Don’t let the winter cold deter you from doing your part as an advocate for the bleeding disorders community!

HACA kicked off the advocacy “season” with an advocacy dinner on Sunday, November 17, at Maggiano’s Restaurant in McLean.

Miriam Goldstein of the Hemophilia Federation of America talked about issues facing the bleeding disorders on the federal level.

Thanks to our 2019 advocacy sponsors: CSL Behring, Genentech, Novo Nordisk, Sanofi and Takeda.

Advocacy Events

The 2020 Advocacy Training and Richmond Days event will take place Sunday, January 19, and Monday, January 20 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 6 to reserve your hotel room and make an

Mission Statement

HACA’s mission is to support advocacy, education, and awareness efforts that build and sustain community among all people impacted by bleeding disorders.

Hemophilia Association of the Capital Area
8136 Old Keene Mill Road, Suite A312
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E-mail: admin@HACArears.org • www.HACArears.org
CHAPTER NEWS

Scholarship Opportunity with HFA

The Hemophilia Federation of America will have its annual Symposium April 23-25, 2020, in Baltimore, MD, and the organization is generously offering scholarships to cover hotel costs for three nights for HACA members. If you are interested in attending Symposium, click here for program guidelines and application. Deadline to apply is December 31.

Board Members Wanted

The annual election of HACA board members will take place at Family Education Day on Saturday, March 28, 2020, with new board members beginning their term in June 2020. If you are interested in becoming a board member, please email Brenda Bordelon at director@hacacares.org for a short questionnaire. The governance committee will meet to approve the slate in mid-March, and the membership will vote during the annual meeting portion of the education day event.

Board members must be able to attend four meetings each year, preferably in person. Meetings usually take place at various libraries around Northern Virginia.

Volunteers Needed

The NBC-4 Health & Fitness Expo is coming up January 19-20, 2020, and HACA needs volunteers to man the booth both days.

Hours on Saturday are 9 a.m.-5 p.m., and shifts are 8:30-11 a.m.; 11 a.m.-1 p.m.; 1-3 p.m.; and 3-5 p.m. Sunday hours are 9 a.m.-4 p.m., and shifts are 8:30-11 a.m.; 11 a.m.-1 p.m.; and 1-4 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.

Holiday Fundraiser with Minted

Still need to order holiday cards? See the special offer below to save through Minted and support HACA.

2019-2020 HACA

CALENDAR OF EVENTS

To register for any event, contact admin@hacacares.org or 703-352-7641.

DECEMBER

8      FIRST Focus Group with HFA, Arlington, VA
14     Holiday Gathering, Sherwood Center, Fairfax

JANUARY

12     Board of Directors Meeting, Arlington, VA
19-20  Advocacy Training & Richmond Days, Omni Hotel, Richmond Virginia. RSVP here
26     Women’s Group, 1-4 p.m., VisArts, Rockville, MD. RSVP here
Fishing fun at the National Mall

When you think of an outdoor activity like fishing, the National Mall isn’t usually what you would expect as a destination to hook a big one! But HACA members learned there are plenty of fish in the pond at the Constitution Gardens pond in the heart of the mall near the Lincoln Memorial.

Event sponsors Octapharma, Aptevo and Biomatrix teamed up to bring Brandon Young of Country Boy Fishing to the DC area for a day of fun. Brandon provided the rods, reels and advice on baiting and casting. No fish were killed as a result—it was a catch-and-release event.

The mission of Country Boy Fishing is to engage the youth and hemophilia communities with innovative ways to go back into nature by utilizing the platform of fishing.

According to an article in NHF’s HemAware magazine, Brandon, who has severe hemophilia A, went fishing for the first time at age 3 … and was hooked! He wasn’t allowed to play traditional sports because of his bleeding disorder, so he’d spend weekends watching fishing shows. Country Boy Fishing is a culmination of his desire to promote an activity he loves and connect with others in the bleeding disorders community. Thanks, Brandon, for bringing your program to HACA and the DC area!

Photos by Bethany Swain
HACA well-represented at Bleeding Disorders Conference

The annual National Hemophilia Association Bleeding Disorders Conference took place October 3-5 in Anaheim, CA. More than 2,500 people from around the country participated in the conference.

