

Matrix Health Group

A BIOMATRIX^{SpRx} Company

NEWS

DEDICATED
TO MAKING A
DIFFERENCE



SPRING 2018

“ If we could see the
miracle of a single flower
clearly, our whole life
would change.

~ Buddah



MISSION + VISION

The **MISSION** of Matrix Health Group is to provide individualized, focused pharmacy and support services to people with chronic conditions nationwide.

Our mission and vision are realized through the value we place in our five guiding principles. These principles represent our commitment to our employees, patients, and the community – driving our organization to excellence.

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

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

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

Our **VISION** is to enhance the lives of those we are privileged to serve.

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 healthcare professionals or hemophilia treatment center. Please consult with your health care professionals when medical questions arise.

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Welcome to our Spring issue featuring the finest selection of personal stories, advocacy, education and more!

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We remember the life of an extraordinary community member.

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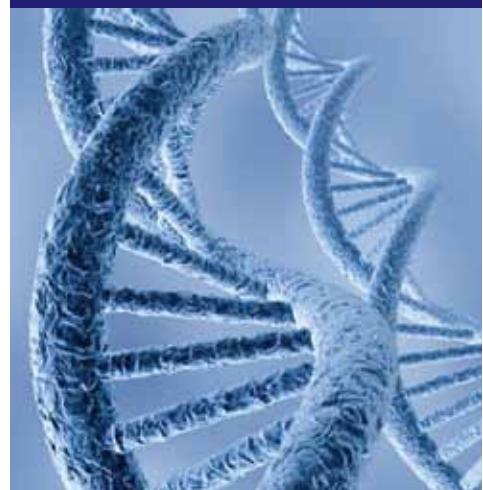
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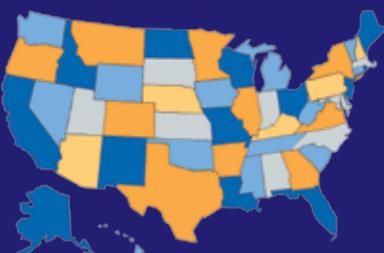
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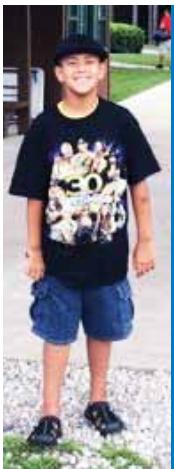
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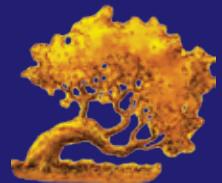
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A NOTE FROM THE EDITOR

Welcome!

We bring you our latest issue of Matrix Health Group News filled with interesting reading and great information!

First and foremost, the loss of Barry Haarde has hit us all very hard. My friendship and connection with Barry goes back many years. Losing him was especially difficult for me as I also lost my youngest brother this past year. Barry was encouraged to tell his stories and over the years, shared many of them in articles in this newsletter. We encourage all of you, whether you knew him personally or not, to read these stories and understand what a true gem we've lost.

On a happier note, spring has sprung and with it comes thoughts of warm weather, opening windows, washing vehicles, cleaning out garages,

planting gardens and preparing for the long, sunshiny days of summer.

As many of us shrug off the frigid coat of winter, our thoughts turn to the exhilarating anticipation of bleeding disorders camp! Many children (and adults too!) eagerly anticipate this special week - seeing friends, bonding with new ones, participating in crazy fun activities, learning new skills, gaining confidence, but most importantly, not feeling alone in having a bleeding disorder. Tradition continues with our list of bleeding disorder camps across our great country. As you or your children attend camp this summer, please consider sharing your experience with us for publication next spring.

We hope you enjoy this issue!

Maria Santucci Vetter, Editor-in-Chief, Matrix Health News
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Informative quarterly newsletter, MATRIX HEALTH GROUP NEWS



WE REMEMBER BARRY HAARDE

November 14, 1965 - February 17, 2018

We are saddened to share the loss of Barry Haarde, an advocate, philanthropist and well-known member of the bleeding disorders community. Barry had severe hemophilia, hepatitis C and HIV as the result of receiving contaminated blood products used to treat hemophilia in the 1980s. In the face of great adversity, he learned to persevere and channeled his energy into doing good for others. He organized a series of fundraisers in which he cycled across

the entire country, raising over \$250,000 benefiting Save One Life, an organization providing care and support to individuals with bleeding disorders in developing countries. Through his efforts, he generated awareness about bleeding disorders and co-morbidities. Many in our organization knew Barry personally. He was featured often in our quarterly newsletter, and our company was a corporate sponsor for many of his rides. He will be deeply missed.





Felix, Mona and family

AN ARTIST'S VISION AND A MAN WITH A MISSION

CHINEDU FELIX OSUCHUKWU *"I LIVE TO CREATE!"*

BY TERRY STONE

Every artist has a muse, a thought, a memory or experience that inspires them. "My students inspire me every day," said Chinedu "Felix" Osuchukwu, art teacher at Meridian Public Charter School. Each day brings a new inspiration to Felix. He is a teacher, yes, but he is so much more.

A celebrated professional artist, his paintings and sculptures are proudly displayed in private homes, galleries, government office buildings, 911 call boxes and even on shoes! A Renaissance man? I would say yes, without question. He is an artist, an activist, a severe hemophiliac and the newly appointed Washington DC Commissioner of the Arts and Humanities. He is, without a doubt, a man with a mission and a vision of a world filled with art! Don't be fooled if you think having hemophilia slows him down - it's what helps to keep him focused. Art helps heal the mind while clotting factor heals the body.

To the 600 children who enter his art room each week, he is Mr. Osuchukwu, the coolest teacher EVER! He loves teaching the arts to the tall and the small, and has been doing so for more than 20 years. "I nurture the talents of each student with a mentor

approach, which brings out their very best effort," Felix explains. He says some kids have a very hard life outside of his classroom, and others have worries, but when they cross the threshold of Mr. O's art class, they check all of that at the door! "My students love my art class," shared Felix. For some, it's the highlight of their day where they can just be free to express themselves with paint, clay, or whatever cool surprise Mr. O has ready for them.

Felix and I met many years ago at a local hemophilia event where he had volunteered to work with the kids while the members of Hemophilia Association of the Capital Area conducted their annual meeting. Felix was in his element that day. After all, he was engaging his two favorite passions, KIDS and ART! He shared with the children that he grew up in a small village in Nigeria and he explained it in vivid detail.



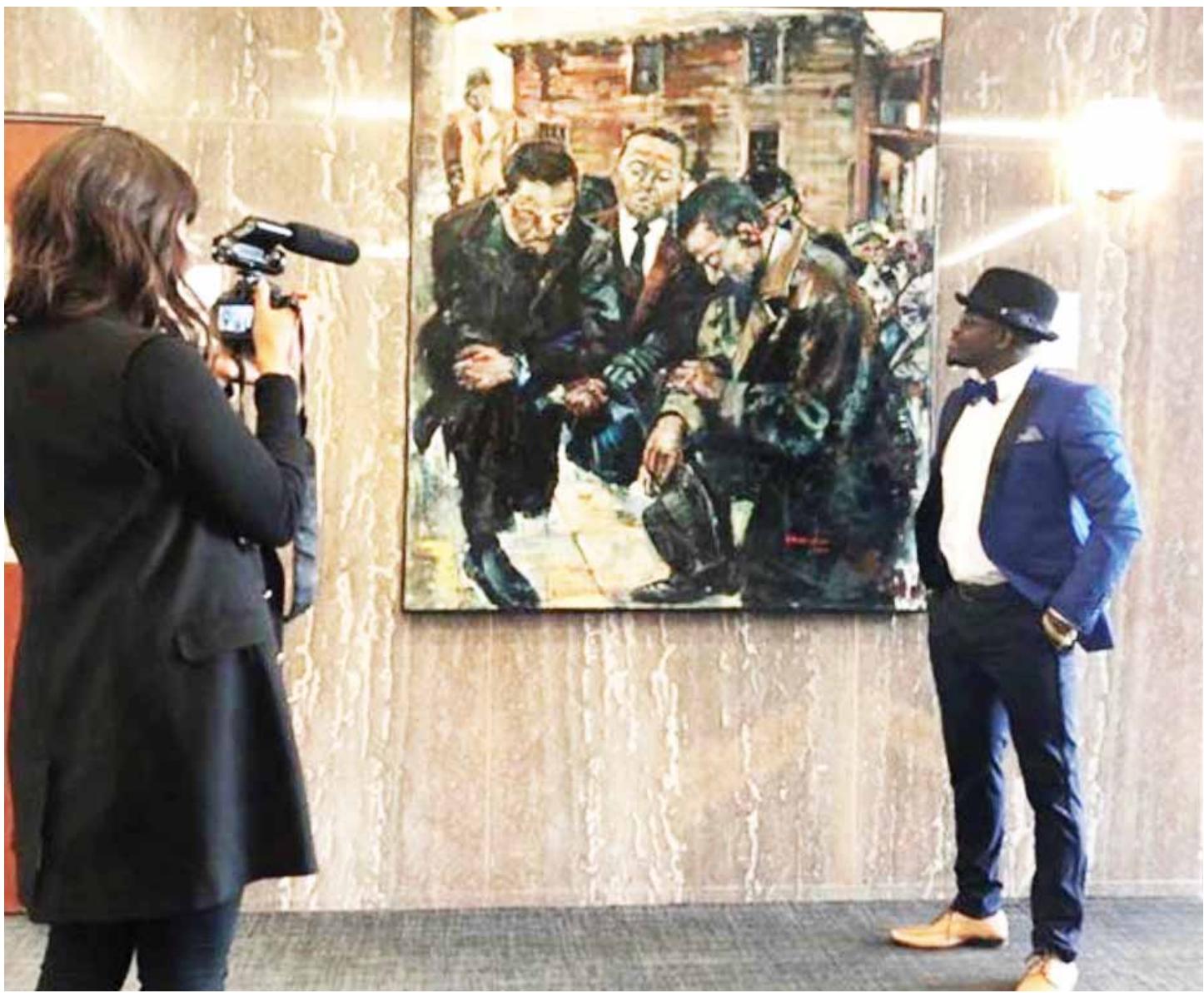
Through this door is where the magic happens.



Felix's studio at Duke Ellington's School of the Arts.



Felix with Mayor Bowser and his first lady of art, Mona.



Felix and Mona share new artwork of Treyvon Martin at Public Defenders office, DC.

Their mission was to create the village on canvas from his explanation, complete with the ever-present free-range roosters.

With his guidance, each child contributed a section and together they created a scene straight out of Felix's memory, a moment of time in his life in Nigeria, the boy who lived with hemophilia in this small community. It was beautiful, truly beautiful! The kids were so proud as they presented their masterpiece to the chapter, and I was a fan from that moment on.

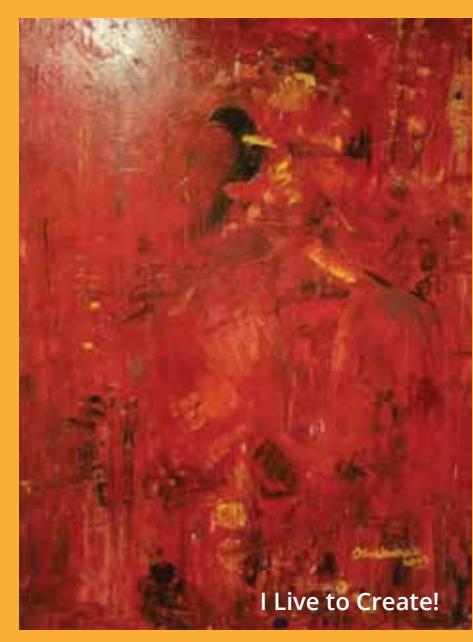
It was during his pre-teen years

in Nigeria that Felix learned the love of family, responsibility and faith. When he was 5 years old, he would create Christmas cards and deliver them to his local neighbors. They in turn would thank him by giving him candy. It wasn't easy growing up in Nigeria with hemophilia. He found that art distracted him from his pain caused by joint and muscle bleeds. Knowing that caring for his bleeding disorder would be better managed in the US, his teenage years brought him to Washington DC, where Felix attended the Duke Ellington School of the Arts. This special high school that nurtures students in the arts is where

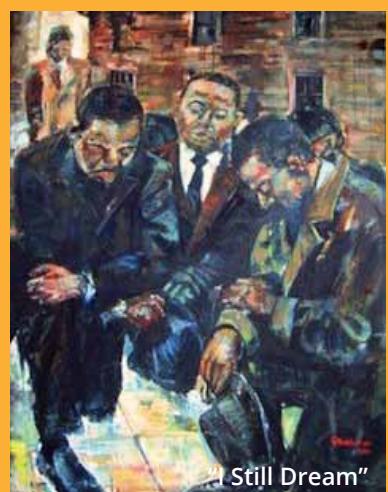
Felix thrived and where his "I Live to Create" mantra became his calling.

His studies continued at the Corcoran College of Art just a linear line away from the White House. It was here where he fine-tuned his craft and proudly holds the record for the highest number of pieces sold of any Corcoran alum to date. His work is a collection of everyday moments, and highlights those who may not have been noticed in society. He captures a narrative of the human experience. His art tells a story, invokes awareness, and encapsulates humanity all while making us pay attention to the important social issues of our time.

Felix's works can be found all around the city and beyond, just like Felix. Whether it's his painting of Trevor Martin, hanging in DC's Public Defenders office, or Felix and his family leading the parade on MLK Day with DC Mayor Muriel Bowser - that's just how he rolls. Life is good for Felix. As much as he loves art, he really loves his family and is a dedicated husband and father. Along with his wife Mona (a hardcore arts education advocate), and children (three of his greatest masterpieces), they are active in their community and are typically out enjoying time together throughout the Nation's Capital every chance they get.



Felix hanging with former first lady, Michelle Obama.



"I Still Dream"



"Redtails"



"Spiritual Freedom - Mandela"



"Facing Reality"

Living the life of a person with hemophilia has its continuing challenges at times; however, life is so full for Felix that he doesn't dwell on it. Art calms the creaky joints and the creative process soothes the muscle mayhem. Felix is active in his local hemophilia community. A natural advocate and teacher, he has submitted some of his work over the years for the Bloodworks Exhibition at annual National Hemophilia Foundation's Bleeding Disorders Conferences. What better way to express your feelings on living life as a bleeder than through your art?

The Master continues to be a student, it keeps his mind searching and his skills developing. Past summer vacations from school allowed time for Felix to take his one-man art show on the road sharing his talents with students around the world. Felix has been to several countries to teach; Jamaica, Madrid and Senegal. In the small village school of Senegal French was the spoken language, and though he speaks English, Felix used the universal language of art, and communication was never a problem!

"Every moment is a teachable moment," said Felix. Through his teaching, passion and love for the arts and humanities, Felix shows us by example that if you simply find something that feeds your soul, fuels your inspiration and keeps you looking forward, the world is yours for the taking. Oh, and hemophilia? It's what you have, not who you are.

Paul R. Brayshaw, M.P.H.

Director of
Healthcare Advocacy and Programs



THE HEALTH ADVOCATE

LONG TERM CARE PLANNING – START WHILE YOU ARE YOUNG!

Having endured and survived the challenges of a chronic condition for 44 years, I often wonder when I may achieve some respite from the constant worry associated with hemophilia. Although I am gainfully employed, have solid retirement savings, own a mortgage on a house and have education funds established for two children, planning for the future has been a work in progress for more than 20 years. Even with these milestones established, I continue to dwell on new and emerging threats to this semblance of stability.

In another 23 years, if all goes as planned, I will be able to qualify for Medicare, purchase supplemental Medigap health coverage and rely on retirement savings to provide adequate living expenses. The thought of aging gracefully toward this future is precarious due to unknown costs associated with my future well-being.

While I may have the good fortune of relying on my family or friends to provide some assistance, with qualifying conditions Medicare may cover some costs of acute medical care, as well as some of the costs associated with skilled nursing facilities (SNF), and home health benefits, usually associated

with a hospital stay or outpatient procedure. Because payment for these services is part of a larger bundling, access to clotting factor may be restricted in these settings.

Medicaid may be an alternative, but eligibility generally depends on limited income and assets, age 65 or older, having a permanent disability as defined by the Social Security Administration, blindness, being a pregnant woman, and/or a child, parent or caretaker of a child.

After age 65, early 50% of US adults will need a nursing home or other type of assistive care.¹ Given those facts and aside from hemophilia, my golden years will most likely require long-term care (LTC) services. According to AARP, the phrase “long-term care” refers to the help people with chronic illnesses, disabilities or other conditions need on a daily basis over an extended period of time.

The type of care needed can range from assistance with simple activities, such as bathing, dressing and eating, to skilled care provided by nurses, therapists or other professionals. Without assistance from family or friends, I may also need help with other types of support including housework,

managing money, taking medication, preparing and cleaning up meals, shopping for groceries or clothes, using a telephone or communication device, caring for a pet, and/or responding to emergency alerts like a fire alarm.

The cost of LTC services vary greatly based on age at time of purchase, type of policy, and coverage level selected. Most people will use a variety of options to ensure adequate coverage, including long term care insurance, personal income and savings, life insurance, annuities, and reverse mortgages to help pay for the care required.

In many ways, just beginning to think about these scenarios has helped me gain some confidence to deal with my future health care needs. In the next 20 years, many things will impact my planning; beginning to prepare now will provide some assurance to me and my family our lives will not be drastically impacted by unforeseen medical costs related to hemophilia, aging, or both.

1. “Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief.” ASPE, 27 Mar. 2017, aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief.

