Winter 2020-21

KHF Hemosphere

2020 Virtual Unite for Bleeding Disorders Walk

Mid-year, we made the difficult but necessary decision for the safety of our Walk participants to join many other chapters in moving from an in-person Unite Walk to a virtual Unite Walk Celebration.

Thanks to the efforts of our Kentucky bleeding disorders community, eleven Walk Teams were formed by their respective Team Captains comprised of sixty-three participants to whom we give a big shout out of gratitude and appreciation: Team Blood Brothers, Mason Stout, Team Captain; 4GG Babies, Ursela Kamala, Team Captain; Team Ike-a-Maniacs, Laura Webb, Team Captain; Team Jack, Cory Meadows, Team Captain; Team LEVI, Karen Lucky Halburnt and Levi Hill, Team Captains; Teams Ohana and Marauder's Half-Bloods, Bobbie Rodriguez, Team Captain; Team Roblynn, Constance Wheat, Team Captain; Team Tag & Trey's Turtles, Monica Poynter, Team Captain; Team XL, Dianne Hardman, Team Captain; and The Walking Bled, Venus Marcum, Team Captain.

Through their enthusiastic and diligent peer-to-peer fundraising and our generous sponsors' support, we were able to raise a total of $32,801.

The Walk Day Celebration united all of us via Zoom and featured awards and prizes for the top team winners, the top fundraisers, the winners of the "Halloween Costume Contest," the best photo capturing the "I Unite for…spirit," door prizes, pinwheel ceremony, and musical interludes. At the time of the Walk Day Celebration, we recognized in 1st place, Team LEVI from Cynthiana with $1,195; in 2nd place, Team Jack from Louisville with $925; and in 3rd place, Team Tag and Trey's Turtles from Bowling Green with $825.

Top individual fundraisers were in 1st place with $1,170, Karen Lucky Halburnt and Levi Hill of Cynthiana; in 2nd place with $790, Dianne Hardman of Louisville; and in 3rd place with $725, Cory Meadows of Louisville. The "I Unite for…" photo award went to Team Roblynn of Louisville, whose photo inspiringly portrayed their family unity and support for each other. *(continued on pg. 6)*

Special News

The First National Patient Satisfaction Survey of U.S. HTCs

The federally funded hemophilia treatment center (HTC) network, with its model of a multidisciplinary care team (MDT) and regional infrastructure, has proven itself, over several decades, to be well suited to deliver quality, integrated healthcare to bleeding disorders patients across the U.S. While this system has allowed for various surveillance and data collection projects focused on patient demographics, clinical status, and mortality, it has not, until recently, been leveraged to gauge patient satisfaction on a national level.

The authors of a new paper published in the journal Haemophilia posit that patient satisfaction with the delivery of care is an important metric that is associated with treatment adherence and better overall health outcomes. Therefore, a first-of-its kind nationally uniform and comprehensive patient satisfaction survey (PSS) was conducted and made possible via the coordination of the HTC network's robust regional infrastructure. A steering committee made up of three of the network's regional coordinators initiated and managed the PSS. They were guided by performance standards of the hemophilia program of the U.S. Health Resources and Services Administration (HRSA); the agency provides limited funding to support the eight designated regions that make up the HTC network.

The survey was designed to assess patient demographics, their satisfaction with the HTC's core MDT, plus affiliated clinicians, services, and care processes. The MDT core includes the hematologist, nurse, nurse practitioner, social worker, and the physical therapist. In addition, three fundamental HTC services were rated, including shared decision making and care coordination with both the primary doctor and with other specialists/providers. Lastly, five key HTC processes were evaluated for patient satisfaction: timeliness of care, ease of getting needed information, ease of understanding how the HTC clinic staff explained things, time spent with clinic staff, and being treated with respect.

All 138 HTCs that were operating in 2014 were invited to participate in the PSS. The eight regional coordinators of the Network helped facilitate the promotion and dissemination of the survey to HTCs and provided technical assistance to ensure a nationally consistent administration. In February-March 2014 the survey was disseminated to an estimated 28,289 households of patients with which the HTC had a "significant clinical interaction" that same year. The subsequent data collection period through June of 2015, with the University of Colorado serving as coordinating institution for all data collection and aggregation. To make possible comparisons to other populations, regions were collapsed from eight to four standard regions including West, Midwest, South, and Northeast.

The overall participation rate for HTCs was high as 133 or 138 centers (96.4%) opted into the survey. In sum, 5006 individuals who received care from a center in 2014 completed the PSS, representing a 17.7% national response rate. At 29.2%, females represented almost a third of the participants, the majority of which were White, non-Hispanic. A look at participants grouped by age shows a fairly even breakdown amongst the groups, while there were significant differences in participation levels amongst the four geographic regions with 42.1% (2109) from the Midwest, 27.9% (1398) from the Northeast, 19.0% (952) from the West and 10.9% (547) from the Southeast. The majority of the respondents, 3,106 (62%) had hemophilia, 1299 (25.9%) had von Willebrand disease (VWD), and 601 (12.0%) reported diagnosis as "other," "unknown" or did not specify. Overall, those with a severe hemophilia and type 3 severe von Willebrand disease represented 29.4%, of respondents, while those with a moderate bleeding disorder, including VWD type 2 or moderate hemophilia accounted for 17.8% of participants. Those with a mild bleeding disorder (VWD type 1 or mild hemophilia) comprised the largest group at 32.8%.

