



DATELINE

F E D E R A T I O N

Issue 48 | Volume 17 | Summer 2016

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**SYMPOSIUM 2016 PHOTOS AND
AWARD RECIPIENTS. pg. 14**



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In This Issue:

2 Executive Corner

5 Help Shape HFA's Research Program



6 Community Member Spotlight: Shawn Nease

7 Member Org Spotlight: NEHA

8 What One Man Found While "Lost"



10 Control the Things You Can

12 In Absence of the Patient Voice, Health Industry Decisions Affect Quality of Life



14 Symposium 2016

18 ¡Juntos somos más resistentes! (Together we are Resilient)

20 The Amazing Race: Symposium Edition

22 Days for Girls Project



24 3rd Annual Community Fly-In



26 Getting in on the Ground Floor with Helping Hands

Dear Community Members,

Sunny, dynamic Las Vegas was a wonderful setting for our 21st annual Symposium! While the sessions and workshops always provide us with invaluable information, oftentimes the personal interactions offer some of the most profound lessons and inspiration. I remember when my husband and I were attending our second Symposium, we shared with a dear friend and Blood Brother our anxiety about preparations to remove our son's port and begin his peripheral infusion regimen. Within minutes, we found ourselves swept into this friend's hotel suite, holding needles and receiving a course in "Infusing 101." That was the first step we so desperately needed to start on the path of peripheral infusions, and it's a moment of generosity and kinship that we'll cherish forever.

We've been independently infusing at home for five years now but Nick, my 13-year-old-son, was not yet self-infusing. In my mind, I'd determined to practice the same parental discipline around self-infusing as I had with potty training, thinking "he'll infuse when he's ready" and pressure from me might actually delay the process. We'd had many conversations about it, but he simply said he wasn't there yet. When we arrived at Symposium in Las Vegas, Nick's presence prompted many people to comment on how tall he'd become. As adults will do, they marveled at how quickly he'd grown towards manhood, and as it happened, almost all conversations led to the same question: "Are you self infusing?" Self-infusion is a rite of passage, a mark of independence with the community, and people were naturally curious. Nick doesn't like to disappoint anyone but most especially his Blood Brothers. Was this going to be the push he needed?

The next day was a scheduled infusion for Nick. As we started our routine and I prepared to infuse him, I noticed that Nick's voice and body language had changed. We both knew that he knew what to do, but he had to choose to make the leap. I assured him of my faith in him. Within a few minutes my not-so-little boy had made a momentous step towards independence for a person with hemophilia, he self-infused. I've never seen a more determined young man. When he sets his mind to doing something - he does it!

What excited me even more than his successfully self-infusing for the first time, was his excitement and desire to share his news with his Blood Brothers. Typically, Nick is extremely

private and doesn't share a lot of information about his hemophilia with others. I watched him spend the rest of Symposium approaching friends and Blood Brothers with a big grin to tell them his news. Watching the happiness and pride that filled his heart and beamed from his smiling face was a memory from Symposium that I'll carry with me forever.

As you read through this issue of *Dateline Federation*, I hope our highlights of Symposium will warm your heart as they do mine. Our photos (p. 14), the description of the first-ever Spanish-speaking track (p. 18), and the report on the teen program's "Amazing Race" scavenger hunt (p. 20), will provide you with a good sense of the breadth of programming offered, but that only skims the surface. You'll have to join us in Providence, RI in April 2017 for the next Symposium to see what it is all about! This *Dateline* issue also highlights the work of some of our member organizations, including the New England Hemophilia Association (p. 7), and the Hemophilia Foundation of

Michigan (p. 22). In addition, we offer the inspiring story of Chris Seistrup's 1900-mile endurance cycling trip to raise money and awareness about bleeding disorders (p. 8), as well as Shawn Nease's second annual fundraiser, pitting brave souls against monsters in an afternoon of Dungeons and Dragons (p. 6). The capacity of our community to think creatively, act courageously, and share generously is a daily inspiration to me, as I hope it is to you.

Warm regards,

Tracy L. Cleghorn

Tracy Cleghorn
Board President





Help Shape HFA's Research Program Where should we focus?

By Wendy Owens, Staff Member

In the last issue of *Dateline Federation*, we provided an overview of HFA's CHOICE Project, a first-of-its-kind effort in which the CDC asked patients, not their providers, to report directly on their health outcomes. Using the data from the CHOICE Project as a springboard, HFA has initiated several research projects this year. We will conduct each project with the goal of using the results to improve the lives of our community, including health outcomes and personal advocacy capabilities, among other advancements. To achieve these goals, it is critical to have the community involved.



HFA is calling on you for your input on research ideas, to formulate questions for further study, and to participate personally in this exploration. Because our research is about you, we can't do it without you. HFA's research program is community-centered, community-focused, and community-driven. Ideas abound on what research topics deserve our focus but we want to hear from YOU on what topics matter most.

You can reach us at research@hemophiliafed.org. Also, look for this question on Facebook, Twitter, and our website. ■■



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Turn to page 14 for the complete photo-recap of Symposium 2016!

