Members Empowered at Richmond Days

More than 20 HACA members participated in the 12th Annual Advocacy Training and Richmond Days, held January 14-15.

HACA and Virginia Hemophilia Foundation members gathered at the Omni Hotel in downtown Richmond on Sunday afternoon for several educational sessions. Miriam Goldstein of HFA 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, talked about tips on sharing your story with lawmakers.

Monday morning kicked off with a breakfast at the Omni and an inspirational talk from Kim Bobo,

Continued on page 4

HACA, Children’s Team Up for Event

Join HACA and HTC staff at Children’s National Health System for an educational Couples Conference in February.

The Couples Conference is a discussion and educational event for people in a relationship, over the age of 18, with a connection to hemophilia.

The intended goal is to provide education and support to couples whose current or future family is - or may be - affected by hemophilia. We hope to support you both on your journey by providing basic information you will need to know as a couple, with a family or future family.

The event will take place on Saturday, February 24, from 9:00 a.m.-noon in Falls Church, VA. Breakfast and lunch will be provided.

Please contact Brenda Bordelon at director@hacacares.org if you are interested in attending. Your information will be forwarded to the HTC staff at Children’s National who are handling the program, they will contact you with the final information on the event and a registration form. Please register by February 16. Thank you to the Hemophilia Alliance for providing funding for this event.
Pediatric Infusion Class Set for February

The pediatric infusion class will take place on Tuesday, February 20, at the Pediatric Specialties of Virginia offices at 6565 Arlington Boulevard in Falls Church. Attendees will view a demonstration that reviews the procedures, followed by hands-on teaching with expert nurses. Everyone will be treated to a light dinner and the opportunity to network.

The class is recommended for Children’s National patients and their families who are starting home infusion. If you are not a patient at Children’s but are interested in attending, contact Chris Guelcher at cguelche@childrensnational.org or 202-476-3622. You must register through Children’s in order to attend; RSVP by February 14 to Lynda Dattilio at ldattili@childrensnational.org or 202-476-5786.

HFA Program at Next Families Group

The next Families of Young Children group is set to meet on Saturday, March 10, from 11:00 a.m.-1:00 p.m. at Coffield Community Center, 2450 Lyttonsville Road, Silver Spring. Marissa Zanno of Children’s National Health System will be our special guest speaker, presenting the HFA program “Hitting a Homerun at Your Clinic Visit.” Lunch will be served, and there will be some activities for the kids as well. Sign up today by clicking here.

Sign Up for Family, Summer Camp

Applications are now available for both Family Education Weekend and Camp Youngblood, which will take place at Camp Holiday Trails in Charlottesville, VA.

Family Education Weekend will be held April 27-29 and will include education, support and traditional camp fun for the whole family. There is a $25 registration fee.

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 30. There is a $25 registration fee per child.

Go to www.campholidaytrails.org to register for both the family weekend and summer camp.

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.
Items Available from Member

A HACA member recently contacted the chapter about some items to be donated. These items are available:

- One pair of wooden crutches, adult size 2 and one pair of wooden crutches, child size (goes up to about 36 inches), both used.
- Three boxes of drapes for a total of 150 drapes, new and in package.
- 20 cc and 10 cc syringes, new and in package.
- Two coolers for the cryo-cuff system, which is used for easier icing of joints, new and in package.

Email director@hacacares.org if you are interested in any of these items to arrange pickup.

Save the Date for These Spring Events:

APRIL 22: Chapter Day at “Roz and Ray” at Theatre J

Join HACA members at Theatre J in Washington, DC, for a showing of “Roz and Ray.” The event will include a pre-show reception, as well as a post-show Q&A session with members of the bleeding disorders community.

MAY 6: Spring Fundraiser

Enjoy an afternoon of hors d’oeuvres, wine and a silent auction at the Stone Mansion in Alexandria for HACA’s annual Spring Fundraiser. Tickets will be $40 per person, or $75 per couple.

MAY 12: Family Education Day and Annual Meeting

This year’s education day will take place again at Northern Virginia Community College and will include three tracks of education, childcare and programming for children and teens.

