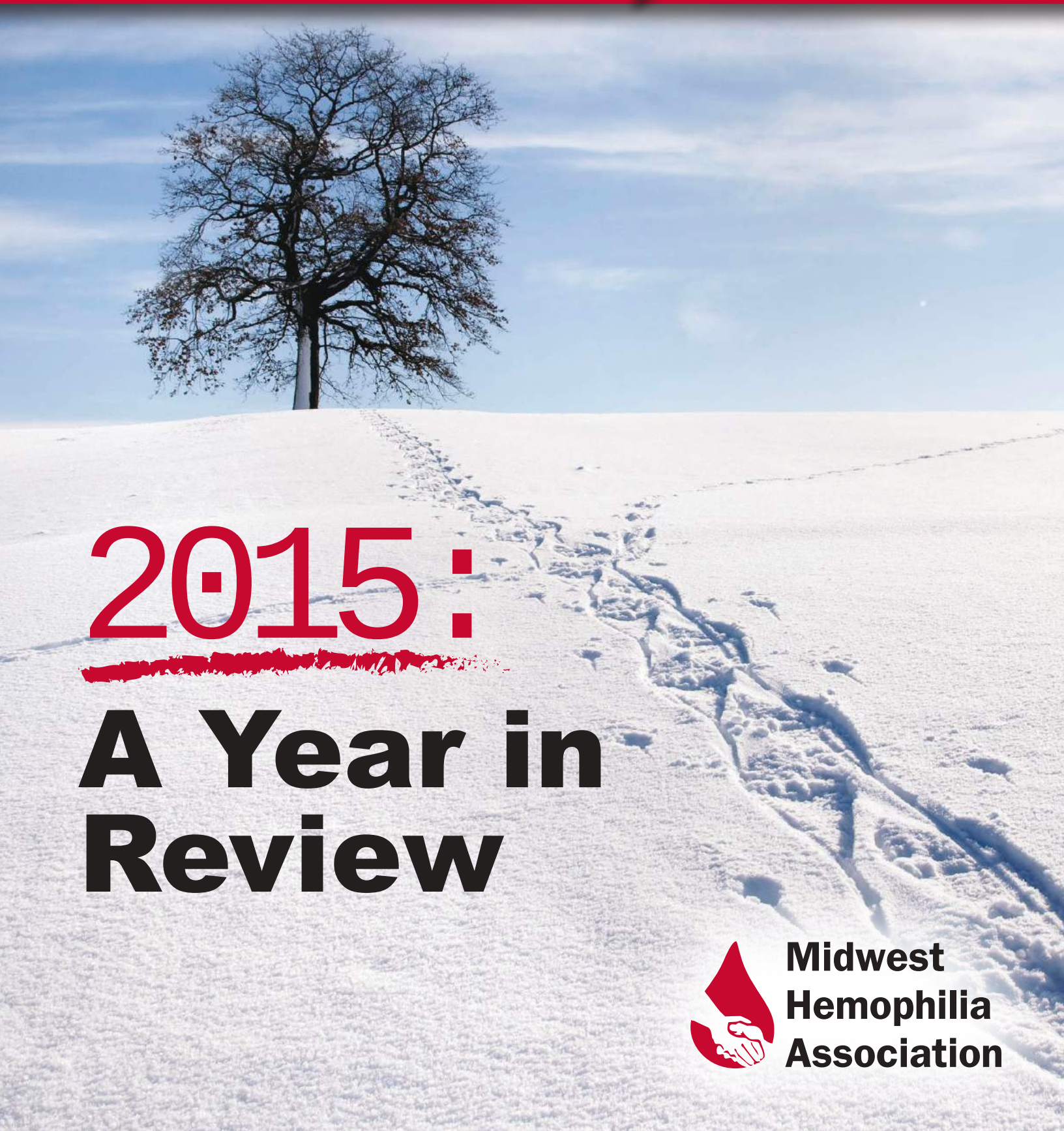
# CHAPTER Factors

WINTER 2015



# 2015: A Year in Review

Midwest Hemophilia Association

Chapter Factors is published by:

**The Midwest Hemophilia Association**

PO Box 412866
Kansas City, MO 64141
(816) 479-5900
*www.midwesthemophilia.org*







# News and Notes

One of the most important things we do here at MHA is communicate. We communicate event information. We communicate research information. We communicate industry programming. We communicate educational programming. Most importantly we communicate this information to you in a variety of methods including our Chapter Factors newsletter, our MHA Facebook page and through our blast email database and our mailing database. While all are effective the mailing database takes the most time to manage in keeping names and addresses current.

