Getting used to a new normal during COVID-19

During these strange and challenging times, the lack of interaction with other people (except for those that live in your immediate household) has been one of the most painful aspects of the COVID-19 pandemic.

The Hemophilia Association of the Capital Area’s mission is to support advocacy, education, and awareness efforts that build and sustain community among all people impacted by bleeding disorders. We are trying our best to continue to achieve our mission through the webinars and Zoom meetings that we have offered the last couple of months. But it’s not the same as having face-to-face interactions at chapter events. If you’ve seen me the last few months, it’s just been as a face in a Zoom box like above!

We are following the state guidelines for events, as well as using common sense. But we visualize a future in which we will have limited in-person gatherings, and possibly virtual access as well for those who don’t want to venture out.

Right now, we have cancelled our in-person events in June, including the “Bombardier Blood” screening and industry symposium, and are looking for a new, creative way to host the event. We are taking it month to month, monitoring the cases in our areas. The governments in the DC Metro area are rightfully taking a cautious approach, since in DC, suburban Maryland and Virginia, the case number is higher..

We are having to think creatively for some of our beloved traditional events, like summer camp. Camp Holiday Trails has cancelled all of their summer camp sessions, but we will be working with camp staff, and chapter staff and leaders to come up with a virtual experience each day during camp for the kids and teens that participate. It’s not the same, we know, but we will work to still make it as memorable as possible.

At this time we are still hoping to provide the chapter picnic and women’s retreat, which are both scheduled for August. But we will keep you posted as time goes by.

Remember, HACA has dedicated funding for its COVID-19 relief fund, which was created to help our members who are facing hardships during this time, such as loss of job. You can receive up to $500 in assistance, or a gift card for groceries if needed. You can self-refer for this fund, so click here for the application on our website. We want to thank the Hemophilia Alliance Foundation for the recent grant of $6,000 that is solely dedicated to COVID-19 relief for the chapter. If more

Continued on page 2
CHAPTER NEWS

Families group webinar
The Families of Young Children group will gather on Wednesday, June 17, at 7:30 p.m. for a program led by two pediatric psychologists at Children’s National Medical System. Megan Connolly, PhD, and Dana Footer, Psy.D., will discuss “Strategies to Improve Children’s Behavior and How Communication Impacts Cooperation.” Register via Zoom.

vWD event expands to two days
The annual vWD education event will take place virtually over two days on Saturday, July 25, and Sunday, July 26.

Saturday’s session will take place from 11 a.m. to 1 p.m. and will feature special guest speaker Dr. Danielle Nance. Dr. Nance will speak on “I Have vWD, Now What?” She will share practical tips on managing bleeds in vWD, review hemostasis, review signs and symptoms of bleeds, present treatment options for bleeding symptoms; and talk about preventing bleeds for planned procedures: dental work, biopsies, surgeries and cosmetic procedures. Physical therapist Jeffrey Kallberg will also speak on joint and tendon injuries.

Sunday evening’s presentation will take place starting at 6 p.m., and will feature Kelly Gonzalez, senior educational specialist with Biomatrix. Her talk is titled “vWD: Not the Little Sister of Hemophilia.” People with von Willebrand are sometimes dismissed, their struggles minimized because “it’s just vWD.” vWD can significantly impact lives of affected persons and their families. Although we experience a variety of symptoms and severity, it’s important to know and validate the experiences we face. Join us as we discuss the challenges of living with vWD, become empowered to explain to others the impact vWD can have on lives, and connect with community members from our vWD community.

Thank you so much to this year’s sponsors: Biomatrix, CSL Behring, CVS Specialty, Octapharma and Takeda. Our sponsors will each get the opportunity to say a few words before each day’s session.

Update from Camp Holiday Trails
Hello CHT Family!

We are so excited to announce that the week of July 5-10th, we will be offering some exclusive programming as part of Staying Connected: CHT at Home for families who are affiliated with the HACA and VHF in honor of Camp Youngblood! While we will continue to share posts for our larger community on social media platforms that week, we will have some exclusive content on the Zoom platform for these families and campers. As part of this week we will be hosting a virtual campfire, an online infusion clinic, and much more!

