Get ready to walk with HACA!

Form and team and join the fun at this year’s HACA Fall Festival & Walk, which will take place on Saturday, September 28, at Lake Accotink Park in Springfield, VA.

The event will take place from 8:30 a.m.-1 p.m. at the large lakefront pavilion again this year, which can be accessed from the main entrance on Accotink Park Road or the Heming Avenue entrance.

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. There will be a predetermined 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.

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.

See you at the walk in September!

Click here to register for the 2019 Walk!

Why I Walk

Kate Greene is the walk chair for the 2019 HACA Fall Festival & Walk

I walk for my son three-year-old son Eddie, my mother Jane, and in memory of my grandfather John.

When I found out that our son had hemophilia, I was very afraid. Hemophilia was a scary word to me growing up. My mom lost her father to hemophilia when she was only 10 years old. Before then, she remembers his many stays in the hospital.

Continued on page 9
**CHAPTER NEWS**

**Families to meet at park**
The Families of Young Children group will meet on **Saturday, June 15**, from noon-2 p.m. at Locust Grove Nature Center, 7777 Democracy Boulevard, Bethesda, MD.
The group will meet at the picnic pavilion for noon for lunch and playtime, then check out the exhibits at the nature center.
To register, click [here](#).

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**2019 HACA CALENDAR OF EVENTS**

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

**JUNE**

9 **Teen Task Force Gathering**, 2-5 p.m., Penrose Square Apartments community room, Arlington, VA. [RSVP here](#)

13 **Dine & Discuss**, 6:30-8:30 p.m., Maggiano’s, Washington, DC. Program with Pfizer. Topic: “Balancing Emotional Wellness.” [RSVP here](#)

15 **Families of Young Children Group**, noon-2 p.m. Locust Grove Nature Center, Bethesda. [RSVP here](#)

17 **Board Meeting**, 7-9 pm, Richard Byrd Library, Springfield, VA.

22 **Program on Emerging Therapies: Panel Discussion with CNMC**, 10:30 a.m.-12:30 p.m. Thomas Jefferson Library, Falls Church, VA. [RSVP here](#)

23 **Kids and Sports Program**, 1-4 p.m., Top Golf, Ashburn, VA. Program with CSL Behring. [RSVP here](#)

**JULY**

13 **vWD Education Event**, 9:30 a.m.-1:30 p.m. Walter Reed Community Center, Arlington, VA. [RSVP here](#)

20 **Women's Group**, 1-3 p.m., Green Spring Gardens, Alexandria, VA. [RSVP here](#)

27 **Dine & Discuss**, National Harbor, time TBD. Program by Bioverativ

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**Program on emerging therapies**

Many new products for the treatment of bleeding disorders have emerged on the market in the last few years, and the Hemophilia Association of the Capital Area and the Hemophilia Treatment Center at Children’s National are teaming up for an educational session to discuss emicizumab, gene therapy, fitusiran and more.

The highlight of the event will be a discussion about the new hemophilia A therapy, emicizumab (Hemlibra) through a panel discussion with local medical experts and patients, including Dr. Michael Guerrera of Children’s National, Dr. Craig Kessler of Georgetown and Kim Drucis of Johns Hopkins. Chris Guelcher of Children’s will moderate the panel.

Please join us at the Thomas Jefferson Library, 7415 Arlington Blvd., Falls Church, VA, on **Saturday, June 22**, for an interactive discussion. The talk will run from 10:30 a.m.-12:30 p.m., and HACA will provide coffee and light refreshments.

This is a clinical discussion, not a branded event with any particular company, nor is this an endorsement of any company or therapy. There have been a lot of questions about these new therapies and this is an opportunity to answer questions and receive information from both the pediatric and adult HTC representatives.

Register [here](#).

**Kids and Sports event at Top Golf**

HACA and CSL Behring will partner for an event on Sunday, June 23, from 1-4 p.m. at Top Golf Ashburn. Professional athlete Pete Dyson will talk about “Pushing Through With Positivity,” where he talks about overcoming tough times in his athletic career. He will also be joined by HACA members and recent high school graduates Brien Krug and Jack Prophett (and their parents), who will talk about growing up as young athletes with hemophilia. Lunch will be served, and participants will also practice their golf swings after the program.