At the last MHA Board Meeting it was agreed upon that we should do an evaluation of our mailing database to learn if there are folks on there that no longer wish to be contacted by mail. So with that in mind we are asking if you would still like to be on our mailing list. If you do wish to remain on the mailing that is great and you do not need to do anything else. However, if you wish to be removed please contact me by phone or email or clip the form below and mail it to me.

We certainly hope that you will remain on the mailing list. Even if you wish off the mailing list we can add you to the email blast database. We believe it is job one to get you the best information in a timely and responsible manner. Thank you for staying connected!

Mark Cox
Executive Director

## Midwest Hemophilia Association Mailing List

**If you would like to be REMOVED from our mailing list, you may do so by following one of the three options listed below. You can be added back onto the mailing list at any time.**

Complete the form below and mail to Midwest Hemophilia Association at
***8900 State Line Road, Suite 411, Leawood, Kansas 66206***

Name: _____

Address: _____

City/State/Zip: _____

Call Executive Director Mark Cox at **816-479-5900**

Or email Executive Director Mark Cox at ***mcox@midwesthemophilia.org***

## Message from the President

It has been a busy year for Midwest Hemophilia Association! We had the Wichita education event at Laser quest where Angela Brown gave an amazing presentation from the Steps for Living Program. Kansas also hosted its first ever Advocacy Day thanks to Jennifer Rentschler. The Western Kansas education event had a record turnout and was held at the Lee Richardson Zoo in Garden City. John Carlton was the presenter for education. Springfield's education event was again at the Springfield Cardinals game. Brenda Adamson, RN provided the education.

We had an amazing Family Fun Fair this year for our Annual education event. Last but not least how could we forget Camp! This was our first year at our new location, Lake Doniphan. We also had several Industry sponsored education dinners/events scattered throughout the year in all our regional geographic areas.

In amongst our education we had several fundraisers including the Skeet Shoot, Golf Tournament and Hemophilia Walks.

There were two Skeet Shoots this year, one in Kansas City and the second one just outside of Springfield. The Golf Tournament was again a success and our three Hemophilia Walks (Kansas City, Springfield and Wichita) raised a lot of awareness and funds to be used for our educational programming. These events take place every year thanks to our amazing chair persons and volunteers. We are in search of a few more committee members to help take over some responsibilities and come up with ideas in their prospective geographic areas.

***Left to Right: Aimee Tempera, MHA President, presents Brooke Connell with the 2015 MHA Volunteer of the Year Award. Congratulations Brooke!***

Here is a list of all the committees and their role for MHA:

- Events/Education
- Wichita Education Event
- Western Kansas Education Event
- Springfield Education Event
- Family Fun Fair
- Skeet Shoot
- Camp
- Golf Tournament
- Hemophilia Walks
- Advocacy (MO and KS)

If any of these committees interest you, please call Mark Cox and he will be able to direct you to the appropriate person.

The future of MHA is still going full steam ahead. We are in the process of developing a new 3 year strategic plan as well as a youth program. We are ramping up our education events with current

topics and style of delivery. We are in the process of setting the 2016 calendar of events as of our December 5th Board meeting.

