Countdown to the 2019 Fall Festival & Walk

It’s walk time again! The HACA Fall Festival & Walk is coming up soon, Saturday, September 28, at Lake Accotink Park in Springfield, VA.

Join us again at the large lakefront pavilion from 8:30 a.m.-1 p.m. to enjoy a morning of networking, education, fun, food and a lovely walk along beautiful Lake Accotink!

As in years past, we will have a variety of games and activities, and there will be a picnic lunch following the walk. Teams are also encouraged to create their own team t-shirts. Awards will be given for the top individual fundraiser and top team, as well as best T-shirt, team name and more. The B’s Knees, Rock Steady for Eddie, Mountain Grindles, Kickin’ Inhibitors, the Little A Team, Evan’s Hemophilia Heroes, Walkers for Wes, Seize the Day, and Saul’s Patrol have already signed up to join us. There are incentives for team captains and walkers to sign up:

- Individuals who register between August 1 and August 30 will be entered into a drawing for a $25 gift card
- The team captains of the first 10 teams formed by August 15 will be entered into a drawing for a $25 gift card
- Individuals who raise $300 by August 30 will be entered into a drawing for a $25 gift card

Like last year, you can register as a walker and create your own team. You can also add other family members as well when signing up. You can create a team page, and will receive a URL that you can share with friends and family to raise money for your teams. If you have friends and family who would like to donate but not walk, they can do so as well by clicking on Donor instead of Walker and can donate directly to your team.

There are some tutorials on the HACA website that can help with setting up a page. Click here for more information.

Buddy the Blood Drop and T-Rex will lead the walk along the shore of Lake Accotink again this year. There will be a pre-determined route with varying lengths, and participants are also welcome to walk, run or bike the entire 4-mile length of the lake. There will be plenty of free parking, as well as parking for the disabled and restrooms at the pavilion.

REGISTER HERE

The material provided in HACA News is for your general information only. HACA does not give medical advice or engage in the practice of medicine. HACA under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.

Publisher
Hemophilia Association of the Capital Area
Editor
Brenda Bordelon, Executive Director

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
Springfield, VA 22152
Phone 703-352-7641, Fax 540-427-6589
E-mail: admin@HACaCares.org • www.HACaCares.org
CHAPTER NEWS

Fun at the Waterpark for Chapter Picnic

HACA will have its annual chapter picnic at the Water Mine Family Swimmin’ Hole at Lake Fairfax Park in Reston, VA, on Sunday, August 18. We will be meeting at the Top Railer canopy, and will have a picnic as well.

In 2018, we had almost 100 people in attendance—but were unable to use the waterpark because of bad weather. This year, we have reserved the Top Railer for the entire day. The official time for the event will be from 11 a.m.-3 p.m. However, if bad weather is predicted for earlier in the day, we will shift the hours of the event and will communicate that to participants a few days before.

Click here to register

2019 HACA CALENDAR OF EVENTS

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

AUGUST

10-11 Teen Retreat (w/VHF), Founders Inn, Virginia Beach
18 Chapter Picnic, 11:00 a.m., The Water Mine, Lake Fairfax Park, VA. RSVP here
22 Dine & Discuss with Genentech, 7-9 p.m., Lebanese Taverna, McLean, VA. Topic: “The Science of Optimism: Staying Optimistic While Navigating Change.” RSVP here

SEPTEMBER

6-8 Women’s Retreat, Meadowkirk at Delta Farms, Middleburg, VA. RSVP here
9 Board Meeting, 7-9 p.m.
18 Dine & Discuss with Takeda, 6:30-8:30 p.m. Topic: “Making the Grade.”
28 Fall Festival and Walk, 8:30 a.m.-1 p.m. RSVP here

Congratulations to Scholarship Winners

The HACA scholarship selection committee chose Jack Prophett and Brien Krug as the 2019-2020 George and Linda Price Scholarship winners. Each young man will receive a $3,000 scholarship.

Both are longtime members of HACA and have volunteered and served as mentors through the infusion classes hosted by the HTC at Children’s National. They are also cousins.

Jack will be attending William & Mary this fall, and Brien will be a student at James Madison University.

Women’s Retreat Coming Up in September

The Women’s Retreat will take place from Friday, September 6 -Sunday, September 8 at Meadowkirk in Middleburg, VA. The event was so popular last year that we’ve added a night this year!

The weekend will kick off at 7 p.m. Friday night with check-in and social time. Programming will take place on Saturday, with a general session on Saturday morning, followed by lunch then two tracks of programming for the afternoon. There will also be free time in the afternoon, with games and art projects after dinner. One last session on Sunday morning will round out the weekend before everyone heads home.