SPOTLIGHT ON RESEARCH

BY DIANE HORBACZ
BIOMATRIX RESEARCH AND EDUCATION DEVELOPMENT SPECIALIST

GENE THERAPY BECOMES REALITY

The promise of a cure for hemophilia through gene therapy has been anticipated since the early 1990s and was based upon scientific breakthroughs in the field, highlighted by the curing of a four-year-old girl with a rare and fatal genetic autoimmune disease in 1990. In fact in 1994, the World Health Organization predicted that a cure for hemophilia, using gene therapy, would be found by the year 2000. Unfortunately, the tragic death of an 18-year-old in 1999 overshadowed successful treatments of gene therapy, halting trials and dashing the hopes for a near-term cure.

Challenges related to immune responses also emerged as a significant obstacle to gene therapy. However, these previous setbacks led to significant research and development focused on more efficient and safer gene therapy delivery mechanisms.

Nearly 25 years later, it appears we may have reached a watershed moment for gene therapy and its promise of a cure. We are again seeing headlines suggesting we are on the cusp of success – “children born with this devastating disease could benefit from a life without bleeding.”¹ But are these headlines simply more hype or is there reason for hope?

Parents and patients that believed in the promise of a cure in the 1990s rightly remain skeptical. However, the magnitude of the current gene therapy studies, the stunning success of early trials that has led to three FDA approvals, and the financial backing of major corporations in a race to a cure, all point to a far more hopeful future for those living with hemophilia.

Perhaps this time, it's different.

According to the Alliance for Regenerative Medicine, there are currently 946 clinical trials underway on gene and cellular therapies worldwide as of January 2018. Over half of these trials are already in phase II (testing for efficacy and side effects) and nearly 10% are in phase III (new treatment has worked in phase 2 and now comparing new treatment to the standard treatment).

The breadth of indications (ailments) covered by these trials has grown significantly and highlights the opportunity of gene and cell therapy to address a broad array of diseases that reaches beyond well-understood genetic mutations (e.g., hemophilia). Hematology is only one of eighteen areas of study and currently accounts for 22 separate trials.

SIGNIFICANT FINANCIAL BACKING OF GENE AND CELL THERAPY RESEARCH AND DEVELOPMENT

4.5 billion dollars in funding was raised across the globe in 2017 to promote research and development in the gene and cell therapy fields. With the promise of a near term cure, corporations are investing heavily in a race to the “finish line” with the goal of producing a mass-market drug that can improve the lives of those suffering from a difficult to treat disease while earning a high rate of return to its investors.

As an example of the potential

THREE FDA GENE THERAPY APPROVALS IN 2017

FIRST GENE THERAPY APPROVED IN U.S.

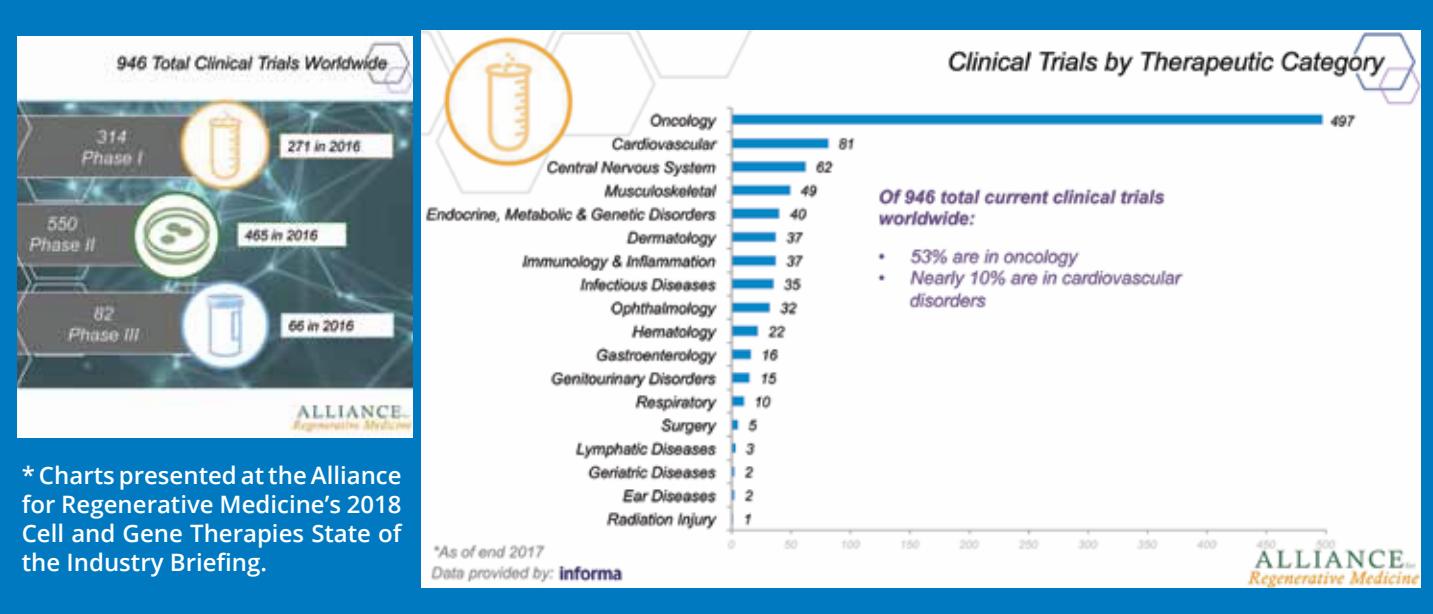
August 30, 2017 – Novartis' Kymriah, a cell-based gene therapy, for the treatment of children and young adults with acute lymphoblastic leukemia (ALL).

SECOND GENE THERAPY APPROVED IN U.S.

October 18, 2017 – Gilead/Kite Pharma's Yescarta, a cell-based gene therapy to treat adult patients with certain types of large B-cell lymphoma.

FIRST DIRECTLY ADMINISTERED GENE THERAPY FOR AN INHERITED DISEASE APPROVED IN U.S.

December 19, 2017 – Spark Therapeutics' Luxturna, a gene therapy to treat children and adults with an inherited retinal disease that may result in blindness.



financial benefits to pioneers in the field, in December 2017, the FDA approved a gene therapy (LUXTURNA) from Sparks Therapeutics involving blindness caused by inherited retinal diseases. Spark recently announced that this life-changing treatment is expected to cost \$425,000 per eye, or \$850,000 to treat both eyes. Many expect this pricing to be an indication of future costs of gene therapy in hemophilia.

During the Alliance for Regenerative Medicine's 2018 Cell and Gene Therapies State of the Industry Briefing on January 8th, President and CEO of Adverum Biotechnologies cautioned, "When referring to anticipated costs of future gene therapies, we need to be careful not to paint them with the same brush."

The pricing of gene therapy for one disease should not be compared to a gene therapy treatment for a completely different disease.

According to President and CEO of Sangamo Therapeutics, "We need to look at pricing in a holistic way, considering standards of care and overall treatment costs." Also called to attention during this industry briefing was the need to talk about the value of these therapies as it changes the fate of these individuals.

CONCLUSION

The pace at which science is advancing in the fields of gene and cell therapy is astounding and the early results are promising. While there are many reasons to hope for an even brighter future for those living with hemophilia, we need to be realistic in our expectations (a "healthy dose of skepticism" is probably warranted). Even if the trials continue to produce positive results and are followed by FDA approvals, there are several potential issues that must be resolved before any "cure" can reach the mass market. These issues include long-term safety and efficacy, pricing, insurance coverage, patient suitability to the therapy and the potential for patient-specific responses that are less than optimal.

While eliminating hemophilia is still a hazy notion for many, approvals in gene therapy and positive results from clinical trials is generating optimism. According to FDA Commissioner, Scott Gottlieb, M.D., "I believe gene therapy will become a mainstay in treating, and maybe curing many of our most devastating and intractable diseases."²

Over the longer term, a cure seems inevitable given the number of brilliant minds focused on the technology coupled with billions of dollars of financial support and stunning success in trials. And that should give us reason for hope.

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2 US Food and Drug Administration, FDA approves novel gene therapy to treat patients with a rare form of inherited vision loss, FDA New Release, December 16, 2017 <https://www.fda.gov/newsevents/newsroom/pressannouncements/ucm589467.htm>

ADVOCACY TEAM

THE EYE ON US: THE RISING COST OF FACTOR

BY SHELBY SMOAK, Ph.D., ADVOCATE|EDUCATION SPECIALIST

Every day, we hear about rising drug prices, which according to CMS (Centers for Medicare and Medicaid), topped \$328 billion in 2016. Recent data has shown these costs are generated by the chronically ill who, on average, cost 5 times more than healthy patientsⁱⁱ and are responsible for 86% of the total price of healthcareⁱⁱⁱ.

While hemophilia has always been marked as an expensive, life-long disease, it now ranks as the 8th most expensive specialty illness according to data from United Health Group^{iv}, and the majority of this cost (86%) is for plasma products^v, which totaled over \$13.8 billion in 2016^{vi}. That same year, fractionators processed over 36 million liters of plasma for use in medications^{vii}. It is not surprising then that insurers, who pay these costs, turn their eye toward hemophilia. As the gaze shifts, it seems vital to have an understanding of the “factors” which contribute to hemophilia’s rising therapy price-tag.

I’ve broken these down into the following four categories:

INCREASED UTILIZATION:

While the value of gaining prophylactic coverage to reduce injury and bleeds cannot be over championed, the economist’s picture tells a different story; as more prophylactic therapies are prescribed instead of on-demand treatment, the annual treatment price rises. For example, hemophilia A patients in 2007 averaged 156 days of factor usage within a year at an average cost of \$155,239. By 2012 with an increased prophylactically-treating population, those same patients averaged 251 days of factor usage at a cost of \$206,027—a cost increase of \$50,788^{viii}.

Another study published in January 2017 estimates the annual cost difference between on-demand versus prophylactic therapy using a recombinant product at \$189,308 more^{ix}. That difference, as more patients shift to prophylaxis, catches the payors eye as more funds are pulled from their bottom line.

INHIBITORS:

The stark rise in inhibitor diagnoses also casts the gaze upon hemophilia. One insurer in 2017 went so far as to claim a million-dollar-a-month inhibitor patient as reason for the company’s decision to stop selling policies within the state’s market exchange^x. An inhibitor diagnosis guarantees 100% usage of factor products versus 74% for non-inhibitor patients. Moreover, the average inhibitor cost rises to \$697,000 annually per patient^{xi}. According to HFA, adding to this cost is the approximately 30% of severe hemophilia A and 2-3% of hemophilia B patients who will face inhibitors^{xii}. Therefore, about 1/3 of hemophilia patients will cost much, much more than the average user.

A CROWDED MARKET:

As more factor products become available, the legacy pharmaceutical industry loses market shares, and new ones seek to gain a share. While within a standard capitalistic system increased competition serves to drive cost down, that is not the case with the pharmacy industry, and there are a few reasons why. For one, this is not a pure capital market; the drug industry is very expensive and difficult to enter. According to PhRMA—the drug industry lobbying group—it takes 10 years to successfully bring a drug to market at an estimated cost of \$2.6 billion; furthermore, only about 12% of drugs make it to the market^{xiii}. Thus, the investment and possible losses for a drug manufacturer are quite large. For another, once a stake in the market is gained, companies must regain their investments and look to ongoing and future drug development—ergo drug prices rise.

Adding to this is the increasingly competitive factor market. Today, there are more competitors within the market than ever before, each vying for what has, and will be a rather flat consumer market of 20,000 hemophiliacs^{xiv}. In other words, unlike the iPhone, whose customer base is widespread and can endlessly grow their product business to increase earnings, the number of possible consumers for hemophilia products is restricted.



In 2012 for example, there were 8 major competitors and 18 products in the plasma protein market^{xv}; now there are 14 with 48 available products^{xvi}. In 2012, then, if sales were shared equitable between competitors (which it is not), each competitor could expect 12.5% of the market, but today, that same competitor could only realistically expect to see a little over half of that amount (7.5%). An expectation of this scenario is that a particular company's hold on market share will decline, and to offset that decline in volume, a raise in price becomes an option.

PREDICTIVE VERSUS REAL-WORLD USAGE:

Often the predicted utilization of a factor product strays from the analyst's mark. Many times this is a result of biology and metabolism, for, as a biological product, factor's metabolism within the body can vary wildly from patient to patient. Consequently, a patient's factor usage may fall outside the average, usually requiring higher utilization and then higher cost.

To use myself as an example, the package insert for my drug indicates a dosing amount of 2220 IU per infusion based on my weight, which would tabulate to an annual cost of \$511,488 for prophy therapy. The reality is much different. A PK study was used to chart my half-life and revealed a very high metabolism of the drug within my body. This

resulted in a dosing increase to 7000 IU per infusion at an annual cost of \$1,612,800; more than a million dollar cost difference that was likely impossible for any economist to predict. In other situations, a patient's activities may lead to periods of increased dosing frequency, which again raises utilization and cost, and which again, shows up on the payor's bottom line.

Ultimately, these factors help explain hemophilia's increased scrutiny by the insurance industry. As costs rise, hemophilia may gain more of the spotlight and conversations about cost, utilization, and outcomes may become more commonplace. How then do we talk about the cost of a medication that keeps us alive and healthy? How will this impact access to therapies as insurers become more involved in care management?

For now, these cannot be answered, but being informed and aware of the status of hemophilia within the healthcare industry is a start. And being a good advocate always involves keeping abreast of industry changes and understanding why they are happening. So pause for a moment. Consider the view from the insurer's eye. Tabulate your factor cost as I have, and think: what does it mean? How can I argue for continued access to successful therapies? Or said another way—how can I not?

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2018 BLEEDING DISORDER CAMPS ACROSS THE NATION!

For 10 years straight, we continue our tradition of bringing you an extensive directory of national bleeding disorders summer camps! While most camps are for children between 7 and 14 years old, there are many that also include a junior counselor leadership program. Additionally, many weekend camps are open to the entire family!

Summertime is quickly approaching, so it's time to develop your camp game plan. Use this list to identify a camp in your area and don't miss out on the fun! We try to include every camp across the nation, but there is the possibility we may have missed one or two. Please let us know of any camp that should be included and we'll be sure to add it next year. If you are having trouble finding a camp in your area, check with your local chapter, hemophilia treatment center or a Matrix Health Group Regional Care Coordinator and we will help you locate a camp!

1. Alabama Camp Clot Not

June 16-21, 2018 Ages: 6-18

Open to: Boys & Girls with a bleeding disorder, Carriers

Location: Children's Harbor Mariner's Adventure Camp; Alexander City, AL
Contact: Amanda Jennings, Consumer Relations Manager, 334-478-7822 amandajennings525@gmail.com Hemophilia & Bleeding Disorders of Alabama, Inc., www.hbda.us



1. Alabama Camp Harvest Family Camp

October 26-28, 2018

Location: Children's Harbor – Harbor Lodge; Alexander City, AL

Contact: Amanda Jennings, Consumer Relations Manager, 334-478-7822 amandajennings525@gmail.com Hemophilia & Bleeding Disorders of Alabama, Inc., www.hbda.us



2. Alaska Camp Frozen Chosen

June 12-16, 2018 Ages: 7-18

Open to: Boys & Girls with a bleeding disorder and their siblings

Location: Wasilla, AK
Contact: John Palmatier, ED 907-212-6711 or 907-343-9232 Michelle Palmatier, Camp Director 907-229-6017 Alaska Hemophilia Association and Bleeding Disorder Center of Alaska alaskahemo@gmail.com



3. Arizona Camp HUG

October 5-7, 2018 Ages: All ages

Open to: AZ families with a parent or child with a bleeding disorder

Location: Prescott Pines; Prescott, AZ
Contact: Chelsea Guffy, Camp Director 602-955-3947 chelsea@arizonahemophilia.org Arizona Hemophilia Association www.arizonahemophilia.org