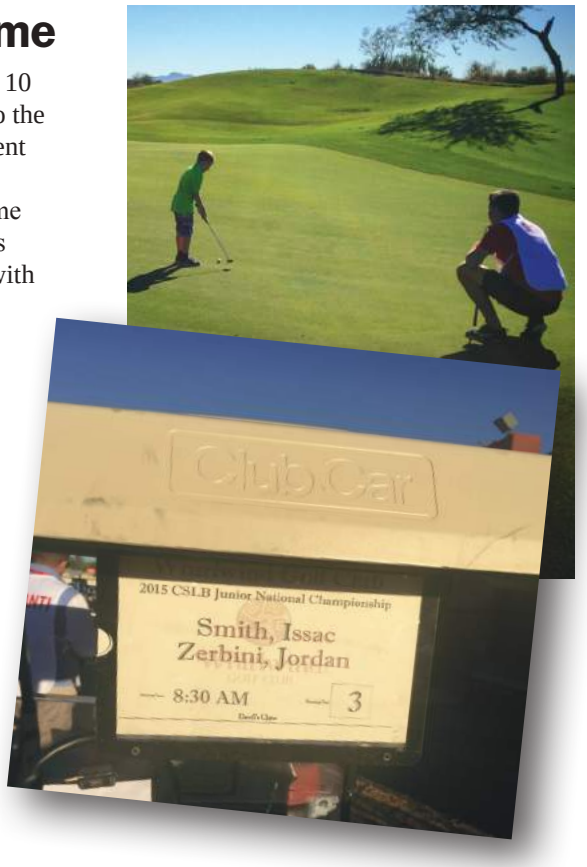
Thanks for a great year everyone! Can't wait to see y'all in 2016!!!

*— Aimee Tempera, President*

## Getting in the Game

My name is Isaac Smith, I am 10 years old. I was nominated to go to the Getting in the Game golf tournament in Phoenix Arizona, sponsored by CSL Behring. This was the first time I got to fly on a big airplane. It was fun in Phoenix. I got to play golf with a professional golfer who also had hemophilia. The tournament was fun because I had my own caddie. He helped me hit the ball so I could get it in control and it would go far. I liked the Whirlwind Golf Course. The caddie knew a lot about golf, and he helped me get the right angle for putting. At the awards dinner I was sitting at the table with the guy who won first place in the golf tournament. I really enjoyed this trip and hope to go to this event again!

***Left: Group picture of the Getting in the Game golf tournament sponsored by CSL Behring held in Phoenix, Arizona. Below Top: Issac Smith with his father, Kevin, at the Whirlwind Golf Course. Below Middle: During the tournament, Issac was assigned his own caddie. Below Bottom: Issac was paired with professional gofler Jordan Zerbini during the tournament.***


## Thank you to our Industry Sponsors

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Emergent

Grifols USA

HPC International

Midwest-IV

National Cornerstone Healthcare

Novo Nordisk

Soleo Health

Option Care

Pfizer

# 2016 Calender of Events

We have some amazing events planned for 2016! Please join us for any or all of these events to celebrate and support hemophilia awareness. Watch your mail and check our website throughout the year for more event details.

Clip and save this calendar for reference so you don't miss out!

## January

**January 30, 2016**
**Wichita Education Event**
*Laser Quest*
*Wichita, Kansas*

## March

**Missouri & Kansas Advocacy Days**
*Dates to be announced*

## April

**April 23, 2016**
**KC Pull for a Cure - A Sporting Clay Event**
*Powder Creek Shooting Park*
*Lenexa, Kansas*

**April 30, 2016**
**Western Kansas Event**
*Location to be announced*

## June

**June 25, 2016**
**Springfield Education Event**
*White River Conference Center*
*Springfield, Missouri*

## July

**July 31, 2016 - August 5, 2016**
**MHA Summer Camp**
*Lake Doniphan Conference & Retreat Center*
*Excelsior Springs, Missouri*

## August

**August 13, 2016**
**Ozarks Pull for a Cure - A Sporting Clay Event**
*Ozark Shooters Sporting Complex*
*Walnut Shade, Missouri*

## September

**September 9, 2016**
**MHA Annual Golf Tournament**
*Drumm Farm Golf Club*
*Independence, Missouri*

**September 10 - 11, 2016**
**MHA Family Fun Fair**
*Hilton Garden Inn*
*Independence Missouri*

## October

**October 8, 2016**
**Kansas City Hemophilia Walk**
*Shawnee Mission Park*
*Shawnee, Kansas*

**October 16, 2016**
**Wichita Hemophilia Walk**
*Exploration Place*
*Wichita, Kansas*

## November

**MHA Award Banquet**
*Date to be announced*

**www.midwesthemophilia.org**

# 2015: A YEAR IN REV

## GOLF TOURNAMENT

## Kansas City Pull for a Cure

## Family Fun

## SUMMER CAMP

IEW

## n Fair


# Hemophilia Walks

KANSAS CITY

SPRINGFIELD

WICHITA

## NHF Washington Days

## MEN'S RETREAT

# HELPFUL NUMBERS

**KANSAS CITY REGIONAL HEMOPHILIA CENTER**
**1-816-302-6869 • 1-800-236-1713**
Dr. Shannon Carpenter • Dr. William Jennings
Dr. Brian Wicklund • Dr. Jill Moormeier
Katie Foote, LMSW • Andrew Wilson, RN, CFNP
Melissa Armanees, RN, CPNP

