HBDA Quarterly Newsletter

Fall Edition 2022 | Rick Dinkins, Chairman
Volume 55 | Vicki Jackson, Executive Director

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HBDA
Hemophilia and Bleeding Disorders of Alabama, Inc.

Words from the Chair

Happy Holidays! Wow, 2022 is almost gone and your HBDA organization is busy closing out the year and planning 2023…never a dull moment!

This year has been very successful as Vicki and Amanda continue to deliver quality programs and educational events for you. Our membership has grown a bit with multiple new families joining this fall. Camp Clot Not remains the premier event for the kids and along with Children's Harbor's staff and facilities there we expect it to be so in the future.

In 2022, we hosted over 6 educational dinners and look to do even more in 2023. While "fun events" remain part of our plans, the goal is to make sure there is a meaningful educational component that keeps you informed about the latest and greatest resources in the bleeding disorder community.

HBDA's Annual Meeting will be held in Opelika March 17 - 19, 2023. More details to follow and we would love to hear your ideas and suggestions for the agenda.

From a Board perspective, we welcome Tyler Blair as our newest member. Tyler is a beneficiary of all that HBDA has to offer and will bring a great new perspective to the chapter…so make sure you welcome him at the Annual Meeting.

Once again, Happy Holidays to all of you and I look forward to seeing you in April.

All the Best,

Rick Dinkins

HBDA Camp Harvest 2022

Camp Harvest 2022 started off with a bang with dinner and wonderful exhibits by our Pharmaceutical and Specialty Pharmacies. The evening came to a close with a haunted reenactment of a ghost story on the lake, topped off with a ghost emerging in a canoe on the water.

The next day started off with some delicious meals prepared by Mrs. Debra and 1220 Café. Informative sessions were presented by some of the leaders in hemophilia treatment with CSL Behring, Bayer, and Octapharma rounding out the day with new and interesting educational topics. After a full schedule of education and learning, we decided to get everyone's brain in gear by engaging the adults in a "Whisper Challenge". Each correct answer, earned them a ticket for 1 entry into the spinning wheel for the prize giveaways at the end of the weekend provided by HBDA. While the adults were exercising their brains in this difficult challenge, the kids were reeling in fish with Country Boy Fishing. They had a wonderful time fishing with old and new friends and could not wait to fish again on Sunday.

Thanks to donations from our friends at Colburn-Keenan Foundation and Hyundai Motor Manufacturing, our families had a wonderful carnival to enjoy on Saturday afternoon. The day had a true carnival feel featuring rides, an obstacle course, caramel apples, popcorn, carnival games, and pumpkin carving!

BELLADONNA MORTEM WELCOMES OUR MEMBERS AND SPONSORS TO CAMP HARVEST 2022

HBDA Camp Harvest 2022

That night, we dressed up and our members experienced the “Trail of Fears”, a haunted walk around the Harbor Lodge grounds. There interactive scenes at every turn with live costumed characters with themed haunted settings in many of the cabins.

Some of the characters and themes featured included a Dark Ages Doctor, Freddy Kreuger, Michael Myers, and Jason and many more!

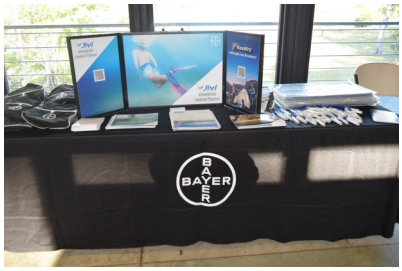
Sunday morning, everyone prepared for their departure before coming in to enjoy Genentech’s educational presentation on Hemlibra. Camp Harvest is always an event full of education, bonding, and making new memories with our hemophilia family.

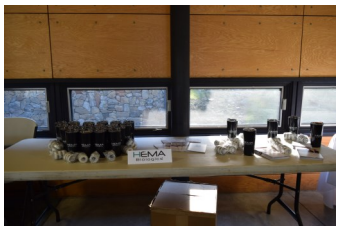
We are grateful for our members and were so excited to have 8 new families who attended Camp Harvest for the first time!

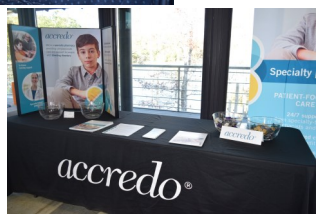
Thank you to our sponsors and volunteers who come in early and stay up late to make sure our events are successful for our families.

