



# DATELINE

F E D E R A T I O N

Issue 42 | Volume 14 | Fall 2014



“I ride to **support** those in need and to show others that a bleeding disorder **can't stop** me from being physically active.

– Kim, moderate hemophilia,  
Gears for Good rider

## Dear HFA Friends and Family,

Welcome to fall. Did I really just say that? Where did the summer go? If you have school age children, summer is officially over and you're now trying to settle in to the back to school routine. It's an exciting time as children go back to school. Some may be undertaking new journeys – perhaps they are attending school for the first time as pre-schoolers or Kindergartners, they may be transitioning to middle school, high school or perhaps college.

HFA is beginning a new and exciting journey as well. We are celebrating our 20th year! There are many things that have stayed the same over the past 20 years – our continued focus on families affected with bleeding disorders and being a consumer advocate for safe, affordable, and obtainable blood products, and health coverage.

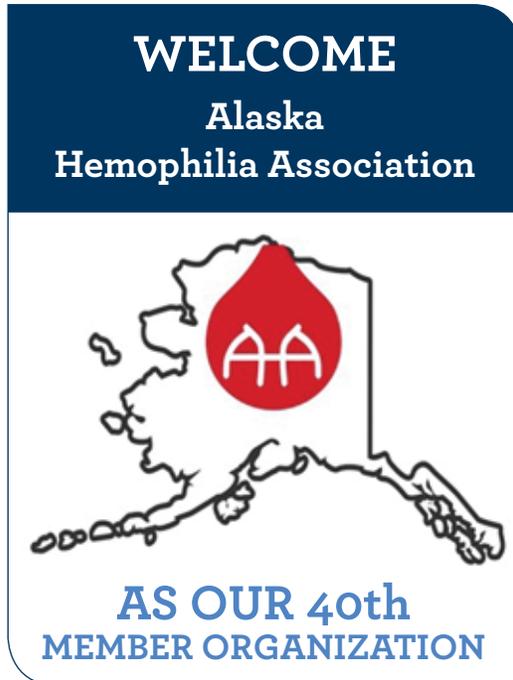
At the same time, we have seen tremendous change and growth in our organization. We are thrilled to announce the addition of our 40th member organization – Alaska! When I joined the HFA Board of Directors over 10 years ago, we had about 25 member organizations. To have grown so much is amazing! The growth is also a true testament to the fantastic work that we're doing in our community.

The work is far from over; there are numerous challenges that we, as a community, are facing. But the challenges are exciting. It's what makes us learn and grow as an organization and community – as a family! So while our children are embracing this time to undertake their new journeys, we're doing the same at HFA. I'd like to take this opportunity to extend a very warm welcome to Alaska and also to welcome our community to fall! It's an exciting time to be part of HFA!

*Warm regards,*



**Tracy Cleghorn**  
Board President




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The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the bleeding disorders community.

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# An Advocacy Corner For Real Community Questions

To help you and your family understand complicated advocacy issues like the Affordable Care Act (ACA), “Dear Addy” was created as a resource for the bleeding community. Each question submitted are real concerns and scenarios from community members across the country. Questions submitted to this column are edited in order to protect privacy and should be considered educational only, not individual guidance.

## EDUCATING THE ER

Dear Addy,

We went out of town for vacation and I had to take my son to the ER for a bleed. Unfortunately, none of the doctors were familiar with hemophilia. I knew more than they did. Instead of comforting my son, I spent my time educating doctors. Is there something I can do better next time?

Signed,  
ER Educator

## UNAFFECTED SIBLINGS

Dear Addy,

I have two sons with hemophilia and one daughter who is not affected by a bleeding disorder. My two sons get so much attention and I know that my daughter feels left out. How can I help my daughter understand that we love her just as much as her brothers?

Signed,  
Dad of Disheartened Daughter

Dear Educator,

*You are an educator and always will be one when it comes to your son's hemophilia. Because only a small fraction of people in the United States has hemophilia, it is a condition with which most doctors have little understanding or knowledge. So your experience is not uncommon, but nonetheless it's not an easy position to be in.*

*There are things you can do before an emergency occurs, and steps you can take when you and your son get to the ER to make sure he receives the best care possible.*

*Among its many resources on emergency preparedness, HFA has a Surviving The ER Toolkit that provides tried and true tips from others living with hemophilia on the steps to take before an emergency happens. The toolkit includes what to do before an emergency, what to do just before you leave for the ER, and what to do when you get to the ER. Lastly, discuss your ER experience with your son's hematologist. The hematologist may have additional tips to help you manage the experience.*

Sincerely,  
Addy

Dear Disheartened Dad,

*You are not alone. Many parents who have both affected and unaffected kids face the same challenge. HFA can help you cope and find a way for the whole family to flourish in what is otherwise a tough situation. Have a look at our Siblings Toolkit on the HFA website.*

*On the site you will find presentations (past webinars and slides), downloads (articles, blog entries, tools/documents), and links to other resources. For example, there is a webinar that reviews the social and emotional stages of childhood development, addresses common issues siblings face, and gives tried and true tips for parents on how to deal with children living with a bleeding disorder. Best of luck!*

Sincerely,  
Addy

Submit your questions to: [dearaddy@hemophiliafed.org](mailto:dearaddy@hemophiliafed.org)  
Your name will be changed in the response.

# Are you ready for Open Enrollment?

By Wendy Owens

Summer is over and already it is time to start making your list and checking it twice. No, not that list; the list of the things you need to make sure your health insurance plan covers when your open enrollment period starts. An open enrollment period is the time when individuals can enroll themselves and any dependents in Qualified Health Plans for the following year. Open enrollment usually lasts about 30 days. The first step is knowing when your open enrollment period is; the second is finding the right plan.

The Affordable Care Act (ACA) requires insurance companies to provide an easy-to-read chart of benefits for any plan it offers. This is great for the general benefit items, but for patients with chronic conditions, it is the details that count. For example, bleeding disorder patients around the country have found that their hemophilia treatment center (HTC) is in the network of providers their insurance will cover only to learn that the doctor they see at their HTC is not. In addition, many insurance companies now are limiting pharmacy choice for patients, and moving factor from major medical coverage to pharmacy coverage. This allows them to charge a percentage for the cost of factor (20-50%) versus a copay!

This is not all. Though the ACA capped annual out-of-pocket costs, some patients have to pay the full out-of-pocket limit in the first month that the

insurance policy is effective. For example, in 2015 the out-of-pocket maximum for an individual is \$6,600, for a family it is \$13,200. Already, patients with chronic diseases in California are reaching their out-of-pocket maximums in one month and they can't afford to pay. Legislation is in the works to allow California residents who quickly reach their out-of-pocket max to pay down the balance over 12 to 24 months. However, patients are still at risk for financial hardship until this and similar legislation is passed around the country.

