Although advocacy is year-round in the bleeding disorders community, winter is the time when our state and national organizations come together for visits with lawmakers on the state and federal levels.

On Sunday, November 18, HACA had an advocacy dinner to talk about the issues facing the community on both levels at Heavy Seas Alehouse in Arlington, VA.

Miriam Goldstein of the Hemophilia Federation of America talked about issues facing the bleeding disorders on the federal level. With the election of a majority Democratic Congress, no direct attacks on the Affordable Care Act are expected. However, a pending lawsuit – Texas vs. the United States – has some concerned. This lawsuit questions the constitutionality of the ACA since the tax relief act was passed earlier this year (for more details, click here). Miriam also talked about accumulator adjustors, short-term health plans and other policy decisions that will influence the long-term health of the ACA.

Becky Bowers-Lanier of B2L Consulting, who works with HACA and the Virginia Hemophilia Foundation on state issues, talked about the expansion of Medicaid.

Thanks to our event sponsors, Genentech and the Hemophilia Federation of America, for allowing us to provide this important educational event.

Continued on page 3
Volunteers Needed

The NBC-4 Health & Fitness Expo is coming up on January 12-13, and HACA needs volunteers to man the booths both days.

Hours on Saturday are 9:00 a.m.-5:00 p.m., and shifts are 8:30-11:00 a.m.; 11:00 a.m.-1:00 p.m.; 1:00-3:00 p.m.; and 3:00-5:00 p.m. Sunday hours are 9:00 a.m.-4:00 p.m., and shifts are 8:30-11:00 a.m.; 11:00 a.m.-1:00 p.m.; and 1:00-4:00 p.m. The event will take place in Halls B and C at the Washington Convention Center.

If you have a minor child or teen who would like to volunteer for service hours, an adult must accompany him or her during their shift. To register, click here.

vWD Event

HACA is partnering with CSL Behring to present an art workshop and vWD education program on Saturday, January 26, from 11:00 a.m.-2:00 p.m. at VisArts in Rockville, MD.

Come explore painting without a brush! Fluid painting is a type of abstract art that uses acrylic paints mixed with different pouring mediums to create a fluid, flowing consistency. The acrylic paints react with each other when combined to create extraordinary patterns and designs.

This class will focus on pouring techniques such as puddle pouring, dirty pour, and swiping. Each student will complete two paintings in the class. The canvases will need to be left at VisArts for a week after the class for drying and glaze time.

There will also be an education program on von Willebrand disease as well.

Sign up here to participate.

Women’s Group Updates

The women’s group will get together on Sunday, January 27, from 5:00-7:00 p.m. at Sweetwater Tavern in Falls Church. It will be an informal social gathering and dinner; plan to join us! Click here to register.

Great news! HACA will return to Meadowkirk at Delta Farm for a two-night retreat September 6-8, 2019. Look for more details as the year progresses, including some surveys on topic ideas. We had a memorable event this fall, and look forward to another one in 2019!
Advocacy Events

The 2019 Advocacy Training and Richmond Days event will take place Sunday, January 20 and Monday, January 21 at the Omni Hotel in Richmond. The event starts on Sunday with advocacy training starting at 1:45 p.m., and includes separate programming for adults, teens and children. There’s childcare for ages 5 and under, and dinner and overnight accommodations will be provided.

On Monday, the day will start with a breakfast at the Omni and will be followed by meetings with legislators at the Pocahontas Building.

Remember, this is a family friendly event – kids of all ages are welcome! Overnight accommodations are covered as well. The chapter can help with transportation through distribution of gas cards and can also help with the parking fee at the hotel if needed.

RSVP by January 2 to reserve your hotel room and make an appointment to meet with your legislator. Click here to register.

The Hemophilia Foundation of Maryland will have its Maryland Advocacy Days February 18-19 at the Westin Annapolis. The event kicks off at noon on Monday with lunch and advocacy training, followed by dinner and role playing. Members will walk the halls of the state house on Tuesday and meet with their local legislators. Register by contacting Emma Miller at Info@hfmonline.org

NHF’s Washington Days is coming up a little later this year. It will take place March 27-29 at the Hyatt Regency at Capitol Hill. This is a great opportunity for people affected by bleeding disorders to advocate for issues that are important to them. Last year’s Washington Days had more than 500 volunteer advocates from 47 states that met with legislators and staff to discuss maintaining key patient protections in the ACA. Look for more information on registering in January and February.
HACA’s Families of Young Children group met at Montpelier Farms in Upper Marlboro, MD, on October 27.