If your family is affiliated with VHF or HACA and would like to have access to this week of content in addition to CHT’s other virtual programming all summer long, please follow the link to fill out our waiver and sign up for virtual programming! Filling out the waiver is mandatory for families who would like to participate on Zoom calls as part of Staying Connected: CHT at Home. We can’t wait to see you there! - Camp Holiday Trails Staff

2020 HACA CALENDAR OF EVENTS

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

All June in-person events are cancelled

JUNE
7 Cooking Healthy Virtual Cooking Class, 4-7 p.m. Registration closed
11 Branded Webinar with Takeda, 7 p.m.
15 Board of Directors Meeting, via Zoom
17 Families of Young Children Webinar, 7:30 p.m.

JULY
5-10 Virtual Camp Youngblood
25 Virtual von Willebrand Disease

Note from the Executive Director
Continued from page 1

funding is necessary, the Hemophilia Federation of America also has a relief fund, but you have to be referred by a provider or the chapter, so please reach out to me if you require additional assistance.

Please reach out to me if you have any questions, concerns or if you just want to talk! You can reach me by email or phone, 703-352-7641 (checking the office voice mail every two days).

Stay Safe!
Brenda Bordelon
Executive Director
The Krug family recently celebrated a college graduation! **Danny Krug** graduated from the University of Virginia with a BS in Environmental Systems on May 16, 2020. He will continue at UVA next year and graduate May 2021 with a graduate degree in Leadership and Public Policy. Congratulations, Danny!

**Kathy Krug** also reports that the silver lining of the pandemic is their nightly family dinners. “As a family of five, we have not had consistent family dinners for the past eight years,” she said.

**Donna Starkey** was sick for eight days with a high fever as she battled COVID-19. As a result, her family had to quarantine. After recovering, she’s been working from home while her daughter, Alissa (pictured, with family dog Roxanne), continues her job as a social worker at UMUC in Baltimore, and her son, Ricky, continues work as well. “It’s been a stressful time for all of us, but we are now enjoying the nice summer sunshine,” she said.

**The Stielper family welcomed a new family member during the midst of the pandemic! Michelle Stielper** gave birth to Jackson John Stielper on May 20 at the University of Virginia Hospital Center. He was 8 pounds, 1 oz, and 20 inches long. Congratulations to Michelle, Nick, and big brother Mason on Jackson’s arrival!

**Kirstin Drye** and her husband, Brian, have both been working from home during the pandemic. “We have become creative to have things delivered versus going out to the store. We have taken all precautions and really haven’t ventured out since the stay at home order. The dogs (pictured below) are absolutely loving having us home all the time,” she said.

**Aaron Christopher Jackson-Mackey** is a proud member of the Charles Herbert Flowers High School Class of 2020. Aaron participated in Student Government Association, Principal’s Action Council, Manhood, and Koutoure. He will attend the University of Pittsburgh in the fall pursuing his degree in education. Congratulations to Aaron! Pictured are Aaron and his mom, Stephanie Jackson.

**Patrick Kanu** was recently inducted into Phi Theta Kappa Honor Society. Phi Theta Kappa is an honor society that recognizes and encourages the academic achievements of students and provides opportunities for individual growth and development through participation in honors, leadership, service, and fellowship programming. Patrick is a student at Montgomery Community College. Congratulations, Patrick, on your achievements!

*Do you have some news that you would like to share with the HACA community in the August newsletter? Please email director@hacacares.org with your news and photo.*
HACA holds first-time online election

HACA recently had its first-ever online voting for board members. Thank you to everyone who took the time to visit SurveyMonkey to review and vote on the slate of board members and officers.

The new board members and officers began their term on June 1.

New board members for 2020-22 are Steve Long, Lindsay Runion and Luke Runion.

Returning board members are Chris Guelcher, Artura Jackson, Robin Monin, April Owens, Jennifer Sleboda, and Callie Victor.

