Richmond Days cancelled, in-district visits to be scheduled, new program planned for fall

For HACA and the Virginia Hemophilia Foundation, Martin Luther King Day has been synonymous with state advocacy in Richmond. For 14 years, state advocates gathered at the Omni Hotel, attended training, and spent Monday morning in meetings with their lawmakers.

However, that changed in 2020. An influx of people was expected in Richmond on Monday, January 20, to protest fire-arm legislation during this year’s session, and Virginia Governor Ralph Northam declared a state of emergency after credible threats were received. Because of the declaration, HACA and VHF decided to postpone this year’s state advocacy training. Luckily, it ended up being a peaceful day in Richmond.

Now HACA and VHF are working together to plan other advocacy opportunities for our members. Here’s how you will be able to get involved in 2020:

In-District Meetings—We will be encouraging members in both Virginia and Maryland to visit with their state legislators after the session ends at their home offices. In the meantime, we will keep you posted on what’s happening during this legislative session and let you know if any action needs to be taken.

Chapter Education Day in March

HACA will have its annual Chapter Education Day on Saturday, March 28, at Northern Virginia Community College in Annandale, VA, again this year.

The day will kick off with a joint session on gene therapy led by Dr. Michael Guerrera of Children’s National Medical System. There will then be two tracks, one for parents of children with a bleeding disorder, and the other for adults with a bleeding disorder and their family members.

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.

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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CHAPTER NEWS

Science Show for Families Group

HACA’s Families of Young Children group will meet on Saturday, March 14, in the classroom at the Coffield Community Center in Silver Spring, MD. We will have a fun science show led by Mad Science called Pre-K 1-2-3. The kids will learn about chemical reactions in an age-appropriate way. We will also have lunch, and there will be time for parents to network. RSVP here.

Board Members Wanted

The annual election of HACA board members will take place at Family Education Day on Saturday, March 28, 2020, with new board members beginning their term in June 2020. If you are interested in becoming a board member, please email Brenda Bordelon at director@hacacares.org for a short questionnaire. The governance committee will meet to approve the slate in mid-March, and the membership will vote during the annual meeting portion of the education day event.

Board members must be able to attend four meetings each year, preferably in person. Meetings usually take place at various libraries around Northern Virginia.

Camp Registration Open

HACA and the Virginia Hemophilia Foundation (VHF) are teaming up again for Camp Youngblood in 2020! The dates are Sunday, July 5th – Friday, July 10th.

NEW THIS YEAR: In order to make the registration process run more smoothly, the enrolling parent or guardian will fill out a short Camp Youngblood prescreening survey to determine eligibility. This is required for all applicants, even returning campers.

Camp staff will review each survey and those who meet the criteria will be sent a password to access the 2020 Camp Youngblood application. Those who do not meet the criteria will be notified as well.

ALSO NEW IN 2020: We will also be offering a Family Camp weekend at Camp Holiday Trails (CHT) that will take place Friday, July 10th – Sunday, July 12th, which is immediately after the summer camp session. Families will participate in the same fun activities as campers, stay in cabins and come to know the meaning of “camp magic” at CHT. If you are interested in registering for Family Camp, add all your family members to your account before starting the application, then select “Camp Youngblood & Youngblood Family Camp Weekend” as your session. This is open to summer camp families only at this time.

The Camp Youngblood application process is open enrollment and not first come first served. This will allow VHF, HACA, and CHT the chance to review applications and manage the roster according to the application/admission guidelines. All application deadlines must be adhered to in order to be considered. Family Camp has limited space. Eligible families will be chosen from confirmed Camp Youngblood campers using a lottery system.

The application process is now open on the Camp Holiday Trails website. The deadline for submitting applications is March 30, and all camp paperwork and the medical assessment is due by April 30. These dates are earlier than in years past, which is why the application has opened earlier as well.

Thank You, Fitness Expo Volunteers

HACA participated in the NBC4-Telemundo Health and Fitness Expo for the ninth year in a row as an exhibitor January 18-19 at the Washington Convention Center.

Thank you to the following volunteers: Steve Long, Beth Plummer, Veronica Scott and Ian Fullard (right), Dana Brayshaw, Patrick Kanu and April Owens.
Ho Ho Holiday Fun for the Family

HACA had its annual holiday gathering on Saturday, December 14, and it was standing room only at the Sherwood Center in Fairfax, VA!

More than 75 HACA members were in attendance for the event, which included food and music, a photo booth and photographer, crafts for the kids, and a visit from Santa Claus!

Thanks to this year’s holiday gathering sponsors: Biomatrx, Colburn-Keenan Foundation, Genentech, Novo Nordisk and Octapharma.

Photos by Bethany Swain
National Organizations Select New Leaders in 2020

Valentino to lead NHF

The Board of Directors of the National Hemophilia Foundation (NHF) recently announced that Dr. Leonard A. Valentino will be the foundation’s next President & Chief Executive Officer. Dr. Valentino will take the helm on February 17, 2020, and work to advance the foundation’s mission of education, advocacy, and research. Dr. Valentino was a standout candidate who was identified through a national process.

