

Hemophilia News and Views

Spring Edition 2017

Inside this issue:

Calendar of Events	3
Washington Days	6
Sign up for the Hemophilia Walk	9
Prediabetes: No Excuses	10
Winter Wine Fest	13
Camp Independent Firefly 2017	14
Come to the Reno Ace's Game	16
Register for Events on our Website	17

Chapter News

Spring has arrived and along with it a very busy time for NHF Nevada. As this newsletter hits your mailbox, chapter staff and volunteers will be participating in our State Legislative Day on April 10th in Carson City. Everyone is looking forward to sharing their stories and advocating for all Nevadans with bleeding disorders. Next up in April will be our Leaders in Training/Jr. Counselor Training.

Our Golf 4 the Kids Tournament will start off with a bang on May 1st at Red Rock Country Club. There are several foursomes still available. Please let us know if you or someone you know would like to participate. Then it is onto our second

annual Hispanic Education Day. Please see the bottom of this page for more information.

As many of you know, Camp Independent Firefly is being held earlier this year, June 13–17, 2017. If you have submitted a camper application for your child you will be notified by April 15th if they have been accepted. Unfortunately, we have more applications than camper spots available this year.

For those of you who reside in Northern Nevada, please save the date for our upcoming Northern Nevada Education Weekend, July 21–23, 2017. The weekend will take

place in Elko, Nevada and will include a day camp experience for the kids as well as many interesting education topics for adults.

In closing, we would like to thank everyone who attended our Winter Wine Fest! The event was a huge success for the second year in a row and raised \$30,000 for program services! Thank you to our board members and wine committee for knocking this event out of the park!

Kelli, Anne, & Maureen

RSVP Today!
Hispanic Education Day
Saturday, May 6, 2017
9:30 am-2:30 pm
Texas Station Convention Center

Please join us for our 2nd annual Hispanic Education Day. All sessions will be given in Spanish. There will be sessions on: What do you know about vWD, Hemophilia is a Genetic Disorder, and Continuing the Conversation.

We also have a fun and exciting day planned for our youth program.

You can RSVP at hfnv.org (click on the Calendar of Events), by emailing Maureen at mmagana@hemophilia.org or by calling 702-564-4368.

**LIVING!**
with HEMOPHILIA

Looking for a new, fresh perspective on living with hemophilia?

Introducing your all NEW guide to **Living With Hemophilia**

Discover the new online destination for learning about hemophilia, living a healthy life and even leading in the hemophilia community. It's all at the new **LivingWithHemophilia.com**. Our site has been totally redesigned to give you more of the information you want and less of the stuff you don't want.

See What's New at

www.LivingWithHemophilia.com



Nevada Chapter of the National Hemophilia Foundation 2017 Program and Events Calendar

April 10, 2017

State Legislative Day
Carson City, NV

April 22-23, 2017

Leaders In Training

April 30, 2017

Youth Golf Clinic
Red Rock Country Club

May 1, 2017

Golf for the Kids
Red Rock Country Club

May 6, 2017

Hispanic Heritage Event
Texas Station

June 13-17, 2017

Camp Independent Firefly
Big Bear, CA

July 15, 2017

Couples Retreat
Henderson, NV

July 21-23, 2017

Northern Nevada Family Weekend
Elko, NV

August 5, 2017

Back to School Picnic
YMCA Pool

August 24-26, 2017

NHF Annual Meeting
Chicago, IL

September 16, 2017

Reno Walk & 5K
Bartley Ranch Park

September 23, 2017

Las Vegas Walk & 5K
Floyd Lamb Park

Cheer him on—
Because you can help prepare your
active guy for moments like these

xyntha[®] solofuse[®]
Antihemophilic Factor (Recombinant)

BRING IT
DON'T WING IT, MOM

XYNTHA SOLOFUSE is a factor VIII that brings together bleed prevention and control with all-in-one reconstitution in a travel-ready kit

From financial support to community connections, whatever questions you have, we can help—Pfizer Hemophilia Connect 1.844.989.HEMO(4366)



What is XYNTHA?

XYNTHA[®] Antihemophilic Factor (Recombinant) is indicated in adults and children for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for the prevention of bleeding during surgery in patients with hemophilia A.

XYNTHA does not contain von Willebrand factor and, therefore, is not indicated for von Willebrand's disease.