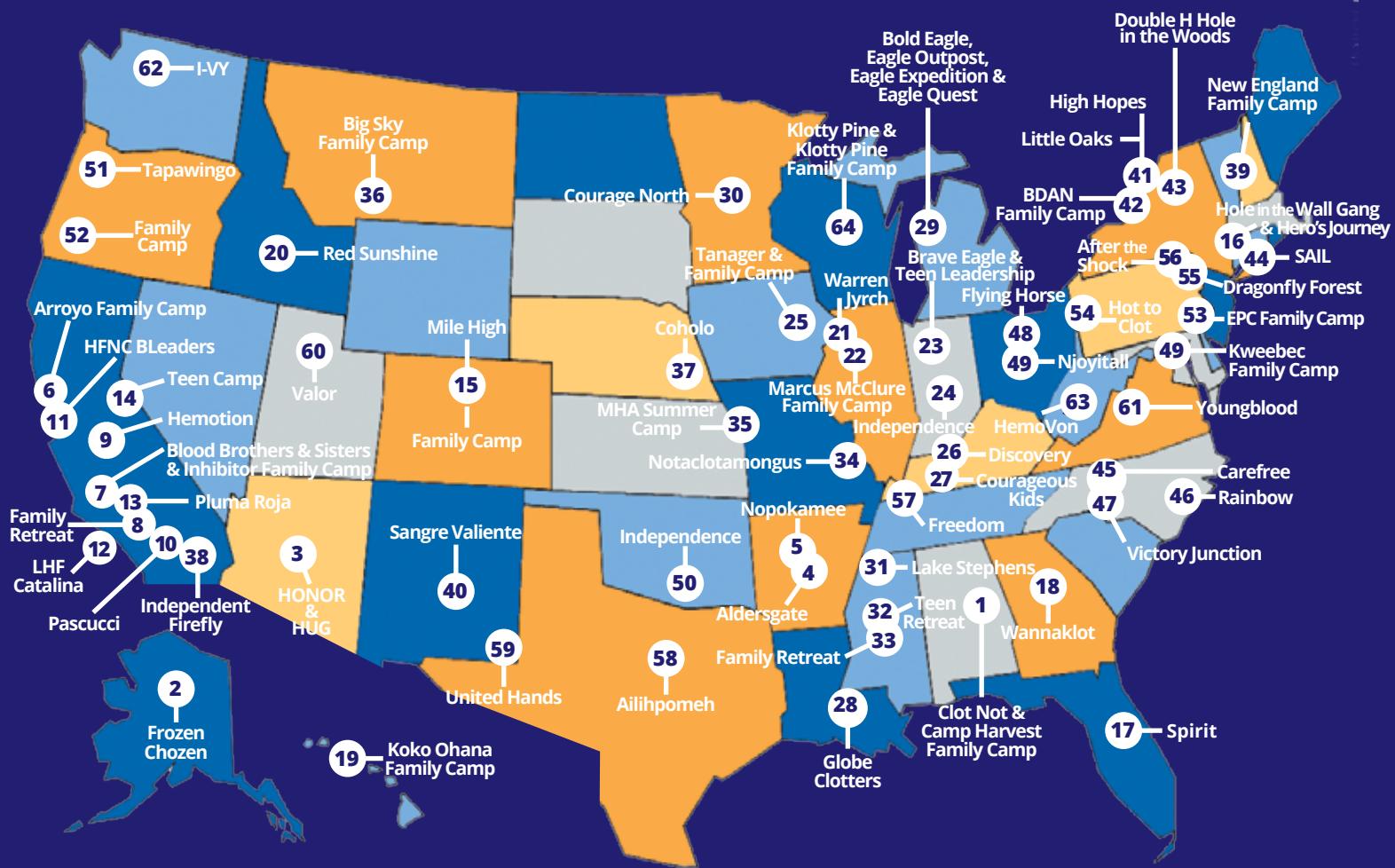
4. Arkansas Camp Aldersgate

July 29 – Aug. 3, 2018 Ages: 6-16

Open to: Boys & Girls with a bleeding disorder, Carriers, Siblings

Location: Little Rock, AR
Contact: Kara Burge, 501-364-6662 burgekb@archidren.org Arkansas Center for Bleeding Disorders





5. Arkansas Camp Nopokamee

July 22-26, 2018 Ages: 8-18

Open to: Boys & Girls with a bleeding disorder, Carriers, Siblings, space permitting

Location: C.A. Vines Arkansas 4H Center

Little Rock, AR

Contact: Co-Directors, Angela Dickens 479-414-015, angela.dickens@cvshealth.com or Laura Barnhart, 501-428-5754 toliveasruth@yahoo.com

Hemophilia Foundation of Arkansas

arkhemofoundation.org



6. California Camp Arroyo Family Camp

January 18-20, 2019 Ages: All ages

Open to: All family members affected by a bleeding disorder

Location: Camp Arroyo; Livermore, CA

Contact: Patrick Dunlap, ED, 510-658-3324

patrick.dunlap@hemofoundation.org

Hemophilia Foundation of Northern California, www.hemofoundation.org



7. California Camp Blood Brothers and Sisters

July 18-22, 2018 Ages: 7-16

Open to: Boys & Girls with a bleeding disorder
Leader in Training, Ages: 17-18

August 3-7, 2018 Sibling Camp Ages: 7-16

Open to: Siblings of boys and girls with a bleeding disorder

Location: The Painted Turtle Camp

Lake Hughes, CA

Contact: Michelle Kim Esq., ED

626-765-6656

michelle@hemosocal.org

Hemophilia Found. of Southern California

www.hemosocal.org

7. California Inhibitor Family Camp

Sept. 28 - Oct. 1, 2018

Open to: Families of a child (age 6-19) managing an active or previously active inhibitor within the last 3 years

Location: The Painted Turtle

Lake Hughes, CA

Contact: CHES, 781-878-8561

info@ches.education

www.ches.education



8. California Hemophilia Found. of Southern CA Family Retreat

June 1-3, 2018

Open to: Anyone with a bleeding disorder and their immediate family

Location: Pali Mountain Retreat

Running Springs, CA

Contact: Michelle Kim Esq., ED

626-765-6656

michelle@hemosocal.org

Hemophilia Found. of Southern California

www.hemosocal.org

9. California Camp Hemotion 40th Anniversary!

June 17-23, 2018 Ages: 7-14

Open to: Boys & Girls with a bleeding disorder, Siblings
Jr. & Assist. Counselors Ages: 15-20

Location: Coarsegold, CA

Contact: Patrick Dunlap, ED

510-658-3324

patrick.dunlap@hemofoundation.org

Hemophilia Found. of Northern California

www.hemofoundation.org





10. California Camp Pascucci

August 12-17, 2018 Ages: 7-14
Jr. Counselors Ages: 16-17
Counselors/General Staff Ages: 18+
Open to: Boys & Girls with a bleeding disorder (priority given), Siblings, Carriers
Location: YMCA Camp Whittle; FawnSkin, CA
Contact: Nooshin Kosar, ED
619-325-3570, info@hasdc.org
Hemophilia Assoc. of San Diego County
www.hasdc.org



11. California HFNC BLEaders Annual Retreat

July 13-15, 2018 Ages: 13-18
Open to: Boys & Girls with a bleeding disorder, Siblings
Location: Bay Area, CA
Contact: Patrick Dunlap, ED, 510-658-3324
patrick.dunlap@hemofoundation.org
Hemophilia Foundation of Northern CA
www.hemofoundation.org



12. California LHF Catalina Camp

April 20-22, 2018
Open to: Latino bleeding disorders families
Location: Campus by the Sea; Avalon, CA
Contact: Jorge Catedral 626-427-2735
jacatedral@gmail.com, www.hemolatino.org



13. California LHF Camp Pluma Roja Kids Camp

June 18-23, 2018 Ages: 7-16
Open to: Latino Boys & Girls with a bleeding disorder
Location: YMCA Camp Arbolado
Angelus Oaks, CA
Contact: Jorge Catedral, 626-427-2735
jacatedral@gmail.com
www.hemolatino.org

14. California Teen Camp

July 8-12, 2017 Ages: 14-17
General Staff Ages: 21+
Open to: Boys & Girls with a bleeding disorder (priority given), Siblings, Carriers
Location: South Fork - American River
Lotus, CA
Contact: Nooshin Kosar, ED
619-325-3570, info@hasdc.org
Hemophilia Assoc. of San Diego County
www.hasdc.org/events



15. Colorado Family Camp

June 8-10, 2018
Open to: Adults with bleeding disorders and their families; Families with a child with a bleeding disorder too young for camp, and young adults
Location: Highland Presbyterian Camp and Retreat Center; Allenspark, CO
Contact: Sean Jeffrey, Camp Director, 720-545-0755, sjeffrey@hemophilia.org
Colorado Chapter of the NHF
www.cohemo.org



15. Colorado Mile High Camp

July 15-20, 2018 Ages: 7-18
Siblings Ages: 7-18
Open to: Boys & Girls with a bleeding disorder, Siblings
Location: Rocky Mountain Village at Easter Seals; Empire, CO
Contact: Sean Jeffrey, Camp Director 720-545-0755
sjeffrey@hemophilia.org
Colorado Chapter of the NHF
www.cohemo.org



16. Connecticut The Hole in the Wall Gang Camp

General Sessions: June 15-21, June 24-30, July 13-19, July 23-29, Aug. 11-16, 2018
Ages: 7-15
Open to: Boys and Girls with bleeding disorders and other serious illnesses August 19-25, 2018 Sibling Session
Open to: Siblings of campers attending the summer program or Hero's Journey
Location: Ashford, CT
Contact: 860-429-3444 admissions@holeinthewallgang.org www.holeinthewallgang.org



a seriousfun camp
www.holeinthewallgang.org

16. Connecticut The Hole in the Wall Gang Hero's Journey Program

Adventure-based wilderness search and rescue program in the woods of CT
General Sessions: June 15-21, June 24-30, July 3-9, July 13-19, and July 23-29, 2018 **Ages:** 16-18
Open to: Adolescents with bleeding disorders and other serious illnesses
Sibling Session: August 1-7, 2018
For siblings of campers attending the summer camp program or who have attended Hero's Journey **Ages:** 16-18
Location: Ashford, CT
Contact: Greg Yeager 860-429-3444 x226 greg.yeager@holeinthewallgang.org www.holeinthewallgang.org



17. Florida Camp Spirit

July 8-13, 2018 Ages: 7-16
Open to: Boys & Girls with a bleeding disorder
Family Retreat Weekend: Sept. 21-23, 2018
Open to: Families with a bleeding disorder
Location: Camp Boggy Creek; Eustis, FL
Contact: Fran Haynes, ED, 800-293-6527 info@hemophiliaflorida.org
Hemophilia Foundation of Greater FL
www.hemophiliaflorida.org





CAMP HEMOTION 40 YEARS OF AWE AND MAGIC!

BY BOBBY WISEMAN

In June 2018, the Hemophilia Foundation of Northern California (HFNC) will host its 40th annual residential summer camp program for children and youth with bleeding disorders in the Northern and Central California regions. This year is monumental for the program. Forty years of joy, laughter, tears and excitement will culminate in a week packed with a variety of activities to entice and thrill all participants! Be it participating in our world famous Ga-ga and basketball tournaments, aqua Ga-ga, mobile infusion or creative crafts, all will walk away from this week with a renewed sense of community, a feeling of true brother and sisterhood, as well as a unique perspective of our extensive history.

To help celebrate the accomplishment of 40 annual weeks of life-changing moments, we are inviting many of our veteran staff to participate in a number of jam-packed activities on the final day of camp. We envision a wonderful time of storytelling, a few tears, and a TON of smiles and laughter. Our theme this year will incorporate music through the decades of

our wonderful program. We are looking to dust off some old dance moves for theme night, maybe some special performances for campfire night and yes, some surprise guests.

Camp Hemotion 2018 is not only a look at where we have been, but a map to chart the course for our future. Over the past 40 years many advances have taken place in the bleeding disorders community. Our program has embraced the various changes in a way that supports inclusion, diversity and an overall sense of both community and family. It has continually evolved to meet the needs of its members. This fact will remain true as current and future leaders strive to develop a comprehensive, all-inclusive and fun-filled program for all participants.

Stay tuned to our social media outlets to hear about the many wonderful happenings for 2018!

Website: www.hemofoundation.org
Facebook: www.facebook.com/Hemofoundation/



18. Georgia Camp Wannaklot

July 15-20, 2018

Ages: 7-12 Junior Camp

Ages: 13-17 Teen Camp

Open to: Boys & Girls with a bleeding disorder

Location: Rutledge, GA

Contact: Kim Williams, 770-518-8272

kawilliams@hog.org

Hemophilia of Georgia www.hog.org



19. Hawaii Camp Koko Ohana Family Camp

July 20-22, 2018 **Ages:** All ages

Open to: Families or Individuals with a bleeding disorder

Location: Kilauea Military Camp Facility, Hawai'i Volcanoes National Park

Big Island (Hawaii), HI

Contact: Ziggy Douglas, ED

808-782-5506, ddouglas@hemophilia.org

Hawaii Chapter- NHF, hawaiinhf.org



20. Idaho Camp Red Sunrise

June 21-23, 2018 **Ages:** All Ages

Open to: Families affected by a bleeding disorder

Location: Sawtooth Methodist Camp

Fairfield, ID

Contact: Marlyn Walker, 208-344-4476

mwalker@hemophilia.org

ID Chapter of NHF, www.idahoblood.org



21. Illinois Camp Warren Jyrch

August 5-11, 2018 **Ages:** 7-17

Open to: Boys & Girls with a bleeding disorder or diagnosed carrier status

Location: Camp Benson; Mt. Carroll, IL

Contact: Lily Schwartz, 312-427-1495

lschwartz@bdai.org, Bleeding Disorders

Alliance IL, www.bdai.org



22. Illinois Marcus McClure Family Camp

June TBD, 2018

Open to: Families of children with a bleeding disorder, ages 6-10, who have not yet attended summer camp

Location: TimberPointe Outdoor Center Hudson, IL

Contact: Lily Schwartz, 312-427-1495

lschwartz@bdai.org, Bleeding Disorders Alliance IL; www.bdai.org



23. Indiana Camp Brave Eagle

June 10-15, 2018 **Ages:** 7-16

Open to: Boys & Girls with a bleeding disorder, Siblings, Carriers

Location: North Webster, IN

Contact: Angel Couch, Community Outreach Coordinator

800-241-2873, acouch@hoii.org

www.campbraveeagle.org

Hemophilia of Indiana, Inc., www.hoii.org



23. Indiana Doug Thompson Teen Leadership Camp

A Traveling Adventure Camp

July 16-20, 2018 **Ages:** 14-17

Open to: Young men with bleeding disorders

Location: TBD

Contact: Angel Couch, Community Outreach Coordinator

800-241-2873, acouch@hoii.org

Hemophilia of Indiana, Inc., www.hoii.org



24. Indiana Camp Independence

June 24-29, 2018

Ages: 8-18

Open to: Boys & Girls with hematological disorders

Location: Bradford Woods; Martinsville, IN

Contact: Alisha Survant

asurvant@iuhealth.org or Marri Hampton

mhampto2@iuhealth.org, 317-948-3111



25. Iowa Bleeding Disorder Summer Camp at Camp Tanager

June 27-29, 2018 **Ages:** 6-17

Open to: Boys & Girls with a bleeding disorder and one guest per family

Location: Mount Vernon, IA

Contact: Hannah Beardy

Hemophilia of Iowa, Inc., 319-393-4007

hemophiliaofiowa.org or Michelle Krantz, RN

319-356-2890, micelle-krantz@uiowa.edu

or Karla Watkinson, RN, 319-356-4271

karla-watkinson@uiowa.edu

Iowa Hemophilia and Thrombosis Center



25. Iowa Family Camp at Camp Tanager

Aug. 4-5, 2018

Open to: Families of a child age 3-6 with a bleeding disorder

Location: Mt. Vernon, IA

Contact: Hannah Beardy

Hemophilia of Iowa, Inc., 319-393-4007

hemophiliaofiowa.org or Michelle Krantz, RN

319-356-2890, micelle-krantz@uiowa.edu

or Karla Watkinson, RN, 319-356-4271

karla-watkinson@uiowa.edu

IA Hemophilia and Thrombosis Center

26. Kentucky KHF Camp Discovery

July 15-19, 2018 **Ages:** 7-15

Junior Counselors in Training **Ages:** 16-17

Open to: Boys, Girls, Teens with a bleeding disorder, Siblings (if space available)

Location: Cedar Ridge Camp; Louisville, KY

Contact: Ursela Kamala, ED, 502-456-3233

Kentucky Hemophilia Foundation

info@kyhemo.org, www.kyhemo.org



27. Kentucky The Center for Courageous Kids

June 24-28, 2018 **Ages:** 7-15

Open to: Boys & Girls with a bleeding disorder (Hemophilia, vWD, ITP, SCA)

Location: The Center for Courageous Kids; Scottsville, KY

Contact: 270-618-2912

bchandler@courageouskids.org

www.courageouskids.org



Camp HONOR CELEBRATES 25 YEARS!

BY ANDY BLACKLEDGE
CAMP CO-DIRECTOR



Camp HONOR celebrates its 25th anniversary this summer! In 1994, leadership of the Arizona Hemophilia Association, in partnership with the Hemophilia Treatment Centers in Phoenix and Tucson decided to start a camp for children with bleeding disorders. The executive director at the time, Mike Rosenthal, organized a camp committee to begin the planning of our new venture. First a name was needed, so a contest was held. The winner of the contest was Andrew Heinze, just 13 years-old at the time. He came up with the name and acronym for Camp HONOR - *Hemophiliacs Overcoming New Obstacles Resourcefully* and was one of our first campers!

Part of the original crew who made camp happen included many individuals such as Marilyn August, Lori Wagner, Barb Eady, Rachel Blackledge, Mary Lou Damiano, Isaac Provencio, Rick and Penny Murphy, Laurie Lamb, Karen Keogh, Yleana Hughes and myself.

The 1994 inaugural Camp HONOR was held at Camp Charles Pearlstein in Prescott, Arizona. That first year we had just over 50 excited campers – boys and girls with bleeding disorders and their siblings. Given the bleeding disorders community's connection with the HIV community at the time, we welcomed children from the local HIV clinic to our new camp as well. This special partnership continues. Today, Camp HONOR welcomes over 125 campers for a week filled with joy and friendship!

Camp HONOR's early traditions included a camp-wide slime fight,

a memorial tree planting, talent show, camp songs and fun final night dinner made even more fun with a crazy dance party! Since then, we have added more activities such as Hemolympics, overnights, a teen out-camp and various themed evening activities.

From the beginning and continuing today, independence with self-infusion has been promoted and celebrated. The camp's medical team encourages and teaches those who are ready to learn. When a camper takes that important step and successfully completes the infusion process independently, they are praised and given the Big Stick award!

Camp HONOR is one of Arizona Hemophilia Association's largest annual programs. We are proud to have over 80 volunteers give of their time and effort to ensure the campers have the best summer of their life! Due to the growth of our program over the years, we have used 5 different camp facilities. For our 25th anniversary, we will be at a new location - Lost Canyon Camp in Williams, Arizona, but the truth is, where we meet doesn't matter. Summing it up quite eloquently, one young camper stated, "Camp HONOR isn't about where it is, but what it is."



THE POWER OF CAMP

BY JUSTIN HORBACZ

As I jumped off a 40-foot wall, my life changed forever.



Growing up as a child with a severe bleeding disorder wasn't always easy. Sure, the only difference between my friends and me was that my blood didn't clot well, but I always felt different. I grew up as the child that kept his shirt on at the beach in fear I would be made fun of or judged when the scars on my chest - the result of numerous surgeries to install intravenous ports to receive medications - were unveiled.