The kids enjoyed a variety of attractions, including a hayride, corn maze, plenty of play structures, farm animals and much more.

The group will meet again in February 2019. Look for more details to come in January. The Families of Young Children group is for families that have a child age 5 or under with a bleeding disorder.

Thanks to Novo Nordisk for supporting the group in 2018.

*Photos by Bethany Swain*
On Sunday, November 11, Two Twisted Posts Winery in Loudoun County held its second annual fundraiser for HACA. Several HACA families stopped by to enjoy the beautiful fall day, delicious Virginia wine and music by iliandi.

The event was organized by Lynda Dattilio, a nurse at Children’s National Medical Center, whose family operates the winery. Several members of the Children’s HTC were in attendance, including Lynda, Dr. Michael Guerrera and physical therapist Eena Kapoor.

A special thanks to Brad and Theresa Robertson, proprietors of Two Twisted Posts, for hosting a benefit for HACA and for their generous donation to the chapter.

Two Twisted Posts Winery is located 12944 Harpers Ferry Road in Purcellville and is open on the weekends.
Ceremony Honors Outstanding Teens

The 4th Annual Teen Impact Awards honored 70 teens in the bleeding disorders community for creating a positive impact in their home, school or community. Kicking off opening night of the National Hemophilia Foundation’s Bleeding Disorders conference, the Teen Impact Awards were hosted by Patrick James Lynch and featured guest presenters included Super Bowl champion Josh Gordy and mountaineer Chris Bombardier, as well as NHF Education Program Coordinator Nikole Scappe and members of the National Youth Leadership Institute.

Attendees of this year’s show entered the theater to find themselves at a taping of fictional “Reasonable Hour Night Time Show” with host Patrick James Lynch as a late-night comedian, quipping jokes about life with a bleeding disorder with his on-stage bandmates, before inviting attending awardees up on stage as “invited guests” to give more insight into what inspired their impactful actions. Three honorees were further featured in “Spotlight Videos” that brought cameras into the teens’ homes and lives to capture their impressive commitments firsthand.

HACA’s own James Cosman was honored at the awards ceremony.

I am humbled and inspired by people who never give up – by communities who work hard to support their members and, create a strong sense of belonging and empowerment. This year marked the 70th annual national conference put on by the National Hemophilia Foundation in October. This was the FIRST year with the new title “Bleeding Disorders Conference.” Nearly 3,000 were in attendance from all over the world.

It was a jam-packed weekend, filled with educational sessions, connecting with others and seeing old friends. It was humbling to speak with Baiba Ziemele from the Latvia Hemophilia Society. Listening to her struggle to bring factor not just to her family, but to her country, was humbling.

We were able to attend a pre-screening of “Bombardier Blood.” Meeting with Chris’ Bombardier’s mom was probably one of the highlights for me. Watching the movie and meeting her, motivates me to stand behind James and never let a bleeding disorder stand in his way!

I may be a little biased, but by far my favorite session was the Teen Impact awards. 70 teens were nominated by their chapters for doing great things in the bleeding disorders community and in their local communities. As a parent of one of these kids, I found it humbling, and heartwarming as I sat next to another mom who put it in words that I had been feeling: “This is just who he is.” It reminds all of us that this incredible community of kids can do amazing things. Our families, but especially our kids, never give up.

It was amazing to see NHF reach out to the rare community, and for me I felt more connected than I have in a long time. It was amazing to relate to other families whose journey isn’t so straightforward.

The chance to listen to other families’ journeys gives you hope and a will to continue to fight. We are hopeful for things to come.
First, I want to thank HACA for the opportunity to attend NHF. It was my first time attending a bleeding disorders conference. I must admit that I had many jitters going into the meeting. Would I fit in? Would there be any familiar faces? This was also my first time traveling without friends or family, so could I handle it all? So much, right? My experience at NHF made all those jitters fade away. Attending the NHF Bleeding Disorders Conference in October was one of the most amazing experiences. I only knew the bleeding disorders community from a regional perspective. I was pleasantly surprised to see that there were so many people across the country and the world who had a bleeding disorder just like me.

NHF offers many tracks for attendees. I choose to focus my time at the conference on sessions related to von Willebrand disease, women with bleeding disorders, and bleeding disorders chapters. It was a lofty task to attend every session but I went to as many as I could. I arrived early so that I could attend the vWD pre-con. I was truly excited about this. I had a lot of hope about what I would learn and it did not let me down. I met so many people who are affected by vWD. I was encouraged by the fact that NHF dedicated the first portion of their conference to vWD. It speaks to NHF’s goal to create a more inclusive community.

