Vital Link

...For Hoosiers Living with a Bleeding Disorder

December 2019

The Vital Link is published quarterly by Hemophilia of Indiana, Inc.

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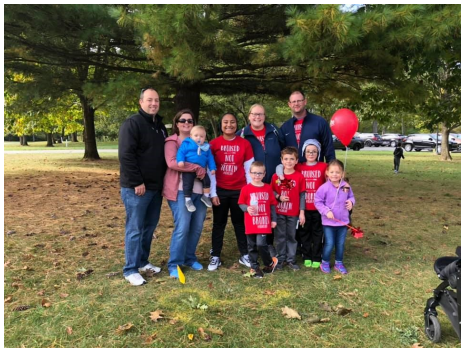
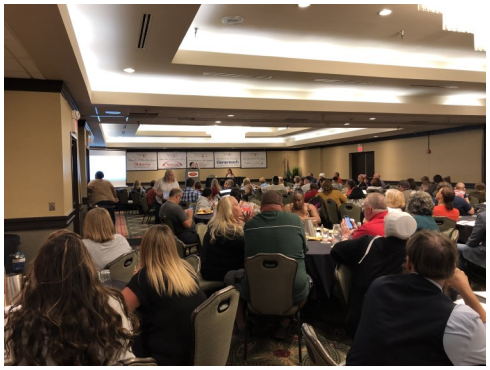
www.hoii.org

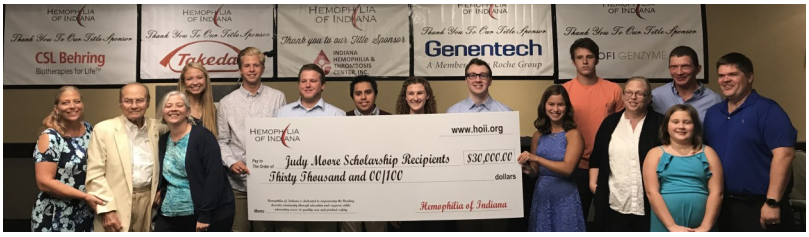
2019 Year In Review

It is hard to believe that we are coming to the end of 2019! It has been another successful year for Hemophilia of Indiana (HOII). HOII is proud to announce that we have been able to support more than 1400 members of Indiana's bleeding disorders community with assistance, educational programs, advocacy opportunities, scholarships, and camps. These programs and services have been made possible through our fundraising events, private donors, and industry partners. The year started with the 2019 Hearts for Hemophilia "Bow Ties & Tiaras" Gala. Lisa Swaney was this year's keynote speaker and did an incredible job sharing her story. Washington Days in March provided HOII staff, IHTC representatives, and patient advocates the opportunity to meet with staff from Indiana's Senators and Representatives to advocate on behalf of Indiana's bleeding disorders community, In each meeting, we were able to discuss the importance of 340B funding for our HTC's and the need for affordable health insurance. This was also the 2nd year for the Bowling for Bleeding Disorders in April and it was a fun afternoon of education, fundraising, and bowling! The Bowling for Bleeding Disorders is a fundraiser for the Judy Moore Scholarship Program. HOII, through the Judy Moore Scholarship, was able to award $30,000.00 in higher education scholarships to 11 members of the bleeding disorders community. In addition, the Hemophilia of Indiana Ed Magoni Scholarship was implemented and awarded $5,000.00 to 3 deserving individuals. We lucked out again with beautiful weather for the 2019 Course to a Cure. 29 teams participated, followed by a successful silent and live auction. The Hemophilia of Indiana Annual Meeting took place in August and had another record attendance year with over 250 patients and families. Keynote speakers included Dr. Amy Shapiro, Jennifer Maahs, and Eric Gray from the Indiana Hemophilia & Thrombosis Center. The afternoon breakout sessions included a variety of incredible educational topics followed by the Saturday evening awards dinner. Planning has already begun for the 2020 Annual Meeting. The date for the 2019 Unite for Bleeding Disorders Walk may have changed, but fundraising was still the name of the game! This year's Walk raised over $50,000! Congratulations again to Team Shafer, who were the top fundraising team on the day of the event! The Fit Livin' Thanksgivin' Day Run had over 450 participants raising funds and more importantly awareness for the bleeding disorders community! Hemophilia of Indiana would like to thank all that participated in all of our events, donated, and/or volunteered! Planning has already begun for 2020! Go to www.hoii.org for more information!