**UNIVERSITY OF MISSOURI HOSPITAL AND CLINICS HEMOPHILIA TREATMENT CENTER**
**1-573-882-9355**
Dr. Barbara Gruner • Dr. Carl Freter
Dr. Tamara Hopkin • Lauren Grana, MSW

**NATIONAL HEMOPHILIA FOUNDATION (NHF)**
**1-800-42-HANDI • www.hemophilia.org**

# UNLOCKING YOUR SELF-POTENTIAL

ADVATE
[Antihemophilic Factor (Recombinant)]
There's more to life.

## ADVATE HAS A PROVEN SAFETY PROFILE[1-7]

**Low risk of inhibitor development in previously treated patients (PTPs) demonstrated in clinical studies[1-5]**


(95% confidence interval, 0.02%–2.13%)

**6** CLINICAL STUDIES / **270** PATIENTS WITH MODERATELY SEVERE TO SEVERE HEMOPHILIA A

- **1 low-titer, nonpersistent inhibitor (<1%)** in a pivotal study*†[3] (n=108)
- **0 inhibitors** in a continuation study*†[2] (n=82); a pediatric study‡[5] (n=53); a surgery study*†[4] (n=59); a Japanese study[2] (n=15); and a prophylaxis study*§[1] (n=73)

*Patients with an estimated ≥150 factor VIII exposure days.[1,3,4]
†Some patients participated in more than 1 study.[2]
‡Patients with an estimated ≥50 factor VIII exposure days.[5]
§There was 1 case of a possible low-titer factor VIII inhibitor, which was unconfirmed, unaccompanied by symptoms of inhibitor presence, and disappeared at the subject's subsequent test.[1]

## 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 following page for Brief Summary of ADVATE full Prescribing Information.**

**References: 1.** Valentino LA, Mamonov V, Hellmann A, et al. A randomized comparison of two prophylaxis regimens and a paired comparison of on-demand and prophylaxis treatments in hemophilia A management [published correction appears in *J Thromb Haemost*. 2012;10(6):1204]. *J Thromb Haemost*. 2012;10(3):359-367. **2.** Shapiro A, Gruppo R, Pabinger I, et al. Integrated analysis of safety and efficacy of a plasma- and albumin-free recombinant factor VIII (rAHF-PFM) from six clinical studies in patients with hemophilia A. *Expert Opin Biol Ther*. 2009;9(3):273-283. **3.** Tarantino MD, Collins PW, Hay CRM, et al, and the rAHF-PFM Clinical Study Group. Clinical evaluation of an advanced category antihaemophilic factor prepared using a plasma/albumin-free method: pharmacokinetics, efficacy, and safety in previously treated patients with haemophilia A. *Haemophilia*. 2004;10(5):428-437. **4.** Négrier C, Shapiro A, Berntorp E, et al. Surgical evaluation of a recombinant factor VIII prepared using a plasma/albumin-free method: efficacy and safety of Advate in previously treated patients. *Thromb Haemost*. 2008;100(2):217-223. **5.** Blanchette VS, Shapiro AD, Liesner RJ, et al, for the rAHF-PFM Clinical Study Group. Plasma and albumin-free recombinant factor VIII: pharmacokinetics, efficacy and safety in previously treated pediatric patients. *J Thromb Haemost*. 2008;6(8):1319-1326. **6.** Oldenburg J, Goudemand J, Valentino L, et al. Postauthorization safety surveillance of ADVATE [antihaemophilic factor (recombinant), plasma/albumin-free method] demonstrates efficacy, safety and low-risk for immunogenicity in routine clinical practice. *Haemophilia*. 2010;16(6):866-877. **7.** Auerswald G, Thompson AA, Recht M, et al. Experience of Advate rAHF-PFM in previously untreated patients and minimally treated patients with haemophilia A. *Thromb Haemost*. 2012;107(6):1072-1082.