Officers for 2020-21 are Robin Monin, president; Callie Victor, vice-president; Daniel Hay, secretary; and Lindsay Runion, treasurer.

A special thanks to Dana Brayshaw, who served as HACA board president from 2018-2020. Thank you for all of the time you put into your service to the chapter! Dana also served on the board from 2013-2017, and was secretary during part of her first tenure.

Other departing board members are Mark Antell and Sandesh Mohan. Eena Kapoor also departed the board in late 2019, and was replaced by Chris Guelcher.

Welcome, new board members

Steve Long

Board member from 2013-2019; 2020

Connection to the Community: Hemophilia B

Professional Information: Diagnosed after seven years in the Air Force, I was allowed to stay in and retire after 27.5 years. My career was spent in Intelligence with numerous varied reserve tours over the last 18.5 years. Most of my work was in long range planning and crisis management. Currently, I work as a realtor at Jobin Realty and enjoy helping people to find the right place to live.

I have been and remain a very active volunteer in the State and National soccer communities, holding numerous offices and chairing and serving on many committees. I still referee and serve as a Delegate at Large to the Metro-DC Virginia Soccer Association. From 1986-1990 I was President of the Brookland-Bush Hill Civic Association, serving on the Van Dorn Metro Station Development Committee.

About nine years ago, I became active in the hemophilia community, first serving as secretary then president of HACA. I now serve on the Scholarship and Accountability Committees of the Hemophilia Federation of America (HFA) and on the Executive Committee as Secretary of the HFA Board. I will begin a term of vice-chair for the HFA board in August.

Lindsay Runion

Board Position: Treasurer

Board Member since 2020

Connection to the community: Carrier and parent of a young son with severe hemophilia A.

Professional Information: Regional Recruiter at Whole Foods Market, Mid-Atlantic Region.

I’m originally from the suburbs of Philadelphia and moved to College Park to attend the University of Maryland. It was here that I met my future husband (and fellow HACA board member!) Luke. We’ve learned so much from HACA and about the world of bleeding disorders since our relatively recent introduction to the hemophilia community in early 2018.

Luke Runion

Board Member since 2020

Connection to the community: My son has severe hemophilia A, he was diagnosed after birth in 2018. Hemophilia was new to our family and we have experienced great value from both connecting with and contributing to the bleeding disorder community. I feel privileged to serve on HACA’s board and have the opportunity to make meaningful contributions.

Professional Information: I am a Federal Government Relationship Partner at Bloomberg Industry Group (INDG), supporting the executive and legislative branches with information services. I enjoy working at INDG where the corporate values are innovation, collaboration, knowing your customer, working harder and smarter, and doing the right thing. These values exemplify how I will guide my personal efforts for HACA. My previous non-profit experience includes serving on the board of a collegiate club sport organization’s national governing body. I welcome others to connect with me on Linkedin: https://www.linkedin.com/in/luke-runion-824b46139/
Bleeding disorders meetings to go virtual

Both the National Hemophilia Foundation and the Hemophilia Federation of America have made the decision to have virtual conferences in August due to COVID-19.

Every year NHF’s Bleeding Disorders Conference brings together thousands of families and passionate professionals for in-person education and networking. This year’s conference will now take place August 1-8 online. More details to come soon regarding registration for sessions.

Attendees who have already completed a paid registration and have reserved sleeping rooms via NHF’s BDC Housing Bureau will receive a 100% refund.

According to NHF’s website, the virtual educational conference will be full of interesting sessions and fun networking activities for all members of the bleeding disorders community. Everyone will be able to find something to pique their interest or strengthen their professional skills. Affected individuals and families will find sessions on nearly every aspect of living with a bleeding disorder, from the basics of hemophilia and vWD to the latest in gene therapy treatment. Providers will find information on the latest treatments and techniques, and chapter staff will be able to learn more about best practices and ways to strengthen their local organizations.

The Hemophilia Federation of America’s Executive Committee and staff also recently made the decision to turn the annual Symposium into a virtual conference.