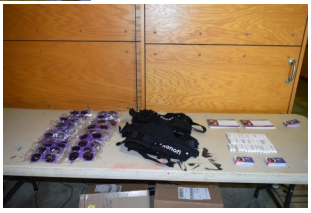
“I’m so glad I live in a world where there are Octobers.”
- Anne of Green Gables

Camp Harvest 2022 Exhibitors









[a]Rebinyn® achieved and maintained higher factor levels than recombinant Factor 9 based upon a phase 1 study comparing 25, 50, and 100 IU/kg doses of Rebinyn® to a 50 IU/kg dose of standard half-life recombinant Factor 9 in 7 adults and a 50 IU/kg dose of plasma-derived Factor 9 in 8 adults. For Rebinyn®, estimated average Factor 9 activity is adjusted to a dose of 50 IU/kg. Incremental recovery at 30 minutes (IR_{30}) and half-life were higher and longer with Rebinyn® than recombinant Factor 9 (IR_{30} 0.0131 vs 0.0068 (IU/mL)/(IU/kg) and half-life 93 vs 19 hours). The clinical relevance of these pharmacokinetic differences is unknown.
Incremental Recovery: The increase in plasma concentration per IU/kg of factor administered.
Half-life: The time it takes for the level of factor in the blood to fall by half (50%).

[b]Data represent mean steady-state pharmacokinetic (PK) profiles from previously treated adolescent/adult patients with moderate-to-severe hemophilia B (N=9) taking repeated doses of Rebinyn® 40 IU/kg once weekly. Factor 9 levels were within the non-hemophilia range (greater than 40%) for 5.4 days (about 80% of the week).

[c]Based on analysis using a 1-stage assay in patients (N=6) aged 18 and older, the half-life at steady state was 115 hours following once-weekly (40 IU/kg) dosing; in patients (N=3) aged 13 to 17, the half-life at steady state was 103 hours. Following single-dose administration (40 IU/kg) in the same patient population, the half-life was 83 hours (adults) and 89 hours (adolescents).

Indications and Usage

What is Rebinyn®, Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat, prevent, or reduce the frequency (number) of bleeding episodes in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for immune tolerance therapy.

Important Safety Information

What is the most important information I need to know about Rebinyn®?

- **Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.** Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

Who should not use Rebinyn®?

Do not use Rebinyn® if you:

- are allergic to Factor IX or any of the other ingredients of Rebinyn®.
- are allergic to hamster proteins.

What should I tell my healthcare provider before using Rebinyn®?

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 plan to become pregnant.
- have been told you have inhibitors to Factor IX.

How should I use Rebinyn®?

- Rebinyn® is given as an infusion into the vein.
- **Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.**
- Do not stop using Rebinyn® without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?

- **Common side effects include** infusion site reaction (bruising, bleeding, swelling, pain, or redness), itching, and rash.
- Your body can also make antibodies called "inhibitors" against Factor IX, including Rebinyn®, which may stop Rebinyn® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.
- **Call your healthcare provider right away or get emergency treatment right away if you get, for example, any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

What are the possible side effects of Rebinyn®? (cont'd)

- You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness, or swelling.
- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) in certain cells in the brain. The potential human implications of these animal tests are unknown.

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

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

novo nordisk®

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

rebinyn®
Coagulation Factor IX (Recombinant), GlycoPEGylate

rebinyn®

Coagulation Factor IX (Recombinant), GlycoPEGylated

Brief Summary Information about:
REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/REBINYN.pdf to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill, as 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 REBINYN® after reading this information, ask your healthcare provider.

What is the most important information I need to know about REBINYN®?

Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.
You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing REBINYN® so that your treatment will work best for you.

What is REBINYN®?

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

REBINYN® is used to treat, prevent, or reduce the frequency (number) of bleeding episodes in people with hemophilia B.

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

Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

What should I tell my healthcare provider before I use REBINYN®?

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. It is not known if REBINYN® passes into breast milk or if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if REBINYN® may harm your unborn baby.
- Have been told that you have inhibitors to Factor IX (because REBINYN® may not work for you).

How should I use REBINYN®?

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

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

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

Use in children

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

If you forget to use REBINYN®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and speak to your healthcare provider if you have any questions or concerns.

If you stop using REBINYN®

Do not stop using REBINYN® 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 REBINYN®?

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of REBINYN®?

Common Side Effects Include:

- infusion site reaction (bruising, bleeding, swelling, pain, or redness)
- itching
- rash

Your body can also make antibodies called "inhibitors" against Factor IX, including REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

You could have an allergic reaction to coagulation Factor IX products. **Call your healthcare provider right away or get emergency treatment right away if you get, for example, any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

These are not all of the possible side effects from REBINYN®. 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 REBINYN® dosage strengths?

REBINYN® comes in four different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The four different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial
Dark Gray	3000 IU per vial

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

How should I store REBINYN®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 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 REBINYN® and hemophilia B?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use REBINYN® for a condition for which it is not prescribed. Do not share REBINYN® with other people, even if they have the same symptoms that you have.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 08/2022

REBINYN® is a trademark of Novo Nordisk A/S.