Community Member Spotlight: Shawn Nease, Organizer of Delves for Donors



For the second year in a row, Shawn Nease organized a charity game of Dungeons & Dragons, a fantasy tabletop role-playing game, to raise money for HFA's Helping Hands Program. *Delves for Donors II: Out for More Blood* offered gamers in Maryland and Eastern Pennsylvania the opportunity to purchase a seat in a two-hour game held at Captain Chuck's Comics, located in Essex, MD, northeast of Baltimore.

Participants, 25 in all, raised almost \$700 during the one-day event, a remarkable achievement when compared to the 2015 event that raised just over \$700 over the course of two days. The fundraising derived from the players participating in three Delves (Delves are individual mini-dungeons where the players encounter different challenges), four raffles, and a new fundraiser entitled *The End Delve*. You can bet that there was some significant monster-slaying going on that day—and all for a great cause!

Shawn is the father of twin 10-year-old boys with severe FVIII and inhibitors. He is an avid gamer and has been a strong advocate of the Helping Hands program. When asked about the next event he said "I'm eager to see what Delves for Donors can do to raise additional funds and encourage more people to step into a fantasy-world filled with adventure!" ■■

You can bet that there was some significant monster-slaying going on that day—and all for a great cause!



Shawn, left, pictured with the owner of Chuck's Comics.



Member Org Spotlight: New England Hemophilia Association (NEHA)



Since 1957, the New England Hemophilia Association (NEHA) has been serving, assisting, and advocating for the bleeding disorders community throughout New England. NEHA has been an HFA member organization since 2014 and provides programs and services, like Blood Brotherhood and Dads in Action, to more more than 1,500 individuals annually

across 6 states including, Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont. NEHA also hosts two large conferences (SpringFest and FallFest), offers Family Camp, women's retreats, and an emergency assistance program, and provides services and programming for Spanish-speaking community members, teens, and couples.



In April, the organization welcomed Rich Pezzillo as their executive director. Rich previously worked as HFA's Communications Director. Headquartered in Dedham, MA, NEHA has a staff of five and a ten-member board of directors.

On Saturday, April 23, 2016, the Hemophilia Alliance of Maine (HAM) and the Connecticut Hemophilia Society (CHS), both formed in 2010, along with NEHA board members and staff, met for the first time to discuss collaboration. The three organizations committed to forming a collaborative partnership to develop larger, longer, transformative, and sustainable projects and programs. The organizations launched a joint advocacy and policy effort across the region and will meet regularly to set goals and objectives for the next five years. ■ ■

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What One Man Found While “Lost”

By Kyle McKendall, Staff Member

When we think about typical physical activities engaged in by people living with hemophilia, endurance cycling doesn't really come to mind. Okay, it doesn't even make the top ten. Two-wheeling around your neighborhood, sure. Endurance cycling, nope. But for Chris Seistrup, a 35-year-old resident of Prescott, AZ, it sounded like the logical next step in his quest to push the boundaries set by his hemophilia. On June 11, Chris embarked for Imperial Beach, CA with nothing more than a few bags strapped to his bicycle. His starting point? Vancouver, BC — 1,900 miles away! If everything went according to plan, Chris would be on the road for 14 days by himself, with no “following car” to provide creature comforts, companionship, or other support, all to benefit HFA's Helping Hands program.

Living with a bleeding disorder adds a level of complexity to any physical activity, but it can become especially thorny with an endurance cycling event covering hundreds of miles over a span of many days. To prepare for this 1,900-mile excursion, Chris knew it was important to consider his training in incremental steps. “Knowing your body and listening to what it's telling you is key,” says Chris. The change of seasons in his hometown of Prescott provided him with exposure to varied

temperatures and elements, including snow and ice in addition to desert heat and sun, prepping Chris for the vagaries of whatever Pacific Coast weather he might encounter along his journey.

While hugging the coast line, he cycled principally on paved roads, though he did encounter several gravel paths woven into his route. The choice to be self-supported during this trek meant that Chris had to carry everything he would need with him, including camping equipment. On the fourth day into the excursion, Chris experienced excruciating pain in his Achilles tendons and thought he'd be forced onto an early train home. After adjusting the bicycle seat and powering through some intense stretching sessions, he was back on the bike and back on pace, finishing his journey in just 13 days, 9 hours. One of the greatest concerns for Chris, as it would be with any other person living with a bleeding disorder, was the inability to carry medication and bleed-related products, should he need them. To lessen that anxiety, he carried a GPS tracking unit so that his wife, friends, and fans could know his exact location, and to signal for help should an emergency arise.

A man wearing a black and white cycling jersey with "LOST ON A BIKE" printed on it, black cycling shorts, and a black cap stands next to his bicycle. The bicycle is heavily loaded with gear, including a white bag on the rear rack and a helmet on the handlebars. They are positioned in front of a weathered, corrugated metal wall. The man is looking directly at the camera with a neutral expression.

“YOU’RE A REMARKABLE GUY. WE’RE AMAZED BY YOUR POSITIVE OUTLOOK AND YOUR HUGE ADVENTURE. KEEP DREAMING BIG!”