The First National Patient Satisfaction Survey of U.S. HTCs

By virtually all measures, results of the PSS suggest consistently high levels of satisfaction with HTCs amongst the more than 5,000 respondents. Overall, 94.2%-97.9% reporting responded that they were 'always' or 'usually' (A/U) satisfied with the overall care they received at their center. Participants also rated highly their satisfaction with members of their HTC's core MDT, including the hematologist, nurses, nurse practitioners, social workers, and physical therapists (PTs). A national breakdown by member showed that 97.3% of respondents were A/U satisfied with the hematologist, 97.0% with the HTC nurse and nurse practitioner (combined), 95.1% with the social worker and 95.6% with the PT.

HTC care processes considered integral to PSS also scored very well nationally, with more than 95% of respondent's A/U satisfied with each of the five processes. These included timeliness of care (94.9%); ease of getting needed information (95.0%); ease of understanding how the HTC clinic staff explained things (97.3%); time spent with clinic staff (97.0%); and being treated with respect (98.0%). On a regional level, A/U satisfaction for each of the five care processes was at least 91.2%.

The survey also reflected well on transition issues nationally. Of respondents aged 12-17 years, 90.2% reported being A/U satisfied with how their HTC talked about how to care for their bleeding disorder as they became adults. Similarly, 92.8% of adolescents were A/U satisfied with how their HTC encouraged them to become more independent in managing their bleeding disorder.

The authors point to this initiative's success as a "proof of concept" in the far-reaching utility of a regional infrastructure to deliver meaning and impactful national assessments now and in the future.

"This HTC PSS initiative provides new national data, reducing evidence gaps in quantifying the extent to which patients value the different healthcare professionals on the integrated HTC team, HTC services, processes and overall care. These high levels of patient satisfaction were articulated regardless of patient diagnoses, severity of disease, gender, race or ethnicity, or geographic location, and pose several implications, "explained the authors. "First, these data indicate that patients highly value the HTC multidisciplinary team approach."

While the authors do acknowledge limitations, including an imbalance in regional representation, the take home message remains the same; there exists a strong correlation between patient satisfaction and quality of care. Further, such PSS data may be employed in various advocacy efforts, to engage payers, and ensure the viability of the HTC Network.

"The high level of patient satisfaction documented in this inaugural national survey of the US HTC Network's ambulatory services has several important policy implications. Specifically, in the United States, access to HTC care must be guaranteed," conclude the authors. "All payers must include HTCs in their networks to maintain high-quality patient care."

Riske B, Shearer R, Baker J. Patient Satisfaction with US Hemophilia Treatment Center Care, Teams and Services: The First National Survey. Haemophilia. 23 October 2020.

Event News

2020 Virtual Year-End Community Event

Every year, the KHF Year-End Community Event celebrates the spirit of the Holiday Season. This year, this uplifting and joyful event had to be held virtually because of pandemic restrictions and to protect everyone's health and safety. The invitation asked all children in our bleeding disorders community to send letters to Santa, some of which would be read during the Zoom event and a drawing for prizes would be held. Santa received many letters at the KHF Office and he was pleased to interact virtually with the authors during the event. In addition to Santa's and Mrs. Claus's appearance, the reading of wonderful letters, Connie Thacker's demonstration of an easy assembly of pretty ornaments, we also had a drawing for door prizes.

The highlight of this family event was watching the screening of the Bombardier Blood movie, a documentary featuring Chris Bombardier who has severe hemophilia as he climbs Mount Everest, the tallest mountain in the world. Each family who had registered for the event received a package with a bag of Holiday cookies baked by EM, an UNO game, two ornament kits to assemble, and as a surprise all the children received a gift that they had wished for in their letters to Santa. Santa's satellite workshop here at KHF was quite busy creating smiles and happy hearts right before the Holidays. Several of the older children and parents expressed poignant wishes for families to be united and healthy as well as for peace, harmony, and good tidings for all people in the world. We thank our sponsors who supported this important event. They were CSL Behring, Genentech, Novo Nordisk, octapharma, Takeda, and uniQure.

Remember: KHF Cares

Kentucky Hemophilia Foundation continues to provide financial assistance to bleeding disorder families whose household income has decreased because of loss of job, lay off, furlough, or reduced hours during the current COVID-19 health crisis and who are unable to pay a specific household bill.

Requesting families must reside in Kentucky, and the person seeking assistance must either have a bleeding disorder or be the parent of a minor child with a bleeding disorder. Assistance is contingent on the availability of funds. Call 502-456-3233 or 800-582-CURE (2873) or send an email to info@kyhemo.org to make a request.

Event News

2020 Poinsettia Fundraiser

The ongoing pandemic regretfully had a negative impact on the success of this annual fundraiser. A number of churches did not hold in-person services and were not able to participate in our fundraiser, but we are so grateful to all the individuals, businesses, churches, and volunteers who did support our poinsettia fundraiser. Because of your efforts and generosity, we have been able to continue with our mission and provide needed services to our bleeding disorders community.

We especially appreciate the support of Republic Bank and Trust Company, Mr. & Mrs. Terry Forcht, Mr. & Mrs. Glen Hitt, and Mr. & Mrs. James Ray as wells as the dedicated volunteer efforts of Sharon McMahan of Owensboro, Sadalia Sturgill or Lebanon Junction, Myra Loeser and Gail Yates of Louisville.