For Patent Information, refer to: http://novonordisk-us.com/products/product-patents.html

Manufactured by:
Novo Nordisk A/S
Novo Allé, DK-2880 Bagsværd, Denmark

More detailed information is available upon request.

Available by prescription only.

For information about REBINYN® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

US22REB00153 August 2022

novo nordisk®

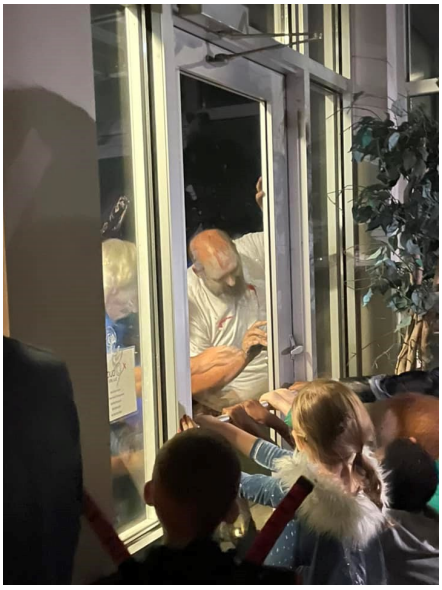
Haunted Airport Fundraiser

Our incredible friends, Paul and Elisabeth Gardner held a fundraiser benefiting HBDA at their airport hanger on Halloween weekend! They had friends from all around come and dress up and created amazing scenes behind every door!

Ghouls and zombies even flew in on an airplane! But alas, the kids helped hold the door tight and would not let them in!

Thank you Paul and Elisabeth for all you do as volunteers and supporters of HBDA. We are incredibly blessed to have you in our lives!

$1,700 raised!



Golf Tournament 2022

This year's tournament was no exception to the rule. Once again, we were honored to have one of our biggest supporters attend our tournament! Dr. David Bronner and his team was on hand to help raise awareness and funds for Alabama's Bleeding Disorders Community.

The Robert Trent Jones Golf Course at Capitol Hill graciously opened its doors for our golfers and even though it was overcast and a little misty, our golfers had a wonderful time!

Pro baseball player, Pete Dyson joined us for the afternoon on the pristine greens. He shared with us at the luncheon, sponsored by CSL Behring, that having hemophilia himself, does not have to "define" who you are, it's just what you have. His inspiring approach to life could be a lesson to us all!

Our participating teams had a blast! Friendly, and sometimes a bit of competitive golfing, fabulous food, a high-end putter and even a TV to bid on and some awesome surprises, made their day outstanding!

HBDA does not put on an event of this caliber without a little help from our friends. We are very grateful to our industry partners, volunteers and friends who make this exciting fund-raiser a huge success each year!

Have a great rest of 2022 and we look forward to seeing you again in 2023!

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.[1]

ADVATE
[Antihemophilic Factor (Recombinant)]
REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

Prophylaxis with ADVATE prevented bleeds[1]

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment.

53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.† This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

†Median is the middle number in a group of numbers arranged from lowest to highest.

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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 Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.

Reference: 1. ADVATE Prescribing Information.

Takeda

ADVATE
[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

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

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

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

What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

Tell your healthcare provider about any side effects that bother you or do not go away

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADVATE for a condition for which it is not prescribed. Do not share ADVATE with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

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.

Patented: see https://www.takeda.com/en-us/patents/

U.S. License No. 2020
Issued: 12/2018

US-ADV-0030v1.0 02/20

Takeda

CLOT Line Assistance Program

Members:

If you are going through a difficult time, please remember, your HBDA family is here for you!

If you need assistance due to an unexpected circumstance, please reach out to us.

Tyler Blair Joins HBDA Board Of Directors

A message from Tyler:

My name is Tyler Blair. I am twenty-two years old and recently graduated from the University of Alabama with a bachelor's in Computer Science from the Department of Engineering and a second degree in Religious Studies. Currently, I am a software developer for Insuresoft and have enjoyed starting my career there for the past few months.

I was diagnosed with severe hemophilia B at just two weeks old and have been a part of the bleeding disorders community in Alabama since I was very young. I started going to Camp Clot Not when I was twelve and have attended almost every year since - starting as a volunteer at age eighteen. I have also participated in martial arts since I was twelve and am currently a volunteer instructor and 5th degree black belt.

I look forward to continuing to serve the bleeding disorders community through whatever opportunities God provides me in the future. I want to help provide similar guidance and opportunities to others that I was afforded.

On behalf of HBDA, we want to officially welcome Tyler to our board! It has been a privilege to watch him grow into the bright young man he is today and we know he will quickly become an asset to our board and our community.

On behalf of the Staff and Board of HBDA, we hope you have a very Merry Christmas and a Happy New Year. We have enjoyed serving each and every one of our members, old and new, and look forward to a fresh and bright new year with each of you! We pray for peace, warmth, and happiness for you this holiday season!