Health Fair Volunteers Needed

This year, HACA will again have a booth at the NBC4 Health & Fitness Expo March 10-11 at the Washington Convention Center. This a great opportunity for the chapter to spread awareness of bleeding disorders to the public. Volunteers will answer questions and pass out information about the bleeding disorders and the chapter. Teens are welcome to volunteer for school service hours but will need an adult to volunteer with them. Sign up here, and you can select specific shifts (although if we get too many volunteers for a particular shift, we may ask if you can select another one).

Want to Know More about your factor options?

When it comes to your factor therapy, you have choices. And at Bioverativ, we recognize the importance of continued research as well as supporting the hemophilia community. See if now might be the right time for you to make a change—learn more about our therapy options as well as our range of financial, educational, and community support programs.

To learn more about these options, contact your CoRe Manager:

Sue Cowell | Phone: 609.602.6303 | E-mail: sue.cowell@bioverativ.com
executive director of the Virginia Interfaith Center for Public Policy. Then it was off to the offices of state delegates and senators, who recently moved into the Pocahontas Building.

The session just began the previous week, and Martin Luther King Jr. Day is a popular day for advocacy groups to visit, so hallways were crowded throughout the building. Many of the delegates that members visited with are also brand-new to the process, and it was a great opportunity to spread information about the bleeding disorders community and talk about important issues.

There were two “asks” this year: Support for the expansion of Medicaid (and increasing access to healthcare for everyone) and support for clear and fair limits on step therapy (or fail first therapies, which is when insurance companies, not doctors, make decisions about what medication a patient should try).

HACA members visited with delegates Kathy Tran, David Bulova, Marcus Simon, David Reid, Patrick Hope and Bob Thomas and staffers in the offices of Hala Ayala, Jennifer Carroll Foy and Vivian Watts; and senators George Barker, Scott Surovell, David Marsden, Richard Black, Richard Stuart and Jeremy McPike, and staffers in the offices of Janet Howell, Chapman Peterson and Richard Saslaw.

HACA member Derek Flake felt empowered by the experience.

“As a first-time participant since moving to Northern Virginia three years ago from Tennessee, my experience visiting with state legislatures in Richmond was very empowering,” he said. “I received training that developed my advocacy skills from HACA, VHF, and HFA the day before the meetings. The legislator meetings gave me an immediate opportunity to share my story directly with lawmakers on both sides of the aisle. This led to meaningful conversations and a spirit of empathy towards the access to healthcare concerns of those with chronic bleeding disorders.”
NHF will host its annual Washington Days advocacy event March 7-9 on Capitol Hill in DC.

This is an opportunity for people affected by bleeding disorders to advocate for issues important to them. Last year more than 500 volunteer advocates from 47 states met with legislators and staff to discuss maintaining key patient protections in the Affordable Care Act. HACA had more than 20 participants from the chapter.

The hotel for 2018 Washington Days lodging and trainings will be the Hyatt Regency at Capitol Hill, 400 New Jersey Ave NW, Washington DC 20001.

Click here to sign up for Washington Days.

THE AGENDA FOR THE EVENT INCLUDES:

**Wednesday, March 7:**
- 1:00 - 4:30 p.m. – Registration
- 3:30 - 4:00 p.m. – Social media training
- 4:00 - 4:30 p.m. – Coffee Break
- 4:30 - 6:30 p.m. – Washington Days Training
- 6:30 - 8:00 p.m. – Dinner Reception

**Thursday, March 8:**
- 7:00 - 8:30 a.m. – Breakfast
- 8:30 - 9:30 a.m. – Legislative Briefing
- 9:30 a.m. - 4:30 p.m. – Legislative Appointments and Coffees
- 3:30 - 5:00 p.m. – Participants Return to Hotel
- 4:00 - 6:00 p.m. – Post-Appointment Check-in
- 6:30 - 8:30 p.m. – State Advocacy Recognition Dinner

**Friday, March 9:**
- 7:30 - 8:30 a.m. – Breakfast
- 8:30 a.m. - Noon – State Advocacy Training

You are not required to attend all the events. It’s recommended that you attend the training on Wednesday and meetings on Thursday.
Speaker Offers Insight to Members with vWD

HACA and Octapharma teamed up on Saturday, January 27, for a program geared toward members with von Willebrand disease and their caregivers.