Chris grew up with mild Factor IX hemophilia and was encouraged early by his family and doctor to participate in swimming to get the necessary exercise and recreation. Though he excelled at the endurance challenges of swimming, it wasn't an activity he particularly enjoyed, and the high contact nature of team sports were a non-starter as well. Despite his parent's reluctance, Chris gravitated toward cycling, raising enough money at the age of 14 to purchase his first BMX bike. He had found his sport! Several years later he experienced an ankle bleed caused from cycling and was forced to visit the local hospital. The doctor assured him that this bleed should not deter him from cycling, so Chris continued to focus on training for longer and longer rides. The result? He's been cycling literally for decades now with zero additional medical complications.

His perspective on the challenges of living with hemophilia has broadened and been tempered over the years. In May of 2015, he was preparing for a 100-mile ride, the first time he would attempt such a distance. Around that time his grandfather, who also had hemophilia, had been in an accident and experienced severe bruising and blood loss. It was a scary time for the entire family as his grandfather's health went downhill because of complications with internal bleeding, donor blood, and blood clotting products. Watching his grandfather cope with the challenges of aging and hemophilia was a thought-provoking experience for Chris. He saw for the first time that people living with a bleeding disorder have to consider what impact the aging process has on their treatment and self-care regimen. That insight, added to his natural impulse to help others, prompted Chris to start planning his 1,900-mile fundraising excursion. "There are a lot of other people out there who have it way worse than I do. I was inspired to do something to raise awareness among people who don't know about hemophilia and to raise money for people in our community who need it most."

Two months before he took off, and with a fundraising goal of \$5,000 in mind, Chris began soliciting donations from friends, family, and community members. He decided to call his journey "Lost on the Pacific Coast" and he turned to social media, including a crowd-sourcing platform, to promote the cause. He documented it on Instagram and a cycling blog called "Lost on a Bike," inspiring supporters to comment "You're almost there, Chris! Ride on!" and "You're a remarkable guy. We're amazed by your positive outlook and your huge adventure. Keep dreaming big!" Many donors made contributions in honor or in memory of loved ones. One couple's gift was made with this dedication: "In honor of our two great sons, who both are afflicted with hemophilia. This has not stopped them from being great husbands and dads. We pray that this donation will help others." We know that prayer will be answered because Chris exceeded his goal and **raised a grand total of \$5,500 for HFA's Helping Hands!** This vital program aids hundreds of families each year with urgent basic living expenses, the reimbursement of durable medical items, and medical/education travel and educational support for families affected by inhibitors. Thanks to Chris's love for his community, not to mention his amazing stamina and determination, many individuals and families will be helped.

For more photos from his "Lost on the Pacific Coast" adventure, and to find out what ride he's planning next, follow him at www.lostonabike.com. ■■



Control the Things You Can

By Wanda McLendon

Staying fit has been a concern for me most of my life, but it became a real struggle when I began to have children. The challenges of being a caregiver and nurturer, as well as working mom and wife were tough. Like so many new mothers, I found that in this new chapter of my life, there was less time for me, and for a long time I was afraid I would never be able to recover from the unfortunate results of indulging in too much comfort food and television.

My challenges started early in motherhood: Ryan, my first-born child, was diagnosed with Hemophilia B and at 16 months old the most frightening thing happened.

I went to check on him and noticed the left side of his body was shaking and he had a glazed look in his eyes. I immediately called emergency services and told them that my baby was shaking, seizure-like, and couldn't stop. When we arrived at the hospital they began to run tests straightaway to identify the cause of the seizure. It turned out that my baby had a blood clot on the right side of his brain and had had a stroke. Ryan was then transported to Children's Hospital for immediate neurological surgery to deal with the bleeding and to remove the growing clot. The neurologist met with us explaining that the procedure to remove the clot and ultimately stop the bleeding would be quite invasive. Ryan had a 50/50 chance of survival. If he lived, there could be damage to his brain which could result in partial paralysis.

Fortunately, the surgery was successful, even though the doctors weren't sure if he would ever walk or speak. Ryan remained in the intensive care unit for three weeks. During that time, the hematology/oncology social worker shared information about the Hemophilia Association of the Capital Area and how they would help me to understand this bleeding disorder. She also told us about the opportunities available to us to meet other families who were successfully living with hemophilia. I later met Carletha Gates who provided information about the Hemophilia Foundation of Maryland (HFM) and encouraged me to become involved.

Photos from one of HFA's FitFactor session held during Symposium 2016 in Las Vegas.

After those weeks in the hospital, Ryan was released to go home with follow up visits scheduled for occupational and physical therapy. When we returned to the hospital for occupational therapy, the doctors were astonished to see Ryan walking and waving hello. Happily, he didn't need to visit there again for OT, but he would have many subsequent visits for physical therapy. As our family grew and Ryan grew older, I would take him and his sister to play outside, ride their bikes and go swimming. I knew these activities would strengthen their agility and mobility, and help build strength. When their father was diagnosed with kidney disease, we all changed our diet.