At the age of eight, I discovered the Hole in the Wall Gang Camp - a magical place that provides a "different kind of healing" to seriously ill children. I attended camp for 7 years and participated in Hero's Journey during my final year. This program teaches campers to be the hero of their own journey through life. On the last day of Hero's Journey, I was challenged to climb a 40-foot rock wall in the middle of the night. This wall represented the challenges I faced in life living with a life-threatening illness. Some parts of the wall were easy to reach while others required me to

have courage, to reach beyond my comfort zone and to literally take a leap of faith.

As I reached the top of the tower, I found my journey mentor waiting for me. It was pitch dark and I could see nothing below. He challenged me to zipline down into the dark abyss. Before I made that leap of faith, he told me the 40-foot wall represented all my fears, worries, and doubts. The wall represented anything unfortunate that happened in my past. If I conquered the wall, I would leave all those fears, worries and doubts behind me forever.

He also told me I would be able to achieve any and all future goals and aspirations, but only after I conquered my past. The jump was symbolic of replacing my past - filled with doubts and the hopes and dreams of what I might accomplish in the future. From that time forward, I realized I could do anything I wanted and that my bleeding disorder, rather than serving to limit my potential, in fact, makes

THE SOLDIER AND THE OAK BY ELLIOTT PARKER

This is a story that began long, long ago
I was a young oak tree in dark Missouri soil
And like all other saplings
I had dreams of growing strong and tall

One day a rebel with a bullet in his chest
Hung his rifle on my limbs and laid to rest
And there beside me as the blood soaked to my roots
The soldier sang a song of grace

The heavy rifle bowed me over to the ground
Two years I stayed this way until the rifle fell
And in this manner for a hundred years I grew
All my dreams, not meant to be

Then one day two men came with a cross cut saw
They spoke of how my arch would hold a weight so strong

And I feared not the blade for such a worthy cause
And so I fell, I gladly fell

Three winter days aboard a northbound train
Three more beneath the hewer's careful blade
And while he worked ,he praised my rich, red grain
Perhaps it was the soldier's blood that day

Now I'm the wooden arch that holds a mighty bell
Three stocks before me cracked, but I shall never fail
Up in a tall cathedral high above my dreams
Of long ago

And on Sunday mornings when I hear that sweet refrain
I see the soldier's face like it was yesterday
Calling angels down from heaven with that hymn
He softly sang of God's good grace

me unique. So, I took two steps forward, took a deep breath and leaped into the unknown.

As my personal Hero's Journey came to a conclusion, my mentor played a song, The Soldier and the Oak by Elliott Parker, which has a deep personal message I will carry for life. The song describes a young oak tree that had dreams and aspirations of becoming a strong, tall tree until a soldier placed his gun on the young tree's branch causing it to grow sideways.

Given its "abnormality," the tree lives its life thinking it's worthless until two men come by and see potential in the crooked tree. The oak tree discovers that its uniqueness enabled it to hold a heavy and all-important church bell, while "normal" trees would crack under its weight. Due to its uniqueness, it achieved a goal greater than it ever thought possible. The day the soldier placed the gun on its branch altering its growth wasn't a day of sadness or misfortune, but rather a day to be celebrated.

Like the "abnormal" oak, I couldn't see my potential. Leaping from a 40-foot tower into total darkness helped illuminate my uniqueness and potential. I've learned the importance of having positive influences in life. My uniqueness is now the driving force behind my future goals and ambitions. I'm currently a sophomore in college, but still go to camp every summer to volunteer as a camp counselor. It's now my turn to serve as that mentor at the top of that 40-foot wall and hopefully impact the lives of other children, like the twisted oak and that young kid with hemophilia.

28. Louisiana Camp GlobeClotters

May 27-31, 2018 Ages: 7-16
Open to: Boys & Girls with a bleeding disorder and their siblings (as space is available)
Location: Camp Istrouma
Baton Rouge, LA
Contact: Erica Simpson, 225-291-1675
director@lahemo.org or
Kaelen Oubre, outreach@lahemo.org



29. Michigan Camp Bold Eagle

July 1-7, 2018 Ages: 13-17
July 15-19, 2018 Ages: 6-9
July 21-27, 2018 Ages: 10-12
Open to: Boys & Girls with a bleeding disorder
Location: Holton, MI
Contact: Tim Wicks, 734-544-0015
twicks@hfmich.org or Anthony Stevens
734-961-3510, astevens@hfmich.org
Hemophilia Foundation of Michigan
www.hfmich.org

29. Michigan Eagle Outpost Traveling Camp

June 17-23, 2018 Ages: 14-15
Open to: Boys & Girls with a bleeding disorder
Location: Throughout Michigan
Contact: Tim Wicks, 734-544-0015
twicks@hfmich.org or Anthony Stevens
734-961-3510, astevens@hfmich.org
Hemophilia Foundation of Michigan
www.hfmich.org

29. Michigan Eagle Expedition

Aug. 1-9, 2018 Ages: 16+
Open to: Youth from MI, IN, OH
Location: Northern California
Contact: Tim Wicks, 734-544-0015
twicks@hfmich.org or Anthony Stevens
734-961-3510, astevens@hfmich.org
Hemophilia Foundation of Michigan
www.hfmich.org



29. Michigan Eagle Quest

Backpacking excursion
June 2-8, 2018 Ages: 18+
Location: North Manitou Island in Lake Michigan
Contact: Tim Wicks, 734-544-0015
twicks@hfmich.org or Anthony Stevens
734-961-3510, astevens@hfmich.org
Hemophilia Foundation of Michigan
www.hfmich.org

30. Minnesota Camp Courage North

July 8-13, 2018 Ages: 8-17
Open to: Boys & Girls with a bleeding disorder
Location: Camp Courage North
Lake George, MN
Contact: Jim Paist, ED, 651-406-8655
info@hfmd.org, Hemophilia Foundation of Minnesota/Dakotas, www.hfmd.org

31. Mississippi Camp Lake Stephens

June 4-9, 2018 Ages: 7-14
Open to: Boys and Girls with a bleeding disorder
Location: Camp Lake Stephens
Oxford, MS
Contact: Rachel Henderson, 601-503-3626
mshemfoundation@gmail.com
www.mshemophilia.com

32. Mississippi Camp Teen Retreat

June 15-16, 2018 Ages: 13-19
Open to: Boys with a bleeding disorder
Location: The Gray Center; Canton, MS
Contact: Rachel Henderson, 601-503-3626
mshemfoundation@gmail.com
www.mshemophilia.com

33. Mississippi Camp Family Retreat

August 10-12, 2018
Open to: Patients and family members of the Mississippi Hemophilia Community
Location: Yogi on the Lake
Pelahatchie, MS
Contact: Rachel Henderson, 601-503-3626
mshemfoundation@gmail.com
www.mshemophilia.com



34. Missouri Camp Notaclotamongus

June 6-9, 2018 Ages: 7-17
Open to: Boys & Girls with a bleeding disorder
Location: Imperial, MO
Contact: Bridget Tyrey, 314-482-5973
info@gatewayhemophilia.org
www.gatewayhemophilia.org

35. Missouri Midwest Hemophilia Association Summer Camp

July 30-August 3, 2018 Ages: 7-17
Open to: Boys & Girls with a bleeding disorder
Location: Lake Doniphan Retreat Center
Excelsior Springs, MO
Contact: Luke Saulsberry, Camp Director
402-274-8002
mhacampdirector@gmail.com
or Mark Cox, ED, 816-479-5900
mcox@midwesthemophilia.org
Midwest Hemophilia Association
www.midwesthemophilia.org





Much like Inhibitor Family Camp by CHES, **After the Shock** is a camp experience for families with a child, **ages 0-18** years old, managing a currently active or previously active inhibitor within the last 3 years. This year, *After The Shock* replaces our Inhibitor Family Camp program with partner camp Victory Junction and will be held June 22-25th at Camp Zeke in Lakewood, Pennsylvania. The venue change allows us to accept families with a child younger than age 6.

Sponsored by Comprehensive Health Education Services, our goal is to reinforce support networks

through the shock of a new diagnosis and the steep learning curve that comes with it.

In addition to lots of fun, you will have an opportunity to gain valuable information through an assortment of sessions, including round-table discussions, separate programs for siblings, and a teen track, as well as self-infusion classes. Our camp offers a sense of acceptance and understanding for all families.

For more information, please visit www.ches.education



INHIBITOR FAMILY CAMP AT THE PAINTED TURTLE!



Inhibitor Family Camp's mission is to provide a camp experience for those affected by an active inhibitor and their family. We at Comprehensive Health Education Services, more simply known as CHES, understand from a deeply personal level the feeling of being the only child with an inhibitor at regular bleeding disorders camp. Inhibitor Family Camp was developed "because everyone deserves a camp to call their own."

Now in its 9th year, we are committed more than ever to welcome new families and returning campers to our camp family September 28th – October 1st at The Painted Turtle in Lake

Hughes, California. Inhibitor Family Camp is 100% free to all families with a child between the ages of 6-19 with an active inhibitor. Families who have tolerated within the last 3-4 years are also welcome to attend, as space allows.

Sponsored by Comprehensive Health Education Services and supported by an educational grant from Novo Nordisk, we offer educational sessions, rap sessions, and self-infusion classes woven into a weekend of fun! There are also separate sessions for Sibling Connection, Inhibitor Brothers, and one specifically for teens. Our families have described this experience as life changing. One camper exclaimed, "I would rather come here than Disney!" The sense of acceptance, understanding and love is palpable each time we meet.

For more information, please visit www.ches.education

36. Montana/Wyoming Big Sky Family Camp

August 10-12, 2018

Open to: Families or caregivers managing a bleeding disorder
Location: Flathead Lake Methodist Camp Rollins, MT
Contact: Brad Benne, ED 406-586-4050, brad@rmhbda.org Rocky Mountain Hemophilia & Bleeding Disorders Assoc., www.rmhbd.org



37. Nebraska Camp CoHolo

July 22-25, 2018 Ages: 6-11

July 25-29, 2018 Ages: 12-17

Open to: Boys & Girls impacted by cancer or blood disorders
Location: Eastern NE 4H Center; Gretna, NE
Contact: Berta Ackerson, Camp Director 402-707-2154, director@campcoholo.com www.campcoholo.com, or Anisa Hoie, RN 402-955-3950, ahoie@childrensmaha.org www.campcoholo.com



CAMP BOGGY CREEK

My 9 year-old son, Kaleb, has been attending camp for two years now. Camp Boggy Creek gives him the sense of independence he needs. It's a wonderful place filled with caring staff that have made him feel welcomed and included. I am comfortable knowing he is in a safe place - Camp Boggy Creek is



38. Nevada Camp Independent Firefly

June 12-16, 2018 Ages: 7-17

Leaders in Training Ages: 16-17

Open to: Boys & Girls living in NV with a bleeding disorder, Siblings
Location: Camp Whittle; Big Bear, CA
Contact: Maureen Salazar-Magana 702-564-4368, mmagana@hemophilia.org Nevada Chapter of NHF, www.hfnv.org



39. New England Hemophilia Assoc. Annual Family Camp

June 27-30, 2018

Open to: Families with a bleeding disorder living in New England
Location: Geneva Point Center Moultonborough, NH
Contact: Heather Case, Program Director, 781-326-7645 hcase@newenglandhemophilia.org New England Hemophilia Assoc. www.newenglandhemophilia.org



40. New Mexico Camp Sangre Valiente

June 4-9, 2018 Ages: 7-17

Open to: Children with a bleeding disorder and siblings

Location: Fort Lone Tree; Capitan, NM
Contact: Alfonso Jaramillo, 505-901-7315 alfonso.jaramillo@sangredeoro.org Sangre de Oro, Inc., Bleeding Disorders Foundation of New Mexico www.sangredeoro.org



41. New York Camp High Hopes

July 29-Aug. 4, 2018 Ages: 7-17

Open to: Boys with a bleeding disorder, male siblings and male family members of women with a bleeding disorder

Location: Lowville, NY
Contact: Matt Palmeri, Camp Co-Director 607-644-6969 badlands056@gmail.com www.camphighhopes.org

CAMP BOGGY CREEK

equipped with a hematologist and a nurse, and have a medical protocol in place to ensure he stays safe.

Kaleb has met many new friends and has learned so much about his condition; he is learning to be more of an advocate for himself and he has learned to self infuse. His favorite activities have included fishing and swimming.

Our family has also attended family retreats at Camp Boggy Creek. The retreats offer our family a chance to spend time with other families who face the same types of difficulties as we do. I am also able to see first hand the activities my son enjoys. It's wonderful meeting his camp friends and their families, and to exchange information so we can continue our friendships beyond the warmth of summer.

BY PATSIE GIBSON



CAMP HELP KIDS GROW (AND MOMS TOO!)

BY MILYBET CEPEDA

Even though I have never attended camp, and had no idea what it was all about, I did not want my son, my only child, to miss out on the experience. The first time Omar attended camp, he was just 7 years-old. He looked so sad and didn't want to stay, but we all knew it was for the best.

As my husband and I left camp that day, I cried. I'm not going to lie, I almost fainted. I was excited for him and yet so scared. Though we lived an hour away from the campgrounds, I wanted to go back and get him. I called that night and spoke with his counselor and read a prayer, begging him to write it down so he could recite it to Omar. I had a tough time and was totally kid-sick, but as days passed, I felt more comfortable. It helped that he wrote letters telling us how much he missed us, but at the same time was having a blast.

Much to my surprise, I was judged harshly for sending my son to camp. I heard, "Are you just crazy? I would never!" Was I to be judged by letting him go or do I keep him wrapped up in a bubble at our home? I'm glad we let him go.

My son and other campers embark in outdoor adventures and indoor activities, get unplugged (no technology!), relax and be actual kids. All three camp sites have been safe, fun and low-pressure environments that have offered my son fun activities, life-long friendships and lasting memories. Omar's experiences have always been wonderful - he says it's a "magical place." My husband and I also get a little break and don't feel guilty about it. By the way, kids need a break from their parents too. I know Omar gets the break he needs by going to camp, and at the same time we are giving him

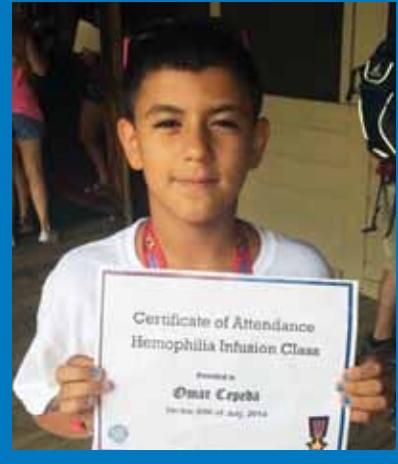
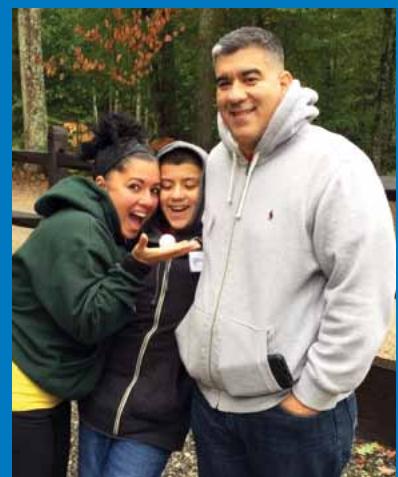
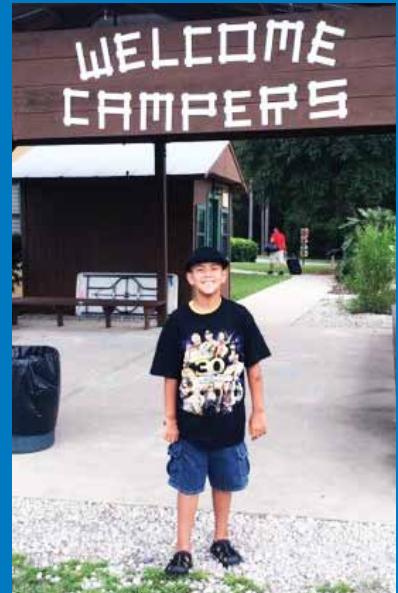
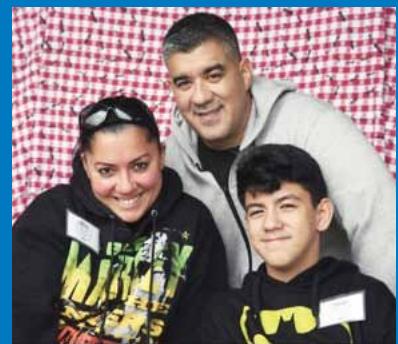
the opportunity to live and thrive without us being with him 24/7.

Camp teaches something that school doesn't. It is designed to build confidence and support self-esteem in an encouraging and nurturing atmosphere. In a medically-sound environment, camp helps kids develop skills and teambuilding methods - they explore nature and are taught riding, horsemanship skills and swimming. They participate in arts and crafts and have an opportunity to discover and display their skills in a talent show as well as in a recording studio! It was at camp that Omar experienced one of his most important skills - he learned to self-infuse!

Attending camp has transformed my son, helping him become a well-rounded individual. He benefits from the space and the downtime to learn critical skill sets that will serve him well in the future. Omar has had the opportunity to test himself outside his home and learn what he is capable of, which will help him connect on a deeper level with more people.

Unlike his first time, now when we drop him off at camp, he wants us to leave as soon as we let him out of the car! And when the week is over, Omar has the "camp blues." He doesn't want the adventure to end.

Lastly, I want to say thank you - to the donors and corporate sponsors, to the chapters and foundations, to all the angels that give of their time and energy making camp possible for my son, and to Mr. Paul Newman, wherever you are, for thinking outside the box and building this magical place for children who have been diagnosed with chronic life-threatening conditions.





