HBDA Quarterly Newsletter

Fall Edition 2019
Volume 43
Rick Dinkins, Chairman
Vicki Jackson, Executive Director

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Hemophilia and Bleeding Disorders of Alabama, Inc.

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HBDA Camp Harvest Went To Hogwarts

October 25 – 27, 2019

Another year of Camp Harvest is in the books! The weekend was filled with all of the things that make us look forward to this event each year: family, community, and education. There was also a heaping helping of fun and good food… sprinkled with a little rain.

Camp Harvest 2019

Friday night the families arrived, checked in with Amanda and had some delicious chili and chicken and dumplings. We had apple cider and hot chocolate by the main lodge and roasted marshmallows by the beach. Hugs were plentiful as we caught up with each other. It was so good to see all of our friends, old and new, trickle in! While the parents mingled, the kids enjoyed a fun Halloween movie, sponsored by Hyundai Manufacturing!

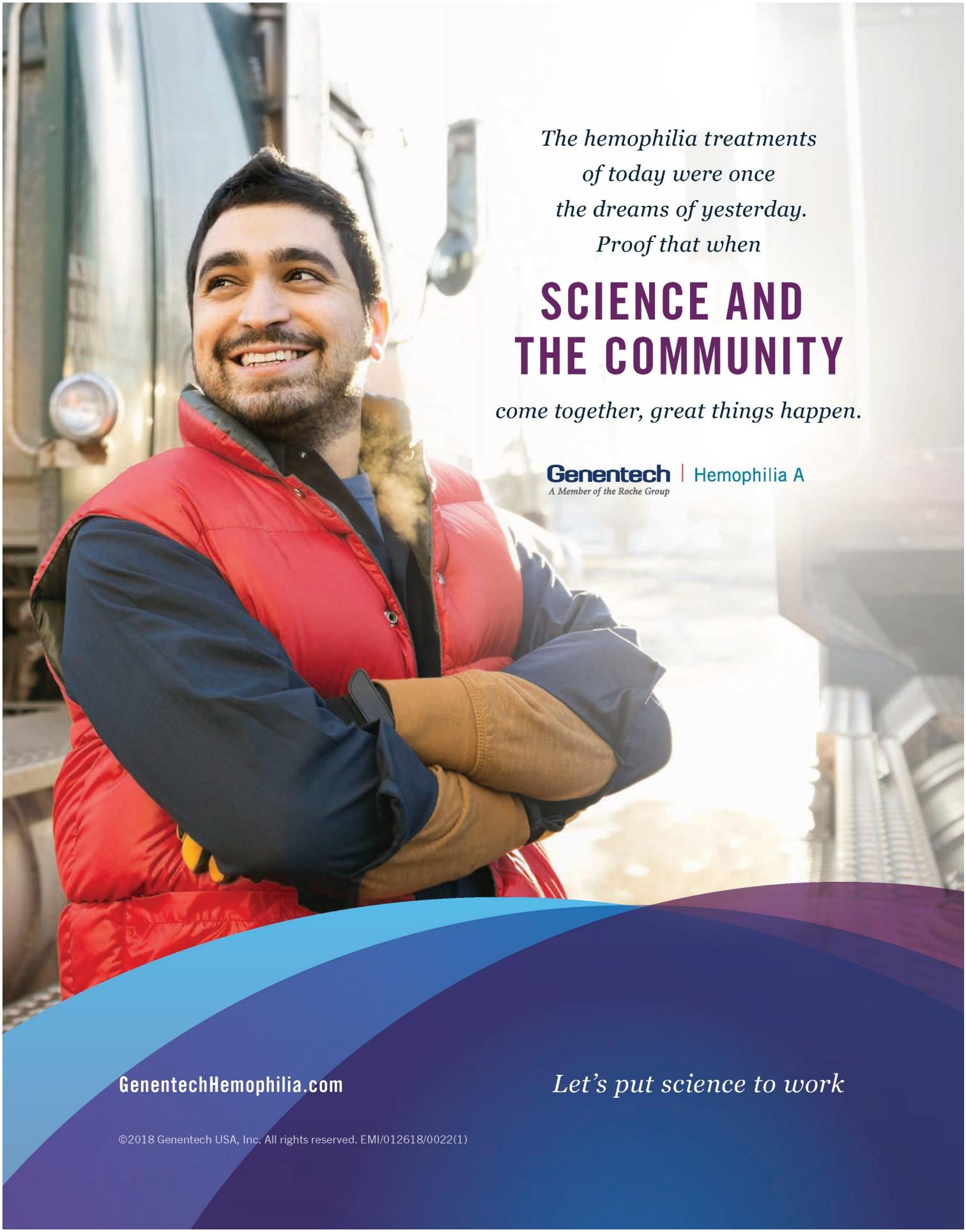
Saturday morning's focus was on education. We broke into three groups: the kids, the adults and the youth ambassadors. Relay races, graham cracker haunted houses and scavenger hunts kept the younger kids busy while the youth ambassadors attended educational sessions to learn more about advocating for themselves. The parents attended educational sessions that included insurance advocacy, gene therapy, and navigating transitions. There was an impressive
line-up of speakers: Dr. Tami Singleton, Dr. Patrick Fogarty, and Dr. Joanna Davis. After a delicious lunch of pulled pork and BBQ chicken it was carnival time!!

Camp Harvest 2019

The rain certainly didn't stop the fun at the carnival, but we did have to shuffle some of the activities under cover, such as pumpkin carving sponsored by Hyundai Manufacturing. We had cotton candy, caramel apples and popcorn while we enjoyed rides and crafts. The petting zoo, sponsored by Hyundai Manufacturing, is always a big hit and this year featured a 7-month-old baby kangaroo named Lego. There was also an assortment of goats, sheep, mini horses and even a baby camel! The smaller kids enjoyed the bouncy obstacle course, the fishing booth and face painting, while the older ones were all about the Twin Spin and the Shutter Xpress photo booth, sponsored by the Colburn Keenan Foundation. The biggest hit of the carnival though was Toxic Meltdown!! It was almost as much fun being a spectator as it was to participate. It truly brought out the big kid in many of the adults! I know for a fact there were several people, big and small, who were a little sore in the morning after that one. The evening ended with a costume contest and some Harry Potter trick-or-treating fun sponsored by HBDA! The costumes were AMAZING. We saw a Star Wars family, the Jolly green giant and his sprouts, and a line-up of dominos!

Sunday morning the fun didn't stop. Who doesn't love making slime and having dance parties?! We had 2 more wonderful patient advocate speakers, Brett and Ryan, who shared their hemophilia journeys and how they advocated for themselves growing up. Everyone posed for family pictures before they packed up their cabins and returned to the main lodge for door prizes!

Thank you so much for joining us this year at Camp Harvest!! We love this time together as much as you do! This event would not be possible without all of the wonderful volunteers and industry partners who gave so generously of their time and money. A special shout out to our friends at Spire, Hyundai Manufacturing, Colburn Keenan Foundation and National Hemophilia Foundation for their continued support of HBDA and Camp Harvest. We are already looking forward to 2020!!



Words from the Board

I hope everyone had as fantastic a year as we have and are ready for some well-deserved time to spend with friends and family this holiday season. After what seems like months of traveling, Brittnee, Tucker, and I finally have a few weeks off to recharge and focus on our family.

As always, Vicki and Amanda hosted yet another wonderful Camp Harvest and it was great seeing everyone there. We have truly been blessed to have such a wonderful staff, amazing sponsors, and most importantly the best volunteers anyone could ask for! Our volunteers spent countless hours behind the scenes planning and preparing for what ultimately was a "wizzarding" weekend! Thank you for all your hard work and support!

HBDA has made some great progress in 2019 and the future keeps looking better! We have been able to streamline quite a few programs with help from our new website in an effort to get community updates and information to our families faster than ever. If you haven't signed up for the website yet you are really missing out! We also have some great programs scheduled for the upcoming year so stay tuned!

We are looking forward to seeing everyone at the Year End Luncheon and at all of our events in 2020! I hope everyone has a great Thanksgiving, a Merry Christmas, and a Happy New Year!
God bless!

Here We Grow Again...

HBDA is proud to announce the launch of our new website as part of an ongoing evolution of our brand.

We have redesigned our website to better represent who we are today and to symbolize the bright future ahead.

We launched a new version of our website last September, but due to some issues, we chose to transition to a new developer to reformat and build and ongoing upgrade to our site!

It has been a labor of love, but we are SO PROUD of our new website. It will be instrumental in making our communication with our members more streamlined and registration for our events can now be integrated into our Member Portal.

Please visit us at www.hbda.us to sneak a peek!

Golf Tournament 2019

We were honored to have one of our biggest supporters, Dr. David Bronner, on hand to help raise awareness and money for Alabama's bleeding disorders community.

We would like to thank Dr. Bronner as well as our wonderful Industry Partners and our volunteers for making our Golf Tournament a huge success!!

The Robert Trent Jones Golf Course at Capitol Hill was once again the location and we had a great turn -out! Our golfers had a blast and we had some fabulous raffle baskets and items to bid on thanks to some amazing donors!

Pro golfer, Perry Parker was also on site to play in our golf tournament this year. It is always such an honor to have him participate in our tournament and show that Hemophilia does not have to define who you are, it is just what you have.

For the first time EVER at our tournament, one of our players, Mr. Clarence Hampton, hit a Hole in One on the hole with a CAR! A big thank you to Vision Insurance and Jack Ingram Motors for sponsoring this hole and car! And a big **CONGRATULATIONS** to Clarence on your NEW CAR!

HBDA is very grateful to the many generous industry partners and volunteers who make this such a huge success! Thank you again, and we look forward to seeing you in 2020!

We wish our members, sponsors, and volunteers a Merry Christmas and a prosperous New Year! Thank you for all of your support of HBDA in 2019 and we look forward to growing together in 2020!

Sincerely,

The Staff and Board of HBDA

Show and Tell: Disclosing a Diagnosis in the School Setting

School's in session! And with the start of a new school year comes a question for the principal: "When can I meet my child's teachers to discuss his hemophilia?"

I feel a sense of apprehension at the beginning of each school year, as I find my notes and instructions for emergency care, and determine the basic information I need to cover, including my youngest son's connection to the disorder. Every piece of information I give the school paints a broader picture of my son's struggles as he lives with hemophilia and an inhibitor. Disclosing information about hemophilia and inhibitors prepares my son's principal, teachers, and caregivers in the event of a bleeding episode.

Disclosing your child's bleeding disorder allows the educational team at the preschool, elementary, middle school, and high school levels the opportunity to provide the necessary support to empower your child's learning and well-being.

When your child is a preschooler, you are responsible, as parent or guardian, for informing the school of his or her bleeding disorder. Meeting with the teacher and staff may be nerve-wracking, so reach out to your hemophilia treatment center (HTC) for guidance. The balance between educating and frightening a teacher can be tricky, but if you stay positive and approachable, and encourage questions, you can establish a healthy and open relationship.

Both of my sons attended daycare before entering elementary school. My husband and I provided in-service to the principal and teachers directly involved in our sons' care. I emphasized how important it was for teachers and staff to call us after an injury occurred. I told them that I preferred they call me right away to report an incident, instead of waiting until the day was over. If they wanted either of us to come to school to check on our son, we would drop what we were doing and arrive as soon as possible. If an accident did happen, it usually wasn't necessary to give my son an extra infusion or take him to the HTC. After a few weeks of reassuring visits to the school, or talking through the incident over the phone, the calls from the school clinic became fewer. We made the school staff comfortable, insisting that we would not place blame on anyone, but we were prepared to teach and treat as necessary.

As children get older, it's important to allow them to become involved in their own care. In the early elementary years, you will continue to disclose and educate school staff about your child's bleeding disorder. But when your child can verbalize his condition, it's time to let him speak with adults and classmates about his bleeding disorder. This gives him the chance to take control. When my youngest son, Caeleb, was in first grade, I came to his classroom to read the story *Joshua, Knight of the Red Snake*, by Laureen A. Kelley. The story is about a preschooler with hemophilia. Many of the children had never heard of hemophilia, so reading about this young boy living with a bleeding disorder, and close to their age, made Caeleb's condition more understandable. *Joshua* offers an excellent way to engage children and allow them to ask questions. Caeleb answered his classmates' questions, and disclosing his hemophilia became a positive experience. During the year, when Caeleb missed school due to bleeds and often returned in a wheelchair, his friends were very empathetic and understood that he needed some extra help. Seeing these young children rally around their friend was an experience that any parent would be grateful for.

Once your child reaches middle school, your role may begin to change. I have made it a point to contact the nurse and principal at the beginning of each school year during middle school. Because my youngest son has a 504 Plan1 in place, I meet annually to review changes that need to be made in Caeleb's 504 Plan, and to discuss medical limitations related to hemophilia. I have also included Caeleb in these meetings starting in sixth grade. He doesn't say much, but sometimes teachers will ask him questions, and this allows him to be actively involved in his care. I emphasize that disclosing his condition is up to Caeleb. It's not the place of the teacher to tell any students about his hemophilia. Fortunately, Caeleb keeps the people hemophilia brings me joy.

In the high school years, your child will become more independent and play a much bigger role in disclosing to teachers and staff. With more freedom comes more control over the bleeding disorder. With my oldest son, Julian, I didn't have annual meetings with the nurse at the high school level. Julian was never on a 504 Plan, so I had to make sure that his teachers received information about care. I made a phone call to the nurse and sent the updated medical information for his file. Julian went to the school clinic, and introduced himself to the nurse so they could put a name with a face. He even kept a dose of factor and ancillaries in the clinic in case of emergencies. Julian was also very good at keeping his close circle of friends in the know about his hemophilia.

At the preschool, elementary, and secondary levels of education, disclosing pertinent medical information to the team involved in your child's care is crucial for his education and security. Disclosing information about a bleeding disorder helps those in charge become advocates for our children's safety and welfare. Modeling how we disclose hemophilia to educators also gives our children the tools they need as they grow into young adulthood. I hope that as my boys grow older, the importance of sharing needed information will transfer into their adult lives. As parents or caregiv-

Yes: Dogs Can Have VWD, Too!

The most common bleeding disorder in people is also the most common one in dogs
Author: Ian Landau

When we think of genetic disorders in dogs, hip dysplasia, heart defects and epilepsy are likely some of the ones that come to mind. What probably doesn't come to mind is von Willebrand disease (VWD), the bleeding disorder caused by missing or defective von Willebrand factor clotting protein. But if your dog has any of the following symptoms, it could have VWD:

- Frequent bloody noses
- Bleeding from the gums
- Prolonged bleeding after an injury or surgery
- Blood in the stool or urine
- Bruising

Anyone familiar with VWD will recognize these signs as the same ones that are common in people. And just as VWD equally affects human males and females, can be diagnosed at any age, and is found in people of any race or ethnicity, any type of dog can have VWD - male or female, old or young, pure breed or mutt. Dogs also may be VWD carriers.

However, over the years veterinarians have found some breeds do have a higher incidence of VWD. Doberman pinschers are most frequently affected, while other common breeds prone to VWD include: German shepherds, golden retrievers, Bernese mountain dogs, Shetland sheepdogs, standard poodles, Pembroke Welsh corgis, basset hounds and miniature schnauzers.

What to do if your dog has bleeding symptoms

If you notice any of the above signs, bring your dog to your veterinarian. However, often the first indication a dog has VWD occurs at the vet's office itself, when the pet is spayed or neutered and experiences unexpected hemorrhaging. Several tests can be performed to diagnose the condition, including a genetic test and a blood test to measure levels of von Willebrand factor.

Care for a dog with VWD depends on the severity of its condition. Just as in humans, dogs can be diagnosed with type 1, 2 or 3 VWD, with type 1 being the most common and usually the least severe form. The condition isn't curable, but it is manageable. In dogs with mild to moderate VWD, bleeding as a result of an injury is typically controllable with bandages, sutures or liquid stitches. If a dog needs surgery, it may require an infusion of cryoprecipitate in advance, a blood product that contains von Willebrand factor. Dogs with more severe forms of VWD must be monitored closely for bleeding and may need regular blood transfusions. Owners should avoid giving their pets certain medications - including antihistamines, aspirin, nonsteroidal anti-inflammatory drugs, sulfa-type antibiotics and penicillin - as they can cause bleeding.

Should you screen your dog?

The simple answer is, speak with your vet. If your dog is one of the at-risk breeds and you have noticed any signs of VWD, screening is likely a good idea. If you plan to breed your dog, a VWD screening should be done beforehand. Even if a pet doesn't have any symptoms it may have VWD, or it could be a carrier. If the test indicates your dog has VWD or is a carrier, it certainly should not be bred with another animal with VWD, and many vets advise not breeding it at all.

Bleeding disorders, dogs and people

It may be surprising at first that a dog can have the same rare genetic bleeding disorder as a person. But when you consider that dogs and humans share some of the same genetic material, it no longer seems so extraordinary. Dogs also have even rarer genetic bleeding disorders like hemophilia A, hemophilia B, factor II and factor VII deficiency. In fact, dogs have a long and storied role in the research and treatment of bleeding disorders, especially hemophilia A. Since 1947, a colony of dogs with hemophilia A and B (as well as some with VWD) has been cared for and studied at The University of North Carolina at Chapel Hill's Francis Owen Blood Research Laboratory. Among other advances, the UNC colony is responsible for the development of the partial thromboplastin time test used to diagnose hemophilia and the discovery that the gene responsible for hemophilia is on the X chromosome. The colony has also played a part in VWD research over the years.

