Virginians visit General Assembly during annual Richmond Days event

About 15 HACA members braved freezing cold temps to visit their state lawmakers at the 13th Annual Advocacy Training and Richmond Days, held January 20-21.

HACA and Virginia Hemophilia Foundation members gathered at the Omni Hotel in downtown Richmond on Sunday afternoon for several educational sessions. Michelle Rice of NHF presented a federal update; Becky Bowers-Lanier, HACA’s advocacy consultant, gave a state update and reviewed the talking points; and Ann Kendall, state advocacy chair, and Krista Davidson talked about tips on sharing your story with lawmakers.

Monday morning kicked off with a breakfast at the Omni with a visit from a special guest, Congresswoman Abigail Spanberger of Virginia’s Seventh District. She offered some words of advice on meeting with legislators, and also talked a little bit about her new job in the U.S. House of Representatives.

Chapter Education Day Comes Early This Year

HACA’s annual Chapter Education Day is scheduled this year for Saturday, March 30, at Northern Virginia Community College in Annandale, VA.

Like last year, the event will feature 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 will also be one joint session at the end of the day, as well as HACA’s annual meeting.

There will also be programming for teens and children, as well as free childcare with White House Nannies. Lunch will also be provided.

HACA’s industry partners will also be on hand with exhibits about their products and services.

This year’s sessions are:

FAMILIES:
“When to Freak Out … Or Calmly Pick up the Phone” — Sue Geraghty, HFA
“Communicating with Providers” - NHF

The Kendall family and Sleboda-Kaseko family met with Kevin Saucedo-Branch, LA for Del. Alfonso Lopez, D-49.

Congresswoman Abigail Spanberger was the guest speaker at Monday breakfast during Richmond Days.

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

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

Board Members Wanted

The annual election of HACA board members will take place at Family Education Day on Saturday, March 30, with new board members beginning their term in June 2018. If you are interested in becoming a board member, please email Brenda Bordeaux 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 at 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.

2019 HACA CALENDAR OF EVENTS

To register for any event, contact admin@hacacares.org

FEBRUARY

2  Board of Directors Strategic Planning Retreat
10  Spanish-Language Dinner, 6:30 p.m., Trio Grill, Falls Church, VA, RSVP here
18-19  HFM Maryland Advocacy Days, Annapolis, MD
19-21  NHF Leadership Conference, Denver, CO
21  Dine & Discuss, 7:00 p.m., FireWorks Pizza, Arlington, VA. Program by Octapharma. Topic: “Transitioning Throughout the Lifespan.” RSVP here
23  Pediatric Infusion Class, 9:30-11:30 a.m. Children’s National Health System, DC. RSVP here

MARCH

9  Families of Young Children Group, 11:00 a.m.-1:00 p.m., Chinquapin Recreation Center, Alexandria. RSVP here.
30  Family Education Day, Northern Virginia Community College, Annandale, VA, 9:30 a.m.-2:30 p.m. RSVP here.

Learn to Infuse at Saturday clinic

Children’s National Health System Hemophilia Treatment Center will present its next infusion class on Saturday, February 23, from 9:30-11:30 a.m. This is the first time a Saturday clinic has been offered.

Attendees will have a chance to view a demonstration that reviews the procedures, followed by hands-on teaching with our expert nurses. Everyone will be treated to a light breakfast and an opportunity to network, sponsored by HACA.

The infusion clinic is recommended for Children’s National patients and their families who are starting home infusion. If you are not a patient at Children’s and are interested in attending, please contact Chris Guelcher at 202-476-3622 or via email.

To RSVP, please call Lynda Dattilio at 202-476-5786 or via email.

Families of Young Children to Meet in March

HACA’s Families of Young Children group will have its next gathering on Saturday, March 9, at the Chinquapin Recreation Center in Alexandria, VA.

The event will feature an hour of play in the center’s soft playroom from 11 a.m.-noon, followed by lunch. Only children age 5 and under can play, and both adults and children must wear socks at all time. Space is limited.