HOME AWAY FROM HOME

BY OMAR WILSON CEPEDA, Age 13

Since I was 7-years-old, I have attended hemophilia camps - first in Florida, now in Connecticut and New York. As my parents and I entered the parking lot at Camp Boggy Creek in Eustis, Florida - the first camp I went to - I didn't know what to think. I remember my mom holding back tears and I remember seeing many happy faces, and hearing applause and cheers greet us. When we entered the dining hall, I felt a burst of energy as I saw kids singing, dancing and just having fun.

Having gone to 3 camps - Boggy Creek, Double H Ranch and Hole in the Wall - I can say they were each different, yet the same. Each camp gave that amazing feeling of being in a safe, protective place, yet still able to be yourself and have fun. This is magical. The camps provide an action-packed week of fun with activities to share with new friends. One of my favorite parts of camp is meeting new people and listening to their personal stories of camp experiences and of having a chronic illness. About new friends, I've told my parents, "he understands me, " or "he gets me."

From learning a new board game or which rock to grab on the climbing tower, to participating in fun adventures and selecting a cool mug for hot chocolate, the volunteers and camp counselors are the go-to people and are with

you at camp throughout the entire week. I turn my head and they are there. Probably some of the greatest people I know personally are my camp counselors. We get to enjoy the week together as we share activities in archery, horseback riding, arts and crafts, swimming, recording studio, wood shop, outdoor rock climbing, zip lining, camp fires, basketball, talent shows and so much more! So much more!

Camp is my home away from home. Through all these years of going to camps and family weekend camps, I have had many amazing experiences, met the coolest people and learned so much each time. I highly recommend to anyone thinking about going to GO! You will not regret it. You will have the time of your lives.

This article is dedicated to my dear grandmother Ana Cepeda who passed away November 16, 2017. She was very involved in my life and in the bleeding disorders community. She did it all - family weekend retreats, hemophilia walks, community activities, educational dinner events and fundraisers. Ironically, Matrix and CSL sponsored an event in Newark, NJ the night before my grandma passed. She had been involved right up to her last day on earth. I miss her dearly. Rest in Peace Grandma. Love, Papo.





CAMP IS COOL!

I have gone to camp for 2 years. My favorite activities are swimming, Capture the Flag and hanging out in the cabin. I like swimming because it cools me down and it's fun. I like Capture the Flag most because it's cool to work as a team. I like hanging in the cabin because it gives me time to relax.

My best camp experience is hanging out with my friends and getting to know other people who have hemophilia because they can tell you something about hemophilia that you might not know and the other way around. I think it is important for kids like me to go to camp to learn more

BY BLAKE N. (8 years old)

about hemophilia and to show that it does not have to hold you back from activities.

Camp taught me to be careful, how to treat myself when I have a bleed and that swimming helps my joints and muscles. It also encourages me to do my own shots. I'm most proud of getting my Big Stick award because I was really afraid to stick my vein. I always use my port, but I feel better about sticking my vein now. I think all kids should go to camp because you will learn lots of things about hemophilia and it's fun! Camp rules and you should totally go!

41. New York Camp Little Oak

July 22-28, 2018 Ages: 7-17

Open to: Girls with a bleeding disorder, Carriers, Sisters of boys with a bleeding disorder

Location: Greig, NY

Contact: Hannah Russell, Camp Director
425-770-1801, h.russell@byu.net



42. New York BDAN Family Camp

October 6-8, 2018

Open to: Families and Adults with a bleeding disorder

Location: Aldersgate Camp and Retreat Center; Greig, NY

Contact: Bob Graham, 315-396-2944
bobgraham04@msn.com
www.bdaninc.org



43. New York Double H Ranch

June 21-26, June 29-July 4, July 7-12, July 16-21, July 24-29, August 1-6
August 9-14, 2018 Ages: 6-16

Open to: Boys and Girls with bleeding disorders

Location: Lake Luzerne, NY

Contact: Tara Bogucki, 518-696-5676 x222
tbogucki@doublehranch.org
www.doublehranch.org



44. New York Camp SAIL (Self Advocacy, Independence & Leadership)

September 14-16, 2018 Ages: 13-18

Open to: Boys and/or Girls with a bleeding disorder, Carriers in NY State
1 parent mandatory for attendees under 18

Location: Camp Quinipet
Shelter Island Heights, NY

Contact: Tyshawn Constantine, Program Director, 212-682-5510
tconstantine@hemophiliany.com
Hemophilia Assoc. of New York
www.hemophiliany.com



45. North Carolina Camp Carefree

July 22-28, 2018 Ages: 6-16

Open to: Boys & Girls with a bleeding disorder

June 17-23, 2018 - Well children with a chronically ill sibling

July 15-21, 2018 - Well children with a chronically ill parent

Location: Stokesdale, NC

Contact: Program Directors Grace Turner and JeNai Davis, 336-427-0966
directors@campcarefree.org
www.campcarefree.org



46. North Carolina Camp Rainbow

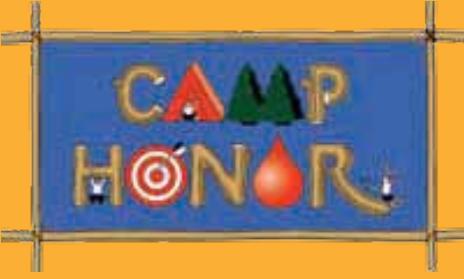
June 10-16, 2018 Ages: K-18

Open to: Boys & Girls with a bleeding disorder treated by the Brody School of Medicine at East Carolina University

Location: Camp Don-Lee Neuse River near Arapahoe, NC

Contact: Jacquelyn Sauls, MS, CCLS
252-744-3304, saulsj@ecu.edu





A FAMILY AFFAIR!



JESSICA (age 13)

I enjoy Camp HONOR because camp develops friendships that soon feel like family. At first I was jealous that my brother Dillon could go and I couldn't. When I was finally old enough to go, my expectations were exceeded.

I love staying in the cabins and spending time with my friends. I very much enjoy the activities, especially the giant swing - it is a thriller and is very exciting. The parties are so much fun with the dancing and the music and just having a good time. Also, the Color Olympics is something I look forward to, especially with everyone competing to win.

Oh, and don't even get me started on the Slime War! That is ONE of the many things I look forward to every year! It's always hard to leave camp, but I know it will happen again next year!



JORDAN (age 13)

Camp HONOR has impacted my life by giving me the opportunity to make new friends. I have found a lot of new friends at Camp HONOR that go through the same struggles as I do. And I don't feel left out because I am able to do all the things I'm not able to do at home, like going on the giant swing, climbing the rock wall, paintball and archery. I'm also glad that we have cabins because it brings everyone together and usually all my friends are in the same cabin with me. The Golden Pinecone Award is cool because if your cabin is the cleanest, you get the award.

My personal favorite would have to be the ropes course - it is super fun! The slime fight is a lot of fun too. At the beginning of camp, you are chosen to be on one of four different teams - red, yellow, green, and blue. Last year I was on the green team. Everyone gets mustard bottles and water guns filled with slime and you just squirt everyone. At the end, whoever is the least wet, wins. I love Camp HONOR!



DILLON (age 17)

Every year I go to Camp HONOR in Arizona, my experience gets better and better. I meet new people and grow in my relationships with kids I have met in previous years. It is a week I look forward to all year long.

As a camper, I was able to experience things I have never been able to do because of my bleeding disorder, like playing paintball and doing high ropes courses. I also met people with bleeding disorders who go through the same things I do on a regular basis. I got to connect with others and share my stories and advice, while learning things from them too.

I have gone to Camp HONOR the past ten years, the last two years as a counselor-in-training. I am looking forward to this year as a full-fledged counselor.



BY BOB GRAHAM



NACCHO 2018!

More than 160 attendees from bleeding disorders camps across America, Canada, Turkey, Romania, New Zealand, Australia, Nicaragua and India met in January for the 15th Annual NACCHO Camp Conference in Phoenix, Arizona!

Hosted by the Arizona Hemophilia Association and sponsored by Pfizer and Bioverativ, the NACCHO conference provides the only forum for bleeding disorders camp directors and staff to exchange ideas, learn new camp skills and develop new programs to meet the needs of an ever-changing community.

This year featured several big developments. The Director's Pre-Conference was transformed into a Director's Intensive Workshop to help camp leaders prepare focused staff training and orientation programs. Thanks to the team from Director's Camp for leading this workshop!

Another development was the plenary on the changing face of camp. A large majority of the bleeding disorders community is now over age 18 (2017 ATHN Dataset). Those leading the session discussed ways to keep people with bleeding disorders over 18 engaged in the community through camp. An increasing number of family camps are opening across America (and in other countries too!) for parents of new patients as well as adult patients, many of

whom are raising families of their own. New proposals included redefining camp to mean more than a traditional summer program for kids. Will camps specifically for adults soon be common?

GutMonkey, a camp community favorite organization led by Patrick Torrey, energized the NACCHO theme of Pay It Forward with a conference-long game called Play It Forward. Attendees learned a wide range of new camp games while earning money for a family camp program in the Philippines (supported by nationally recognized, Save One Life organization).

Finally, to help camps grow their staff, the National Camp Exchange (NCE) was created as an extension of the NACCHO conference. The Wingmen Foundation has partnered with the Arizona Hemophilia Association to facilitate the exchanges throughout the summer.

Thanks to a generous sponsorship grant by Octapharma, NCE connects experienced camp directors and staff personnel with bleeding disorder camps in need of

help. The program offers funding for travel, provides talented camp staff to camps looking to re-build or develop, and helps promote the broadening of best practices and proven activities for youth and family camps.

To learn more about NACCHO, visit them on Facebook: www.facebook.com/nacchoconference/





A camper (center) with Bob Graham (BDAN Family Camp), and Heather Britton (West Virginia Family Camp).

Partnering with Wingmen Foundation, Arizona Hemophilia Foundation has received a generous grant from Octapharma for the second year to facilitate a national camp exchange program where participants are able to share their expertise and foster new ideas.

A perfect adjunct to NACCHO (North American Camping Conference for Hemophilia Organizations), NCE offers experiential, hands-on learning and sharing.

- It provides the opportunity for camps and future



This summer, camp professionals and host camps will have the opportunity to share their expertise, develop leadership skills and foster new ideas that will significantly improve the summer camp experience for youth who live with a bleeding disorder.

leaders to learn from one another on how best to improve camp and share best practices.

- It provides a forum to pass along traditions and build community for those with bleeding disorders nationally and internationally.
- It is a chance to give back to the developing camps and expand bleeding disorder camps across the globe.

Here's how it works:
If you are a camp or individual who would like to participate, please visit this website to apply: wingmenfoundation.org/national-camp-exchange-nce/.

The grant provides financial support for camp staff to participate in other camps. This allows for a sharing of best ideas among our camps!

The deadline is May 30th for summer camp programs.

47. North Carolina Victory Junction

June 24-28, 2018 Ages: 6-16

Open to: Boys & Girls with a bleeding disorder

Location: Victory Junction Randleman, NC

Contact: Amy Jo Nicholson

amyjo@victoryjunction.org

www.victoryjunction.org



48. Ohio Flying Horse Farms

July 16-21, July 25-30, 2018 Ages: 8-15

Open to: Hematology and Oncology patients

Aug. 6-11, 2018 Sibling Camp,

Ages: 8-15

Open to: Siblings of diagnosed children

Family Camps: April 13-15, May 4-6, May 18-20, Sept. 14-16, Sept. 28-30,

Oct. 12-14, Oct. 26-28, Nov. 2-4, 2018

Location: Mt. Gilead, OH

Contact: Olivia Miller, 419-751-7077

olivia@flyinghorsefarms.org

www.flyinghorsefarms.org



49. Ohio Camp Njoyitall

July 15-20, 2018 Ages: 12-16

July 22-27, 2018 Ages: 7-12

Open to: Current patients of the Cancer and Blood Diseases Institute at Cincinnati Children's Hospital Medical Center

Location: Camp Joy; Clarksville, OH

Contact: Kelly Range, Camp Director or Heather Binning, Admin. Asst., 513-636-6569 (NJOY)

cdbi.camp@cchmc.org

www.cincinnatichildrens.org/service/cancer-blood/patients/camp



50. Oklahoma Camp Independence

June 24-29, 2018 Ages: 6-18

Open to: Boys & Girls with a bleeding disorder, Siblings

Location: Camp Bond; Tishomingo, OK

Contact: Kathleen Montgomery, ED

918-889-5166, www.okhemophilia.org

Nathan Holloway, Camp Director

918-804-8184

nathan@okhemophilia.org

www.campindependence.org



51. Oregon Camp Tapawingo

Aug. 4-10, 2018 Ages: 7-15

Open to: Boys & Girls with a bleeding disorder, Siblings

Counselors in Training Ages: 16-17

Location: Falls City, OR

Contact: Madonna McGuire Smith
541-753-0730

madonna@hemophiliaoregon.org
Hemophilia Foundation of Oregon
hemophiliaoregon.org



52. Oregon Family Camp

June 28-July 1, 2018 Ages: All ages

Open to: All families living with bleeding disorders

Location: Camp Myrtlewood

Myrtle Point, OR

Contact: Madonna McGuire Smith

541-753-0730

madonna@hemophiliaoregon.org
Hemophilia Foundation of Oregon
hemophiliaoregon.org

53. Eastern Pennsylvania Chapter Family Camp

Sept. 21-23, 2018 Ages: All ages

Open to: Families affected by a bleeding disorder in Eastern PA

Location: Camp Kweebe

Schwenksville, PA

Contact: Lindsay Frei, 484-445-4282

lindsayf@hemophiliasupport.org

Eastern PA Chapter of NHF

www.hemophiliasupport.org



54. Pennsylvania Camp Hot-To-Clot

August 5-11, 2018 Ages: 7-17

Leaders-in-Training Ages: 15-17

Open to: Boys & Girls with a bleeding disorder, Siblings

Location: YMCA Camp Kon-O-Kwee Fombell, PA

Contact: Katherine Bush

or Kathleen Schnur, 412-209-7344

camph2c@itxm.org, www.hcwp.net

Hemophilia Center of Western PA

www.wpcnhf.org



55. Pennsylvania Camp Dragonfly Forest

July 22-27, 2018 Ages: 7-14

Open to: Boys & Girls with a bleeding disorder

July 15-20, July 22-27, 2018 Teen

Leadership Program Ages: 15-16

Location: YMCA Camp Speers in Pocono Mountains; Dingmans Ferry, PA

Contact: Ryan Tressler or Josh Holmes
610-298-1820

ryan.tressler@philaymca.org

joshua.holmes@philaymca.org

dragonflyforest@philaymca.org

www.dragonflyforest.org



56. Pennsylvania After the Shock An Inhibitor Family Camp

June 22-25, 2018

Open to: Families with a child (age 0-18) managing a currently active or previously active inhibitor within the last 3 years

Location: Camp Zeke; Lakewood, PA

Contact: Comprehensive Health

Education Services, 781-878-8561

info@ches.education

www.ches.education



57. Tennessee Camp Freedom

July 7-13, 2018 Ages: 7-15

Leaders-in-Training Ages: 16-17

Open to: Boys & Girls with a bleeding disorder and carriers

Location: Brandon Springs Group Center; Dover, TN

Contact: TN Hemophilia and Bleeding Disorders Foundation, 615-900-1486

www.thbdf.org



58. Texas Camp Ailihpomeh

July 15-20, 2018 Ages: 7-14

Leadership Program Ages: 15-17

Open to: Boys with bleeding disorders

Location: Camp John Marc Meridian, TX

Contact: info@camp-ailihpomeh.org

www.camp-ailihpomeh.org



59. Texas Camp United Hands

July 2-7, 2018 Ages: 7-17

Open to: Boys & Girls affected by a

bleeding disorder

Location: Fort Lone Tree; Capitan, NM

Contact: Yolanda Ortiz

915-859-6688 or 915-204-4013

yortiz.hoep@gmail.com

Hemophilia Outreach El Paso

www.hemoelp.org

60. Utah Camp Valor

August 6-9, 2018 Ages: 8-13

Children with a bleeding disorder and carriers, Siblings of children with bleeding disorder and children of affected parents

Open to: Children with a bleeding disorder, carriers, and children of affected parents Ages: 10-11

Location: Camp Wapiti; Tooele, UT

Contact: Scott Muir

smuir@hemophiliautah.org

or Jan Western, 801-484-0325

western@hemophiliautah.org

Utah Hemophilia Foundation

www.hemophiliautah.org



61. Virginia Camp Youngblood

July 8-13, 2018 Ages: 7-17

Open to: Children with inherited bleeding disorders, their siblings and children of members of the inherited bleeding disorder community in VA

Location: Camp Holiday Trails; Charlottesville, VA

Contact: 434-977-3781

campisgood@campholidaytrails.org

vahemophilia.org, 804-740-8643



62. Washington Camp I-VY

July 23-27, 2018 Ages: 7-16

Open to: Children affected by a bleeding disorder and their siblings

Location: Camp Huston; Gold Bar, WA

Contact: Luke Phifer, Camp Director

206-533-1660, general@bdfwa.org

Bleeding Disorder Foundation of Washington

www.bdfwa.org



63. West Virginia Camp HemoVon

June 11-15, 2018 Ages: 7-16

Open to: Boys & Girls with a bleeding disorder

Location: Camp Twin Creeks

Marlinton, WV

Contact: Anita Graham 304-293-1205

agraham@hsc.wvu.edu, WV University Medical Center



64. Wisconsin Camp Klotty Pine

July 9-14, 2018 Ages: 7-15 Age exceptions made on a case-by-case basis

Leader-In-training Program Ages: 15-17

Open to: Boys & Girls with a bleeding disorder or diagnosed carrier status

Location: Wautoma, WI

Contact: Karin Koppen, 414-937-6782

kkoppen@glhf.org, Great Lakes Hemophilia Foundation

www.glhf.org



64. Wisconsin Camp Klotty Pine Family Camp

April 28-29, 2018

Open to: Families of children with a bleeding disorder, Ages 5-9

Location: Wautoma, WI

Contact: Karin Koppen, 414-937-6782

kkoppen@glhf.org Great Lakes Hemophilia Foundation

www.glhf.org

AND A TRADITION CONTINUES



BY AMELIA HERNANDEZ

As a child, having a bleeding disorder wasn't always easy. I remember many times when I was told to avoid certain activities or sports because of the risk of having a bleed. A lot of time was spent indoors reading and drawing, until one year my mom signed me up for a trip to the most amazing place - Camp Bold Eagle in Michigan. Though it was a three-hour drive from Chicago, each summer we took the trip back and forth for that one great week, and it was always the highlight of my whole year.