To register, click [here](#).

**Save the date 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
Welcome, New HACA Board Members

At Chapter Education Day in March, HACA’s newest slate of board members was approved, and they will begin their two-year terms this month. Welcome to the following board members:

Mallory O’Connor

**Connection to the community:** Hemophilia carrier

**Professional information:** Employed by Biotechnology Innovation Organization, a non-profit healthcare trade association

**Why I wanted to join the HACA board:** Serving on the HACA board would give me the ability to help give back to a community that has helped me grow both personally and professionally. I would love the opportunity to help the community in their fundraising, education and advocacy efforts through serving on the board. I have previously served as a part of the National Hemophilia Foundation’s (NHF) National Youth Leadership Institute (NYLI), including as the NYLI representative to the NHF Board of Directors. I also currently serve on the Board of the DC Area Arizona State Alumni Group and PAC-12 Alumni Group.

Melissa Alba

**Connection to the community:** My mom and two younger sisters have VWD type 1. Our family has participated in HACA since around 2015.

**Professional information:** I’ve been working for Bridges International, a Christian student ministry at George Mason University since 2014. I spend the majority of my time connecting and welcoming international students to our campus.

**Why I wanted to join the HACA board:** My family has been very blessed and supported by the HACA community. As a family member of someone with a bleeding disorder, I want to learn more about this community and also give back. My desire is to serve and use my skills to better the HACA family.

Daniel Hay

**Connection to the community:** My son has severe hemophilia B.

**Professional information:** Litigation associate at Sidley Austin LLP

**Why I wanted to join the HACA board:** We’ve been so grateful for the HACA community since we received our son’s diagnosis nearly two years ago. I want to join the board to use my experience in law and policy to help advocate for families living with hemophilia.

Patrick Kanu

**Connection to the community:** I was diagnosed with hemophilia at birth and have lived with it my entire life.

**Professional information:** Student at Montgomery Community College, Class of 2022

**Why I wanted to join the HACA board:** I always wanted to be part of a well-organized board that supports hemophilia and its complications. I have great computer skills and am very open-minded to things.

Current board member Michelle Stielper was also re-elected to serve a third term.
Families enjoy fun weekend at Camp Holiday Trails

HACA and the Virginia Hemophilia Foundation teamed up for Family Bleeding Disorders Camp at Camp Holiday Trails April 26-28.

It was a beautiful weekend, with temps warmer during the day and cooler in the evening. The event kicked off with dinner on Friday night as the families arrived. They got to know each other through some icebreakers and games, and capped off the evening with a campfire.

Saturday morning started off with three educational sessions. The first two were geared toward the adults: “Constructive Conversations” with Linda Pollhammer of Pfizer and “Braving Change” with Sue Cowell of Bioverativ/Sanofi. The kids enjoyed messy art and games on the sports court during this time. They rejoined their parents for the final session, “Factor Feud” with Sherenne Simon of NHF.

After lunch and rest time, the overall group was divided into two for climbing wall and waterfront time. At the waterfront, families canoed, kayaked and fished.

Thanks to this year’s Family Camp sponsors: Bioverativ, CSL Behring, Octapharma, Novo Nordisk and Shire.
Saturday morning featured educational sessions from Pfizer, Bioverativ and the National Hemophilia Foundation for the adults, while the kids enjoyed messy art and time at the sports court.

Even the adults got into the spirit of fun, singing camp songs at the flagpole before lunch.

Saturday afternoon activities included time fishing and kayaking at the waterfront, as well as climbing the rock wall.
The HACA women’s support group gathered at the Lawton Community Center in Chevy Chase, MD, on **Saturday, May 4**.

The event kicked off with lunch from Panera and a game of Blood Sisterhood Bingo, led by Andy Anderson of the Hemophilia Federation of America. As terms were chosen, participants shared stories and had some laughs as well.

Following the game, it was time for some gardening! Charles and Candy Barrett of Art Emporium showed everyone how to create miniature terrariums. The group had fun picking out their stones and sand, succulents and decorations, and creating terrarium masterpieces!

Thanks to HFA, Art Emporium and all the ladies who attended.

The next women’s group will be on **Saturday, July 20**, from 1-3 p.m. at Green Spring Gardens, Alexandria, VA. We will have a short historical program led by the historic house coordinator, followed by an English tea. Register [here](#) to attend.