If you are not sure, now is a good time to learn when your open enrollment starts and ends. It is typical to have a 30 day window, often in the fall. Check with your human resources department, if you can. Some open enrollment dates to keep in mind:

- **Marketplace plan coverage starting in 2015:**  
**November 15, 2014- February 15, 2015**
- **Medicare plan coverage starting in 2015:**  
**October 15 - December 7, 2014**
- **Medicaid and CHIP are open 365 days a year**

## IMPORTANT THINGS TO KNOW BEFORE SIGNING UP:

So what can you do? How do you find out if the policy you are considering is the right one? How do you plan for reaching out-of-pocket limits quickly? The checklist on page 5 can help you determine whether the insurance plan you have in mind has what you need to meet your health insurance coverage needs for the coming year.

- **Create a list of the benefits you need.** List the services you used in the past year, then think about what services you may need in the coming year. This includes use of your health care providers such as doctors and physical therapists, specialists, your HTC, your hospital, your prescription drugs, and other treatments you feel your family is likely to need. Don't forget about optical care and dental care!



- Necessary Benefits**
- Healthcare Providers**
- Specialty Pharmacies**
- Plan Options**
- Monthly Premiums**
- Yearly Deductible**

• **Create a budget.** Find out the monthly premium and deductible for any plans you consider. Remember, monthly premiums do not count towards out-of-pocket costs. If you know you will have many medical expenses in the coming year because you do regularly or you anticipate surgery or other procedure, consider paying a high premium and lower deductible to make it easier to budget. If available to you, review health savings accounts (HSA) and flexible spending account (FSA) options for your family. These are two types of health funds that let you save money to pay for certain medical expenses tax-free.\*

• **Invest the time to review plans in detail.** Allocate time to reviewing the plans to which you have access. Read the plan options carefully but don't be afraid to ask questions about the plan. Contact your human resources person for help if you have a private plan through your employer, call your insurance provider if you have a self-insured plan, or call 800-318-2596 if you are looking at Marketplace plans.

• **Check your healthcare providers.** Verify that your regular healthcare providers, HTC, clinics, and hospitals are in-network. Remember, your HTC may be in-network but the doctor you see there may not. Look carefully at the details. Call your healthcare provider to find out if they are in-network under any plan you consider.

• **Check your pharmacy or specialty pharmacy.** Like healthcare providers, pharmacies contract with insurers to provide medication and related services. You may have a specialty pharmacy, homecare, or 340B pharmacy that you prefer. It is important to check if they are in-network under the plans you consider.

• **Know the rules.** Find out if you need prior approval to see a specialist. Many health plans require that you get advance permission, called "certification," in order to have tests, procedures, or surgery that a doctor recommends.

• **Explore discounts.** Health plans may offer discounts for services like dental care or eyewear. These programs aren't insurance but they can offer savings on services your family needs, and these discounts can add up. You might be able to balance these discounts with out-of-pocket costs.

Once you make a decision, obtain a copy of your Certificate of Coverage, which provides a detailed explanation of your plan's health benefits in your plan. Review this carefully and keep it in a safe place as a reference.

In summary, to choose a health plan wisely, think through your needs, build a budget, do your homework, and seek help in making your selection. You are going to be stuck with the plan you choose for 365 days; do all you can to make sure you get everything on your list.

\*There are many support services for people with bleeding disorders. Most of pharmaceutical companies that provide therapies for bleeding disorders have co-pay and patient assistance programs. HFA provides a comprehensive list at:

[www.hemophiliafed.org](http://www.hemophiliafed.org)

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community nationwide!

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## First Regional Gears for Good Bike Ride

**Northern Rail Trail,  
Andover, New Hampshire  
June 27-29, 2014**

**28** riders arrived at the Highland Lake Inn in Andover, New Hampshire, on a beautiful Friday afternoon in June to get ready for an unforgettable weekend. Members of the bleeding disorders community in New England, as well as friends from FL, DC, and MI, gathered on June 27 to raise funds for the first regional Gears for Good bike ride. During one of New England's warmest weekends of the summer, these amazing individuals pedaled with a purpose and completed the 100 mile challenge to raise funds for HFA's Helping Hands program.



**100  
MILES**  
**28  
RIDERS**



## Fourth Annual National Gears for Good Bike Ride

**C & O Canal Trail,  
West Virginia, Maryland,  
and Washington, DC  
September 26-28, 2014**

**A**nd in September, we did it again! Our Fourth Annual Gears for Good DC bike ride was held September 26th-28, with riders from across the country gathering to start the 156 mile journey from the Paw Paw tunnel in Maryland all the way into Washington, DC. Community members, industry friends,

and supporters of the community spent 3 days pushing themselves while sharing experiences, laughter, and tears as they completed this physical challenge to help raise awareness and funds for all of us in the bleeding disorders community.

At HFA, we understand that living with a bleeding disorder can affect families not only physically and emotionally, but also financially. We are proud to be an organization that helps individuals and families going through temporary financial crisis due to reasons related to their bleeding disorder. In 2013, HFA distributed over \$95,000 in funds via the Helping Hands program. A large portion of the funds for Helping Hands are raised through the Gears for Good bike rides. This year, we continue to help families each and every day, and we need your help to continue lending a hand to those in need in our community. Please help us help others. Donations will be accepted until October 31st, 2014.

**156  
MILES**  
**25  
RIDERS**

Donate today at: [www.gearsforgood.com](http://www.gearsforgood.com)

# 100% OF THE FUNDS RAISED BY THE RIDERS

will go directly to our Helping Hands program. Help us help others by donating now!

[www.hemophiliafed.org](http://www.hemophiliafed.org)



# Project RED: The Sequel

By Lori Long and Catie Cheshire

Working to identify problems and explore solutions among the bleeding disorders healthcare system, the Care Access Working Group (CAWG) continues the efforts on behalf of Project Reaching Everyone Directly (RED).

CAWG listens to stories from across the bleeding disorders community and looks for patterns in the healthcare system. While CAWG has recognized that several factors can detriment the care our community receives, problems like geography and a lack of awareness pale compared to poor communication. Communication is never easy, but the monetary, emotional, physical, and temporal costs associated with bleeding disorder care make proper dialogue essential. Unfortunately, it's often those costs that make proper communication all the more difficult, too.

While there is no single solution to improving dialogue among the bleeding disorders community, we can begin to build a better environment together. CAWG is currently exploring patient advisory groups and ombudsman programs with community leaders, while building communications-strengthening tools for caregivers and patients. To do that, we need to hear from you, though. Please share your story with CAWG and Project RED at [voices@hemophiliafed.org](mailto:voices@hemophiliafed.org).

“We are all  
IN THIS  
TOGETHER.”

## A message as you read this article:

The stories below illustrate specific communication challenges faced by families with bleeding disorders in advocating for care. CAWG regularly collects stories and looks for emerging patterns. While these family stories do reference care at HTCs, they could be in any clinical setting where a family with a bleeding disorder does not feel heard.

Understand that while these are challenging stories, there are positive ones as well. A widely acknowledged reality is that not every HTC operates the same, and not every doctor, nurse, or social worker is the same. The CAWG and Project RED is about reaching our community to further understand what patterns exist so that we, as a community, can take action and advocate for our own care.

