pinot's Pallet! The creative juices were flowing March 29th as fourteen mothers of children with a bleeding disorder gathered for ***Mom's Night Out*** to try their hand with a paintbrush.

Starr and daughter Brooklyn show off their work!

Painting instructor Dorina places final touches on her artwork.

Not the winners, but happy all the same! Marcus O., MHG's Felix Garcia, and Steve C.

The evening started with dinner and a discussion led by Shire's True Identity Speaker Rhea Hoston, who reviewed *Pharmaceutical Step Therapy*. Step therapy, also called *step protocol* or *fail first treatment*, is a type of prior authorization, which requires trying other less costly medications first before "stepping up" to the more expensive drugs. As moms enjoyed their meal at Moosehead Restaurant in Olmsted Falls, they fell into deep discussion about step therapy protocols and how it impacted their lives.

After dinner the ladies walked next door to Pinot's Pallet for a fun paint therapy activity, using paintbrushes on canvas to relieve the stress of the day and of being a mother. There was no shortage of laughter as everyone followed the instructions from the talented activity leader and set about creating their very own masterpiece. The face paintings were beautiful, but no match when compared to the smiling faces of the group.

FLORIDA

Felix Garcia

The first ***Annual Golf Tournament*** was held to benefit The Coalition for Hemophilia B March 30th. This inaugural event took place at the prestigious Sawgrass Marriott Golf Resort & Spa in beautiful Ponte Vedra Beach. Eager to enjoy the afternoon, 48 golfers took to the greens following a tee-off clinic led by Perry Parker, a golf professional who also lives with hemophilia B.

This is one of the most stunning courses I have ever seen and, though I was I lucky enough to be in the mix, I will be the first to admit that my golf skills are nothing to be envious of. The spectacular course even provided each team with their very own caddie, although not even he could help my game.

After the gorgeous day golfing, players gathered for a chance to be winners of the many silent auction items, which included jewelry, golf outings, and stays at luxurious resorts. Then came the most impressive of all… the dinner. Everyone in the room was in awe over our feast, yours truly included. I heard more than one person say, "That was the best tournament meal ever." Credit for the fantastic fare goes to Kim Phelan, Vice President of the Coalition and her staff, who organized this top-notch, awesome event!

Funds raised will be used to support the Coalition's Patient Assistance Fund. Everyone is looking forward to next year's tournament and we have no doubt it will be a sold-out affair!

FLORIDA

Terry Stone

This year the Coalition for Hemophilia B celebrates its 25th anniversary of providing education and empowerment to those families affected with hemophilia B. What better way to celebrate than to take their big show, the ***11th Annual Symposium***, on the road and head south…way south…to the tranquility of Marriott Sawgrass Golf Resort & Spa in Ponte Vedra Beach, Florida, March 31st - April 2nd. Sunshine was on our shoulders, and YES…it made us so very happy!

For years, the Symposium was held in New York City; however, the change in scenery with the sunshine, palm trees, green grass, and tranquil waterfalls set the mood for an enriching and memory-filled program that was all-inclusive. Whether you were a patient, caregiver, spouse, or kiddo - YES, there was a meeting topic for you!

Booth neighbors and friends - Sue of Aptevo and Terry Stone.

Grant of Aptevo and Tina McMullen so happy to see each other AGAIN!

Friday morning's sunrise welcomed those who crave the slow-motion transfer of energy, commonly known as Tai Chi, as early risers joined renowned Master Rick Starks for class. After a leisurely breakfast, free time gave attendees an opportunity to explore activities and surprises this resort had to offer. Some enjoyed splashing in the pool, others had therapeutic spa time, while others strolled the grounds with friends to catch up the "B" life we share.

After a family meet & greet luncheon, the swarm of B's migrated and found refuge with their own kind, ladies and gentlemen to B exact! The gentlemen went off to do, well… what gentlemen do. The ladies did the same at the afternoon social hour. Everyone had some quality time rich with stories about kids, spouses, home life, bleeds, and the presidential election. The evening concluded with dinner and visits to the exhibit hall where industry sponsors were at the ready to share the latest and greatest news about products, and services, and new science…OH MY! Matrix Health Group was a proud sponsor and we were excited to welcome fellow B's at our booth!

If you're a B…you buzz on the dance floor!

Saturday's agenda was chock full of presentations after another morning of Tai Chi with The Master, formerly known as Rick Starks! Breakfast had us checking our GutMonkey with Patrick Torrey, reflecting on what inspires us and what we are passionate about. Good stuff to ponder as next on the docket was Dr. Christopher Walsh, HTC Director at Mt. Sinai Hemophilia Center, NY. Dr. Walsh updated the audience on available treatments including the new longer lasting products, and touched on new emerging therapies being studied that offer advancements in science and other ways of treating bleeding disorders such as gene therapy and non-factor replacement. He also encouraged all who may be dealing with hepatitis C to get on treatment and get cured, or as he so passionately expressed, "Get with it! The cure is here and it's not a difficult process."

Other topics of the day included a fun and unique presentation by Dr. Robert Friedman entitled *The Healing of the Drum*. Dr. Robert Sidonio, Associate Director of Hemostasis and Thrombosis at Children's Healthcare of Atlanta, Emory University, marches to the beat of his own drum as he has become a true champion of women's bleeding disorders. He

Beach party date night!

presented interesting case studies, which highlighted the uniqueness of each patient and family history. Lastly, a presentation facilitated in both English and Spanish addressed health insurance.

The evening wrapped up with a spectacular beach party complete with great food, music to move your good and bad joints to, sandy toes, and swimming for all! It was a perfect evening. For some, it was extra exciting as the local police stopped by to check on us, and to nicely ask us to lower the volume of the music. Those B's sure know how to party! Even more exciting was a planned by many, but a surprise to a beautiful young lady as her knight in shining beach glow went down on one knee and asked her to marry him. She said YES!

As another successful symposium wrapped up with breakfast and infusion practice led by Hope Woodcock, RN, families said their goodbyes. Thanks to generous sponsors that made this weekend possible. Before long, the Coalition with its dedicated team and inspired members will take to the road again for more wonderful events in new destinations. Thanks to Kim Phelan, Wayne Cook, Dr. David Clark, and all the volunteers whose dedication to this B-eautiful group have and will continue to enrich their members and collectively make living the "B" life a Blessed life!

NEVADA

Kelly Gonzalez

A fun filled day for the NHF Nevada Chapter bleeding disorder community came April 1st as patients and families gathered at the Circus Circus Convention Hall in Las Vegas to celebrate ***Spring Fest Education***

Day, a family event hosted by the NV Chapter of NHF. The crowd of over 250 participants joined to share educational sessions, such as *Impact on Unaffected Siblings* by Jessica Klass, Customer Relations Manager with Bioverativ, *Be Active* by Cassie Stark, Presenter for *Reconnecting the Mind and Body Through Fitness* with Aptevo Therapeutics, and additional updates from Kelli Walters, Executive Director. While parents were soaking up information, children were on their own exciting activities at the *Circus Circus Adventuredome Theme Park*!

We are grateful for our awesome chapter, the amazing volunteers and sponsors, the presentation speakers and for all the happy attendees in our Nevada bleeding disorder community!

ILLINOIS

Eva Kraemer

With possible changes to the Affordable Care Act (ACA), Bleeding Disorder Alliance Illinois (BDAI) hosted ***Legislative Advocacy Day***, its annual overnight retreat April 3rd-4th in Springfield. Bleeding disorder community members, eager to share their stories on how the ACA has impacted their lives, gathered at the Northfield Inn on the evening of the 3rd to learn more about how to comfortably and confidently talk to a senator or legislative representative.

Early on the morning of the 4th, everyone headed to the Illinois State Capitol. In small groups, we made our way to our legislators' offices to disseminate information.

**IL BDAI Legislative Advocacates:
Nick, Dino, Kathleen and Anthony with Eva Kraemer.**

Our mission was to discuss the importance of ACA to our community, such as maintaining the elimination of lifetime caps, expanding Medicaid eligibility, and to ensure insurance companies do not discriminate based on pre-existing conditions.