Mark your calendars as well for the Women’s Retreat, which will take place **September 6-8** at Meadowkirk in Middleburg, VA. More details to come soon!
A child with a chronic illness, such as a bleeding disorder, needs a lot of special care and attention from his or her parents. That can leave unaffected siblings feeling neglected, angry or sad.

Brothers and sisters may feel jealous that their sibling with a bleeding disorder seems to get most of the attention.

Emily Incledon, MD, a clinical psychologist at the Rehabilitation Service of the Royal Children’s Hospital in Melbourne, Australia, was the lead author of a 2013 review of mental health issues in siblings of children with chronic diseases.

“Family life starts to revolve around the needs of the other child,” Incledon told The New York Times in 2018. Thus siblings may withdraw or act out in response.

Helene Zereik, a mother of three in Montreal, has some firsthand experience in juggling sibling needs. Her oldest son, Gabriel, 11, has severe hemophilia B. Her other two children—son Robert, 9, and daughter Naomi, 7—do not.

“It’s a struggle for parents who have kids who have needs because you put so much effort in, but you don’t want the other two to suffer,” she says. “So it’s almost like you have to work in overdrive to make sure that the other children’s needs are met without spoiling any of them.”

Below are some tips from experts and Zereik to help parents meet the needs of siblings of children with bleeding disorders.

Communicate
Talking to kids is key. Let them know it’s OK to feel angry or resentful sometimes about the way their sibling’s bleeding disorder affects their life and the family. Help them express how they feel and validate those feelings. In a study published in ISRN Family Medicine, researchers found that siblings of chronically ill children who perceived their abilities to communicate with parents and adult caregivers as poor were more likely to report social detachment, problems with relationships and alcohol abuse.

Zereik says she talks to her younger children about Gabriel’s bleeding disorder and about how they’re feeling about it, and she makes sure they know she’s available to listen if they want to talk more.

Educate
Help siblings learn about the bleeding disorder. It’s important for kids to understand what’s happening. Share age-appropriate information. “If information is being kept from them, they may become more worried, using their imagination to create scenarios,” Incledon told the Times.

Zereik says explaining Gabriel’s bleeding disorder has helped all of her kids cope.

“Awareness creates acceptance,” she says. “The more you talk about it, the more that it becomes OK. Even for my older son, it doesn’t feel like he has something that’s wrong with him or something that’s different. It’s just part of the process.”

Include
If you can, involve brothers and sisters in the treatment process. Siblings can help—and feel important and included—by doing simple things such as organizing supplies or holding an ice pack. Older kids can help mix factor. Including siblings in doctor appointments and hospital visits can also help demystify the bleeding disorder.

Zereik says when Gabriel has a regular doctor’s appointment at the hospital and he’s not hurt and in pain, the family will make a day of it. “I’ll take them to breakfast first and then we’ll all go together, so that they’re part of the process.”

Zereik also makes sure Robert and Naomi share any benefits of Gabriel’s treatment.

“If Gabriel got a chocolate because he did well, all three of them would get a chocolate,” she says. The same went for little toys or cool bandages.

Make time for everyone
Ensure there’s one-on-one time for each child, where your focus is solely on them. It’s important to make time when the bleeding disorder is not the center of attention. Doing an activity together where talking is not the focus may make it easier for kids to open up and share what’s on their minds.
hospital, and the worry that he might spontaneously bleed at any time.

Fortunately, though, Eddie will have a very different life from my grandfather. The treatments available for hemophilia in 2019 are much more effective compared to when my grandfather was born more than 100 years ago. Eddie hasn’t had any bleeds since he started prophylaxis.

And unexpectedly, having a son with hemophilia has introduced me and my family to a small but mighty community and given us a renewed sense of purpose. We have learned so much from others in the bleeding disorders family, and have felt an incredible sense of support. For example, the first time we went to the emergency room with Eddie, it only took 30 seconds for another hemophilia mom to respond to my text messages on what to do.

We have also become very engaged in HACA’s advocacy efforts, and feel strongly that people with bleeding disorders and other conditions have the right to affordable health care. This walk offers me the opportunity to give back to the community that means so much to me and my family. I walk for Eddie, my mom, my grandfather, for all of us – let’s go!