The center is located at 3210 King Street, and we will be meeting in Club Room 3. Click here to register.

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.

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.

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.
vWD event encourages artistic expression

Members with von Willebrand disease and their families were treated to an educational program with CSL Behring, followed by a fluid painting class at VisArts in Rockville, MD, on January 26.

Jessica Graham, community support liaison for CSL Behring, did a short program on the history of von Willebrand disease, and how the disease is inherited. Using Dove chocolates as a prop, her interactive presentation showed how the gene is passed from parents to children.

Following the educational program, participants learned about fluid painting from instructor Hiral Joshi. It was a fun painting technique that required absolutely no artistic skills! The activity involved filling small cups with layers of acrylic paint that contained silicone, which then created little bubbles and interesting patterns when poured onto a canvas. Each painting is totally unique. Everyone left their paintings at the art center to dry and get varnished.

Thanks so much to CSL Behring for providing the education, lunch from Panera and the artistic opportunity for our members!

HACA’s next vWD event will be the vWD Mini-Education Day on Saturday, July 13.
Families enjoy HACA holiday event

By Brenda Bordelon

HACA

The highlight of HACA’s annual holiday gathering was watching the reactions of the youngest members when Santa walked into the room.

Some little faces lit up, while others crumpled into tears. And the reactions continued as Santa (played by David Stone for the third year in a row, along with Terry Stone’s Mrs. Claus) called out names and handed out gifts.

Once the presents were opened, boxes were torn apart and soon the children were on the floor playing with each other, having a great time while their parents enjoyed the opportunity to visit.

This year’s event took place on December 8 at the Falls Church Community Center in the spacious senior center (which happened to be decorated for the holidays, Christmas tree and all!). Members enjoyed a light dinner, cake, the visit from Santa and some casual time to visit.

Thanks to our event sponsors, the Colburn-Keenan Foundation (whose donation paid for the location rental and gifts), Genentech, Matrix Health Group and Novo Nordisk.

Santa’s appearance brought on a variety of reactions from the youngest attendees.

Some of the adults enjoyed playing as much as the kids!
New guidelines for family camp go into effect in 2019

HACA and the Virginia Hemophilia Foundation (VHF) have teamed up the last two years to provide Family Weekend to members of both chapters at Camp Holiday Trails in Charlottesville. A few changes have been enacted for 2019.

The application process for both Camp Youngblood and Family Weekend are now 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.

These guidelines are:

- Participants must live in HACA’s coverage area. If outside of coverage area then constituent’s location of primary bleeding disorder treatment (i.e. Hemophilia Treatment Center (HTC), hematologist, etc.) is within VHF/HACA coverage area.
- Late cancellation, excessive cancellation, and/or no-show history
- Attendance and participation at additional educational events over the past year
- Target audience of event (families, adults, teens, etc.
- Number of RSVP’s vs. capacity of the event

Once the admissions have been confirmed, each family will pay a $25 registration fee to the chapter before attending camp.

Family Weekend is an event for families impacted by an inherited bleeding disorder with at least one child living at home who is between the ages of 5 – 17. This family program is designed for those families whose children are camp ready and/or are looking to attend camp in the next two years. Starting in 2019, families should make other arrangements for children under the age of 5 since the camp is not equipped for younger children and babies.

Also, if a family “no-shows” or cancels within one week of the first day of family weekend, families may be responsible for reimbursing VHF and/or HACA the full amount (cost per family is $650+) and/or paying CHT to reserve your spot for the following year.

Registration is now open for 2019 Family Weekend, which will take place April 26-28. Click here to register by March 15.

Chapter Education Day

Continued from page 1

ADULTS

“Physical Therapy: Best Practices for Adults With A Bleeding Disorder” - Dr. Secili DeStefano, Orthopedic Certified Specialist

“Maintaining Boundaries” - HFA

JOINT SESSION

Insurance and Advocacy Issues—Miriam Goldstein, HFA

There will also be a variety of programming for kids and teens. HACA is working to create an active teen task force, so the group, spearheaded by Matthew Stone, will have a planning session during the day, where they will talk about activities for the teens in the chapter, as well as planning a service project for the summer.

