Thank you to the walkers, donors and sponsors that made the 2018 Fall Festival and Walk on September 29 a success! We raised more than $90,000 this year!

Funds raised through the walk support a variety of programs, including patient assistance; scholarships for educational meetings and college; summer camp for kids; and research through contributions to the National Hemophilia Foundation's Judith Graham Poole Postdoctoral Research Program.

It was a beautiful early fall day at Lake Accotink Park. After weeks of endless rain, the sun came out and the weather cooled down, making the setting and temperature just about perfect.

This year's walk moved to the large lakefront pavilion that looks down over Lake Accotink. The day kicked off with check-in from 8:30 to about 10 a.m., and the opportunity for participants to visit with event sponsors.

Executive Director Brenda Bordelon welcomed the group of more than 150 participants and Walk Chair Veronica Scott said a few words. The crowd had

Continued on page 4
Infusion Class at Children’s

All hemophilia patients and their families are encouraged to participate in the next infusion class, Thursday, October 11, from 6:30-8:30 p.m. at Children’s National Health System, 111 Michigan Ave., Washington, DC.

2018 HACA CALENDAR OF EVENTS

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

OCTOBER
11 Pediatric Infusion Class, 6:30 p.m., Children’s National Medical System, Washington, DC.
11-13 NHF Annual Meeting, Orlando, FL
18 Dine & Discuss, 6:30-8:30 p.m., Red Hot and Blue, Fairfax, VA. Topic: Persistent Pain. Presented by Pfizer. RSVP here
27 Families of Young Children Group, 10:00 a.m.-1:00 p.m, Montpelier Farms, Upper Marlboro, MD. RSVP here
29 Genentech Branded Dinner, 6:30-8:30 p.m., Maggiano’s Tysons Corner. RSVP here

NOVEMBER
10 Coalition for Hemophilia B Family Education Weekend, Richmond, VA. Information and registration here
11 Two Twisted Posts fundraiser, 11:00 a.m. - 6:00 p.m., Purcellville, VA
17 Spanish Education Event, 10:00 a.m.-2:00 p.m. UVA Northern Virginia Center, Falls Church, VA. RSVP here
18 Advocacy Dinner, 5:00-7:00 p.m., Heavy Seas Alehouse, Arlington, VA. RSVP here
29 Bioverativ Branded Dinner, 6:30-8:30 p.m., Succotash, National Harbor, MD. RSVP here

Look for more details to come on some events in weekly HACA updates.

For more upcoming HACA events, visit our website.

Coalition to Hold Family Meeting in Virginia

The Coalition for Hemophilia B will hold a Family Meeting at the Westin Richmond on Saturday, November 10, from 9:00 a.m.-4:00 p.m. HACA members with hemophilia B or who have a family member affected are invited to attend this statewide meeting.

The organization has secured a room rate of $139 for any families that might want to travel up Friday and stay overnight (call 804-282-8444 to make a reservation). The event will kick off with a pre-meeting dinner gathering that evening, but the main educational event starts at 9:00 a.m. Saturday.

Gas and tolls will be reimbursed, and parking will be paid for by the Coalition. Breakfast and lunch will be served on Saturday. The event also features free childcare, and a fun day trip for teens and tweens. There will also be a dinner Saturday night.

Click here to register.

For more information on the Coalition for Hemophilia B, click here.

Fundraiser at Winery Rescheduled for November

Two Twisted Posts winery in Purcellville, VA, will donate a portion of the proceeds from the day’s sales on Sunday, November 11, to HACA. Our favorite duo iliandi will perform from 2:00-5:00 p.m. The staff of the Children’s National HTC will also be in attendance, and this is a great opportunity to get to know your HTC team in a casual setting.

The winery features a large covered area, a big lawn

The infusion class is recommended for Children’s National patients and their families who are starting home infusion. If you are not a patient at Children’s and are interested in attending, email Chris Guelcher at cguelche@childrensnational.org.