Women are often underserved in our community; NHF realizes that more must be done to make women feel included. Many of the sessions I attended focused on advocacy and treatment. Most women struggle with getting they care that they need. Our chapter has a strong women’s group and I hope to cultivate more conversation on care and doctor and patient relationships. As a woman with vWD, I am excited about the international effort to develop a better understanding of women with vWD and that there are doctors working on treatment standards especially for women.

I also made certain that I attended sessions related to hemophilia chapters. I wanted to know more about what other chapters were doing. I also wanted to have a better understanding of how they operate so that I can be a better board and community member. I attended a couple of sessions about fundraising. I learned a lot about how chapters use local resources and pop culture to raise money. I heard so many great ideas and it challenged me to think of creative and innovative ways that I can support our chapter. I have some ideas and I am looking forward to being a participant in our next walk and upcoming fundraisers.

The most valuable experience I had at NHF was the opening session. I was inspired that NHF realizes that the bleeding disorders community is changing. They are taking the lead in making it more inclusive, so much that the annual meeting has been changed to the bleeding disorders conference, signaling a change in our community. No longer when we think of NHF will we only think of hemophilia; when we think of NHF we will think of all bleeding disorders. As a person who does not have hemophilia it shows that there is a change in our community to treat all people the same.

This year was NHF’s 70th anniversary and they spoke a lot about the progress that has been made in the 70 years. Although the 1980s were a tumultuous time for people in community, it did not stop us! One of the most profound things I heard during the opening session was that there is a cure coming. When you think of a cure, you think of cancer, diabetes, or heart disease. You do not think of the bleeding disorders. I am not sure when the “cure” will come but it gives me hope that we are closer than we ever been. I am encouraged because I know a bleeding disorder will not be a challenge for my children or future generations. We often take for granted our access to healthcare in this country. Although there is much that needs to be done in the United States, we have access to care and medication. I met so many people from around the world who are not as fortunate as we are. It was humbling to hear that in some countries, access to factor is limited. When people get access to medicine, they refuse to take it all, just in case some else needs some, too. Living in this country the idea of not having enough medicine is not a daily concern for most people. I know that a cure for us will improve the quality of our lives. I am excited for what cure means to people outside of the United States, a cure will provided them with a chance to live.

I could go on, but I am extremely grateful for our chapter and the opportunity to attend NHF Bleeding Disorders Conference.

Artura Jackson is a member of the HACA board of directors.
Thanks to Our Donors, Sponsors and Granters

The Hemophilia Association of the Capital Area gratefully acknowledges our donors who have given so generously. Below are donations received from September 1-October 31. We have made every effort to ensure all donations are listed.

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Hemophilia adoption is very close to our hearts. Our biological son Jack was born with hemophilia, and as we grew our family, we came to see that adoption was our ideal next step. When Jack was about a year old we decided to make the leap and start the adoption process. As time went on, we were amazed at how many fees there are associated with adoption, and how few grants were available. None of them were for children with bleeding disorders. We decided then that we wanted to do something to help other families expand through adoption.

We brought our son Luke home in December of 2017. Luke is a warm, funny, smart and resilient little boy, a perfect addition to our family. Shortly after bringing him home, we began looking into starting a non-profit of our own that would raise awareness about hemophilia adoption by offering grants to families looking to adopt a child with a bleeding disorder. Boy, were we in over our heads! Luckily, we knew Shari Luckey. Shari is one the administrators on The Hemophilia Adoption Facebook Page, a website that was our lifeline during our fifteen month adoption process. She runs the Hemophilia Adoption Program through The Hemophilia Foundation of Michigan. We met her at Washington Days, and again at the HFA conference. Shari is one of the most passionate hemophilia adoption advocates that we have ever met. We knew she could help. We called Shari and she told us that not only was she willing to help, but she already had everything needed to get a grant off the ground!

With that in mind we are happy to announce that, in partnership with The Hemophilia Foundation of Michigan, we officially established the Luke and Jack’s Together Forever Adoption Grant on October 25, 2018! It is a $1,000 grant that is offered annually to a family matched with a child with a bleeding disorder. Shari, her colleagues at the Hemophilia Foundation of Michigan, and our family worked together to set up this grant to support and promote hemophilia adoption. In this small way, we hope to help fill a gap so that more families are able to bring their children home.