*Kimberly Haugstad, Executive Director*

## DINA and DAVIE

When Dina was a child she remembers that, hemophilia was treated like a bad word in her household. She never understood why until she learned about the bad blood epidemic. Dina had lots of cousins die from hemophilia: one from not wanting to get treatment due to the risk of AIDS, one from getting his tooth pulled, and another who had a head bleed. Her family would never talk about it. Now, two of Dina's three sons have hemophilia, and her family has faced several difficulties in receiving care.

When Dina's oldest son, Davie, developed an inhibitor, the nearest HTC, which is over 2 hours away, was just too far. One day, Davie developed bleeds in both an arm and a leg. Working with the HTC, Dina was instructed to administer a 100% dose of factor and call the HTC with an update on his condition. When no relief came within an hour, Dina had to pack up the family and make the 2-hour trek in to the HTC. Not only did the HTC deny that Davie had an inhibitor, but they questioned whether Dina had even infused him! Horrified by the accusation, Dana watched as Davie was infused again, this time bringing his factor level to 50%. Over the next two weeks, Davie underwent countless infusions and tests to reveal that he had a low-titer inhibitor; that is, his body was fighting his factor infusions!

“Living with an inhibitor was a nightmare,” said Dina. “My son was suffering and I couldn't do anything to help.” Davie had to be switched to a medication that could only be administered by the hospital every 2 hours. Meanwhile, Dina's other son with hemophilia, Mark, had to have prophylactic treatment through a Port-A-Cath, so Dina hired a nurse to help her other son while she was at the hospital with Davie. Unfortunately, Mark's port became infected. Dina felt hope-

## DINA and DAVIE *continued...*

less; one son battling an inhibitor and another fighting a port infection was incredibly taxing. All Dina could do was pray that everything got better for both of her sons, and soon.

This nightmare occurred 2 years ago. Even though Davie's inhibitor tolerized, Dina worries about it returning with every bleed. What's more, she lives in fear of Mark developing his own inhibitor. She also wonders if the inhibitor could have been avoided had her HTC listened to her on that long ago night.

## JANIE and JOE: The Sequel

*(Continued from our spring issue. Janie's son, Joe, has struggled with an inhibitor. Joe's HTC refused to test until Janie was able to convince a nurse to do run an inhibitor test on the sly.)*

On the same day that Joe's inhibitor was diagnosed, I called the HTC social worker to try and get my son access to a home-school teacher. She informed me that this was what "caused" the inhibitor; my son hated going to school and so, to stay home, continually lied to me about bleeds, leading me to overdose him with factor and triggering his inhibitor. She further stated that I was de-socializing him and intimated that homeschooling would cost thousands of dollars, especially once factoring in the qualifications process.

After I had slightly recovered from those verbal hits, she told me that my son didn't qualify for medically-necessary homeschooling. I tried to explain that this was impossible; not only had Joe's body had begun to swell again, but we were totally off factor. More importantly, the doctor had already prescribed homeschooling because the he felt Joe would need it. In the end, she only reiterated that I had caused Joe's inhibitor, and that my mistrust of the HTC was appalling, suggesting that I go to another HTC since the whole staff at this one was tired of me and my complaints.

When the nurse got on the phone, I repeated what the social worker had said and the social worker, now easily heard in the background of the call, flatly denied having ever said any of it. She simply said she'd mentioned cases where someone had developed an inhibitor after infusing 120 times. Crying, I told them both that if I were capable of so injuring my son — even unknowingly — that they should relieve me of my parenting responsibilities. The nurse stated this wasn't so, revisited the study.

Given the Social worker's actions and demeanor, I researched the complaint process of the hospital and expressed my concerns with the social worker. When I received a response, I was directed to a specific person who would address the issue. Unfortunately, I heard no response from this individual, and tried to start the complaint process anew. Receiving a call from the same person who handled my first complaint, I notice that she seemed colder. She was not personable and addressed me by last name only — the total opposite was true of the initial call back. She stated that she'd talked to the social worker's superior, who I learned was the nurse to whom she'd lied about our conversation, the same nurse who had secretly taken the inhibitor test. It became clear to me: she lied to her boss because she had been, at the very least, unethical (not to mention cruel).

*continued on next page...*

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## JANIE and JOE: The Sequel *continued...*

Soon after this incident, I asked the social worker to help me connect with other parents who had children with inhibitors so that I could find more support and information. Despite expressing my isolation, the social worker told me that it was against HIPAA regulations to send me even the diagnosis of a patient, let alone their contact information. The thing is, she had already done this several times in the previous year, providing me with the names, email addresses, diagnoses, and even home addresses of other families prior to my complaint. Turning to her supervisor, the nurse, I was again met with a cold response, and told that this was against the HTC's policy. Furthermore, the nurse remained cold toward me as she explained that I had the option to use an alternate HTC.

Over the four years since this happened, this social worker has done everything in her power to limit me socially. She has reduced my access to monthly cab vouchers down to twice a year and has refused to speak to me at social functions. What's more, the social worker always seems to have an excuse for avoiding us when Joe and I are in the HTC. She will reply curtly and professionally to my emails, however, but will not include me on the group messages in which I was previously included. All of her messages now come addressed both to me and her professional peers. All of this makes me feel that she is doing only the minimum to get the job done. That is, her horrific behavior is what passes for appropriate in an HTC. It's truly upsetting, as I feel that I've got no further recourse.

I hope that sharing my own lack of access can, in some small way, better our community. Please share yours as well, and we can effect change together. ■ ■

*Lori Long lives in the Southwest and has Hemophilia B. She is also raising a son (age 10) with Hemophilia B. She is passionate about building community and believes strongly in community strength making a difference in the world (even if it's just her little corner of it). Her interest in serving rural communities stems from the number of blood brothers and sisters she has in her area who live without phone, Internet, and even water service. Her interest in serving in general is inspired by her father, who died at the age of 68 from a head bleed due to a lack of access to factor.*

*Catie Cheshire, the daughter of an obligate carrier, became interested in bleeding disorders through her cousin who has Hemophilia B. Catie hopes to advance awareness among today's younger generation by becoming engaged in the bleeding disorders community and sharing information.*



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# HFA Member Spotlight:

## The Hemophilia Foundation of Northern California

By Brent Mascorro

“Who ever said dads of children with bleeding disorders weren’t involved in the community? Who ever said dads of children with bleeding disorders couldn’t share personal stories with other men who, 10 minutes before, were total strangers?”

The recent addition of Dads in Action (DIA) to the Hemophilia Foundation of Northern California (HFNC) has been instrumental in encouraging our dads to connect, participate and learn from each other. While we worried how successful we would be (Would dads who didn’t know each other open up, share, or even show?!), we were driven by the knowledge that success, no matter how small, would still be success. After all, even in last meetings of our chapter’s previous DIA group three years earlier, we could still find beautiful stories of dads bonding with sons they had never before been alone with! *It’s the impact* an event can have on just one father and his child.

