

FAMOHIO



KEEPING OHIO BLEEDING DISORDER
FAMILIES CONNECTED SINCE 1992

FAMILY EDUCATION NIGHT



OCTOBER 16, 2020

Dear Friends,

It is with great honor as the President of FAMOHIO, I welcome you all to the 2020 Family Education Night.

Sixteen years ago, my late husband Greg, daughter Ali and I welcomed baby boy Lucas into our family who was diagnosed with hemophilia not long after he was born. Our daughter, who is now 25, has recently been diagnosed with this condition as well. FAMOHIO has helped our family personally by connecting us with other families who could help us navigate life with a child with a lifelong, chronic condition as well as supply us with educational and financial resources.



Not long after Lucas was born, I became involved with our local chapter. I volunteered for a fundraiser and met other mothers of boys like ours. We attended many events and eventually made it to our first FAMOHIO. It was amazing to meet all the families from across the state of Ohio who were a lot like us. The educational opportunities were endless and networking with families helped our family form lifelong friendships with people we most likely would have never met had circumstances been different.

Fast forward a few years to when my good friend and fellow hemo mom Pam talked me into joining the Planning Committee. That Planning Committee position then led me to a Board position where I participated in many FAMOHIO's until eventually the opportunity for me to become Board President presented itself. I am a work in progress. Learning and growing every day with the help and support of an awesome Board and community. I am very thankful for the all the hard work and dedication the Board has put forth in planning this virtual event.

Enjoy tonight's educational offerings, network with one another, build the lifelong friendships that my family and I have, and most of all have fun. I promise you will not be disappointed.

Tina Ascough
FAMOHIO Board President

A GIFT FROM THE BOARD OF FAMOHIO

Each family attending the Family Education Night will receive a free copy of "The Anxiety First Aid Kit".

"If you're feeling unprecedented levels of stress and anxiety right now, please know that you aren't alone. In these extreme and uncertain times, it's natural to be in a constant state of mental and physical strain. Whether you're dealing with job loss, a sick loved one, or just feeling the weight of the world during your 2 a.m. — you need quick tools you can use right now, whenever and wherever you are, to lower stress and soothe anxiety. This emergency kit has you covered."

Hope you enjoy!



AGENDA 2020

Friday, October 16, 2020
6:30-8:30pm

To join: <https://zoom.us/j/95051751887>
Meeting ID: 950 5175 1887
If you would like to call in: 929-436-2866

Please wear your shirts and take photos of your family. Post online using #FAMOHIO

There will be 4 door prizes given away – you must be present to win those

If you have any technical issues text/call: 513-604-9097

PROGRAM

6:30pm New family orientation (1st door prize drawn, only new families are eligible)

6:45pm Zoom opens for people to network/get acquainted (optional)

7:00pm Welcome

Platinum Sponsors: Cascade, Takeda, Novo Nordisk

Announce Scholarship Winners

Announce Trivia contest

Bleeding Disorder Education program
Denny Baker, Ventriloquist

7:55pm Closing remarks

8:00pm Split the Pot Winner announced (need not be present to win)

8:05pm Zoom Rooms open to families/patients only (optional)
New families, parents, adult patients, young adults, women, etc.

Dinner gift cards will be mailed out the week of October 19th
to families who participate on the Zoom

FAMOHIO FOUNDING FATHERS

In March of 1992, during the AIDS (acquired immunodeficiency syndrome) crises, six men came together to discuss their future and the future of their blood brothers. These men all carried the diagnosis of hemophilia and as a result of treatment for hemophilia had contracted HIV (human immunodeficiency virus). Instead of wallowing in self-pity they channeled their anger and feelings toward a positive goal. These men believed education was the key to ensuring the future for all people affected with bleeding disorders. In the summer of 1992, their creation, a state-wide, educational symposium was held called FAMOHIO. That year, FAMOHIO was the acronym for “first annual meeting of hemophiliacs in Ohio.” Going forward, FAMOHIO became known as “family annual meeting of hemophiliacs in Ohio.”

In the beginning the attendees generally carried the diagnosis of hemophilia. As time progressed the meeting grew in size to include people and families living or treated in Ohio with numerous bleeding disorders. The FAMOHIO founders believed that an annual meeting of people/families with bleeding disorders provided opportunities for shared information and increased knowledge through education and camaraderie. The current FAMOHIO board shares the founders’ beliefs.

