Why I Walk

I walk because of my one-year-old son, Ian. My son has been my pride and joy since the very first moment I found out about him.

After finding out about his diagnosis, I was afraid that my kid wouldn’t be able to be a “normal” kid. I remember growing up with my brother (who has hemophilia A severe) and he wasn’t allowed to really do anything. Most of the time he had to sit on the steps and watch us play. I never understood why until after Ian was born in 2016 and I started researching hemophilia very heavy. If only I knew what my brother was experiencing, I probably would have sat on the steps with him. I can’t even imagine what he went through or how he felt. But I do know

Walk Website Now Up and Running

Registration for the 2018 HACA Fall Festival and Walk is now open. Click here to sign up.

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 team. 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.

The HACA Fall Festival and Walk will take place a little earlier this year: Saturday, September 29, at Lake Accotink Park in Springfield, VA, from 8:30 a.m. - 1:00 p.m. This year we are moving to the large shelter that overlooks the lake, which can be accessed from both the Heming Avenue entrance (and a short walk from the parking lot) and the main entrance on Accotink Park Road.

The walk itself will take place along the shore of Lake Accotink. 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

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

CFC #42259
Sign Up for June Infusion Class

All hemophilia patients and their families are encouraged to participate in the next infusion class, Thursday, June 14, from 6:30-8:30 p.m. at Children’s National Health System, 111 Michigan Ave., Washington, DC.

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.

RSVP by June 11 to Lynda at ldattili@childrensnational.org or by calling 202-476-5786.

Fun with Families

The Families of Young Children Group will meet again at 11 a.m. Saturday, June 16, at Hidden Oaks Nature Center, 7701 Royce Street, Annandale, VA.

The group will meet at the Nature Playce, a 1/3-acre unstructured woodland play area near the center. It is a perfect place to introduce young children, or even yourself, to the wonders of nature. It’s an opportunity for kids to just go outside and play in the woods.

Bring a picnic lunch, and we’ll scope out a picnic table where we can eat. The Nature Center itself opens at noon, so after lunch, stop by the center and check out the displays. The visitor center houses a kid-friendly exhibit, “Urban Woodlands: Habitats and Havens.” The youngest visitors will enjoy the Acorner area, filled with discovery boxes, tea sets, costumes and a big tree to cuddle up inside to read a nature story.

Click here to register.
Save the Date!

HACA FALL FESTIVAL AND WALK

Saturday, September 29, 2018
Lake Accotink Park
Springfield, VA

THIS YEAR’S EVENT WILL INCLUDE:

Games and activities
Walk along scenic Lake Accotink (or run or bike)
Easy access from the Beltway and plenty of free parking
A picnic following the walk

REGISTRATION NOW OPEN!
https://tinyurl.com/2018HACAFallWalk
HACA held its annual Family Education Day on Saturday, May 12 at Northern Virginia Community College in Annandale, VA.

This year’s format was a little different, with two tracks: one for parents, and another for adults with a bleeding disorder and their family members.

HACA vice-president Eboni Morris led the annual meeting and walk chair Veronica Scott spoke about what the walk means to her and her family.


An all-new executive board is taking the reins. They are: Dana Brayshaw, president; Stephanie Phillips, vice-president; Chrissy Burbank, secretary; and Sandesh Mohan, treasurer.

A big thank-you goes out to departing board members Eboni Morris, Joe Victor, Blane Endale and Meg Bradbury.

Morning sessions included “The Basics of School Advocacy” with Carrie Koenig of HFA and “Disclosing Your Child’s Bleeding Disorder” with Sherenne Simon, MPH, of NHF, in the parent track, and “It’s Not Too Late to Save Your Joints” with Angela Forsyth, PT, DPT, of NHF, and “Understanding Medicare and Protecting It for Tomorrow” with Ridge Multop of AARP, in the adult track.