Member Spotlight of the CSL Behring Junior National Championship

We are so proud to have had the opportunity of representing our chapter HBDA in this time-honored event. The Gettin' in the Game (GIG) Junior National Championship (JNC) was the first and currently only national sports competition designed specifically for the bleeding disorders community. The program gives children with bleeding disorders an opportunity to learn golf, baseball, and swimming and provides education and information-sharing opportunities for participants and their parents/caregivers. Christian was ecstatic to receive the invitation. We had no expectations of the event, and even if we did, the reality of our experience would have exceeded it.

There were more than 50 children with their parents representing 54 chapters across the country, Christian and I packed up Friday morning and traveled to Phoenix, Arizona (which was absolutely beautiful) Unfortunately, due to a travel delay, we missed the entire clinic that Friday and arrived just in time for the evening dinner. The Friday itinerary was jammed packed with amazing opportunities. The attendees participated in clinics, preparing them for the friendly competition on Saturday. After dinner, we checked into the AAA Four-Diamond Scottsdale Resort, which had multiple pools and access to the McCormick Ranch Golf Club, an award-winning golf course.

We also had the opportunity to attend the Educational seminars, which focused on the importance of physical fitness, and other related topics were provided on-site. At the conclusion of the JNC, each child was recognized for his or her participation, and the champions were announced. This is where our little hot shot was awarded Best Sportsmanship Award.

I'll explain to you how this little 53lb 42inch tall boy won this award. Not only was I constantly being told how excited he was, encouraging to others, and determined there was one situation that I think showed his true love and passion for this game. During the playoff game, the teams were made up evenly. A 16-year-old batter came up with the bases loaded in the sixth. The first pitch was sharply hit to shortstop. This kid, also about that age, fielded it cleanly with a smooth pickup and sent a rocket to first. That's where Christian was prepared to catch this 60-mile-per-hour throw from short. He was in the first baseman position with his foot on the bag and glove out in front of his chest like he was prepared. However, he had never seen a ball thrown that hard (probably EVER to anyone) Luckily, the shortstop was used to players his size, and the ball went right over Christian's head where a taller boy would have caught it for the winning out. But Christian didn't flinch. He was fearless and determined to make that play. I think he was in a bit of shock, but it was by far the coolest play he has ever experienced.

We cannot express our appreciation to the HBDA for choosing Christian to participate in the JNC. This was our first experience playing sports with other kiddos with hemophilia. It was the first time he would talk about his bleeding disorder with other friends that also play baseball. He normally is shy and reluctant when doing so. I truly believe this changed his perspective, and since this event, he has continued to grow in his baseball journey. I wouldn't exchange this experience with the world.

-Brittany

2023 Event Dates and Locations

Event	Date	Location
Annual Meeting	March 17 - 19, 2023	Auburn/Opelika Marriott
Camp Clot Not	June 18 - 22, 2023	Children's Harbor
Camp Harvest	October 20 - 22, 2023	Children's Harbor
Golf Tournament	November 2023 - TBD	Robert Trent Jones Prattville
Year End Luncheon	December 9, 2023	Children's Harbor

We will also have a host of Educational Dinners with presentations throughout the year in 2023, including some in the first few months of the year. Please keep an eye on your email for more details on all of our upcoming events.

HBDA Annual Meeting 2023

The HBDA Annual Meeting will be held at the Marriott Auburn Opelika Hotel and Conference Center in Opelika, AL.

Make plans now to attend!

Date: March 17 - 19, 2023

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What to Expect:

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Current Educational Information

Inspirational and Interactive Sessions

HBDA Information

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Website: www.hbda.us

Facebook: www.facebook.com/hbda4u

Birthday Blessings

November

Jennifer Anderson
Clayton Findley
Cameron Jones
Casey Sanders
Laura Pitman
Chelynn Pargo
Robin Blair
Brayden Botts
Quintez Renfroe
William Speros
Myra Cooper
Patsy Lewis
Makaylie Kelley
Grace Chung
Ciara Pargo
Alexandra Hall
Fantine Martin
Rusty Chapman

December

Joseph Clarke
Mary Cathrine Noa
Tricia Watts
Debby Dinkins
Giulaya Goldsby
Camdyn Pressley
Kimberly Wood
Daniel Botts
Cheyenne Warren
Nichole Goldsby
Dawson Findley
Joseph King
Amanda Jennings
Michael McElhaney
Leslie Bailey
TJ Nicholson
Gavin Chapman

January

Madilynn Clarke
Nathan Sanders
Mary Beth Clarke
David Hall
Marcus Chung
Robert Masline
Jayla Lewis
Amare Banks
Takiya Wells
Eyleighn Goldsby
Elizabeth Chapman
Bentley Golden
Erin Hassan
Donna Bate
Bryan Utterback
Carolann Sorrells
Jeremy Jones