"This article originally appeared in *HemAware* Magazine. Reprinted with permission. @National Hemophilia Foundation (2019)".
Author: Ian Landau HemAware Website: https://hemaware.org/bleeding-disorders-z/yes-dogs-can-have-vwd-too

Upcoming HBDA Events

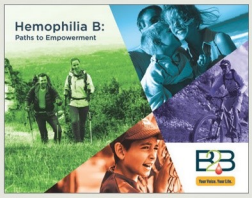
Event Name	Event Date	Event Location
Year End Luncheon	December 14, 2019	Embassy Suites Montgomery
HBDA Advocacy Day	March 2020	Montgomery, Alabama
Annual Meeting	April 24 - 26, 2020	Marriott Auburn/Opelika
Camp Clot Not	June 13 - 18, 2020	Children's Harbor on Lake Martin
Camp Harvest	October 23 - 25, 2020	Children's Harbor on Lake Martin
Golf Tournament	November 2020	Robert Trent Jones Prattville

There will also be many Educational Dinners throughout the state during the course of the year. Please keep an eye on your email and our website for updates about dinners near you!

Attendance at all events and educational dinners is very important for us to continue to provide up-to-date information and support from our industry partners. If you have any questions about any of these events, please email us at hbdaevents@gmail.com or call us at 334-478-7822.

B2B: Your voice. Your life.

Interested in stories and personal experiences *from* the hemophilia B community *for* the hemophilia B community? Turn to B2B.



Download or view books
filled with patient stories that can inspire, empower, and educate

Listen to podcasts
that capture the voices of the hemophilia B community

View videos
that feature members of the community sharing their personal experiences

And there's much more, too!

More topics include . . .

- Educating your child's school about hemophilia B
- HEMO 101 for caregivers
- Managing relationships with hemophilia B
- Life for girls and women with hemophilia B

VISIT WWW.HEMOPHILIAVILLAGE.COM

to explore all B2B materials

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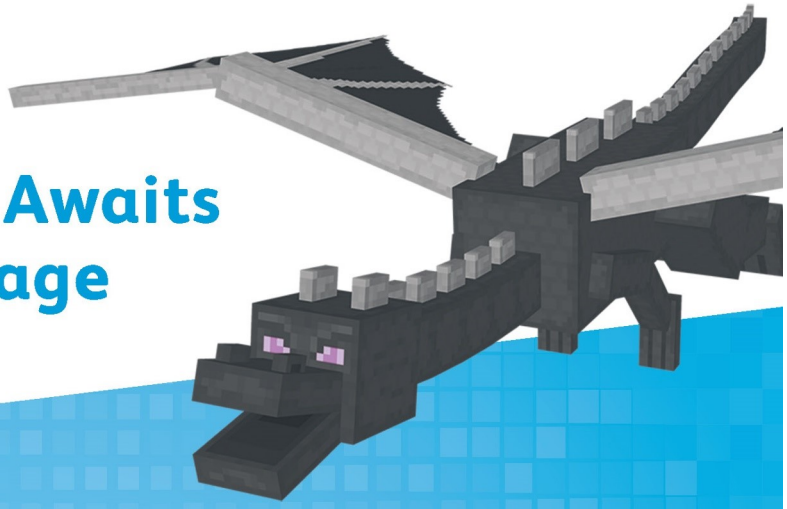
Pfizer Hemophilia

The Ender Dragon Awaits at Hemophilia Village



HEMOCRAFT™

INFUSION ADVENTURE

Adventure and education in a virtual world

We've blended education with adventure to bring you an experience that emphasizes the importance of staying prepared and sticking to a treatment plan. Craft an infusion kit, keep an eye on your "factor bar," and share your game strategy with friends and family—but beware of the Ender Dragon!

Visit www.hemophiliavillage.com to learn more about HEMOCRAFT and start your own adventure

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Pfizer

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**.

HEMLIBRA.
emicizumab-kxwh
injection for subcutaneous use

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 (aPCC; 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
  - stomach (abdomen) or 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
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

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.

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 miss a dose of HEMLIBRA 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 dosing 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 ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018

Genentech
A Member of the Roche Group

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Website: www.hbda.us

Facebook: www.facebook.com/hbda4u

Birthday Blessings

November

Cameron Jones
Casey Sanders
Laura Pitman
Chelynn Pargo
Robin Blair
Brayden Botts
Quintez Renfroe
Patsy Lewis
Makaylie Kelley
Grace Chung
Ciara Pargo
Charlie Hoover
Jason Branch
Alexandra Hall
Fantine Martin

December

Joseph Clarke
Mary Cathrine Noa
Tricia Watts
Debby Dinkins
Camdyn Pressley
Kimberly Wood
Daniel Botts
Cheyenne Warren
Dawson Findley
Joseph King
Travis Reed
Amanda Jennings
Kelly Champagne

January

Madilynn Clarke
Nathan Sanders
Mary Beth Clarke
David Hall
Marcus Chung
Robert Masline
Jayla Lewis
Amare Banks
Takiya Wells
Bentley Golden
Lauren Killgore
Donna Bate
Bryan Utterback
Carolann Sorrells
Jeremy Jones