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.

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Hemophilia Association of the Capital Area

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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.

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CFC #42259

The 6th Annual HACA Fall Festival and Walk is coming up a little earlier this year, and now is the time to form your team and start fundraising.

This year’s walk will take place on Saturday, September 29, at Lake Accotink Park in Springfield, VA, from 8:30 a.m.-1:00 p.m. Participants can use either the main entrance on Accotink Park Road or the Heming Avenue entrance to access the large lakefront shelter, where we will have the bulk of the activities. Look for the signs from the main entrance parking lot and along Heming Avenue to access the park.

The day will start with check-in and exhibits from our walk sponsors. There will be a photo booth and some activities to keep the kids entertained before the walk begins. Our still-unnamed blood drop mascot will be on hand, as well as another fun costumed character.

Continued on page 10
Register 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 12, from 4:00-7:00 p.m. We will be meeting at the Top Railer canopy and will have a picnic dinner as well. Everyone is invited to attend, even if you do not plan on participating in the water activities.

The Water Mine Family Swimmin’ Hole offers more than an acre of slides, flumes, sprays, showers, floatables, and an interactive water playground. Careen off covered wagons, float on wild animals and dash through showers tipped from water-filled ore carts. The activity pool is encircled by Rattlesnake River, a 725-foot lazy river you can enjoy a relaxing float as the current gently nudges you along.

Click here to register.

Medicaid Expansion Info Session

The Hemophilia Association of the Capital Area will have an informational session on Medicaid expansion in Virginia on Thursday, September 6, from 7-9 p.m. at George Mason Library in Annandale, VA.

Becky Bowers-Lanier of B2B Consulting will be on hand to provide information on the expansion and about signing up for coverage, which starts January 1. You are welcome to submit questions ahead of time to Brenda Bordelon at director@hacacares.org. We will take questions at the event as well, but feel free to submit more detailed question ahead of time.

For more information on Medicaid expansion in Virginia, go to http://www.coverva.org/. Click here to sign up for the session.

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 a.m.-4 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, 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.

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

2018 HACA CALENDAR OF EVENTS

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

AUGUST

3-5 Teen Advocacy Weekend (w/VHF), Washington, DC
12 Chapter Picnic, 4:00-7:00 p.m., The Water Mine Family Swimming Hole, Lake Fairfax Park, Reston, VA. Register here.

SEPTEMBER

6 Medicaid Expansion Information Session, 7:00-9:00 p.m., George Mason Library, Annandale, VA. Register here.
8-9 Women’s Retreat, Meadowkirk at Delta Farms, Middleburg, VA. Register here.
10 Board Meeting, 7:00-9:00 p.m., Richard Byrd Library, Springfield, VA
20 Dine & Discuss with Shire, 6:30-8:30 p.m., Carmines, Washington, DC. Register here.
29 Fall Festival and Walk, 9:00 a.m.-1:00 p.m., Lake Accotink Park, Springfield, VA. Register here.

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

For more upcoming HACA events, visit our website.
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
The women’s support group gathered on Saturday, July 14, at the Fairlington Community Center in Alexandria, VA, for lunch and a program on the issues facing women with hemophilia.

The discussion was led by Kirstin Drye, a longtime HACA member and woman with hemophilia B. It was part of Aptevo’s B Active series. She talked about her struggles with getting a diagnosis, the frustration of being called a “symptomatic carrier,” and how she’s had to advocate for herself for many years now to get prophylaxis treatment. She was joined by nurse Jill Rowley, who addressed the clinical issues.

After the program, the women enjoyed lunch from Alexandria Pastry Shop, and worked on the craft, a vision mirror, which was sponsored by Biomatrix Health Group. Michelle Stielper explained the craft at the beginning of the event, and participants worked on their mirrors throughout the session, cutting pictures from magazines and affixing stickers.

Thanks again to Aptevo and Biomatrix for supporting this event.
HACA will have a Women’s Retreat for all ladies in the chapter September 8-9 at Meadowkir at Delta Farm in Middleburg, VA.

The event will kick off with arrival at 11:00 a.m. Saturday, followed by lunch and two sessions on stress management by the Hemophilia Federation of America. There will be time to roam around outdoors, an art therapy project, dinner and an evening activity that will include a fire pit. Sunday will kick off with breakfast and a session on relationships and intimacy by the National Hemophilia Foundation before everyone heads home.

This promises to be a relaxing 24 hours at a beautiful location in the horse country of Virginia. All women of the chapter are invited. If you have transportation issues, please reach out to Brenda at director@haca-cares.org to arrange a ride.

Space is limited, so register here today.

Thanks to the retreat sponsors:
The Colburn-Keenan Foundation, Bioverativ, Matrix and Novo Nordisk.
HACA sent 14 children and teens to Camp Youngblood in Charlottesville, VA, July 8-13, for the annual summer camp program with the Virginia Hemophilia Foundation.