The impact we have on informing and making things happen within government is immeasurable, and well worth the time and effort. Small, but strong - we make a difference, and I feel privileged to advocate alongside the extraordinary people of BDAI.

NEVADA

Kelly Gonzalez

Sunday, April 9th was a crisp spring day in the quiet town of Carson City, the capitol of Nevada. Patients, parents and advocates came together to practice putting on our advocacy hats and ask state lawmakers to preserve our healthcare rights. Led by the Nevada Advocacy Team of NHF Nevada Chapter, we were well prepared for our ***Nevada Advocacy Day*** Monday meetings with state legislators. In support of the National Hemophilia Foundation's Red Tie initiative, we donned our ties and headed to the Capital.

Nevada Advocacy Team.

Advocates Angelica, Kelly Gonzalez, Amber and Carlos with Assemblyman John Hanbrick (center).

Carlos, Angelica, Senator Patricia Farley, Kelly Gonzalez meet to discuss NV's "any willing provider" amendment.

As the Nevada Advocacy Team flew to Carson City to participate with State Advocacy Days, they got the crew of the Southwest flight involved in the Red Tie Challenge. Kelly and her companions educated them about bleeding disorders. The crew responded by announcing the challenge over the loudspeaker to everyone on board, sparking awareness to all passengers on the flight!

We are grateful to our lawmakers taking time to hear our stories and committing to stand with us as we make strides toward ensuring healthcare coverage for our bleeding disorder community.

TENNESSEE

LeAnn Wilson and David Tignor

Matrix Health Group and Bayer hosted an ***Educational Dinner*** April 11th in Memphis. Angela Lambing MSN, ANPC, GNPC, Bayer Clinical Support Specialist – Hematology, gave an enlightening presentation on *Being Prepared for a Hemophilia Emergency*.

Leann Wilson visits with community member James.

The program discussed the various ways people in the bleeding disorders community can be prepared for emergencies and ER situations. Angela discussed keeping a go-pack ready with factor, supplies, documentation, and medical identification, and how to assertively communicate with emergency room staff.

At the end of her presentation, Angela provided time for open discussion so attendees could share personal stories of emergency situations and their efforts in being prepared.

NEW JERSEY

Richard Vogel

Over 100 community members and pharmaceutical representatives dressed to the nines to honor our very own Sal J. Rafanelli, R.Ph. COO / Co-founder of BiologicTx April 15th at the Hemophilia Association of New Jersey's (HANJ) ***37th Annual Humanitarian Award Dinner Dance*** at Fiddler's Elbow Country Club in Bedminster.

Sal founded BiologicTx, now a member of the BioMatrix family of companies, with his two partners, Darrin Carrico and Todd Krasinsky, RN, and assumed his current role as COO after holding management and executive positions with some of the top specialty and infusion pharmacies in the industry. As a founding partner of American Disease Management Associates (ADIMA), he was director of clinical operations and an instrumental part of ADIMA's growth into a leading specialty and home infusion pharmacy.

Karen Spano, Maria Rafanelli and Diane Horbacz celebrate with Sal Rafanelli as he is honored with the Steuben Eagle Award.

BiologicTx was founded on the principle of creating a company that would make a true difference in patient quality of life. Sal and his team have embarked on forming unique programs that produce positive patient outcomes and ultimately save lives. Among his list of accomplishments, Sal has earned the reputation for building innovative companies with a key focus on providing excellence in patient care.

Beginning with hors d'oeuvres, cocktails and conversation, the evening progressed to the award ceremony, dinner and, of course, dancing. The Master of Ceremonies, last year's award recipient, Peter O'Malley, VP of US Patient Advocacy for Shire, presented Sal with the Steuben Eagle Award. There is no greater symbol of achievement than this magnificently carved statue standing proudly as a sign of outstanding success.

The celebration lasted well into the evening with everyone enjoying the sounds and dancing to the music of *Night Moves*.

CALIFORNIA

Cindy Picos

Central California World Hemophilia Day held April 17th brought members of the Central California Hemophilia Foundation (CCHF) together to celebrate at the Studio Movie Grill in Rocklin. A photo opportunity with the Sacramento Kings Basketball Cheerleaders got this fun event off to a great start! Foundation President Bonnie Leidheisl and Vice President Sean Hubbert welcomed the group and gave a summary of the NHF Annual Meeting in Providence, Rhode Island. They also spoke about the foundation's upcoming events and warmly thanked everyone for their loyal support.

Sean Hubbert and Bonnie Leidheisl present NHF banner to CCHF.

CCHF Chapter Services Director Lynne Kinst and daughter, Ashley.

The celebration continued with dinner and a movie - attendees chose between *Beauty and the Beast* or *Fate of the Furious*. A lovely time was had by all. Many thanks to CCHF and devoted supporters for bringing everyone together to celebrate on this special day!

MAINE

Cheryl Ashmore

The beautiful state of Maine was the backdrop for a ***World Hemophilia Day Celebration*** by highlighting connection, local community and interconnectedness. Throughout the state, community members celebrated together, and two prominent buildings went red for the first time. Monday, April 17th at the Sea Dog in Bangor, the Hemophilia Alliance of Maine (HAM) Northern PIGLET (People Interested in Grass roots, Local Engagement – Together) hosted 17 families in partnership with Matrix Health Group and Aptevo Therapeutics. The HAM PIGLET program is a unique model, comprised of local sub-chapters based on geographic location. HAM facilitates meetings and educational programming for small groups of membership within their own communities.

In a state where it takes 7 hours to drive from top to bottom, participation is growing quickly. These groups provide a significantly higher level of access to education throughout the state. At present, there are 3 PIGLETS, with plans to kick off another 4 this year.

HAM's Executive Director, Jill Packard opened the evening with a large screen video call with the Southern Maine PIGLET, where an additional 10 families had gathered for dinner and education. The connection of

these two groups from afar strengthened our sense of coming together with blood brothers and sisters all over the state on a day set aside for our community. After a terrific dinner, Jill conducted a spontaneous needs assessment survey with the group, sparking good discussion and feedback on future programming suggestions.

Meanwhile, 29 children with an instructor and several assistants had space in their own room to make Mother's Day gifts. The younger children personalized bookmarks with stickers, markers and découpage, while the teens designed and crafted unique key chains and bracelets out of abalone beads. Abalone is a unique salt-water organism that produces no clotting factor, adding a layer of meaning to the gift. HAM did a wonderful job coordinating the two gatherings of community, bringing even more meaning to World Hemophilia Day in Maine.

CALIFORNIA

Gabriela Griffin and Marina Vera

On the warm Friday afternoon of April 21st, 78 Spanish-speaking families gathered in high anticipation of a 3-day trip to Catalina Island for Catalina Family Camp hosted by the Latino Hemophilia Foundation. Families from California, Nevada, Texas, Florida and even one from Oaxaca, Mexico, met for the preliminary ***Catalina Camp Luncheon*** at the Acapulco Restaurant in San Pedro where everyone enjoyed a delicious lunch, registered, visited industry booths and socialized with friends.

With a forecast of perfect weather awaiting them, the group made their way to the Catalina Express San Pedro Port where they boarded a boat for the 2-hour journey to begin their camping adventure. Though we did not continue on the camping trip, we had a lot of fun meeting and talking with families before they left. Everyone was energized and eagerly looking forward to the great fun ahead!

MICHIGAN

Enrique Morey and Shelia Biljes

Hemophilia Foundation of Michigan celebrated the arrival of spring with the annual consumer education conference, ***SpringFest***! New location, yet an amazing time as always! More than 650 parents, children and individuals came together at the Ann Arbor Marriott Ypsilanti at Eagle Crest for a weekend packed with fun, education and plenty of interaction April 21st - 22nd. The weekend included family programs Friday and Saturday evenings and educational sessions for all ages provided throughout. HFM uses proceeds from this event to help support the many educational opportunities provided throughout the year for families and individuals to connect and learn more about their bleeding disorder.