Sara Ceresa, vWD patient educator for Octapharma, talked about “Taking Care of You.” As a mother of twin girls with vWD, she shared stories of their journey with vWD. Participants were broken into small groups and given time to talk and share stories with each other.

The event took place at McCormick and Schmick in National Harbor, MD.
HACA had its annual holiday gathering on Sunday, December 11, at the Sherwood Center in Fairfax, VA.

The afternoon event featured food, the opportunity for members to visit and network, of course, lots of presents handed out by Santa and Mrs. Claus (thank you to Terry and David Stone for taking on the roles).

Thanks to board member Michelle Stielper for helping with the gifts.

Event sponsors were Matrix, Genentech and HPC Specialty Pharmacy. Thanks for your support!
you step into my shoes right now, it may seem like I’m living a normal, even picture-perfect life. You wouldn’t know that to get here, I’ve had to fundamentally change who I was and overcome challenges that seemed insurmountable at the time. Today, I am sharing my story of survival and redemption in hopes of inspiring and healing others along the way. Here’s my story.

Growing up with hemophilia

I was diagnosed with mild hemophilia A as an infant in 1967. Back then, you couldn’t keep factor replacement therapy at home. Having hemophilia meant countless trips to the emergency room, long nights waiting for doctors to thaw the blood plasma product, and hours spent watching the slow drip, drip, drip of treatment fall from a large bag. It was tough on me, but especially difficult for my parents. To try and protect me from bleeds, they would constantly keep me on bed rest, and sheltered me to the point where I felt like I was living in a bubble. They grew tired while I grew resentful – and rebellious.

Death sentence at 19

At 19, I was told that I had contracted HIV and Hepatitis C from tainted blood used to make my blood-derived hemophilia treatment – and that I had fewer than two years to live. My parents and I were devastated. While we grieved and tried to cope with this new reality, news of my diagnosis spread like wildfire through the neighborhood. Because of the stigma associated with HIV, I was publicly humiliated, bullied, and shunned from public spaces like our community swimming pool. My parents even received death threats over the phone.

As I grew older, I tried to hide my HIV status to avoid the scrutiny. But people began to learn that many with hemophilia were also HIV positive – so I began to hide my hemophilia as well. The walls I built between myself and the rest of the world bred feelings of intense isolation, resentment and despair. I felt like I was doomed no matter what I did, and succumbed to substance abuse and thoughts of suicide.

A second chance

Ten years came and went. I watched as many of my friends with hemophilia died, and I continued to live in silence (Story continued on the following page)

Indications and Usage

Novoeight® (Antihemophilic Factor [Recombinant]) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

Important Safety Information

You should not use Novoeight® if you are allergic to factor VIII or any of the other ingredients of Novoeight® or if you are allergic to hamster proteins.

Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction: rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands.

Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII.

Your body can make antibodies called “inhibitors” against Novoeight®, which may stop Novoeight® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Common side effects of Novoeight® include swelling or itching at the location of injection, changes in liver tests, and fever.

Novoeight® is a prescription medication. You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.
(Story continued from the previous page)

about my conditions. Finally, after hitting rock bottom, I realized that I was still here – and I didn’t want to live the rest of my life this way. I met my wonderful wife, slowly changed my trajectory, and used my difficult experiences as stepping stones to a stronger, better me. I began to take control of my health through mindful meditation, weight and endurance training, and a nutritious diet. I also lifted my self-imposed silence and isolation to share my story and connect with others in the hemophilia community.

Now, I have two beautiful children, I’ve defeated Hepatitis C, and at 50, I am one of the longest living HIV-positive people in the world. My advice to those who might be struggling like I was would be: don’t let your diagnosis become the end of the world. With the advances and knowledge available now, hemophilia and HIV can both be highly manageable conditions.

