Members enjoy day of education

HACA’s annual Chapter Education Day was held a little earlier this year on Saturday, March 30, at Northern Virginia Community College in Annandale, VA.

The event featured two tracks of education: one for parents, guardians and family members of a child with a bleeding disorder, and one for adults that have a bleeding disorder and their family members or caregivers. There was also a joint session at the end of the day, as well as HACA’s annual meeting.

There was programming for teens and children, as well as free childcare with White House Nannies.

HACA’s industry partners were also on hand with information about their products and services. Thanks to this year’s exhibitors: Aptevo, Bayer, BioMatrix, CSL Behring, CVS Specialty, Genentech, Novo Nordisk, Octapharma, Pfizer, Sanofi Genzyme, Spark Therapeutics and Takeda.

Thanks to our wonderful speakers: Sue Geraghty, Sherenne Simon, Dr. Secili DeStefano, Andy Anderson, Miriam Goldstein, Will Hubbert, Kirstin Drye, Betsy Koval, Linda Pollhammer and Sara Ceresa.

And a big thank you to everyone who attended this year!
CHAPTER NEWS

Scholarship application available

Applications are now available for the George and Linda Price Scholarship program. This scholarship program is offered to both members with a bleeding disorder and their siblings or parents. Two $3,000 scholarships are awarded each year. The funding can be used for tuition at any accredited non-profit college, university, vocational or technical school in the United States. More details are available within the application, which can be found [here](#). Deadline is May 15.

Registration now open for summer camp

Applications are now available for Camp Youngblood, which will take place **July 7-12** at Camp Holiday Trails in Charlottesville, VA.

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### 2019 HACA CALENDAR OF EVENTS

To register for any event, contact [admin@hacacares.org](mailto:admin@hacacares.org)

**APRIL**

- **4-6** HFA Symposium, San Diego, CA
- **11** Dine & Discuss, 7-9 p.m., Trio Grill, Falls Church, VA. Program with Bioverativ. Topic: “The Power of Empowerment.” [RSVP here](#)
- TBD Board Meeting, 7-9 p.m., Richard Byrd Library, Springfield, VA
- **26-28** Family Camp with Virginia Hemophilia Foundation. Camp Holiday Trails, Charlottesville, VA
- **28** CSL Behring Branded Dinner (rescheduled from January), 5:30-7 p.m., Wild Fire, McLean, VA. [RSVP here](#)

**MAY**

- **4** Women’s Group with Blood Sisterhood Program, 11 a.m.-2 p.m.
- **19** Takeda Branded Dinner, 5-7 p.m., Rosa Mexicano, National Harbor. [RSVP here](#)
- **30** Dine & Discuss. Program with Pfizer.

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Summer camp is open to children ages 7 to 17 with bleeding disorders, their siblings and children of members of the bleeding disorders community. The weeklong camp features a variety of fun activities such as canoeing, swimming, hiking, arts and crafts, drama and much more. Space is limited and online applications are due by **April 29**. There is a $25 registration fee per child that will be payable to the chapter after the application has been approved.

Click [here](#) to register for summer camp.

**Thank you, volunteers!**

[Photo of James and Diana Cosman at the D2Z Community Health Fair.]

Thank you to **Diana and James Cosman** and **Veronica Scott** for spreading the word about HACA and bleeding disorders at the Delta Zeta Zeta Community Health Fair on Saturday, March 23, in Glenarden, MD. This was a new event, which reached between 100 and 200 members of the local community. The organization hopes to expand into other communities next year.

**CatJammers raise money for chapter**

For the fourth year in a row, a local group of bluegrass musicians have donated the proceeds from their March CatJam fundraiser to HACA in honor of Bleeding Disorders Awareness Month. Thank you to Nancy Lisi for coordinating the event, which included a raffle for a refurbished acoustic Carlos guitar. All tips and proceeds from the raffle went to HACA, which totaled $540. Thank you, CatJammers, for supporting HACA!
Advocates flock to DC for annual Washington Days events

About 450 bleeding disorders advocates from 48 states flocked to Washington, DC, March 27-29 for the National Hemophilia Foundation’s (NHF) annual Washington Days.

NHF’s Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that are important to them. There were 27 advocates from the state of Virginia, and several HACA members from Maryland in attendance.