The conference was originally scheduled for late April in Baltimore and moved to late August after the pandemic began. In mid-May, HFA sent out a survey to community members for their thoughts on attending the Symposium in person. Results showed, while many wanted to attend in person and enjoy the “family reunion” aspect of the event, an equal number expressed their uncertainty with the health situation involving COVID-19.

Instead of meeting in person, Symposium will now take place virtually August 24-29. All registered attendees for Symposium will receive registration for the virtual event and HFA staff will work with all stakeholders to make other arrangements when and where appropriate.

If you have questions, please visit Frequently Asked Questions page or contact symposium@hemophiliafed.org.

Teens from throughout the country invited to celebrate at Virtual Prom

The New York City Hemophilia Chapter is partnering with Believe Limited to present the Bleeding Disorders Community Virtual Prom 2020 on Saturday, June 13, from 8-9 p.m.

The theme for the BDC Virtual Prom 2020 is "Dress for the Prom Theme of Your Dreams!" You get to decide, decorate, and dress up as whatever your dream Prom theme is: from ball gowns to banana suits, from starry night to superheroes!

Featuring:

• Musical guest & live performance
• Live awards - including Most Uniquely Dressed, Most Prom Spirited, Most Epic Hair, Most Creative Corsage, and others
• A photo booth
• Games, dancing, and so much more

Need help deciding on a theme or what to wear? RSVP below and receive the Bleeding Disorders Community Virtual Prom Style Guide to help you "Dress for the Prom Theme of Your Dreams!"

Pre-Prom:

• RSVP to the Prom and get your official Virtual Prom Style Guide!
• Join the BDC Virtual Prom 2020 Facebook Group for theme ideas, to see the attendee list, and for additional info!

Before the prom, don’t forget to get all dolled up and take some classic prom pics!

Prom Night:

• Join the Zoom link and prepare to dance the night away at a prom like no other!

This event is open to juniors and seniors in high school. Click here to register.
All Virginians, especially those with pre-existing conditions, need quality health insurance and the Healthy Market VA Coalition applauds Governor Ralph Northam for vetoing SB 861, SB 235, and HB 795, bills which would have created several different types of Association Health Plans (AHPs). Expanding the availability of these plans in Virginia could lead to instability in the individual and small group markets by enticing healthier consumers away from the larger marketplace risk pool. If healthier consumers select AHPs, the effect will likely involve premium hikes for those who need comprehensive coverage. These premium increases will hurt Virginians with pre-existing conditions, older Virginians, and small business owners who want to provide comprehensive coverage to their employees the hardest.

AHPs are particularly harmful to small businesses and their employees because they can effectively cherry pick their enrollees. These plans may, for example, set higher rates for small groups and businesses whose workers are likely to have preexisting conditions or who are sicker, older, or otherwise at risk. They could even set higher rates or not offer coverage based on where workers live.

“I am grateful to Governor Northam for vetoing these dangerous Association Health Plan bills – Virginians, especially those with pre-existing conditions are more vulnerable than ever as a result of the COVID-19 pandemic and this is not the time to destabilize the insurance market. The premium increases resulting from AHPs could hurt Virginians with pre-existing conditions as their lives quite literally depend on access to comprehensive coverage,” said Chelsi Bennett, Co-Lead, Healthy Market VA Coalition & American Heart Association Virginia Government Relations Director.

Federal regulations related to AHPs are currently subject to a challenge in court. Virginia is part of a lawsuit brought by eleven states and the District of Columbia, seeking to block the Trump Administration’s proposed rule which two of these vetoed bills – SB 235 and HB 795 - rely on. This lawsuit is still pending.

The Healthy Market VA Coalition represent hundreds of thousands of Virginians, including those with serious health conditions, small business owners, and older adults. We have a unique perspective on what it takes to prevent disease, cure illness, and manage and improve health over a lifetime. Our organizations are united around a set of guiding principles that we believe are necessary to maintain Virginians’ access to affordable, high-quality healthcare coverage: Accessibility, Affordability, and Adequacy. These principles guide the work we do and shape the policies that we champion in an effort to strengthen Virginia’s health insurance marketplace.

