

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

NOT ALL HEROES WEAR CAPES!

At age eight, Elise VanBibber has already shown that her support goes above and beyond that of a typical big sister. In her little brother's eyes, she is a superhero! Elise's brother, Timothy, was diagnosed with Type A, Severe Hemophilia when he was three days old. As she adjusted to her role of big sister and learned more about her brother's bleeding disorder, she decided that not enough people know what Hemophilia is and "that is not okay." She started making bracelets and keychains, selling them for \$3 each. The family thought it would just be a few friends and extended family who supported her efforts via her mom's Facebook posts. Then Elise had the idea to set up a table at Northmont Farmers Market on Sundays where her mom sold baked goods. She also was cheering for The Vandalia Wee Aviators so she sold bracelets at the football field at Smith Middle School. She helped raise funds for their family 5K team "Timothy's Iron Man Army" and earned the "Red Tie award" at our 5K Event for her extraordinary efforts in creativity, team-building and overall SWOHF spirit! What a wonderful sister, supporter and fundraiser! Way to go, Elise!



SWOHF WELCOMES NEW STAFF

The Southwestern Ohio Hemophilia Foundation is pleased to welcome our new Executive Director, Kay Clark. Kay has worked in the health care field in various roles including Insurance Billing, Practice Management Software, Medical Records and Front-Office manager at Cedarville University Medical Services. She is married to high school sweetheart, Paul, and lives in Beavercreek. She enjoys reading, puzzles and spending time with her family, especially her two grandchildren. Kay is pleased to join Alison Shofner in the SWOHF office in Moraine. Feel free to contact Kay or Alison during normal business hours Monday through Friday.



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Winter 2017



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

SHOUT OUT!

A big thank you to The Ohio Painting Company who donated their services to paint our Moraine office earlier this month! They did a fantastic job – fast, professional, friendly! Please consider contacting Kevin for your next painting job. We appreciate their support and generosity to SWOHF!

(937) 409-4443
Centerville, Ohio
www.theohiopaintingcompany.com
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& SPEAKING of PAINTING...

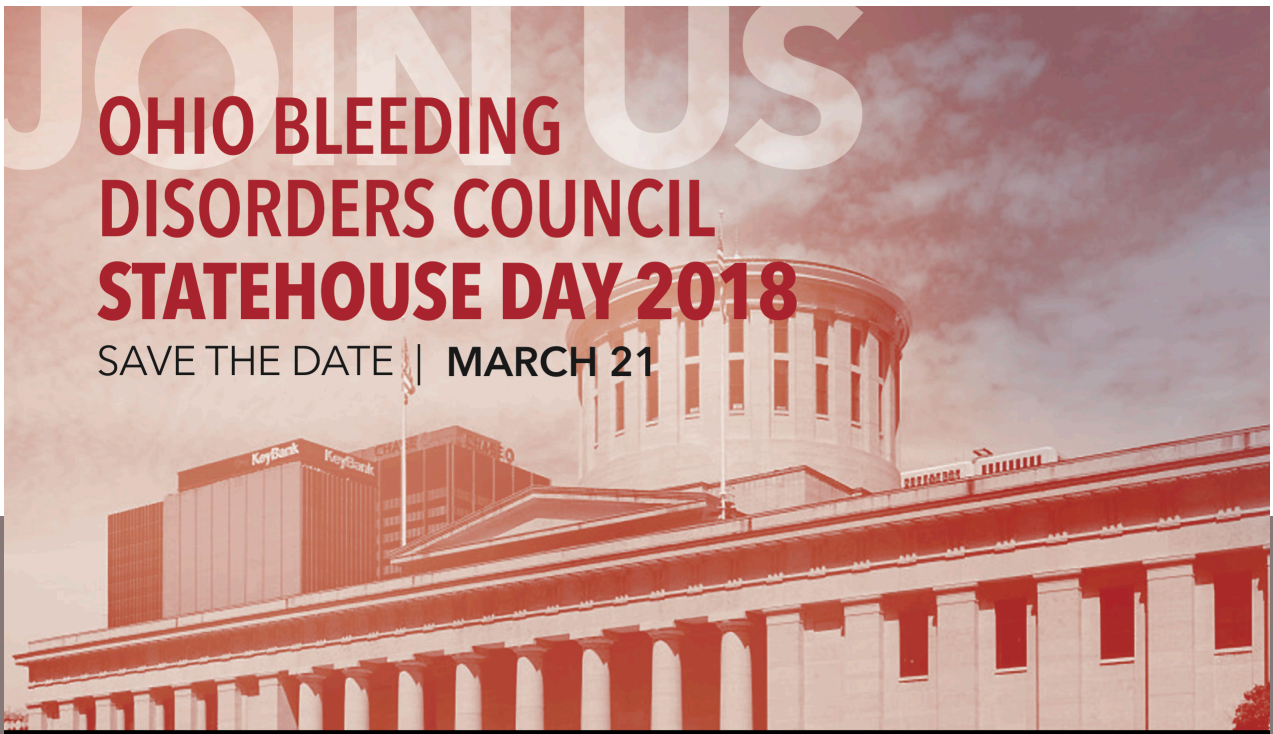
Check out our very own SWOHF artists!



“Laughing Through Stress” attendees pose proudly with their masterpieces at Painting With a Twist in Centerville.



CSL Behring recently sponsored a “Laughing Through Stress” night out for women caregivers at Painting with a Twist in Centerville, Ohio. We enjoyed a delicious dinner followed by a speaker, Lori Kunkel, who shared her story as a mom/caregiver of two sons with hemophilia. She challenged us to keep a sense of humor even in times of difficulty and then we got a chance to practice our painting skills. It was a fun and stress-relieving event and we appreciate Gwen (CSL Behring) for putting that together for our SWOHF community.



OHIO BLEEDING DISORDERS COUNCIL STATEHOUSE DAY 2018

SAVE THE DATE | MARCH 21

Each year, the Ohio Bleeding Disorders Council hosts Statehouse Day, where people affected by bleeding disorders educate their state elected officials about issues important to the Ohio bleeding disorders community. **Join us and let your voice be heard.**



OHIO BLEEDING DISORDERS COUNCIL STATEHOUSE DAY 2018

WEDNESDAY, MARCH 21ST
Columbus, Ohio

Dinner and training will be provided on Tuesday, March 20th.

Registration will open in February. Please visit www.ohiobdc.org for registration information.

For more information, contact Randi Clites at 330-730-1259 or randiobdc@gmail.com.

Hotel rooms and travel stipends available upon request with priority given to new attendees and those driving more than 60 miles.

DEDICATION AND PERSONAL SUPPORT

The Patient Affairs Liaison role was created based on community feedback about the importance of helping to connect patients and caregivers with Pfizer Hemophilia tools and resources.



Working for you—From the home of Motown to the Bluegrass State

Name: *Chris Liddell*

Home state: *Michigan*

Fun fact: *If I'm watching TV, it's most likely sports-related. Go Tigers!*

Ideal vacation spot: *Anywhere quiet, unplugged from all electronics*

What past experiences can you bring to this job? *I've worked in hemophilia for over 10 years, so I've collaborated with and advocated for different members of this community.*



**To get in touch with Chris, call
Pfizer Hemophilia Connect 1.844.989.HEMO(4366)**

What we do:

- ✓ Provide helpful information about Pfizer Hemophilia programs and services
- ✓ Serve as a resource to hemophilia treatment centers to help patients obtain access to Pfizer medicines
- ✓ Serve as a primary point-of-contact for local advocacy groups
- ✓ Participate in local and national events and programs
- ✓ Upon request, meet with patients and caregivers to answer questions related to Pfizer Hemophilia resources

“IT’S IMPORTANT TO CONNECT ON ALL LEVELS: HTC’s, PATIENTS, FAMILIES, THE WHOLE COMMUNITY.”

—Chris Liddell



Finish Line Firsts for Awareness!



1st Overall: Nicolas Brown with a time of 22:54 (7.23/mile)

Thanks to all who came out in support of our 2017 Bleeding Disorder Awareness 5k! It was a hot and humid September morning, but 109 individuals registered to walk or run and it was great to see so many family teams participating. What a great way to show support of the SWOHF community and our individual family members!

Other 1st Place results by Age Groups (youngest to oldest)

- | Male: | Female: |
|-----------------|----------------|
| Paxton Bostater | Georgia James |
| Nicholas Brown | Ashley Brown |
| Kevin Bostater | Laura Perry |
| Steve Bostater | Jenny Bostater |
| Steven Brown | Katie Justice |
| Greg Williams | Donna Elson |

SAVE

THE DATE

2018 SWOHF Calendar of Events

March

Annual Meeting
Saturday, March 3
Sulphur Grove UMC
Huber Heights, OH

NHF Washington Days
Wednesday, March 7 - Friday,
March 9
Washington, DC

OBDC Meeting
Tuesday, March 20

Ohio State House Days
Wednesday, March 21

April

Evening Out
Friday, April 20
Dayton Women's Club
Dayton, OH

June

Family Fest
Friday, June 22 - Sunday, June 24
Higher Ground Retreat Center
West Harrison, IN

August

Brad Miller Birdie Busters Golf
Outing
Thursday, August 16
Beavercreek Golf Club
Beavercreek, OH

September

Bleeding Disorders Awareness 5K
Saturday, September 22
Rice Field
Miamisburg, OH

October

Fall Outing
Sunday, October 7
Young's Dairy
Yellow Springs, OH

NHF Annual Meeting
Wednesday, October 10 - Sunday,
October 14
Orlando, FL

Additional 2018 events are being planned - Be sure to check the website or Facebook page for current events and registration info!

UNLOCKING YOUR SELF-POTENTIAL



ONLY ADVATE® HAS 13 YEARS OF EXPERIENCE IN THE REAL WORLD AS A RECOMBINANT FACTOR VIII¹

- Proven in a pivotal clinical trial to reduce the number of bleeding episodes in adults and children when used prophylactically*²
- Third-generation full-length molecule, similar to the factor VIII that occurs naturally in the body^{1,2}

*Multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20-40 IU/kg every 48 hours, or pharmacokinetic-driven, 20-80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis.²

The market leader in Hemophilia A treatment (as of October 2016)³

Learn more at ADVATE.com

ADVATE [Antihemophilic Factor (Recombinant)] Important Information

Indications

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery.

ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash.

Tell your healthcare provider about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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

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

Please see the following page for the ADVATE Important Facts.

For full Prescribing Information, visit www.ADVATE.com.

References: 1. Grillberger L, Kreil TR, Nasr S, Reiter M. Emerging trends in plasma-free manufacturing of recombinant protein therapeutics expressed in mammalian cells. *Biotechnol J*. 2009;4(2):186-201. 2. ADVATE Prescribing Information. 3. Elsayed M. Hemophilia Treatment. London, United Kingdom: Datamonitor Healthcare; 2016.

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S32116 07/17



[Antihemophilic Factor (Recombinant)]



[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

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

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

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADVATE.

What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA approved product labeling can be found at www.ADVATE.com or 1-888-4-ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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U.S. License No. 2020
Issued: 11/2016

S32554 06/17



TIS THE SEASON FOR GIVING

... SWOHF appreciates your support!

SWOHF would like to send Christmas greetings for fun-filled family times to all... *Happy Holidays!*

WEBSITE:

Use our convenient "Donate" button on our website to send a year-end gift (www.swohiohemophilia.org)

WORKPLACE GIVING

If you are a United Way donor, you may direct your gift to "Southwestern Ohio Hemophilia Foundation" as a designated gift.

ONLINE

Shop online at www.smile.amazon.com/ch/31-1527065 and Amazon donates to Southwestern Ohio Hemophilia Foundation.

Support us when you shop this holiday season

Buy your gifts and holiday essentials at
smile.amazon.com. You shop. Amazon donates.



amazonsmile

AmazonSmile is a simple and automatic way for you to support your favorite charitable organization every time you shop, at no cost to you. When you shop at smile.amazon.com, you'll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that Amazon will donate a portion of the purchase price to SWOHF.

How do I shop at AmazonSmile?

To shop at AmazonSmile simply go to smile.amazon.com from the web browser on your computer or mobile device. You may also want to add a bookmark to smile.amazon.com to make it even easier to return and start your shopping at AmazonSmile.

How do I select a charitable organization to support when shopping on AmazonSmile?

On your first visit to AmazonSmile smile.amazon.com, you need to select a charitable organization to receive donations from eligible purchases before you begin shopping. Search for Southwestern Ohio Hemophilia Foundation and make us your charity of choice. Amazon will remember your selection, and then every eligible purchase you make at smile.amazon.com will result in a donation.

My Life, Our Future Research Repository Enrollment to end December 31, 2017



My Life, Our Future is a nationwide campaign for progress in hemophilia. Leaders in our community have come together to offer free genotyping, so that participants may gain a deeper understanding of their hemophilia today, while helping to advance the breakthrough treatments of tomorrow. People

from across the country have contributed to create the world's largest genetic hemophilia repository.

Please note that genotyping and participation in the repository require that a blood sample be collected at a participating Hemophilia Treatment Center (HTC).

Participation in the repository will come to a close as of December 31, 2017, so contact your local HTC as soon as possible to schedule an appointment to participate. For more information, please visit mylifeourfuture.org

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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Southwestern Ohio Hemophilia Foundation

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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.

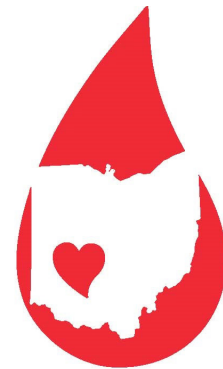
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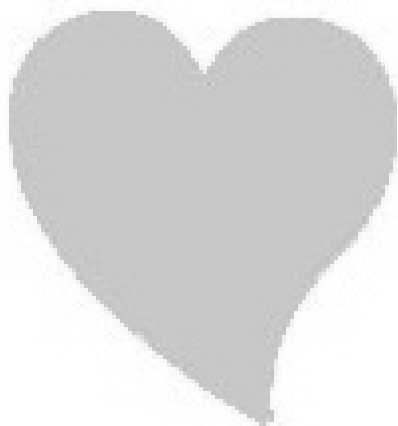
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