At Camp Bold Eagle, we swam, played Ultimate Frisbee, sang and laughed with all kinds of different people. Bold Eagle provided a safe environment not only to have fun, but also to learn tons of information about my bleeding disorder and how I could manage it on my own.

Going to camp was truly a life changing experience for me. It opened my eyes and showed me that I was one of many children affected by von Willebrand's Disease, and with precautions, I could do whatever I wanted. It was at camp I learned I wanted to become a nurse. Not only did I find my calling, but also made many lifelong friendships.

Now that I am a parent, I am proud to say for the first time this past summer, my son Angel attended bleeding disorders camp, and he loved every bit of it! He has already asked when camp will be this summer. And so it appears the camp tradition will continue in our family for many years to come! I know he will enjoy it just as much as I did!

If you look at my life now you'll see a guy who loves every aspect of his life; you'll see a guy who truly appreciates every lesson he's been taught; you'll see a guy who embraces everyone around him. However that hasn't always been the case; I haven't always been this bright eyed, cheery, happy go lucky person that many see today.

At one point in my life, I didn't see any hope for the future. All I saw was continued pain and needle, after needle, after needle. Why, I thought, did the world have it out for me?



HOPE

BY GABRIEL ANSPAUGH

When I was about 9, my mom announced we were going on a very special trip to a place called Camp Boggy Creek. "A camp?" I asked eagerly? She told me how it was a place just for kids with hemophilia. The news that I was going to be able to meet kids like me made me very excited. However, she explained it was still a couple of months away and I would have to wait.

When it was finally time, I was ecstatic and could hardly compose myself. I've continued going to Boggy Creek every summer since. Looking back, I can see my drive to live better was influenced more with each time I went to camp. One older camper in particular made a huge impact - he wasn't afraid to be himself and would just really let loose and have fun. I remember wanting to be more like him. By 8th grade, his influence gave me what I needed and it was then I decided I was tired of feeling sorry for myself and I was going to live my best life, just as I would at camp. Well, you know, minus the whole eating-with-your-face thing.

I can remember others could clearly tell that I was feeling much better. People would say things to me like, "Well, not all of us have no stress at all." Comments like that honestly made me happy - it meant I was "living" camp away from camp. At 15, I was diagnosed with inhibitors. For parents, it's one of the scariest things to hear. As a teenager, it was the most instantly crushing thing that ever



happened to me. It nearly caused me to go back to the "why me?" mindset, and I would have, if not for the amazing group of people I knew from camp. Known as GSQUAD, these people stuck by me when it felt like I had nothing and no one. Just ask my parents - my phone was constantly going off with messages from these guys. They would not be in my life if it weren't for camp. I never fully realized how much I would ever need a group of people like that until I needed them the most. They were right by my side every step of the way.

At the time of my inhibitor diagnosis, I was in the hospital for ten very long days. On the last day, the doctors told me I could no longer be part of my high school band, JROTC and everything else that gave my life purpose. GSQUAD kept me motivated and I knew that inhibitor or not, I'd find a way to pursue my ambitions.

Through the help of my Camp Boggy Creek family and my amazing support team, not only was I able to get through the next year doing everything I used to do, but I also went on to become my school band's exhibition drill team commander - a position that normally takes 3 years to accomplish. Now 18, I know that none of this would ever have been possible without the support from the friendships made at those amazing 232 acres of land that make up Camp Boggy Creek.



Represent! Paul Brayshaw, Kelly Gonzalez, Michelle Stielper, Sean Hubbert, Terry Stone, and Felix Garcia.

On March 8th, nearly 500 attendees gathered in Washington DC to participate in Washington Days, the National Hemophilia Foundation's annual advocacy event to support issues important to the bleeding disorders community. Constituents collectively donned red ties in support of Bleeding Disorders Awareness Month and conveyed the importance of access to comprehensive insurance. They stressed that the ability to lead healthy, productive lives critically depends upon maintaining access to care.

Due to partisanship and the shifting balance of power in Congress, states are gaining added flexibility to establish insurance rules that dictate varying levels of coverage for the insured population. The change in leadership has empowered Congress to consider legislation undermining the Essential Health Benefits established by the Affordable Care Act. To speak to that point, the visits with members of Congress included requests to maintain rules that prevent exclusions based on preexisting conditions and that ban lifetime and annual cap limits. Congress has also considered changes to Medicaid, including work requirements, and we asked our Congress to oppose any changes that would diminish coverage and potentially threaten those with complex medical conditions like bleeding disorders.

NATIONAL HEMOPHILIA FOUNDATION 2018 WASHINGTON DAYS



BY PAUL BRAYSHAW

Other issues we addressed involved possible threats to funding for Hemophilia Treatment Centers. President Trump's budget proposal for 2019 suggests cuts to the Centers for Disease Control (CDC) and the Health Resources and Services Administration (HRSA). The CDC program provides critical funds for surveillance and prevention to HTCs, as well as outreach support to education programs provided by national patient organizations. HRSA funding helps HTCs provide multi-disciplinary services, such as physical therapy assessments, social work, genetic testing, and case management. As HRSA grantees, HTCs are eligible to participate in the 340B drug discount program which allows participating centers to purchase drugs at a discount and use that savings to further fund comprehensive care for patients.

As always, we were inspired by our time in our nation's capital and were especially humbled to see our blood brothers and sisters returning again or joining for the first time to advocate for healthcare. Our community of advocate leaders spoke eloquently and pointedly in meetings with representatives. Witnessing bleeder leaders advocate for our community is a step in the right direction. Together we can and will make a difference!





MATRIX ON THE MOVE !



NEVADA

Kelly Gonzalez

The Nevada bleeding disorders community was in full education and celebration mode the first week of December as Santa made his rounds! Education and festivities were held across the state from **Family Day and Winter Celebration** December 3rd in Henderson to the December 6th **Family Day & Winter Celebration** in Elko, to another **Family Day and Winter Celebration** held in Reno December 7th. Each event featured an educational piece fostering patient empowerment, a delicious dinner, and yummy treats sprinkled along the way. And of course, no holiday party is complete without a visit from Jolly ole' Saint Nick surprising each child with a special gift! We are blessed to have the support of our bleeding disorders chapters, industry partners and providers, and especially our community members! We look forward to a fantastic year together!



Justin, Parker, Skyler and Kimberly share a moment with Santa!

NEW JERSEY – Correction

In the Spring 2018 issue of Matrix Health Group News, a Matrix on the Move event recap (beginning on page 39) regarding the Hemophilia Association of New Jersey's September 18, 2017 event, **Gourmet Dinner and Wine Tasting Event** requires a correction. The last sentence should have read, "Matrix Health Group was one of several proud sponsors of this event, and happy to support HANJ and the fantastic work they do for the bleeding disorders community!"

For a complete list of sponsors, please contact HANJ board member, Mark Scudery at mscudery@mac.com or hemnj@comcast.net.

We apologize for any misunderstanding this may have caused.

TEXAS

Felix Garcia

In December the Texas hemophilia community had no shortage of opportunities to come together and enjoy the holiday season with one another. Lone Star Chapter of NHF took their act on the road for the **Winter Education Events**, also affectionately known as the Texas Tour. Visiting 5 cities, community members had the opportunity to mix and mingle, gain information and share goodwill. Hats off to the two amazing executive directors, Melissa Compton of the Lone Star Chapter and Traci Mayer of the Texas Central Chapter, along with their dedicated volunteers for putting on such great programs throughout the state:

December 6th in San Antonio at the Marriott Plaza Hotel: The Texas tour kicked off with a gathering of over 100 community members. With holiday lights, garland and candy canes decorating our booth, Matrix Health Group was there to support the event along with industry partners and other specialty pharmacies. The chapter held an election to vote for board members and everyone was encouraged to volunteer and consider a position on the board in the future. I too, encouraged community members to give it a try since my first "official" role in the hemophilia community was as a board member on the Lone Star Board of Directors (sigh... so long ago!). Of course, no winter gathering is complete without good ole' Saint Nick stopping by to visit our kids and those of us who are kids at heart. It was a wonderful time for all!



December 7th in Austin at Embassy Suites Arboretum: Less than a 2-hour drive from San Antonio, we united again for the second stop of the Texas Tour. This time we might as well have been in Canada; a heavy snowfall hit everyone by surprise (remember, this is Texas!). Good thing I packed my winter coat, because it was needed. Those who did brave the weather enjoyed a great meal, good company and goodies from all of us who were there to support the event, as well as Santa Claus. Considering the weather, it was still a great event, and we look forward to next year—hopefully Mother Nature will cooperate and more people can attend.



Felix Garcia greets Martha Boria and, HFA Spanish Program Coordinator and Nora Casares.

December 9th in Dallas at Southfork Ranch in Parker: Our third stop on the Texas Tour was hosted by the Texas Central Hemophilia Association (TexCen). We converged on Southfork Ranch, home of the famed 1980s TV series "Dallas." After our festivities, interested families took a tour of the property and home where the show was filmed. TexCen kicked off the event with a "La Fuerza" meeting for all Spanish-speaking community members. This included a presentation by Martha Boria from the Hemophilia Federation of America on the transitions children go through as they age from the perspective of a mother. She was well received and the crowd was very interactive. Manufacturers and specialty pharmacies were on hand to discuss their products and services and offer some holiday goodies - though the best candy canes were found at the Matrix Health Group booth! The event was a great success with well over 100 community members enjoying time together before the holidays.

December 10th in McAllen at Doubletree Suites: The Lone Star Chapter does not forget about its members in South Texas! Included in the Tour, this is just another way the chapter shows their dedication to the entire area served. Voting and volunteerism were on the agenda - it was inspiring to see so many people from rural areas wanting to contribute to their chapter. Our hearts really warmed up just watching the joyful smiles of the children as Santa made his entrance! South Texas families were grateful to have the opportunity to get together with their fellow

bleeding disorders community members before years' end. December 16th in Houston at the Sugarland Marriott, The 5-stop Texas Tour wrapped up with the largest of the gatherings - over 150 in attendance! Chapter leaders presented the winner



Melissa Compton, ED. with
Melissa Reifke,
*Phil Bloomquist Volunteer of the
Year* award winner!

of the *Phil Bloomquist Volunteer of the Year* award to Melissa Reifke. Following, the chapter also wrapped up their board elections. Not uncommon given the friendliness of Texas, everyone had a great time visiting and sharing with one another. Santa did have to work overtime though, as there were just as many adults as kids in line to have their photo taken with Santa. It was a festive, jovial event!

ARKANSAS

LeAnn Wilson



Booths were filled with candy and other goodies as industry representatives visited with members of the bleeding disorders community at Hemophilia Foundation of Arkansas' **Year End Event** December 9th. Held at The Jones Center in Springdale, Board President Cody Kester opened the event by extending



Eden and Sally



Gabriel with LeAnn Wilson

a warm welcome to everyone. Tammy Jones, Treasurer, introduced guest speaker Darlene G. Shelton, Founder/President of Danny's Dose. Mrs. Shelton gave an update on the involvement she has had with government officials in various states and the Emergency Medical Services (EMS) Association. She explained the 3 main goals of Danny's Dose:

1. Raise awareness of the changes needed to medical emergency protocols for those with rare medical conditions and see the changes made
2. Provide specialized education for paramedics and emergency room physicians
3. Provide emergency preparedness education for bleeding disorder families

In May 2017, Missouri passed SB503, which allows Regional Medical Directors to set protocols for those with special medical needs and for paramedics to administer in an emergency, life-saving medications kept on hand by the patient.

Following the presentation, excited children decorated holiday cookies and met with a special visitor – Santa, of course! Everyone gathered for dinner and then boarded buses to Fayetteville Square to see Lights of the Ozark. Wonderful attractions – from exciting camel and pony rides, to an elegant journey in a carriage and the chance to see a real live reindeer - along with a festive display of more than 400,000 brilliant lights made for a delightful evening with our bleeding disorder families. Thank you to Hemophilia Foundation of Arkansas for hosting this informative and enjoyable event!

CALIFORNIA

Gaby Griffin

The Hemophilia Foundation of Southern California **Snowflake Festival** took place December 9th at the Santa Ana Zoo. Though a little warmer than usual for this time of the year, it was a beautiful day without a snowflake in sight. Community members came together to do crafts, decorate gingerbread cookies, play games, take pictures with Santa and Olaf, enjoy a delicious In-N-Out Burger, but most of all, had the opportunity to spend treasured time together in celebration of the holiday season.



Gaby Griffin poses for a photo with Alize and Joshua.



Following the festivities, families had the chance to visit the gorgeous 20-acre zoo that focuses on animals and plants from Central and South America. Thank you to the chapter for hosting this annual event!

OHIO

Rania Salem

"You just can't miss the world's biggest gift exchange," stated Tauna Batiste, Executive Director of the Central Ohio Chapter of NHF. Tauna, along with Linda Slocum, Development Coordinator, and Steph Mazzoco, Events Manager, did a FANTASTIC job putting together **The Great Exchange/Year End Celebration** December 9th at Quest Conference Center in Columbus.

First on the agenda were some great



educational sessions, followed by a selection of activities from which to choose including decorating holiday cookies, putting together ingredients for a chocolate chip cookie recipe in a mason jar or creating their own ooey, gooey slime.

Everyone was anxious to see what the Great Exchange was all about, and when it was time, everyone gathered in a large circle and each person was handed their gift bag with instructions not to look inside it. Tauna stood in the center the circle and read 'Twas the Night Before Christmas, but with an interesting twist. Whenever the word 'right' or 'left' was read, each person had to pass the gift in that direction. When Tauna finally came to the end of the famous story, everyone was laughing and a bit dizzy as they opened their goody bag. What an exciting and fun way to kick off the holiday season!

NEW JERSEY

Richard Vogel

As new therapies are introduced to the hemophilia community we need to know how they work and the difference between them. Is it recombinant, plasma or a brand-new therapy? Human or hamster cell line? Half-life? On December 10th, over 20 community members braved the aftermath of an early winter snowstorm and made their way to Chateau of Spain, in Newark to get the answers to these questions and more.



Alex and Trevor enjoyed the presentation.

As part of a series regarding new products and the science behind them, this event explored the factor VIII product from Bayer, Kovaltry. The presentation was very informative and easy to understand.

As we enjoyed a family style lunch of salad, lemon chicken, seafood paella, roasted potatoes and pasta we heard from factor VIII patient Ryan, who is a Kovaltry user. A very entertaining speaker, Ryan spoke about growing up with severe hemophilia A. Now an IT specialist who was once very active, Ryan has since slowed down a bit and finds that twice weekly dosing works well for him.

After mingling over dessert, we all left with a better understanding of another new product.

VIRGINIA

Terry Stone

Nothing says "Happy Holidays!" better than when members of the Hemophilia Association of the Capital Area are brought together for great food, holiday activities for the kids, a photo selfie booth, and the head elf dressed in a red suit with a twinkle in his eye and a bag full of goodies for all the good children of HACA! The spirit of the season was celebrated together December 10th at HACA's **Holiday Gathering** held at the Sherwood Community Center in Fairfax.

It was an old-fashioned holiday gathering with time to simply enjoy the company of fellow HACA families over dinner and holiday treats. There was no surprise Santa had a bag full of toys and gifts for ALL the HACA kids because, well...they are always good and always on the nice list! After Santa visited with the children, they opened their gifts and started to play with their new toys. It made Santa happy to have a few helpers this year to make all the arrangements. Thanks to chapter staff Brenda Bordelon and Stephanie Burns, as well as Santa's elf, Michelle Stielper, for all their hard work to make this holiday gathering so fun. Holiday memories made together are the best!

OHIO

Shelia Biljes

Frosting and sprinkles is all you need to turn a cold Ohio night into an amazing fun time! Panini's Grille in Strongsville was the place to be December 20th as Grifols and Matrix Health Group co-sponsored an **Educational Dinner** with cake decorating classes for the kids. During dinner, Virginia Kraus presented Blood Product Safety. Kelly Gonzalez, Educational Development Specialist, shared her talk, *It's Ok to Not be Ok* over a big brownie dessert.

Meanwhile, in the room next door, Miya Timura used her cake decorating skills to entertain a room full of young bakers. Looking adorable in their aprons, each child was taught the skills to decorate cupcakes.



Cameron concentrates on decorating.



You're never too old to sit on Santa's lap, right Curt!



Carmelo helps guide Chardea with her cupcake.

Cameron is proud of his decorating skills

It was heart-warming to see the children engrossed in learning a new skill. Of course, several adults made their way over to join the decorating fun!

At the end of the evening, each family was given a Christmas tree centerpiece, and everyone left with a smile on their face, frosting in their bellies and sprinkles all over the floor!