2020 YETI Conference

Sam Johnson of Evansville, IN, and Isaac Webb of Louisville, KY participated in the 2020 Virtual YETI Conference. This national conference is a train-the-trainer conference that provides training for teen and adult leaders for organizing and implementing teen programs that prepare youngsters with bleeding disorders for successful transitions to adulthood. Pacific Northwest Bleeding Disorders offers this annual training opportunity for representatives of Chapters, HTCs (Hemophilia Treatment Centers), and other organizations serving the bleeding disorders community.

Isaac remarks that his participation in the Virtual YETI Conference was a great learning experience because they integrated technology in a fun and engaging way. Sam also states that the conference was a fun educational event. She adds that the conference was a great resource for developing creative virtual activities and games for effective virtual programming and for allowing adults to have some fun as well. Sam Johnson is a Junior Counselor at KHF's Camp Discovery for children and teens with bleeding disorders and Isaac Webb is a Junior Counselor in Training at KHF's summer camp!

Photos

Hello Parents! We are all missing our family and friends, including those in the KHF family. Please email us photos of your children that show how they have managed to learn and have fun during the pandemic. Photos of how they have remained happy and connected with their friends learning, playing, and communicating in creative ways. We would like to feature these photos in our newsletter, and in other KHF materials, to share with and inspire others. If we get a good response, we are considering having a photo of the month prize.

More News

2020 Virtual Unite for Bleeding Disorders Walk

continued from page 1

The winners of the Halloween costume contest were Aaron Webb, Trey Poynter, Tag Poynter, Levi Hill, Easton Hill, and Garnett Hill, whose costumes were adorably scary and superheroic, except for Garnett's cute little cow costume. Each Walk participant received a Walk t-shirt and a KHF gaiter. All monies raised by the Walk stay here locally and benefit Kentucky's bleeding disorders community through our programs and services. In addition to thanking our walkers, team captains, and donors, we also thank our corporate sponsors. They were Gold Sponsor, Novo Nordisk; Silver Sponsors, CSL Behring, Genentech, octapharma, Pfizer, and uniQure; and Bronze Sponsors, BMR Partners, CVS Caremark, Republic Bank, Sanofi Genzyme, and Takeda.

2020 – 2021 Fall/Winter Donations

We thank the following individuals and companies for their generous support!

Donor, $7,500
National Hemophilia Foundation (NHF)

Donors, $1,500 - $2,500
BioMarin
Terry & Marion Forcht
for poinsettias
Snow Companies
Zoeller Company
via Louisville Community Foundation

Donors, $200 - $400
Glen & Deborah Hitt
for poinsettias
Kroger Community Rewards
Donald L. Mattingly
William (Bill) Stopher

Donors, $100 - $199
H. Sandy Franklin
Michael A. Gatton
for summer camp
Mr. & Mrs. James Ray
for poinsettias
Mary A. Robinson

Donors, $50 - $99
Mr. & Mrs. Jack Dague
for poinsettias
Robert L. & Shirley B. Gardner
Elizabeth Hart
Cory E. Meadows
David & Terry Moore
Robert N. Nestmann
for poinsettias
Carol Nord
Glenn & Laura Webb

Donors, Up to $49
Amazon Smiles
Dolores T. Davis
Father L. Fichteman
for poinsettias
Stanley E. Hankins
for poinsettias
David R. Hatfield
for poinsettias
Richard E. Sloan
Rita Stephenson
for poinsettias
Dr. Donald T. Stokes
for poinsettias

More News

2020 — 2021 KHF Membership

We thank all of the members of the Kentucky Hemophilia Foundation for their support of the current program year!

Individual/Family Memberships, $20
Sara Ceresa

Supporting Memberships, $35
Holly Hadley
Judy Hayes
in memory of Jason Hayes
Evelyn Kramer
Donald L. Mattingly

Patron Memberships, $50
Maritza & Danny Adams
Cory W. Meadows
Charles Music

Sustaining Memberships, $100
John & Leah Graham
Barbara W. Grayson
D. Spalding Grayson
Arthur Hackman
Michael Johnson
Eric & Venus Marcum
Keith Peterson
Glenn & Laura Webb

Benefactor Membership, $250
Glen & Deborah Hitt

Champion/Corporate Membership, $500
LTC (R) John & Pat Tharp

In Memory

October 1, 2020 – December 31, 2020

Gone from our sight but never our memories; gone from our touch but never our hearts… May their memory be a blessing!

Jeremy Clary
Lisa Mattingly

Rev. Daniel Goff
Lisa Mattingly

Martha Ann Lex
Mr. & Mrs. Henry W. Boyd, III

Do The Five

Follow these steps to prevent or reduce complications of bleeding disorders

1. **Get an annual comprehensive checkup at a hemophilia treatment center.**
2. **Get vaccinated – Hepatitis A and B are preventable.**
3. **Treat bleeds early and adequately.**
4. **Exercise to protect your joints.**
5. **Get tested regularly for blood-borne infections.**

To find out more about the National Prevention Program developed by the National Hemophilia Foundation in collaboration with the Centers for Disease Control and Prevention (CDC), click on www.hemophilia.org or call toll-free 800-42-HANDI.