“Facing Transitions,” a panel discussion led by Eena Kapoor and Lynda Dattilio of Children’s National and featuring Eileen and Jack Prophett, Erica McLeod and Dajon McLeod-Matthews, and Dayani Reyes, was the afternoon session for the family track. “Pain, Anxiety and Depression,” led by Georgia Panopoulos, Ph.D, was the adult session.

A special program at this year’s event was an art workshop led by Chinedu Felix Osuchukwu. He worked with the younger kids in the morning, then with the teens in the afternoon. He talked to them about his experiences as a person with hemophilia and how it led him to his career as an artist, and then helped them with their individual art projects.

The teens had two sessions in the morning: “Advocacy Is All Around Us” with Sarah Shinkman of HFA, and “Getting Real: Being a Teen with Hemophilia” with Linda Pollhammer of Pfizer. Darla Clayton of Diplomat led a “Creative Kids Writing Workshop” for the 7-12-year-olds in the afternoon.

Thank you to this year’s exhibitors: Aptevo, Bayer, Bioverativ, CSL Behring, CVS Health, Diplomat, Genentech, Matrix Healthcare, Novo Nordisk, Octapharma, OptionCare, Pfizer, and Shire.
“Spring at the Mansion” was the theme of HACA’s annual spring fundraiser, which took place Sunday, May 6, from 4-7 p.m. at the Stone Mansion in Alexandria, VA. More than $14,000 was raised through sponsors, ticket sales and the auction/raffle.

The beautiful afternoon included food, drinks, and a silent auction and drawings. Guests enjoyed socializing throughout the house and on the back veranda.

The duo of iliandi - Spencer Duggan and Iliana Fernandez – provided the beautiful musical backdrop for the afternoon.

Thanks to this year’s event sponsors: The Marriott Foundation, Shire, Novo Nordisk, Aptevo and Matrix Health Group. Thanks as well to the companies that provided items for the auction, as well as members of the board who contributed gift baskets and other items.
Members of the women’s group were treated to an afternoon of history, tea and sisterhood at Cherry Hill Farmhouse in Falls Church, VA, on April 21.

The event started with a costumed docent giving a first-person account of life in the farmhouse during the 19th century. She described life in the house from the perspective of Mrs. Blaisdell, the matron of a middle-class farming family that moved to Virginia from Massachusetts and lived at Cherry Hill between 1856 and 1868.

Following the talk, guests moved into the tea room, where they enjoyed a variety of tea sandwiches, scones and mini-desserts. Executive Director Brenda Bordelon led a “Never Have I Ever” Blood Sisterhood activity as well. After tea, there was a tour of the house.

Thanks to the Hemophilia Federation of America for sponsoring this Blood Sisterhood event.

The next meeting of women’s group will be on Saturday, July 14, from 11:00 a.m.-2:00 p.m. at Fairlington Community Center in Arlington. The group will meet for lunch and a program on “FACTOR IN the Family,” an Apteo Therapeutics educational session. Women with hemophilia don’t just face unique bleeding challenges—getting the right diagnosis and treatment can be an uphill battle. This program will help community members advocate for girls and women who have a bleeding disorder. There will also be a craft activity sponsored by Matrix Health Group. Register here for this upcoming event.
Cleveland was the setting for the Hemophilia Federation of America’s Symposium 2018. This year’s theme was “Together We Rock,” a fitting theme for the city best known for the Rock & Roll Hall of Fame.

This annual educational event attracted patients and families from throughout the country. HACA attendees included Mark Antell; Diana and James Cosman; Robin and Phil Monin and their sons Jack and Luke; Steve Long; and Brenda Bordelon. Several members also participated as presenters or panelists, including Anna Bell, Eboni Morris and Miriam Goldstein (who works for HFA).

The conference took place April 26-29 at the Hilton Cleveland Downtown Hotel.

There were educational tracks for chapter staff, Blood Brotherhood, Blood Sisterhood, Moms and Dads in Action, as well as inhibitor, von Willebrand disease and Spanish tracks. There were also events for teen attendees, as well as childcare.