A different treatment option

While I fought tooth and nail every day to take back my life and my health, I felt like my hemophilia treatment wasn’t keeping up with my new lifestyle. One day, a friend recommended that I look into Novoeight® (Antihemophilic Factor [Recombinant]), an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery.

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Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII.

Your body can make antibodies called “inhibitors” against Novoeight®, which may stop Novoeight® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Common side effects of Novoeight® include swelling or itching at the location of injection, changes in liver tests, and fever.

Novoeight® is a prescription medication. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Brief Summary of Prescribing Information on the following page.

Novoeight® is a prescription medication. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.
Novoeight®
Antihemophilic Factor (Recombinant)

Brief Summary Information about Novoeight® Antihemophilic Factor (Recombinant)

Rx Only
This information is not comprehensive.
- Talk to your healthcare provider or pharmacist.
- Visit www.novo-wi.com/novo-edb.pdf to obtain the FDA-approved product labeling.
- Call 1-844-30-eight.

Read the Patient Product Information and the instructions for use that come with Novoeight® before you start taking this medicine each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about Novoeight® after reading this information, ask your healthcare provider.

What is the most important information I need to know about Novoeight®?
Do not attempt to do anything unless you have been taught how by your healthcare provider or a hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Novoeight® so that your treatment will work best for you.

What is Novoeight®?
Novoeight® is an injectable medicine used to replace clotting factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally. Novoeight® is used to control and prevent bleeding in people with hemophilia A.

Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

Who should not use Novoeight®?
You should not use Novoeight® if you:
- Are allergic to factor VIII or any of the other ingredients of Novoeight®
- Are allergic to horse proteins
Tell your healthcare provider if you are pregnant or nursing because Novoeight® might not be right for you.

What should I tell my healthcare provider before I use Novoeight®?
You should tell your healthcare provider if you:
- Have or have had any medical conditions
- Take any medications, including non-prescription medicines and dietary supplements
- Are nursing
- Are pregnant or planning to become pregnant
- Have been told that you have inhibitors to factor VIII.

How should I use Novoeight®?
Treatment with Novoeight® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

Novoeight® is given as an injection into the vein. You may infuse Novoeight® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to use infusers by your hemophilia treatment center or healthcare provider. Many people with hemophilia A learn to infuse the medicine by themselves or with the help of a family member. Your healthcare provider will tell you how much Novoeight® to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may need to have blood tests done after getting Novoeight® to be sure that your blood level of factor VIII is high enough to control your bleeding. This is particularly important if you are having major surgery. Your healthcare provider will discuss your dosing of Novoeight® (in international units, IU) depending on your condition and body weight.

Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Development of factor VIII inhibitors
Your body can also make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly.

If your bleeding is not adequately controlled, it could be due to the development of factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of Novoeight® or even a different product to control bleeding. Do not increase the total dose of Novoeight® to control your bleeding without consulting your healthcare provider.

Use in children
Novoeight® can be used in children. Your healthcare provider will discuss the dose of Novoeight® you will receive.

If you forget to use Novoeight®
Do not inject a double dose to make up for a forgotten dose. Proceed with the next injection as scheduled and continue as advised by your healthcare provider.

If you stop using Novoeight®
If you stop using Novoeight®, you are not protected against bleeding. Do not stop using Novoeight® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much Novoeight®?
Always take Novoeight® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you inject more Novoeight® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of Novoeight®?

Common Side Effects Include:
- Swelling or itching at the location of injection
- Changes in liver tests
- Fever

Other Possible Side Effects:
You could have an allergic reaction to coagulation factor VIII products. Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction:
- Rash or hives
- Difficulty breathing, shortness of breath or wheezing
- Tightness of the chest or throat, difficulty swallowing
- Swelling of the lips and tongue
- Light-headedness, dizziness or loss of consciousness
- Pale skin color, fast heart beat which may be signs of low blood pressure
- Red swollen face, body, or hands

There are not all of the possible side effects from Novoeight®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

What are the Novoeight® dosage strengths?
Novoeight® comes in six different dosage strengths. The actual number of international units (IU) of factor VIII in the vial will be indicated on the label and on the box. The six different strengths are as follows:
- Dosage strength of approximately 100 IU per vial
- Dosage strength of approximately 150 IU per vial
- Dosage strength of approximately 200 IU per vial
- Dosage strength of approximately 300 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your doctor.