60 Years of Service!

Please remember KHF when doing your estate planning! This will help us continue our service to Kentuckiana's Bleeding Disorders Community.

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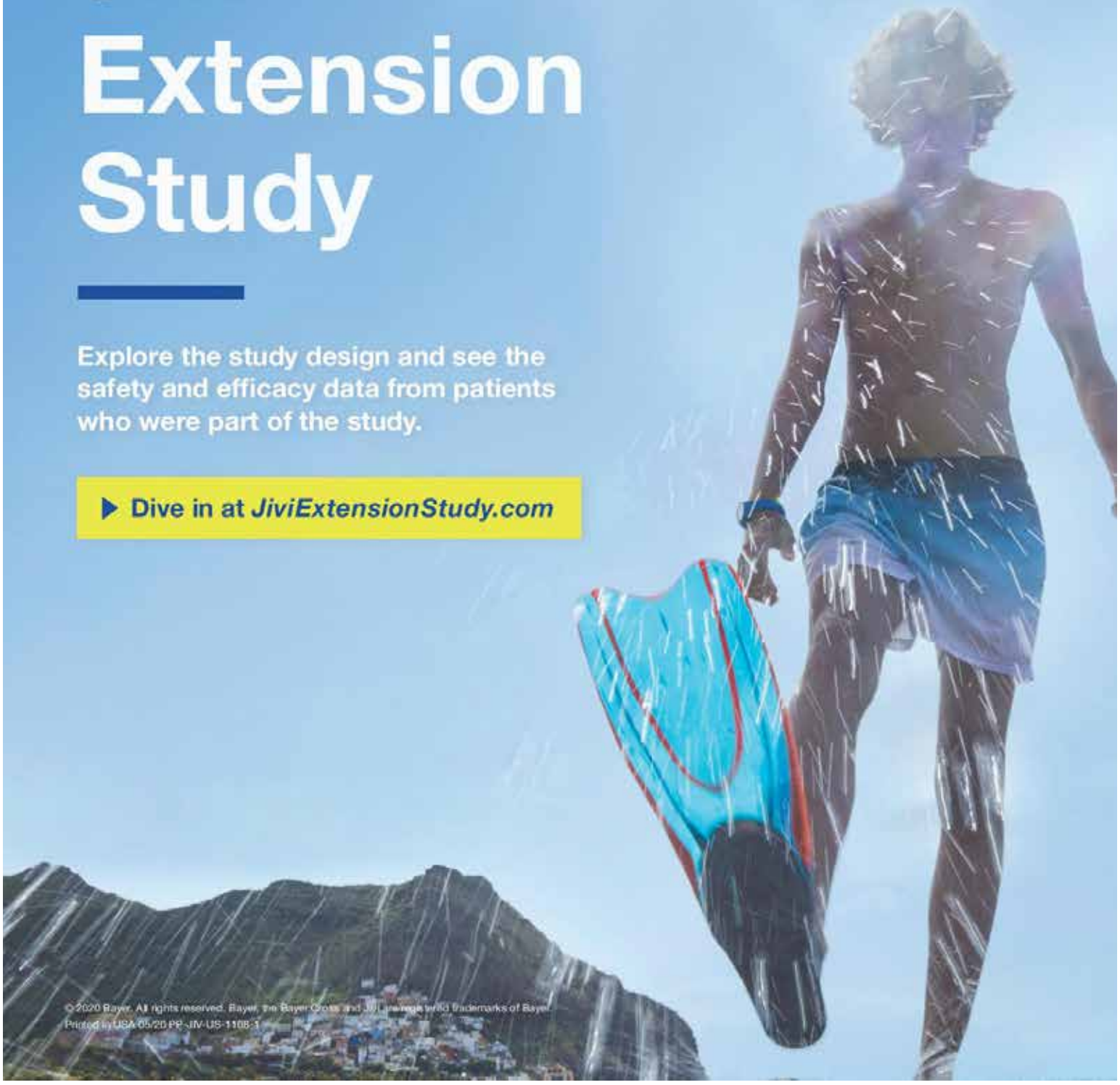
LET'S GO

BAYER

Jivi® Extension Study

Explore the study design and see the safety and efficacy data from patients who were part of the study.

▶ Dive in at *JiviExtensionStudy.com*



For people with hemophilia A or B with inhibitors, it's time to

Spread your wings

Controlling bleeds, whenever they happen

- Proven to treat bleeds for people with hemophilia A or B with inhibitors

Safety supported by clinical experience[a]

- Low rate (0.2%) of blood clots reported in clinical trials

Speed when it's needed

- Fast to mix, fast to infuse, and fast to control bleeds[b]

NovoSeven® RT—committed to your experience

- More than 30 years of research and long-term clinical experience[c]

[a]For people with hemophilia A or B with inhibitors.
[b]Administer as a slow bolus injection over 2-5 minutes, depending on the dose administered.
[c]Compassionate use, also known as expanded access, began enrolling in 1988; FDA approval received in 1999.

Chase, 5 years old, *has hemophilia A with inhibitors, and loves anything that has to do with cars, planes, or playing golf.*

Visit **NovoSevenRT.com** today to learn more.

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What is NovoSeven® RT?