The event kicked off on Wednesday with Washington Days training at the Hyatt Regency at Capitol Hill. Participants learned about the 2019 talking points, and Jill Boland, senior policy advisor for Sen. Jack Reed (D-RI) was the featured speaker.

This year’s talking points were:

- Support funding for the National Institutes of Health, Centers for Disease Control and Prevention, and the Health Resources Service Administration, which provides funding for HTCS to provide multi-disciplinary services such as PT and social workers.

- Support patient protections for everyone with pre-existing conditions by co-sponsoring legislation to stop the regulation that expands short-term plans. These plans do not have to follow ACA patient protections, and undermine the stability of the individual market.

The training was followed by a dinner reception.

On Thursday, the day kicked off with breakfast and a legislative briefing, with freshman Rep. Joe Morell (D-NY) as the special guest speaker. He encouraged everyone to share their stories, and shared how meeting with constituents was helpful to him during his time in the state legislature for New York.

Then it was off to Capitol Hill! HACA members visited with staffers for Sen. Tim Kaine and Sen. Mark Warner, and Reps. Ben Kline, Gerald Connolly, Rob Wittman, Don Beyer and Jennifer Wexton.

Thanks to HACA members who participated this year: Jennifer and Simon Blaisdell, Dana Brayshaw, Paul Brayshaw, Diana and James Cosman and Gracie Potts, Ethan Jansen, Ann and Elsa Kendall, Robin Monin, Linda Price, Kitty Richardson, Jennifer Sleboda, Terry and Matt Stone, and Allison and Christopher Strong.
HACA’s Families of Young Children group got together for a morning of fun on Saturday, March 9, at the Chinquapin Recreation Center in Alexandria, VA.

The kids had a blast playing in the center’s soft playroom, a space filled with soft surfaces, items to climb and a ball pit. The parents

Thanks to Genentech and Novo Nordisk, who are supporting our group in 2019.

Thanks to Bethany Swain for the awesome photos!
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 January 1-February 28, 2019. We have made every effort to ensure all donations are listed.

Organizational Contributors
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What is HEMLIBRA?

HEMLIBRA® is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider’s instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including Serious Side Effects.
Medication Guide
HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider’s instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (pCC; FEIBA®), including:

- Thrombotic microangiopathy (TMA). This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination

- Blood clots (thrombotic events). Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aCC (FEIBA®) total.

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors. Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.
- You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.

- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you have a dose of HEMIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal closing schedule. Do not give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredients: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.
Aging well with a bleeding disorder: what women should know

By Emily Rogan

Hemaware

Having a bleeding disorder means you need to pay closer attention to your lifestyle and self-care as you grow older. “We want you to live well as you age,” says Tammuella Chrisentery Singleton, MD, a hematologist at the Louisiana Center for Bleeding and Clotting Disorders at Tulane University School of Medicine who is passionate about women and girls with bleeding disorders. “It’s especially important to be informed and aware of additional complications to make good decisions.”

While there hasn’t been ample research focused on how aging affects women with bleeding disorders, Singleton says it’s good news that the issue is a matter of discussion today. “Ten years ago, we didn’t have this topic,” she says. And she expects the conversations to push researchers to address the issue. “I think we will see a paradigm shift. Hematologists and gynecologists are coming together to look specifically at women with bleeding disorders.”

Three common issues facing women with bleeding disorders.

Menopause and bleeding disorders

Singleton suggests talking with your gynecologist and hematologist about options to make the transition through menopause smoother. After an overall health evaluation, hormone therapy or birth control pills might be considerations, she adds. “It’s a different conversation than for a woman who doesn’t have a bleeding disorder,” Singleton says.

It’s also important to continue to see a gynecologist even when menses ends, says Jeanette Cesta, 54, a national bleeding disorders educator who has von Willebrand disease. “Just because monthly menstrual bleeding is no longer an issue, we need to remember there are other reasons to see a gynecologist regularly,” Cesta says. “Pap smears, mammograms and other gynecological health monitoring is still critical and shouldn’t be ignored.”

Concerns about osteoporosis

Loss of bone density and increased risk of fractures are a concern for all women as they age. However, there is an additional risk for women with bleeding disorders if surgery is necessary as a result of a fracture, says Singleton.