Dr. Valentino brings more than 35 years of clinical and research experience related to bleeding disorders to the role, aligning with the board’s strategy of a more research-focused agenda. Prior to his most recent work with Spark Therapeutics, a biotech startup, he founded and led the Hemophilia and Thrombophilia Center at Rush University Medical Center in Chicago, where he successfully balanced a $10 million budget to support research grants, research and clinical teams — keeping the patient and their families as his core focus. Additionally, he has held leadership roles with key industry groups. In these roles, Dr. Valentino was responsible for managing the global medical teams who successfully led strategic planning for multiple worldwide hemophilia product launches.

He earned his undergraduate and medical degrees from Creighton University and Creighton University School of Medicine. He then completed the University of Illinois at Chicago’s Pediatric Medicine Residency before completing a fellowship in pediatric hematology-oncology at the David Geffen School of Medicine at UCLA. Dr. Valentino remains an active member of multiple professional organizations, including The American Society of Hematology; International Society of Thrombosis and Hemostasis; Medical Affairs Professional Society; and The Hemophilia and Thrombosis Research Society.

Under the leadership of Dr. Valentino, the National Hemophilia Foundation will continue to be at the forefront of education, advocacy and research. Dr. Valentino aims to hone NHF’s strategy to better achieve the foundation’s mission.

Dr. Valentino succeeds Val Bias, who, late in 2019, announced his plans to retire after a little over a decade of leadership. NHF appointed Dawn Rotellini as interim Chief Executive Officer of NHF effective December 5, 2019. Rotellini has been with NHF for eleven years, most recently as Chief Operating Officer, a role she will resume after Dr. Valentino assumes the role of President and CEO.

Meyers takes reins at HFA

Hemophilia Federation of America announced the board of directors has selected Sharon Meyers, M.S., CFRE, as president and chief executive officer, effective Jan. 16, 2020.

Meyers is a strategic, energetic, action-oriented nonprofit leader who has been part of HFA’s leadership team for more than four years, most recently serving as the vice president of the advancement team, overseeing fundraising, marketing and communications, and research. Meyers has 15 years of healthcare and university nonprofit leadership experience at the local, state, regional and national level. Meyers previously led major organizational change initiatives as well as multimillion-dollar fundraising campaigns.

Prior to joining HFA, Meyers was president and chief development officer of the St. Anthony North Health Foundation in Denver, vice president of the Penrose-St. Francis Health Foundation in Colorado Springs, foundation executive director and director of advancement of the St. Michael’s Catholic Academy in Austin, and associate executive director of the University of Southern Mississippi Foundation.

Meyers is a Certified Fund Raising Executive (CFRE) and holds a Nonprofit Management Executive Certificate from Georgetown University in Washington, D.C. She is currently working on a doctorate in education at the University of Southern California in Organizational Change and Leadership. Additionally, she holds a master’s in political science from the University of Southern Mississippi. Earlier in her career, she was a public servant working on an ambulance as a nationally-certified EMT-I and answering 911 calls. She has volunteered and served as a board member for various nonprofits serving the poor and those in need.

Meyers has served as interim president and CEO since September after long-time president and CEO, Kimberly Haugstad, resigned to accept a position at Global Genes.
Women get their art on at Blood Sisterhood event

Dr. Kim Mauer of Oregon Health and Sciences University in Portland, OR, was the featured speaker on pain management at HACA’s women’s group and Blood Sisterhood event on January 26.

The event kicked off with an informative presentation by Dr. Mauer, who talked about the different types of pains and treatments specifically related to pelvic pain for women.

After the talk, everyone donned smocks and gloves for fluid painting. The event took place at VisArts, an art studio in downtown Rockville, MD. Michelle, our class instructor, showed the different types of ways to create artwork using this technique, which basically involves putting paint on a small canvas, and moving it around to see what emerges. The paint has silicone in it, which creates little bubbles and swirls. Every person’s paintings were unique!

Thank you to the Hemophilia Federation of America for presenting this Blood Sisterhood event, and Novo Nordisk for supporting HACA’s women’s programming.
Dave & Busters event for teens set for February 22

HACA’s Teen Task Force is kicking off 2020 with a program on advocacy, followed by an afternoon of fun at Dave & Buster’s.

The TTF is designed for HACA members age 13-18 and will be meeting a few times a year to participate in a variety of fun activities and educational programs. Teens get to socialize while gaining knowledge and developing skills related to bleeding disorders, advocacy, school, and much more.

On Saturday, February 22, the TTF will have its first meeting of the year at Dave & Buster’s in Springfield, VA. Come prepare for Washington Days and have fun with old and new friends! The afternoon will kick off with the program “Your Voice Has Weight: Let’s Advocatel,” led by Sarah Shinkman of the Hemophilia Federation of America. After the program and a buffet lunch, attendees will get PowerCards to play games while hanging out with one another.

Teens are invited to bring along one parent since space is limited. For more details and to register, click here.