NovoSeven® RT (coagulation Factor VIIa, recombinant) is an injectable medicine used for:

- Treatment of bleeding and prevention of bleeding for surgeries and procedures in adults and children with hemophilia A or B with inhibitors, congenital Factor VII (FVII) deficiency, and Glanzmann's thrombasthenia with a decreased or absent response to platelet transfusions
- Treatment of bleeding and prevention of bleeding for surgeries and procedures in adults with acquired hemophilia

Important Safety Information

What is the most important information I should know about NovoSeven® RT?

NovoSeven® RT may cause serious side effects, including:

- **Serious blood clots** that form in veins and arteries with the use of NovoSeven® RT have been reported
- Your healthcare provider should discuss the risks and explain the signs and symptoms of blood clots to you. Some signs of a blood clot may include pain, swelling, warmth, redness, or a lump in your legs or arms, chest pain, shortness of breath, or sudden severe headache and/or loss of consciousness or function
- Your healthcare provider should monitor you for blood clots during treatment with NovoSeven® RT
- You should not use NovoSeven® RT if you have ever had allergic (hypersensitivity) reactions, including severe, whole body reactions (anaphylaxis) to NovoSeven® RT, any of its ingredients, or mice, hamsters, or cows. Signs of allergic reaction include shortness of breath, rash, itching (pruritus), redness of the skin (erythema), or fainting/dizziness

What should I tell my healthcare provider before using NovoSeven® RT?

- Tell your healthcare provider if you have any of the following, as these may increase your risk of blood clots:
  - congenital hemophilia and are also receiving treatment with aPCCs (activated prothrombin complex concentrates)
  - are an older patient particularly with acquired hemophilia and receiving other agents to stop bleeding
  - history of heart or blood vessel diseases
- Tell your healthcare provider and pharmacist about all the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies

What are the possible side effects of NovoSeven® RT?

- The most common and serious side effects are blood clots
- Tell your healthcare provider about any side effects that bother you or do not go away, and seek medical help right away if you have signs of a blood clot or allergic reaction

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

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

NovoSeven® RT
Coagulation Factor VIIa (Recombinant)

NOVOSEVEN® RT
Coagulation Factor VIIa (Recombinant)

Rx only

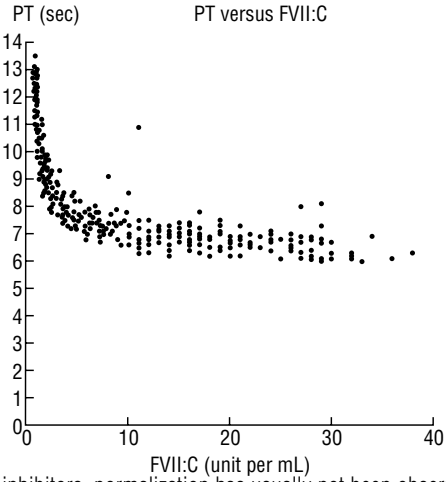
BRIEF SUMMARY. Please consult package insert for full prescribing information.

WARNING: THROMBOSIS: Serious arterial and venous thrombotic events following administration of NOVOSEVEN® RT have been reported. *[See Warnings and Precautions]* Discuss the risks and explain the signs and symptoms of thrombotic and thromboembolic events to patients who will receive NOVOSEVEN® RT. *[See Warnings and Precautions]* Monitor patients for signs or symptoms of activation of the coagulation system and for thrombosis. *[See Warnings and Precautions]*

INDICATIONS AND USAGE: NOVOSEVEN® RT, Coagulation Factor VIIa (Recombinant), is indicated for: Treatment of bleeding episodes and peri-operative management in adults and children with hemophilia A or B with inhibitors, congenital Factor VII (FVII) deficiency, and Glanzmann's thrombasthenia with refractoriness to platelet transfusions, with or without antibodies to platelets; Treatment of bleeding episodes and peri-operative management in adults with acquired hemophilia.

CONTRAINDICATIONS: None known.

WARNINGS AND PRECAUTIONS: Thrombosis: Serious arterial and venous thrombotic events have been reported in clinical trials and postmarketing surveillance. Patients with congenital hemophilia receiving concomitant treatment with aPCCs (activated prothrombin complex concentrates), older patients particularly with acquired hemophilia and receiving other hemostatic agents, or patients with a history of cardiac, vascular disease or predisposed to thrombotic events may have an increased risk of developing thrombotic events *[See Adverse Reactions and Drug Interactions]*. Monitor patients who receive NOVOSEVEN® RT for development of signs or symptoms of activation of the coagulation system or thrombosis. When there is laboratory confirmation of intravascular coagulation or presence of clinical thrombosis, reduce the dose of NOVOSEVEN® RT or stop the treatment, depending on the patient's condition. **Hypersensitivity Reactions:** Hypersensitivity reactions, including anaphylaxis, can occur with NOVOSEVEN® RT. Patients with a known hypersensitivity to mouse, hamster, or bovine proteins may be at a higher risk of hypersensitivity reactions. Discontinue infusion and administer appropriate treatment when hypersensitivity reactions occur. **Antibody Formation in Factor VII Deficient Patients:** Factor VII deficient patients should be monitored for prothrombin time (PT) and factor VII coagulant activity before and after administration of NOVOSEVEN® RT. If the factor VIIa activity fails to reach the expected level, or prothrombin time is not corrected, or bleeding is not controlled after treatment with the recommended doses, antibody formation may be suspected and analysis for antibodies should be performed. **Laboratory Tests:** Laboratory coagulation parameters (PT/INR, aPTT, FVII:C) have shown no direct correlation to achieving hemostasis. Assays of prothrombin time (PT/INR), activated partial thromboplastin time (aPTT), and plasma FVII clotting activity (FVII:C), may give different results with different reagents. Treatment with NOVOSEVEN® has been shown to produce the following characteristics: PT: As shown below, in patients with hemophilia A/B with inhibitors, the PT shortened to about a 7-second plateau at a FVII:C level of approximately 5 units per mL. For FVII:C levels > 5 units per mL, there is no further change in PT. The clinical relevance of prothrombin time shortening following NOVOSEVEN® RT administration is unknown.