FLORIDA

Diane Horbacz

Each year to help raise awareness of bleeding disorders, the Hemophilia Foundation of Greater Florida (HFGF) hosts four signature ***5K Run & Fun Walks*** – in Tampa May 13th, Jacksonville October 14th, Orlando October 29th, and the first for this year, in Gainesville, April 22nd.

Just down the road from the University of Florida (UF), home of the Florida Gators, HFGF members and supporters gathered for the ***6th Annual Gator Clot Trot 5K & Fun Walk***. Participants from the community, medical professionals from UF Shands Hospital, UF students and alumni assembled near "the swamp" at Depot Park dressed in their best Gator gear working

Team Peds Clinic take 3rd place in Annual Gator Clot Trot Diane and Justin Horbacz, with Dr. Tung Wynn (center).

their #gator chomp in support of HFGF. With Star Wars music and characters in the mix, the Walk provided an enjoyable way for chapter members to get together and support a great cause. Over $20,000 was raised through this much-anticipated event, benefiting HFGF and the many services and programs it offers.

ILLINOIS

Eva Kraemer

The Bleeding Disorder Alliance Illinois (BDAI) hosted its annual ***Statewide Education and Fun Weekend*** April 22nd - 23rd, at the Chicago Marriott in Naperville. Our community's very own celebrity, James Patrick Lynch, well known for his comedic web series, *Stop the Bleeding!* gave the keynote speech, talking about obstacles and challenges he faced during his life with hemophilia, and how he turned those into opportunities for success.

John and Isaiah stop to visit Eva Kraemer.

After lunch, Dr. Lisa Boggio of RUSH University Medical Center Hemophilia Treatment Center discussed what's new for the community on the product pipeline. Breakout sessions included *Blood Brotherhood - Aging with Hemophilia*, *My Factor, My Body,* as well as *Transitioning Your Child to Independence* - facilitated in Spanish, a session about *Inhibitors, Communication in the Workplace* - how to discuss a bleeding disorder with an employer, and a *Blood Sisterhood* program.

Families enjoyed dinner while commemorating World Hemophilia Day, with sprinkles of laughter and fellowship while networking and reconnecting with other families from around Illinois.

Sunday morning's session, led by Laurel Pennick, MSSW, LCSW, and Cathy Tiggs, MSSA, LISW, was dedicated to knowing how to ask for support in areas such as education, the workplace, social life, dating, sports, childcare and health care. Matrix Health Group was pleased to be part of it all.

MISSOURI

Danny Hicks

Just north of Branson in Walnut Shade, the Midwest Hemophilia Association (MHA) held its annual ***Ozarks Pull for a Cure Sporting Clay Event*** at Ozark Shooters Sports Complex April 22nd. Even rain did not stop expert and novice shooters from teaming up for a very worthy cause and to raise funds to support the MHA Chapter and the services they provide for the bleeding disorders community. With the smell of barbeque and gunpowder in the air, it almost felt like the 4th of July!

Community member Rex selects the raffle winner.

NEW JERSEY

Richard Vogel

Sunday April 23rd, Matrix Health Group hosted an ***Educational Dinner*** with Shire at Adega Grill, a Portuguese restaurant in the Ironbound section of Newark. Our group was in a private lounge and made for an intimate cozy environment to enjoy appetizers of stuffed clams, Portuguese sausage, calamari, mussels, turkey wrapped in bacon and garlic shrimp, everything served family style since we, as a bleeding disorder community, are family. If that wasn't enough, main course of grilled steak and seafood paella put us over the top. The meal ended with cheesecake and flan for dessert.

Aunt Lily and Mom Milly share a moment with Omar.

A program was presented by Trish Underland, RN on the importance of dental care for persons with bleeding conditions. Trish is a Senior Clinical Specialist at Shire and has over 30 years of hospital nursing experience at the Johns Hopkins Hospital in Baltimore, Maryland.

Our discussion started with proper dental care and the importance of dental hygiene, especially in those who have artificial joint replacements and ports. These artificial devices are susceptible to infections, which can enter through the mouth and seed in these artificial devices, causing real problems.

We discussed how difficult it can be finding a dentist to treat persons with a bleeding disorder, especially the co-infected. The key takeaways from the presentation were that caring for your teeth and gums will promote general good health, decrease the risk of bleeding from gums, and reduce the risk of infection. Those with artificial joints and ports should take antibiotics before all dental procedures as a preventative measure. Always inform your dental team about your type of bleeding disorder, the severity, and of any complications such as HIV or hepatitis, and make sure they know you infused before your dental procedure. This will help alleviate any concerns they may have of treating a person with a bleeding disorder. Education is the key.

VIRGINIA

Terry Stone, and Paul Brayshaw

The Virginia Hemophilia Foundation welcomed many members and friends of the chapter to its annual ***Spring on the Avenue*** fundraiser on a lovely Sunday afternoon, April 23rd at The Branch Museum of Architecture and Design in Richmond's famed historic district. Formerly the Spring Wine Tasting fundraiser, the event truly outgrew its name originally starting as a quaint and intimate wine tasting experience with some lovely raffle items. It grew to be an exciting gathering, rich with amazing, coveted raffle baskets, artwork, silent auction packages, great food and spirits, and an ensemble of fabulous people.

It was a classy affair worthy of the beautiful building in which it was held. Who doesn't love getting all dolled up in your favorite spring attire, while your man gets all polished up in his Sunday best, lightening up your wallet to do your part to ensure that VHF has the much needed funds to carry on its mission and sending kids to camp. Many industry sponsors and representatives were there throwing in their support, but how amazing it was to see so many people together connected by love for this great organization?

Congratulations to chapter leadership Kelly Waters, Executive Director, and Heather Conner, Program and Communications Director, for continuing to grow this fun and worthy event for all to enjoy.

NORTH CAROLINA

Peggy Klingmann

April 25th proved to be a gorgeous sunshiny day for Hemophilia of North Carolina's ***3rd Annual Charlotte Family Festival & 5k Walk for Bleeding Disorders***. It was the kind of day that just beckoned people outdoors and over 340 people did exactly that for this wonderful cause! The festival and walk included a variety of activities for families from visiting with industry sponsors, entertainment, raffles and giveaways to lunch and lots of tasty treats!

This very successful event raised $6000 over the initial goal of $50,000, which will benefit the chapter's services and programs. Congratulations to the HNC staff and volunteers for hosting this fun event!

OHIO

Rania Salem

The hat… it's all about the hat - and fundraising, of course! The Northern Ohio Hemophilia Foundation decided to spice things up a bit for their annual ***Black and Blue Ball*** held at the beautiful Ritz-Carlton, Cleveland April 28th. Night at the Races was the theme of this year's gala and the party-goers came dressed to impress Kentucky Derby style for this amazing evening. Ladies donning gorgeous derby hats graced the scene with the award for best hat going to Edna S. of Richfield, Ohio.

Winner of the Best Derby Hat Edna, with son Forrest.

Dancing the night away! Rania and Naji Salem.

Horse races on a big screen were the highlight of the evening. It felt like we were really at the Derby – it was that exciting! The foundation hosts the most fabulous and successful events with this one raising an impressive $72,000. Everyone had a terrific time and we all look forward to seeing what the foundation has in store for us next year!

ARKANSAS

LeAnn Wilson

Everyone gathered in the large ballroom of the Chancellor Hotel in Fayetteville for the Hemophilia Foundation of Arkansas' ***Third Annual Northwest Arkansas Educational Day*** April 29th. After a tasty breakfast and time to visit the industry exhibits, Tammy Jones, Foundation President, welcomed the group and spoke on the recent activities of the Foundation. She also spoke about the benefits the chapter and community would receive as a new member organization with the Hemophilia Federation of America. Dr. Joe Moleski, a family practice physician in St. Louis, Missouri, captivated the audience with his life story and his personal struggles of having severe hemophilia. He shared how he overcame the obstacles – starting with a bleed in his brain when he was just 6 months old, and what obstacles he still faces today.

MHG's Brenda King and the boys, Ian and Ryan B.