The teen track will also feature a very special session: longtime member Kirstin Drye, who is a human resources specialist, will be leading a session on job hunting, resume building and other skills that teens can utilize. There will also be a session called “Failure is an Option” led by NHF.

The kids programming will include “Silly Science, “ led by Kayla Klein of Octapharma; “My Factor My Body” with Betsy Koval of Shire/Takeda; and a session on bullying with NHF.

To register for this year’s event, click here.
Virginians visit legislators at annual advocacy event

Continued from page 1

An extreme cold front settled over the region, so wind chills were in the single digits when participants lined up outside the Pocahontas Building. The session just began last week, and Martin Luther King Jr. Day is a popular day for advocacy groups to visit, so hallways were crowded throughout the building.

There were two “asks” this year: Support for House Bill 2126, which puts in place an exception process for step therapy that doctors can utilize when appropriate. It is sponsored by Delegate Glenn Davis, R-84. We also asked for support for HB 2515 and SB 1596, which would require health insurance carriers to count any payments made by patients or on behalf of patients, when calculating overall contribution to any out-of-pocket maximum or the patient’s deductible. Increasingly, insurance companies are refusing to count copay assistance program payments to any out-of-pocket maximum or the patient’s deductible, and are creating various cost-sharing arrangements, such as “co-pay accumulation adjustments” or “accumulators.” These bills are sponsored by Del. Timothy Hugo, R-40 and Sen. Siobhan Dunnivant, R-12.

HACA members visited the offices of delegates Hala Ayala, Patrick Hope, Alfonso Lopez, Bob Thomas, Kathy Tran, and Vivian Watts; and the offices of senators George Barker, Barbara Favola, Janet Howell, Richard Stuart, Jeremy McPike, Chapman Peterson and Richard Saslaw.

Jennifer Sleboda and her son, Adrian Kaseko, of Falls Church, attended for the first time this year.

"Richmond Days was a fantastic experience," she said. "It allowed us the opportunity to mobilize and practice hands-on democracy—sharing our voices with state legislators to support critical health care reforms for the Virginia bleeding disorders community."

Thanks to our advocacy event sponsors: Bioverativ (Sanofi), CSL Behring, Novo Nordisk and Shire (Takeda).
Three things that worry older men with hemophilia

By Donna Behen
Hemaware

What are the issues of highest concern to older men with hemophilia?

According to an “Aging People with Hemophilia” survey conducted by the National Hemophilia Foundation (NHF) from December 2016 through February 2017, they are:

- Worsening of joint disease and joint pain
- Insurance that fully covers hemophilia
- Planning for retirement

For the online survey, 110 respondents rated on a five-point scale how concerned they were about 22 issues, both at present and for the future. Issues were grouped in five categories: insurance and future planning; function and mobility; health and medical; social support; and mental health.

Joint disease and pain

While 28% of the men said “worsening of joint disease and joint pain” was among their greatest concerns now, that figure jumped to 49% when thinking about future concerns. Ongoing joint pain was an issue for 86% of the respondents.

“The survey shows that most older men are dealing with pain all the time whether they talk about it or not, but as providers we haven’t done a good enough job of addressing pain control for this older patient population,” says hematologist Barbara Konkle, MD, associate director of the Washington Center for Bleeding Disorders at Bloodworks Northwest, in Seattle, and a member of NHF’s Aging Working Group.

To Dana Francis, MSW, a social worker at the University of California San Francisco Hemophilia Treatment Center and a member of the Aging Working Group, the findings on joint pain offer one glaring takeaway. “Some men are using high doses of opioids to deal with their pain, but nobody talks much about it, and it needs to be a conversation that’s above the radar,” says Francis.