INR: NOVOSEVEN® has demonstrated the ability to normalize INR. However, INR values have not been shown to directly predict bleeding outcomes, nor has it been possible to demonstrate the impact of NOVOSEVEN® on bleeding times/volume in models of clinically-induced bleeding in healthy volunteers who had received Warfarin, when laboratory parameters (PT/INR, aPTT, thromboelastogram) have normalized. aPTT: While administration of NOVOSEVEN® shortens the prolonged aPTT in hemophilia A/B patients with inhibitors, normalization has usually not been observed in doses shown to induce clinical improvement. Data indicate that clinical improvement was associated with a shortening of aPTT of 15 to 20 seconds. FVIIa:C: FVIIa:C levels were measured two hours after NOVOSEVEN® administration of 35 micrograms per kg body weight and 90 micrograms per kg body weight following two days of dosing at two hour intervals. Average steady state levels were 11 and 28 units per mL for the two dose levels, respectively.

ADVERSE REACTIONS: The most common and serious adverse reactions in clinical trials are thrombotic events. Thrombotic adverse reactions following the administration of NOVOSEVEN® in clinical trials occurred in 4% of patients with acquired hemophilia and 0.2% of bleeding episodes in patients with congenital hemophilia. **Clinical Trials Experience:** Because clinical studies are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug product cannot be directly compared to rates in clinical trials of another drug, and may not reflect rates observed in practice. Adverse reactions outlined below have been reported from clinical trials and data collected in registries. Hemophilia A or B Patients with Inhibitors: In two studies for hemophilia A or B patients with inhibitors treated for bleeding episodes (N=298), adverse reactions were reported in ≥2% of the patients that were treated with NOVOSEVEN® for 1,939 bleeding episodes (see Table 3 below).

Table 3: Adverse Reactions Reported in ≥2% of the 298 Patients with Hemophilia A or B with Inhibitors

Body System Reactions	**# of adverse reactions** (n=1,939 treatments)	**# of patients** (n=298 patients)
Body as a whole		
Fever	16	13
Platelets, Bleeding, and Clotting		
Fibrinogen plasma decreased	10	5
Cardiovascular		
Hypertension	9	6

Serious adverse reactions included thrombosis, pain, thrombophlebitis deep, pulmonary embolism, decreased therapeutic response, cerebrovascular disorder, angina pectoris, DIC, anaphylactic shock and abnormal hepatic function. The serious adverse reactions of DIC and therapeutic response decreased had a fatal outcome. In two clinical trials evaluating safety and efficacy of NOVOSEVEN® administration in the perioperative setting in hemophilia A or B patients with inhibitors (N=51), the following serious adverse reactions were reported: acute post-operative hemarthrosis (n=1), internal jugular thrombosis adverse reaction (n=1), decreased therapeutic response (n=4). *Immunogenicity:* There have been no confirmed reports of inhibitory antibodies against NOVOSEVEN® or FVII in patients with congenital hemophilia A or B with alloantibodies. The incidence of antibody formation is dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to NOVOSEVEN® RT with the incidence of antibodies to other products may be misleading. Congenital Factor VII Deficiency: Data collected from the compassionate/emergency use programs, the published literature, a pharmacokinetics study, and the Hemophilia and Thrombosis Research Society (HTRS) registry showed that 75 patients with Factor VII deficiency had received NOVOSEVEN®: 70 patients for 124 bleeding episodes, surgeries, or prophylaxis; 5 patients in the pharmacokinetics trial. The following adverse reactions were reported: intracranial hypertension (n=1), IgG antibody against rFVIIa and FVII (n=1), localized phlebitis (n=1). *Immunogenicity:* In 75 patients with factor FVII deficiency treated with NOVOSEVEN® RT, one patient developed IgG antibody against rFVIIa and FVII. Patients with factor VII deficiency treated with NOVOSEVEN® RT should be monitored for factor VII antibodies. The incidence of antibody formation is dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to NOVOSEVEN® RT with the incidence of antibodies to other products may be misleading. Acquired Hemophilia: Data collected from four compassionate use programs, the HTRS registry, and the published literature showed that 139 patients with acquired hemophilia received NOVOSEVEN® for 204 bleeding episodes, surgeries and traumatic injuries. Of these 139 patients, 6 patients experienced 8 serious adverse reactions. Serious adverse reactions included shock (n=1), cerebrovascular accident (n=1) and thromboembolic events (n=6) which included cerebral artery occlusion, cerebral ischemia, angina pectoris, myocardial infarction, pulmonary embolism and deep vein thrombosis. Three of the serious adverse reactions had a fatal outcome. Glanzmann's Thrombasthenia: Data collected from the Glanzmann's Thrombasthenia Registry (GTR) and the HTRS registry showed that 140 patients with Glanzmann's thrombasthenia received NOVOSEVEN® RT for 518 bleeding episodes, surgeries or traumatic injuries. The following adverse reactions were reported: deep vein thrombosis (n=1), headache (n=2), fever (n=2), nausea (n=1), and dyspnea (n=1). **Post marketing Experience:** Adverse reactions reported during post marketing period were similar in nature to those observed during clinical trials and include reports of thromboembolic adverse events.