Representatives from HACA included Executive Director Brenda Bordelon, Board of Directors Vice President Robin Monin, Board Member Mallory O’Connor, Terry Stone, Matthew Stone, Veronica Scott and Blane Endale. Veronica and Blane attended as panel members for some of the sessions. Program Assistant Patti Williford attended as well as an NYLI participant.

The three days of the conference were packed with sessions, with tracks for persons with von Willebrand disease, women with bleeding disorders, rare bleeding disorders, spouses and partners, adult men, chapters, en espanol, teens, nurses, social workers, physical therapists and more. There were industry breakfast symposiums, a packed exhibit hall, and a fun final night event. Topics ranged from mental health to medical marijuana, from alternative therapies to emerging therapies, from healthcare policy to how to communicate with your spouse—just to name a few!

HACA was also recognized with other chapters at the awards ceremony on Saturday for receiving the Chapter of Excellence Award in three categories: Board Governance and Leadership, Advocacy and Public Policy, and Programs and Services.

Stone honored during Teen Impact Awards at NHF meeting

One of the highlights of the annual Bleeding Disorders Conference is the Teen Impact Awards. The annual awards program recognizes teens in the bleeding disorders community ages 13-18 who are making a positive impact in homes, schools and communities.

This year, HACA nominated Matthew Stone, a longtime chapter member who has been instrumental in getting our new Teen Task Force up and running. Matt is a great leader who wants to give back to the chapter as a mentor and role model to the younger teens in the group.

Matt was one of 75 teens from 31 states honored at the awards show, a mix of serious and silly. Each teen was introduced and asked a question; some were highlighted in short videos that aired throughout the evening.

The Teen Impact Awards are hosted by Believe Limited’s Patrick James Lynch, creator of “Stop The Bleeding!” and other community programs. Special guests included Chris Bombardier, mountaineer and executive director of Save One Life Foundation, NFL player Josh Gordy, and Nikole Scappe.

You can watch this year’s Teen Impact Awards here.
HACA board member recounts experience at meeting

By Robin Monin

The NHF conference this year was a great mix of networking, socializing, and informative decisions ranging from how to comfort your child during infusions, to fundraising for your chapter, new medical advancements in the bleeding community, and updates on federal healthcare policy.

With all of these different sessions, my favorite by far, and the one that really stayed with me, was the keynote speaker. Mike Rayburn brought up the idea of “What if”. What if you could reprogram your brain to stop saying I can’t, and start looking for I can.

I feel like sometimes we get caught up in the I can’ts. It’s easy to do, I can’t play football, I can’t go on vacation because of a bleed, and we start down an unhealthy spiral of doubt and sadness, but if we could turn that all around, and start looking at the opportunities instead of the pitfalls, our lives and the lives of those we touch would be happier and better because of it.

He went on to say that this isn’t easy, the “What If” mentality does not always come naturally, but once you let go of the naysayers, and once you start asking yourself “what’s holding me back” then you can start owning it, uncertainty can equal opportunity if you can just ask yourself “what if.”

I felt like his words were the common thread throughout the conference, from a talk teaching you about new techniques to calm a terrified toddler (what if we could find a new way to comfort them?), learning about the new healthcare bills going through congress (what if I could convince my rep to vote for the bill, how would I do that?), or learning how to deal with marital stressors while raising a child with a bleeding disorder (What if this obstacle needs to be overcome, how do we do it together?)

Mike Rayburn ended with saying “To do things you have never done before, you need to start with doing something you’ve never done before.” I did that by attending the NHF conference, and I am so happy that I did.
The Virginia Hemophilia Foundation, in partnership with HACA, received a State-Based Advocacy Coalition grant for 2019 to support its already-successful state advocacy program. One of the goals of this grant was to have an advocacy stakeholders meeting, which took place on Friday, November 15, in Richmond.

The event started with an overview of the Virginia Bleeding Disorders Program, led by coordinator Jan Kuhn, RN, MPH.

Marvin Figueroa, Deputy Secretary of Health and Human Resources for the state of Virginia, stopped by and talked about the future of short-term health plans. Even though Governor Ralph Northam vetoed a bill in 2019, he expects it will be on the table again in 2020.

Becky Bowers-Lanier, HACA and VHF’s advocacy consultant, gave a state update, while Miriam Goldstein of HFA talked about what’s happening on the federal level.