How should I store Novoeight®?
Prior to Reconstitution:
Store in original package in a cool, dry place. Do not freeze Novoeight®.

Novoeight® vials are stored in the refrigerator (36°F to 46°F or 2°C to 8°C) for up to 30 months or up to the expiration date, or at room temperature (up to 86°F or 30°C) for a single period not exceeding 12 months.

If you choose to store Novoeight® at room temperature:
- Note the date that the product is removed from the refrigerator on the box.
- The total time of storage at room temperature should not exceed 12 months. Do not return the product to the refrigerator.
- Do not use after the 12 month expiration date on the vial.

The expiration date is the last day of that month.

After Reconstitution (mixing the dry powder in the vial with the diluent):
The reconstituted Novoeight® should appear clear to slightly cloudy without particles.
The reconstituted Novoeight® should be used immediately.

If you cannot use the Novoeight® immediately after it is mixed, it should be used within 4 hours when stored at < 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about Novoeight® and hemophilia A?
Mild cases are sometimes prescribed for purposes other than those listed here. Do not use Novoeight® for a condition for which it is not prescribed. Do not share Novoeight® with other people even if they have the same symptoms that you have.

For more information about Novoeight®, please call Novo Nordisk at 1-844-30-EIGHT.
Show a Success for HACA Artist

Artist and educator Chinedu Felix Osuchukwu’s show “Facing Reality” at Vivid Solutions Gallery in DC was a big hit, with reviews from the Washington Post, a packed opening reception, and an artist talk.

Chinedu - a longtime HACA member with severe hemophilia A - is not new to the art world but the pieces that were featured at his show were never-before-seen paintings and sculptures. Chinedu reflects on the reciprocal relationship between teacher and student, especially in his sculptures. One of his featured pieces, “I Live to Create,” is a representation of him overcoming his struggle with hemophilia.

Chinedu will be leading an art workshop for kids and teens at HACA’s Family Education Day on May 12.

Click here to see more of Chinedu’s work.

Click here to read the review of his show in the Washington Post.

Click here to read an article about Chinedu in Hemaware.

Thank you to Monikah Osuchukwu for submitting this article and photos.

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, 2017. We have made every effort to ensure all donations are listed.

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Thank you to our donors, sponsors, and granters for your support.

Thank you to Monikah Osuchukwu for submitting this article and photos.
Build a Bleeding Disorder Support Network

A solid team can help in many ways

For parents of a child with a bleeding disorder, life can seem pretty overwhelming at times. To ease stress, worry and isolation, it’s helpful for families to build a solid support team—one they can rely on for everything from medical assistance to baby-sitting. This network can be comprised of several groups:

Your Hemophilia Treatment Center

Issues are bound to arise that leave you confused. At times like these, your hemophilia treatment center (HTC) is there for you to lean on. For Dan Levy, of Voorhees, New Jersey, whose 7-year-old son, Max, has hemophilia A, one such recent incident was when Max was about to lose his first tooth. The Levys were concerned about Max having a mouth bleed when the tooth finally fell out. “We knew it was coming, so we talked with our HTC about a plan, and they were able to get us an updated prescription of Amicar,” he says. Levy says being able to work with the HTC to come up with a plan in advance made the whole situation less stressful.

Family and friends

The people closest to you are likely to be your most ardent supporters. However, adjusting to a new diagnosis can be hard. “A lot of times family members are well-meaning, but if they’ve never had to live with a bleeding disorder, sometimes they don’t completely understand what you’re going through,” says Lucy Ramirez, MSW, LCSW, a social worker at Rush Hemophilia and Thrombophilia Center in Chicago.

Max Levy spends a few days a week after school with his grandparents, and “there has been a learning curve,” says his father. “Early on, when everyone was still trying to figure out how to handle Max, some of the warning signs had to be learned. It’s harder for people who don’t see him every day.” But today, while his grandparents may not be experts at diagnosing a bleed, they know what to do if they have a concern.