Baxalta

ADVATE
[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 |
| 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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# It's Time to Help Support Your Hemophilia Treatment Center

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- All brands of factor in a wide assortment of vial sizes
- A broad list of infusion supplies
- Customer Care Coordinators who know Hemophilia and are ready to be of assistance
- Interpreters who are fluent in over 180 different languages
- Coordination of in-home nursing services
- Shipments to your home or choice of location

Contact us at 816-221-4544
Ask for Cyndi Donate

Children's Mercy

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- No monthly maximums
- No waiting period; patients may use the offer as soon as they enroll
- No income requirement
- Program enrollment is required
- Restrictions apply
  - Patients must have commercial insurance
  - Patients must have a valid ALPHANATE or AlphaNine SD prescription
  - Patients may not participate in Medicare Part D, Medicaid, Medigap, Veteran's Affairs, Department of Defense, TRICARE, or any other federal or state-funded programs or be enrolled in a health plan that does not permit members to participate in copay assistance programs

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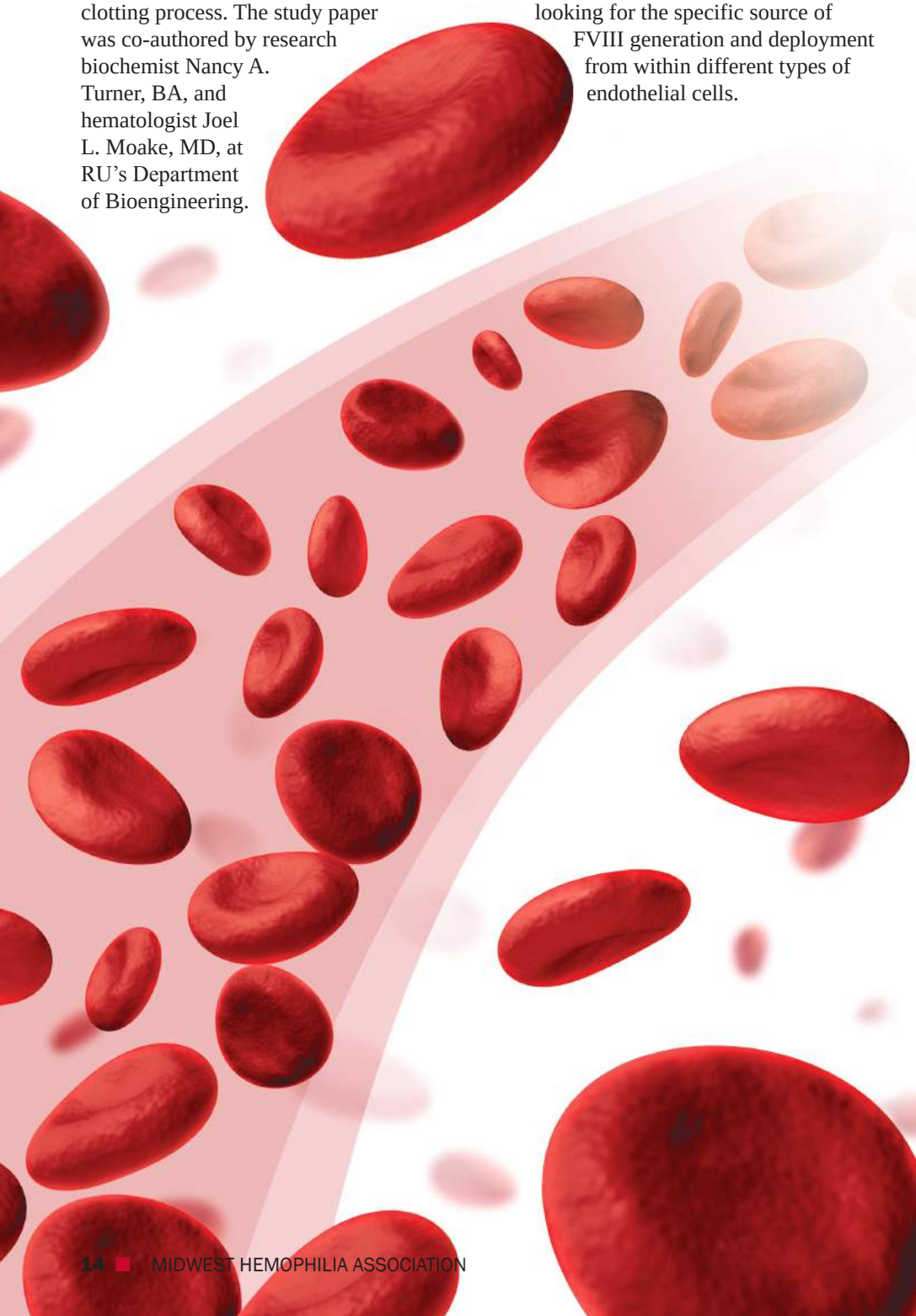
AlphaNine SD Pay as Little as $0 CoPay program