Taking this into consideration, HFNC set up a modest first event goal of 10 participants. To our surprise, within days we had more than 35 people say they were going! The response to our first event was so encouraging, and it told us two things: not only did dads in our community want and need to be connected, but they had an eagerness and willingness to learn and to share. During our first gathering, we covered topics as basic as day-to-day life raising a child with a bleeding disorder, preparing for camp, and participating in sports. We had a wonderful and very well-



*The Hemophilia Foundation of Northern California Dads in Action event in June 2014.*

known inspirational story teller and author, Craig McLaughlin, join us and tell some of his wonderful stories of triumph and tribulation. Craig is a master storyteller and a very well respected member of the bleeding disorders community. After some of Craig’s stories, dads really started to open up and share both their own experiences and ask questions. This event was held at an Oakland A’s baseball game, and one of the topics discussed was how to prepare and deal with our child’s participation in sporting events.

As the father of a 2-year-old son with severe Hemophilia A, one of my first thoughts when my son was diagnosed was that he would never be able to play sports. While I always envisioned my son learning to play music and create, I also saw soccer matches and Little League games in his future. That day, Craig taught me that my son didn’t have to be sidelined; he could play any sport he wanted — except football, of course. I know I wasn’t alone in my epiphany. One of the most amazing things at our first event was witnessing fathers not only learn, but also change their way of thinking about how to deal with their child’s bleeding disorder.

One father, in a matter of two hours, went from not knowing his son could be active to explaining to the group how happy and relieved he was to now understand his son could possibly play just like the other kids at his school. The same father was almost

in tears when he said he didn't know before that day that other families were handling their child's bleeding disorder differently than his family. *Hearing the different perspectives of fathers and what we have all been through was both eye opening and emotional. Hearing another father share intimate stories of injuries and bleeds his child has been through is so helpful and powerful to other fathers.*

We are very thankful for HFA's Dads in Action program and are proud to be a host site. We are seeing the added benefits in our local community, too, from increased attendance at our other events to more dads becoming friends within the community. Dads now have each other to talk to and understand the day-to-day battles we go through, together. We have a greater sense of purpose now that we have helped other fathers by sharing tips and coping strategies. We have laughed, cried, and even high-fived so many times. Not only have we made new friends, we *have created a new community of dads within our local Northern California community.* There is always someone we can go to for support, to help us turn those long stressful, nights into better days... Dads in Action has let us know it's going to be all right! ■■



*Brent Mascorro, 41, is father to 2-year-old Lawson (Hemophilia A), and son-in-law to Robert (Hemophilia A with an inhibitor). Brent, Lawson, and Brent's wife Julia live outside Sacramento, California. Brent and*

*Julia are both active volunteers and fundraisers for both the Hemophilia Foundation of Northern California and the Central California Hemophilia Foundation. Brent is an outdoor enthusiast and encourages kids and families in the bleeding disorders community to participate in outdoor activities.*

Dads now have each other to talk to and understand the day-to-day battles we go through, **TOGETHER.**

**DAD**s in Action and MomsConnect are programs HFA offers to families through our participating member organizations. These organizations work with HFA staff to decide what topics are of most interest in their local area. Below is just a sampling of the topics and programs HFA can offer to our local member organizations to help build stronger families. If you'd like more information on these topics or how to schedule a Dads in Action or MomsConnect meeting in your area, contact our staff at: [hfaprograms@hemophiliafed.org](mailto:hfaprograms@hemophiliafed.org).

- ★ Dad... It's An Action Verb
- ★ I Never Signed Up For That: Finding Joy in Family Life
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- ★ Stop Sibling Quibbling
- ★ When to Freak Out and Calmly Pick Up the Phone
- ★ Hitting a Homerun at Your Clinic Visit
- ★ Infusion Workshop
- ★ "Been There, Done That": Growing Up With Hemophilia
- ★ Bleeding Disorders Jeopardy

*\*Full descriptions available by contacting HFA Families Coordinators.*



*HFA President Tracy Cleghorn, her son Nick, and US Senator Sheldon Whitehouse at HFA's June reception.*

## HFA 'Champion Award' Given to Four Members of Congress

By Katie Verb

This June, we hosted a successful Hill Day in Washington, D.C. alongside an online Virtual Hill Day to gain support for bill H.R. 460, The Patients' Access to Treatment Act in the US Senate, and other issues like the ability for third-party non-profits to help make payments on behalf of patients, and funding for the Centers for Disease Control and Prevention (CDC).

H.R. 460 prohibits insurance companies from charging more for drugs that they place on a specialty tier than drugs on their non-preferred drug tier. When clotting factor is placed on a specialty tier, the co-insurance payment for the patient can range from 20% to 50% of the total cost of the drug, like clotting factor.



### In total we had:

- 14 community members from 10 different states met with members of Congress and their staffs
- 239 people participated in our online Virtual Hill Day and sent letters to their members of Congress
- 127 people and 2 members of Congress attended our Capitol Hill reception
- 4 "Champion Awards" were given during our Capitol Hill Reception to: US Senator Sheldon Whitehouse (RI), and US Representatives Lois Capps (CA), David McKinley (WV), Hank Johnson (GA) for their tireless advocacy efforts

### Read more about our 'Champion Award' Recipients:

#### US Senator Sheldon Whitehouse (RI)



Senator Sheldon Whitehouse was elected in 2006 from Rhode Island. Since taking office, Senator Whitehouse has tirelessly advocated to ensure each American has access to affordable health care. As the Affordable Care Act (ACA) was being debated in Congress, Senator Whitehouse went to the Senate floor numerous times to advocate on behalf of people with hemophilia.

During these floor speeches Senator Whitehouse highlighted the extreme cost to treat hemophilia, and the importance of eliminating preexisting conditions and lifetime caps (both of which were devastating to those with bleeding disorders). In 2012, Senator Whitehouse spearheaded a Dear Colleague letter to seek other senators' support for restoring funds to our vital Hemophilia Treatment Centers. Senator Whitehouse has truly become an ally and friend to the hemophilia community.

#### US Congresswoman Lois Capps (CA)

Congresswoman Lois Capps has been a resident of Santa Barbara, California since 1963 and represents the state's beautiful Central Coast. She was sworn in as a member of Congress in 1998, succeeding her late husband, Congressman Walter H. Capps.



Congresswoman Capps is committed to helping people improve their daily lives through better schools, quality health care, and a cleaner environment. She is a respected and effective leader in Congress, especially on issues related to public health. As one of the first members of congress to cosponsor H.R. 460, the Patients' Access to Treatment Act, Congresswoman Capps took leadership in ensuring that all patients with chronic and expensive conditions continue to receive their lifesaving medication. She is truly a Champion.

### US Congressman Hank Johnson (GA)



As the US Representative for Georgia's Fourth Congressional District since 2007, Congressman Hank Johnson has distinguished himself as a substantive, hard-working legislator who delivers results.

Congressman Johnson has consistently supported legislation to ensure that all Americans have access to employment opportunities and affordable health care. As one of the cosponsors of the Part D Beneficiary Appeals Fairness Act (H.R. 2827), Congressman Johnson is fighting to ensure that all Medicare Part D beneficiaries have

the right to request lower co-pays for high-cost specialty drugs used to treat chronic illnesses. We are honored to present him with our Champion Award.

### US Congressman David McKinley (WV)



Congressman David McKinley has represented the 1st District of West Virginia since 2011. He previously served West Virginia in the state legislature.

As a grandfather to a child with special needs, Congressman McKinley is no stranger to overcoming the obstacles of disabilities. He has long been an advocate for access to health care. While in the state legislature, David authored a West Virginia law which prohibited insurance companies from canceling insurance to individuals diagnosed with HIV.

Congressman McKinley sponsored H.R. 460, the Patients' Access to Treatment Act, and has long been a Champion for those with chronic illnesses. He is invaluable in the fight of ensuring patients' access to care and as advocates, we are honored to stand with him in the fight to make specialty treatments affordable. We consider Congressman McKinley a true Champion and are honored to present him this award. ■■



Community members participating in HFA's Hill Day (from left to right): Sonji, Michelle, John P., John S., Maria, Tony, and Jeff.

# The Overlooked Benefits of Martial Arts

By Janet Chupka

When considering a physical activity for yourself or a family member with a bleeding disorder, many overlook the possibility of martial arts. Martial arts can be defined as any of the traditional forms of oriental self-defense that utilizes physical skill and coordination without weapons, such as karate, aikido, judo, jiu-jitsu or kung fu, often practiced as a sport.

Martial arts are often depicted as high contact, high intensity activities. While there are certain forms of martial arts that do use sparring and contact, many do not. When looking for a program, it is important to do your homework and ask the right questions to know what style of martial arts is right for you.

Martial arts should be considered for their many benefits beyond building muscle tone, flexibility, and general health. The

practice of martial arts also builds emotional health. Some of the biggest benefits that come from practicing any of the martial arts are self-esteem and self-confidence, self-control, responsibility, respect, and most importantly fun!

Many in the bleeding disorders community are finding success practicing the art of tai chi.

Tai chi is a practice originating from Chinese martial arts and traditional Chinese medicine. It involves a series of slow, meditative body movements that were originally designed for self-defense to promote inner peace and calm.

Tai chi can increase flexibility, strengthen muscles & tendons, aid in the treatment of heart disease, high blood pressure, arthritis, digestive disorders, skin diseases, depression, cancer, and many other illnesses. Research has also shown that tai chi helps to improve balance and prevent falls. Because tai chi movements are slow and deliberate with shifts of body weight from one leg to the other in coordination with upper body movements, it challenges balance. This technique improves balance and reduces fall frequency which is key, especially for older adults with bleeding disorders.

Whether the choice is tai chi, taekwondo, some other form of martial art, or any other sport, we encourage you to do your research to find a qualified instructor and a program that is safe and right for your needs. As always, consult with your physician, physical therapist, or HTC before beginning any physical activity or exercise program.

## BENEFITS OF TAI CHI

- Movements are low-impact and gentle, putting minimal stress on your muscles and joints.
- The risk of injury is very low.
- You can do it anywhere, anytime, and at your own pace.
- It requires very little space and no special clothing or equipment.
- It is non-competitive.
- There are lots of movements to keep you interested, and as you become more accomplished you can add those to your routine.



“My pain is gone. My high blood pressure that lead to my heart attack, resolved. Flexibility and strength, greatly improved. My braces? They now sit in the closet, collecting dust; I no longer need them, though I do occasionally look at them to remind myself of where I was. Most importantly, I experience fewer bleeds.”

– Rick Starks, 59, Hemophilia B, certified instructor and practitioner of tai chi.

“Our son began Taekwondo when he was in Kindergarten, and over the years has gained confidence and understanding of his body, and has experienced less bleeds.

Martial arts was the right decision for us.”

– Kimberly, HFA Executive Director and mom of a 12 year-old with hemophilia

## Questions to Consider Before Enrolling in Martial Arts:



### What medical training does the staff have?

(i.e. CPR, bloodborne safety, first aid, etc.)



### What overall training does the staff have?

- i. Who did this person learn from?
- ii. How long did he or she study with this person?
- iii. How long has he/she practiced this art?
- iv. Does the teacher have any experience as a teacher, or is he or she simply a skilled martial artist? Just like great football players can make bad coaches (and vice versa), great martial artists are not necessarily great teachers.



### Can I sit down with the staff before starting to educate the instructor(s) about my child's bleeding disorder?



### Is there physical contact; student to student, student to staff?



### How do you avoid getting hurt practicing martial arts? Is there protective equipment?



### Is there physical contact with breaking boards or other items?



### What is the cost of the classes/equipment?



### How could you accommodate/include my child if he has a bleed? What about pro-rating tuition if my child is unable to attend for a majority of a month?



### Can I stay to watch my child?



### Are there certain forms of martial arts that are safer than others?



### At what age can my child begin taking classes?



### Am I able to observe a class or two before committing to the classes? ■■

\*While extensive efforts are made to ensure accuracy of the content of each FitFactor article, these entries are not intended to be construed as medical advice or the official opinion/position of HFA, its staff, or its board of directors. Readers are strongly encouraged to discuss their own medical treatment, diet plan, and physical activities with their healthcare providers.

“Brazilian jiu-jitsu is the best form of martial arts for people with hemophilia.

It builds muscle strength and provides cardiovascular fitness, and is one sport where you can give 110%.”

– Darian Ross, 18, severe Hemophilia A, has practiced the art of Brazilian jiu-jitsu for 2 years.



“I wouldn't be who I am today if it wasn't for Martial Arts. I am stronger, healthier, and more confident because of practicing this sport for the past 15 years.”

– Anthony Pezzillo, moderate Hemophilia A, Taekwondo instructor and 3rd degree black belt.

“Taekwondo was the best thing I ever did for my health!”



– Jeff Kallberg, PT, severe Hemophilia A, black belt in Taekwondo, trains in various martial arts.

# The Silent “Carriers” of Hemophilia

By Rachel Neyland

**W**omen have been the silent “carriers” of hemophilia and lived with other undiagnosed bleeding disorders for too long. HFA is committed to providing women with the information and support they need to reach a diagnosis and continue that support through the stages of their life with a bleeding disorder.

HFA’s Blood Sisterhood program was established to help meet this unmet need for women. A main component of the program is to create a peer network of women to support each other during diagnosis, treatment, and day to day living. Ultimately, through furthering the conversation among women, we seek better health outcomes and a better quality of life for women with bleeding disorders. Be empowered. Read one woman’s story from Texas who was told that she was a “carrier” for years, but had symptoms throughout her life of mild hemophilia:



## Q. HOW LONG DID IT TAKE YOU TO RECEIVE A DIAGNOSIS?

When I was 22 years old my first son was born with severe Hemophilia A. I have no family history so it came as a big shock and I, like most, didn’t know anything about hemophilia. I was also told that women don’t usually have hemophilia. Then, when I was 24, my second son was also born with severe Hemophilia A. I still didn’t know much about hemophilia but tried to learn as much as possible.

In April 2013 I attended my first HFA symposium and went to a women’s breakout session. There was a hematologist there who was speaking about women with bleeding disorders. He said most women that are carriers have some form of bleeding disorder. I thought that surely I would know if I had hemophilia – I don’t bleed like my boys, so I couldn’t. He spoke about joint pain, heavy menstrual cycles, and much more. I had 98% of the issues women with a bleeding disorder face.

I spoke to other women that had a bleeding disorder and everything lined up; for many years I would tell the doctor about a specific issue and they could never find anything wrong, but I knew it wasn’t just in my head. I knew I should get my factor levels checked. In August 2013, two days after I turned 30, I got tested and found out I have low factor VIII, and that I have mild hemophilia.

## Q. HOW HAS YOUR LIFE CHANGED SINCE YOU RECEIVED THE DIAGNOSIS?

It was actually a relief to receive my diagnosis. For years, family members and friends would tell me that I wasn’t tough, that I just couldn’t handle pain, that I had growing pains, or I slept wrong. As I got older, I still had those same pains, and I was definitely done growing. It really made me feel as though I wasn’t tough. I would get frustrated because, even though I would experience pain, doctors could never find a problem. Family members would say, “See, nothing is wrong,” or “You’re a hypochondriac.” But I knew that I was too young for all of the pain I was experiencing.

After receiving my diagnosis, everything made sense. I finally had answers for my joint pain and my heavy menstrual cycles. Without a diagnosis, I had no access to factor when, in October, 2011, I had an ablation. I didn’t heal properly, which resulted in my needing a hysterectomy in March, 2014. Now, though, I had factor before the hysterectomy and for a week after. I ended up healing wonderfully.



**Q.** WHAT DO YOU HOPE FOR WOMEN IN THE COMMUNITY FOR THE FUTURE?

My hope for women in our community is that they get tested! If your child has a bleeding disorder, or a family member has a bleeding disorder, get tested. Don't put yourself on the back burner. I hope that doctors will soon take women with bleeding disorders seriously. We bleed too!

*Rachel Neyland lives with her husband Jason and their three kids, Mason (8), Gavin (7) and Emmalyn (3) in Texas. Both of her boys have severe Hemophilia A. Rachel is a stay-at-home mom who works for Hope for Hemophilia & the Texas Bleeding Disorders Coalition in her spare time.*

**Q.** WHAT WAS YOUR INVOLVEMENT IN THE COMMUNITY BEFORE YOU RECEIVED THE DIAGNOSIS?

Before my diagnosis, I was involved some with our local chapter and would try to attend events to learn as much as I could for my boys.

**Q.** HAS YOUR INVOLVEMENT IN THE COMMUNITY CHANGED SINCE YOU RECEIVED THE DIAGNOSIS?

Since finding out my diagnosis, I have become even more involved in the hemophilia community. I started working with Hope for Hemophilia, a non-profit organization that helps families and individuals in crisis caused by hemophilia.

I also started working for the Texas Bleeding Disorders Coalition, advocating for our community. My goal is to be a voice for parents of children with a bleeding disorder, and also to be a voice for women with bleeding disorders. Women do have hemophilia — we aren't just symptomatic carriers! ■■

**WHY SHOULD YOU GET INVOLVED WITH THE BLOOD SISTERHOOD?**

“HFA gave me the strength and the security to have my daughters get tested. And when I found out that both of them had von Willebrand Disease, it was not as scary as I thought it would be. I had a world of information and people to help us get through it.”

– Suzanne, mild hemophilia

**“Women do have hemophilia  
– we aren't just symptomatic carriers!”**

# I'm Not Bossy. I'm a Hemo Mom!

By Wendy Chou

You may have seen the new campaign, “Ban Bossy” that features Beyonce, Michelle Obama, Sheryl Sandberg and other prominent female figures. This campaign is focused on encouraging girls to be confident leaders, while discouraging labels such as bossy, aggressive, angry, or one of the many other commonly used epithets.

I think we as Hemo Moms are often faced with a similar challenge, where we're perceived as bossy, demanding, b\*#!%y and even crazy. The simple fact is that we need to be in control and we need to be assertive in order to advocate for our child to get them what they need. No apology necessary.

The Ban Bossy campaign is promoting activities and information sharing to move the cause forward, including a list of the top 10 leadership tips. Although these tips have been designed for girls, I've taken the liberty of translating them into a language that every Hemo Mom can understand. Hopefully, moms can use these in their everyday dealings, especially with their medical team, school, caretakers, and even family members.



Wendy,  
hemophilia mom

## Top 10 Leadership Tips for Hemo Moms:

### 1. Speak Up

You have every right to voice your opinion about what you want for your child. Most of the time you'll find that people are quite receptive and willing to help.

### 2. Stop Apologizing Before You Speak

Again no apology necessary.

### 3. Challenge Yourself

Step out of your comfort zone. Don't be afraid to request a team meeting at school or go right to the top to talk about your child or a specific incident. If that's already within your comfort zone, then maybe you can challenge yourself in another way, like volunteering at your local chapter. The important thing here is to not let fear get in the way of progress.

### 4. Ask for Help

There are so many things hemo moms need to do. First acknowledge that you need help. Then pinpoint a few specific things you need help with, and then ask. Don't be shy. You'll find that people like helping and often times just don't know how.

### 5. Don't Do Everyone Else's Work

Hemo Moms tend to take control of situations, but don't try to do everything yourself. Believe me - its not easier. And you'll end up feeling resentful. So have your partner help you infuse, get the kids to help you with chores, and call grandma to babysit.

### 6. Speak Up in Friendship

It's important to tell your friends and your child's friends (or at least their parents) that your child has hemophilia. Your friends will support you if they are truly your friends, and your child's friends' parents should know in case an emergency situation arises. Just be honest and open and people will respond to that.

## 7. Trust Your Inner Voice

When it feels like something's not right, chances are something is not right. Sometimes the best medical advice in the world isn't the right advice for your child. Go with your gut.

## 8. Change the World

Change the world by spreading awareness: wear your "I Love Someone With Hemophilia" shirt on World Hemophilia Day, share facts during Hemophilia Awareness Month, visit your state or national legislators to talk about the issues that matter to you, educate yourself about global issues facing bleeding disorders. Little things make big a difference when we are all doing something to make the world a better place.

## 9. Remember: It's Not Always Easy to Speak Up, But It's Worth It

Sometimes it can be tough to be direct about what we want for our child. It may feel like we're going against the grain or opposing advice of a well-respected professional. But it's important to speak up and have that dialogue. It doesn't

have to be your way or the highway, but you are certainly entitled to express your concerns and discuss anything related to your child's well-being. Another positive consequence of doing so is that you're modeling this behavior for your child and letting them know that you are their advocate and that eventually, they can be their own advocates.

## 10. Practice

You'll have many chances to practice speaking up and advocating for your child - at school, the hospital, the playground, playdates, family gatherings...the list goes on. There's no shortage of opportunities. That's for sure.