Why I Walk

Continued from page 1

Living with vWD topic of event

HACA will have its second annual von Willebrand disease mini-education day on Saturday, July 13, from 9:30 a.m. to 1 p.m. at the Walter Reed Community Center, 2909 16th Street South, Arlington, VA.

Like last year, we will have two tracks of education, both presented by the National Hemophilia Foundation. The first will be on “Advocating for Your Care in the ER with vWD.” This workshop will cover 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 will be led by a nurse and is called “vWD: Ask the Experts.” Participants will learn some of the basics and have plenty of time to ask questions about managing life with vWD.

This year’s event will also include a session in Spanish on the basics of vWD led by a representative from Shire.

HACA will also provide coffee upon arrival, and a lunch break. Thanks to this year’s sponsors, CSL Behring, Takeda and the National Hemophilia Foundation.

There is no childcare or youth programming, but children are allowed to attend.

Click here to register.
5 consejos para ayudar a los hermanos de niños con trastornos hemorrágicos

Por Gillian Scott

Hemaware

Un niño con una enfermedad crónica, como el trastorno hemorrágico, necesita mucho cuidado y atención especial de sus padres. Eso puede hacer que los hermanos no afectados se sientan descuidados, enojados o tristes.

Los hermanos y hermanas pueden sentirse celosos de que su hermano con un trastorno hemorrágico parece recibir la mayor parte de la atención.

Emily Incledon, MD, psicóloga clínica del Servicio de Rehabilitación del Royal Children’s Hospital de Melbourne, Australia, fue la autora principal de una revisión de 2013 de los problemas de salud mental en hermanos de niños con enfermedades crónicas.


Helene Zereik, madre de tres hijos en Montreal, tiene experiencia de primera mano en el manejo de las necesidades de los hermanos. Su hijo mayor, Gabriel, de 11 años, tiene hemofilia B grave. Sus otros dos hijos: Robert, de 9 años, y Naomi, de 7 años, no la tienen.

“Es una lucha para los padres que tienen hijos que tienen necesidades porque uno se esfuerza mucho, pero no quiere que los otros dos sufran”, dice. “Así que es casi como si tuvieras que trabajar en exceso para asegurarte de que las necesidades de los otros niños se satisfagan sin mirar a ninguno de ellos”.

A continuación, se presentan algunos consejos de expertos y de Zereik para ayudar a los padres a satisfacer las necesidades de los hermanos de niños con trastornos hemorrágicos.

Comunique

Hablando con los niños es clave. Hágalos saber que está bien sentirse enojado o resentido algunas veces por la manera en la que el trastorno hemorrágico de su hermano afecta su vida y a la familia. Ayúdelos a expresar cómo se sienten y a validar esos sentimientos. En un estudio publicado en ISRN Family Medicine, los investigadores encontraron que los hermanos de niños con enfermedades crónicas que percibían que sus habilidades para comunicarse con los padres y los cuidadores adultos eran deficientes eran más propensos a reportar desempleo social, problemas para relacionarse y abuso de alcohol.

Zereik dice que habla con sus hijos menores sobre el trastorno hemorrágico de Gabriel y sobre cómo se sienten al respecto, y se asegura de que sepan que está disponible para escucharlos si quieren hablar más.

Eduque

Ayude a los hermanos a aprender sobre el trastorno hemorrágico. Es importante para los niños saber qué está pasando. Comparta información apropiada para su edad. “Si se les oculta información, podrían preocuparse más, usando su imaginación para crear escenarios”, dijo Incledon al Times.

Zereik dice que explicar el trastorno hemorrágico de Gabriel ha ayudado a todos sus hijos a lidiar con ello.

“La conciencia genera aceptación”, dice. “Cuanto más se hable de ello, más aceptable será. Incluso para mi hijo mayor, no se siente como si tuviera algo malo o que es diferente. Solo es parte del proceso”.

Incluya

Si puede, involúcrase a los hermanos y hermanas en el proceso de tratamiento. Los hermanos pueden ayudar, y sentirse importantes e incluidos, haciendo cosas simples como organizar los suministros o sostener una bolsa de hielo. Los niños mayores pueden ayudar a mezclar el factor. Incluir a los hermanos en las citas con el médico y en las visitas al hospital también puede ayudar a desmitificar el trastorno hemorrágico.