HACA and the Virginia Hemophilia Foundation are members of the coalition.
HTC still scheduling telemedicine visits during pandemic

The Hemophilia Treatment Center multidisciplinary team at Children’s National Hospital is available during the COVID-19 pandemic. We are scheduling telemedicine visits for some patients. We are also able to schedule in-person visits as needed. As the Metro area begins phasing in services, we will expand access to comprehensive care visits in the District of Columbia, Maryland and Virginia. We do continue to recommend a comprehensive visit at least once a year, but may continue to use telemedicine for appropriate follow-up going forward.

Children’s National Hospital is ready and prepared to meet your essential care needs and we are here to help all kids grow up stronger despite these challenging times. We are ready to take care of your child, with safety measures in place to protect the health of patients, families and staff. Currently, we require that everyone wear a mask at all times within our facilities; if you do not have a mask, one will be provided. We are still limiting the number of visitors in our facilities, and we have adapted our waiting areas and appointment schedules to support social distancing.

These recommendations may change so please visit the website for the most up to date information to help you navigate your visit.

Links to past webinars

Several of our recent webinars have been recorded and are available to view.

“Legal Toolkit for Families” with Donnie Akers Jr.

“Financial Considerations for People Living with Serious Medical Conditions” with Carolyn T. Walder, CFP

“Gene Therapy Update” with Dr. Michael Guerrera

HACA/VHF Advocacy Webinar with Miriam Goldstein of HFA and Becky Bowers-Lanier. Access code: 7h=25IL&

Women keep in touch via Zoom

HACA’s Women’s Group is one of the most active groups in the chapter, and through the COVID-19 pandemic, the women have kept in touch through Zoom check-ins, and our recent Zoom crafting event.

Board member Michelle Stielper, our resident crafting guru, led the women through step-by-step instructions to build a small decorative lantern with two boxes of wooden blocks (Tumbling Tower game from Dollar Tree was used).

The participants all received a box of craft supplies the week before the May 17 session, which included two boxes of blocks, paint, a paintbrush and either glue or glue sticks.

While not the same as meeting in person, it was still great to interact and see peoples’ faces, even in little Zoom boxes!

Michelle used mini wooden blocks to craft this cute candle holder!
News You Can Use: COVID-19 links and other information

COVID-19

Hemophilia Federation of America has a dedicated hub for coronavirus updates and information

The National Hemophilia Foundation is keeping tabs on product availability

The World Federation of Hemophilia has also issued statements on COVID-19

Keep up with the Centers for Disease Control and Prevention for guidelines and information

State health departments also update their information daily:

Virginia
Maryland
District of Columbia

If you are interested in seeing how states are responding through their state legislatures, click here

INDUSTRY NEWS

Industry Forms Alliance to Develop Potential Treatment for Patients with Serious COVID-19 Complications

Hemlibra Can Interfere with Tests of COVID-19 Associated Coagulation Problems

Pfizer and Biontech Dose First Participants in COVID-19 Vaccine Development Program

BioMarin’s Gene Therapy for Hemophilia A Continues to Prevent Bleeds After Four Years, Trial Shows

RNA Gene Therapy Seen to Effectively Treat Hemophilia A Mouse Model

Early Treatment Linked to Reduced Joint Damage in Young Adults with Severe Hemophilia A
Thank you to our Educational Webinar Sponsors

HACA’s annual Chapter Education Day was cancelled because of COVID-19, and instead of an in-person meeting, we presented a series of webinars from April-June that covered the topics that were to be offered at the event, as well as some additional education. Thank you to the sponsors who agreed to fund our online education.

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Thanks to our donors, sponsors

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, 2020. We have made every effort to ensure all donations are listed.

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Center for Hemophilia and Thrombophilic Disorders
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Washington, DC 20007
202-687-0117

CHILDREN:
Children’s National Health System
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Sheikh Zayed Campus
for Advanced Children’s Medicine
111 Michigan Avenue, NW
Washington, DC 20010
202-476-5000

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