Chapters and national gatherings

National Hemophilia Foundation (NHF) chapters across the country offer families a range of opportunities to connect with other families. This is especially helpful for parents and kids who are new to bleeding disorders, says Ramirez. “We encourage involvement in the local NHF chapter,” she says of the HTC at Rush. “It’s really overwhelming when a family first learns about the diagnosis, so during their first few comprehensive clinic visits, we try to introduce them to another family or another patient who’s involved in the bleeding disorders community. It makes it less scary and less stressful.”
Social media

Both Levy and Ramirez say there are risks and benefits to seeking social support online. “One of the risks of going online is that the people who tend to post their stories on certain sites are only going to tell you about the worst-case scenario or a bad experience they had with their medical center or their doctor,” says Ramirez.

She suggests looking to chapter websites for reliable online support groups.

Levy cites Instagram as his social media support tool of choice. “It’s amazing to see, and then to be able to share our experiences with other people in the community,” he says, “That has been awesome because it makes me feel like I’m part of something even when I’m not at one of the national events.”

Reprint courtesy of Hemaware.
News You Can Use: Links to Articles, Websites

Reprinting articles in HACA News can be tricky because of copyright laws. However, since the newsletter is now in digital form, we will provide links to articles of interest, as well as websites where you can find up-to-date news on bleeding disorders topics. This is by no means a comprehensive list.

Drug formerly known as Vioxx could help with joint pain
New patient assistance program now available
Sanofi to purchase Bioverativ

Industry News
Alnylam –FDA lifts clinical hold on fitusiran
Catalyst – Phase 2/3 trial of marzeptacog alfa begins
Genentech – An open letter to consumers
Shire – Software receives FDA clearance
UniQure – Gene therapy shows long-term efficacy in patients

Is Your Child Ready for Camp?

Each summer, HACA teams up with the Virginia Hemophilia Foundation to send kids to Camp Youngblood in Charlottesville.

Camp is free of charge for children with a bleeding disorder, as well as siblings (there is a $25 registration fee per child, but HACA covers the rest of camp expenses). It’s open to kids ages 7-17.

If you haven’t sent your child to camp before, you may be wondering if he or she is ready to attend. Join us for a dinner program in English and Spanish on Sunday, Feb. 11, from 5-6:30 p.m. at On the Border Mexican Grill and Cantina, 11880 Spectrum Ctr., Reston, VA.

This program will be presented by Bioverativ and will address common fears such as “Is my child ready to be on his own?” Will she have friends? Will he infuse on time? Who will look out for him? Will she be safe?” The presentation will provide an in-depth look at the camp environment, including key elements such as socialization, self-advocacy and support resources.

Click here to register for the event.
Crear una red de apoyo para trastornos hemorrágicos

Un equipo sólido puede ayudar de muchas maneras

Para los padres de un niño con trastornos hemorrágicos, la vida puede parecer bastante abrumadora a veces. Para aliviar el estrés, la preocupación y la soledad, es de ayuda para las familias crear un equipo de apoyo sólido; se puede contar con ellos para todo tipo de cosas desde asistencia médica hasta el cuidado de los niños. Esta red puede estar compuesta por diversos grupos:

Centro de Tratamiento de Hemofilia

Los problemas pueden surgir de forma que lo dejan confundido. En momentos como estos, su centro de tratamiento de hemofilia (Hemophilia Treatment Center, HTC) estará ahí para que pueda apoyarse en ellos. Para Dan Levy de Voorhes, Nueva Jersey, cuyo hijo de 7 años de edad, Max, tiene hemofilia A, uno de los accidentes más recientes ocurrió cuando Max estaba por perder su primer diente. La familia Levy estaba preocupada porque Max tuviera una hemorragia bucal cuando el diente finalmente se cayera. “Sabíamos que sucedería pronto, así que hablamos con nuestro HTC sobre un plan y ellos pudieron darnos una prescripción actualizada de Amicar”, señala el padre. Levy afirma que haber podido trabajar con el HTC para elaborar un plan por adelantado hizo que toda la situación fuera menos estresante.