#HOIIAM2019


CSL Behring
Genentech
www.hoii.org
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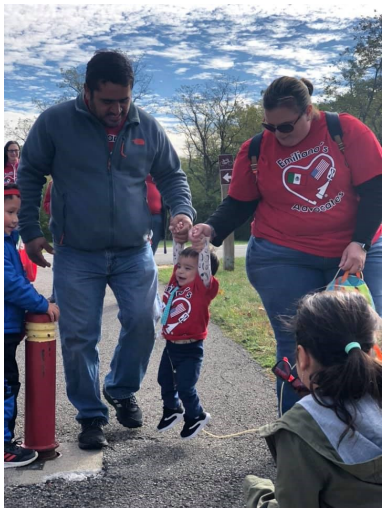
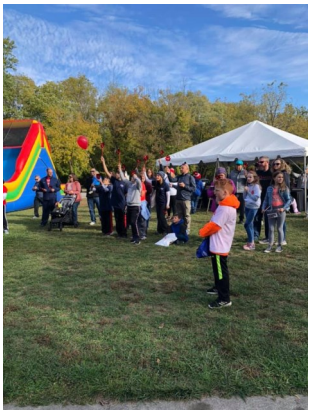
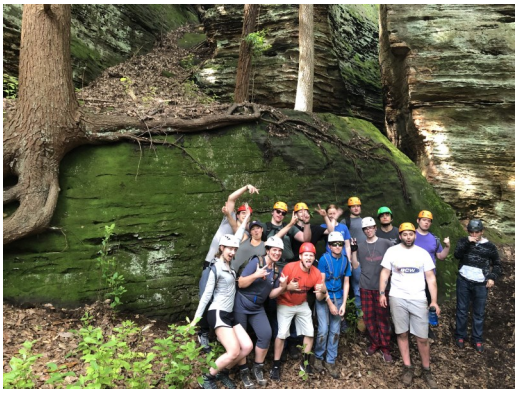
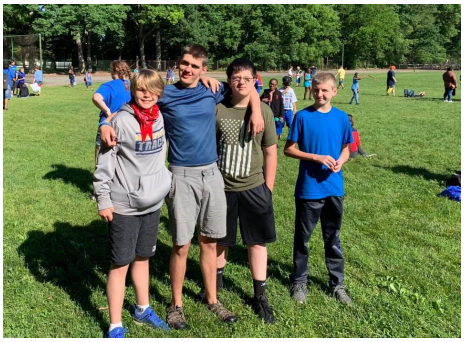
Hemophilia of Indiana

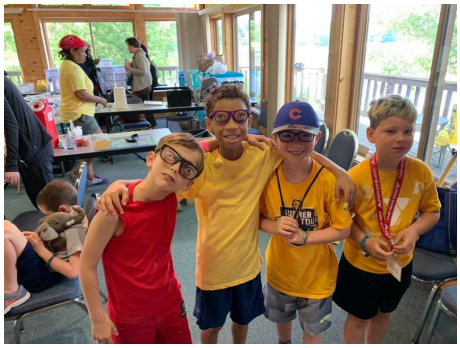


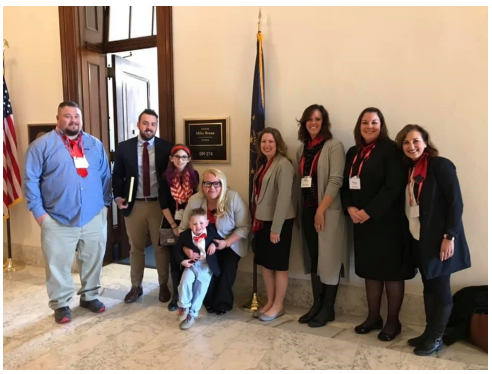


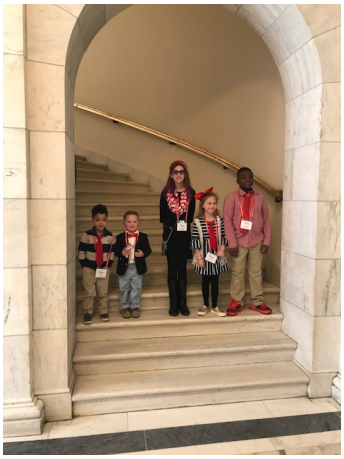



Camp Crosley







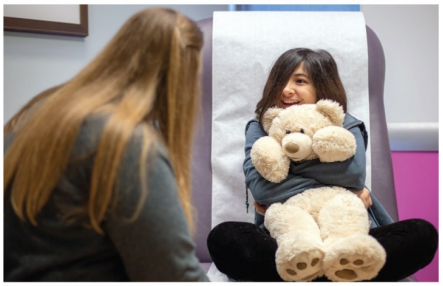
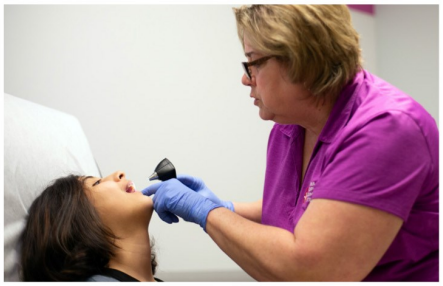