DRUG INTERACTIONS: Avoid simultaneous use of activated prothrombin complex concentrates. Do not mix NOVOSEVEN® RT with infusion solutions. Thrombosis may occur if NOVOSEVEN® RT is administered concomitantly with Coagulation Factor XIII. *[See Warnings and Precautions]*

USE IN SPECIFIC POPULATIONS: Pregnancy: Risk Summary: There are no adequate and well-controlled studies using NOVOSEVEN® RT in pregnant women to determine whether there is a drug-associated risk. Treatment of rats and rabbits with NOVOSEVEN® in reproduction studies has been associated with mortality at doses up to 6 mg per kg body weight and 5 mg per kg body weight respectively. At 6 mg per kg body weight in rats, the abortion rate was 0 out of 25 litters; in rabbits at 5 mg per kg body weight, the abortion rate was 2 out of 25 litters. Twenty-three out of 25 female rats given 6 mg per kg body weight of NOVOSEVEN® gave birth successfully, however, two of the 23 litters died during the early period of lactation. No evidence of teratogenicity was observed after dosing with NOVOSEVEN®. In the U.S. general population, the estimated background risk of major birth defect and miscarriage in clinically recognized pregnancies is 2-4% and 15-20%, respectively. **Lactation:** Risk Summary: There is no information regarding the presence of NOVOSEVEN® RT in human milk, the effect on the breastfed infant, and the effects on milk production. The developmental and health benefits of breastfeeding should be considered along with the mother's clinical need for NOVOSEVEN® RT and any potential adverse effects on the breastfed infant from NOVOSEVEN® RT or from the underlying maternal condition. **Pediatric Use:** Clinical trials enrolling pediatric patients were conducted with dosing determined according to body weight and not according to age. Hemophilia A or B with Inhibitors: During the investigational phase of product development NOVOSEVEN® was used in 16 children aged 0 to <2 years for 151 bleeding episodes, 27 children aged 2 to <6 years for 140 bleeding episodes, 43 children aged 6 to <12 for 375 bleeding episodes and 30 children aged 12 to 16 years for 446 bleeding episodes. In a double-blind, randomized comparison trial of two dose levels of NOVOSEVEN® in the treatment of joint, muscle and mucocutaneous hemorrhages in hemophilia A and B patients with and without inhibitors 20 children aged 0 to <12 and 8 children aged 12 to 16 were treated with NOVOSEVEN® in doses of 35 or 70 micrograms per kg dose. Treatment was assessed as effective (definite relief of pain/tenderness as reported by the patient and/or a measurable decrease of the size of the hemorrhage and/or arrest of bleeding within 8 hours [rated as excellent = 51%], within 8-14 hours [rated as effective = 18%] or after 14 hours [rated as partially effective = 25%]) in 94% of the patients. NOVOSEVEN® was used in two trials in surgery. In a dose comparison 22 children aged 0 to 16 years were treated with NOVOSEVEN®. Effective intraoperative hemostasis (defined as bleeding that had stopped completely or had decreased substantially [rated as effective = 86%] or bleeding that was reduced but continued [rated as partially effective = 9%]) was achieved in 21/22 (95%) patients. Effective hemostasis was achieved in 10/10 (100%) patients in the 90 mcg/kg dose group and 10/12 (83%) in the 35 mcg/kg dose group at 48 hours; effective hemostasis was achieved in 10/10 (100%) in the 90 mcg/kg dose group and 9/12 (75%) in the 35 mcg/kg dose group at 5 days. In the surgery trial comparing bolus (BI) and continuous infusion (CI) 6 children aged 10 to 15 years participated, 3 in each group. Both regimens were 100% effective (defined as bleeding has stopped completely, or decreased substantially) intra-operatively, through the first 24 hours and at day 5. At the end of the study period (Postoperative day 10 or discontinuation of therapy) hemostasis in two patients in the BI group was rated effective and hemostasis in one patient was rated as ineffective (defined as bleeding is the same or has worsened). Hemostasis in all three patients in the CI group was rated as effective. Adverse drug reactions in pediatric patients were similar to those previously reported in clinical trials with NOVOSEVEN®, including one thrombotic event in a 4 year old with internal jugular vein thrombosis after port-a-cath placement which resolved. Congenital Factor VII deficiency: In published literature, compassionate use trials and registries on use of NOVOSEVEN® in congenital Factor VII deficiency, NOVOSEVEN® was used in 24 children aged 0 to <12 years and 7 children aged 12 to 16 years for 38 bleeding episodes, 16 surgeries and 8 prophylaxis regimens. Treatment was effective in 95% of bleeding episodes (5% not rated) and 100% of surgeries. No thrombotic events were reported. A seven-month old exposed to NOVOSEVEN® and various plasma products developed antibodies against FVII and rFVIIa [*see Adverse Reactions and Overdosage*]. Glanzmann's Thrombasthenia: In the Glanzmann's Thrombasthenia Registry, NOVOSEVEN® was used in 43 children aged 0 to 12 years for 157 bleeding episodes and in 15 children aged 0 to 12 years for 19 surgical procedures. NOVOSEVEN® was also used in 8 children aged >12 to 16 years for 17 bleeding episodes and in 3 children aged >12 to 16 years for 3 surgical procedures. Efficacy of regimens including NOVOSEVEN® was evaluated by independent adjudicators as 93.6% and 100% for bleeding episodes in children aged 0 to 12 years and >12 to 16 years, respectively. Efficacy in surgical procedures was evaluated as 100% for all surgical procedures in children aged 0 to 16 years. No adverse reactions were reported in Glanzmann's thrombasthenia children. **Geriatric Use:** Clinical studies of NOVOSEVEN® RT in congenital factor deficiencies and Glanzmann's thrombasthenia did not include sufficient numbers of subjects aged 65 and over to determine whether they respond differently from younger subjects.

