

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

READY FOR CAMP?

For many children, camp is a first step toward independence and plays an important role in their growth and development. SWOHF partners with the Hemophilia Foundation of Michigan by sending children and young adults to camp in Michigan. Again in 2019, **there are scholarships available for camp so there is no cost to the family except a small registration fee!**

If you are interested in camp, contact Dayton Children's HTC as applications are completed in their office. You can talk to Cheryl Coffey at 937-641-5877 or Monica Dushane at 937-641-5045. They will work with SWOHF to provide camper/ travel scholarships. The last day to register is May 24, 2019!

Session 1: (Ages 6-9)
5 days, 4 nights (July 14-18, 2019)

Session 2: (Ages 10-12)
7 days, 6 nights (July 20-26, 2019)

Teen Camp: (Ages 13-17)
7 days, 6 nights (June 30-July 6, 2019)

For children with bleeding disorders, camp is a place where they can learn the valuable skills they need in order to become independent teens and adults. At Camp Bold Eagle, kids experience a traditional summer camp environment complete with archery, arts and crafts, canoeing, swimming in a lake, and nature walks. Campers and counselors stay in rustic cabins in the woods and eat meals together in the dining hall. Many children who meet at camp become lifelong friends and develop strong support systems.



2019
ISSUE #1

- P. 1 Ready for Camp?
- P. 2 Be Brave and Let Go
- P. 2 Save the Date
- P. 5 Advocacy Events
- P. 6-7 NHF's Bleeding Disorders Conference
- P. 10 SWOHF Women: Community Connections
- P. 11 HTC Corner

SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

3131 S. Dixie Dr., Ste. 103
Moraine, OH 45439

P: (937) 298-8000
www.swohf.org

F: (937) 298-8080
info@swohf.org



FOR MORE INFO ABOUT
CAMP BOLD EAGLE,
check their website
<https://hfmich.org/camp>

FOR MORE INFORMATION ABOUT CAMP FROM A
PARENT'S PERSPECTIVE, TURN TO THE NEXT PAGE!

BE BRAVE AND LET GO

By Debra Kremer-Smith, SWOHF Board Secretary



The camp adventure is a milestone for kids and mothers. **I encourage all families to participate in the wonderful camp experience.** You can be sure your children are in excellent hands. There are experienced doctors and nurses at camp to care for and educate the campers. Their goal is to educate and empower kids with bleeding disorders to live a life of freedom and independence.

About 40 years ago, I experienced hemophilia camp from a sister's perspective when my brothers went off to camp one summer. Back then, our day-to-day lives were always arranged around my brothers' hemophilia. My sister and I thought we "had died and gone to heaven" when my two brothers left home for one glorious week to attend camp. I do remember my Mom being nervous about letting go though.

Then when I became a mom, it was my turn to practice the art of letting go when our boys were ready for camp. Our son Paul went to camp pretty fearlessly. As a nurse, I knew teaching him to self-infuse would be tough. I trusted the awesome reputation that Camp Bald Eagle has,

but it was still intimidating to send Paul off to camp. He loved it though -- and for months we would hear him singing camp songs at random times.

One year both our sons, Paul and Dean, were able to go to camp together. This scenario made Mom's "letting go" much easier as Dean was only six years old at that time. They both earned the coveted "Butterfly Award" which is given to campers who have successfully learned to self-infuse. It was very empowering for them to learn the skill of sticking themselves (this way they did not have to endure Mom's teaching).

My advice to parents: The rewards are many! Be brave and let go!!

SAVE THE DATE

2019 CALENDAR OF SWOHF EVENTS

MARCH

OBDC Statehouse Day

Wednesday, March 13
Columbus, OH

MAY

Evening Out Casino Night

Friday, May 10
Dayton Woman's Club
Dayton, OH

JUNE

Family Fest

June 14-16
Higher Ground Retreat Center
West Harrison, IN

AUGUST

FAMOHIO

August 2-4
Columbus, OH

Brad Miller Birdie Busters Golf Outing

Thursday, August 15
Beavercreek Golf Club
Beavercreek, OH

SEPTEMBER

Bleeding Disorders Awareness 5K

Saturday, September 21
Rice Field
Miamisburg, OH

OCTOBER

Fall Outing

Sunday, October 13
Young's Dairy
Yellow Springs, OH

NOVEMBER

Women's Day Together

Saturday, November 9

BUY TICKETS
ONLINE NOW
FOR BONUS
CHIPS!!