More information followed lunch with a session on *Gateway to Education: Exploring Opportunities that May Be right for You* with Tres Major, Community Relations Manager with Bioverativ, and a question & answer discussion about plasma donation led by Paul Wilson, Hemostasis Sales Representative of Grifols.

The day wrapped up with a great time at Fun City Pizza, where a play area, arcade games and miniature golf awaited us!

NEW JERSEY

Richard Vogel

Red t-shirts were abundant at the Hemophilia Association of New Jersey's (HANJ) ***6th Annual Hemophilia Awareness Walk*** April 30th. Friends, family and members of the local community came out in full force to the soccer field at pastoral Raritan Valley Community College in Branchburg to show their support for persons with a bleeding disorder.

Community is in Our Blood was the tagline for the day. Lots of activity was included on this special day refreshments, ice cream, two bouncy houses, face painting, balloon making, games for children and live music. Industry and specialty pharmacies were there in full force, educating all and placing the spotlight on hemophilia.

Bob and Joanne with Rich Vogel (right).

Rich Vogel, Carolina, Sean, Ed and Denzel.

Walk Team BiologicTx

Starting at 11:30 am with opening remarks from HANJ President, David Lechner, deejay Carlos loosened up the crowd and the walk was off! Four times around the track was a mile – those more ambitious did additional laps. A barbeque lunch of hot dogs, cheeseburgers, chicken, salads and all the fixins' awaited the energized walkers.

Over $50,000 was raised to support HANJ programs and patient financial support, making this their most successful walk yet. Matrix Health Group is proud to support HANJ and sponsor this popular and flourishing event.

VIRGINIA

Terry Stone and Paul Brayshaw

Do you wine? No, not whine…WINE! Well it's apparent that friends of the Hemophilia Association of the Capital Area do as they came out to WINE together for HACA's ***Third Annual Spring Fundraiser and Wine Tasting*** event on an exquisite Saturday afternoon, April 30th at the historic Hunter House in Vienna.

It was a real treat to have the owners of Pearmund Winery facilitate the wine tasting portion of the event. Everyone was eager to taste each wine along with the perfectly paired delicious food samples that blended together to bring out the best of the wine.

After the tastings, folks strolled through the house to discover and found great surprises from a silent auction with treasures awaiting the highest bidder, to themed baskets ready to be won by the person with the lucky ticket! After the raffle tickets were dropped and the silent bids were done, one could make their way to the screened patio to listen to the beautiful sounds of our hometown duo, *Iliandi*, whose calming

FLORIDA

Justin Lindhorst

Matrix Health Group proudly supported the Florida Hemophilia Association's ***7th Annual Walk in the Jungle***. Participants gathered early in the morning Sunday, April 30th at Jungle Island in sunny Miami for pre-walk festivities. The deejay helped amp up the morning energy levels along with plenty of coffee, juice, doughnuts and other healthy breakfast options.

Walkers mingled with vendors and participated in some fun activities before joining their team on the trek through the beautiful Jungle Island trails. Team Matrix was well represented by individuals and families from our corporate office staff, Regional Care Coordinators, and local community members. In fact, our t-shirt design took the "Most Creative" winning prize!

Thank you to all who supported this event, which is the chapter's largest fundraiser of the year. Proceeds will support the many beneficial programs and services offered by the Florida Hemophilia Association. See you next year!

Ally, Angie and Pamela of the Matrix Health Office.

Jenn and Michelle enjoying live music on the patio.

melodies fragranced the air and enticed guests to grab a chair and take it all in.

It was a delightful afternoon for all who came. This event continues to grow in popularity and will need to book an even larger venue for next year. For some, it was a great date afternoon; for others, it was a nice time to WINE with friends; yet for all, it was a fun and classy afternoon that raised much needed funds for HACA to continue to serve the bleeding disorders community with essential programming and educational opportunities. Matrix was honored to sponsor this lovely event.

NEVADA

Kelly Gonzalez and Holly Shaw

This year's golf event began on Sunday, April 30th with afternoon lessons and a youth clinic with golf pro Perry Parker. Kids from the Las Vegas community attended the golf clinic and received instructions from Mr. Parker, who is inspirational in that he has had a successful golf career and has hemophilia. Lucky parents also attended the clinic in preparation for the next day's golf tournament.

Practice with the pro paid off as 120 golfers met on a picturesque, sun-drenched day to support the ***Golf 4 The Kids Annual Golf Tournament*** at Red Rock Country Club in Las Vegas. Rounds began with a shotgun start and featured special holes such as, *Beat the Pro*, *Closest to the Pin*, *Hole in One* and *Shots for Success*. We had a blast hosting a *Sunblock and Snack Station*! When the last swing was swung, players gathered for a late lunch, an auction and prize drawings!

The day was gorgeous, the golf exciting, the company engaging, and the event very successful in raising over $65,000 to send deserving kids to bleeding disorders camp. Thank you to the Nevada Chapter of the National Hemophilia Foundation for organizing this worthy event!

PENNSYLVANIA

Tina McMullen and Rich Vogel

The Eastern Pennsylvania Chapter of the NHF held their ***Annual Family Dinner*** at the Hilton Hotel City Avenue in Philadelphia May 2nd. Approximately 380 people attended this year's event, which included an exhibit hall and dinner program. The agenda featured presentations by community members Sandy Krouse, Cheyenne Gansell and Steve Nicolosi, while Dr. Kathy High, Sparks Therapeutics, and Dr. Bhavya Doshi, Children's Hospital of Philadelphia, gave updates on

Carle and Christine visit with Tina McMullen (left).

hemophilia. Congratulations to Executive Director Curt Krouse and his staff, Lindsay Frei, Program Manager, and Charlotte Conmy Development Manager, for offering the Eastern Pennsylvania families another wonderful event.

CALIFORNIA

Marina Vera and Gaby Griffin

Over 400 members of the bleeding disorders community gathered for education and enjoyment at Knott's Berry Farm Hotel in Buena Park. Hemophilia Foundation of Southern California (HFSC) hosted its ***Family Information Day*** May 5th-6th and though the day began with a little rain, families were greeted with sunshiny smiles from the wonderful staff and volunteers of the HFSC. Even a Snoopy character from Knott's Berry Farm made a photo op appearance as children were registered to attend workshops geared to their ages. As the children went off to start the day with fun and education in mind, Michelle Kim, Esq., Executive Director, was ready as well to start the workshop for adults.

Dr. Steven Pipe, Pediatric Medical Director, Hemophilia and Coagulation Disorders Program, University of Michigan, addressed the group first with an update on

Sally N. and Marina Vera.

Ivan G. visits Marina Vera.

Gene Therapy for Hemophilia A and B: *From Promise to Reality*. Families had an opportunity to ask questions and were assisted by our young teen volunteers as they scampered about providing microphones for those with a question. Kudos to our teens who make themselves available and are always willing and ready to volunteer at these events!

Award-winning actor, director, host and producer living with severe hemophilia A, Patrick James Lynch moderated a lively panel discussion regarding new therapies, aging with hemophilia, pain management and the benefits of attending a hemophilia treatment center. The gifted panel consisted of Dr. Julie Jaffray, Pediatric Hematologist, CHLA, Dr. Doris Quon, Hematologist, Director, OTC, Dr. Vanessa Salinas, Pediatric Hematologist COH, and Dr. Nina Hwang, Pediatric Hematologist, CIBD.

Board President Sandy Davis introduced new board members, the 2016 Christopher Pitkin Scholarship Winners - Alex E. and Davis F., the 2016 Big Stick Summer Award winner, Ethan O., and the 2016 Volunteer of the Year, Donald "Ziggy" D. After a lunch break, Cazandra Campos-MacDonald, HFA Families, a fantastic speaker in our community, presented a helpful session, *We Need to Talk: Communication Strategies for a Healthy Relationship*.

The day sped by and at the close of the educational sessions, everyone was given tickets to enjoy the rest of the day at Knott's Berry Farm Amusement Park! Way to go HFSC for an education-filled, fun-packed, community event!

