

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

MEET YOUR BOARD PRESIDENT!



SWOHF is pleased to announce our new Board President, Lindsay Carlson.

Lindsay has been involved with SWOHF since her oldest son was born in 2005. She has been on the SWOHF Board of Directors since 2014 and served as Vice President last year. She has three children affected by Hemophilia and recently became a Parent Advocacy Ambassador through OBDC. Lindsay's dedication to our SWOHF community includes attending state and federal-level advocacy days, but her commitment to SWOHF comes from a strong belief that it's at this local level where affected families can be directly helped and knowledge can be shared.

As we welcome Lindsay, we also want to express our appreciation to our 2017 Board President. Special thanks to Chad Shellabarger for his leadership and service to SWOHF during a year of staff transitions. We appreciate Chad's commitment to SWOHF and willingness to show his support by giving his time and wisdom to further our mission. If you'd like to send Chad a personal "Thank

You" note, just mail your card to Chad c/o the SWOHF office and we will be sure he gets it.

The members of the Board develop policies, procedures and regulations for the operation of SWOHF. They monitor finances, programs and performance of employees.

CURRENT 2018 SWOHF BOARD

Lindsay Carlson, President
Dena Shepard, Vice President
Denise Croley, Treasurer
Debra Smith, Secretary

Jenny Bostater
Darla Edds
Sandra Hibner
Dick Miller
Eric Shepard (Emeritus)

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Issue #1 **2018**

Advocacy Events

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.**

REGISTRATION is now open at www.ohioobdc.org for individuals who are interested in joining us. Please inform the SWOHF office if you want to meet up with us in Columbus, Ohio. Hotel rooms for Tuesday evening and travel stipends are available on a limited basis -- contact the SWOHF office for more details.

For people who have never been to Statehouse Day before or have never done any sort of legislative advocacy, the Advocacy Coordinator will be doing regional trainings. Additionally, Randi Clites from OBDC will be at our Annual Meeting on March 3 to give our SWOHF community an update.

On Tuesday, March 20 (the night before Statehouse Day) there will be a dinner presentation which will teach us what to expect when we meet with our legislators and prepare us to talk about the issues important to the bleeding disorder community in Ohio. Meetings with legislators are already scheduled for us on Wednesday, March 21, throughout the day.

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."

Your Health. Your Voice. Our Future.

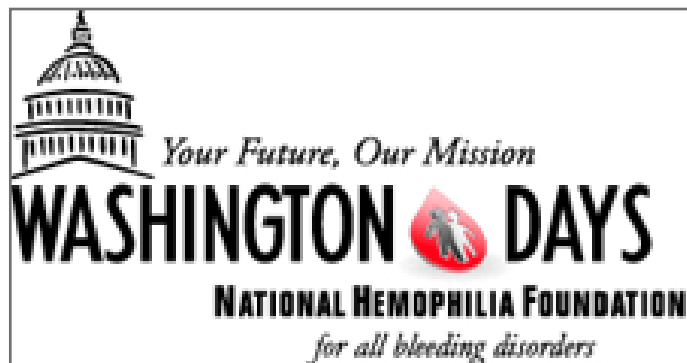


Ohio Bleeding Disorders Council



The National Hemophilia Foundation (NHF) will host their annual Washington Days advocacy event March 7-9, 2018 on Capitol Hill in Washington, DC. NHF's Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that are important to them. Last year's Washington Days had more than 500 volunteer advocates from 47 states that met with legislators and staff to discuss maintaining key patient protections in the Affordable Care Act (ACA).

Registration is closed for this 2018 event - SWOHF is sending Lindsay Carlson and her son Gunnar, as well as Kay Clark, our Executive Director. Watch for their report in the next issue of Factor Notes! If you are interested in attending next year's Washington Days, contact the SWOHF office for more information.





ADYNOVATE

[Antihemophilic Factor
(Recombinant), PEGylated]

ADYNOVATE® is FDA approved
for patients of all ages with
Hemophilia A

PROVEN PROPHYLAXIS +
SIMPLE,* TWICE-WEEKLY DOSING SCHEDULE =

moments **YOUR WAY**

*ADYNOVATE allows you to infuse on the same 2 days every week.

The pediatric study of children <12 years of age (N=66) evaluated the immunogenicity, efficacy, PK (as compared to ADVATE® [Antihemophilic Factor [Recombinant]]), and safety of ADYNOVATE twice-weekly prophylaxis (40-60 IU/kg) and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.^{1,2}

The pivotal trial of children and adults ≥12 years (N=137) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis (40-50 IU/kg) vs on-demand (10-60 IU/kg) treatment, and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.¹

+Children (<12 years) experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds^{1,3}

+38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds¹

Talk to your doctor and visit ADYNOVATE.com

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indications

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor [Recombinant]]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE 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 ADYNOVATE 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 ADYNOVATE 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 ADYNOVATE.

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.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

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 ADYNOVATE Important Facts.

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

References: 1. ADYNOVATE Prescribing Information. 2. Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2016 Nov 27. doi: 10.1111/hae.13119 [Epub ahead of print].

3. Data on file.

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ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. 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 ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

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

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 ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

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

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE 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 ADYNOVATE by themselves or with the help of a family member.

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

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

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

How should I use ADYNOVATE? (cont'd)

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

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

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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

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.

The common side effects of ADYNOVATE are headache and nausea. 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 ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE 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 ADYNOVATE 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 ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE 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 ADYNOVATE. The FDA-approved product labeling can be found at www.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

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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INFORMED INTENTIONAL INVOLVED INVESTED

ALL IN!