Typically, preventive measures include weight-bearing exercises, spending time outdoors in sunshine and taking oral vitamin D supplements. However, it’s important to talk with your doctor before you take any supplements, as they may affect your bleeding disorder.

Grace defined

Along with regular exercise and eating a well-balanced diet, a positive mental outlook is critical. “I believe attitude has a major impact on our health,” says Cesta. “By continuing to work toward personal goals and being supportive to the people in our lives, we will thrive.”

Questions remain regarding typical recommendations for aging women and how they might affect those with bleeding disorders. For example, “natural remedies such as antioxidants might be heart-healthy for others, but will they interfere with bleeding or platelets?” says Cesta.

Despite such lingering uncertainties, Cesta says she is encouraged by the progress so far. “I love watching the next generations of women coming up and seeing them have better-quality healthcare for their bleeding disorder,” she says. And alongside hope for the next generation is an admiration for her own. “I feel pride for my generation of women, who have endured so many challenges yet have succeeded in lighting the path for women coming behind them.”

Reprinted from Hemaware, www.hemaware.org
Saber envejecer con un trastorno hemorrágico: información importante para las mujeres

Por Emily Rogan
Hemaware

Padecer un trastorno hemorrágico significa que usted debe prestar especial atención a su estilo de vida y a su cuidado personal a medida que envejece. La Dra. Tammuella Chrisentery Singleton, hematóloga del Centro para los Trastornos Hemorrágicos y de Coagulación en la Escuela de Medicina de la Universidad Tulane, Louisiana, y a quien le apasiona la investigación acerca de mujeres y niñas con trastornos hemorrágicos, dice "queremos que las mujeres vivan bien a medida que envejecen". "Es particularmente importante estar informados y ser conscientes de las complicaciones adicionales para tomar buenas decisiones".

Si bien no se han realizado abundantes investigaciones centradas en cómo el envejecimiento afecta a las mujeres con trastornos hemorrágicos, Singleton resalta lo positivo que resulta saber que este asunto sea un tema de discusión en la actualidad. "Hace diez años no conversábamos sobre este tema", señaló. Asimismo, espera que estos debates motiven a los investigadores a abordar el asunto. "Creo que presenciaremos un cambio de paradigma, pues los hematólogos y los ginecólogos están colaborando para estudiar a las mujeres con trastornos hemorrágicos específicamente".

Tres problemas comunes que enfrentan las mujeres con trastornos hemorrágicos.

Menopausia y trastornos hemorrágicos

Singleton recomienda conversar con su ginecólogo y con su hematólogo acerca de las opciones que ayuden a que su transición a la menopausia sea más fluida. Tras una evaluación general de salud, la terapia hormonal o las pastillas anticonceptivas pueden ser dos opciones que considerar, agrega. "Es una conversación distinta a la de las mujeres que no tienen un trastorno hemorrágico", dice Singleton.

También es importante seguir acudiendo al ginecólogo, incluso después de que finalicen los ciclos menstruales, dice Jeanette Cesta, de 54 años de edad, una educadora sobre trastornos de la enfermedad de von Willebrand. "Solo porque ya no se presente el sangrado menstrual cada mes no quiere decir que no existan otros motivos para consultar a un ginecólogo de manera regular", afirma Cesta. "Las pruebas de Papanicolaou, las mamografías y otros controles de salud ginecológica son fundamentales y no deben ignorarse".

Inquietudes acerca de la osteoporosis

La pérdida de densidad ósea y un mayor riesgo de sufrir fracturas representan inquietudes para todas las mujeres a medida que envejecen. Sin embargo, existe un riesgo adicional para las mujeres con trastornos hemorrágicos si necesitan someterse a una intervención quirúrgica debido a una fractura, dice Singleton.

Generalmente, entre las medidas preventivas se encuentran los ejercicios con pesas, tomar sol al aire libre y tomar suplementos orales de vitamina D. Sin embargo, es importante que hable con su médico antes de que tome cualquier suplemento, puesto que estos pueden afectar su trastorno hemorrágico.

Actitud de gracia

Además del ejercicio regular y de llevar una dieta balanceada, es fundamental tener una actitud mental positiva. "Creo que la actitud tiene un impacto importante sobre nuestra salud", afirma Cesta. "Prosperaremos en la medida en que sigamos esforzándonos por mejorar nuestra salud, apoyándonos y brindándonos apoyo a las personas presentes en nuestras vidas".