FEEL EMPOWERED
to step up to the challenge
with **Jivi[®]**

Are you ready to see what Jivi offers?
Visit www.explorejivi.com to learn more.

Ask your doctor if Jivi may be right for you.

© 2019 Bayer. All rights reserved. Bayer, the Bayer Cross and Jivi are registered trademarks of Bayer.

Printed in USA 02/19 PP-JIV-US-0467-1

Jivi[®]
antihemophilic factor
(recombinant) PEGylated-auct

LET'S GO



Your dreams. Our dedication.

At Shire we are driven to help improve the lives of members of the bleeding disorders community. You inspire us. Each pioneering new product and program represents another step toward our ultimate goal: **a life full of dreams and free of bleeds.**

Michelle
vWD
Nevada



bleedingdisorders.com

Your Health. Your Voice. Our Future.

ADVOCACY EVENTS



OHIO BLEEDING DISORDERS COUNCIL STATEHOUSE DAY: MARCH 13, 2019

- REGISTRATION is now open at www.ohioobdc.org for individuals who are interested in attending. Please inform the SWOHF office if you want to meet up with us in Columbus, Ohio. Hotel rooms and travel stipends are available on a limited basis -- contact the SWOHF office for more details. <https://obdc2019statehouseday.eventbrite.com>

- On Tuesday, March 12 (the night before Statehouse Day) there will be a dinner presentation which will include training and teaching everyone what to expect when they meet with their legislators. As a SWOHF advocate, you will be given information so you are prepared to talk about the issues important to the bleeding disorder community in Ohio.

- **Ohio Bleeding Disorders Council: "Ohioans working together to ensure and enhance the quality and accessibility of comprehensive care and services for children and adults with hemophilia and related bleeding disorders through information sharing, public education and advocacy."**

- *PHOTO: SWOHF Advocates pictured with Senator Peggy Lehner, who is the State Senator for the 6th District of the Ohio Senate which includes Kettering and parts of Montgomery County.*

NHF'S BLEEDING DISORDERS CONFERENCE

OCTOBER 3 - OCTOBER 5, 2019
ANAHEIM, CALIFORNIA



2019 REGISTRATION IS OPEN!

Each year the Southwestern Ohio Hemophilia Foundation budgets to send at least two families to this NHF Conference. SWOHF will pay for transportation and lodging for one affected individual and a second immediate family member to attend. Individuals who receive Conference funds agree to be interviewed about their experience for our newsletter or speak at the SWOHF Annual Meeting.

If you are interested in attending, please email kay@swohf.org for an application form by May 1, 2019.

*You will be responsible for Conference registration fees but you can apply for a waiver from NHF. SWOHF Board will review all applications. If numerous individuals express interest in attending, a drawing may be held to determine who will receive the funding.

A few things to look forward to at this year's conference:

- A full track for rare factor deficiencies
- Sessions to improve your infusion technique
- A three-day track for teens and young adults

SWOHF Travel Scholarship winners for 2018 were:

- Paxton Bostater, accompanied by his dad Steve
- Chloe Henninger, accompanied by her mom Wanda
- Allison Shawen, accompanied by her mom Amber
- Mitchell Zeiter, accompanied by his mom Carole

MEMORABLE & MEANINGFUL: THOUGHTS ABOUT THE 2018 NHF CONFERENCE FROM SWOHF FAMILIES

Amber Shawen said, "During the hemophilia conference we learned so much. Watching my family smile was such a blessing -- everyone made them feel welcome. We are very thankful and blessed."

Allison (age 11) loved all the hands-on projects and meeting kids her age she could relate to.

Preston said, "I didn't realize all the work my wife does for the kids." He really enjoyed learning more about the "behind-the-scenes" for bleeding disorders.

Bentley (age 8) loved when our SWOHF table joined together and made different shapes for marbles to go through the tubes.



Here's what Carole had to say about the conference:

Attending this conference allowed us to engage in meaningful and memorable conversations with individuals with bleeding disorders as well as meeting Kay and families right from our chapter!

