FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

DID YOU SEE THIS?

As part of SWOHF's ongoing efforts to raise awareness and offer support to the community we arranged a reminder. Let us know if you catch a glimpse!

2021

ISSUE #1

SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION
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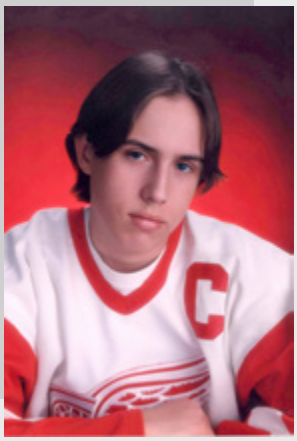
IN RECOGNITION: THE MILLERS

The Annual Meeting is a good time to recognize those who have made it their life's work to support the mission of the Southwestern Ohio Hemophilia Foundation. In doing so, we certainly didn't have to look far to recognize **the Miller family: Dick, Mary and Ellyn**. Inspired by their son Brad to make a better world for those affected by bleeding disorders, this family has served the community in untold and numerous ways. Most notable, Dick has served as the chairman for the Annual Birdie Busters Golf Outing, renamed in 2010 with Brad Miller as the namesake. Dick has served on the SWOHF board for over twenty years and he, along with his wife Mary and daughter Ellyn, have raised thousands of dollars to support education, research, and advocacy or the bleeding disorders community.

Thank you Miller Family! The SWOHF board honors you and in Brad's name we create the Brad Miller Memorial scholarship.



BRAD MILLER MEMORIAL SCHOLARSHIP

The **Brad Miller Memorial Scholarship** has been created to commemorate and remember an exceptional young man from the bleeding disorder community. Brad was born with severe hemophilia in 1979, a time when hemophilia treatment was less refined and many treatment products were ultimately found to be unsafe. These and other life issues contributed to the many challenges experienced by this scholarship's namesake. Throughout his 29 years, Brad held his head high and did his very best to live each day fully. Brad's immediate and extended family members supported him during his short life and continue to be active volunteers and mentors for the bleeding disorder community. Through this scholarship, Brad and his family's spirit of living and dedication to giving will continue to honor Brad and the entire bleeding disorder community for many years to come.

The SWOHF board and the members of the scholarship committee acknowledge the many challenges students face during their journey to complete a post-secondary educational program or beyond. It is hoped that the financial assistance provided by the Brad Miller Memorial Scholarship of $1,000 will help recipients continue their quest for knowledge and the attainment of their dreams.

The Brad Miller Memorial Scholarship is open to any person with a bleeding disorder diagnosis, i.e., hemophilia, von Willebrand disease or other inherited bleeding disorders, who receive treatment at Dayton Children's Hemostasis and Thrombosis Center. The applicant must be seeking post-secondary education at a university/college or technical school or be enrolled in a graduate school program.

The scholarship application and supporting documents must be submitted by July 12, 2021. The decision by the scholarship committee will be announced by July 30, 2021. Payment will be made directly to the student's university/college or technical school.

For more information about the application process, check our website for a list of requirements and to download the application form. The completed application and all supporting documentation should be submitted via email to joy@swohf.org by July 12, 2021.

SAVE THE DATE

2021 CALENDAR OF SWOHF EVENTS

APRIL

Genentech Educational Program - Hemlibra
Sunday, April 11
Virtual Event

JUNE

Sanofi Genzyme Educational Program - Joint Health
Tuesday, June 8
Virtual Event

Family Fest
June 25-26
Virtual Event

JULY

Bombardier Blood Movie
Thursday, July 29
Neon Theatre
Dayton, OH

SEPTEMBER

Bleeding Disorders Awareness 5K
Saturday, September 18

OCTOBER

Fall Outing - Young's Dairy
Sunday, October 10
Yellow Springs, OH

NOVEMBER

Women's Day
Saturday, November 13
The Golden Lamb
Lebanon, OH

TBD

New Family Event

Teen Event

Evening Out

At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team

PP-HEM-USA-1120-01

Printed in USA/November 2018

1st IN PERSON EVENT OF 2021

from Executive Producer
ALEX BORSTEIN

BOMBARDIER BLOOD

Join SWOHF for a special screening!

THURSDAY, JULY 29, 2021

THE NEON THEATRE (DOWNTOWN DAYTON)

CHECK OUR WEBSITE FOR MORE INFORMATION!

FAMOHIOInfo@gmail.com www.famohio.org 614-344-1075

FAMOHIO

2021 Conference

July 30th - August 1st

ADMIT ONE

Save the Date!

registration will open in mid May

Your ticket to the Virtual FAMOHIO 2021 Conference

FAMILY EDUCATION WEEKEND

FAMOHIO

2021

The Third National HTC Patient Satisfaction Survey is now open!

We need your voice and experience to tell us what we're doing right, and areas we need to improve!