Zereik dice que cuando Gabriel tiene una cita regular con el médico en el hospital y no está herido y con dolor, la familia le dedica el día entero. “Primero los llevo a desayunar y luego vamos todos juntos, para que formen parte del proceso”.

Zereik también se asegura de que Robert y Naomi compartan los beneficios del tratamiento de Gabriel.

“Si Gabriel recibe un chocolate porque lo hizo bien, los tres recibirían un chocolate”, dice. Lo mismo ocurría con los juguetes pequeños o los vendajes genitales.

Haga tiempo para todos

Asegúrese de que haya un tiempo para cada niño, en el que se concentre únicamente en ellos. Es importante hacer tiempo cuando el trastorno hemorrágico no es el centro de atención. Hacer una actividad juntos donde hablar no es el centro de atención puede hacer que sea más fácil para los niños abrirse y compartir lo que piensan.

“Quieres dividirte por igual para tus hijos, pero la verdad es que no puedes”, dice Zereik. “Mi hijo mayor tiene más necesidades que el menor”.

Como ama de casa, Zereik dice que es difícil conseguir largos lapsos de tiempo para cada uno. En cambio, dice que la familia hace muchas cosas como una unidad, incluyendo leer juntos todas las noches. “Siempre le digo a mis hijos que somos un equipo. No quiero que se sientan excluidos”.

Encuentre recursos

Busque un campamento de verano para personas con hemofilia que incluya a hermanos y hermanas junto con niños con trastornos hemorrágicos. De esta manera, pueden conocer a otros hermanos que tienen experiencias similares a las suyas. Aprenda más sobre los efectos positivos de ir a un campamento de verano en Pasos para vivir de la Fundación Nacional de Hemofilia.
Calling All Teens  
*Sign up for these two summer programs*

Looking for some weekend activities for your teens this summer? HACA has two teens-only events planned for June and August!

**Teen Task Force**

HACA member and teen Matt Stone is the coordinator for the Teen Task Force, and their first gathering will be on **Saturday, June 8**, at the Penrose Square Apartments in Arlington, VA.

Ann Kendall, our Virginia advocacy working group chair, will lead a session for the teens on “Telling Your Story” in the complex’s community room. There will also be pool and foosball, plus pizza! All teens ages 12-17 and their parents are welcome to attend. Come and meet other teenagers in the HACA community! Register [here](#).

**Teen and Young Adult Retreat**

HACA and the Virginia Hemophilia Foundation will host a joint Teen/Young Adult Retreat **August 9-11** at the Founder’s Inn in Virginia Beach. Join other teens and young adults with similar challenges for a weekend of fun and learning.

Sessions for teens include information on educational opportunities, scholarships, storytelling and advocacy, and a panel discussion with the young adults.

Young adults will have the chance to develop tools for self-advocacy and continued learning through interactive sessions on navigating the insurance landscape, do’s and don’ts of career success, disclosure, relationship building, and more.

The teen session is for ages 13-17, and young adult session for ages 18-24. Participants must live within HACA/VHF territory and meet one of the following criteria: have a bleeding disorder; are the sibling of someone with a bleeding disorder; or have a parent/caregiver with a bleeding disorder.

Overnight accommodations at the Founder’s Inn will be available on Friday, August 9, and Saturday, August 10. If a hotel room is needed, teens and those up to age 20 will need to have a parent/caregiver in attendance as well; young adults age 21-24 can register individually. Educational programs, scheduled meals, community event, and overnight accommodations are provided at no cost for constituents that live in the HACA/VHF coverage area. There is a $25 registration fee per family for the **teen** retreat or young adults who need to bring a caregiver; or $25 per individual for young adults age 21-24 who are attending alone (if the fee is a barrier to attendance for young adults, please check “pay by check” on the payment form and email heather@vahemophilia.org to discuss options). Thanks to Bayer and Takeda who are HACA sponsors for this event.

Click on the links below for more information, including the tentative agenda:

- [Teen Retreat](#)
- [Young Adult Retreat](#)

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**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 March 1–April 30, 2019. We have made every effort to ensure all donations are listed.