The exhibit halls provided Mitchell a time to ask questions and partake in discussions.

I was intrigued by the "My Life, Our Future" Advancing in Medicine. Since Mitchell had enrolled in this program, it was interesting to learn about the investment and research presented.

Wrapping up our time Saturday morning at the "Living with Gratitude" symposium to support the Bostater family (with Jenny as one of the guest speakers!) reminded Mitchell and me that we too are grateful and thankful for our local chapter and bringing these families together for this event.

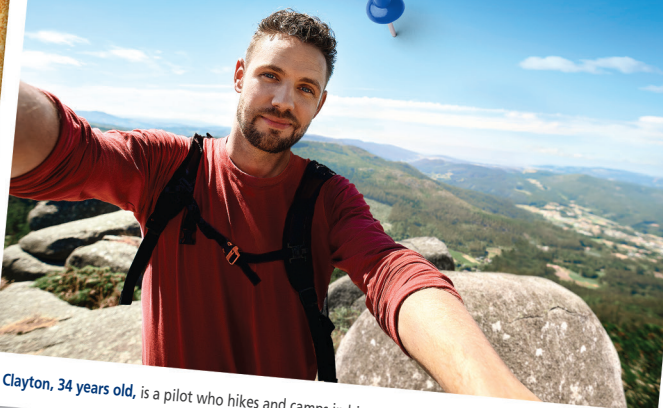


SWOHF WINS \$\$\$

Thanks to Paxton and the Bostater family playing an insane amount of Hemophilia Trivia, our chapter won \$1500 in the Bioverativ Wheel of Gratitude Chapter contest. It was so close in the end -- Oregon came in 1st with 6280 points and SWOHF came in 2nd with 5950 points. **Way to go, Paxton!**



In hemophilia B
**TAKE CONTROL TO A
HIGH LEVEL
WITH REBINYN®**



Clayton, 34 years old, is a pilot who hikes and camps in his spare time. Clayton lives with hemophilia B.

Rebinyn® elevates factor levels above normal levels^a

+94% Factor IX (FIX) levels achieved
immediately after an infusion^b

17% FIX levels sustained
after 7 days^a

With a single dose of Rebinyn® 40 IU/kg in adults with $\leq 2\%$ FIX levels^a

^aIn two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebinyn® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years.

Image of hemophilia B patient shown is for illustrative purposes only.

^bBased upon a 2.34% increase in factor levels per IU/kg infused in adults.

INDICATIONS AND USAGE

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

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for routine prophylaxis or for immune tolerance therapy.

IMPORTANT SAFETY INFORMATION

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

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

Who should not use Rebinyn®?

Do not use Rebinyn® if you:

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

What should I tell my health care provider before using Rebinyn®?

Tell your health care provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

How should I use Rebinyn®?

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

What are the possible side effects of Rebinyn®?

- **Common side effects include** swelling, pain, rash or redness at the location of the infusion, and itching.
- **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- **Tell your healthcare provider about any side effect that bothers you or that does not go away.**
- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

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

Rebinyn® is a prescription medication.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Learn more at rebinyn.com



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

Rebinyn® is a registered trademark of Novo Nordisk Health Care AG.

Novo Nordisk is a registered trademark of Novo Nordisk A/S.

© 2018 Novo Nordisk All rights reserved. USA18BIO00594 August 2018

rebinyn®
Coagulation Factor IX
(Recombinant), GlycoPEGylated

rebinyn[®]

Coagulation Factor IX (Recombinant), GlycoPEGylated

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

Rx Only

This information is not comprehensive.

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

Read the Patient Product Information and the Instructions For Use that come with REBINYN[®] before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN[®] after reading this information, ask your healthcare provider.

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

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

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

What is REBINYN[®]?

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

REBINYN[®] is used to treat and control bleeding in people with hemophilia B.

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

REBINYN[®] is not used for routine prophylaxis or for immune tolerance therapy.

Who should not use REBINYN[®]?

You should not use REBINYN[®] if you

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

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

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

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

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor IX.

How should I use REBINYN[®]?

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

REBINYN[®] is given as an infusion into the vein.

You may infuse REBINYN[®] at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to

infuse the medicine by themselves or with the help of a family member.