Remember - it's up to us to lead, educate and advocate for our child. While we might be called bossy, controlling, or angry, we'll sleep better at night (and so will they) knowing that we've done our best to keep our child safe. ■■

*Wendy lives with her three children Kaya (15), Tai-yan (15) & Khaliq (13) in Brooklyn, NY, HFA Board Member, and Vice President of the New York City Hemophilia Chapter (NYCHC).*



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At CSL Behring, we are committed to providing treatments and supportive services that make a meaningful difference in the lives of people with bleeding disorders and those who care for them.

We set out on this journey with you more than a century ago, starting with the development of treatments for those with rare and serious diseases.

As we look to the future, we see the promise of new innovations and opportunities—just as we always have.

**Over the years, we have never lost sight of what matters most: you and the countless others who inspire our efforts every day.**

COAGULATION

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# Brighter Outlook for Community Members Affected by HCV

By John Reed and Mark Antell

**H**epatitis C (HCV), often referred to as the “silent killer,” has been a serious crisis for the bleeding disorders community, who contracted the disease from contaminated blood products prior to the early 1990s. Treatments exist, but with many difficult side effects and mediocre efficacy. However, advocacy in the bleeding disorders community has contributed to the current availability of new treatments and the likelihood of additional therapy improvements.

Mark Antell and John Reed are two men living with hemophilia and HCV. Read their personal experiences of enduring older treatments, advocating for better access to therapies, and finding success with newly available treatments.

*\*Note: This article is not intended to be construed as medical advice or the official opinion/position of HFA, its staff, or its Board of Directors. Patients are strongly encouraged to discuss their own medical treatment with their healthcare providers.*

## Why has HCV treatment been difficult in the past?



**JOHN:** As a very involved patient, I have seen firsthand innumerable horror stories of treatments involving PEG and RIBA. These treatments did not work and put people through the most horrific side effects we have seen in a long time. As a pharmacist and a patient, it was disheartening to me that we had no better alternatives to offer. I

was like most people in the hemophilia community, “waiting on a new drug” — until such time that I could wait no longer.



**MARK:** I tried Interferon and RIBA ‘therapy,’ an experience which was among the worst in my life. Not only was it unsuccessful, but shortly thereafter I experienced several transient but acute attacks of liver inflammation that caused oedema, ascites, and bleeding varices. Knowing that advancing hepatitis threatened my survival as well as that of others in similar circumstance, I became

an advocate, and with Paul Brayshaw (then HFA President) created an informal group (People with Bleeding Disorders and HCV) to lobby against barriers preventing the most rapid possible development and availability of improved HCV therapy.

## How did you proceed with advocating for better access to HCV therapy?

**MARK:** In 2009, the standard medical advice for almost anyone with HCV was treat — treat now. But the personal reports from our community mirrored my own: high rates of therapy failure, and nasty side effects followed by rapid progression of disease. Not only were better treatments needed, but for those with advanced HCV they were needed now.

## And what were your plans and goals?

**MARK:** Our first goal was inclusion of people with bleeding disorders in clinical trials of advanced HCV therapies. Until recently, members of our community were often excluded. Even when allowed to participate, requirements for liver biopsy — a dangerous procedure for us — were dissuasive. Knowing the importance of a united community voice, we focused on buy-in from the HFA and the National Hemophilia Foundation (NHF), on a petition to FDA requesting focus on our need for better therapy. FDA called a hearing on the matter, which resulted

HCV is often referred to as the  
**“silent killer,”**

and is the leading cause of death in adults with hemophilia.

in their removing exclusionary language from their clinical trial guidance.

We also joined coalitions with similar charges, one of which successfully lobbied Congress to change FDA enabling law to encourage expedited availability of 'breakthrough therapies' when patients have poor medical options and desperate need. This change has led to/resulted in rapid progress in development and approval of better HCV therapy.

Next, we pushed for a large clinical trial for our community. One company developing a product with a good safety/efficacy profile agreed to sponsor a trial, and about a dozen Hemophilia Treatment Centers signed on to participate. Over 100 people with bleeding disorders are now taking otherwise unavailable advanced therapy.

## Can you share more about the latest HCV drugs?

**JOHN:** Promising combinations on track for yearend or early next year release include:

- **Sofosbuvir/Ledipasvir is extremely effective against both types 1a and 1b, and has shown very few side effects so far. A trial of this combination specifically for hemophiliacs, is now underway.**
- **Sofosbuvir/Daclatasvir, which is pan-genotypic (meaning effective against all types of hepatitis), is relatively side effect-free and should be available before the first of the year. This is a promising treatment for patients with types 2 and 3.**
- **Sofosbuvir/GS5816 is also pan-genotypic and is another regimen that is being looked at with much anticipation.**

*continued on next page...*

“Knowing that advancing hepatitis threatened my survival,  
**I BECAME AN ADVOCATE...**”

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# Almost all patients with hemophilia who used factor products before 1988 were infected with HCV.

- **Asunaprevir/Daclatasvir, which seems to be fairly specific for Genotype 1B, is already on the market in a couple of countries.**
- **MK5172/MK8742 has shown very good results and a very good side effect profile. This combination is now in a trial specifically targeting the co-infected population.**
- **The ABT-450/r/ombitasvir, dasabuvir and RIBA combination has also shown favorable results.**

## How have you personally been affected by these new therapies?

**JOHN:** Last October, I received bad lab results showing that I had Stage 4 Cirrhosis. I actively started pursuing new treatments that were due to be approved by year-end. In January, I had a FibroScan, which is a test that is far more accurate than the standard blood test for HCV progress (some feel it may be as accurate as a biopsy). It revealed that my liver was in much better shape than I had first thought. Nevertheless, I still sought active treatment. By spring, my physician and I had settled on Sovaldi/Olysio as a treatment regimen and sent all the gathered paperwork we had, not only on effectiveness, but also cost benefit. I finished up in July after 12 weeks; I am now Hepatitis free and show few side effects. Mark started this therapy in May after an attack of bleeding varices. His positive treatment experience is similar to mine. Had it not been for the work of patients like Mark and Paul, advocating not only for ourselves but others, I do not know if any of us would have been in a situation to take advantage of these new treatments.

## Any lessons? How do you view the future of HCV for people with hemophilia?

**MARK:** Advocacy for yourself and family is powerful. It is important as well to learn and work with a community of people with similar issues. Persistence is necessary. Most of the leads we pursued did not work out.

**JOHN:** We are excited about what the near future holds, and have made a commitment to ourselves to try and make sure that everyone in the US with hemophilia has a chance at a cure over the next two years. We feel this is a reachable and reasonable target. We want to thank HFA in advance for their support on this project. ■■

*Mark Antell has Hemophilia A. He serves as the Co-Vice President of the HFA Board of Directors and is a Principal in People with Bleeding Disorders and HCV.*

*John Reed is a pharmacist with Hemophilia A who serves as the Co-Chair of the HFA Blood Brotherhood Committee. He is also a Principal in People with Bleeding Disorders and HCV.*

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*John and Carol Reed*



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# CONGRATULATIONS

## to the HFA Scholarship Winners!



### Sydney

#### School of the Art Institute of Chicago

The HFA Artistic Encouragement Scholarship will help me to achieve my goals in fashion. I am appreciative to HFA for this chance to pursue a creative field at a wonderful school.