We all have choices regarding our level of involvement in the community around us - at SWOHF, we'd like to encourage you to consider 2018 as the year to "Go All In" - to be informed, intentional, involved, AND invested in SWOHF.

Many will benefit simply from being informed and more aware of bleeding disorders; some will become more intentional in making a difference in our community; others may take the next step of being involved and invested - giving of time, talent and funds to improve the quality of life for those in our community who courageously face each day's challenges.

If you are interested in volunteering for any of our events, please contact us in the office at 937-298-8000 or send us an email: info@swohiohemophilia.org

March

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

April

Evening Out
Friday, April 20
Dayton Woman'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!

INFORMED INTENTIONAL INVOLVED INVESTED

NHF BLEEDING DISORDERS CONFERENCE

NHF's Bleeding Disorders Conference (formally known as Annual Meeting), will be held October 11 - October 13, 2018 in Orlando, Florida. Registration is open! You can expect three full days of innovative educational sessions for the entire bleeding disorders community with workshops and social events designed to empower and support the community.

If you are interested in attending NHF's Bleeding Disorders Conference, please **contact the SWOHF office** for an application form for our travel scholarship. One scholarship for 2018 will be awarded to an individual or family and is open to SWOHF members who live in the Greater Dayton area. This award will be applied to registration fees, hotel accommodations and air/ground transportation for two attendees.



CAMP BOLD EAGLE

Session 1: (Ages 6-9) 5 days, 4 nights (July 15-19, 2018)

Session 2: (Ages 10-12) 7 days, 6 nights (July 21-27, 2018)

Teen Camp: (Ages 13-17) 7 days, 6 nights (July 1-7, 2018)

For children with bleeding disorders, camp is a place where they can learn the valuable skills they need to become independent teens and adults. They will learn from each other and from their counselors (many of whom live with bleeding disorders themselves) about ways to manage their disorder both medically and socially. 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.

Camp Bold Eagle registration is open now and SWOHF has limited scholarship applications! If you have a child (ages 6 to 17) with a bleeding disorder who may be interested in attending camp this summer, please **contact the SWOHF office** by calling us at 937-298-8000 or email director@swohiohemophilia.org for additional information and application process.



INDUSTRY PARTNER SPONSORS FOR 2017

In 2017 our annual events were well-attended and inspiring! Since our funding comes entirely from grants, fundraisers and contributions, we are grateful for the involvement and generosity of our corporate sponsors and industry partners. SWOHF offered special events and programs that were focused on our mission to educate, advocate for and support our community! We are **STRONGER TOGETHER!**

Accredo
Aptevo
Bayer
Bioverativ
CSL Behring
CVS Health
Dayton Children's Factor
Diplomat
Grifols
Matrix
Novo Nordisk
Pfizer
Shire

WHAT A DIFFERENCE A “GRANT” MAKES!

Cascade Hemophilia
Consortium

The Hemophilia Alliance
Foundation

Shire

FamOhio

The Allstate Foundation

Roto-Rooter

The Dayton Foundation

In 2017 SWOHF was awarded several grants to help fund projects and programs. Here's a few highlights:

Because of the Cascade Hemophilia Consortium, we designed and printed a new SWOHF brochure, as well as purchasing a template and software for publishing our full-color newsletter. Thanks to the Hemophilia Alliance Foundation, SWOHF was able to purchase a new donor database and donation management program, Network For Good. Both of these initiatives have been on the Strategic Plan 2013-2018 so we are excited to make these changes in technology that will increase office efficiency and communication.

Generous grants from FamOhio, Shire, The Allstate Foundation, Roto-Rooter and The Dayton Foundation were also received for expenses associated with our Family Fest, 5K and Gala events in 2017!

C A S C A D E
H E M O P H I L I A
C O N S O R T I U M



Shire



Our #GIVINGTUESDAY Story

On Tuesday November 29, SWOHF celebrated #GivingTuesday as we joined a global giving movement and launched our very own Facebook Giving Challenge. This was our first year participating in the worldwide event and we were astonished at the response. Our largest gift was \$50 and we had several first-time donors. THANKS TO YOUR GENEROSITY, we raised over \$250!

When we analyzed the FB statistics, here's what we found for that day: **Total page views was up 246 % and Total reach was up 340% -- This basically means many of you liked and shared our post requesting funds for SWOHF.**

We will launch the campaign again for 2018. **Be sure to LIKE us on Facebook** so you get the post and can join in the fun! For more information, check out their website <https://www.givingtuesday.org>



Something's Different

Check out www.swohiohemophilia.org



We are so excited to be able to offer ONLINE REGISTRATION FOR EVENTS through our SWOHF website and Network For Good. For upcoming SWOHF events, you will have the option of easy and secure online registration and payment (if necessary).

Just a couple things to note:

1) Your online donation/registration receipt may look different. Network for Good will issue an email receipt automatically upon successful completion of each transaction so instead of receiving an email from PayPal or SWOHF, you will receive one from Network For Good. It will include our name and message to you, our email, the amount donated/paid, etc.

2) Up-to-date contact information is necessary to assure you receive invitations, notices, newsletters, etc. If you've moved recently, if you have a new phone number or if you haven't given us your email address, please contact us in the office at 937-298-8000 or send an email update to info@swohiohemophilia.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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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.

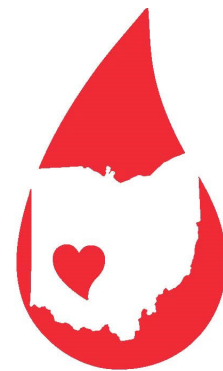
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