For information on the grant, including how to apply, please go to www.hfmich.org/adoptiongrant or contact Shari Luckey at sluckey@hfmich.org.
On September 28-30, CSL Behring hosted the 2018 Gettin’ in the Game Junior National Championship (JNC) held at Wild Horse Pass in Sunny Phoenix, Arizona. This marks the 17th year in which CSL Behring has hosted an annual national golf, baseball and swimming competition for children with bleeding disorders. Children from across the country with bleeding disorders were able to attend in this year’s event.

During the program, children participated in either a golf, baseball or swim clinic hosted by CSL Behring’s Gettin’ in the Game pro golfer Perry Parker, baseball players Jesse Schrader and Peter Dyson, and swimmer Tim Grams. These athletes, all of whom have bleeding disorder themselves, instructed the children on the importance of physical fitness in managing a bleeding disorder. My son, James, focused on the swim clinic. It was no joke. The three stations focused on speed (25-yard sprint), breath control (retrieving items from bottom of the pool) and power (the kids were tethered with an elastic tether anchored to the starting blocks). The swimmers were broken up into age groups 10 and under, 11-13, and 14 and up. James turned 14 the day before we arrived in Arizona.

On the following day, children had the opportunity to show off their golf, baseball or swim abilities and compete for a national title with fellow participants. I cannot comment on how the golfers or the baseball players did. I know the pool was nuts! The swimmers were defiantly ready for competition. It was hot, loud and wet.

The 14 and overs started off with the 25-yard sprint. Watching the kids fly through the water, watching one older swimmer swim his first successful 25 yards, witnessing true brother/sisterhood as the other swimmers encouraged one another in a way not often found in other competitions.

Next was the tether. CSL volunteers make a deal with the swimmers. If you can reach the other end (no one had yet) they could pull Don in the water. Don wasn’t exactly prepared for this but was an amazing sport. Again, and again with the 14 and over kids, he went in the water. For James specifically, the tether is his nemesis... All the swimmers went against the tether, then a second time. James goes again, and again. FOUR times against the tether it was really a show of perseverance, and a bit of tenacity. He didn’t beat the tether this year.

Finally, there was the breath control station. It is no joke when you look up and James is carrying FOUR five-pound bricks up from the bottom of the pool. Sometimes all you can do is smile and shake your head. Again, James just doesn’t give up.

During some amazing competition James hit it off with a couple of other swimmers. This resonates more for me as parent than anything. These three became fast friends, stayed in touch with one another and are making plans for next year JNC, as well as Junior Olympic within the USA Swimming world. I believe with the determination and resolve of the three of them they will make it.

Parents were then asked to drop the kids off for a talk with only the athletes and the competitors. Parents then were given a session on the current state of insurance for about 45 minutes. Then we were in for a real treat we were able to do a music therapy session with Tim Ringgold, what a treat, this by far was one of the best educational sessions I have ever had the opportunity to attend.

We are forever thankful to HACA for allowing James to compete at JNC, and to CSL Behring for such an amazing program. A huge shout out to the GIG Athletes, Perry Parker, Jesse Schrader, Peter Dyson especially Tim Grams and Michael Josh. Everyone knows that swimming is the best sport!
Highlights from James Cosman’s recent trip to the Junior National Championship in Arizona
The National Hemophilia Foundation held its 70th Annual Bleeding Disorders conference October 11-13 at the Marriott World Center in Orlando. The daily schedule was full of a wide array of sessions especially designed for targeted audiences. The teen programming was well-planned this year, with topics that were helpful. One of my favorite sessions was “Jobs & Scholarships,” which gave us timely and updated information on what we need to be aware of when applying for a first-time job.

Professional athletes and mentors were on hand to work with participants to improve their skills. It was great to work with the professionals like Perry Parker (golf), Peter Dyson (baseball) and Tim Grahams (swimming), to name a few. Although it was really fun to practice and compete, the weekend offered so much more. Making friends from across the country was amazing. I made new friends from Utah and Hawaii, and we are keeping in touch. The friendships made in the pool and during competition are equally important. For a couple of days we are swimmers at competing, regardless if we all have bleeding disorders. Meeting other kids like yourself and learning their story helps all of us and makes us better advocates.

Friends we meet at events like this become friends for life! Meeting people from across the country is wonderful, especially for military kids. I know that I will run into these guys again.

The biggest lesson I learned from this event having participated three years is that you need have determination in everything you do. Just “keep at it,” and you will have success!

A huge shout out to HACA for this opportunity! It was an amazing weekend!!