Attendees will have a chance to view a demonstration that reviews the procedures, followed by hands-on teaching with nurses. The evening also often features a veteran patient and parent who share their infusion story. There will be a light dinner sponsored by HACA.

RSVP by October 8 to Lynda at ldattili@childrensnational.org or by calling 202-476-5786.
with picnic tables and chairs, and of course, lots of great wines to sample and purchase. Bring the whole family! There will be a food truck on hand for purchasing food or bring a picnic lunch of your own. The winery is open from 11:00 a.m.-6:00 p.m. The event was originally scheduled for September, but the rain led to its postponement. Two Twisted Posts is located at 12944 Harpers Ferry Road.

**Save the Date for Holiday Event**

HACA will have its annual holiday event on **Saturday, December 8**, from 4:00-7:00 p.m. in the senior center at Falls Church Community Center, 223 Little Falls Street, Falls Church. There is plenty of on-site parking.

Santa will pay a visit for the kids, so be sure to sign up and indicate the age of your child. There will also be crafts for the kids, plenty of food and drink, and the opportunity for some pre-holiday cheer with your fellow HACA members.

Look for more details to come in HACA weekly updates beginning in November.

**Medicaid Expanding in Virginia**

Beginning January 1, Medicaid will expand in Virginia, and many people with bleeding disorders will be eligible for insurance coverage.

On September 6, HACA had an information session led by Becky Bowers-Lanier, who walked everyone through the information about who would be covered and how to obtain coverage.

The session was recorded and can be found on Facebook.

To watch the video of the information system, click [here](#).

For more information on Medicaid expansion, click [here](#).

**New Health Care Coverage for Adults**

Beginning January 1, 2019, more adults living in Virginia will have access to quality, low-cost health insurance. The new coverage includes hospital stays, doctor visits, preventive care, prescription drugs and much more!

The rules have changed! So, if you applied for Medicaid in the past and were denied, you may soon be eligible.

For more information, visit [www.coverva.org](http://www.coverva.org).

**Connecting Virginians to Affordable Health Insurance**

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the opportunity to vote for a name for our new blood drop mascot, who has now been christened Buddy the Blood Drop. Then the walk began, led by Buddy and T.rex.

The walk course was the same as last year, a two-mile out and back walk along the shore of the lake. When the walkers returned, carnival games were set out for the kids to enjoy, and there was a face painter and caricature artist. Lunch arrived shortly afterward from Willard’s Barbecue, and the fun wrapped up around 1 p.m.

A special thank-you to the brothers of Chi Psi fraternity at George Mason University, who assisted with everything from sign placement to set-up, costume-wearing to cleanup. Their help is invaluable, and we couldn’t do it without them!

Awards were handed out following the walk as well. The most funds raised by a team went to Kristen and Keith Urbahn of Team William the Conqueror, which raised more than $15,000 and was the top team for the fourth year in a row. The most funds raised by an individual was Kate Greene of Rock Steady for Eddie, who raised more than $3,900. Rock Steady for Eddie also had the largest number of donations to a team (more than 55). The largest team was Saul’s Patrol, which had about 30 team members.

Here are the teams that participated this year and their fundraising totals:

William the Conqueror - $15,060
Rock Steady for Eddie - $4,675
Walkers for Wes - $3,015
The B’s Knees - $2,248
Team Kulenguski - $2,055
The Little A Team - $1,780
Saul’s Patrol - $1,345
Blisters for Bleeders - $1,000
Harley Heroes - $700
Elias 6.0 - $590
Bloody Wonderful - $380
Mountain Grindles - $370
Lauryn’s Legion - $300
HACA Walk Supporters - $300
Kickin’ Inhibitors - $255
Keep Calm and Carry On... Again and Again - $230
Overflow - $200
9ers - $200
HTC Hikers - $150
TD Bank - $125
Alphie’s Red Warriors - $100
Benny’s Blood - $25

THANK YOU TO OUR EVENT SPONSORS:

Presenting Sponsor: Shire
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Silver Sponsors: CSL Behring, Novo Nordisk and TD Bank
Bronze Sponsors: Accredo, Aptevo and Matrix Health Group
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Kilometer Sponsors: Ubelhart Rogstad and Associates

Thanks to Ernesto Rivera of Austral Lights Photography, who took the photos for the event. Photos from this year’s event will be on the HACA Facebook page.

All photos by Ernesto Rivera
Thunder and lightning put a damper on the HACA picnic on August 12 but didn’t stop the fun entirely!

As participants gathered at the Water Mine Family Swimmin’ Hole in Reston that afternoon, clouds began rolling in and pretty soon the skies opened up with pouring rain, thunder and lightning. The downpour did not abate, so the group was not permitted to go into the waterpark.

However, the covered pavilion with the concrete floor that the chapter had secured was still high and dry, so the party took place despite the rain (although everyone was asked to stay away from the metal poles holding up the tent... just in case).

More than 80 people attended and enjoyed a barbecue dinner from Willard’s Barbecue in Chantilly. One parent had the foresight to bring along a few toys, so many of the little ones played together, while others ventured to play in the rain when the thunder and lightning passed.

Thanks to everyone who attended despite the terrible weather! We will try to schedule next year’s picnic there again so we can hopefully enjoy a day at the waterpark!

Thanks to our event sponsors: Accredo, Diplomat, Matrix Health Group, and Novo Nordisk.
Almost 30 women attended HACA’s women’s retreat the weekend of September 8-9 at Meadowkirk at Delta Farm in Middleburg, VA.

It was a weekend filled with tears, laughter and the both the strengthening of old friendships and forging of new ones. It may have been raining outdoors, but inside it was cozy and comfortable, a perfect weekend for hunkering down and enjoying some quiet time together.

Meadowkirk is located in Northern Virginia “horse country,” and the property features rolling hills, pastures, hiking trails, and several lodging options. HACA occupied the entire Inn, which features 20 rooms, a conference room and a common area where the educational sessions were presented in a laid-back setting.

Saturday’s sessions were both led by Anna Bell, LICSW-C, LCSW-C, LISW, who talked on the topics of “Taking Care of You” and “Putting Stress in its Place” on behalf of HFA. The entire afternoon was spent sharing and learning and offered many participants the opportunity to speak up and talk about stressful, difficult life situations. The afternoon was rounded out with a relaxing, guided meditation led by HACA member (and retreat participant) Dr. Marcelle Williams, Ph.D.

Meals took place in Meadowkirk’s beautiful dining hall, resplendent with strings of lights crisscrossing the ceiling. After a delicious dinner, the women gathered in the inn’s conference room for some crafting activities led by Michelle Stielper of Matrix Healthcare, which provided the supplies for the crafts. Unfortunately, the weather put a damper on the outdoor fire pit, but the ladies enjoyed free time to visit in the social spaces throughout the inn.

The next morning kicked off with breakfast, then Karen Boyd, LMSW, led a session for NHF on relationships and intimacy. Participants then departed between 11 a.m. and noon.

A special thanks to our event sponsors: the Colburn-Keenan Foundation, Bioverativ, CSL Behring, Matrix Health Group and Novo Nordisk.

All photos by Bethany Swain
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 July 1-August 31, 2018. We have made every effort to ensure all donations are listed.

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More than a dozen teens from throughout Virginia attended a joint teen advocacy weekend organized by the Virginia Hemophilia Foundation and HACA in August.

Participants stayed at the Hyatt Regency in Washington, DC, and the event kicked off on Friday night with a nighttime bus tour of the city for the teens and their families.

On Saturday morning, the teens were escorted to the Hemophilia Federation of America offices a few blocks away for the day’s sessions. Eric Burgeson and Deema Tarazi of HFA facilitated the programs.

The first session was “Your Voice Has Weight: Let’s Advocate,” and was led by Eric. He talked to the kids about the definition of advocacy, the different types of advocacy and helped them develop an elevator speech.

Deema spoke on the topic of “On Capitol Hill: Advocacy in Action,” giving the teens an update on what’s happening on the federal level, and how to get involved.

The highlight of the day was a panel discussion with young professionals in the public service sector: Anna Vetter, deputy chief of staff/communications director for Rep. David G. Valadao (R); Johanna Gray, MPA, senior vice president of CRD Associates and federal policy advocacy consultant for NHF; Tony Mitchell, senior manager, state government affairs, CSL Behring; and HFA interns Alexandra Abreu Boria and Catherine Anderson.

The chaperones and teens then walked over to the U.S. Capitol Visitor Center for a guided tour before heading back to the hotel. That evening was an educational dinner about transitioning to an adult HTC at Carmine’s Restaurant.

Thanks to the sponsors that made this event possible: Bayer, CSL Behring, Novo Nordisk and Shire.
As individuals with hemophilia live longer and reach life expectancy rates comparable to the general population, their healthcare providers will continue to encounter clinical challenges inherent in treating and managing aging patients, including cardiovascular disease (CVD). There are several established risk factors associated with CVD such as hypertension, overweight, obesity and an abnormal lipid profile. With this knowledge in hand and with an eye towards prevention, investigators at the Rady Children’s Hospital San Diego (RCHSD) Hemophilia and Thrombosis Treatment Center (HTC) decided to look at CVD risk factors in some of their younger hemophilia patients.

The lead author of the study was RCHSD medical director Courtney Thornburg, MD, MS. She and her research team approached patients during their comprehensive care visits, ultimately recruiting 43 males with hemophilia A or B between the ages of 5 and 20 (average age 12). Patient data and additional information was culled from a combination of electronic health records for clinical data, standardized measurements of weight, height, waist circumference and blood pressure and screenings of glucose and lipids. Patients and/or their caregivers also completed questionnaires relevant to medical history, lifestyle and family history (FH).

The results showed high rates of overweight and obesity among the participants. Investigators also observed other CVD risk factors, including (pre)hypertension in 28% and “borderline” high lipids in 19% of the subjects. Higher levels of physical activity correlated with normal weight levels, while higher weights were linked to greater factor consumption. Seven participants (16%) reported a FH of CVD. These and additional findings prompted the authors to hypothesize that cardiovascular risk factors could be identified and measured as part of a comprehensive clinic visit and that best practices to mitigate those risks could be integrated by the entire HTC team.

“HTCs may utilize internal resources, including dieticians, physical therapy (PT) and child life specialists to recommend therapeutic lifestyle changes for a healthy diet plus avoidance of tobacco and alcohol use. In addition, if children are identified with overweight or obesity at a comprehensive clinic visit they may be referred to the primary care physician for follow-up and/or to obesity and behavioral health programs as appropriate. PTs may perform targeted joint and muscle examinations and provide patient-specific recommendations to increase conditioning and sports participation.”

The authors cited study limitations. The data was based on one HTC visit instead of over time, which is important for longer term monitoring of factors such as body mass index (BMI), blood pressure, lipid profiles. While physical activity, smoking and nutrition data were collected only by self-reporting without validated questionnaires, future studies could be augmented using food logs to measure caloric intake and accelerometers to measure physical activity. Lastly, future studies would also benefit from the inclusion of a healthy control group. The authors note that by addressing certain limitations, future studies could be more effective in CVD risk reduction, especially in concert with the primary care physician (PCP).

“Ultimately, resources will be required to monitor the impact of interventions on BMI, cholesterol, hypertension and physical activity. Further study is warranted to determine if HTCs can partner with PCPs and appropriate specialists to promote cardiovascular health and risk reduction. Interventions should include shared decision-making strategies to set realistic goals and methods of self-monitoring” concluded the authors.

“This study “Risk Factors for Cardiovascular Disease in Children and Young Adults with Haemophilia,” was published in the June 2018 issue of Haemophilia.
Annual Spanish Education Day Coming Soon

HACA will have its fourth annual Education Day for Spanish-speaking members on Saturday, November 17, from 10:00 a.m. to 2:00 p.m. at the UVA Northern Virginia Center in Falls Church, VA.

The programs will be conducted in Spanish, with topics of interest for both adults and young people. There will be no child care, but kids of all ages are welcome to attend with their parents.

Our industry partners will also be in attendance with Spanish speaking representatives to answer any questions about products and services, and participants will have the opportunity to visit them as well.

Registration will start at 10:00, with sessions beginning at 10:30 a.m. There will be two sessions, with a catered lunch for an hour between them.

The first session begins at 10:30 am and the theme is “Work-Life Balance,” presented by the National Hemophilia Foundation. During this workshop, participants will discuss 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 will also learn some stress management and task management techniques that support balance.

The second session from 1:00-2:00 p.m., will be on the topic of “You Have the Right,” and will be presented by the Federation of Hemophilia of America. This session will help you understand your right to use an interpreter to have good communication between you and your doctor/healthcare provider.

The UVA Northern Virginia Center is located at 7054 Haycock Road, Falls Church, VA. Parking at the facility is $2.00. If you need to travel by metro, the West Falls Church station is located next to the facility, a few steps away. HACA can provide gas cards or reimburse transportation costs if necessary.

We hope to see our Spanish-speaking members at this annual event! Go online to register at https://tinyurl.com/EspanolEducacionDia. You can also send an email to admin@hacacares.org with any questions, or call 703-352-7641 to speak with the program coordinator, Stephanie Burns, who speaks Spanish fluently.

El día Anual de la Educación en Español Llegará Pronto

HACA tendrá su cuarto Día de Educación anual para miembros quien hablan español el sábado 17 de noviembre de 10:00 a.m. a 2:00 p.m. en el UVA Northern Virginia Center en Falls Church, VA.

Los programas se llevarán en español, con temas de interés tanto para adultos y para jóvenes. No habrá cuidado de niños, pero los niños de todas las edades pueden asistir con sus padres.

Nuestros socios de la industria también estarán presentes con representantes quien hablan español para responder cualquier pregunta sobre productos y servicios, y los participantes tendrán la oportunidad de visitarlos también.

La inscripción comenzará a las 10, con sesiones que comienzan a las 10:30 a.m. Habrá dos sesiones, con un almuerzo atendido por una hora entre ellas.

La primera sesión comienza a las 10:30 a.m. y el tema es “Equilibrio trabajo-vida”, presentado por la Fundación Nacional de Hemofilia. Durante este taller, los participantes discutirán cómo entender el equilibrio trabajo-vida, cómo participar en conductas que promueven el trabajo - El equilibrio de la vida y cómo entender las prioridades y aprender a reevaluarlas regularmente. Los participantes también aprenderán algunas técnicas de gestión del estrés y gestión de tareas que respaldan el equilibrio.

La segunda sesión, de 1 a 2:00 p.m., versará sobre “Usted tiene el derecho” y la presentará la Federación de Hemofilia de América. Esta sesión lo ayudará a comprender su derecho a usar un intérprete para tener una buena comunicación entre usted y su médico / proveedor de atención médica.

El UVA Northern Virginia Center está ubicado en 7054 Haycock Road, Falls Church, VA. El estacionamiento cuesta $2.00. Si necesita viajar en metro, la estación de West Falls Church se encuentra junto a la instalación, a pocos pasos de distancia. HACA puede proporcionar tarjetas de gasolina o reembolsar las cuestas de transporte si es necesario.

¡Esperamos ver a nuestros miembros hispanos en este evento anual! Vaya en línea para registrarse en https://tinyurl.com/EspanolEducacionDia. También puede enviar un correo electrónico a admin@hacacares.org con cualquier pregunta, o llame al 703-352-7641 para hablar con la coordinadora del programa, Stephanie Burns, que habla español.
# Hemophilia Association of the Capital Area

## Board of Directors 2018-2019

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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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