Insurance worries

When survey respondents rated their concern regarding “having insurance that fully covers hemophilia treatment, including all the replacement factor you need,” 37% said it was among their greatest concerns now. That figure nearly doubled (62%) when thinking about concerns for the future.

Those results did not surprise Francis. “There’s a desperate need for financial security in old age, and right now every person with a bleeding disorder is very worried about what will happen with their health insurance,” he says.

Concerns about retirement

Another top concern is planning and saving for the future, with only a relatively small difference between the present (34%) and the future (42%). Only 45% of the men said they had saved enough money to maintain their standard of living after retirement.

To Konkle, a key issue regarding future planning involves the spouses of men with hemophilia. “Losing a partner has more consequences for men with hemophilia because (the partner) may enable care,” she says. “We have older patients whose spouses infuse them, so if a man with hemophilia loses his partner or his partner becomes disabled, then he loses that support.”

A mental health disconnect

Even though a significant number of men reported having mental health issues, these issues were among the lowest-ranking concerns of the respondents. The survey revealed that 37% of men said they were “not at all concerned” about “living with anxiety and/or depression and the effects on daily living” now, and that dropped to just 25% when thinking about the future.

Those conflicting statistics “tell us everything we need to know about the lack of education and awareness about mental health issues among men,” says Francis. “Lots of men suffer from depression, but they may never even call it that.”

Reproduced with permission from the National Hemophilia Foundation’s Hemaware website.
¿Cuáles son los problemas de mayor preocupación para los hombres mayores que padecen hemofilia?

De acuerdo con una encuesta denominada “Personas mayores con hemofilia” realizada por la Fundación Nacional de Hemofilia (FNH) desde diciembre de 2016 hasta febrero de 2017, estos problemas son:

• Empeoramiento de las enfermedades y los dolores articulares
• Poseer un seguro que cubra por completo la Hemofilia
• Planificar para la jubilación

Para la encuesta en línea, los 110 encuestados calificaron en una escala de cinco puntos qué tan preocupados estaban sobre 22 problemas, tanto en el presente como en el futuro. Los problemas se agruparon en cinco categorías: seguro y planificación futura; función y movilidad; salud y medicina; apoyo social y salud mental.

Enfermedad y dolor articular

Aunque el 28% de los hombres dijo que el “empeoramiento de las enfermedades y los dolores articulares” estaban entre sus preocupaciones más grandes en este momento, ese número cambió a 49% al pensar en preocupaciones futuras. El dolor articular continuó fue un problema para el 86% de los encuestados.

“La encuesta muestra que la mayoría de los hombres mayores deben lidiar con el dolor todo el tiempo, aunque no lo digan, pero como proveedores no hemos hecho un buen trabajo atendiendo el control del dolor para esta población de hombres mayores”, dice la hematóloga, Dra. Barbara Konkle, Directora Asociada del Centro para Trastornos Hemorrágicos de Washington (Washington Center for Bleeding Disorders) en Bloodworks Northwest, en Seattle y miembro del Grupo de Trabajo de Personas Mayores de la FNH.

Para Dana Francis, con Maestría en Trabajo Social (Master of Social Work, MSW), trabajador social en el Centro de Tratamiento de la Hemofilia de la Universidad de California en San Francisco y miembro del Grupo de Trabajo de Personas Mayores, los hallazgos sobre el dolor articular ofrecen un aporte evidente. “Algunos hombres están utilizando altas dosis de opiáceos para manejar su dolor, pero nadie habla mucho de eso y necesita ser una conversación que esté a la orden del día”, indica Francis.

Preocupaciones por el seguro

Cuando los encuestados calificaron su preocupación con respecto a “tener un seguro que cubra por completo el tratamiento de la hemofilia, incluyendo todos los factores de reemplazo que usted necesita”, 37% indicó que esa era una de sus mayores preocupaciones en este momento. Este número casi se duplicó (62%) al pensar en las preocupaciones futuras.

Estos resultados no sorprendieron a Francis. “Hay una necesidad desesperada por seguridad financiera en la tercera edad y ahora mismo cada persona con un trastorno hemorrágico está muy preocupada sobre lo que pasará con su seguro de salud”, indica.