Important Safety Information for XYNTHA

- Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction: wheezing, difficulty breathing, chest tightness, turning blue (look at lips and gums), fast heartbeat, swelling of the face, faintness, rash, low blood pressure, or hives. XYNTHA contains trace amounts of hamster protein. You may develop an allergic reaction to these proteins. Tell your healthcare provider if you have had an allergic reaction to hamster protein

- Call your healthcare provider right away if bleeding is not controlled after using XYNTHA; this may be a sign of an inhibitor, an antibody that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests to monitor for inhibitors
- Across all clinical studies, the most common side effects (10% or more) with XYNTHA in adult and pediatric previously treated patients (PTPs) were headache (26% of subjects), joint pain (25%), fever (21%), and cough (11%). Other side effects reported in 5% or more of patients were: diarrhea, vomiting, weakness, and nausea
- XYNTHA is an injectable medicine administered by intravenous (IV) infusion. You may experience local irritation when infusing XYNTHA after reconstitution in XYNTHA[®] SOLOFUSE[®].

Please see Brief Summary for XYNTHA and XYNTHA SOLOFUSE on the following page.

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.



Antihemophilic Factor (Recombinant)



Antihemophilic Factor (Recombinant)

R_x only

Brief Summary

See package insert for full Prescribing Information, including patient labeling. For further product information and current patient labeling, please visit XYNTHA.com or call Pfizer Inc toll-free at 1-800-879-3477.

Please read this Patient Information carefully before using XYNTHA and each time you get a refill. There may be new information. This leaflet does not take the place of talking with your healthcare provider about your medical problems or your treatment.

What is XYNTHA?

XYNTHA is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia A. Hemophilia A is also called classic hemophilia. Your healthcare provider may give you XYNTHA when you have surgery.

XYNTHA is not used to treat von Willebrand's disease.

What should I tell my healthcare provider before using XYNTHA?

Tell your healthcare provider about all your medical conditions, including if you:

- have any allergies, including allergies to hamsters,
- are pregnant or planning to become pregnant. It is not known if XYNTHA may harm your unborn baby.
- are breastfeeding. It is not known if XYNTHA passes into your milk and if it can harm your baby.

Tell your healthcare provider and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

How should I infuse XYNTHA?

Step-by-step instructions for infusing with XYNTHA are provided at the end of the complete Patient Information leaflet. The steps listed below are general guidelines for using XYNTHA. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedures, please call your healthcare provider before using.

Call your healthcare provider right away if bleeding is not controlled after using XYNTHA. Your body can also make antibodies against XYNTHA (called "inhibitors") that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests from time to time to monitor for inhibitors.

Call your healthcare provider right away if you take more than the dose you should take.

Talk to your healthcare provider before traveling. Plan to bring enough XYNTHA for your treatment during this time.

What are the possible side effects of XYNTHA?

Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction:

- wheezing
- difficulty breathing
- chest tightness
- turning blue (look at lips and gums)
- fast heartbeat
- swelling of the face
- faintness
- rash
- hives

Common side effects of XYNTHA are

- headache
- fever
- nausea
- vomiting
- diarrhea
- weakness

Talk to your healthcare provider about any side effect that bothers you or that does not go away. You may report side effects to FDA at 1-800-FDA-1088.

How should I store XYNTHA?

Do not freeze.

Protect from light.

XYNTHA Vials

Store XYNTHA in the refrigerator at 36° to 46°F (2° to 8°C). Store the diluent syringe at 36° to 77°F (2° to 25°C).

XYNTHA can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA at room temperature, carefully write down the date you put XYNTHA at room temperature, so you will know when to either put it back in the refrigerator, use it immediately, or throw it away. There is a space on the carton for you to write the date.

If stored at room temperature, XYNTHA can be returned one time to the refrigerator until the expiration date. Do not store at room temperature and return it to the refrigerator more than once. Throw away any unused XYNTHA after the expiration date.

Infuse XYNTHA within 3 hours of reconstitution. You can keep the reconstituted solution at room temperature before infusion, but if you have not used it in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

XYNTHA SOLOFUSE

Store in the refrigerator at 36° to 46°F (2° to 8°C).

XYNTHA SOLOFUSE can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA SOLOFUSE at room temperature, carefully write down the date you put XYNTHA SOLOFUSE at room temperature, so you will know when to throw it away. There is a space on the carton for you to write the date.

Throw away any unused XYNTHA SOLOFUSE after the expiration date.

Infuse within 3 hours after reconstitution or after removal of the grey rubber tip cap from the prefilled dual-chamber syringe. You can keep the reconstituted solution at room temperature before infusion, but if it is not used in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

What else should I know about XYNTHA?

Medicines are sometimes prescribed for purposes other than those listed here. Talk to your healthcare provider if you have any concerns. You can ask your healthcare provider for information about XYNTHA that was written for healthcare professionals.

Do not share XYNTHA with other people, even if they have the same symptoms that you have.

This brief summary is based on the Xyntha® [Antihemophilic Factor (Recombinant)] Prescribing Information LAB-0516-5.0, revised 1Q/14, and LAB-0500-9.0, revised 1Q/14.



NHF Nevada once again participated in the National Hemophilia Foundation's (NHF) annual Washington Days advocacy event on March 8-10, 2017 on Capitol Hill in Washington, DC. Our chapter was lucky enough to have seven wonderful people participate and advocate for all Nevadans with Bleeding Disorders. We would like to thank Amber Federizo, Kelly Gonzalez, Sonia Arevalo, Lisa Cervantes, Jacey Gonzalez, and Maureen Salazar-Magana, for participating! Maureen was a first time attendee and said "It was an amazing experience to be in a room of so many people fighting for the same things!"

There was a record-breaking number of participants in this year's Washington Days. More than 480 volunteer advocates from 46 states met with legislators and staff to discuss maintaining key patient protections in the Affordable Care Act (ACA). NHF's Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that are important to them. NHF's advocacy this year focused on the debate surrounding the repeal and replacement of the ACA and how that has affected the bleeding disorders community.

This year we asked our volunteer advocates to ask Congress to keep several key patient protections in any healthcare legislation that might be introduced to replace the Affordable Care Act (ACA).

Maintain the elimination of lifetime and annual limits on essential health benefits.

Maintain federal requirements for essential health benefits to ensure patient protections are meaningful.

Maintain the Medicaid expansion, including the categorical eligibility for childless men and women and the enhanced federal funding for the expansion population.

During the first day, attendees participated in training sessions on how to present the issues to members of Congress and how to effectively use social media for advocacy. Former Senator Byron Dorgan (D-ND) spoke to attendees about the power of their personal story when speaking with members of Congress. The following day all participants met on Capitol Hill with a full day of meetings, followed by a State Advocacy Recognition Dinner, which honored the many chapters who worked to have March recognized as Bleeding Disorders Awareness Month in 2016 and 2017. Washington Days concluded with breakfast and a state advocacy training, where participants learned effective local advocacy approaches.





He's free to infuse only
once every 14 days.
Are you?

The only FDA-approved treatment for hemophilia B with up to 14-day dosing.* **Visit us at IDELVION.com.**



Dosing schedule that fits into your lifestyle



High and sustained Factor IX levels at steady state[†]



Zero median annualized spontaneous bleeding rate (AsBR) when dosed at 7 or 14 days in clinical trials

Protection with peace of mind—**low incidence of side effects**

*Appropriate people 12 years and older may be eligible for 14-day dosing. Talk with your doctor.
†Average FIX levels with 7-day dosing over 92 weeks in clinical trials.

Important Safety Information

IDELVION is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing,

lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

In clinical trials for IDELVION, headache was the only side effect occurring in more than 1% of patients (1.8%), but is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away, or if bleeding is not controlled with IDELVION.

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 brief summary of prescribing information for IDELVION on next page.

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein
Initial U.S. Approval: 2016

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use IDELVION safely and effectively. Please see full prescribing information for IDELVION, which has a section with information directed specifically to patients.

What is IDELVION?

IDELVION is an injectable medicine used to replace clotting Factor IX that is absent or insufficient in people with hemophilia B. Hemophilia B, also called congenital Factor IX deficiency or Christmas disease, is an inherited bleeding disorder that prevents blood from clotting normally.

IDELVION is used to control and prevent bleeding episodes. Your healthcare provider may give you IDELVION when you have surgery. IDELVION can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use IDELVION?

You should not use IDELVION if you have had life-threatening hypersensitivity reactions to IDELVION or are allergic to:

- hamster proteins
- any ingredients in IDELVION

Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using IDELVION.

What should I tell my healthcare provider before using IDELVION?

Discuss the following with your healthcare provider:

- Your general health, including any medical condition you have or have had, including pregnancy, and any medical problems you may be having
- Any medicines you are taking, both prescription and non-prescription, and including any vitamins, supplements, or herbal remedies
- Allergies you might have, including allergies to hamster proteins

- Known inhibitors to Factor IX that you've experienced or been told you have (because IDELVION might not work for you)

What must I know about administering IDELVION?

- IDELVION is administered intravenously, directly into the bloodstream.
- IDELVION can be self-administered or administered by a caregiver with training and approval from your healthcare provider or hemophilia treatment center. **(For directions on reconstituting and administering IDELVION, see the Instructions for Use in the FDA-Approved Patient Labeling section of the full prescribing information.)**
- Your healthcare provider will tell you how much IDELVION to use based on your weight, the severity of your hemophilia B, your age, and other factors. Call your healthcare provider right away if your bleeding does not stop after taking IDELVION.
- Blood tests may be needed after you start IDELVION to ensure that your blood level of Factor IX is high enough to properly clot your blood.

What are the possible side effects of IDELVION?

Allergic reactions can occur with IDELVION. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

IDELVION might increase the risk of abnormal blood clots forming in your body, especially if you have risk factors for such clots. Call your healthcare provider if you experience chest pain, difficulty breathing, or leg tenderness or swelling while being treated with IDELVION.

A common side effect of IDELVION is headache. This is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full prescribing information, including FDA-approved patient labeling.

Based on November 2016 PI revision.

References: 1. Data on file. Available from CSL Behring as DOF IDL-002.

IDELVION is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC. IDELVION® is a registered trademark of CSL Behring Recombinant Facility AG. Biotherapies for Life® is a registered trademark of CSL Behring LLC.

©2017 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA
www.CSLBehring-us.com www.IDELVION.com IDL16-02-0032(1) 1/2017



WALKING DOESN'T MAKE BETTER TREATMENTS FOR BLEEDING DISORDERS, BUT FUNDRAISING DOES! WILL YOU STEP UP?



Saturday, September 17th in Reno
Saturday, September 24th in Las Vegas
Registration is Now Open!



The first 10 people to register and raise or donate \$50 will receive your choice of Hemophilia Walk branded headphones or picnic blanket.
To Register go to www.hfnv.org

The Nevada Chapter of the National Hemophilia Foundation is dedicated to improving the quality of care and life for people with hemophilia, von Willebrand disease, and other inherited bleeding disorders through education, peer support, and advocacy.

Staff

Executive Director-Kelli Walters
 Chapter Events Manager-Anne McGuire
 Chapter Bilingual Program Manager-Maureen Salazar-Magana

Advisory Board of Directors

President-Brandi Dawkins
 Vice President-Marcela Custer
 Treasurer-Doug May
 Secretary-Doug May
 Board Member-James Arriola
 Board Member-Tanya Butler
 Board Member-Lupe Torres

Hemophilia News and Views is published 4 times a year by the Nevada Chapter of the National Hemophilia Foundation (NHF-NV). We welcome advertisers. Please contact the office at 702.564.4368 for advertising rates.

The material in this newsletter is provided for your general information only. The Nevada Chapter does not give medical advice or engage in the practice of medicine. NHF-NV does not recommend particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

Prediabetes: No Excuses

CDC and partners launch awareness campaign

By Sarah M. Aldridge, MS | 10.31.2016

Eighty-six million Americans are walking around with a precursor to a disease they don't know they could develop, but one they can help prevent. It's called prediabetes and it's so important that the US Centers for Disease Control (CDC), American Diabetes Association (ADA), American Medical Association and the Ad Council are linking arms to make you aware of it. The theme of the new campaign is "No one is excused from prediabetes." It will get your attention via TV, radio, print and social media ads and videos, provided in English and Spanish. A simple seven-question risk assessment test on the website: doihaveprediabetes.org can help you figure out if your risk is high.

What is prediabetes?

Type 2 diabetes results when your body doesn't use the hormone insulin effectively. Insulin moves glucose, a type of sugar that results when carbohydrates are broken down during digestion, out of the bloodstream and into cells. A warning sign of diabetes is a condition called prediabetes. With prediabetes, your blood sugar levels are above normal, but not high enough for an official diabetes diagnosis. (See Sidebar, "Testing for Prediabetes.") But that doesn't mean you're home free. Elevated sugar levels in the blood are known to contribute to cardiovascular disease, such as heart disease and strokes. According to the CDC, 15%–30% of people with prediabetes will develop type 2 diabetes within five years.

Who's at risk?

The ad campaign uses a real-time test during 60-second TV commercials so viewers can find out on the spot if they're at risk. Here are the main risk factors for prediabetes:

- Age: Over 45 years old
- Weight: Being overweight or obese
- Family history: a sibling or parent with diabetes
- Ethnicity: African American, Hispanic/Latino, American Indian, Asian American, Pacific Islander
- Low HDL (good) cholesterol and/or high triglycerides
- Sedentary lifestyle
- High blood pressure or taking high blood pressure medication
- Gestational diabetes when pregnant; delivering a baby weighing 9 pounds or more
- Polycystic ovary syndrome

People in the bleeding disorders community have their own risk factors that increase the likelihood of prediabetes leading to full-blown diabetes. Viral infections, such as HIV and hepatitis C infection (HCV) contracted decades ago from contaminated factor products, can cause chronic inflammation, which can lead to diabetes. Further, some HIV medications are linked with higher rates of diabetes. In addition, HCV is known to prevent the body's regulation of blood sugar levels, another contributor to diabetes. (Read "The Details on Diabetes")

Group accountability

Although some people are self-motivated, lots of us need the accountability of a group to take action when it comes to our health. The CDC's National Diabetes Prevention Program uses lifestyle coaches in a small group setting to encourage people to proactively manage prediabetes. The groups meet weekly for about six months. Each week they tackle such topics as: "Be a Fat and Calorie Detective," "Talk Back to Negative Thoughts," "Jump Start Your Activity Plan" and "Ways to Stay Motivated." The coach helps participants learn to choose healthy foods, add some activity into their daily planner and maintain a healthier lifestyle permanently. Find out if your insurance company or employer covers such programs, which also may be offered by your local YMCA.

Small steps, large improvements

If you're feeling overwhelmed by the changes you want to make, remember that small steps can lead to large improvements. According to the CDC, losing just 5%–7% of your body weight (around 10–14 pounds for a 200-pound person) can slow or reverse prediabetes. To start, you might swap sugary sodas for water or substitute a crunchy apple for your nightly ice cream habit. If you've been inactive, taking up a new sport may seem daunting, but most everyone can walk. Give up 30 minutes of TV watching to take a daily walk with your spouse or grandkids. The CDC recommends at least 150 minutes of activity each week. "Activity" can mean anything from house cleaning to weeding.

Lastly, having a plan can keep you motivated. Set realistic goals, such as making one change in your diet or adding one new activity. The ADA says some of the keys to weight loss success in people with prediabetes or diabetes are: eating breakfast, reducing daily calories and fats consumed, being active most days of the week and documenting your data. No longer do you have to write down in a journal everything you eat and drink, when you exercised last and how much you weighed. There are phone apps that do all of that and more, such as MyFitnessPal.com, a web-based program that includes a smartphone app.

Defeating prediabetes

If you've taken the prediabetes risk test and scored a 5 or higher, don't make a list of excuses for why you can't deal with it right now. Schedule an appointment to see your primary care physician. Together you can map out a strategy for defeating prediabetes. Your payback for investing in yourself will be a longer, healthier life.



ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]

For patients with Hemophilia A, the FDA has now approved ADYNOVATE[®] for

- + Use in children under 12
- + Use in surgery

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 (N=73) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months.^{1,2}

+Sixty-six patients (32 patients aged <6 years and 34 patients aged 6 to <12 years) received 40-60 IU/kg of ADYNOVATE prophylactically, twice weekly²

+Children 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^{1,2}

+38% (n=25) of children 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 following page for ADYNOVATE Important Facts.

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

References: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc. 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; Shire US Inc.

©2017 Shire US Inc., Lexington, MA 02421. All rights reserved. 1-800-828-2088.

SHIRE and the Shire Logo are registered trademarks of Shire Pharmaceutical Holdings Ireland Limited or its affiliates. ADVATE and ADYNOVATE are trademarks or registered trademarks of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc. S17617 0V17





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.

Baxalta, Advate, and Adynovate are trademarks of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc.

Baxalta US Inc.
Westlake Village, CA 91362 USA
U.S. License No. 2020
Issued 12/2016

161045-ADY-US 524587 01/17



Winter Wine Fest

Our 2nd Annual Winter Wine Fest was a huge success. We have tallied the numbers and have raised over \$30,000! Thank you to our 200+ attendees for coming and enjoying a successful event. Many, many thanks to our incredible sponsors, Board Members and Wine Committee members that made this event so successful.

As Bleeding Disorders Awareness Month comes to an end, we want to express our sincere gratitude towards those who support our mission of helping the bleeding disorder community of Nevada.



Winter Wine Fest

Thank you to the sponsors who helped make this event SPARKLE!

Gold Sponsors

BAYER **Shire**
Science For A Better Life

Biotherapies for Life™ **CSL Behring**

Silver Sponsors

octapharma **FACTOR**
SUPPORT NETWORK
an hemo-lympho-platelet company

Bioerativ

Bronze Sponsors

NOVO NORDISK **Pfizer** **Hemophilia**

In Kind Sponsors

Constellation Brands **BRIO** **TIVOLI**



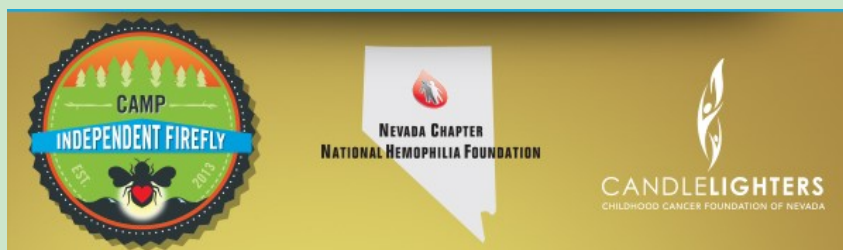
Camp Independent Firefly 2017

June 13 – 17, 2017

What fun we have in store for our campers!
This year's theme is Lights, Camera, Action!

Campers and Parents: keep a look out for your Camper packet – it should be arriving in your mail box after May 1st. If you do not receive it, please call our office at 702.564.4368.

Please start planning now and make sure that you have the appropriate amount of factor and/or other medications on hand to send to camp with your child. All medications will need to be checked into the nurse at the bus drop-off location. Please remember to pack closed toe shoes, long pants and a jacket for nighttime. All campers are required to check-in their cell phones before getting off the bus in Big Bear. They can power them up again once they are on the return bus back to Las Vegas.



HEMOPHILIA TREATMENT CENTER OF NEVADA

LAS VEGAS ♦ RENO ♦ WINNEMUCCA ♦ OWYHEE DUCK VALLEY INDIAN RESERVATION ♦ ELY ♦ ELKO

NEVADA'S ONLY FEDERALLY RECOGNIZED HTC

**We are PROUD to have
two HTC Locations!**

Las Vegas

3121 S. Maryland Pkwy., Suite 206
Las Vegas, NV 89109
702-732-1956

Reno

540 W. Plumb Lane, Suite 200
Reno, NV 89509
775-657-8981

Outreach Clinic Locations

Winnemucca, Owyhee Duck Valley
Indian Reservation, Ely and Elko

Comprehensive Care Plan

Our comprehensive care plan includes a diagnostic evaluation for hemophilia, von Willebrand disease and other bleeding and clotting disorders.

We maintain inventory of all factor therapies and assays to minimize delays in your care.

We promote positive health outcomes for all our patients and help coordinate home nursing services when needed.

Join our 340B Program Today!

Benefits of enrolling in HTC NV 340B

- ♦ Reduced factor costs
- ♦ Generates resources for:
 - ♦ Outreach clinics
 - ♦ Youth groups
 - ♦ School visits
 - ♦ Community educational events
 - ♦ Family retreats & summer camp
- ♦ Full time Nurse Practitioners
- ♦ Full time Social Worker
- ♦ Full time Physical Therapist
- ♦ Dental Assistance Program

Contacts:

Becki Berkowitz, R.N.
Hemophilia Nurse
Coordinator
702-732-1956

Jennifer Roberts, CPht
Patient Care Coordinator
340 B Compliance
702-732-1956

340 B Contract Pharmacy
Factor Support Network
Kelly Gonzalez
Regional Care Coordinator
702-858-2525

Meet Jessica, your CoRe Manager



Hello! I'm Jessica Klass, and my brother has hemophilia A. I'm also a CoRe Manager for Bioverativ. It is my job to connect you with others in the community, share insights taken from my personal experience, introduce our educational programs, and to support you on your journey. I am here so we can take action together!

Contact me!

[Jessica.Klass@bioverativ.com] | [623.238.0244]





HEMOPHILIA TREATMENT CENTER
OF NEVADA

Sunday May 28th, 2017 @6:05pm

Reno Aces

VS

Sacramento River Cats

\$16 Tickets

Half of the proceeds will be benefiting

Camp Independent Firefly

For More Information, to Purchase Tickets, or Make a Donation

Please Contact

Lisa Cervantes @ 775-657-8981 or lcervantes@htc4nv.org

Show your Support and help us in sending our Amazing kids to camp!!

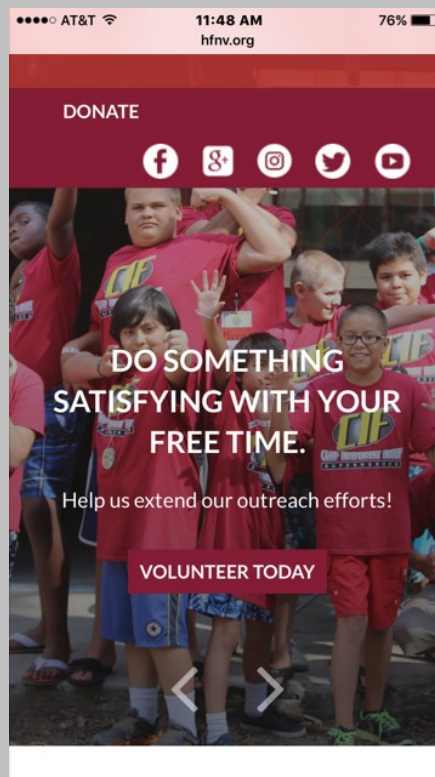
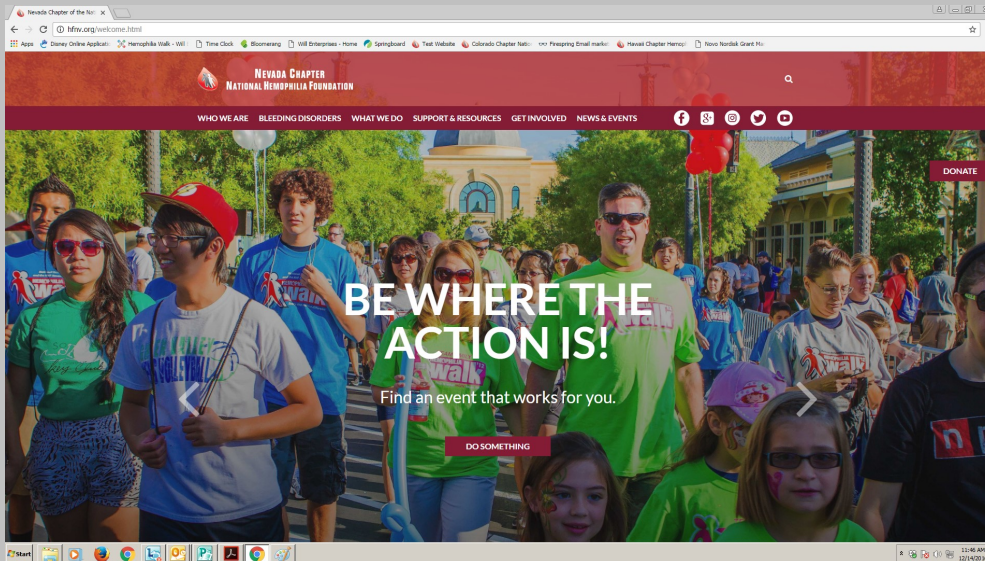
Last Day for Ticket Purchase is 5/14/2017



Register for Events on NHF Nevada's new Website!

We are excited to announce that NHF Nevada has a new and improved website! The website is updated daily and gives you the ability to register for programs and events! It is mobile friendly too! Check it out at www.hfnv.org. It also includes links to national resources!