### Emily

#### University of Nebraska Medical Center

This support from the bleeding disorders community will help me tremendously during my education to become a physician assistant, where I can treat my own patients with the same amount of respect and empathy that I have received from my own hematologists.



### Cassandre

#### Washburn Institute of Technology

This scholarship means I can pursue my education without causing my family added stress. I look forward to using my nursing degree to give back to the hemophilia community.



### Steven

#### Salt Lake Community College

This scholarship not only eases my burdens as I pursue legal studies, but it also reminds me how lucky I am to be a part of the bleeding disorders community.



### Justine

#### Nebraska Wesleyan University

I always looked up to many in the medical community as heroes. With this scholarship, I will be able to study biology, and hope to join them one day.



### Mihir

#### University of California, Berkeley

The bleeding disorder community has always provided the support, kindness, and opportunities that I've needed to succeed thus far in my life. This scholarship will help me on my path to become a doctor.



### Natalie

#### University of Kansas

My bleeding disorder has given me a unique perspective on life, which I hope to cultivate through journalism. This scholarship has allowed me to accept an internship next semester and grow in my studies.



### Damian

#### Texas A&M University

Thanks to this scholarship, I can continue my education and, ultimately, give back to the community that has given me so much and made me who I am.



### Michael

#### Indiana University

This scholarship will help me pursue my passion and study medicine. As a medical provider, I hope to give back to the bleeding disorders community, which has helped to make me who I am today.



### Kathleen

#### Boston University

This scholarship will help me become a marine biologist. The oceans have always been my version of therapy after treatments for my blood disorder, and I'd love to help preserve its creatures for the future generations.

# HFA's Policy and Advocacy: Through the Eyes of Interns

By Stephen Fitzmaurice

Earlier this summer we welcomed our summer policy & advocacy interns to our DC office. Lewis and Maria are part of the bleeding disorders community and were chosen to participate in a 8 week internship because of their leadership qualities and interest in the field of policy and advocacy. Throughout the summer, Lewis and Maria participated in:

- Legislative, policy and advocacy training
- Build communication and media skills
- Attended hearings and Capitol Hill office visits
- Visited Executive Branch Agencies
- Worked on projects with APLUS and PPTA
- Authored a specific policy work paper or issue brief
- Supported HFA staff on activities including: Dear Addy, Action Alerts, social media outreach
- Worked with their local HFA member organization



Lewis and Maria touring a Grifols plasma donation facility in July.

Thank you to Baxter for giving HFA a grant to make this internship possible. Learn more by reading their first-hand experiences:

## 1). What was your favorite part of your summer at HFA?

 **Lewis:** My favorite part of the summer at HFA was being a member of a small but highly effective policy and advocacy team. I always felt like my input was valued and saw how my work had a direct impact on the community. A highlight for me was attending congressional hearings where I could see how the bleeding disorders community fits into current legislation and bring this information back to HFA to ensure they stay up to date with trends in health policy.

 **Maria:** I loved learning about the latest developments in healthcare policy while attending briefings, lunch meetings and hearings on the Hill. I also really enjoyed touring the plasma center where I learned about issues of safety in plasma collection.

## 2). What was the most surprising thing you learned over the summer?

 **Lewis:** HFA's extensive network of professional relationships surprised and impressed me. Over the last 20 years HFA has built up an excellent reputation in Washington. By maintaining working relationships with congressional offices, federal agencies and related nonprofits, HFA is able to provide extensive services and influence policy in a big way.

 **Maria:** I learned about the process of donating plasma and how complicated this process is in order to insure that the products that come from plasma are safe.

## 3). What was the most important thing you learned?

 **Lewis:** This summer reinforced the power of effective communication. Health policy is a very broad topic and even when focusing on a specific disease like Hemophilia it is easy to get lost in the details. Powerful messages are delivered by identifying the crucial information and understanding the audience. I was able to develop my oral and written communication skills through this internship by participating in meetings with congressional staffers, writing issue summaries and blog posts like this one.

 **Maria:** The most important thing I learned was how incredibly critical it is that advocates listen to the to the community, the actual patients that HFA represents. Consumers must be heard when working through the public policies that impact their treatment and well being.

#### 4). What advice do you have for others interested in applying for this internship?

 **Lewis:** My advice to anyone interested in applying for this internship would be to gain some familiarity with current trends in federal health policy in order to hit the ground running in Washington. Policy and advocacy work requires careful study from many perspectives such as sociology, statistics, and medical science so a strong background in a related area would make you a better candidate for any health policy related job.

 **Maria:** Ask questions. Get to know the professionals in the office and learn what they do. Be useful. HFA has an amazing and dedicated team and each member plays a unique role. That's worth learning about and supporting. HFA has many different dimensions that go beyond advocacy. HFA staff and volunteers work together to make sure that consumer's needs are heard and respected.

#### 5). How has this internship helped you to become a stronger advocate and leader?

 **Lewis:** This internship offered a lot of freedom with high professional expectations. Helping prepare and run the successful Hill Day was a great opportunity to practice my leadership and advocacy together working with HFA's team and our community member advocates at meetings with federal legislative offices throughout the day.

 **Maria:** I have become more informed about the intricate issues pertaining to hemophilia health policy and therefore have become much more confident as an advocate.

#### 6). How are you going to stay involved in the bleeding disorders community?

 **Lewis:** I will stay involved in the bleeding disorders community by continuing to participate in HFA's Blood Brotherhood Program and volunteering at Camp High Hopes. I have always tried to connect my experience with the bleeding disorders community with my academic pursuits and hope to take policy analysis and genomics courses in college in order to gain a better understanding of the issues facing our community.

 **Maria:** I am hoping to become a full time health policy advocate or at the very least to support my local chapter by volunteering with different projects. ■ ■

*“I left HFA's Hill Day feeling inspired that I can make a difference.”*

Maria, Policy Intern

## Baxter's Vision: PURSUING A LIFE WITHOUT BLEEDS one person at a time

**Our pursuit will continue until a life without bleeds is a reality for all.**

**OUR PROMISE TO YOU CAN BE SEEN IN EVERYTHING WE DO.**

For more than 60 years, Baxter has consistently pursued advancements in the treatment of bleeding conditions. Through our leading investments in research, vast array of programs and support, and people who are dedicated to serving you every day, we partner with you on your life's journey to strive toward our vision.

We have a bold vision for the future of bleeding conditions: "A Life Without Bleeds." We're passionate about this vision—it inspires us, motivates us, and defines us. Baxter is dedicated to doing everything we can to help make your life better by delivering cutting-edge treatments and an extensive selection of critical resources. We have more than 10 ongoing clinical trials, including those in hemophilia A, hemophilia B, inhibitors, von Willebrand disease, and acquired hemophilia A. For people with bleeding conditions, the future has never been brighter.

Our proven past, the advancements we're making today, and our passion for the future fuel the Baxter promise. **Our relentless pursuit continues until a life without bleeds is a reality for all.** This promise to you can be seen in everything we do, and this is what makes us the company we are.

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