Todavía hay interrogantes sobre las recomendaciones típicas para las mujeres que envejecen y sobre cómo estas recomendaciones pueden influir en aquellas mujeres que padecen trastornos hemorrágicos. Por ejemplo, "los remedios naturales, tales como los antioxidantes, podrían contribuir con la salud cardíaca de algunas personas, pero ¿qué impacto ejercerán en el sangrado o las plaquetas?", dice Cesta.

A pesar de este tipo de incertidumbres constantes, Cesta afirma que el progreso alcanzado hasta ahora continúa motivándola. "Me encanta la idea de que las próximas generaciones de mujeres ayuden a mejorar la atención médica para tratar su trastorno hemorrágico", asevera Cesta. Y junto con la esperanza para la próxima generación siente también admiración por la suya propia. "Me enorgullece mi generación de mujeres porque, a pesar de la cantidad de dificultades que han tenido que afrontar, han logrado pavimentar con éxito el camino para las mujeres que las siguen".

Reimpreso de Hemaware, www.hemaware.org
The “short” General Assembly session finished its 46-day session in 47 days, ending February 24, 2019. Because the short session marks the second year of the biennium, legislators worked to make amendments only to the biennial budget, primarily based on the recommended amendments that Governor Northam put forward in December 2018.

In addition to amending the budget, the House and Senate deliberated on 3,334 bills, either introduced (3,128) or carried over from the first year of the biennium (206). In total, 1,897 were passed out of both houses and were sent to the Governor for his actions, for a total passage rate of 57 percent. That’s a lot of deliberating in 47 days!

The General Assembly’s work remains uncompleted, as they return on April 3 for the reconvened session to deliberate on the Governor’s actions. The Governor approved 824 bills and vetoed 15 bills. We expect that the Governor will make comments on many of the remaining bills or simply allow the bills to become law without his signature.

In the reconvened session, we will be watching carefully several of the vetoed bills. Overriding of gubernatorial vetoes will be nearly impossible, since each chamber is close to parity with the Republicans controlling the House of Delegates by a margin of 51-49. Similarly, the Republicans control the Senate 21-19. A two-thirds majority vote is required to override vetoes.

The bleeding disorders community had a very good legislative session. During Richmond Days in January, we talked about two types of bills that we were supporting: the step therapy and the accumulator adjuster measures. Passage of both bills has the potential to improve the lives of our community, and both passed!

The step therapy bill, HB 2126, is designed to put constraints on the use of step therapy, or fail first, practices required by some insurers. Use of fail first practices could mean that an individual with hemophilia might be required to use a product that is not as effective as a more expensive product, solely to save money for the insurer. Del. Glenn Davis, patron of this bill, has pursued this legislation since 2015. We are grateful for his work on the bill and his perseverance to see it through to the finish line.

The accumulator adjuster bills (HB 2515 and SB 1596) were carried by Del. Tim Hugo and Sen. Siobhan Dunnivant. Both passed, which will mean that individuals who have health insurance plans regulated by the Commonwealth will not have to worry that their use of drug assistance cards will penalize them by not counting toward their annual deductible. This is a practice that is gaining in popularity particularly among self-insured plans, such as with large employers; unfortunately, these bills will not apply to self-insured plans.

Finally, we worked with other advocacy groups representing chronic conditions to ask the Governor to veto bills that are designed to siphon healthy consumers away from the larger marketplace risk pool, thus leaving sicker patients or those with chronic conditions like hemophilia in plans with fewer enrolled people. The result of the implementation of these plans would mean that our community members may have to pay much more for their insurance coverage than they currently pay. The Governor vetoed four of the bills: SB 1674, SB 1240, HB 2260 and SB 1027. As of this writing (March 27th), three bills remained unsigned: HB 1661, HB 2443 and SB 1689. All of these are “association” health plans that are theoretically available to individuals associated with certain organizations or fields. We will work to make certain that the Virginia General Assembly fails to override the vetoes.

Thanks to all of you for your advocacy during the 2019 General Assembly session. If you have questions, don’t hesitate to contact Becky Bowers-Lanier at bowerslanier@gmail.com.
SAVE THE DATE

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

Registration details to come soon!
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