We began to eat more green leafy vegetables (broccoli is Ryan's favorite) and fruit; no more canned food, no more pork or beef.

In life things change, children become older and there's less rambunctious activity in their teenage years. This also meant that I was less active. The older the kids became, the less I would do. One day, I found myself going to the emergency room because I was having an excruciating headache. Tests showed that the headache was the result of high blood pressure. I realized then that I had been in denial about my "healthy lifestyle." I had prided myself on being a healthy person, but was

I really?

After I confirmed my diagnosis with my family physician, I discussed my condition with my mom. She shared with me that high blood pressure was apparently prevalent in our family. It was then I decided that if I was going to live my life to the fullest, I had to get serious about living healthy. I searched our local community centers for aerobic classes to begin my quest and found a kick-boxing class close to my house. Kick-boxing was fun (and exhausting!) at the time but it only lasted for a short while. Then I began working out to exercise CDs in my basement. One day, while visiting my cousin, I heard her friend talking about Zumba® and how much fun she had in this class. I searched for a nearby class and found one on Saturday mornings. I've never looked back! I now have an exercise regimen that excites me and has kept me going strong for five years. I love it! I have achieved a healthier lifestyle, weight loss, and kudos from my doctor.



Fast forward to today: I actively participate in the HFM educational events and was given an opportunity to teach a class at our annual family retreat; and I recently participated in HFA's Symposium in Las Vegas, NV where I was able to share my love for Zumba. My goal is to encourage everyone I meet to live better through exercise and healthy living.

On June 29, 2016, I celebrated four years as an instructor with the Zumba Fitness organization. Zumba is an exhilarating, effective, easy-to-follow, Latin-inspired dance-fitness program. It is exercise disguised in dance movement: a fun way to incorporate meaningful, but not strenuous, physical activity into your day. In the past four years, I have introduced Zumba to my family, friends, and co-workers as well as the hemophilia community. My daughter and I regularly attend weekly classes where I teach, and participate in local fundraisers, known as "Zumbathons." I hope to be licensed soon in teaching Zumba classes for younger children and teens and I'm currently taking an on-line class, Plate by Zumba, focused on incorporating healthy eating into our everyday lives. Final score? Healthy living, one - comfort food, zero! ■■

About the Author:

Mitchellville, MD resident Wanda McLendon has been a licensed Zumba® Fitness instructor for the past 4 years, as well as a full-time employee with the federal government. She's happily married to Michael McLendon, Sr. and they have four adult children: Zennea McLendon, Ryan Vincent Ford, Michael McLendon, Jr. and Victoria Ford. She earned licenses in Zumba Basic, Basic 2, Toning and Zumba Gold and she hopes to become licensed soon in Zumba Kids and Zumba Kids Jr. (teens).



In Absence of the Patient Voice, Health Industry Decisions Affect Quality of Life

By Katie Verb, JD, Staff Member and Mary Richards

The recent Health Datapalooza converged payers, providers and other relevant industry stakeholders to discuss the era of big data we are entering in health care. But with too few patient organizations and advocacy leaders on the conference's agenda, Health Datapalooza exemplifies the challenges we face as the demand for big data in health care grows. If advocacy groups don't have seats at the discussion table, we risk losing the most crucial factor to meaningful health reform—the patient voice.

While we must continue to understand and expand quantitative data on our health industry, it is imperative that health reform decisions are deeply informed by the qualitative data that can only come from meaningful, on-going conversations with patients. Many health care stakeholders and policymakers are eager to work with patients, but neglect to pursue them for fear of the amount of time, energy, and resources necessary to engage individuals in discussions about their health system experience.

are able to translate the experiences of individuals into broad trends and policy recommendations. HFA's Project CALLS (Creating Alternatives to Limiting and Lacking Services) spoke directly to members of the bleeding disorders community to determine how current policies were affecting each patient's ability to treat their disorder effectively. CALLS found that many patients were forced to use pharmacies that did not meet their needs, participate in lengthy prior authorization processes, or have their medicine infused by a physician at a greater cost than the standard of care for home infusion. Such information is not only immeasurable, but also immeasurably valuable, particularly since these issues led patients to delay their care.

That's why HFA joined Partners for Better Care, a partnership of patient advocacy groups and responsible industry leaders representing more than 100 million individuals living with chronic conditions nationwide. The coalition's patient advocacy leadership recently released a bipartisan Patient Charter

Engaging patient advocacy groups as equal partners in health reform decisions is essential to improving the cost, quality, transparency and accessibility of health care.

The solution, is simple: engage the advocacy organizations that lead patient communities. It is these advocacy organizations, created by patients, that maintain expert and on-going relationships with individuals in order to understand the common issues faced by those with a particular condition. From recognizing consistent challenges in care delivery to improving the patient decision-making experience in the exchange, patient advocacy organizations see the big picture.

Hemophilia Federation of America (HFA)'s most recent initiative exemplifies how patient advocacy organizations are experts on their communities and the issues affecting them, and

that addresses the critical need for patients to have an active and formal voice in the transformation of health care, which must be facilitated through the advocacy groups that represent them.