The positive rippling effects of FAMOHIO are difficult to quantify. However, attendees largely agree that the FAMOHIO experience provides increased knowledge and a better understanding of how to live with a bleeding disorder.

FAMOHIO BOARD OF DIRECTORS

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Tina Asco’ugh

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Dwanna Rutter
Teresa Rutter
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Jodi Skinner

Event Coordinator
Lisa Raterman

FAMOHIO AWARDS

The six founding fathers of FAMOHIO were active and strong advocates of the bleeding disorder community. These brave men knew firsthand what having a bleeding disorder entailed in a time when treatment was very limited. In addition, they suffered through the tainted blood/factor tragedy. However, rather than wallowing in self pity our founders came together and created an educational forum known then as First Annual Meeting of Hemophiliacs in Ohio and now known as Family Annual Meeting of Hemophiliacs in Ohio or FAMOHIO. These founders realized EDUCATION is POWER!

To honor our great founders and current advocates, a series of awards have been created and are awarded annually. On the FAMOHIO website the description of awards are listed. We wholeheartedly accept nominations and would love to review any nominations we receive. Please consider nominating someone who has helped you on your journey.

The FAMOHIO board sends sincere congratulations and appreciation to this years' most worthy winners.
The 2020 award winners will be announced at the 2021 in-person event

The highest award given by FAMOHIO, Inc. is the IRA GAFFIN MEMORIAL AWARD. This award is presented to an individual who has provided extraordinary voluntary service to the hemophilia community. This merit based award is offered once each year and is open to any individual or couple whose unstinting service on behalf of the hemophilia community of Ohio exemplifies the generous spirit of Ira Gaffin. The following names are the awardees who have achieved this great honor.

2019: Amy Dunn, MD	2006: Randy Clites
2018: Josh and Krista Crossgrove	2005: Linda Wacha
2017: Elizabeth Miller	2004: Ruth Saylor
2016: Cindy Michael	2003: Sylvia Jordan
2015: Glenn Pierce, M.D., Ph.D.	2001: Jim Sites
2014: Karen Gillespie	2002: Joseph Palascek, M.D.
2013: Les and Gloria Gutter	2000: Bill Dennis
2012: (none awarded)	1999: Rick Sites
2011: Teresa Bridges Rutter, Madeline Heffner, & Nancy Duffy	1998: Michael Para, M.D.
2010: Elizabeth Billow	1997: Ralph Gruppo, M.D.
2009: Dena Shepard	1996: Dirk Scheerhorn, Ph.D.
2008: (none awarded)	1995: Paul and Rosie Haas
2007: Polly Partin-Welch	1994: Tom & Monica Burr

LES GUTTER MEMORIAL SCHOLARSHIP

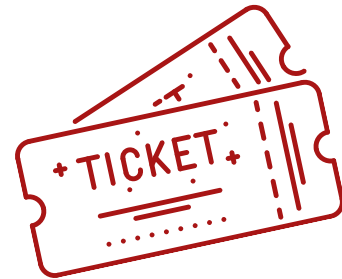


The board of FAMOHIO and the members of the scholarship committee acknowledge the many challenges students face during their journey to complete a post-secondary educational program. These challenges are significant in normal times and even more intensive during the current pandemic.

One of FAMOHIO's initiatives to combat the current crises is to provide enhanced support to members of the bleeding disorder community. Consequently, the scholarship awards for 2020 have been increased both in the number and the amount of the scholarship.

The current scholarship process will be reviewed and updated before the next school year.

SPLIT THE POT



Just announced – the **WINNER OF THE SPLIT THE POT WILL RECEIVE A GUARANTEED \$250** thanks to some offline purchases we've received this week!

- Depending on additional purchases, online or off, the pot could go even higher, so don't forget to get your tickets.
- You must be in the State of Ohio to purchase online. If you live outside the state and would like to purchase tickets, please email me and we will make arrangements.
- The winner does not need to be on the Zoom, so feel free to send to your family and friends.