Space is very limited and attendees are asked to share a room if at all possible so that we can allow more people to attend. This is a very popular event, and we look forward to our second year!

Click here to RSVP.
I Walk Because

I walk because I love my kids
I walk because my kids are both affected
I walk because of the heroes who came before us
I walk because of the heroes who walk amongst us
I walk because of the suffering of the past
I walk because of the fears of the past
I walk because of the tears I have shed
I walk because of the sadness I have endured
I walk because of the potential for better treatments
I walk because of the need for better access to treatment
I walk because of the ongoing research
I walk because of the hope for a cure
I walk because of the advancements that have come
I walk because of the accomplishments that have been achieved
I walk because of the hope for a brighter future
I walk because there are those in need of support
I walk because of those in need of education
I walk because of those in need of financial assistance
I walk because of those in need of emergency assistance
I walk because of the children who want to attend camp
I walk because of the camaraderie that has grown over the years
I walk because of the extended family I have found in this community
I walk because I have been blessed by the bleeding disorders community
I walk because I love my kids

By Nina Duggan

Nina and her family’s team, The B’s Knees, have participated in every HACA walk since 2013
HACA and CSL Behring partnered for a fun event at TopGolf in Loudoun County on Sunday, June 23.

Pete Dyson gave a talk on “Pushing Through With Positivity,” where he shared stories about overcoming tough times in his athletic career. He also talked about the Junior National Championship and its importance.

HACA members and recent high school graduates Brien Krug and Jack Prophett also talked about their experiences as young athletes with hemophilia.

Thanks to CSL Behring for sponsoring this event.
HTC panel discusses emerging therapies at June event

HACA partnered with the Children’s National Medical System Hemophilia Treatment Center for a panel discussion on June 22 about the new therapies that are in development and on the market.

We were honored to have Dr. Michael Guerrera and Chris Guelcher, nurse practitioner and coordinator, of Children’s, as well as Dr. Craig Kessler from Medstar Georgetown University Hospital’s HTC and Kim Drucis from the Johns Hopkins Hospital HTC as presenters for this discussion.

Dr. Guerrera talked about the new non-factor therapies such as emicizumab, fitusiran and concizumab (if you are interested in a copy of the presentation, please email Brenda at director@hacacares.org). He presented information on how each of these treatments work, results of trials, and discussed the adverse events that have occurred with some of them.

Dr. Kessler spoke about gene therapy, and its potential effects on the bleeding disorders community, and Kim Drucis, the HTC nurse practitioner and coordinator at Hopkins, talked about emicizumab from a nursing perspective.

George Stone, a patient who is on emicizumab, also spoke about life since he began the new treatment regimen.

Again, thank you to our wonderful HTC providers who spent a Saturday morning presenting this information.

Georgetown HTC welcomes new social worker

Jacqueline Sanders, BSW, MSW, joined the hemophilia treatment center staff at Medstar Georgetown University Hospital in June. She is new to the bleeding disorders community and attended two HACA educational events this summer to learn more about bleeding disorders and meet the patients she will be working with.

Jacqueline recently relocated to DC from her hometown of Las Vegas, where she received both a bachelor’s and then master’s degree in social work from UNLV.

“Although I interned, then worked with teens and those intellectually disadvantaged, my practices has always had a medical focus, which provided a strong foundation for the positions held,” she said. “Now I am here in DC learning to support the hemophilia population of Georgetown University Hospital. I view this as an excellent opportunity and look forward to working with you all.”
HACA sent 13 children and teens to Camp Youngblood in Charlottesville, VA, July 7-12, for the annual summer camp program with the Virginia Hemophilia Foundation.

Camp Youngblood takes place at Camp Holiday Trails, created to provide camp experiences for children with chronic medical conditions. Participants enjoy a variety of activities such as canoeing, fishing, swimming, horseback riding, nature hikes, climbing walls, arts and crafts and more. The oldest campers also get to take on leadership positions in various ways including a service project, assisting with camp activities, and spending time with younger cabins. At camp, children are given the chance to make meaningful, lifelong friendships and memories.

Thanks to this year’s camp sponsors: Bayer, CVS Caremark, Grifols, Novo Nordisk, Pfizer and Shire.

Noah Nguyen attended camp for the first time this year. “I loved it... ‘10 out of 10,’” he said, when asked about his camp experience.

At the other end of the spectrum, Rebekah Rowe attended as a camper for the last time this summer. “It’s hard to put into words how important camp is to me,” she said. “Camp has helped to shape me into the person that I am while still allowing me to learn about myself and others. I wouldn’t be the way I am without camp and the family I have made there.”

But it’s not goodbye forever. Rebekah plans to return next summer as a camp counselor.