LOUISIANA

LeAnn Wilson

Hope for Hemophilia held a ***Crawfish Boil*** to remember at BREC'S Baton Rouge Zoo May 6th! This event began over 20 years ago by members of the bleeding disorders community. Originally with 120 lbs. of crawfish, the Crawfish Boil of Louisiana has grown to feature 800 lbs. of boiled crawfish with over 150 people in attendance.

This was Hope for Hemophilia's first time hosting this popular gathering. The event began with an educational presentation by Tres Major, Community Relations Manager with Bioverativ, *Gateways to Education: Exploring Opportunities That May Be Right for You*.

Ericka and daughter, Dajah, visit with LeAnn Wilson.

He captivated everyone's attention by revealing resources available to students with hemophilia.

A large inflatable slide and face painting was a hit among the children as was a special presentation by a zookeeper who showed everyone a few animals up close including various types of snakes and a cute hedgehog.

Everyone was also given free tickets to enjoy the zoo! This event was filled with a lot of laughter, fellowship and a Cajun-style feast. It was an honor to present Matrix Health Group at this very classic event, which will be around for many years to come!

MARYLAND

Paul Brayshaw and Terry Stone

Families gathered at the Hilton BWI Airport in Baltimore for Hemophilia Foundation of Maryland's ***Annual Family Educational Dinner*** May 6th and enjoyed "food, friendship and education." Bioverativ sponsored the dinner presentation and representatives addressed the topic of *Evolving Landscape of Hemophilia.* During the discussion, attendees learned what happens in the body during a bleed and why preventing bleeds is just as important as treating them. The program also explored various new and emerging technologies that may work to address bleeding episodes.

Paul Brayshaw and Jack Shoff of Bayer.

It is an exciting time in the bleeding disorders community with so many new therapies being developed and marketed. Attendees of the dinner were provided critical information to assess the most advanced therapies and technologies.

NEVADA

Kelly Gonzalez

Over 120 bleeding disorder community members came together May 6th, gathering in Hispanic-themed rooms of the Texas Station Convention Hall in Las Vegas. ***Annual Hispanic Education Day*** is an opportunity for the Spanish speaking Nevada community to learn - in their most familiar and comfortable language - more about living with a bleeding disorder. Sponsored by Shire, the meeting consisted of small group breakout sessions, covering a variety of topics including parent and community involvement.

All in the family! Sofia and Andrés with mom Maureen.

A special thanks to the NHF Nevada Chapter and HTC of Nevada for working with Shire to bring this special event to the community!

TENNESSEE

Shannon Cassada

May 6th was the perfect morning for a run – cool, bright, and not a cloud in the sky. The Tennessee Hemophilia and Bleeding Disorder Foundation (THBDF), along with the Jameson family of Loudon did another fantastic job hosting the ***Be A Factor 5K Run*** held at the local high school. This annual event is the brainchild of Dusty Jameson in honor of his son Karson, who has hemophilia. Dusty, Karson and their dog, Bella, ran the entire race!

The rest of the Jameson family cheered with pride as they watched the trio come around the track on their final stretch of the 5k. They know having hemophilia hasn't always been easy for Karson, and it's heartwarming to see him participate with such strength and endurance.

Be a Factor! Shannon Cassada, sons Teigan and Raleigh with Shire representative, Mark O'Brian.

The male overall winner for the day, Ron W., finished with a time of 18:49. Kari P. was the female overall winner for the day with a time of 22:25. Congratulations to both winners!

Not wanting to be left out, my sons, who also have severe hemophilia, and I ran the 5k as well! Teigan finished first in the 11-14 age group while Raleigh finished 3rd in the 10 and under group. Before the day was over, my sons were making plans with Karson for the 2018 event!

NEW JERSEY

Richard Vogel

Greetings from Asbury Park! While "the fireworks were not hailin' over little Eden tonight," the fires were burning at Hot Sands Glass Blowing Studio where community members met May 7th for an ***Educational Event*** hosted by Matrix Health Group and sponsored by CSL Behring, which I called, "You're Not as Fragile as Glass." We explored and discussed overcoming adversities in pursuit of a career.

Our inspirational speaker, John Vieke, grew up in rural central Indiana and has severe hemophilia B. He told us how he persisted in pursuing his life dream despite being advised not to follow it. Through hard work and determination, he earned his bachelor's degree in Criminal Justice and through years of trying to get hired by a police force, was finally accepted. He has been a police officer for nearly ten years. His motivation was uncovered when a much-admired professor told him not to pursue a career as a police officer because of his hemophilia. That inspired him to prove to himself the

Rich Vogel and Sammi

professor was wrong. Our take-away was we should never take no for an answer, and never let anyone interfere with the pursuit of our dreams.

Over a catered lunch of salads and sandwiches, we continued our discussion while participants went into the studio in pairs to learn how to blow glass. We chose from a variety of projects, a glass ball or heart-shaped ornament, a vase, a candy dish, and for the very young, a glass cast of their hands with shells. Everyone came away with a beautiful reminder of the day's discussion. Whenever we feel down or disillusioned, we can look at our hand-blown beautiful piece and remember, "We Are Not as Fragile as Glass."

Julie listens as Sammi explains how to blow glass.

CALIFORNIA

Sean Hubbert

The next generation of advocates for the bleeding disorder community was honored as 2017 Future Leaders during the Hemophilia Council of California's ***Legislative Days*** held at the State Capitol in Sacramento May 9th-10th.

Having been involved in Legislative Days for the last 20+ years, I am always impressed by this group of men and women. Even with their youth, our young adults advocate on behalf of bleeding disorder community members to their state lawmakers, encouraging them to support legislation as it comes their way. HCC's Legislative Days offers them the opportunity to see their legislators in action and feel they have an influence in our future.

CALIFORNIA

Cindy Picos

Over 75 people participated in the Central California Hemophilia Foundation's (CCHF) ***Central California Golf Tournament*** May 11th at Sun City Lincoln Hills Golf Club in Lincoln. Heath Charamuga, CCHF Volunteer and Golf Tournament Chairperson was very pleased with every aspect of this fantastic event from the participation of industry, home health care companies and chapter friends to the caring volunteers as well as the perfect weather. Rounds began at 8:30 a.m. with fun prizes and contests throughout the tournament. The cheerful group gathered back at the clubhouse for a BBQ tri-tip lunch and opportunities to bid on silent auction items and offer donations benefiting the Foundation's Emergency Assistance and college scholarship programs.

FLORIDA

Peggy Klingmann and Marcy Foertch

A beautiful breezy day despite a slight overcast met more than 150 walkers of the Hemophilia Foundation of Greater Florida's (HFGF) annual ***Woodstock Walk*** May 13th at Tampa's Al Lopez Park. The day was filled with plenty of treats and more fun activities including painting a 1967 VW Beetle and jamming to the awesome music of Joe Sena with Aairius DJ Entertainment!

Team Clotting for Carter took home the Traveling Team Walk trophy, and their team captain, Nicki, took home the Top Individual Fundraiser award. The team from St. Joseph's Children's Hospital was the recipient of the Champions in Action award for the top fundraising hemophilia treatment center, and Team CSL nabbed the Team Spirit award for having the most people on their squad!

This popular event raised over $40,000 for HFGF and the bleeding disorders community in Florida. We look forward to next year's walk May 19, 2018. Save the date!

DELAWARE

Richard Vogel

Cowboy Monkey Rodeo! Cheers could be heard all over Delaware as the Cowboy Monkey Rodeo entered the field Friday, May 12th in Wilmington as the hometown Blue Rocks baseball team took on the Frederick Keys. Bioverativ and Matrix Health Group joined in sponsoring community members of the Brandywine Valley Hemophilia Foundation (BVHF) to an evening of information and fun.

Before heading over to the Daniel S. Frawley Stadium, Bioverativ hosted an ***Educational Dinner*** at Timothy's Riverfront Grill, where Christine Rowe, Community Relations and Education Manager, spoke about the science behind bleeds, what happens to the body when we have a bleed, how the body builds a clot, and what happens when we are missing a clotting factor. She then touched briefly on emerging therapies and how they are thought to work.

After a delicious buffet of scallops wrapped in bacon, crab-stuffed tilapia, chicken and pasta marinara, coffee and dessert, we all made our way to an evening of enjoyment and entertainment. Foundation president Gail Vannicola secured tickets for the group so we all sat together. It was a special night with the Cowboy Monkey Rodeo in town, a Wilmington Blue Rocks tradition in which a sheep-herding, chaps-wearing capuchin monkey straddles a border collie and shepherds his flock. While met with some controversy, everyone in the stadium enjoyed the show.

Another highlight was the big-eye race in which people wearing big eyes over their heads race each other. None other than a local ophthalmologist group sponsored this activity. But the best was when the Blue Rocks scored a run and their mascot, Mr. Celery, ran out on the field. Yes, that's right, Mr. Celery! The story goes that when the Blue Rocks first started they had no mascot. A local high school was getting rid of some costumes they used for a production; however, the costumes were of fruit and vegetables. Celery was chosen, and thus Mr. Celery was born. We all had a good laugh.

The Brandywine Valley Hemophilia Foundation is a very family-oriented group and everyone seemed to know each other. I immediately felt welcomed and I'm glad Matrix Health Group joined in and contributed to a fun outing for this deserving community.

Friends all around! Rich, Jill, Gail and Christine.

Families enjoyed meeting Rocky Bluewinkle!

MAINE

Justin Levesque

A Hemophilia Hoedown! The Hemophilia Alliance of Maine (HAM) held their ***7th Annual Family Dance*** at the Back Door Dance Studio in Eddington May 13th. This wild west extravaganza included many a hay bale, square dancing, education and best of all, a community coming together in love and support. Between all the yeehaws! and howdy y'alls!, folks could have their portrait taken in the photo booth or eat to their heart's content from the array of delicious pot-luck treats.

Board President Tracey Gideon originally created this event to support HAM in the early stages of its formation. Her ability to pull so many folks together in one of Maine's rural regions is certainly an amazing accomplishment, but further, it's clearly visible and heartwarming to see the genuine participation and care she instills in others for Maine's bleeding disorders community.

PENNSYLVANIA

Tina McMullen

"Friends, like wine, only get better with age," was the featured quote for the ***38th Annual Luncheon and Fashion Show*** hosted by the Eastern Pennsylvania Chapter (EPC) of The National Hemophilia Foundation. It might have been pouring rain outside, but the sun was shining inside Green Valley Country Club in Lafayette Hills May 13th! Over 170 ladies attended this year's event, which included a luncheon, fashion show, wonderful raffle items and an array of exciting door prizes.

BOC Productions and their lovely models promoted designs by Berta Saywer. State Representative Leanne Krueger-Braneky, representing Pennsylvania's 161st Legislative District in Delaware County was the guest speaker. Leanne made history in 2015 as the district's first female representative, and is a progressive champion and tireless advocate for women, school kids, the environment and working families. Her speech highlighted, "Moms' voices matter and elected officials need to hear from you on the issues you care about!" She was very motivating for all in attendance.

Lovely Ladies, Tina McMullen and Megan C.

The Fashion Show Committee along with Executive Director Curt Krouse and his enthusiastic staff did an amazing job. This event is something to look forward to all year long!

VIRGINIA

Terry Stone and Paul Brayshaw

The Hemophilia Association of the Capital Area held its ***Annual Family Education Day*** on the campus of Northern Virginia Community College at the Ernest Cultural Center May 13th. Members and exhibitors filled the room and made themselves comfortable and ready to learn, while the dancing flames of the fireplace made everyone feel right at home.

HACA's Volunteer of the Year Michelle Stielper (left) with Executive Director Brenda Bordelon.

On the docket for the day of education were timely and sensitive topics. Henry Mead of CSL presented an informative overview of *Upcoming Treatments for Hemophilia*, followed by the tough news of *Legislative Updates*; more commonly discussed as the stuff you need to know to get your factor in the future! HACA's own Miriam Goldstein of HFA gave a detailed update and encouraged folks to stay informed and answer the call when we need to rally! Other presentations were also very well received as they discussed some very hot topics like *You Got This!...The Art of Speaking Up* courtesy of NHF and lastly, *Taming the Social Media Beast* courtesy of HFA.

Just across the hall from all that "learning," little ones were busy playing with their White House Nannies, while teens were busy with physical therapist Eena Kapoor discussing how to *Play it Safe*. Then those teens went all Hollywood on us as they wrote, acted, filmed and edited several short movies for everyone to enjoy at the end of the conference.

Executive Director Brenda Bordelon closed the event with the annual election of new board members and the presentation of the Volunteer of the Year Award. Congratulations to our very own Michelle Stielper, Matrix Regional Care Coordinator, whose service and contributions were honored for a job well done.

IDAHO

Jeff Johnson and Kelly Gonzalez

The Idaho Chapter of NHF held their annual ***Blood, Sweat and Cheers Golf Tournament*** at Plantation Country Club in Boise. May 15th proved to be a lovely, blue sky day as golfers joined community member and professional golfer, Perry Parker on the links to raise support and funding for Idaho bleeding disorders events, including upcoming Camp Red Sunrise. We had a great time on the fifth hole where we staffed a hospitality tent, handed out refreshments and cheered on enthusiastic golfers!

Jeff Johnson hams it up!

Following the event, golfers and volunteers gathered on the clubhouse patio for barbecue as chapter leadership raffled off donated prizes and gift baskets. All in all, it was a fun and very productive day for the Idaho community, and much needed support was raised for local programs!

TENNESSEE

Shannon Cassada

Hosted by the Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF), 19 eager teams arrived at Westhaven Golf Club in Franklin to play in the 30th annual ***Music City Golf Classic*** tournament May 15th.

The men on the Matrix Health Group team had a blast raising funds for THBDF. Monies raised will help support the foundation's programs and services such as family educational events, camp for children with bleeding disorders, and assistance for families when suffering a hardship.

The golf tournament was a great success, and although Team Matrix did not place at the top of the leader board, their day was full of carefree competition and much laughter with all looking forward to next year!

Team Matrix!
Tim D., Chris C., Bobby B. and Eric Lambing

KENTUCKY

Rania Salem

Families and friends of the Kentucky Hemophilia Foundation gathered May 20th for the much-anticipated annual ***Kentucky Zoo Day*** at the beautiful Louisville Zoo and Botanical Gardens. Every year people gather to meet with vendors to learn of their latest offerings, and visit with friends - new and old alike, while enjoying a wonderful day with their loved ones. After a delightful picnic lunch at the gazebo, kids gathered for carnival style games, and met with zookeepers who arrived with live animals to meet and learn about. After names were drawn for fun raffle prizes, families went on to enjoy the awesome day at the zoo. A huge thanks to Executive Director Ursela Kamala and her assistant Sandy Franklin for another fantastic year!

Quinton S. talks to the animals!

NEW HAMPSHIRE

Cheryl Ashmore

It's no secret our community is facing threats to access and quality of care as changes to the Affordable Care Act are coming. In response, last year New England's three chapters formed a working group spanning six states to build a responsive action network to empower members as advocates for our bleeding disorders community.

On May 20th in Concord, New England Bleeding Disorders Coalition (NEBDAC) introduced a fully formed collaborative network to participants of the Bleeding Disorder Advocacy Conference. The daylong event featured national experts in advocacy who focused on the importance of speaking up for our community

Jill, Natashia, Pete and Maryann.

Jill Packard and Rich Pezzillo

and ourselves. They provided tools, resources and a concise roadmap to both initiate and respond to calls of action about proposed legislature that affects our community's quality of care.

The second part of the day provided intensive, hands-on techniques to ensure our voices be heard and officially noted by our representatives in government. NEBDAC introduced to us lead people from each state available to provide individual and group guidance, and each participant was asked to educate and encourage others to actively engage with this network. It was an inspiring and compelling event reminding us of our community's unique history in legislative advocacy and our proven ability to effect change simply by showing up and being heard.

Thank you to the Connecticut Hemophilia Society, the Hemophilia Alliance of Maine and the New England Hemophilia Association for presenting this transformative conference.

CALIFORNIA

Cindy Picos, Sid Ramirez and Sean Hubbert

The Hemophilia Foundation of Northern California hosted their annual ***Dreamers and Achievers Education Day*** event for families impacted by bleeding disorders. The event was held Sunday, May 21st at the Camden Community Center in San Jose. Speakers included the following individuals - all of whom have a bleeding disorder: Perry Parker, professional golfer; Seth Rojhani, accomplished paraplegic athlete and L.A. Aguayo, men's physique bodybuilder.

Additionally, breakout sessions were available covering topics such as *Advocacy*, *vWD*, *Teen Break*, *Nutrition*, and a *Spanish Program*. The overall message was strong and clear…you can do anything you set your mind to, with or without a bleeding disorder!

Cindy Picos, Sid Ramirez and Sean Hubbert

NEW JERSEY

Richard Vogel

On a rainy spring night May 25th, Jersey community members came out in full force to Pines Manor in Edison for Hemophilia Association of New Jersey's ***Annual Meeting*** to hear keynote speaker, Katherine High, MD. Her topic, *Gene Therapy*, is one she has been working on for 30 years. She is the co-founder, president and chief scientific officer of Spark Therapeutics. She shared some data and explained about various vectors being used in gene therapy. They test for antibodies to the vector to make sure the patient will not develop an inhibitor. That's why there are various vectors being developed in the world of gene therapy.

This year, exhibitors shared the ballroom where the meeting took place. During a delicious buffet dinner and coffee/dessert breaks, members gathered information from the industry sponsors.

James Romano, *Congressman Dean Gallo Award*

Dr. Katherine High and Diane Horbacz

A big part of the HANJ annual meeting is the award ceremony. Among the awards given is the *Congressman Dean Gallo Award* for distinguished legislative leadership. This year's award went to our good friend James Romano, Legislative Director for PSI. James has worked hard for the bleeding disorders community since 1995 when, at 19 years-old, he worked on Ricky Ray legislation.

The evening ended with scholarships to individuals who are the future of our community. Between new therapies and our young people, I feel confident we are in good hands.

Scholarship winner Ben with Rich and Diane

Scholarship winner Issaiah

UPCOMING EVENTS

JULY 7-9, 2017 CALIFORNIA
Hemophilia Found.of Northern CA
510-658-3324
hemofoundation.org
Amazing Race
Puma Point Anthony Chabot Regional Park; Castro Valley

JULY 14-16, 2017 CALIFORNIA
Central CA Hemophilia Foundation
916-456-7890, cchfsac.org
Family Camp
California Maritime Academy; Vallejo

JULY 14-16, 2017 GEORGIA
United Hemophilia Foundation
844-We-Bleed,
www.unitedhemophilia.org
Inaugural Family Education Day & Launch Gala
Hilton Garden Inn; Albany

JULY 14-16, 2017 OHIO
Central Ohio Chapter of NHF
614-902-3965, nhfcentralohio.org
COC Education Retreat
Cherry Valley Lodge; Newark

JULY 14-16, 2017 WEST VIRGINIA
West Virginia Chapter of NHF
681-212-9255, wvnhf.org
Family Camp
Ace Adventure Camp; Oak Hill

JULY 15, 2017 NEVADA
Nevada Chapter NFH
702-564-4368, hfnv.org
Couples Retreat
Hilton Garden Inn; Henderson

JULY 21-23, 2017 NEVADA
Nevada Chapter NFH
702-564-4368, hfnv.org
Northern Nevada Family Education Weekend
Elko Convention Center; Elko

JULY 22-29, 2017 CALIFORNIA
Hemophilia Council of California
916-572-7711
hemophiliaca.org
California Coastline Ride
San Francisco to San Diego

JULY 24, 2017 OHIO
Central Ohio Chapter of NHF
614-902-3965. nhfcentralohio.org
Red Tie Challenge Golf Scramble
Delaware Golf Club; Delaware

AUGUST 3-6, 2017 FLORIDA
Florida Hemophilia Association
888-880-8330, floridahemophilia.org
34th Annual Family Education Symposium
Embassy Suites by Hilton, WPB Central; West Palm Beach

AUGUST 4-5, 2017 OHIO
FAMOHIO, famohio.org
Family Annual Meeting State of Ohio "Hit it out of the park!"
Columbus Marriott Northwest; Dublin

AUGUST 4-6, 2017 TEXAS
Lone Star Chapter of the NHF
713-686-6100
lonestarhemophilia.org
Texas Central Hemophilia Foundation
972-386-3865, texcen.org
TX Bleeding Disorders Conference
Woodlands Waterway Marriott; The Woodlands

AUGUST 5, 2017 NEVADA
Nevada Chapter NFH
702-564-4368, hfnv.org
Back to School Picnic
Heinrich YMCA; Las Vegas

AUGUST 5, 2017 TENNESSEE
TN Hemophilia & Bleeding Disorder Foundation
888-703-3269, thbdf.org
Pitchin' for Caleb Cornhole Tournament
Centennial Park; Crossville

AUGUST 5-6, 2017 CALIFORNIA
Central CA Hemophilia Foundation
916-456-7890, cchfsac.org
Family Education Weekend
5th - ***Education Day***
Sacramento Hilton
6th - ***Education Fun Day***
Six Flags Discovery Kingdom; Vallejo

AUGUST 12, 2017 FLORIDA
Hemophilia Found. of Greater Florida
800-293-6527
hemophiliaflorida.org
Annual Family Educational Event
Adventure Island; Tampa

AUGUST 12, 2017 MARYLAND
Hemophilia Foundation of Maryland
410-661-2307, hfmonline.org
Sleeping with the Fish
National Aquarium; Baltimore

AUGUST 13, 2017 VIRGINIA
Hemophilia Association of the Capital Area
703-352-7641, hacacares.org
Family Picnic/Walk Kickoff
Algonkian Regional Park; Sterling

AUGUST 13-14, 2017 CALIFORNIA
Hemophilia Found. of Northern CA
510-658-3324, hemofoundation.org
Vines, Hops & Golf Event
13th - Fairmont Sonoma Mission Inn
14th - Sonoma Golf Club;
Sonoma

AUGUST 19, 2017 KENTUCKY
Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
Summer Family Event/Annual Education Meeting
Hyatt Regency; Louisville

AUG. 19, 2017 NORTH CAROLINA
Hemophilia of North Carolina
800-990-5557, hemophilia-nc.org
Family Day Out
Tanglewood Park; Clemmons

SEPT. 7, 2017 NEW MEXICO
Sangre De Oro, Inc.
505-341-9321, sangredeoro.org
Breaking Blood Men's Group
Main Event; Albuquerque

SEPT. 9, 2017 CALIFORNIA
Central CA Hemophilia Foundation
916-456-7890, cchfsac.org
Family Fit & Fun Day
Sac State Aquatic Center/Lake Natoma State Park; Sacramento

NATIONAL EVENT!

AUGUST 24-26, 2017 ILLINOIS
National Hemophilia Foundation
212-328-3700, hemophilia.org
69th Annual Meeting
"EXPLORING THE NEW FRONTIER"
Hyatt Regency; Chicago

SEPT. 9, 2017 NEW JERSEY
Hemophilia Assoc. of New Jersey
732-249-6000, hanj.org
24th Annual Kelly Brothers Scholarship Picnic
Friendly Sons of Shillelagh; Old Bridge

SEPT. 9, 2017 OHIO
Northern Ohio Hemophilia Found.
216-834-0051, nohf.org
NOHF Walk & Superhero Run
Akron Zoo; Akron

SEPT. 10, 2017 NEW YORK
New York City Hemophilia Chapter
212-382-2974, nyhemophilia.org
Back to School Day
New York Marriott Downtown; New York City

SEPT. 12, 2017 PENNSYLVANIA
Eastern Pennsylvania Chapter NHF
484-445-4282
hemophiliasupport.org
Golf Classic
Rivercrest Golf Club; Phoenixville

SEPT. 15-17, 2017 CALIFORNIA
Hemophilia Found. of Southern CA
626 765-6656, www.hemosocal.org
Familia De Sangre
Anaheim Marriott; Anaheim

SEPT. 16, 2017 CALIFORNIA
Hemophilia Alliance Orange County
714-699-9567, www.haoc.org
Shaka Surf Fest & Beach Day
North of the Pier, Huntington Beach

SEPT. 16, 2017 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Hemophilia Walk
Lincoln Park; Chicago

SEPT. 16, 2017 MAINE
Hemophilia Alliance of Maine
207-631-7550, mainehemophilia.org
Hike 4 HAM
Mount Battie; Camden

SEPT. 16, 2017 NEVADA
Nevada Chapter NHF
702-564-4368, hfnv.org
NHF Walk Reno
Bartley Rancho Park; Reno

SEPT. 16-17, 2017 MISSOURI
Midwest Hemophilia Association
816-479-5900
www.midwesthemophilia.org
24th Annual Family Fun Fair and MHA NHF Hemophilia Walk
Hilton Garden Inn; Independence

SEPT. 17, 2017 OHIO
Central Ohio Chapter of NHF
614-902-3965, nhfcentralohio.org
Hemophilia Walk and Run
Westerville Pavilion; Westerville

SEPT. 18, 2017 NEW JERSEY
Hemophilia Assoc. of New Jersey
732-249-6000, hanj.org
Gourmet Dinner
Il Tulipano; Cedar Grove

SEPT. 22-24, 2017 S. CAROLINA
Hemophilia of South Carolina
864-350-9941, hemophiliasc.org
"Keeping it Coastal" Family Educational Camp
Ocean Creek Resort; Myrtle Beach

SEPT. 23, 2017 NEVADA
Nevada Chapter NHF
702-564-4368, hfnv.org
Hemophilia Walk & 5K
Floyd Lamb Park; Las Vegas

SEPT. 23-24, 2017 VIRGINIA
Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Family Retreat Weekend
Great Wolf Lodge; Williamsburg

SEPT. 24, 2017 DELAWARE
Brandywine Valley Hemophilia Foundation, 610-883-7337, brandywinehemophilia.org
Family Picnic, Lums Pond State Park Pavilion 2; Bear

OCT. 7, 2017 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
An Afternoon of Klairmont Kollections
Klairmont Kollections; Chicago

OCT. 7, 2017 PENNSYLVANIA
Eastern Pennsylvania Chapter NHF
484-445-4282
hemophiliasupport.org
Trick or Treat Trot 5K Run/Walk
Pfizer Campus; Collegeville

OCT. 14, 2017 IDAHO
Idaho NHF Chapter
208-344-4476, idahoblood.org
Hemophilia Walk
Kleiner Park; Meridian

OCT. 14, 2017 KENTUCKY
Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
NHF Annual Walk
Wetherby Park; Middletown

OCT. 14, 2017 NEW JERSEY
Hemophilia Assoc. of New Jersey
732-249-6000, hanj.org
Casino Night
Pines Manor; Edison

OCT. 14, 2017 NORTH CAROLINA
Hemophilia of North Carolina
800-990-5557, hemophilia-nc.org
Family Festival & 5K Walk for Bleeding Disorders
Lake Crabtree County Park; Morrisville

ANSWERS TO PUZZLES ON PAGE 50.

"ALWAYS USE RICE FOR BLEEDING JOINTS."

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

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

TIME FOR FUN!

HI KIDS!

Unscramble the tiles to reveal an important message.
Then try to solve the Soduko puzzles!
Answers are on page 49.

ALWA	NTS.	FOR
SE R	ICE	DING
JOI	YS U	BLEE

_____ ___ _____ ___ _____ _____.

Rest	Resting can help protect, repair and reduce pain in an injured joint. Stop any activity that causes more pain.
Ice	Icing the injured joint can reduce swelling and pain. Don't apply ice directly to your skin! Place a towel between your skin and the icepack.
Compression	Properly wrapping your joint with an elastic wrap can help reduce swelling. Don't wrap too tight!
Elevation	Elevating the bleeding joint can help reduce swelling. Try to keep the injured joint at or above the level of your heart.

When you have a joint bleed, use R.I.C.E. as soon as possible to help control the bleeding, swelling and pain. Using R.I.C.E. will help keep your joint flexible and promote healing.

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

SuDoku!

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

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

A MOMENT IN YOUR SPECTACULAR LIFE 2018 CALENDAR!

Our 2018 calendar will highlight just how amazing life can be, even with a bleeding disorder! Share with us your wonderful, happy photos of living life with a bleeding disorder! Only first names will be listed with the photos in the calendar. Please send your photo and completed, signed Media Release form either by post or email. A fill-able release form is also available on our website: www.matrixhealthgroup.com

Please submit photos by: September 1, 2017
We are unable to return your photos. Please do not send your originals!

Email form and photo to: maria.vetter@matrixhealthgroup.com

Or by post: Matrix Health Group 2018 Calendar
3300 Corporate Avenue, Suite 104; Weston, FL 33331

Matrix Health Group 2018 Spectacular Life Calendar

Please include my photo(s) depicting a spectacular moment in the life of a person with a bleeding disorder in the 2018 Matrix Health Calendar!

Name _____ Printed name of person(s) in photo: Age (if a minor)

Address _____ _____ _____

_____ _____ _____

Phone _____ _____ _____

E Mail _____ _____ _____

Authorization for Media Release

I hereby authorize BioMatrix, and its representatives or agents, to use and disclose information about me or my child, including protected health information as defined by federal and state law, for use in publications and to the general public or media. The information may include my or my child's name, age, treatment, duration of treatment, treatment plan, diagnoses, medication, city and state of residence, photographic images, video, audio, identifying information, and other information about my or my child's life and experience as a patient of BioMatrix. The information may also be disclosed to external media and may be disclosed in the following, but not limited to, forms: press releases, stories, photographs or video clips. It may also be used for publications produced by or on behalf of BioMatrix, including but not limited to advertising, promotional and marketing materials ("Materials"). Such Materials may include sales and educational brochures, display boards, sales campaigns, promotional items, company newsletters, social media, and websites. I authorize BioMatrix to use, reuse, copy, publish, display, exhibit, reproduce, license to third parties, and distribute the materials in any educational or promotional materials or other forms of media, which may include, but are not limited to articles, magazines, advertisements, recruiting brochures, websites or publications, electronic or otherwise, without notifying me. I understand that I will not be compensated in any way for the taking or use of my or my child's information, photographs, films, audio, and/or video. I understand that BioMatrix will not condition treatment on my provision of this authorization. I understand that any information used or disclosed pursuant to this authorization is no longer protected by federal or state law and may be re-disclosed.

Waiver and Release from Liability

In consideration of the parties' mutual promises, the sufficiency of which is hereby acknowledged, I waive any and all claims that I, my heirs and assigns may have, now or in the future, against BioMatrix, its affiliates, employees, agents or assigns and release BioMatrix from any and all liability from damages, arising from or relating to BioMatrix's use and disclosure of my protected health information, identifying information, and photographs or images as described above. I understand that this authorization is voluntary, and that I may revoke the authorization at any time by presenting my written revocation to BioMatrix. To do so, I must send a written notice to the BioMatrix Privacy Officer at 3300 Corporate Avenue, Suite 104, Weston, FL 33331. I understand that such revocation will not apply to information that has already been released in response to this authorization.

X _____ _____ _____
Signature (if under age 18, parent/guardian signature required) Date Basis of representative's authority (i.e. parent, guardian)

All participants will receive a calendar mailed to the address on the release. Please provide names and addresses if you would like a calendar sent to additional locations. Participants will also be added to the Matrix Health Group News mailing list.

- I am not submitting a photo, but please send me a 2018 Matrix Health Group Calendar!
- Please check if you **do not** wish to be added to our newsletter mailing list.

Matrix Health Group

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DEDICATED TO MAKING A DIFFERENCE

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Fax: 805-482-6324

MEDEX BIOCARE

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Bartlett, TN 38133
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Office: 901-380-5899
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BiologicTx

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