OHIO

Shelia Biljes

When the days get short in northern Ohio and it's too cold to play outdoors, the best place to be is on the court – the basketball court that is! That's exactly where Matrix Health Group and Novo Nordisk representatives were December 21st as we co-sponsored **Winter Fitness and Fun**. Forty guests gathered at The Brew Garden Restaurant in Middleburgh Heights for an amazing lunch. Speaking on behalf of Novo, Brian Almquist, Patient Ambassador, shared the story of his active life, prompting many questions from attendees eager to learn more. Herman Robinson, a young man with Factor 7 deficiency was introduced. Herman, who attends college on a basketball scholarship, shared a video of his weekly routine, including early practices and infusion schedule.

Families then drove to the Berea Recreation Center where we had use of the indoor basketball courts. With his basketball expertise, Herman engaged participants in a warm up, drills, tricks and shooting.





He gave tips and one-on-one skill building tools. The kids really seemed to listen intently and take his advice seriously!

This is definitely an event worth repeating!

VIRGINIA

Terry Stone, Michelle Stielper, Paul Brayshaw

One State, two chapters, multiple supporters and a united message is how we advocate here in the Commonwealth! The Virginia Hemophilia Foundation and the Hemophilia Association of the Capital Area recognizes there is power in numbers and messages are better heard from an army than from a soldier. However, the message from just one soldier can make a difference. So together they marched on Martin Luther King Day January 15th to the Virginia State Capitol in Richmond to share their stories of living with a bleeding disorder and what issues concern them.



Jeremy McPike is at Virginia State Capitol.
1 hr · 0 · Richmond, VA ·

Lovely to meet David, Matthew and Terry Stone today and thank them for their advocacy on issues relating to hemophilia and bleeding disorders.



Activist families arrived for **Advocacy Training and Richmond Days** at the Omni Hotel Sunday afternoon to catch up with friends and get the latest news on healthcare and issues that matter from HFA Senior Policy Analyst Miriam Goldstein and Becky Bowers-Lanier, Advocacy Consultant. Teens and toddlers had their own program. The group also heard from Ann Kendall, the chapter's Advocacy Workgroup Chairperson. Talking points were the continuing message about Medicaid Expansion to close the gap in Virginia, and addressing the issues with step therapy. Since there are no generic drugs to replace our clotting factor, let's not second guess the physician by letting insurance companies dictate what product to use. Step therapy is concerning for many patients as not all brands work for all people. We requested that Virginians be given a quick exception authorization should step therapy be asked of the patient, and asked that they support HB386 and SB 574 to help patients get the drug that works for them.

MLK Day legislative visits were a great success and many advocates came back from the state hill feeling heard and supported. The weather was cold, but hearts were warm as our state advocates tall and small filled in their recaps of their visits and said their farewells. Remember, if you see something, say something, but if you NEED something, DO something!

CALIFORNIA

Cindy Picos



For college students and their parents, **College & Career Day** sponsored by the Central California Hemophilia Foundation January 27th was the place to be! Held at Kiwanis House in Sacramento, the program highlighted available college scholarships for patients with a bleeding disorder, essay writing, financial aid, internship opportunities and how to apply for state jobs. Nicole Haynes, Roseville's Oakmont High School Counselor, spoke to students and parents about college preparedness, including the college application process, preparing for SAT tests and the follow-through process. Lisa Noma, another counselor from Oakmont, spoke about the financial aid process and highlighted the importance of a complete and thorough FAFSA application.

Student speakers included CCHF Jr. Board President, Elizabeth Buchmiller who spoke on preparing students for the transition from high school to

college, and Sage Chavez, Junior Board Member, spoke about the challenges of senior year and getting ready to graduate.

The information shared was especially worthwhile and well received!

NORTH CAROLINA

Xaviette Pointer-Kincy

Hemophilia Chapter of North Carolina hosted its 11th annual **Hearts for Hemophilia Casino Night** January 27th. This event is one of the Chapter's largest fundraisers in which guests arrive dressed to impress and ready to raise funds for the bleeding disorders community! Previously, the event had been held in Charlotte and has recently returned to the Raleigh-Durham area, specifically the Durham Convention Center.



All Smiles! Xaviette Pointer-Kincy and CSL's Heather Nassaur.

Great food, drinks and live music enticed guests while they participated in the silent auction, raffle and casino games. Patrick Kinas, sports announcer for the Durham Bulls, hosted the live auction as part of the fundraiser. In all, over 125 guests participated in this elegant event in support of raising funds for those living with hemophilia.

MARYLAND

Paul Brayshaw, Terry Stone and Michelle Stielper

The Hemophilia Foundation of Maryland (HFM) hosted its **Annual Meeting and Educational Dinner**



CSL's Kristen Carter of CSL (center) stopped to visit and shared a smile with Terry Stone and Paul Brayshaw.

at the Four Seasons Hotel in Baltimore February 3rd. At first glance, the gathering looks like the biggest family reunion you've ever seen - about 300 strong! As members checked in they mingled among friends and exhibitors that were on hand to meet and greet, and share all the latest news that matters. As dinner was announced, it was all hands-on deck to get everyone in the ballroom and seated because everyone was enjoying catching up. The Four Seasons in historic Charm City didn't disappoint. It was an exciting night of fun, friends and fabulous food!

As dinner was being tastily relished (and yes, there were crab cakes, a Baltimore staple!), Chapter Administrator Jamie Edwards and Emma Miller-Clark, Executive Director, recognized the many supporters of the evening's event and then presented the chapter's year in review. Every year gets better and better with unique programming, fundraisers, and networking opportunities. Oh, and let's not forget camp!

After the business portion of the annual meeting wrapped, a moment was taken to honor Bethany Swain, HFM's Volunteer of the Year for her tireless service to the chapter. Matrix Health Group congratulates Bethany on this well-deserved recognition. The dinner program was a wonderful update on Bioverativ's humanitarian efforts in cooperation with the World Hemophilia Federation. It certainly was a heart-warming reflection of corporate stewardship abroad to support many of our blood brothers and sisters who although are not here to enjoy our family reunion, are family nonetheless!

OHIO

Rania Salem

Family and friends of the Tri-State Bleeding Disorder Chapter joined February 3rd- 4th for **Family Education Conference** - a memorable weekend filled with education and fun at the Great Wolf Lodge in Mason. On hand for a very popular session called *Ask the Doc* directed toward those with hemophilia were Dr. Joseph Palascak, Director of University of Cincinnati Adult HTC; Dr. Cristina Tarango, Medical Director of Cincinnati Children's Hospital HTC along with Sommer Jones, PA-C, of Cincinnati Children's as well. Meanwhile, those with von Willebrand participated in a vWD *Ask the Doc* session, which featured Dr. Eric Mullins, MD Research Director of Cincinnati Children's HTC and Nina Turner, Nurse Practitioner UC Health.

The afternoon opened with several round table discussions as well as a special presentation by Chris Bombardier, the first person with hemophilia in history to climb Mt. Everest. Sponsored by Pfizer and with GutMonkey, Chris talked about his fantastic adventure, which was inspirational to say the least!

What else does one do after a day of education?



Take to the indoor waterpark of course! Great Wolf Lodge Hotel and Resort has a little something for everyone. Guests have exclusive access to 13 water slides, 5 pools and a lazy river! After a good night's rest, the next morning brought breakfast and farewells. Many thanks to Lisa Raterman and Helen Lamping of the Tri-State Bleeding Disorder Foundation for yet another amazing event!

VIRGINIA

Michelle Stielper and Terry Stone

There was a chill in the air the evening of February 8th in the heart of Virginia Beach, but who really cared? Not the women of the Virginia Hemophilia Foundation because they were off-duty from their family duties for a short while and freed from the nightly question of, "what's for dinner?" as they enjoyed a special **Women's Night Out.**



Michelle Stielper and Kelly Gonzalez

This evening, families were on their own, while the ladies were treated to a delicious dinner at Motsie's Sea Grill. If that wasn't nice enough, after great conversation among old and new friends, our group strolled a few doors down and were cordially greeted at Schakolad, a local chocolatier, with warm hot cocoa and the whimsical scent of chocolate. Now that's how you treat people!

While the staff prepared large, Willy Wonka-style vats of chocolate lava delight, we welcomed Kelly Gonzalez, Educational Development Specialist, who presented a unique and popular program entitled, *It's OK to Not be OK*. It was a powerful presentation as

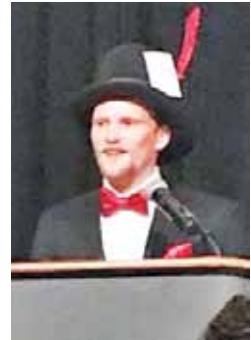
everyone identified with caring for others first and forgetting to take care of ourselves. We discussed stress and stress management techniques, and Kelly gave the women tools and ideas to make sure they knew how to identify their stress, manage it, and practice self-care. What followed were a few tears, a lot of thanks to Kelly, and a happy group of ladies who felt validated, loved and not alone! Then we were off to make chocolate, and oh, make chocolate we did!

The group indulged themselves behind the counter and made some tasty treats, which were wrapped up for us to take home to our special sweeties. Well...let's just say some didn't make it home. Anyone have a napkin? Thanks to Matrix Health Group and Bioverativ for sponsoring this enjoyable evening on behalf of the well-deserving ladies of the VHF! Looking forward to our next adventure!

INDIANA

Enrique Morey

Hemophilia of Indiana hosted its **28th Annual Hearts for Hemophilia Gala** at the Union Station Grand Ballroom Crown Plaza Hotel in Indianapolis February 9th. Filled with dining, dancing and hats! Mad Hatter's Ball was the theme for the night, with festivities including a live and silent auction and a speech from guest speaker, Zachary Crabtree. The elegant evening continued with casino-style gambling and wrapped up with dancing to Stella Luna and the Satellites. A wonderful time was had by all!



CALIFORNIA

Cindy Picos

After months of preparation, the Central California Hemophilia Foundation (CCHF) held another successful **Surf & Turf Crab Feed** Saturday, February 10th at the Sacramento Elks Lodge. Over 500 people attended this spectacular event! Proceeds will benefit the CCHF scholarship, financial aid and education programs. Volunteers began early in the morning preparing crab, tri-tip, pasta, a nacho bar, salads and desserts for the guests.





Throughout the event, guests had the opportunity to bid on silent auction items, purchase additional products to further support the event, and networking with manufacturers, physicians, patients, families and CCHF volunteers. Bonnie Leidheisl, President of CCHF, and Sean Hubbert, Vice-President of

CCHF were impressed by the hard work of the many volunteers and value the support of individuals attending the event. Bonnie and Sean expressed how they continue to be amazed and appreciate the generosity of the bleeding disorders community and reiterated the importance of this event, which helps support the foundation's programs.

NEW JERSEY

Richard Vogel

In a continuing series on the subject of products and the science behind them, this event explored the factor VIII product from Shire, Adynovate. We met at Don Pepe Restaurant in Newark February 11th for a presentation by Jean Marandola, Senior Clinical Specialist for Shire. During non-stop appetizers and dinner, we continued our conversation with the patient speaker portion presented by Jeff A., who told of his life's journey with hemophilia. As an I.V. specialist in a Michigan hospital, Jeff has dedicated his life to helping others with hemophilia through education and inspirational stories. Open and engaging, Jeff had the audience laughing and crying as he recalled how he contracted HIV through blood products. As an energetic 13-year-old, he was playing basketball and twisted his ankle very badly, causing him to leave his friends, go home and infuse.

Ten minutes after he infused, his doctor called and told his mother the factor in their refrigerator was



contaminated with HIV. Too late - after 3½ agonizing weeks, his results came in and confirmed he had contracted HIV. With a positive attitude, Jeff has lived life to the fullest - giving back when he can to the community he cares so much about.

We enjoyed our time with the presenters so much, we mingled after dessert until we were ushered out by restaurant personnel so they could set up for another event.

NEW JERSEY

Diane Horbacz Research and Education Development Specialist, BioMatrix

As students entered the room, questions began to launch before students and parents commenced the ***All Aboard the ScholarSHIP!*** presentation in New Jersey February 13th.

I led this dynamic educational presentation, which was hosted and held at the offices of the Hemophilia Association of New Jersey in New Brunswick. The program revealed trade secrets and strategies on achieving scholarship success. Ten ways to increase the odds of winning a scholarship, organization and tracking methods, as well as an extensive scholarship list was provided to all students to ensure the best possible chance at winning college scholarships. Following each program, continued scholarship support and essay review is offered to students who attended *All Aboard the ScholarSHIP!*



OHIO

Shelia Biljes

Valentine's Day is a wonderful time to tell the one you love just how much they mean to you. Matrix Health Group partnered with Shire February 15th to do just that! Our quarterly ***Couples Night Out*** was held at Moosehead Restaurant in Olmsted Falls. Over dinner, led by True Identity speaker, Rhea Houston, couples conversed on the value of taking care of your spouse, especially when so much time is spent on children with medical disorders.

We enjoyed a game called "Famous Couples," which led to the realization not many people know the name of President Trump's wife. And who doesn't know the famous partner of Mickey Mouse? Well, you would be surprised! The game brought about some great



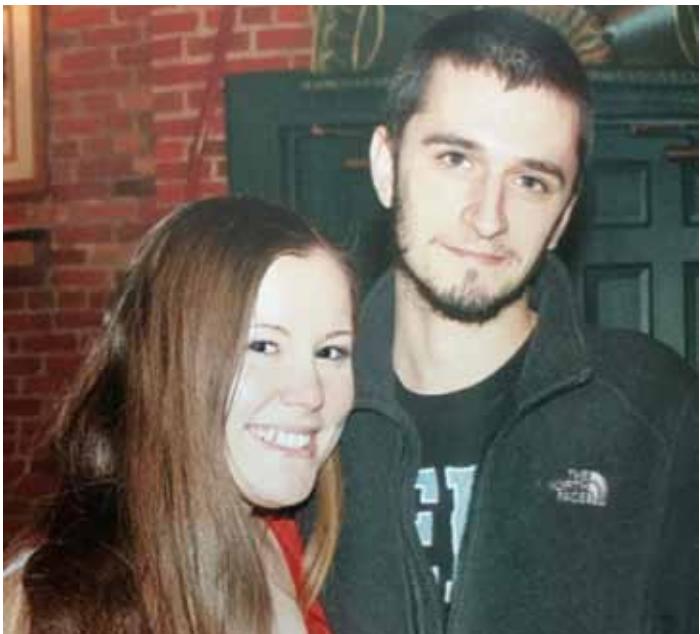
Besaira, Baby Vincent and John.



Charlene and Bob - an awesome couple!

laughs! A table was set up with all the items needed for us to design beautiful cards for each other. Heart-shaped cookies were also waiting to be decorated. We then moved on to painting wooden hearts for the occasion. Some couples chose to capture their handprints together on the plaque, while others painted designs. We ladies also learned that our men have many hidden talents!

As we gathered around the table for dessert - a yummy chocolate moose cake - each couple was given a journal and told to make one loving entry. We encouraged each couple to leave the journal out in their room and write entries for each other, capturing memories and feelings to share later in life. At the end of each couples event, everyone wishes we could stay a little longer to enjoy the fun and adult conversation, but we know the children are anxiously awaiting our arrival home, so we must go...until the next *Couples Night Out* invite!



Darby and Regan enjoy the evening!

MISSOURI

Dan Hicks and Eva Kraemer

Ahoj, mate! Many teens with college on their minds are preparing a voyage to the seas of the treacherous unknown. We had the fine opportunity of providing these knowledgeable teens the map, key and compass to guide their way to success! Taking place February 17th at Favazza's in St. Louis, Educational Specialist Diane Horbacz led an **All Aboard the ScholarSHIP!** workshop with 10 ways to increase the odds of winning a scholarship, how to write an effective scholarship essay, and even provided an updated scholarship list. There is no doubt the labor that goes into applying for scholarships is very intense. In fact, some teens may be writing lengthy essays for scholarships only to find that the scholarship has been postponed or discontinued. Thanks to Diane's passion to enrich lives through her educational programs, she provided these young sailors the sea legs needed for their voyage!



Matrix Health Group gives a special thank you to Gateway Hemophilia Association for collaborating and providing the opportunity to present this important message to its members.

NEVADA

Kelly Gonzalez

By 9:00 am February 23rd, it was snowing in Las Vegas and those of us that were preparing for the **Winter Wine Fest and Silent Auction** began to wonder if "winter" was indeed part of the event! By evening, the snow had stopped and the curtains had been drawn on the beautiful patio of Brio Tuscan Grille in Tivoli Village. Patio heaters and glistening lights set the



Chairperson Kelly Gonzalez; Board President Brandy; and NHF NV staff Maureen, Betsy and Christine.

Provider Amber Federizo and Kelly Gonzalez stop for an Instagram picture!



mood as the wine flowed, silent auction bids increased, and laughter and love filled the air. Over 180 attendees enjoyed wines sponsored by Constellation Brands and delicious food and appetizers sponsored by Brio Tuscan Grille while bidding on auction packages generously donated by the Nevada community. This brilliantly orchestrated event was enormously successful in raising funds for the Nevada Chapter of NHF to benefit the bleeding disorders community. Thank you to all the attendees, supporters, donors and of course, the Winter Wine Fest team!

CALIFORNIA

Gabriela Griffin

A community's favorite event, Hemophilia Foundation of Southern California hosted their **3rd Annual Empowerment Forum and Bloody Salsa Contest** at Pickwick Gardens Conference Center in beautiful Burbank February 24th. In addition to great presentations covering advocacy training and support led by fabulous guest speakers, the event is highlighted by a hot salsa contest full of excitement! Everybody gets the chance to taste truly delicious homemade salsa and choose spicy and mild category winners.

Thank you to SoCal for hosting another outstanding event!



Gaby Griffin congratulates winners of the Salsa Challenge "Spicy" category, Vicki and Omar.