Take the survey at www.htcsurvey.com or fill out and return the survey you received in the mail.

Surveys must be completed by June 30, 2021.

BOB has hemophilia A with inhibitors.

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

novo nordisk®

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

 Printed in the U.S.A. US18NSVN00126 January 2019

In hemophilia with inhibitors,

Bleeds happen:

Take control with NovoSeven® RT

Controlling bleeds, whenever they happen

- Proven effective to treat hemophilia A or B with inhibitors, at home and in the hospital

Safety supported by clinical trial data

- Low rate (0.2%) of blood clots[a]

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.

Visit NovoSevenRT.com today to learn more

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.

NovoSeven® RT
Coagulation Factor VIIa (Recombinant)

NOVOSEVEN® RT
Coagulation Factor VIIa (Recombinant)

Rx only

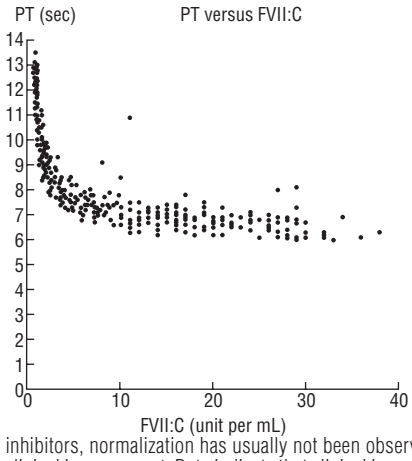
BRIEF SUMMARY. Please consult package insert for full prescribing information.

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)

SAVE THE DATE!

AUGUST 26-28, 2021

NHF's Annual Bleeding Disorders Conference is their signature event and highlights their strong commitment to education. Leading community members and experts on hemophilia and other bleeding disorders come together every year to present the most recent advances, exchange the latest science and discuss the newest clinical applications designed to improve patient care.

Through an extensive lineup of educational sessions for patients, medical provider, chapters, poster and oral communications, state-of-the-art lectures, exhibits and professional networking opportunities, the Conference promotes important advancement for the community.

This year's conference will be fully virtual to ensure the health and safety of all participants.

THANK YOU ANNUAL MEETING SPONSORS!

SPECIAL THANKS TO OUR GOLD SPONSOR:

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A Member of the Roche Group

CSL Behring
Biotherapies for Life™

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SANOFI GENZYME

WORKING TOGETHER

COVID FINANCIAL RELIEF FOR OUR COMMUNITY!

In response to their concern for those with bleeding disorders and the impact on our families due to COVID-19, the **Cascade Hemophilia Consortium** provided our chapter with $30,000 in grant funds to pay rent/mortgage/utilities or buy groceries for our families due to COVID-related loss of income or employment. This announcement was sent to all our members via email and SWOHF received a significant increase in Special Assistance request applications. [NOTE: If you aren't on our email list, you could be missing out on opportunities – please email office@swohf.org and we will update your info in our database for future email blasts.]

To date, SWOHF has used $21,000 of these funds to pay bills for over **35 families** in our Greater Dayton counties – this has improved the quality of life for **over 130 individuals** in our community.

Many families have struggled to keep up with monthly bills and reached out to SWOHF. Special thanks to our SWOHF Board for reviewing all requests.

> One mom's request: "I am a single mom and work 40 hours a week but have been unable to work since my kids have been sick. I cut all unnecessary expenses from my budget, but I am scared I won't be able to pay rent."
>
> Another family's situation: "My husband has been laid off for the last two months. My check doesn't cover much other than groceries and utilities."

All families have been grateful for this special assistance and expressed their appreciation to SWOHF.

> Here's one family's response: "Thank you so very much – I feel like crying tears of joy and am so very grateful."

The COVID-19 pandemic has had a tremendous impact across the globe both on the health and financial well-being of individuals and organizations. To help address this financial challenge for those affected by bleeding disorders and the local chapters that serve them, on June 19, 2020, the **National Hemophilia Foundation (NHF)** announced the launch of the "COVID-19 Relief Fund Bridge Grant Program."

Thanks to the combined financial investments of NHF and generous industry partners **(Pfizer, Sanofi Genzyme, and Genentech)** over 50 chapters have each received a $7,500 grant with this grant program. Additionally, **The Hemophilia Alliance Foundation** provided a matching contribution of $7,500 to fund critical program, service, and operational needs.

SWOHF is extremely grateful for the support of our national organizations and industry partners during these unprecedented days. Like other nonprofits, SWOHF's 2020 event/program income was limited, but expenses continued. The NHF Bridge funds were used to pay operational costs including SWOHF rent, internet/phone and salaries for 4th quarter 2020.

COVID-19 Grant funds were also received from **Novo Nordisk** and **BioMarin** for the purpose of Special Assistance and Education.