Nathan Skowronski had just moved to Virginia when he headed off to camp.

“This year of camp for me was like no other,” he said. “I had just moved from California all the way to Virginia, so I was nervous about going to camp this year. On the first day, two of my cabinmates warmly welcomed me to CHT and to the Blazer Cabin. For the rest of the week we did lots of fun activities and I met a lot of really great friends.”

He said that his favorite parts of camp were swimming and other athletic activities. And even though he just met the other Blazer Cabin teens a few days earlier, he said the last day was emotional because some of the teens he’d met were “graduating.”

“I learned that day that at CHT, everyone is a family. I had an absolute blast and will definitely come back to CHT next year,” he said.
10 Years of Memories at Hole in the Wall Gang Camp

By Mariah Willis

I started attending Hole in the Wall Gang Camp in 2009 as a camper when I was 12 years old. I heard about it from my hematologist, who highly recommended I attend the camp in Connecticut that was founded by the late actor Paul Newman.

My parents and I did some research and it looked amazing, but I was very hesitant to leave home for a week and being so far away. After much convincing, I decided I would go for a session. It changed my life.

My first summer was unforgettable in many ways. I met friends that I still communicate with to this day and memories that will last a lifetime. I was a camper for four summers until I aged out. Every summer I looked forward to seeing my friends from the previous summer and meeting new people. As a camper, the counselors make sure we are always having fun while being safe. Campers enjoy a wide variety of experiences, such as singing and dancing during every meal, swimming, horseback riding, boating and fishing, woodshop, arts and crafts, sports and rec, theater, archery, cooking, and more.

After I aged out, I participated in Hero’s Journey, which is an opportunity for aged-out campers to still be part of the camp community and experience camp on a whole different level. Hero’s Journey is a week of living outdoors with no electricity or running water while hiking through the mountains of Connecticut and really find meaning in our lives and learn new things about ourselves.

After Hero’s Journey is the Leader in Training (LIT) program and LIT 2. LIT 1 is one week at camp learning leadership roles and opportunities while learning the roles of a camp counselor. LIT 2 is the same thing, but for two weeks at camp. For the last four summers, I have been a volunteer cabin counselor at camp. Every summer I get to meet the most wonderful campers and make memories with them for a week. The last 10 summers total have changed my life and I found a community that accepts anyone and treats them with love and respect. I have met lifelong friends and some friends I consider family.

My most recent session was during the Fourth of July week 2019 and some people called me a camp veteran. But I don’t attend camp so I can brag that I have been there for 10 summers. I attend every summer to give back to the campers who need to be reminded that they are still a kid, no matter their illness. I want every camper I meet to know that they can still have fun and forget about the teasing some may experience at home, or the treatments and medicines some have to endure. Every camper at Hole in the Wall experiences a week of love, safety and respect, all thanks to its founder Paul Newman. This camp changes lives in the most fantastic way and I look forward to it every summer. Thank you, Paul, for this Hole in the Wall, this camp’s been good to me.

HACA sent campers to Hole in the Wall Gang Camp in Connecticut for almost 20 years before partnering with the Virginia Hemophilia Foundation to send kids to Camp Youngblood in Charlottesville starting in 2016. Hole in the Wall Gang Camp is now part of the SeriousFun Children’s Network that runs camps throughout the country. Hole in the Wall was founded in 1988 by the late Paul Newman.
On Saturday, July 20, members of HACA’s women’s group met at Green Spring Gardens in Alexandria, Virginia. The event began with a presentation on historical fiction. The attendees learned about various myths throughout history and the reason for their creation. George Washington chopping down his father's cherry tree and his iconic line, “I cannot tell a lie” was one of the most famous myths debunked. The reason for this myth and so many others was to encourage desirable behaviors, such as honesty and integrity. Participants also learned about less well-known myths, such as how two young girls once convinced people that fairies were real with the use of paper fairy dolls and a camera.

Following the presentation, the group entered the historical house for classic English tea. The tea was served hot in beautiful teacups. In the center of the tables were a variety of delicious treats, including mini cakes, fruit tarts, and finger sandwiches. Tea was finished off with some freshly baked scones. This time gave our members the opportunity to chat and catch up with one another.
HACA’s Families of Young Children group, which is for families that have a child age 5 or under with a bleeding disorder, met for an afternoon of fun at the Locust Grove Nature Center in Bethesda in June.

The families enjoyed a picnic under a pavilion and had the chance to network and meet. We welcomed three new families to the group at the June gathering!

Thanks to Jennifer and Evan Blaisdell for helping arrange the event, and serving as the host family for the day, plus providing some photos.