Partners for Better Care and its members recognize that high quality, patient-centered care is available in the US, but it's not yet available to all patients. Each individual's journey through the health system is diverse and their courses of treatment do not have a one-size-fits-all solution. By understanding the diverse experiences of patients, advocacy groups can observe common challenges that, if improved, would change health outcomes within and across diseases and conditions.

While individual patients and providers are responsible for determining the medically-necessary course of treatment to secure the best possible health outcomes, all too often the successful management of a condition is dictated by whether that individual patient can fight to get affordable access to medically necessary treatments, therapies, medications, and devices. Patient groups are willing to identify and advocate for these issues on behalf of the patients they represent, but industry leaders and policymakers must be willing to listen.

Engaging patient advocacy groups as equal partners in health reform decisions is essential to improving the cost, quality, transparency and accessibility of health care. Now more than ever, patients play an active role in their health and continuously seek to own new elements of their care. As policymakers and industry leaders move toward expanded use of data and analytics to guide decision-making strategies, they must not forget to offer advocacy groups a seat at the discussion table. ■■

*This article was first published on
The Hills' Congress Blog.*

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Symposium 2016

More than 1,200 people gathered in Las Vegas, NV to take part in our annual Symposium. This was the largest family-friendly conference for the bleeding disorders community that we've seen yet! From March 31 through April 3, 2015 held more than 50 educational sessions for parents, men, women, teens, children, and stakeholders on a range of topics including navigating insurance issues, coping with pain, aquatic therapy, and raising resilient children. ■■



“It’s great to see the diversity of the group. It helps to know it’s not just a single group dealing with bleeding disorders.”



HFA Annual Awards

Each year, HFA recognizes volunteers who have made a significant contribution to the organization and the bleeding disorders community by presenting awards at Symposium. Nominations are gathered from across the country through HFA's board and 44 member organizations.

Charles Stanley Hamilton
Legacy Award:
Susan Swindle

Award for extraordinary lifetime service that encompasses volunteerism, professionalism, and leadership.

Ron Niederman
Humanitarian Award:
Dana Kuhn, PhD:
Patient Services, Inc.

Award for extraordinary service to the community via one's professional service and work.

Michael Davon Community
Service Award:
Joe Caronna,
Awarded Posthumously

Award for extraordinary service to the community via one's volunteerism and charitable giving.

Volunteer of the Year Award:
Mickey Price

President's Award:
Diane Lima



Left to right: Diane Lima, Susan Swindle, Mandy Herbert on behalf of Dana Kuhn, PhD, Mickey Price, Rich Vogel on behalf of Joe Caronna.



Left, Mandy Herbert on behalf of Dana Kuhn, PhD. Right, Tracy Cleghorn.



Left, Tracy Cleghorn. Right, Rich Vogel on behalf of Joe Caronna.



Left, Susan Swindle. Right, Tracy Cleghorn.

Thank You

HFA WOULD LIKE TO

extend a heartfelt thanks to all of our volunteers and board members who contributed their time and energy to make Symposium 2016 a success!

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“I learned how to advocate on Twitter and effectively reach policymakers. I feel more secure in my ability to advocate than ever before.”



“The speakers know how to communicate with the Spanish-speaking community.”





“My favorite part of Symposium was the **knowledgeable speakers who could easily and effectively answer the questions and concerns** that were expressed during the presentations.”



“I enjoy the interaction.

Not just between the speakers and the attendees, but among the attendees themselves.”



¡Juntos somos más resistentes! — Together we are Resilient

By Kyle McKendall, Staff Member

For the first time ever, HFA offered a comprehensive Spanish-language program at its annual Symposium, held in Las Vegas from March 30-April 2, 2016. More than 50 attendees participated in the program and attended sessions that were designed specifically for the Spanish-speaking community. Of course, HFA has delivered individual sessions in Spanish at previous Symposiums but this was the first time an entire track, comprising five sessions, printed materials, and translation services during general sessions, was offered. And prior to this program at Symposium, the organization had translated several educational sessions and made them available for presentation at the local membership organization level.

While building the materials for the Spanish-language program, HFA welcomed input from community members and it registered loud and clear that having educational materials merely translated is just a small part of delivering an effective program. As one participant stated, “We wish that we had the ability to create personalized programs for each of our communities, not just cookie-cutter programs.” In addition to content, delivery and context are equally important. This input was vital. If merely-translated content can seem generalized then it lacks the tailored approach that HFA aims to offer all community members through its services. The program track offered at Symposium was designed to resonate with the Spanish-

speaking community with a sense of authenticity, addressing the cultural differences that impact individuals.

Program sessions within the track were designed with not only the cultural component in mind, but the intent of providing enhanced networking, social support and educational opportunities. The track started with a “get to know you” which, regardless of the language you speak, evoked a sense of purpose and belonging among the participants and onlookers



in the room. The session’s facilitator held a large ball of yarn. He introduced himself and shared a story about his connection to the community, then, holding on to the end of the yarn, he passed the ball to a participant who introduced themselves and told their story. The ball kept moving, crisscrossing the room, darting in every direction, and as it passed through one set of hands after another, each participant shared a bit of themselves with

the group. By the end of the activity, the group found it had created a crazy, beautiful web that bound them all together. The facilitator used that very tangible metaphor to talk about the importance of community, the shared sense of struggle, and perseverance needed to overcome all of our battles.

The track also included an overview of HFA’s programs and services as well as a group discussion focusing on resources available to local communities. “Taking Care of YOU — Caretaker Stress Relief” was a particular favorite within the





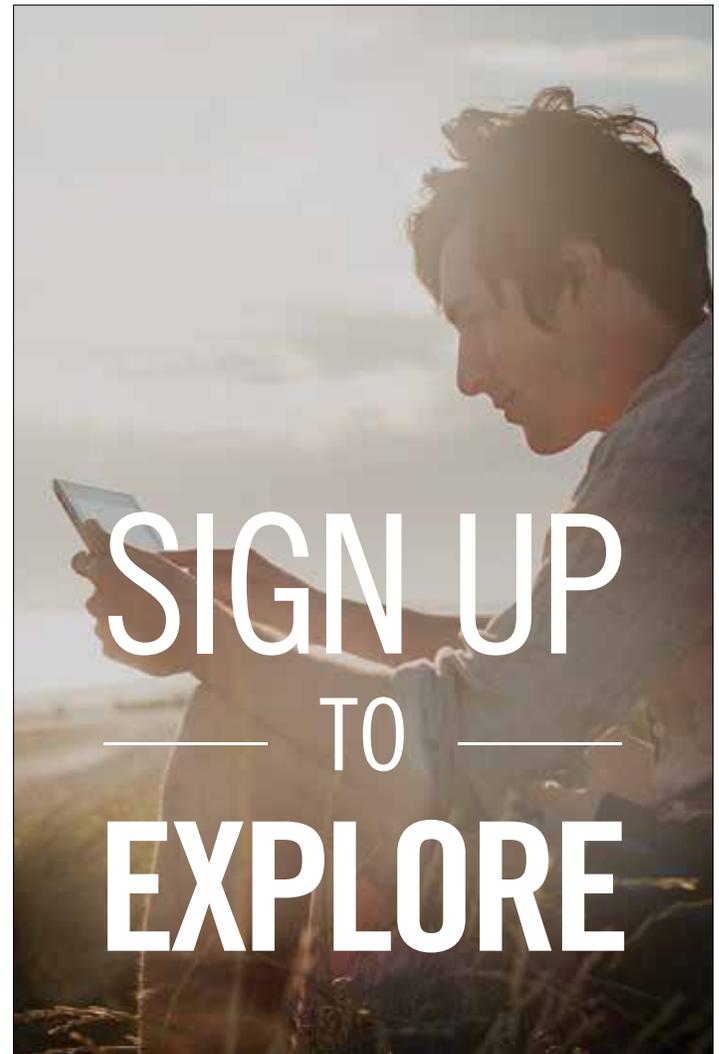
track. This session was designed to address the impact of stress on caretakers and introduce various coping mechanisms that can be used by the entire family. In addition to tips and tricks for dealing with stress, the session included a Q&A with Dave Robinson, PhD, LMFT, director of the marriage and family therapy program at Utah State University. Participants revealed afterwards that this session provided a much-needed forum for families, across the generations, to share their experiences and challenges. At the end of Symposium, a “Spanish Rap Session” was offered, allowing Spanish-speaking participants to come back together to continue the peer learning and networking that had started earlier in the week.

Martha Boria, HFA Program Coordinator, who facilitated the program, says that the families who attended “were extremely satisfied because for the first time a program was directed at them.” She remarked, “I loved seeing the camaraderie among the families and the sincerity with which they spoke of their difficulties and problems. In each of the sessions they showed friendship [and] companionship despite having just met at Symposium.”

Naturally, attendees were eager to make suggestions for additional topics of discussion for future Spanish-language programs and tracks. Some topics offered for consideration were: getting involved on a local level, applying for scholarships, and aiming for success at school or work despite having a bleeding disorder. When asked about needs beyond Symposium sessions, attendees outlined the benefits that would come from having a translated website and printed marketing materials.

HFA hopes to continue to deliver programming for the Spanish-speaking community at Symposium each year. Given that the annual conference moves throughout the country, demand for such a program will be evaluated each year. As always, the organization will continue to listen to the needs of the community and build programming to meet those needs in the most inclusive and appropriate way possible. Understanding and meeting the needs of community members and finding the funding to facilitate those needs are essential aspects of HFA’s ongoing work.

Asked for her biggest takeaway, Martha replied “seeing my Latino family loving each other, supporting each other, and willing to learn to help their families be successful regardless of the obstacles.” We say “Amén!” to that! ■■



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The Amazing Race: Symposium Edition

By Sarah Shinkman, Staff Member

Can you name the three states that do not have a Hemophilia Treatment Center? The youth who participated in this year's Teen Track at Symposium could tell you!