The final night event on Saturday took place at the Rock & Roll Hall of Fame, which featured music, food and time to tour the museum.

2019 Symposium will take place April 4-7 in San Diego, CA. Interested in attending next year? HACA offers scholarships to Symposium through the Qualley Scholarship; look for more details in the fall.
vWD Education Event Coming in July

HACA is hosting a mini-education day for people living with von Willebrand disease and their families on Saturday, July 28, from 9:30 a.m.-1:30 p.m.

The event will take place at the University of Virginia Northern Virginia Center in Falls Church, VA.

The first session will be “vWD: Your Voice Matters,” presented by the National Hemophilia Foundation. Knowing how to advocate for yourself, and feeling like your concerns are heard, can be an obstacle you face as you live with your bleeding disorder. During this workshop, participants will share their stories and gain tools on how to advocate for themselves in many facets of life including in their relationships, with their doctors and in the workplace.

The second session will be “Living Longer and Stronger with a Bleeding Disorder.” This session highlights men’s and women’s health and wellness, including the importance of a healthy weight and diet, and general health risk factors for aging with a bleeding disorder, such as heart and joint health.

There will be a light breakfast upon arrival, as well as lunch and time to visit with exhibitors.

The Northern Virginia Center is easily accessible from I-66 and the West Falls Church Metro.

Click here to register for this event.

CHAPTER NEWS

Young Member Honored by Loudoun County

Makenzie Flake was recently honored by Loudoun County Public School’s Special Education Advisory Council (SEAC) during their annual awards ceremony. She was awarded this honor because she volunteers and helps support special needs students at her high school. Del. David Reid (left in photo) attended the ceremony, and remembered her father, Derek Flake, from Richmond Days visits in January. “Although Makenzie was suffering from a heel re-bleed in this photo, it was a great evening,” said her mother, Sherita Flake. “We had the opportunity to present to a lawmaker a productive member of the bleeding disorders community.”

Have any news you’d like to share with the HACA community? Email director@hacacares.org for possible inclusion in the next newsletter.

Why I Walk

Continued from page 1 (cover)

that I never want to put Ian through that feeling of being left out or lonely.

I allow Ian to be a true kid and I treat his bleeds immediately no matter how small. I walk because I want other sisters, mothers, cousins, etc., to know that having hemophilia is not all that bad and everything will be okay. Our hemophilia kids can and will live normal lives with the proper treatment. Hemophilia does not define my kid. My boy Ian defines hemophilia and he is why I walk.

Veronica Scott
2018 Walk Chair

Walk Website Now Up and Running

Continued from page 1 (cover)

lake. Following the walk will be an awards ceremony and picnic. There will be plenty of free parking, as well as parking for the disabled and restrooms at the pavilion.

See you at the walk in September!
NHF Looking for Study Participants

If you are a female with a family history of hemophilia A or B, and you participated in My Life, Our Future (MLOF), you are invited to enroll in the NHF sponsored Telegenetic Counseling Study.

The goal of the study is to show the value of genetic counseling in providing sensitive MLOF genotyping results. All participants will receive genetic counseling using telemedicine, a secure video chat between the participant and the genetic counselor but the timing between groups will differ. All information produced by the genetic counseling session will remain confidential.

Genetic counselors are professionals who have specialized education in medical genetics and counseling to guide and support patients looking for more information about their genetic health.

This approach will be compared to how treatment centers currently give that information. How centers give that information to MLOF participants is dramatically different across the United States. Comparisons will be made between a) how well the participant understands the information given from a genetic counselor vs. a healthcare provider (any type); b) whether a participant develops a plan of care; and c) how satisfied the participant and the genetic counselor are with using telemedicine for genetic counseling.

Everyone will receive genetic counseling using telemedicine, a video chat between the participant and the genetic counselor using either a smartphone or a computer through a HIPAA secure compliant link. All information produced by the genetic counseling session will remain confidential. Only the participant will receive the information, nothing will go to their health insurance carrier or their healthcare provider. To help measure changes between the two groups, health behaviors will be assessed through secure online surveys.

Study participants will be randomly sorted into two groups. One group will receive free, confidential telegenetic counseling by a licensed HTC genetic counselor shortly after enrollment in the study. The other group will receive their genotyping (genetic testing) results in the way they normally would through their HTC (standard care). After the women in the second group have completed the six-month study they will be offered the same telegenetic counseling.

The objectives of the study are:

- To demonstrate and describe telegenetics (the use of telemedicine for genetic counseling) as a model of care to increase access to specialty genetic counseling within the bleeding disorders community
- To determine if those who have access to a specialized genetic counselor demonstrate incremental improvements in knowledge when compared to those with no previous specialized genetic counseling
- To determine if the specialized genetics counseling session has an impact on the management plan of care
- To describe satisfaction with telegenetics counseling from the point of view of the patient and genetic counselor

To participate in the study, you must:

- Be a female who has undergone genotyping (genetic testing) through the MLOF program
- Received your MLOF genotyping (genetic testing) result
- Have not received any genetic counseling.
- May have gotten results of genotyping (genetic testing) from a healthcare provider, “told” what the report means, or had the report sent to you. This is different from seeing a specialized staff member that is called a “genetic counselor” and would spend an hour or more to discuss your history and talk about what the changes in your genes mean to you and any children you have.
- Be of any age, but females between the ages 12-18 will have genetic counseling done with parent/guardian participation. Under the age of 12, the counseling will be provided to a parent/guardian.
- Have access to a smartphone or computer with a camera and internet connection
- Able to read and speak English (translation services are not available)

Eligible women will be enrolled on a first-come, first serve basis. Participation will be limited by available resources and timeframe.

To participate in this study, please call Maria Santaella at (347) 918-6608 or email her at msantaella@hemophilia.org.

For other questions/inquiries, email mwitkop@hemophilia.org.
Camp Holiday Trails is a peaceful oasis tucked away in Charlottesville. For two days we escaped the modern world and focused on the physical and emotional aspects of keeping our family healthy. The only time I touched any electronics was to take photographs to capture the memories of the weekend.

We are about three years into our bleeding disorder journey and Evan's diagnosis has impacted all of us, including his 7-year old brother, Drew. These special experiences help lessen the blow with the challenges that come along when someone in your family has special needs.

Evan loved experiencing his first s'mores, but I think his favorite part was climbing the rock wall. It was a symbolic example of how he's willing to tackle anything, even something that could be seen as an insurmountable challenge for someone so little.

Besides all of the classic camp traditions, from going out in the canoe, songs around the flagpole and bonding with friends, I think the moment that touched me the most happened at the end of an educational training session. Two teenage boys self-infused in front of us, which is something my family has never seen done in person. Although Evan is only 3, he understood that Levi was getting factor. When he put the band-aid over the injection point on his hand, Evan lowered his shirt and showed off the band-aid over his port from his infusion that morning. Evan was understandably impressed, as were all of us. And I loved that Evan made that connection.

Thank you to everyone who helps make camp happen with time, love and financial support. We look forward to a day when infusion training isn't necessary, but until then, we appreciate getting to experience it outside of a clinic.

Thank you to this year’s Family Camp supporters: Bioverativ, CSL Behring, Novo Nordisk and Shire.
Each year, CSL Behring hosts a three-day golf, baseball and swimming competition designed specifically for youth athletes in the bleeding disorders community.

Gettin’ in the Game Junior National Championship will take place September 28-30 at Sheraton Wild Horse Pass in Phoenix, AZ. The trip includes airfare, hotel accommodations and meals.

During the program, participants will have the opportunity to:

- Take part in either golf, baseball or swimming activities to learn the fundamentals and enhance their skills in the sport.
- Learn about the importance of physical fitness in managing a bleeding disorder and receive instructions on proper stretching techniques and good athletic form.
- Show off their golf, baseball or swimming abilities in a national competition with fellow participants from around the country.
- Connect and build relationships with fellow members of the bleeding disorders community by sharing their personal experiences with one another.
- Each chapter can nominate two participants with a bleeding disorder between the ages of 7 and 18 to attend. There is a questionnaire and short essay, and the application is due Friday, July 13. Winners will be notified by August 1. It can be returned via email to director@hacacares.org.

Those who are considering the swim category, please note that all swimmers must be able to swim 25 yards without assistance (no stopping or holding onto walls or lane lines) and must tread water for 30 seconds without touching the bottom of the pool. Swimmers will be asked to run through these activities to confirm their swim ability. Participants who do not meet the guidelines will be transitioned to baseball.

If selected, parents/caregivers of nominees will be provided with a packet of information and will be contacted by CSL Behring to make travel arrangements.
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 March 1 - April 30, 2018. We have made every effort to ensure all donations are listed.

ORGANIZATIONAL CONTRIBUTORS
- Altrusa Club of Montgomery County
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- CSL Behring
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- Diplomat
- Genentech
- J. Willard and Alice S. Marriott Foundation
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- Patrons of Theater J, who contributed more than $5,700 during run of “Roz and Ray”

MONTGOMERY COUNTY WORKPLACE GIVING
- Jessica Jones

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- Mary Carbone
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For over 60 years we have been inspired by people like you. Shire is the relentless champion that supports you with pioneering products and programs, while always striving toward our ultimate goal: a life full of dreams and free of bleeds.

bleedingdisorders.com
HACA was thrilled to partner with Theater J in DC for the run of “Roz and Ray” in April.

The chapter held a reception before the April 22 matinee performance. Participants enjoyed food from Moti’s Market, and the theater’s artistic director Adam Immerwahr stopped by to say a few words.

Special guests that day were Dr. Naomi Luban of Children’s National and Linda Price, parent and advocate. Following the performance, Dr. Luban and Linda participated in a panel discussion with the theater’s literary director Ellen Peltz.

The performance featured just two actors: Susan Rome as Dr. Roz Kagan, and Tom Story as Ray Leon. It shifted back and forth in time, from the 1980s, when Ray brought his hemophilic twins for treatment from Dr. Roz and they began using factor to treat their hemophilia; to a single day in 1991, after Ray has lost one of his boys to AIDS. It’s a stirring and startling drama, and a realistic portrayal of what happened during that time period. The playwright Karen Hartman based the story on the real-life experiences of her father, a pediatric hematologist who lost most of his young patients with hemophilia to AIDS.

Theater J generously promoted the chapter in the event program, listing HACA as a community partner. They also collected donations at the end of each performance. The chapter received more than $5,700 in donations from the theater’s patrons. The funds are designated toward Camp Youngblood, HACA’s summer camp program in July.

Thank you to Matrix Health Group for sponsoring the reception and tickets to the play.
Dr. Naomi Luban and Linda Price answered questions following the April 22 performance.

Tom Story and Susan Rome, center, portrayed the title characters of “Roz and Ray” in the Theater J performance.

Adam Immerwahr, center, artistic director at Theater J, visited with chapter members during the pre-show reception on April 22.

HACA members enjoyed a reception before the matinee performance of “Roz and Ray” on April 22.
We have good news related to the 2018 General Assembly session! And the good news comes in at least three packages.

First, we had one resolution before the General Assembly, HJ 16, declaring that March 2019 and each succeeding year will be designated as Bleeding Disorders Awareness Month. Del. Dawn Adams carried the resolution for us. Dawn is a new delegate, having been elected in November 2017. She is also a nurse practitioner, and you can tell by the low number of our resolution that ours was the first piece of legislation that she carried. Dawn will be presenting us with our resolution at the annual meeting in Newport News in June. Additionally, she will serve as a panelist in our advocacy session at our meeting. On a personal level, Dawn is a colleague and friend of mine, and I’m thrilled that she gained a seat in the General Assembly!