OVERDOSAGE: Dose limiting toxicities of NOVOSEVEN® RT have not been investigated in clinical trials. The following are examples of accidental overdose. One newborn female with congenital factor VII deficiency was administered an overdose of NOVOSEVEN® (single dose: 800 micrograms per kg body weight). Following additional administration of NOVOSEVEN® and various plasma products, antibodies against rFVIIa were detected, but no thrombotic complications were reported. One Factor VII deficient male (83 years of age, 111.1 kg) received two doses of 324 micrograms per kg body weight (10-20 times the recommended dose) and experienced a thrombotic event (occipital stroke). One hemophilia B patient (16 years of age, 68 kg) received a single dose of 352 micrograms per kg body weight and one hemophilia A patient (2 years of age, 14.6 kg) received doses ranging from 246 micrograms per kg body weight to 986 micrograms per kg body weight on five consecutive days. There were no reported complications in either case.

More detailed information is available upon request.

For information contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA
1-877-NOVO-777
www.NOVOSEVENRT.com

Manufactured by:
Novo Nordisk A/S
2880 Bagsvaerd, Denmark
License Number: 1261

US18NSVN00101 12/18

novo nordisk®

NovoSeven® RT
Coagulation Factor VIIa (Recombinant)

EXPERIENCE MATTERS

BeneFix is FDA approved for once-weekly prophylaxis and on-demand use to fit your dosing needs—from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.*

Not actual patients.

- **More than 20 years* of experience—**the first recombinant treatment for individuals with hemophilia B
- **Dosing options to meet your needs—**for once-weekly prophylaxis and on-demand use
- Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix
- The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes

What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

ASK YOUR DOCTOR WHICH BENEFIX DOSING OPTIONS MAY BE RIGHT FOR YOU

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.

YOUR EXPERIENCE 20+ YEARS* MATTERS

BeneFix®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

*BeneFix was approved February 11, 1997.

BeneFix®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

℞only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

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

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.

Pfizer

GO SEEK. GO EXPLORE.

GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.

Explore more at HEMLIBRAjourney.com

Discover your sense of go. Discover HEMLIBRA.

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. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA),** a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events),** which may form in blood vessels in your arm, leg, lung, or head

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
Revised: 10/2018

Genentech
A Member of the Roche Group

DEDICATION and PERSONAL SUPPORT

Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. We are committed to continuing Pfizer's more than 20 years of listening to the hemophilia community and working to meet its needs.

Chris Liddell

Southern OH, MI, KY, IN

"I've worked in rare disease for 15 years, and I have experience collaborating with and advocating for different members of this community."

PATIENT AFFAIRS LIAISONS

Pfizer Hemophilia

248-660-7384 chris.liddell@pfizer.com

MY WORK IS GUIDED BY:

Compassion

Listening to your needs and addressing questions and concerns that you may have

Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, the Coalition for Hemophilia B, and others

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Pfizer

Hemdifferently

Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information in a way you can understand.

Let's explore gene therapy together at **HemDifferently.com**

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

BIOMARIN®

60 Years of Service!

We are proud of our service to our bleeding disorders community. One of the most important things we do is to help the newly diagnosed and their families cope with all of the life changes that these disorders can cause. A few of the services we provide are:

- Bicycle helmets and other child safety items (soft shell helmets, knee pads, elbow pads)
- Emergency financial, transportation, and lodging assistance
- Medic alert emblems
- Scholarships for post-secondary education
- Cultural and recreational enrichment scholarships for children

Upcoming Events*

February 25
8th Annual Virtual Advocacy Day

March 27- April 3
Easter Lily and Spring Flowers Fundraiser (in person)

June 14
Golf Scramble (in person)

June 26
Family Day at the Louisville Zoo (in person)

July 15
Applications for post-secondary scholarships are due

July 25 – 29
Summer Camp (in person)

September 18
Annual Meeting (in person)

October 16
8th Unite Walk (in person)

December 4 -18
Poinsettia Fundraiser (in person)

December 5
Year-End Event (in person)

* All items scheduled are subject to change.

For more information, call KHF at 502-456-3233 or 1-800-582-CURE (2873) or send an email to info@kyhemo.org