HFA partner Beyond Recreation facilitated an Amazing Race scavenger hunt as part of Symposium 2016's teen program. This dynamic competition emphasized advocacy, a core component of HFA's mission and the focus of the two-day track. "Our goal at Beyond Recreation is to provide intentional, entertaining, and effective programs", co-founder Anne Henningfeld said. "When we planned the Amazing Race, we started with an educational concept such as travel smarts, or dental care, and worked to build clues and challenges that would support learning in those areas. We believe that when people have an enjoyable experience, they have a greater chance of retaining the important information we are trying to relay. With teens, participation is key. A program like the Amazing Race incites participation, and encourages education through enjoyable, community enhancing activities."

After receiving detailed instructions from Anne, participants were split into small groups and given a toolkit to complete a series of challenges throughout the resort. Groups selected the challenge of their choice to start, before taking off with anticipation and a competitive gleam in their eyes!

One of the most important lessons of the race came from a visit to fictional Doctor Emory Means. Participants were expected to be prompt and those who were late to their "appointment" had to wait, losing valuable time with the doctor. Dr. Means explained treatment options for patients with bleeding disorders, including dosage and follow-up information. The teens listened intently, asking questions and taking detailed notes. To advance to the next challenge, groups had to get a form from HFA's exhibitor booth and answer questions about their appointment. This activity demonstrated the importance of active listening and personal advocacy with your medical provider.

“The Amazing Race was an exhilarating experience — it combined elements of critical thought, teamwork, and fun!” Katy, Teen Participant

Next up was the navigation challenge. To find the location of this activity, the teens had to use their toolkits, which included a map of the United States on transparency film and a map of the resort. By strategically lining the maps on top of each other, the location of the subsequent challenge—a gazebo—was revealed. The teens arrived at the gazebo, where they received instructions on how to use a compass. In today’s hyper-connected world, it was refreshing to witness young people using a non-electronic tool!

Upon successfully completing the compass activity, groups received another clue which led them to the next stage: learning magic. The teens watched in amazement as a magician performed tricks, which ultimately led them to a puzzle challenge. Teamwork was a critical component of completing this puzzle. Groups assembled a map of the United States, unveiling the number of HTCs in each state. By carefully flipping over the completed puzzle, the next clue was exposed. This challenge encouraged the teens to think about access to care nationwide, an important issue to people with bleeding disorders.

The Spa Tower hotel lobby provided the next task: several colorful beans and a piece of paper with symbols resembling a math equation. This challenge required critical and creative thinking. The solution to the bean problem was vital to finishing the Amazing Race, as the (presumed) math equation was in fact a phone number leading to the final clue.

In the next activity participants learned the value of support and communication from their teammates when they were blind-folded and told to move cotton balls from one bowl to another with a spoon. Participants were anxious to get as many cotton balls in the correct bowl as possible to earn points in the challenge. Cotton balls were flying everywhere!

Once the cotton balls were in their proper container, the teens learned the importance of knowing the rules when traveling. Plane travel can be stressful, made more so when you have to pack medication for your bleeding disorder, so the next challenge involved a suitcase and boxes of factor. The teens were asked to identify any problems they saw with the suitcase. It didn’t take long for participants to exclaim, “You can’t pack factor in your checked bag! It has to be in a cool container.” This correct response advanced the teens to their next clue.

The final task laid out the financial resources available to community members who want to pursue higher education. Advancing your education can be costly, especially when you have lifelong, recurring medical expenses. The teens were asked to build a tower with newspaper and tape as part of their application to the Indianapolis School of Architecture. Upon successfully completing a free-standing structure, groups received

a list of scholarships available to people with bleeding disorders. The last step involved using the solution from the bean activity—a phone number. By calling the number, groups were given an application code to complete the challenge and finish the race. It was an exhilarating conclusion to a great program!

The detail and creativity that went into each activity encouraged problem solving and participation from everyone in the group. The teens left the Amazing Race as stronger advocates for the bleeding disorders community and eager to share what they had learned with others.

And in case you are still wondering, Wyoming, Kansas, and Montana are the states that do not have HTCs. ■ ■

“Getting out and being active while learning about bleeding disorders was awesome!”

Jack, Teen Participant

“The teens at Symposium were enthusiastic participants, making connections with others from across the country, educating themselves, and actively creating a strong next generation of bleeding disorder community members.”

Anne, Beyond Recreation

Days for Girls Project

By Patrice Thomas, MSW, MS

We all know that access to education is a critical component to living a life in which we as individuals can provide for ourselves and our loved ones. In the US, this access is something we tend to take for granted. In many parts of the world, however, the unfortunate truth is that too many girls are kept from attending school solely because they do not have access to safe feminine hygiene products. When menstruating, these girls have no method of managing their periods and are simply kept out of the classroom. This monthly burden can be a devastating situation for girls who just want an education. In an effort to address this situation, Days for Girls International, a grassroots nonprofit, was founded to create a more dignified, humane, and sustainable world for girls through advocacy, reproductive health awareness, education, and sustainable feminine hygiene.