The kids had a blast exploring the nature center and its grounds, which includes indoor exhibits, an observation deck, hiking trails and a natural playground.

HACA appreciates the support of Novo Nordisk and Genentech for its Families of Young Children group.
Task force gives teens a chance to connect

By Matt Stone
TTF Coordinator

As the school year was winding down, teens from both the Hemophilia Association of the Capital Area and the Virginia Hemophilia Foundation gathered at the Penrose Square Clubhouse in Arlington, VA, on Saturday, June 8, for a workshop on advocacy.

Around a dozen teens participated in the workshop where they learned how to share their story living with a bleeding disorder by brainstorming what information should be included, then forming that into a short shareable narrative. With the help of Ann Kendall and Krista Davidson, the Virginia state advocacy co-chairs, the teens were able to finalize their story and be able to use it for future advocacy opportunities.

After our stories were finalized, the teens enjoyed hanging out playing foosball, billiards, and eating pizza. Everyone got to socialize and had a great time. Thanks to the Kendall family for hosting our teens at their beautiful club house.

Looking towards the future we hope to have more teen gatherings throughout the year, featuring various outings to include advocacy, community service, and leadership training.

Funding for the Teen Task Force is provided by Shire.

Thanks to our donors

The Hemophilia Association of the Capital Area gratefully acknowledges our donors who have given so generously. Below are donations received from May 1-June 30, 2019. We have made every effort to ensure all donations are listed.

Organizational Contributors
CSL Behring

Individual Contributors
The Ceconi Household
Cheryl Glisson
Joanne Gootman
Christie Nix
Linda Price
The Savinar Household

Montgomery County
Workplace Giving
Jessica Jones

United Way
Mary Carbone
Timothy Duggan
Event offers education, networking for members with vWD

HACA hosted its second annual von Willebrand disease mini-education day on Saturday, July 13, at the Walter Reed Community Center, in Arlington, VA.

This year, about 25 people attended the two-track event, which was led by nurse Maria Tovar Herrera on behalf of the National Hemophilia Foundation.

The first session was on “Advocating for Your Care in the ER with vWD,” which covered how to prepare in advance for an emergency and provide information to help navigate difficult situations that you may encounter when in the emergency room. The second session, “vWD: Ask the Experts,” covered vWD basics and treatment. There was also a session in Spanish led by bilingual educator Patricia Espinosa Thomson of Takeda.

Thanks to this year’s sponsors, CSL Behring, CVS Specialty, Takeda and the National Hemophilia Foundation.
REGISTRATION NOW OPEN

HACA FALL FESTIVAL & WALK

Saturday, September 28, 2019
8:30 a.m.-1 p.m.
Lake Accotink Park
Large Lakeside Pavilion
Springfield, VA

THIS YEAR’S EVENT WILL INCLUDE:
Games and activities
Walk along scenic Lake Accotink
Easy access from the Beltway and plenty of free parking
Picnic lunch following the walk

Register at
www.tinyurl.com/HACAWalk2019
<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dana Brayshaw</td>
<td>President</td>
<td>Falls Church, VA</td>
</tr>
<tr>
<td>Robin Monin</td>
<td>Vice-President</td>
<td>Springfield, VA</td>
</tr>
<tr>
<td>Callie Victor</td>
<td>Secretary</td>
<td>Burke, VA</td>
</tr>
<tr>
<td>Sandesh Mohan</td>
<td>Treasurer</td>
<td>Ashburn, VA</td>
</tr>
<tr>
<td>Melissa Alba</td>
<td></td>
<td>Fairfax, VA</td>
</tr>
<tr>
<td>Mark Antell</td>
<td></td>
<td>Arlington, VA</td>
</tr>
<tr>
<td>Wesley Hay</td>
<td></td>
<td>Alexandria, VA</td>
</tr>
<tr>
<td>Eena Kapoor</td>
<td></td>
<td>Washington, DC</td>
</tr>
<tr>
<td>Artura Jackson</td>
<td></td>
<td>Largo, MD</td>
</tr>
<tr>
<td>Mallory O’Connor</td>
<td></td>
<td>Washington, DC</td>
</tr>
<tr>
<td>April Owens</td>
<td></td>
<td>Fort Washington, MD</td>
</tr>
<tr>
<td>Jennifer Sleboda</td>
<td></td>
<td>Falls Church, VA</td>
</tr>
<tr>
<td>Michelle Stielper</td>
<td></td>
<td>Culpeper, VA</td>
</tr>
<tr>
<td>Member at Large</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patrick Kanu</td>
<td></td>
<td>Laurel, MD</td>
</tr>
</tbody>
</table>

**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

Find Us on the Web
www.HACAcares.org

Follow Us on Social Media: