FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

2021
ISSUE #3

BLEEDING DISORDER AWARENESS 5K

THE 11TH ANNUAL BLEEDING DISORDER AWARENESS 5K IS JUST A FEW SHORT WEEKS AWAY.

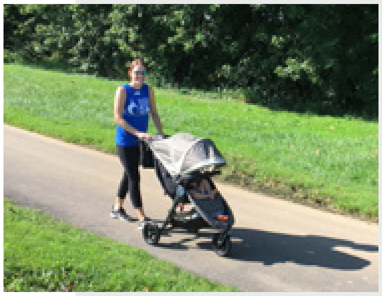
BUY ONE GET ONE FREE

Please join the **Southwestern Ohio Hemophilia Foundation** on **Saturday, September 18th at 9:00 am** for our Annual 5k Walk/Run for Bleeding Disorder Awareness. Registration is only $25 per person and includes bib, timed finish and t-shirt. We would love for you to come be a part of making a difference in the lives of those dealing with blood disorders like hemophilia and von Willebrand's disease as we walk or run our way to victory!

Cascade Hemophilia Consortium is once again sponsoring a **BOGO** in 2021! For every person you sign up another walks for free. This is an **early registration benefit**, so don't forget to **sign up by September 8th**! What a great opportunity … for $25.00 two people can participate. We will be meeting at the beautiful Rice Field-Bike Path at 2001 Dayton-Cincinnati Rd. in Miamisburg, registration begins at 9:00 am.

There will be race awards for the first place male and female in each age category and the *You Make a Difference* award for the person displaying the most enthusiasm and commitment to raising awareness. Don't neglect to add this special event to your fall plans. Can't wait to see you soon!

Register online: https://bleedingdisorderawareness5k.itsyourrace.com



BLEEDING DISORDER AWARENESS
RUN | WALK 2021
5k
Walk / Run for Bleeding Disorder Awareness

SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION
3131 South Dixie Drive, Suite 103
Moraine, OH 45439

P: (937) 298-8000
F: (937) 298-8080
www.swohf.org
joy@swohf.org

SCHOLARSHIP RECIPIENT

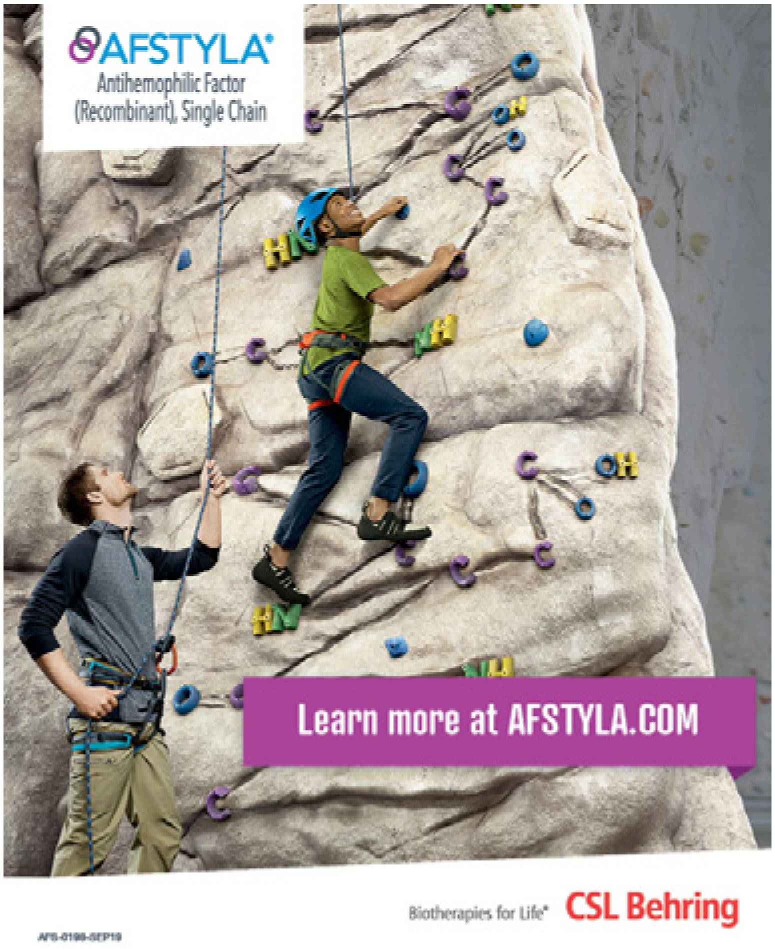
The Southwestern Ohio Hemophilia Foundation (SWOHF) scholarship committee proudly announces, **Chloe Henninger**, as the 2021 recipient of the **Brad Miller Memorial Scholarship**. This first annual award of $1,000.00 is awarded to Chloe to aid her in the cost of post secondary education.

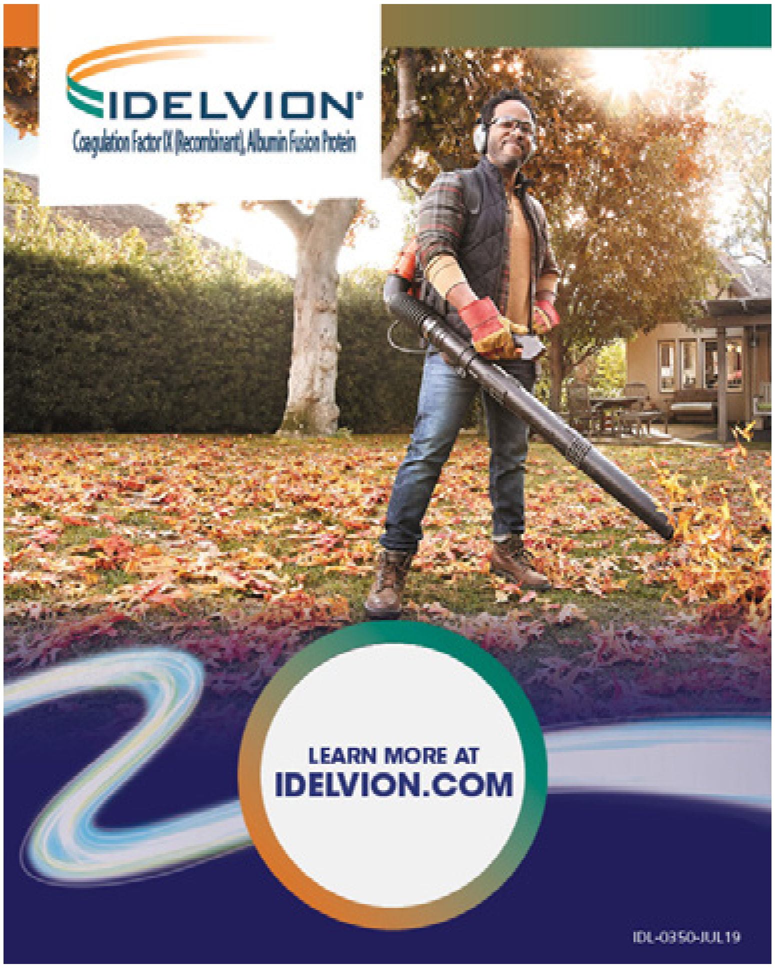
Chloe has chosen education as her major and strives to become a kindergarten teacher. Helping young children learn is her passion. Chloe credits her experience as a counselor in training at *Camp Bold Eagle* as the impetus that helped her discover this love of working with younger children. *Camp Bold Eagle*, founded in 1969 was the first summer camp for children with bleeding disorders (https://hfmich.org/our-story-story/).

Acknowledgment of this passion keeps Chloe on track as she works diligently on her educational preparation. Currently attending Edison State University, Chloe will transition to Wright State University for the Spring Semester 2022.

The Brad Miller Memorial Scholarship originated to honor the late Brad Miller. Brad was born with severe hemophilia and suffered many of the devastating side-effects of the disorder and treatment. Brad lived a very full life and was a hero to many especially his family and friends. The recipients of his scholarship honor his life and legacy by working hard at their educational goals.

The Brad Miller Memorial Scholarship will be awarded annually. All members of the SWOHF who are affected with a bleeding disorder and are attending a post-secondary college/university or trade school are eligible to apply. The timeline and specifics of the application process will be detailed in the SWOHF newsletter, Factor Notes, in the first issue of 2022. The scholarship committee thanks all who applied and wishes each great success in their endeavors.





SWOHF FALL EVENTS

October 10
Fall Outing
Young's Dairy Farm in Yellow Springs
Join us for a fun afternoon at the farm

November 13
Women's Day Together
A connecting time for just the ladies
at The Golden Lamb in Lebanon

Check www.swohf.org/programs-events for more info

AMAZONSMILE

If you are an Amazon shopper, please consider supporting SWOHF every time you purchase from Amazon through AmazonSmile.

To shop at AmazonSmile simply go to smile.amazon.com from the web browser on your computer or mobile device. Search "Hemophilia" and scroll down to find Southwestern Ohio Hemophilia Foundation or type in "Southwestern Ohio Hemophilia" and select SWOHF as your charity.

Support us with amazonsmile
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AmazonSmile

Bookmark AmazonSmile

Create a bookmark or shortcut to smile.amazon.com and always start your Amazon search by typing in smile.amazon.com

KROGER COMMUNITY REWARDS

Did you know you can support our SWOHF community just by shopping at Kroger? It's easy when you enroll in Kroger Community Rewards! To get started, sign up at krogercommunityrewards.com with your Kroger Plus Card and enter our number **#78558** as your organization. Once you've enrolled, you'll earn rewards for SWOHF every time you shop at Kroger and use your Plus Card!

Kroger is committed to helping our communities grow and prosper. Year after year, local schools, churches and other nonprofit organizations earn millions of dollars through Kroger.

Kroger community rewards

TAKE CONTROL TO A HIGH LEVEL

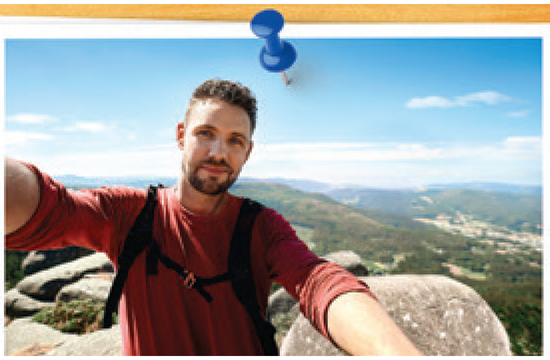
WITH REBINYN®
IN HEMOPHILIA B

Rebinyn® elevates factor levels above your normal levels[a]

+94% Factor IX (FIX) levels achieved after an infusion[b]

83-hr (3.5 day) average half-life in adults[a]

With a single dose of Rebinyn® 40 IU/kg in adults with ≤2% FIX levels[a]



Clayton, 34 years old, is a pilot and enjoys hiking and camping in his spare time. Clayton lives with hemophilia B.

Achieve higher factor levels for longer

Compared with Alprolix®[c], Rebinyn® provides

4x greater factor coverage

6x higher factor levels at 7 days

Image of hemophilia patient shown is for illustrative purposes only.

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[a] In a phase 3 study of adults, single dose pharmacokinetics were tested during the first Rebinyn® 40 IU/kg dose in 6 adults.

[b] Based upon a 2.34% increase in factor levels per IU/kg infused in adults.

[c] Based upon a phase 1 study comparing a single 50 IU/kg dose of Rebinyn® to a single 50 IU/kg dose of extended half-life rFIXFc in 15 adults. To allow for direct comparison between products, all patients received the Alprolix standard 50 IU/kg dose.

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 and connect with your local HCL

novo nordisk®

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

Printed in the U.S.A. US19REB00028 July 2019

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 86ºF (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

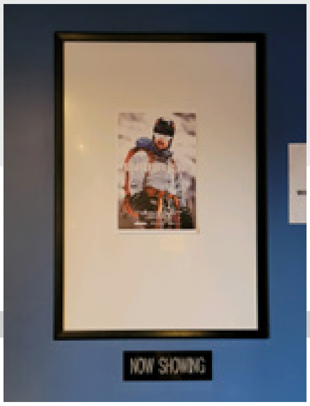
Manufactured by:
Novo Nordisk A/S
Novo Allé, DK-2880 Bagsværd, Denmark

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

USA17BIO03951 12/2017

novo nordisk®

from Executive Producer
ALEX BORSTEIN
BOMBARDIER BLOOD



MOVIE SCREENING:

BOMBARDIER BLOOD

In July, we finally were able to host the Bombardier Blood. Our much awaited first in person gathering. The Movie Screening was presented by Octapharma and shown at The Neon. Several of our families attended and were able to view the story of Chris Bombardier, hemophilia patient and advocate for those living with bleeding disorders across the globe. It was a powerful message of the importance of access to life saving products for impoverished and remote countries. Chris shared the story of his life managing hemophilia. The message of his journey to climb the seven summits and to bring awareness to the world, was truly inspirational. It was an emotional evening in which we watched the struggles and the triumphs of his achievement.

Octapharma sponsored our night with appetizers and free popcorn to donors of Chris's charity, Save One Life. It was a beautiful evening of being together and a glimpse of what it is like to walk in another's shoes or in this case boots. Donations can still be made at saveonelife.net

octapharma®

CELEBRATING
2001 2021
SAVE ONE LIFE
20 YEARS

REMEMBERING A DEAR FRIEND

It is with heavy hearts that we share that our hemophilia community lost a dear friend. Tanya Hunnewell passed away on March 13, 2021. She was an active member of the Southwestern Ohio Hemophilia Foundation, FamOhio and Hemophilia B networks. She attended many educational events, community nights and social gatherings.

Tanya not only participated, she was an amazing volunteer. She volunteered on the Family Fest committee, at the annual Brad Miller Birdie Buster Golf Outing, the Fall Outing, the Bleeding Disorder Awareness 5K and spent time helping in the SWOHF office. Tanya was an advocate for her family and for all those with bleeding disorders. She advocated at the national level at Washington Days. Tanya was recognized many times for volunteering and was named SWOHF volunteer of the Year in 2016. Although she was very humble and did not like the recognition, she wanted to be an example for her children, grandchildren and the hemophilia community.

Tanya always made everyone feel welcome and cared for. Tanya's kindness, empathy and authenticity drew people to her. We are grateful for her presence in our lives and the impact she made. Tanya will be deeply missed by all. She leaves behind her loving husband Bill, children, Krystal, Brad, and Zach and her grandchildren.

A wonderful volunteer is
hard to find
difficult to part with
and
impossible to forget.

A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.

HOW DOES THIS FACTOR IN?

To find out about a prescription option, talk to your doctor or visit **OnceWeeklyForHemophiliaB.com**

February 2021

Pfizer

COVID SPECIAL ASSISTANCE

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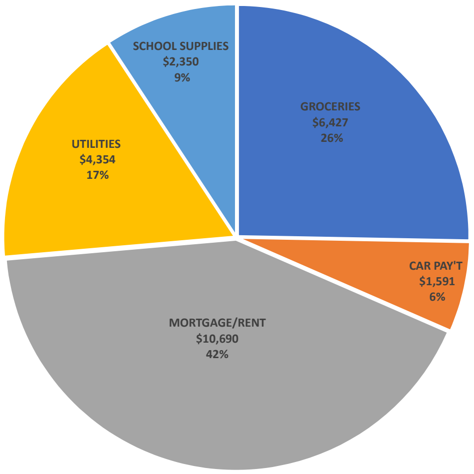
In 2020, SWOHF received grant funds specifically for those affected by COVID. **To date, SWOHF has disbursed over $25,000 to families in need.**

Continued SPECIAL THANKS to Cascade Hemophilia Consortium, The Hemophilia Alliance Foundation, National Hemophilia Foundation (including Pfizer, Sanofi Genzyme, Genentech), NovoNordisk and BioMarin for their generosity during these difficult days.

ASSISTANCE DISBURSEMENTS BY CATEGORY



CASCADE HEMOPHILIA CONSORTIUM

THE HEMOPHILIA ALLIANCE

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

2021 VIRTUAL SYMPOSIUM

After the challenges of 2020, HFA will address the current issues facing parents, adult men and women, young adults, and kids in our bleeding disorders community.

The HFA team is bringing you the latest information on medicine and technology, mental health care, Spanish resources, access to financial resources, barriers to care, and so much more. This year, symposium has its own website, https://www.hfasymposium.org

TO OUR SWOHF FAMILIES:

Thank you for participating in our Education Weekend ! See you next year!

FAMOHIO

Hemophilia Federation of America's

STATE OF THE STATES

Connecting You to the Latest from Your State Capitol

ADVOCACY:

NATIONAL ADVOCACY NEWS

On June 17th, the U.S. Supreme Court handed down its long-awaited decision in *California v. Texas*, a case challenging the constitutionality of the Affordable Care Act The Court's decision leaves the ACA intact and keeps the law's benefits in place.

On July 1, the Administration issued a first set of rules implementing patient protections under the No Surprises Act. Beginning next year, patients will be protected against "surprise" medical bills when they inadvertently get services from out-of-network providers.

For more information and details, visit Hemophiliafed.org News & Perspectives

STATE ADVOCACY UPDATES

Six new states enact prohibitions against copay accumulator adjusters

Bills preventing health plans from using the cost-sharing assistance provided by manufacturers or non-profits were signed into law this session in six additional states. The victories in Arkansas, Connecticut, Kentucky, Louisiana, Oklahoma and Tennessee. **Similar legislation remains pending in Michigan, North Carolina, Ohio, Pennsylvania, and Wisconsin.**

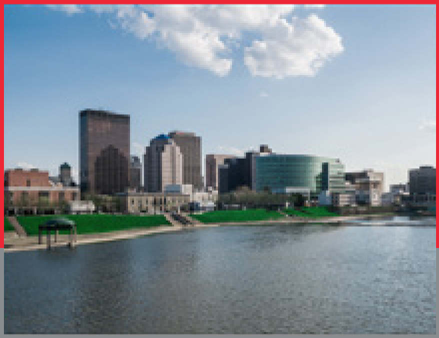
Three states enact consumer protections from step therapy

Arizona, Nebraska and Oregon enacted new laws to protect consumers from the use of step therapy or "fail first" protocols by state-regulated health plans. Step therapy is used by insurers to require a patient to fail on a lower-cost drug therapy before access to the higher-cost therapy prescribed by their physician. It is exceptionally inappropriate for those with bleeding disorders.

Three states create Rare Disease Advisory Councils

Legislation was enacted last quarter to create Rare Disease Advisory Councils (RDACs) in three new states. The victories in Florida, Louisiana and South Carolina brings to 20 the number of states that established RDACs since North Carolina. RDACs are advisory bodies including legislators, providers, patients and patient advocacy organizations, and industry representatives that help ensure the concerns of the rare disease community are heard by state policymakers.

JOY@SWOHF.ORG



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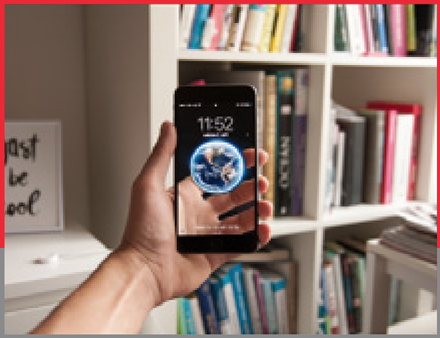
MORAINE, OH 45439



937-298-8000

SWOHF
SOUTHWESTERN OHIO
HEMOPHILIA FOUNDATION

CONTACT US

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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.

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