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

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

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

Use in children

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

If you forget to use REBINYN[®]

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using REBINYN[®]

Do not stop using REBINYN[®] without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much REBINYN[®]?

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

What are the possible side effects of REBINYN[®]?

Common Side Effects Include:

- swelling, pain, rash or redness at the location of infusion
- itching

Other Possible Side Effects:

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

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

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

Animals given repeat doses of REBINYN[®] showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

These are not all of the possible side effects from REBINYN[®]. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

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

What are the REBINYN[®] dosage strengths?

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

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

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

How should I store REBINYN[®]?

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

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

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

If you choose to store REBINYN[®] at room temperature:

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

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

After Reconstitution:

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

The reconstituted REBINYN[®] should be used immediately.

If you cannot use the reconstituted REBINYN[®] immediately, it should be used within 4 hours when stored at or below 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about REBINYN[®] and hemophilia B?

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

More detailed information is available upon request.

Available by prescription only.

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

Revised: 11/2017

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

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

Manufactured by:

Novo Nordisk A/S

Novo Allé, DK-2880 Bagsværd, Denmark

For information about REBINYN[®] contact:

Novo Nordisk Inc.

800 Scudders Mill Road

Plainsboro, NJ 08536, USA

© 2017 Novo Nordisk

USA17BI003951 12/2017



novonordisk[®]



SWOHF WOMEN: COMMUNITY CONNECTIONS



CARING FOR ME: SELF-CARE AND DE-STRESS DAY

Over 20 women enjoyed our first SWOHF Women’s Day Together on November 10, 2018, at The Golden Lamb. Our speaker on the importance of self-care for busy women was Ann LeWalk, VP Communications HFA.

Comments included:

- “very helpful and positive”*
- “I enjoyed that it was specific to women”*
- “I enjoyed getting to know people in the community”*
- “Met a lot of wonderful women and new friends”*
- “Ann gave us great information as well as practical skills and exercises to relieve stress”*

We had a delicious luncheon, enjoyed activities around the tables, made a fall craft and awarded door prizes to attendees. Every woman also received a goody bag with essentials for self-care.

A special “Thank You” to Ellen Poti for a donation allowing SWOHF to give each woman a special gift. Ellen said, “It’s about time we have a day just for women!” And so together we took time to settle in, time to connect, time to focus, time to listen, time to refuel, time to create, time to reflect, time to celebrate and time to shop!

Thanks to HFA for a wonderful time together, learning and encouraging one another.

Don’t miss out on 2019 Women’s Day Together! Mark your calendar for Saturday, November 9, 2019, at The Golden Lamb in Lebanon, Ohio.

HTC CORNER

Article contributed by **Sandra Hibner**
MSN, RN-BC, Coagulation Resource Nurse, Hematology Research Coordinator

COMMON QUESTIONS ASKED ABOUT VON WILLEBRAND DISEASE (VWD)

What is VWD?

VWD is a hereditary bleeding disorder caused by the decreased production or the decreased function of the Von Willebrand factor (VWF).

Persons with VWD produce less VWF or produce a molecule that does not function normally.

What is Vwf?

VWF is a protein that is necessary for normal blood clotting. People with VWD do not bleed any faster than those who do not have VWD, however it may take longer for effective clotting to occur.

Will it help if I eat foods that are high in protein?

While eating high protein foods may improve one's nutritional status, it will not increase one's level of VWF.

Is VWD rare?

VWD is the most common bleeding disorder with worldwide distribution.

It is estimated that 1-3 % of the population is affected.

Any advice for those who have VWD?

Be prepared for the unexpected by having your medication available. Please check the expiration date on your StimatTM Nasal Spray. The expiration date is located both on the top of the box and the bottle label.

Call the Dayton Children's Hospital Hemophilia staff if a refill is needed. Cheryl and Melissa can be reached at 937-641-3111. Normal business hours are Mon-Fri 8:30 AM to 5:00 PM. Please call one week before a new bottle is needed. StimatTM may need to be ordered by your pharmacist and most insurance providers require pre-authorization. These particulars take additional time to complete.



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.

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

Kay Clark

SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

3131 South Dixie Drive #103

Moraine, OH 45439

P: (937) 298-8000 F: (937) 298-8080

www.swohf.org info@swohf.org



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



SWOHF
Southwestern Ohio Hemophilia Foundation