PENNSYLVANIA

Tina McMullen

It might have been raining outside but the thunder was taking place indoors at the Thunderbird Lanes in Philadelphia during Eastern Pennsylvania Chapter of NHF's **Bowling for Fun** Saturday, February 24th. All 36 lanes were filled again this year! The event began with an opportunity to check out all the wonderful raffle items ranging from cleats autographed by Jalen Mills Eagles' cornerback, Phillies' baseball tickets, gift cards to local restaurants, Panera bread for a year, baskets full of Tastykake bakery goods and a beer tower. And of course, bowling! Attendees enjoyed pizza, snacks, beverages, baked goods and Philly pretzels! Every year, co-chairs Pat Felthaus and Cheryl Littig keep bringing the fun and excitement to the families of the Eastern Pennsylvania Chapter!



Bella, Tommy, Jake, Gianna and Johnny (In front)

VIRGINIA

Terry Stone

The AMF Sunset Lanes played host for all the Virginia Hemophilia Foundation bowlers this year in Richmond, Saturday, March 3rd. *Strike, bam, wow!* Sounds like an old Batman and Robin show complete with a dual to the finish. That show was so yesterday, but the **VHF Bowl-a-thon** is what's happening now and every March as friends and families clank the 10 pins to raise funds and have some fun! Well, there was no dual to the finish, but trust me, there was some REAL competition going on. Strike, spare, who cares! It's all for a great cause. Proceeds will help fund VHF's Camp Youngblood, which welcomes our bleeding disorders campers every July in Charlottesville, Virginia at



Camp Holiday Trails. It's a truly magical campus and provides camping for kids with special medical needs. This year's event raised more than \$34,000! S'mores for everyone! Congratulations to VHF for another FUNdraising event.

NORTH CAROLINA

Xaviette Pointer-Kincy, Peggy Klingmann

Hemophilia of North Carolina hosted its **45th Annual Meeting** in Winston Salem March 10th. Held at the Embassy Suites, this is the largest educational opportunity in North Carolina where one can learn about bleeding disorders. Community members engaged in informational sessions that included topics on advocacy, emerging trends and standards of care. Our very own Research and Education Development Specialist Diane Horbacz presented

Factor Fun to the younger community members. This typically 45-minute program went well over an hour, as they were eager to learn about white blood cells, red blood cells and platelets. The kids especially loved the coagulation slime activity. Matrix Health Group was honored to be a sponsor and contribute an instructive program for kids at the largest educational event for HNC.



Discovering components of blood.

OHIO

Shelia Biljes

Matrix Health Group partnered with Shire for a **True ID** ladies program. It was a full house at the Moosehead Hoof and Ladder Restaurant in Olmsted Falls March 15th, where northern Ohio members of the bleeding disorders community were invited to gather and Flamingle! As we wore pink attire, tables were decorated with flamingos and each attendee took home a flamingo garden stone.



Pretty in Pink - Charlene and Connie.

As the ladies waited for dinner to be served, they wrote anonymous encouraging letters to each other, to be mailed later. After dinner, we were joined by guest speaker Laura Grey of *I PRIDE*, who led us in stress-reducing breathing techniques. Laura then invited each lady to join in an inspiring art project. As always when we get together, the room was full of laughter and chatter that boosted spirits of one and all!

NEVADA

Kelly Gonzalez

Held on St. Patrick's Day, **Spring Fest 2018** began with fun and excitement as the pinches went around for those not wearing green! An event no one likes to miss, 255 arrived - eager to network, be educated and show off their Nevada pride.

While the children went to Circus Circus Adventure Dome for exciting rides and games, adults stayed at the convention center for great educational sessions. Genentech presented information on Hemlibra; Novo Nordisk addressed *Healthy Eating and Activity*; Bayer sponsored a session on *Joint Health*, while Shire covered *Insurance Roadmap* and *Believe Limited*, and NCHS led a discussion on *Powering Through*. The plethora of education sessions was beneficial for our community. Thank you to NHF NV for offering such a robust program!



Kimberly, Skyler, Justin and Parker rocked the St. Patty's Day attire while attending Spring Fest!



Now Accepting Applications for the 2018/19 School Year!

BIOMATRIX MEMORIAL SCHOLARSHIP PROGRAM

APPLY ONLINE!

<http://bit.ly/2018-BioMatrix-Scholarship>

The BioMatrix family of companies offers six \$1500 educational scholarship opportunities to students diagnosed with hemophilia or von Willebrand Disease, and in the case of two of the scholarships, immediate family members may also apply. These scholarships are in memory of several amazing individuals who brought remarkable qualities and skills together in a way that truly touched the community they were dedicated to serving. Their efforts to make a difference in the lives of people with bleeding disorders will not be forgotten and shall be

carried on with these scholarship opportunities.

We have partnered with the Hemophilia Federation of America (HFA) to administer our scholarship program. Partnering with HFA allows us to streamline and enhance our growing program with an organization that knows and understands the bleeding disorders community. The scholarship application may be accessed and submitted to HFA online or by visiting:

<https://matrixhealthgroup.com/scholarships/>



Joe Holibaugh (1972-2006)
• \$1500 Scholarship
• For MEN and WOMEN with hemophilia AND an Inhibitor



Tim Kennedy (1962-2011)
• \$1500 Scholarship
• For MEN with hemophilia



Millie Gonzalez (1953-2001)
• \$1500 Scholarship
• For WOMEN with hemophilia or von Willebrand Disease



Ron Niederman (1950-1999)
• \$1500 Scholarship
• For MEN with hemophilia or von Willebrand Disease and their immediate family members



Mike Hylton (1945-1998)
• \$1500 Scholarship
• For MEN with hemophilia or von Willebrand Disease and their immediate family members



Mark Coats (1956-1963)
• \$1500 Scholarship
• For MEN and WOMEN with hemophilia

UPCOMING EVENTS



APRIL 17th WORLD HEMOPHILIA DAY!
WORLD FEDERATION OF HEMOPHILIA
WWW.WFH.ORG

NATIONAL EVENT!



APRIL 26-29, 2018 OHIO
Hemophilia Federation of America
202-675-6984, www.hemophiliafed.org
HFA Symposium 2018
Hilton Cleveland Downtown

APRIL 17, 2018 CALIFORNIA
Central CA Hemophilia Foundation
916-448-0370, cchfsac.org
World Hemophilia Day Celebration
John Smith Community Center
Carmichael

APRIL 17, 2018 LOUISIANA
Louisiana Hemophilia Foundation
225-291-1675, lahemo.org
Louisiana Capitol Day
Baton Rouge Capitol Building

APRIL 17, 2018 MAINE
Hemophilia Alliance of Maine
207-312-4448, mainehemophilia.org
World Hemophilia Day Celebration
Seadog Brewing; Bangor

APRIL 20-22, 2018 MICHIGAN
Hemophilia Foundation of Michigan
734-544-0015, hfmich.org
SpringFest
Ann Arbor Ypsilanti Marriott at
Eagle Crest; Ypsilanti

APRIL 21-22, 2018 ILLINOIS
Bleeding Disorders Alliance Illinois
312-427-1495, bdai.org
Statewide Family Education Weekend
Northfield Inn Suites; Springfield

APRIL 22, 2018 LOUISIANA
Louisiana Hemophilia Foundation
225-291-1675, lahemo.org
Family Day in the Park
Camp Istrouma; Greenwell Springs

APRIL 22, 2018 VIRGINIA
Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Hope Blooms - Spring Fundraiser and Auction
Boathouse at Rockett's Landing
Richmond

APRIL 22, 2018 WASHINGTON DC
Hemophilia Assoc. of the Capital Area
703-352-7641, hacacares.org
Roz & Ray Reception & Play
Theater J; Washington, DC

APRIL 28, 2018 PENNSYLVANIA
Eastern Pennsylvania Chapter
484-445-4282, hemophiliasupport.org
39th Annual Fashion Show
Normandy Farm Hotel and
Conference Center; Blue Bell

MAY 1, 2018 PENNSYLVANIA
Eastern Pennsylvania Chapter
484-445-4282, hemophiliasupport.org
Community Dinner
Hilton City Avenue; Philadelphia

MAY 4, 2018 OHIO
Northern Ohio Hemophilia Found.
216-834-0051, nohf.org
NOHF Black and Blue Ball
Downtown Ritz Carlton Ballroom
Cleveland

MAY 5, 2018 CONNECTICUT
Connecticut Hemophilia Society, Inc.
860-495-0006, cthemophilia.org
Spring Social; Discovery Museum
and Planetarium; Bridgeport

MAY 5, 2018 MISSOURI
Gateway Hemophilia Foundation
314-482-5973
www.gatewayhemophilia.org
Unite for Bleeding Disorders Walk
Forest Park; St. Louis

MAY 5, 2018 NEW MEXICO
Sangre De Oro
505-341-9321, sangredeoro.org
Unite for Bleeding Disorders Walk
Balloon Fiesta Park; Albuquerque

MAY 5, 2018 TENNESSEE
Tennessee Hemophilia and
Bleeding Disorder Foundation
888-703-3269, thbdf.org
Be A Factor 5K
Loudon High School; Loudon

MAY 6, 2018 FLORIDA

Florida Hemophilia Association
305-235-0717
floridahemophilia.org
8th Annual Walk in the Jungle
Jungle Island; Miami

MAY 6, 2018 VIRGINIA

Hemophilia Assoc. of the Capital Area
703-352-7641, hacacares.org
Spring at the Mansion
Stone Mansion; Alexandria

MAY 10, 2018 CALIFORNIA

Central CA Hemophilia Foundation
916-448-0370, cchfsac.org
Legislative Days
Capitol Building; Sacramento

MAY 11, 2018 NEW JERSEY

Hemophilia Assoc. of New Jersey
732-249-6000, hanj.org
Annual Testimonial Dinner Dance
Fiddlers Elbow; Bedminster

MAY 11-12, 2018 CALIFORNIA

Hemophilia Found. of Southern CA
626-765-6656, hemosocal.org
Family Information Day
Knott's Berry Farm Hotel
Buena Park

MAY 12, 2018 NEVADA

NHF Nevada Chapter
702-564-4368, hfnav.org
Women's Retreat
Hilton Garden Inn; Henderson

MAY 12, 2018 VIRGINIA

Hemophilia Assoc. of the Capital Area
703-352-7641, hacacares.org
Family Education Day and Annual Meeting
Northern Virginia Community College, Ernst Cultural Center
Annandale

MAY 18-20, 2018 MARYLAND

Hemophilia Foundation of Maryland
410-661-2307, hfmonline.org
Family Weekend, Hyatt Regency
Chesapeake Bay
Cambridge

MAY 19, 2018 FLORIDA

Hemophilia Foundation of Greater Florida
800-293-6527, hemophiliaflorida.org
Super Hero Fun Walk
Al Lopez Park; Tampa

MAY 19, 2018 MAINE

Hemophilia Alliance of Maine
207-312-4448
mainehemophilia.org
BA-Con Annual Meeting
Black Bear Inn; Orono

MAY 19, 2018 NEVADA

NHF Nevada Chapter
702-564-4368
hfnav.org
Hispanic Heritage Event
Texas Hotel; Las Vegas

MAY 31, 2018 NEW JERSEY

Hemophilia Association of NJ
732-249-6000, hanj.org
Annual Meeting
Pines Manor; Edison

MAY 31, 2018 OHIO

Northern Ohio Hemophilia Found.
216-834-0051, nohf.org
Summer and Travel Safety Event
Whirleyball; Bedford

JUNE 1-2, 2018 SOUTH CAROLINA

Hemophilia of South Carolina
864-350-9941
hemophiliasc.org/
Annual Meeting
Embassy Suites; Greenville

JUNE 2, 2018 KENTUCKY

Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
Kentucky Zoo Day
Louisville Zoo

JUNE 2, 2018 OREGON

Hemophilia Foundation Oregon
541-753-0730
hemophiliaoregon.org
Bloody Fun Run
Lewis & Clark College; Portland

JUNE 8, 2018 MICHIGAN

Hemophilia Foundation of Michigan
734-961-3506
hfmich.org
Community Nights 2018
Michigan Craig's Cruisers
Grand Rapids

JUNE 8-9, 2018 VIRGINIA

Virginia Hemophilia Foundation
800-266-8438
vahemophilia.org
State Educational Meeting
Newport News Marriott

JUNE 10, 2018 NEW JERSEY

Nicholas Cirelli Family Research Fund/NHF
212-328-3700, hemophilia.org
Judith Graham Pool Research Fellowship Walk
Larker Park; East Hanover

JUNE 16, 2018 TENNESSEE

Tennessee Hemophilia and Bleeding Disorder Foundation
888-703-3269, thbdf.org
Race for Ian 5K
Trinity Baptist Church
Jonesborough

JUNE 16, 2018 ILLINOIS

Bleeding Disorders Alliance Illinois
312-427-1495, bdai.org
Driving fore Hemophilia
Silver Lake County Club
Orland Park

JUNE 22-24, 2018 OHIO

Southwestern Ohio Hemophilia Foundation
937-298-8000
swohiohemophilia.org
Family Fest Educational Weekend
Higher Ground Retreat Center
West Harrison, Indiana

JUNE 22-24, 2018 TENNESSEE

Tennessee Hemophilia and Bleeding Disorder Foundation
888-703-3269, thbdf.org
Annual Meeting
Hilton Lake Boulevar
Memphis

JUNE 23, 2018 MARYLAND

Hemophilia Foundation of Maryland
410-661-2307
hfmonline.webs.com
5K/10K Race to Stop the Bleeding
Quiet Waters Park
Annapolis

JUNE 23, 2018 OHIO

Tri-State Bleeding Disorder Found.
513-961-4366
tsbdf.com
Family Education Day
Coney Island; Cincinnati

JULY 21-22, 2018 NEVADA

NHF Nevada Chapter
702-564-4368, hfnav.org
Northern Nevada Family Weekend
Grand Sierra Resort; Reno

BIOMATRIX WELCOMES DECILLION HEALTHCARE



DECILLION HEALTHCARE

BioMatrix proudly announces the addition of Decillion Healthcare (Dublin, Ohio) to its family of companies! Our growing company unites leaders in the specialty pharmacy industry to improve health and empower patients to experience a higher quality of life.



NHF LAUNCHES THE 2018 RED TIE CHALLENGE

In March 2016, thousands of Americans nationwide participated in the inaugural *Red Tie Challenge* during the first-ever Bleeding Disorders Awareness Month. Now, it's time to put on your red ties again for the 2018 Red Tie Campaign! For years, as the largest nongovernment funder of research awards, fellowships and grants, NHF has been leading the fight for bleeding disorders.

To participate in the 2018 Red Tie Campaign:

TO LEARN MORE ABOUT THE RED TIE CAMPAIGN, VISIT: REDTIECAMPAIGN.ORG

SIGN: Join the fight to protect access to quality healthcare for people with bleeding disorders and for all Americans by signing NHF's open letter.

GIVE: Make a donation to support NHF's innovative research, critical advocacy, and education programs.

SHARE: Follow #RedTieCampaign on Twitter, Facebook and Instagram, and create your own red tie style with NHF's customizable photo booth.

1. Far left - blue band on his wrist
2. Far left - purple pants
3. Second from left - pants are blue
4. Second from left - shirt has "00"
5. Third from left - headband is green
6. Third from left - pants are long
7. Sign top left - pants are long
8. Center, front row - says OPA
9. Second from left - shirt is red
10. Third from right - wearing a hat
11. Second from right - shirt has "00"
12. Far right - red bandana gone
13. Sign top left - says OPA
14. Top windows blocked out
15. Center, back - shirt is red

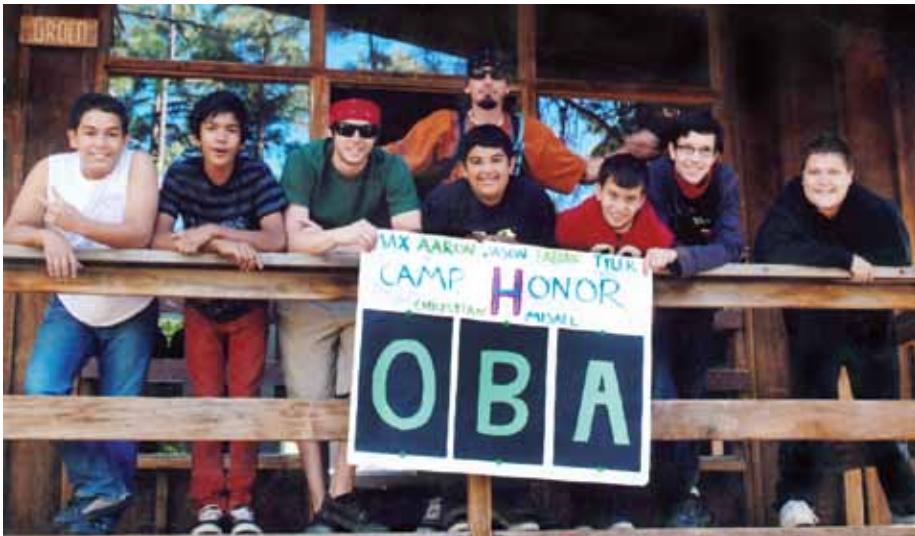


TIME FOR FUN!

ANSWERS TO PUZZLES ON PAGE 51

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

TIME FOR FUN!



HI KIDS!

CAN YOU SPOT THE 15 DIFFERENCES BETWEEN THESE 2 PHOTOS FROM ARIZONA'S CAMP HONOR?

CIRCLE THE DIFFERENCES OR WRITE YOUR ANSWERS BELOW:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____



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

Sudoku!

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

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

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DEDICATED TO MAKING A DIFFERENCE

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BIMATRIX FAMILY OF COMPANIES