**Organizational Contributors**

- Steve Long
- Christie Nix
- Linda Price
- Montgomery County
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- Nina Duggan
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- Jessica Jones
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- Mary Carbone
- Timothy Duggan

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**Helping Siblings**

*Continued from page 8*

“You want to divide yourself equally for your children. But the reality is you can’t,” Zereik says. “My older son has more needs than my younger one.”

As a stay-at-home mom, Zereik says it’s hard to carve out big chunks of one-on-one time. Instead she says the family does a lot of things as a unit, including reading together every night. “I always tell my kids we’re a team. I never want them to feel left out.”

**Find resources**

Look for a hemophilia summer camp that includes siblings along with children who have bleeding disorders. This way, brothers and sisters can meet other siblings who have similar experiences as them. Learn more about the positive effects of going to summer camp at NHF’s [Steps for Living](#). To locate a camp near you, check out NHF’s [Camp Directory](#) (HACA’s camp deadline for 2019 has passed, but siblings are welcome to attend). Zereik also recommends the book, [It’s Always About Nate](#), which explores siblings’ feelings about hemophilia. The book is available free from Diplomat Specialty Infusion Group.

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**Ayudando a los hermanos**

*Continúa de la página 10*

Hemofilia (National Hemophilia Foundation, NHF). Para encontrar un campamento cerca de usted, revise [el directorio de campamentos](#) de la NHF. Zereik también recomienda el libro [It’s Always About Nate](#), que explora los sentimientos de los hermanos sobre la hemofilia. El libro está disponible gratuitamente en el Grupo Diplomático de Infusión Especializada.
NHF launches new patient-powered registry

The National Hemophilia Foundation (NHF) is launching a patient-powered registry for people with bleeding disorders, including hemophilia and von Willebrand disease, called My Bleeding Disorders Community or MyBDC. MyBDC will capture a 360-degree view of living with a bleeding disorder. This patient-powered registry will help researchers understand how current treatments, therapies, and policies affect the bleeding disorders community by collecting information from the people directly affected: people with bleeding disorders, their siblings, partners, and caregivers.

MyBDC will request information from participants consistently and over several years – which will allow researchers to better understand how bleeding disorders affect individuals and their family members over their lifespan. The confidential, deidentified data will contribute to the ultimate goal of improving quality of life, identifying research questions important to the community, and contributing to finding a cure.

For more information about MyBDC, including how to enroll, click here.

News You Can Use: links to recent articles and industry news

Reprinting articles in HACA News can be tricky because of copyright laws. However, since the newsletter is now in digital form, we will provide links to articles of interest, as well as websites where you can find up-to-date news on bleeding disorders topics. This is by no means a comprehensive list.

Recent News

Collaboration announced between St. Jude Children’s Research Hospital and WFH
Researchers look at clinical outcomes of Factor XIII babies
The costliest drug on the planet will treat infants with rare disease. The market fight focused on cost and safety is just getting started.

Industry News

BioMarin – Company presents update of recent study
CSL Behring – Top coagulation researchers awarded grants
Genentech - Web-based calculator helps physicians finetune dosage of Hemlibra

Sigilon Therapeutics – Company releases study data on hemophilia cell therapy

Other links of interest

Hemaware
https://hemaware.org/

Dateline Federation
http://www.hemophiliafed.org/news-stories/dateline/

Hemophilia News Today
https://hemophilianewstoday.com/

If you have a link to an article that you think may be of interest to other HACA members, email director@hacacares.org for possible inclusion in a future edition of HACA News.
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
## Hemophilia Association of the Capital Area

### Board of Directors 2018-2019

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<tr>
<th>Name</th>
<th>Position</th>
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<tr>
<td>Dana Brayshaw</td>
<td>President</td>
<td>Falls Church, VA</td>
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<td>Robin Monin</td>
<td>Vice-President</td>
<td>Springfield, VA</td>
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<td>Callie Victor</td>
<td>Secretary</td>
<td>Burke, VA</td>
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<td>Sandesh Mohan</td>
<td>Treasurer</td>
<td>Ashburn, VA</td>
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<td>Patrick Kanu</td>
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<td>Laurel, MD</td>
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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
    - 111 Michigan Avenue, NW
    - Washington, DC 20010
    - 202-476-5000

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- [www.HACAcares.org](http://www.HACAcares.org)

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