CONGRATS TO OUR SCHOLARSHIP RECIPIENTS



OLIVIA HOFF
SAINT MARY'S COLLEGE



LEE HUNTSBERGER
WRIGHT STATE UNIVERSITY



KEENAN SHARROCK
THE OHIO STATE UNIVERSITY



STEVEN MILLER
YOUNGSTOWN STATE UNIVERSITY



TIMOTHY WOHL
THE OHIO STATE UNIVERSITY

2020 SPONSORS

PLATINUM SPONSORS



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ACCREDITO EXPRESS SCRIPTS
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BAYER
PFIZER

OBDC & CHAPTER UPDATES



website: nhfcentralohio.org
Contact: Wendy Perkins 614-902-3965
email: wperkins@hemophilia.org

The Central Ohio Chapter of the National Hemophilia Foundation is dedicated to providing education, advocacy, and support programs for people with bleeding and clotting disorders, and to driving innovations that lead to a better quality of life for our consumers. We were founded out of a need to raise awareness for voices not heard. We have continued to make a difference with the help of our donors and volunteers that make our mission possible.



Tanya Ricchi
Executive Director
Northern Ohio Hemophilia Foundation
5000 Rockside Road, #230
Independence, OH 44131
216-834-0051
www.nohf.org

At the NOHF, we aim to enhance the quality of life for people with genetic bleeding disorders and their families, through advocacy, education, research and other constituency services.



For information, please contact
Carla Wells at carla@nwohemophilia.org
or at 419-291-5882.

For more than 55 years, The Northwest Ohio Hemophilia Foundation has assisted individuals and families affected by bleeding disorders. Through family networking events, sending youth to a specialized camp, maintaining a family crisis fund, providing medical identifications, facilitating educational workshops, and advocating at the local, state, and national level on critical legislation, our Foundation is committed to helping people manage their condition. Currently we serve more than 2000 individuals within the 22 counties in Northwest Ohio that we serve.

Our Foundation is run by an all-volunteer Board of Directors that includes affected individuals and professionals from Northwest Ohio. We partner with industry and other chapters to ensure that we provide the best service to our members.

OBDC & CHAPTER UPDATE



937-298-8000
www.swohg.org, joy@swohf.org

The Southwestern Ohio Hemophilia Foundation partners with the Hemophilia Treatment Center at Dayton Children's Medical Center to provide services for the bleeding disorders community in the Dayton area and 12 surrounding counties. We provide funding for a Summer Camp, An Annual Family Fest...which is a weekend Retreat to increase families knowledge of bleeding disorders and instruct them on managing issues related to the disorders. Additionally, SWOHF publishes a quarterly newsletter Factor Notes that provides relevant information and chapter activities. We have a website www.swohf.org that is updated regularly to advance issues of the community. We provide Emergency Assistance funds, travel grants for educational purposes, Personal Medical Identification bracelets and work with Industry Partners to assist the community in receiving the latest advances in medical treatment.



Helen@TSBDF.com
Phone - (513) 961-4366
635 W. Seventh Street, Suite 407
Cincinnati, OH 45203
www.TSBDF.com

The Tri-State Bleeding Disorder Foundation is committed to helping support and care for those individuals within our community affected by a Bleeding Disorder.

Our goal is to help those individuals realize their full potential. We do this by educating our community, advocating to our government for support, and helping further research to improve our care and someday find a cure.



www.ohiobdc.org
or talk to your local Chapter Executive Director
about getting involved.

The Ohio Bleeding Disorder Council is comprised of the 8 Hemophilia Treatment Centers and 5 Chapters in Ohio. The mission of OBDC is 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. Each year, the Ohio Bleeding Disorders Council hosts Statehouse Day, where people affected by a bleeding disorder get to meet their state elected officials and voice their concerns about issues important to the Ohio bleeding disorders community. Due to the Pandemic we hosted 6 virtual meetings with Legislators across the State this fall. If you're interested in learning more about OBDC, please check out our website at www.ohiobdc.org or you can talk to your local Chapter Executive Director about getting involved.

DENNY BAKER, VENTRILOQUIST

As a 10-year-old, Denny Baker first got a taste of the power of ventriloquism after a trip to the Vent Haven Museum. Seeing hundreds of ventriloquist artifacts and dummies, Denny decided to tap into the entertainment form and discovered his talent for the unusual and unique art form. Denny performed his first show at 10 years old, and he continued to pursue his love of entertainment through his involvement in the glee club at Elder High School. Thanks to the music teacher, he and one of his “friends”, a ventriloquist puppet, had a spot in every glee club performance, bringing audience members on stage, bantering with a spectator and after some coaxing, finally convincing his puppet to sing a song. Denny went on to win a number of junior competition awards, including several at the International Ventriloquist convention, as well as a 12-week city-wide talent search.

In his adulthood, Denny lives out another lifelong passion as a professional firefighter. He has held positions at Delhi Township, Middletown, Ohio, and is currently a Fire Lieutenant and paramedic with the Cincinnati Fire Department where he’s been since 1996.



www.DennyBaker.com

Judy Doyle

Patient advocate

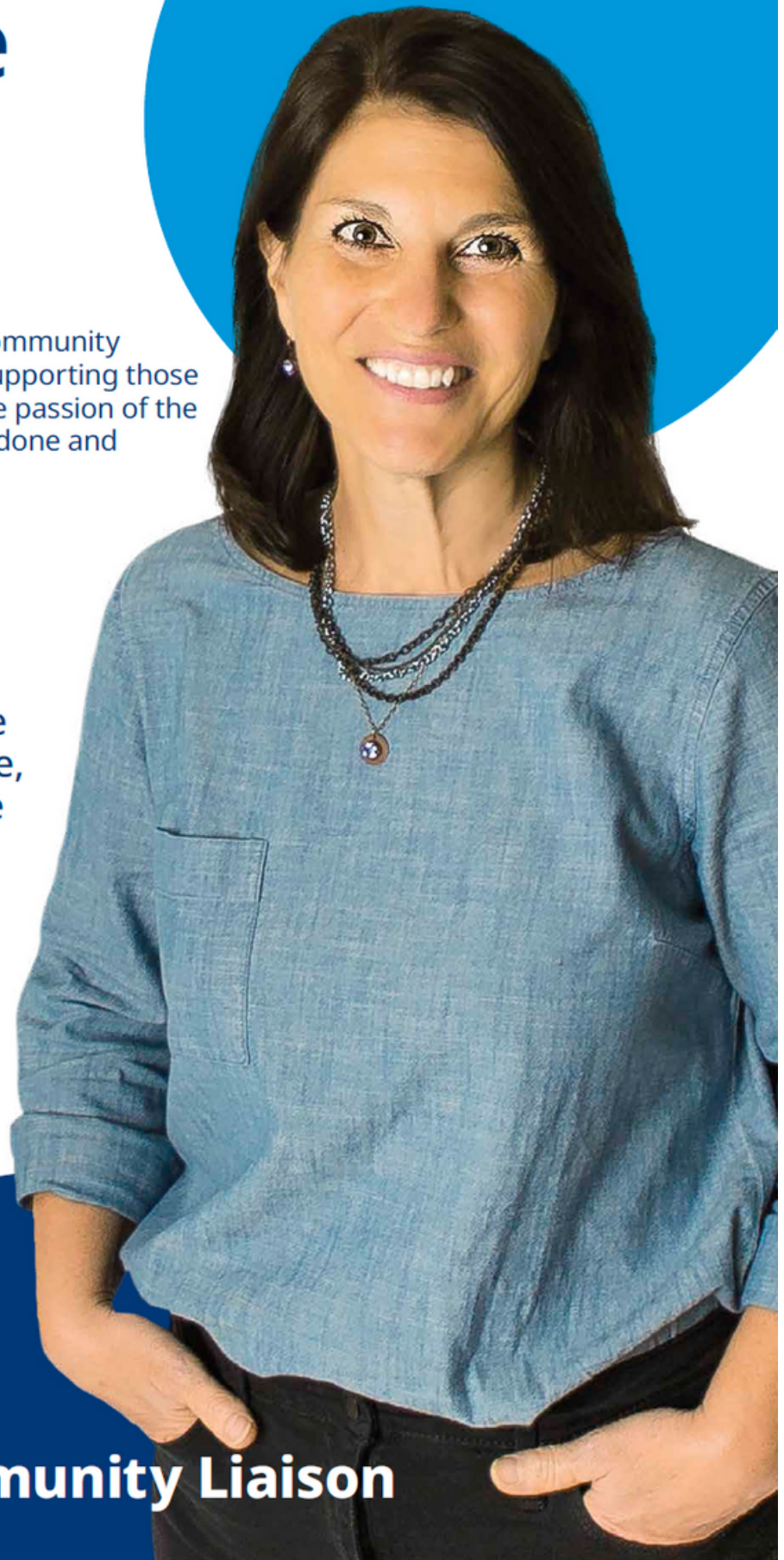
About Judy

Judy is a Novo Nordisk Hemophilia Community Liaison with 18 years of experience supporting those with bleeding disorders. She loves the passion of the hemophilia community to get things done and not let things stand in their way.

Hobbies

- Gardening
- Making jewelry

“I became a liaison because of my desire to help people, specifically those with rare disorders.”



Connect with Judy

JDDL@novonordisk.com
(216) 217-4197

Hemophilia Community Liaison

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

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A Trusted Partner in Your Circle of Care

- Non-profit pharmacy dedicated to respond to the needs of persons affected by bleeding disorders
- A 340B covered entity offering among the lowest prices for factor available
- Governed by a volunteer board of directors from the bleeding disorders community
- Returns all excess revenues to the community for support of patient services and HTC programs

For more information visit us at cascadehc.org



It takes a team for best patient outcomes!

The Factor Care Team consists of your child's Hemophilia Treatment Center physician and primary nurse, a Homecare factor care coordinator, a Homecare infusion pharmacist and a social worker.

Working directly with you and your child, the Factor Care Team provides support and care to help your child be a "kid", while safely and effectively treating their hemophilia.

To learn more visit NationwideChildrens.org/Homecare-Factor or call (614) 355-1100/(800) 466-2727, Monday thru Friday, 8 a.m. - 5 p.m. and ask to speak with the Factor Care Coordinator.

Homecare Factor Program



**NATIONWIDE
CHILDREN'S**

When your child needs a hospital, everything matters.™

We're Listening

At Pfizer Hemophilia, we have always been deeply committed to listening to what you have to say. Our programs and resources are all designed in response to the needs of the hemophilia community.

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

—Your Pfizer Hemophilia Team

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Jivi® Extension Study Results

DIVE IN >

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Specialty Pharmacy. Experienced Care.

At Accredo, we understand it can be difficult to live with a chronic or complex illness and subsequent care.

As one of the nation's leading and largest providers of specialty pharmaceuticals, our dedicated therapy teams work diligently to coordinate solutions for the challenges of those living with a bleeding disorder.

With accurate and timely delivery of medication, as well as expert guidance through ongoing therapy directives, you can trust Accredo to provide experienced care.

Contact us for more information.

Patients call: 866.712.5200
Physician offices call: 866.712.5007

accredo®

Akron Children's Hospital treats every child as if they were our own.



It's our care for children with conditions such as bleeding disorders that sets us apart – from education and surgery planning to a smooth transition from pediatric to adult medical care. It's family-centered care, and what every child deserves.

For more information about the 340B Factor Program, call JD at 330-543-3513 or toll-free 1-800-262-0333 ext 33513.

<https://www.akronchildrens.org/departments/Hemostasis-and-Thrombosis-Center.html>

The 340B Factor Program is proud to support the Akron Children's Hospital Hemostasis and Thrombosis Center's mission of providing exceptional comprehensive care for all bleeding disorders.





[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 1-877-825-3327.

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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Patented: see <https://www.takeda.com/en-us/patents/>

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Issued: 12/2018

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LIFE HAPPENS

AND ADVATE WILL BE THERE WHEN IT DOES

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.¹

ADVATE

[Antihemophilic Factor (Recombinant)]

REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

¹In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

Not an actual patient.

Prophylaxis with ADVATE prevented bleeds¹

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment. 53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.¹ This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

¹Median is the middle number in a group of numbers arranged from lowest to highest.

ADVATE Important Information

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

Who should not use ADVATE?

Do not use ADVATE if you:

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

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

What should I tell my HCP before using ADVATE?

Tell your HCP 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.

What should I tell my HCP before using ADVATE? (continued)

- Are or 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 important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP 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.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

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. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

- 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, and rash. Tell your HCP 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 Important Facts about ADVATE on the following page and discuss with your HCP.

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

Reference: 1. ADVATE Prescribing Information.

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