Laura-Jean Siggins, an HTC nurse, and the Hemophilia Foundation of Michigan, were thrilled to learn about a way that members of the bleeding disorders community could help Days for Girls. The Hemophilia Foundation of Michigan would use its resources and community members to organize an event at which hygiene kits would be put together and sent to Days for Girls for distribution throughout the world. The kits comprise reusable sewn cotton fabric pads and a bag of basic hygiene products such as soap.

In partnership with HFA's Blood Sisterhood program, the Hemophilia Foundation of Michigan chapter held their third Days for Girls event on June 2. The project was a wonderful match of community members' skills and interest in helping other girls and women who do not have access to safe personal hygiene products. Volunteers set

up an assembly line at which fabric was cut according to predetermined patterns, then sewed, then the seams were ironed flat. Volunteers at the final stop packaged the items together to prepare for distribution. Over the course of the event, more than 100 kits were completed by the volunteers!

Hearing stories from girls who benefit from Days for Girls services is heartwarming. Victoria, a 16-year-old girl living in Zimbabwe, now has a safe and healthy solution to caring for her period, thanks to Days for Girls volunteers. She is a bright girl and was determined to stay in school and was using the only thing she had access to – corn husks. The resulting untreated infections were so severe that scarring created crippling adhesions. It's not unusual to hear of young girls developing vaginal infections after they were given corn husks as a method of handling their periods.



Left picture: Jennifer Wakefield, Laura-Jean Siggins. Right picture: Jennifer Wakefield, Laura-Jean Siggins and Alaina Furr.

Over the course of the event, more than 100 kits were completed by the volunteers!



Sewing isn't taught as commonly in schools as it once was, so the Hemophilia Foundation of Michigan plans to include workshops to teach it in future programs at summer camp and year-round retreats. This project gave community members a great opportunity use their skills to help sisters who are struggling in other parts of the world. And it provided an important lesson to appreciate how lucky we are in all that we have. ■■

About the Author: Patrice Thomas has been a social worker and health educator for over 20 years. She has worked with a wide variety of populations and health issues, ranging from HIV/AIDS, sexual health education, and life skills training to wellness programs with teens and young adults. Patrice worked for the National Hemophilia Foundation from 2010 until 2014, where she managed NHF's women's health initiative, Victory for Women. Currently, Patrice is Program Services Director at Hemophilia Foundation of Michigan



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Left: Congressman Kevin Cramer (ND).
Right: Senator Tammy Baldwin (WI).

3rd Annual Community Fly-In

By Katie Verb, JD, Staff Member

On Wednesday, June 22nd, HFA brought 15 community members from eight states to Capitol Hill for the 3rd annual Community Fly-In to talk with members of Congress about key issues that affect those with bleeding disorders. We met in person with staff from 21 offices on the Hill and simultaneously hosted a Virtual Hill Day to allow participation from community across the country. More than 70 advocates emailed or tweeted their Representatives to show their support for legislation. Our in-person and virtual advocates asked their Representatives to support legislation that increases access to insurance and treatment, as well as increased funding for the government agencies that provide the research, programs, and services necessary to support our community.

HFA presented two members of Congress with a Champion Award for their tireless advocacy efforts that have impacted the community. US Senator Tammy Baldwin (WI) and US Representative Kevin Kramer (ND) were honored at our Congressional Reception for the extraordinary work for those with chronic and expensive disease. Whether it be for their work with ensuring affordable healthcare coverage or working to modernize care in this country, each of these legislators is truly a Champion. ■■





Getting in on the Ground Floor with Helping Hands

By Angela Burton, Staff Member

“I am so grateful for all that you did to make my floor look nice and safe. Every time I see my house with its new floor, it makes me think of you.”

—HH recipient living in Florida

HFHA’s Helping Hands Program supports hundreds of families within the bleeding disorders community each year by assisting with urgent basic living expenses, the reimbursement of durable medical items, medical/education travel, and educational support for families affected by inhibitors. It is our aim, and pleasure, to provide support when life presents a serious financial challenge to a family.

Recently, HFA was given the opportunity to support a single mother of three beautiful children, one of whom is an 11-year-old son with mild hemophilia A. HFA was contacted because this family’s home is situated on wetlands and was literally falling apart. The floor had developed unsafe, rotting areas that,

with just everyday use, became actual holes to the outside world. This presented a significant safety hazard for the entire family but, particularly her son with hemophilia, who had already been endangered by falling through a hole in the floor. The applicant had been making efforts to repair the home and used all of her money to repair the holes in his bedroom, the living room, and the hallway. After making these repairs and exhausting her available funds, the family still had two high-traffic areas that were in need of repair.

Thanks to the Helping Hands program and its supporters, our team was able to purchase the supplies needed and work collaboratively with a friend of the family, who provided free labor, to complete the repairs.

This program is supported by charitable donations from individuals like you! For more information about the program and to learn how you can help us help others in the community, please visit www.hemophiliafed.org ■■

THANK YOU to the following funders who make it possible to serve the bleeding disorders community!

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