Thanks to our 2019 advocacy sponsors: CSL Behring, Genentech, Novo Nordisk, Sanofi and Takeda.

Advocacy

Continued from page 1

appointment to meet with your legislator. Click here to register.

The Hemophilia Foundation of Maryland is not gathering in Annapolis this year, but will instead hold a series of advocacy dinners throughout the state. You can learn more on their website or Facebook page.

NHF’s Washington Days will take place February 26-28, with training on Wednesday at the Hyatt Regency Capitol Hill, and visits with lawmakers on Thursday. Friday is reserved for additional state advocacy training. NHF has an introductory webinar for those who have not attended before; click here to view. Registration will open soon; click here for updates and more information.

Advocacy Committee

The HACA board has created a new committee, HACA in Action. The committee will tackle issues that affect the bleeding disorders community as they arise, and keep members apprised as to what’s happening. Look for future articles in HACA News, and information on our Facebook page. If you are interested in getting involved, email Brenda Bordelon to add your name to the list.

Being part of the legislative process is empowering. Make your voice heard and participate in Richmond Days (if you are a Virginia resident) and Washington Days!
Evento reúne a miembros de habla hispana

Gracias a todos los que asistieron a nuestro Día de Educación anual en español el sábado 16 de noviembre. El evento tuvo lugar en el Centro Comunitario Walter Reed en Fairfax, y cinco familias asistieron.

Fel y Laura Echandi, guías de la Fundación Nacional de Hemofilia, dirigieron una sesión sobre cómo controlar el estrés y mejorar el bienestar. Martha Boria con la Federación de Hemofilia de América presentó una sesión sobre abogacía.

Gracias a los expositores de este año: Accredo, Bayer, CVS Specialty, Novo Nordisk, Pfizer, Sanofi y Takeda.
Fundraiser at Two Twisted Posts brings in donations for chapter

HACA members enjoyed a beautiful cool fall day at Two Twisted Posts Winery in Purcellville on Sunday, November 3, for the third annual fundraising day.

Two Twisted Posts donated—to HACA, a percentage of the proceeds from the sales on that day. The tasting room was hopping all afternoon as guests arrived to sample the wines, and many bottles were purchased as well.

Thanks to the talents of Michelle Stielper, Terry Stone, Kirstin Drye and Nina Duggan, HACA also had a table of holiday crafts for sale. There was a wide assortment of both fall and Christmas decorations, as well as hand-poured candles. More than $500 was raised through this effort!

HACA’s favorite duo, iliandi, performed as well that afternoon in the barrel room.
Fun on the farm for families group

The Families of Young Children group met up at Frying Pan Park in Herndon, VA, in October for playtime, a picnic and a wagon ride.

Eight families gathered together to meet, share stories, and tour the farm. Frying Pan Park preserves and interprets farm life in Fairfax County from the 1920s through the 1950s. Kidwell Farm houses draft horses, chickens, peacocks, rabbits, sheep, goats, cows and pigs. The group also took a wagon ride around the park.

The next families group meeting will be in March 2020. More details coming soon.

Thank you to Genentech and Novo Nordisk for supporting the families group in 2019.
Retreat offers opportunity for men to gather, learn

HACA and the Virginia Hemophilia Foundation teamed up November 9-10 for the first joint Men’s Retreat at Wintergreen Resort in Central Virginia.

Saturday featured sessions on the healing power of music, healthy aging, coping with male expectations and physical therapy.

Participants enjoyed time socializing that evening with a tour of local microbreweries and dinner.

Sunday morning featured a session on healthy eating.

Thank you to this year’s sponsor of the men’s retreat for HACA: CSL Behring.

LET’S MAKE TODAY BRILLIANT

JOIN US
The Hemophilia Association of the Capital Area (HACA) and the Virginia Hemophilia Foundation (VHF) are teaming up again for Camp Youngblood in 2020! The **dates are Sunday, July 5th – Friday, July 10th**.

**NEW THIS YEAR:** In order to make the registration process run more smoothly, the enrolling parent or guardian will fill out a short Camp Youngblood prescreening survey to determine eligibility. This is required for all applicants, even returning campers.