Preocupaciones sobre la jubilación

Otra de las preocupaciones importantes es planificar y ahorrar para el futuro, con solo una relativamente pequeña diferencia entre el presente (34%) y el futuro (42%). Solo el 45% de los hombres indicó que han ahorrado suficiente dinero para mantener su estándar de vida después de la jubilación.

Para Konkle, un asunto clave con respecto a la planificación futura involucra a las cónyuges de los hombres que padecen hemofilia. “Perder una pareja tiene más consecuencias para los hombres que padecen hemofilia porque (la pareja) puede permitir el cuidado”, indica. “Tenemos pacientes mayores que dependen de sus cónyuges, de modo que si un hombre con hemofilia pierde a su pareja o su pareja queda incapacitada, entonces él pierde ese apoyo”.

Una desconexión de la salud mental

Aunque un número significativo de hombres informó tener problemas de salud mental, estos problemas fueron los menos calificados por los encuestados. La encuesta reveló que el 37% de los hombres indicó no estar “del todo preocupado” por “vivir con ansiedad o depresión y sus efectos en la vida diaria” en este momento, y ese número bajó a tan solo 25% al pensar en el futuro.

Estas estadísticas contradictorias “nos dicen todo lo que necesitamos saber sobre la falta de educación y conciencia sobre los problemas de salud mental entre los hombres”, indica Francis. “Muchos hombres sufren de depresión, pero puede que nunca la llamen de esa forma”.

Registrarse para la cena HACA

Únase a HACA para un programa en español con Shire el domingo 10 de febrero a las 6:30 p.m. La cena se llevará a cabo en Trio Grill, 8100 Lee Highway, Falls Church, VA (a la derecha de la circunvalación)
Volunteers educate public at DC health fair

Thanks to the dedicated HACA volunteers that gave up time the weekend of January 12-13 to educate the public about bleeding disorders at the annual NBC4-Telemundo Health and Fitness Expo.

Many of these volunteers also traveled to the Walter Washington Convention Center in the snow that weekend to work their shifts.

Thanks go out to the Cosman family, Josh, Diana, James and Gracie, who worked the morning shifts on Saturday and Sunday; Dana Brayshaw; Chrissy and Art Holt; Steve Long; and Veronica Scott and her son, Ian Fullard.

If you live in Prince George’s County, stop by and say hi to HACA members at the Delta Zeta Zeta Health Fair on Saturday, March 23, from noon-4 p.m. This event will take place at the Theresa Banks Aquatic Center/Glenarden Community Center, 8615 McLain Avenue, Glenarden, MD. This event will feature free health screenings, cooking demonstrations, dental screenings for kids through age 12, fitness demonstrations and more.

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 November 1-December 31, 2018. We have made every effort to ensure all donations are listed.

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Make A Difference: Join Us for Washington Days

The National Hemophilia Foundation (NHF) will host its annual Washington Days advocacy event March 27-29 on Capitol Hill in Washington, DC.

NHF’s Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that are important to them. Last year’s Washington Days had more than 500 volunteer advocates from 47 states that met with legislators and staff to discuss maintaining key patient protections in the Affordable Care Act (ACA).

If you’ve thought about getting more involved in advocacy, this is a great opportunity to learn more and have your voice heard. The training starts on Wednesday afternoon with social media training, advocacy training and dinner. The visits with lawmakers will be scheduled for Thursday.

All participants will have a full day of meetings scheduled, usually together with people from the same state.

Some meetings will be with the legislators themselves; others will be with a member of their staff who deals with healthcare issues. Wherever possible, you will visit with your own representatives and others from your state, although you may be asked to visit other offices as well.

HACA usually has a good showing because of our proximity to DC, and hopefully that will continue this year.

The hotel for 2019 Washington Days lodging and trainings will be the Hyatt Regency at Capitol Hill, 400 New Jersey Ave NW.

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