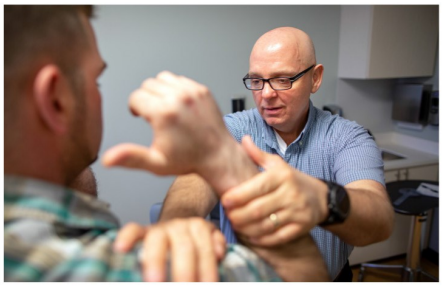
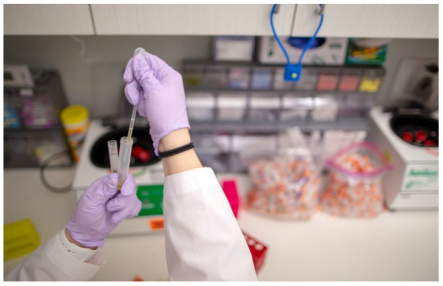
Indiana Hemophilia & Thrombosis Center

COMPREHENSIVE BLEEDING DISORDER CARE ALL AT ONE CENTER

All members of IHTC's clinical care team have extensive experience and deep expertise in bleeding disorders. This offers our patients the comfort and convenience of having every aspect of their bleeding disorder care all in one location.

Pediatric Hematologists
Adult Hematologists
Nurse Practitioners
Physician Assistants
Nurses
Physical Therapists
Dental Hygienists
Pharmacy Team
Psychologist
Genetic Counselor
Research
Social Workers
Registered Dietician
Career & School Counselors
Patient Insurance Coordinators
Child Life Specialist


Indiana's only Center of Excellence for bleeding & clotting disorders

The state's only federally-designated Hemophilia Treatment Center and the first HTC in the U.S. to receive national medical home certification

Certified as a Medical Home by AAAHC Accreditation Association for Ambulatory Health Care, Inc.

ACHC Accredited

Anticoagulation Center of Excellence

8326 Naab Road · Indianapolis, IN 46260 · 317.871.0000 · www.ihtc.org

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]

- ADVATE was proven in a pivotal clinical trial to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)
- The efficacy of ADVATE was studied in a multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20–40 IU/kg every 48 hours, or pharmacokinetic-driven, 20–80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis
  - 98% reduction in median annualized bleeding rate (ABR) from 44 to 1 when 53 patients in the clinical study switched from on-demand to prophylaxis
  - 0 bleeds in 42% (22/53) of patients during 1 year on prophylaxis

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.

Baxalta US Inc.
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Column: Inhibitor Insights, *sponsored by Novo Nordisk Inc.*

Show and Tell:
Disclosing a Diagnosis in the School Setting

Cazandra Campos-MacDonald

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 Plan[1] 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 closest to him in the loop, and watching him take over his hemophilia brings me joy.

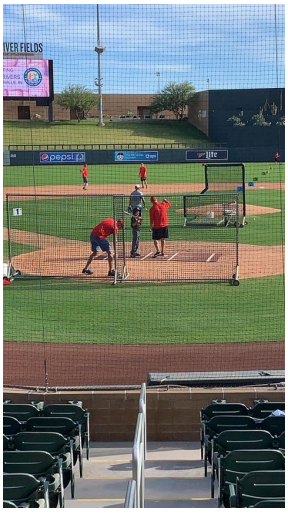
In the high school years, your child will become more independent and play a much bigger role in disclosing to teachers and staff. With more freedom comes more control over the bleeding disorder. With my oldest son, Julian, I didn't have annual meetings with the nurse at the high school level. Julian 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.

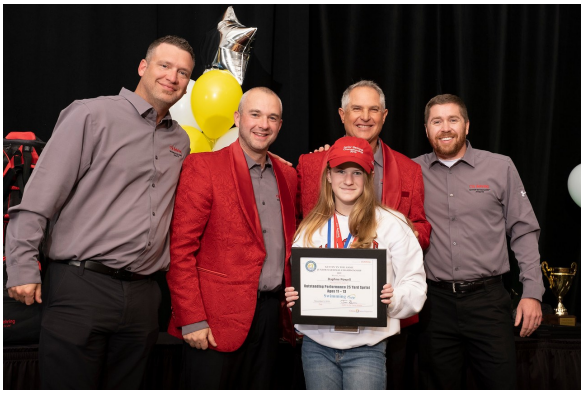
At the preschool, elementary, and secondary levels of education, disclosing pertinent medical information to the team involved in your child's care is crucial for his education and security. Disclosing information about a bleeding disorder helps those in charge become advocates for our children's safety 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 caregivers of children with a bleeding disorder, we do the best we can and hope that our examples positively influence their lives.