CSL Behring’s Junior National Championship: It’s Not Just About the Sports!  By James Cosman

There is no question that healthy strong joints and muscles are less likely to bleed. Thanks to CSL Behring and their Gettin’ in the Game Program, 120 kids from across the country sponsored by their local chapters or HTC participated in the Junior National Championships September 28-30 at the Wild Horse Resort in Phoenix, Arizona. CSL continues to support this event each year and welcomes athletes ready to compete in several sports, including swimming, baseball, and golf.

Professional athletes and mentors were on hand to work with participants to improve their skills. It was great to work with the professionals like Perry Parker (golf), Peter Dyson (baseball) and Tim Grahams (swimming), to name a few. Although it was really fun to practice and compete, the weekend offered so much more. Making friends from across the country was amazing. I made new friends from Utah and Hawaii, and we are keeping in touch. The friendships made in the pool and during competition are equally important. For a couple of days we are swimmers at competing, regardless if we all have bleeding disorders. Meeting other kids like yourself and learning their story helps all of us and makes us better advocates.

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NHF Offers Informative Teen Track at Conference  By James Cosman

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Notice the name change? Yep, NHF Bleeding Disorders Conference! I hope that we can make a difference, there are many great things coming from NHF! I am hopeful that they will continue their expansion of rare disorders track, and that some of my ideas will take off in the coming year!

We had flex time, which allowed us to attend other sessions outside the teen programs, and I found this to be a great advantage. I was so excited to see the sneak peak of “Bombardier Blood” and meet Chris Bombardier and his mom. What an inspiration to meet a guy who was the first person with hemophilia to summit Mount Everest. I can’t wait to see the entire movie. I had to laugh as Chris told me I was crazy for some of my swimming adventures, this coming from a guy who has climbed the seven summits!!

I was also honored with a leadership award for the Teen Impact Awards! I was able to meet Patrick James Lynch and the Gut Monkey Team! It was awesome to hear from others who have done some crazy things with a bleeding disorder. If you have a chance, check out Patrick’s web series “Stop the Bleeding!”

There was plenty of opportunities to visit with old friends while making new ones. I met people from the World Hemophilia Foundation from Canada, India and Latvia. I learned from them and it was great to share stories of how we each handle our bleeding disorders. I think the social time is equally important at these conventions because we learn a lot from each other as well as the sessions provided.
Event Educates Spanish-Speaking Members

HACA hosted its fourth annual Spanish-language education event on Saturday, November 17, at the University of Virginia Northern Virginia Center in Falls Church, VA.

There were two sessions presented: “Work-Life Balance,” led by Fernando and Rhonda of the National Hemophilia Foundation’s Guías Culturales program; and “You Have the Right,” led by Laura Thompson, a speaker for the Hemophilia Federation of America. Both sessions were completely in Spanish.

The “Work-Life Balance” workshop discussed how to understand work-life balance, how to engage in behaviors that promote work-life balance, and how to understand priorities and to learn to reassess them regularly. Participants also learned some stress management and task management techniques that support balance.

Following the first session, participants enjoyed a lunch from Jason’s Deli and visited with event exhibitors.

After lunch, Laura Thompson presented a session that outlined a person’s rights to use an interpreter in order to have good communication with their doctor/health care provider.

Thanks to this year’s sponsors: Accredo, Bioverativ, CVS Specialty, Pfizer and Shire.

Evento educa a miembros quien hablan español

HACA organizó su cuarto evento anual de educación en español el sábado 17 de noviembre en el Centro de Virginia del Norte de la Universidad de Virginia en Falls Church, VA.

Se presentaron dos sesiones: “Balance trabajo-vida”, dirigido por Fernando y Rhonda del programa Guías Culturales de la Fundación Nacional de Hemofilia; y “Tienes el derecho”, dirigido por Laura Thompson, oradora de la Federación de Hemofilia de América. Ambas sesiones fueron completamente en español.

El taller “Equilibrio entre trabajo y vida” trató sobre cómo entender el equilibrio entre trabajo y vida, cómo participar en conductas que promuevan el equilibrio entre trabajo y vida, y cómo entender las prioridades y aprender a reevaluarlas regularmente. Los participantes también aprendieron algunas técnicas de manejo de estrés y manejo de tareas que apoyan el equilibrio.

Después de la primera sesión, los participantes disfrutaron de un almuerzo de Jason’s Deli y visitaron a los expositores del evento.

Después del almuerzo, Laura Thompson presentó una sesión que describía los derechos de una persona a usar un intérprete para tener una buena comunicación con su médico / proveedor de atención médica.

Gracias a los patrocinadores de este año: Accredo, Bioverativ, CVS Specialty, Pfizer y Shire.
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