- Visit www.alphaninecard.com or call (877) 264-1405 and speak with a customer experience center support person

# Researchers Learn More about FVIII Origins

In breakthrough research, Rice University (RU) scientists have uncovered more about the cellular origins of factor VIII (FVIII), a protein that plays a critical role in the blood clotting process. The study paper was co-authored by research biochemist Nancy A. Turner, BA, and hematologist Joel L. Moake, MD, at RU's Department of Bioengineering.

Earlier studies established that FVIII is produced in endothelial cells that line the walls of blood vessels in organs such as the heart, liver and intestines. RU investigators have delved further by looking for the specific source of FVIII generation and deployment from within different types of endothelial cells.



Turner and Moake's experiments focused on human umbilical vein endothelial cells (HUVECs), which are found in large veins, and glomerular microvascular endothelial cells (GMVECs), which are located in the smallest capillaries of the kidneys. Although the presence of FVIII in these types of cells had not been previously confirmed, investigators had recognized them, particularly HUVECs, as a viable focus of research for several reasons.

"HUVECs are the generic human endothelial cells that (biological researchers) use the first time they do anything," Turner said. "They're cheap. They're easy to work with, and they've been the model for endothelial cells for, I don't know, at least 50 years."

With her expertise in biochemistry, Turner first conducted a series of lab tests to verify the presence of FVIII in HUVECs and GMVECs. Follow-up research confirmed that FVIII is not only synthesized in HUVECs and GMVECs, but is also stored in and secreted from Weibel-Palade bodies (WPBs) within these cells. WPBs are specialized organelles (part of a cell with a specific function) that also contain von Willebrand factor (VWF), another critical protein that binds to FVIII during the clotting cascade. VWF works as a carrier for FVIII as it circulates in the bloodstream.

This discovery has future potential therapeutic significance for people with bleeding disorders. "Now that we recognize that factor VIII is normally synthesized in endothelial cells and stored in Weibel-Palade bodies, those become the precise, most effective physiological targets for gene delivery," concluded Moake.

The article, "Factor VIII Is Synthesized in Human Endothelial Cells, Packaged in Weibel-Palade Bodies and Secreted Bound to ULVWF Strings," was published online October 16, 2015, in the journal PLOS ONE. ■

*– Source: Rice University news release dated November 2, 2015*

## **MOVING?** New Address

Name

Address

City State ZIP

(Area Code) Phone Number

E-Mail Address

MAIL TO: MHA • PO Box 412866 • Kansas City, MO 64141
E-MAIL TO: *info@midwesthemophilia.org*

**Midwest Hemophilia Association**
PO Box 412866
Kansas City, MO 64141

# Give the Gift of a Lifetime

You can support the Midwest Hemophilia Association by making a planned giving gift. Whether it is a gift of your estate, a trust gift, stock or life insurance you can give to MHA with a gift that won't alter your daily financial commitments.

A planned gift is a tried and true method of charitable giving. It's the gift that keeps on giving and enables you to support MHA and those with bleeding disorders in perpetuity.

So when you are talking about your estate gifts, please consider a planned gift to the Midwest Hemophilia Association.

**Midwest Hemophilia Association**