We have many other exciting things planned for our Teen Task Force in 2020 in addition to our February event. GutMonkey will bring its Leading Edge teen program to the Chapter Education Day on Saturday, March 28. Register here.

Leading Edge is an interactive program specifically designed to empower teens with bleeding disorders, helping them develop skills around personal motivation, taking positive risks, setting goals, embracing change when change is difficult, and expanding comfort zones and thus capacity.

The Teen Task Force will meet two more times this year, in the summer and the fall. These meetings will focus on developing professional and career skills along with wellbeing as a teen with a connection to a bleeding disorder. Keep an eye out for these events later in the year so you don’t miss out! For more information on the TTF, email Patti Williford at admin@hacacares.org.

Chapter Education Day

Continued from page 1

The adult session will feature:

- Financial Planning (definite title TBD) with Carolyn Walder, CFP, president of Lifetime Wealth Planning and Management
- Kinesio Taping, presented by the Hemophilia Federation of America

The parents track will include:

- Legal Rights for Bleeding Disorders presented by Donnie Akers of the Hemophilia Federation of America
- A panel discussion on parenting children with hemophilia in all ages and stages featuring HACA parents. Within the chapter, we have a range of expertise from patients and parents themselves. For this discussion, parents of kids ranging from preschool to adulthood will share tips they learned and experiences they’ve had, with time for questions and sharing.

We have a very special program for the teens of the chapter this year. GutMonkey will bring their Leading Edge program for teens (see description in article above).

We are also working on several programs for school-aged children, including “Be Digitally Smart” and “My Story of Resilience” with HFA, and another creative program in the afternoon.

We will provide free childcare with White House Nannies downstairs in the dance room, and there will be lunch and time to visit with our event exhibitors. There’s also plenty of free parking!

You can RSVP here. See you on March 28!

Advocacy

Continued from page 1

State Advocacy Training—Training is being rescheduled for Saturday, November 14, in Richmond. We are going to be developing a new format for training. It will still include an overnight trip, with hopefully some fun new components.

We are still looking for people to serve on our chapter advocacy committee, HACA in Action. The committee will tackle issues that affect the bleeding disorders community as they arise, and keep members apprised as to what’s happening. Look for future articles in HACA News, and information on our Facebook page. If you are interested in getting involved, email Brenda Bordelon to add your name to the list.
Study shows higher postpartum hemorrhage in FXI deficiency

Researchers from the Beth Israel Deaconess Medical Center in Boston, MA conducted a study on the link between postpartum hemorrhage (PPH) and women with mild factor XI (FXI) deficiency. The results were included in a research poster abstract presented on December 9, 2019 during the 61st American Society of Hematology Annual Meeting in Orlando, Florida.

Since direct-to-consumer genetic testing companies now often screen for FXI mutations, more people are learning that they have a mild form of the disease. While many of these individuals have never exhibited symptoms, they may still be vulnerable to excessive bleeding related to surgery. The investigators from Beth Israel looked at a particularly at-risk group, postpartum women with mild FXI deficiency, including those who have undergone a cesarean delivery.

Investigators initiated a retrospective analysis that included two groups, a control group that included 200 women who had undergone deliveries between 2016 and 2018, and a second group which included 40 women with mild FXI deficiency.

The FXI deficiency group included 71 deliveries, of which 45 were vaginal and 26 were cesarean. The control group encompassed 200 deliveries, of which 125 were vaginal and 75 were cesarean. PPH was defined as estimated blood loss of at least 1000 milliliters (mL) or reported symptoms of hypovolemia (a decreased volume of circulating blood in the body) related to blood loss within 24 hours post-delivery.

In both groups, median estimated blood loss for vaginal deliveries was 300 mL and median estimated blood loss for cesarean deliveries was 800 mL. Among patients undergoing vaginal delivery, PPH occurred after no deliveries in the FXI deficiency group and after one delivery in the control group. In contrast, women with mild FXI deficiency undergoing cesarean delivery were approximately 2-fold more likely to develop PPH when compared to the control group. The overall rates of PPH among those FXI women who underwent cesarean delivery was 38.4% (10 of 26 deliveries) compared with 18.7% (14 of 75 deliveries).

Investigators ultimately found that a prior history of hemorrhage was the best predictor of PPH following cesarean delivery. In fact, most of the women (7 out of 10) who developed PPH following caesarean had a prior history of bleeding. Notably, only two of the women with PPH received some type of prophylactic care prior to delivery. Among the women 16 cesarean deliveries in the FXI group without PPH, significantly fewer had a history of bleeding.

“In this case control study, we did not observe any cases of PPH among women with FXI deficiency who underwent a vaginal delivery but noted a greater than 2-fold increase in PPH among those women who underwent a cesarean delivery,” concluded the study authors. “In those women with a bleeding history, the risk of PPH following cesarean section was nearly 10-fold higher compared to women without a history of hemorrhage supporting the role for prophylactic measures in this high-risk group.”

Source: Hematology Advisor, December 10, 2019

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