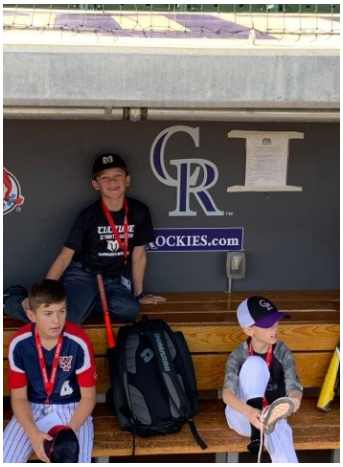
1. Section 504 of the Rehabilitation Act of 1973 (PL 93-112) is a civil rights law prohibiting discrimination against people with disabilities in any program or activity receiving or benefiting from federal financial assistance.

JNC Getting' In the Game

Developed by CSL Behring, the Gettin' in the Game (GIG) Junior National Championship (JNC) was the fist national golf, swimming, and baseball competition designed specifically for the bleeding disorders community. Hemophilia of Indiana has been proud representatives for many years. This year we had the pleasure of sending two kids to represent HOII at CSL Behring's Getting' in the Game, Junior National Championship event held in Phoenix, AZ. Getting' in the Game is a wonderful program that provides so many amazing experiences for young athletes in the bleeding disorders community. It builds confidence in their sport of choice, provides an opportunity an opportunity to give back to their chapter trough competition and allows our athletes to meet other kids from all over the country with similar interests that extend beyond their diagnosis. Tyler Rivers was one of our representatives this year and he participated in the baseball program. Tyler's mom, Lindsey said "Thank you so much for choosing Tyler for JNC. We had an amazing time!! It was so good for my heart and I am so thankful for we were able to attend". Daphne Powell also attended Getting' in the Game and participated in the swimming competitions. Daphne brought home an award for Outstanding Performance in the 25 yard Sprint for the 11-13 year old age group. Both Tyler and Daphne submitted essays to HOII staff on why they should be chosen to represent Indiana at the JNC competition in 2019. Tyler said he "loves baseball because fielding is fun, he gets a lot of exercise, doesn't complain about what position he gets to play and always tries his best" and those are just a few of the reasons we chose Tyler this year. Daphne is a member of her middle school swim and dive team and plans to continue competitive swimming into college. She even overcame a knee bleed this year and had to do physical therapy for a while, but said it only made her stronger in the end!, We are so proud of Tyler and Daphne and thankful for programs like JNC and hope that we can continue to partner with CSL and send kids to Arizona for many years to come! (Photo credits Lindsey Rivers and CSLjnc.com). Information for the 2020 Gettin' in the Game will be posted on the Hemophilia of Indiana's Facebook page (@Hemoindy)!







HEMOPHILIA OF INDIANA

2020

CALENDAR OF EVENTS

Hearts for Hemophilia Gala: *Union Station:* **February 7**

World Hemophilia Day: **April 17**

Bowling for Bleeding Disorders: *Pinheads*: **April 19**

Course to a Cure Golf Outing, *Maple Creek Golf & Country Club*: **June 8**

Camp Brave Eagle, *Camp Crosley:* **June 14-19**

Annual Meeting, *Crowne Plaza Airport Hotel*: **August 29-30**

Polo @ Sunset, *Hickory Hall Polo Club*: **TBD**

UNITE for Bleeding Disorders Walk *Ft. Harrison State Park*: **September 12**

Thanksgiving Day Run, *Dillon Park*: **November 26**

Year End Educational Program: December 5

Our mission:

Hemophilia of Indiana is dedicated to empowering the bleeding disorders community through education and support, while advocating access to quality care and product safety.

Hemophilia of Indiana, Inc.
6910 N. Shadeland, Ave., Suite 140
Indianapolis, IN 46220
Phone: (317) 570-0039 Fax: (317) 570-0058
Website: www.hoii.org
EIN: 35-1278222

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
150 mg/mL

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
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HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

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*The material provided in Vital Link is only for general information purposes. HoII does not give medical advice or engage in the practice of medicine. HoII recommends in all cases that you consult your physician or HTC before pursuing any course of treatment.

Mark your Calendars!

Here are some of our upcoming events…

- Hearts for Hemophilia Gala - February 7, 2020
- World Hemophilia Day - April 17, 2020
- Bowling for Bleeding Disorders - April 19, 2020

Call our office @ (317) 570-0039 or email Kristy McConnell @ kmcconnell@hoii.org if you would like to get involved in any of our events!