Camp staff will review each survey and those who meet the criteria will be sent a password to access the 2020 Camp Youngblood application. Those who do not meet the criteria will be notified as well.

**ALSO NEW IN 2020:** We will also be offering a Family Camp weekend at Camp Holiday Trails (CHT) that will take place **Friday, July 10th – Sunday, July 12th**, which is immediately after the summer camp session. Families will participate in the same fun activities as campers, stay in cabins and come to know the meaning of "camp magic" at CHT. If you are interested in registering for Family Camp, add all your family members to your account before starting the application, then select “Camp Youngblood & Youngblood Family Camp Weekend” as your session.

The Camp Youngblood application process is open enrollment and not first come first served. This will allow VHF, HACA, and CHT the chance to review applications and manage the roster according to the application/admission guidelines. All application deadlines must be adhered to in order to be considered. Family Camp has limited space. Eligible families will be chosen from confirmed Camp Youngblood campers using a lottery system.

The application process is now open on the Camp Holiday Trails website, [https://www.ultracamp.com/clientlogin.aspx?idCamp=398&campCode=cht](https://www.ultracamp.com/clientlogin.aspx?idCamp=398&campCode=cht). The deadline for submitting applications is March 30, and all camp paperwork and the medical assessment is due by April 30. **These dates are earlier than in years past**, which is why the application has opened earlier as well.
Teens represent HACA at annual Junior National Championship

By Elsa Kendall

This November, I had the privilege of playing golf at the CSL Behring Junior National Championship, (JNC) a national event for kids with bleeding disorders such as hemophilia and von Willebrand disease, held annually in Arizona. The JNC encourages kids to stay active despite their bleeding disorders and to use the strength gained from dealing with bleeding disorders to overcome other stressful situations. While there, I also had the pleasure of talking to the founder of the JNC, pro golfer Perry Parker, who started this event 18 years ago with help from CSL Behring.

I first met Perry at a meeting earlier this year when he taught a golf clinic. He shared with me his story of growing up and playing sports with a bleeding disorder, and that his grandmother was the one who suggested he play golf after he was repeatedly injured while playing basketball and baseball. A few years later, when he was 16 years old, he broke par for the first time at the Willowick golf course in Santa Ana, California, the oldest golf course in Orange County. Since then, he has competed in the Asian, Australasian, Canadian, Japanese, Nike, and P.G.A. tours as well as other smaller competitions. Having hemophilia is what Perry credits with allowing him to overcome struggles throughout his life, a message he shared this year with the kids at the Junior National Championship, while encouraging us to dream the impossible. In a 2018 inspirational video produced by Greg Healy, Perry Parker said the following:

“Hemophilia has made me stronger, and I’ve been successful because of it. I know that might sound weird, but the reason why is that I can handle anything that life throws at me after what I’ve dealt with because of hemophilia. I can handle adversity, and I can overcome setbacks, and that’s allowed me to be successful on and off the golf course.”

The JNC was a fantastic and exhilarating experience. It allowed me to connect with other kids from across the country, participate in a friendly golf competition (I hit the longest drive, an accomplishment I am very proud of), and, most of all, have fun! Participating in the JNC has allowed me to feel more comfortable both talking about and playing sports with hemophilia. I hope to continue to play golf in the future and look forward to potentially playing in a youth league or on a high school golf team. In the future, I also will be helping to organize activities for HACA’s Teen Task Force meetings; I am excited to give back to my community. I am so grateful to HACA for providing this opportunity to me, and I hope that I can attend the JNC again in the future.
Thanks to our donors and sponsors

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, 2019. We have made every effort to ensure all donations are listed.

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Season's Greetings

A very merry holiday season to you and your family!

From the HACA Staff and Board of Directors
Hemophilia Association of the Capital Area

Board of Directors 2019-2020

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Hemophilia Treatment Centers

**Adults:**
Medstar Georgetown University Hospital
Center for Hemophilia and Thrombophilic Disorders
Lombardi Cancer Center
3800 Reservoir Road, NW
Washington, DC 20007
202-687-0117

**Children:**
Children’s National Health System
Hemophilia Treatment Center
Sheikh Zayed Campus
for Advanced Children’s Medicine
111 Michigan Avenue, NW
Washington, DC 20010
202-476-5000

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