Familia y amigos

Las personas más cercanas a usted muy probablemente serán sus mayores defensores. Sin embargo, ajustarse a un diagnóstico nuevo puede ser difícil. “Muchas veces, los miembros de la familia tienen buenas intenciones, pero si no han tenido que lidiar con un trastorno hemorrágico, a veces no entenderán completamente por lo que está pasando” afirma Lucy Ramirez, Maestra en Trabajo Social (Master of Social Work, MSW), Licenciado en Trabajo Social Clínico, (Licensed Clinical Social Worker, LCSW), una trabajadora social en el Rush Hemophilia and Thrombophilia Center en Chicago.

Max Levy pasa unos días a la semana con sus abuelos después de la escuela y “ha habido una curva de aprendizaje” indica su padre. “Al principio, cuando todo el mundo trataba de determinar cómo tratar a Max, tuvimos que aprender a identificar algunos signos de advertencia. Es más difícil para las personas que no lo ven a diario”. Pero ahora, si bien sus abuelos no ser unos expertos diagnosticando una hemorragia, saben qué hacer en caso de que tengan una preocupación.

Oficinas y reuniones nacionales

Las oficinas de la Fundación Nacional de Hemofilia (National Hemophilia Foundation, NHF) del país ofrece a las familias una gama de oportunidades para conectarse con otras familias. Esto puede ser de ayuda, en especial para padres e hijos que son nuevos en los trastornos hemorrágicos, dice Ramirez. “Alentamos la participación en la oficina local de la NHF”, refiriéndose al HTC de Rush. “Es realmente abrumador cuando una familia se entera por primera vez sobre el diagnóstico, por lo que, en sus primeras visitas integrales a la clínica, tratamos de presentarles otra familia u otro paciente que participe en la comunidad de trastornos hemorrágicos. Esto lo hace menos aterrador y menos estresante”.

Las redes sociales

Levy y Ramirez señalan que hay riesgos y beneficios en buscar ayuda social en línea. “Uno de los riesgos de conectarse es que las personas que tienden a compartir su historia en ciertos sitios solo contarán sobre el peor escenario posible o una mala experiencia que tuvieron con un centro médico o con su doctor”, indica Ramirez. Sugiere buscar oficinas en sitios web para grupos de apoyo confiables en línea.

Levy indica que Instagram es una red social útil para elegir. “Es increíble ver y luego poder compartir nuestras experiencias con otras personas en la comunidad” afirma. “Ha sido asombroso porque me hace sentir como si fuera parte de algo, incluso cuando no estoy en uno de los eventos nacionales”.

Reimpresión cortesía de Hemaware.
¿Tu hijo está listo para el campamento?

Cada verano, HACA se asocia con la Virginia Hemophilia Foundation para enviar niños a Camp Youngblood en Charlottesville.

El campamento es gratuito para los niños con un trastorno de la coagulación, así como para los hermanos (hay una tarifa de inscripción de $25 por niño, pero HACA cubre el resto de los gastos del campamento). Está abierto para niños de 7 a 17 años.

Si no ha enviado a su hijo al campamento antes, se estará preguntando si él o ella está listo para asistir. Únase a nosotros para un programa de cena en inglés y español el domingo, 11 de febrero, de 5 a 6:30 p.m. en On the Border Mexican Grill y Cantina, 11880 Spectrum Ctr., Reston, VA.

Este programa será presentado por Bioverativ y abordará temores comunes tales como “¿Está listo mi hijo para estar solo?” ¿Tendrá amigos? ¿Infundirá a tiempo? ¿Quién lo cuidará? ¿Estará a salvo?” ¿. La presentación proporcionará una visión en profundidad del entorno del campamento, incluidos elementos clave como la socialización, la autodefensa y los recursos de apoyo.

Regístrese para el evento aquí.

Make your voice heard at NHF’s Washington Days

Wednesday, March 7 - Friday, March 9, 2018

- Meet with lawmakers and staff who shape national healthcare policy.
- Learn about critical issues that affect your continued access to quality care.
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