The second package of good news is that we were among a group of stakeholders that sought the defeat of several bills that would have eroded the requirements of the Affordable Care Act regarding essential health benefits. These were primarily attempts to pass legislation permitting out-of-state plans to be offered in the Commonwealth. All of them failed. Additionally, the Governor has vetoed several “short-term” insurance bills that are less expensive to purchase but have the net effect of draining healthy people from the insurance pool and making insurance much more expensive for those with chronic and/or preexisting conditions (like inherited bleeding disorders).

And finally, the very best news of all (saving the best for last). On Weds, May 30, the Virginia General Assembly passed two budget bills and sent them to the Governor for his action. HB 5001 is dubbed the “caboose” bill, meaning that it amends the budget for the remainder of FY 2018 (ending June 30, 2018). HB 5001 contains provisions authorizing the Department of Medical Services (DMAS) to submit state plan amendments and waivers to implement the expansion of Medicaid using 90% federal funding and 10% state funding for the approximately 400,000 Virginians who do not qualify to purchase health care insurance on the individual marketplace and who do not have insurance through their employers. Qualified Virginians will include childless adults aged 19-65 who earn less than 138% of the federal poverty level. If all goes as anticipated, the expansion will begin January 2019.

The biennial budget bill is HB 5002, and it contains full implementation provisions for Medicaid expansion. Funding of the 10% state match will come from a tax on private hospitals called a provider assessment tax. This tax was supported by the Virginia Hospital and Healthcare Association as a means of relieving the state of the 10% financial burden of Medicaid expansion and as a means of supply steady revenue support to the same hospitals. The budget also will increase the Medicaid reimbursement rates on the dollar to 88 cents. Currently that figure is 77 cents on the dollar, with the remainder being compensated primarily through commercial insurance payments to hospitals.

Special thanks to our community members who advocated in support of Medicaid expansion. In 2014 when we began this Medicaid expansion journey, we had projected several years ago that 38 community members annually would age out of traditional Medicaid (up to age 18). With expansion, these individuals will be eligible for health insurance. In a nod to conservative lawmakers and advocates, the Medicaid expansion provision will include work or school requirements for individuals to maintain eligibility.

HACA and the Virginia Hemophilia Foundation (VHF) have worked to advocate for expansion, along with the over 100 organizations in the Healthcare for All Virginians coalition. Many thanks to you all for your work on this at our last five Richmond Days and in between. There is still a lot of work that needs to be done to shore up expensive health care insurance payments and improve access to health care, but this budget gets us closer to access for all of our community.

If you have questions, please feel free to contact me at bowerslanier@gmail.com or 804-382-0991.

And thanks for all you do to advocate for our community!

Becky Bowers-Lanier is the president of B2L Consulting and handles state lobbying efforts on behalf of HACA and VHF.
Congratulations to Scholarship Recipients

HACA's scholarship committee recently selected Amy Alba and Ishaan Babbar as the recipients of the George & Linda Price Scholarship for 2018-19. Each student will receive $3,000 toward their tuition.

Amy will graduate from Woodson High School in Fairfax, VA, and plans to attend Northern Virginia Community College. She’s going to major in art.

Ishaan will graduate from Briar Woods High School in Ashburn, VA. He will be majoring in computer engineering at George Mason University this fall.

The George and Linda Price Scholarship was established to honor the generous volunteerism of George and Linda Price. From the time their youngest son, Greg, was diagnosed with hemophilia B, George and Linda were actively involved with the chapter. They both became members of HACA’s Board of Directors in 1984 and served in various capacities on that board until the mid 1990s. George passed away in 2015, but Linda is still involved in chapter activities.

Congratulations to these scholars!
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