Special Assistance funds are still available. If you have suffered a financial set back due to Covid-19 please contact the office at joy@swohf.org


BAYER
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Pharmacokinetic (PK)
Study Data
See half-life, clearance and other PK data from the crossover study comparing Jivi® and Eloctate®.
Visit PKStudies.com to find out more.
Pharmacokinetics is the study of the activity of drugs in the body over a period of time.
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Jivi
antihemophilic factor (recombinant) PEGylated aucl
LET'S GO

ADVOCACY - WASHINGTON DAYS

Like so many other events of the past year, Washington Days were held in online meetings across the country the first week of March. Hemophilia Foundation staff and members of the bleeding disorders community filled the virtual halls of Congress to explain the needs and advocate for the changes we would like to see.

BLEEDING DISORDERS CONCERNS ABOUT AFFORDABILITY:

- Having access to and affording comprehensive insurance coverage.
- Paying their out of pocket (OOP) costs for treatment.
- Hitting their OOP limit, often in the first month.
- Needing financial assistance to afford their OOP costs.
- Policies to improve access to treatment and prohibit accumulator Adjustor Programs Ban co-pay accumulator adjustor programs. Ask for support of the McEachin-Davis letter to President Biden urging him to prohibit these programs.
- Improving access to coverage during COVID-19 Public Health Emergency.
- Support for the National Heart Lung and Blood Institute.
- Maintain current funding levels for Health Resources and Services Administration to ensure that HTC participation in the 340B program is maintained.
- Disorders.

HTC CORNER

DAYTON CHILDREN'S HTC IS VERY EXCITED TO WELCOME OUR NEW SOCIAL WORKER, DONNA CAIRES, LISW.

Donna started at Dayton Children's in January 2021 and is finishing her orientation to our HTC. Donna comes to us from Silver City, New Mexico where she worked as a clinical social worker. Donna has gained useful experience from multiple paths she has taken through life, extensive travels into different world cultures, various work experiences, and personal interests.

She desires to find a way to consolidate those experiences in a meaningful and effective way in service to others. She believes this path has prepared her well for this position. Donna states that the HTC landscape is rich with possibilities as she looks forward to putting together the ideas our team has started to develop. She looks forward to building relationships with the bleeding disorders community and regional programs for outreach while developing a comprehensive transition program for teens at Dayton Children's Hospital. She is excited about having an opportunity to engage in the development of new programs for our patients.

When asked what is the one thing she has learned through her life experiences that she wanted to share, she stated "We are all different and multifaceted in our backgrounds but fundamentally the same. We all have hearts, hopes, aspirations and we all face moments of vulnerability at some level. We undeniably need each other."

IN COLLABORATION WITH DAYTON CHILDREN'S HTC, SWOHF HAS RECENTLY SWITCHED TO A NEW PROVIDER FOR OUR MEDICAL ID'S.

We are happy to announce our partnership with American Medical ID. They offer a great variety of quality products at a discount to Chapters. Additionally, their Customer Service is exceptional, their shipping is fast and their prices are significantly less than MedicAlert (our previous supplier).

Free products are included with every order: An emergency medical ID card, a small ID charm and an exclusive engraved rectangular "InCase" phone ID that easily attaches to your cellphone case or any flat object, such as a suitcase, briefcase or laptop.

SWOHF is grateful for grant funding and donations that facilitate these purchases on behalf of our Greater Dayton Bleeding Disorders Community. So when you go to the HTC for your next visit, you can view sample products available and complete a form to request a new bracelet or necklace according to Chapter guidelines.

[Phone not included]

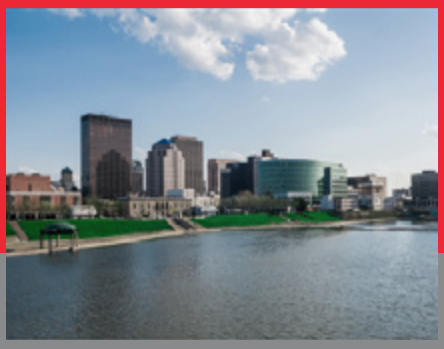
WELCOME

CHERYL COFFEY

TO THE

2021 SWOHF Board of Directors!

JOY@SWOHF.ORG



3131 SOUTH DIXIE DRIVE, SUITE 103
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937-298-8000

SWOHF
SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

CONTACT US

WE WANT TO HEAR FROM YOU!

MISSION STATEMENT

SWOHF helps improve the quality of life for those affected by hemophilia, von Willebrand disease, and other bleeding disorders by providing support education, networking, advocacy, and services to individuals, their families and the community.

EXECUTIVE DIRECTOR

Joy Linder

DISCLAIMER

The material provided in Factor Notes is for your general information only. SWOHF does not give medical advice or engage in the practice of medicine. SWOHF under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.

Southwestern Ohio Hemophilia Foundation
3131 South Dixie Drive, Suite 103
Moraine, OH 45439

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HEMOPHILIA FOUNDATION