Camp Youngblood takes place at Camp Holiday Trails in Charlottesville, 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.

Thanks to this year’s camp sponsors: Accredo, Bayer, Bioverativ, CVS Caremark, Grifols, Novo Nordisk, Pfizer and Shire. Donations from the patrons of “Roz and Ray” at Theater J in April were also used to fund camp.
HACA had its first-ever von Willebrand Disease Mini-Education Day on Saturday, July 28 at the University of Virginia Northern Virginia Center in Falls Church.

There were two presentations that day. The first was “vWD: Your Voice Matters,” an NHF program led by social worker Joann Wagner. She talked about needs versus wants, tips on getting what you need, and overcoming obstacles. Participants did some role playing, and then shared their experiences.

The second program was “Living Longer and Stronger with a Bleeding Disorder,” an HFA program led by Ashley Smith, RN, MSN, CRNI. She talked about a variety of health issues that people face as they age, such as cancer, cardiovascular/heart disease, hypertension, obesity, joint health, anemia and others, and how they would affect a person with a bleeding disorder.

Participants enjoyed a light breakfast and lunch, as well as visits with our event exhibitors. A special thanks to Shire, who was both a sponsor and exhibitor at the event; Octapharma; CVS Health and CSL Behring. Thank you for your support of this meaningful education program!
Form a Team and Join the Walk
Continued from page 1 (cover)

The walk will begin at 10:00 a.m. from the pavilion and there will be a designated route of about a mile and a half along the lake. However, participants are welcome to run the entire 4-mile length of the lake trail, as well as ride their bikes. We will meet back at the pavilion at 11:00 a.m. for announcements and awards recognition.

Just like last year, there will be a carnival and picnic following the walk, with activities for the kids and food for all. There will also be a caricature artist and face painter on hand as well.

There will be plenty of free parking, as well as parking for the disabled and restrooms at the pavilion.

The website for this year’s walk is now up and running. Click here to access the website.

The sign-up is like the past walk website. 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. You can also add money that you receive directly to your page as well.
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.

von Willebrand disease

**NHF to Collaborate on Clinical Practice Guidelines for vWD**

Hemophilia

**Updates on My Life Our Future Genotyping Project**

**Experts Outline Best Surgery Practices for People with Hemophilia**

**Cardiovascular Disease Still a Risk for Those with Moderate or Severe Hemophilia**

Industry News

**Biomarin**

**Biomarin Partners with Believe Limited for Musical Theater Program**

**Pfizer**

**Pfizer Initiates First Stage of Phase 3 Gene Therapy Trial**

Other links of interest

**Hemaware**

**Dateline Federation**

**Hemophilia News Today**

If you have a link to an article that you think may be of interest to other HACA members, please email to director@hacacares.org for possible inclusion in a future edition of HACA News.
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 May 1 - June 30, 2018. We have made every effort to ensure all donations are listed.

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- Mary Carbone
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Commentary:
Patients Weigh in on Patent Lawsuit that Threatens Access

We all see that medical science is advancing toward fundamental improvement in hemophilia therapy. But access to Hemlibra, a revolutionary hemophilia therapy recently approved by the FDA, is threatened by a patent suit. In response, our big national organizations, HFA and NHF, released a joint statement about defending access to therapy... but then decided not to act now, hoping that the giant pharmaceuticals would reach a settlement.

A group of hemophilia patients have gotten together as an “ad hoc” group to represent ourselves now, before decisions are made. We call ourselves Patients for Access to Advanced Hemophilia Therapy and we have already filed two actions in support of patient needs.

Those actions are:

1. An Amicus brief to the court that will decide whether to limit Hemlibra access. The court accepted our Amicus brief. Interestingly, the court proceedings emphasized several arguments we raised in our brief, and the court took note of our presence at two hearings.


We have also asked for support from bleeding disorder community members and local organizations. HACA has endorsed our Citizen Petition to FDA (HOORAY! And thanks to HACA for taking an edgy position to help people with bleeding disorders). Also, several HACA members have signed the petition individually.

HACA is joined by the Committee of Ten Thousand (COTT, which represents hemophiliacs who were infected with HIV from contaminated factor), Hemophilia of North Carolina, the Hemophilia Association of New Jersey, and the Abigail Alliance for Better Access to Developmental Drugs.

We’re hopeful that the court will not limit Hemlibra access. But legal access is only one step to patient access. Hemlibra is very expensive. We plan to meet with Genentech, makers of Hemlibra, to discuss financial aspects of patient access.

Mark Antell
Proud member, HACA board
Proud member, Patients for Access to Advanced Hemophilia Therapy

HACA board members Mark Antell, Steve Long and Dana Brayshaw are all members of Patients for Access to Advanced Hemophilia Therapy
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111 Michigan Avenue, NW
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