To register for one of our upcoming programs and events on our event calendar. Go to www.hfnv.org, click on **News & Events** and then go to the **Event Calendar**.



Biotherapies for Life* **CSL Behring**



For adults and children with hemophilia A

REACH HIGHER

With the Long-lasting Protection of AFSTYLA

2X
WEEKLY
AVAILABLE

FDA-approved for dosing 2 or 3 times a week

ZERO
BLEEDS
(Median ABR*)

In clinical trials, whether dosed 2 or 3 times a week

COMPARABLE TO
NATURAL
FACTOR
VIII

Identical to natural Factor VIII once activated

Zero inhibitors observed—Low incidence of side effects in clinical trials

In clinical trials, dizziness and allergic reactions were the most common side effects.

Visit AFSTYLA.com to sign up for the latest news

*Annualized spontaneous bleeding rate in clinical trials (interquartile range [IQR])—0–2.4 for patients ≥12 years; 0–2.2 for patients <12 years.

Important Safety Information

AFSTYLA is used to treat and control bleeding episodes in people with hemophilia A. Used regularly (prophylaxis), AFSTYLA can reduce the number of bleeding episodes and the risk of joint damage due to bleeding. Your doctor might also give you AFSTYLA before surgical procedures.

AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition. Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

Immediately stop treatment and contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against FVIII, which could stop AFSTYLA from working properly. You might need to be tested for inhibitors from time to time. Contact your healthcare provider if bleeding does not stop after taking AFSTYLA.

In clinical trials, dizziness and allergic reactions were the most common side effects. However, these are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does 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 brief summary of full prescribing information on the adjacent page, and the full prescribing information, including patient product information, at AFSTYLA.com.

AFSTYLA is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC. AFSTYLA® is a registered trademark of CSL Behring Recombinant Facility AG. Biotherapies for Life® is a registered trademark of CSL Behring LLC.

©2016 CSL Behring LLC 1020 First Avenue, PO Box 01501, King of Prussia, PA 19406-0901 USA
www.CSLBehring-us.com www.AFSTYLA.com AFS16-05-0094 5/2016

AFSTYLA®
Antihemophilic Factor
(Recombinant), Single Chain

**AFSTYLA[®], Antihemophilic Factor (Recombinant), Single Chain
For Intravenous Injection, Powder and Solvent for Injection
Initial U.S. Approval: 2016**

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use AFSTYLA safely and effectively. Please see full prescribing information for AFSTYLA, which has a section with information directed specifically to patients.

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

- Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion on your own.
- Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing this medicine.

What is AFSTYLA?

- AFSTYLA is a medicine used to replace clotting Factor VIII that is missing in patients with hemophilia A.
- Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.
- Does not contain human plasma derived proteins or albumin.
- Your healthcare provider may give you this medicine when you have surgery.
- Is used to treat and control bleeding in all patients with hemophilia A.
- Can reduce the number of bleeding episodes when used regularly (prophylaxis) and reduce the risk of joint damage due to bleeding.
- Is not used to treat von Willebrand disease.

Who should not use AFSTYLA?

You should not use AFSTYLA if you:

- Have had a life-threatening allergic reaction to it in the past.
- Are allergic to its ingredients or to hamster proteins.

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

What should I tell my healthcare provider before using AFSTYLA?

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 hamster proteins.
- Have been told you have inhibitors to Factor VIII (because this medicine may not work for you).

How should I use AFSTYLA?

- Administer directly into the bloodstream.
- Use as ordered by your healthcare provider.
- You should be trained on how to do intravenous injections by your healthcare provider or hemophilia treatment center. Once trained, many patients with hemophilia A are able to inject this medicine by themselves or with the help of a family member.
- Your healthcare provider will tell you how much to use based on your weight, the severity of your hemophilia A, and where you are bleeding.
- You may need to have blood tests done after getting 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 this medicine.

What are the possible side effects of AFSTYLA?

- Allergic reactions may occur. Immediately stop treatment and call your healthcare provider right away if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.
- Your body may form inhibitors to Factor VIII. An inhibitor is a part of the body's defense system. If you form inhibitors, it may stop this medicine from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.
- Common side effects are dizziness and allergic reactions.
- These are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

What else should I know about AFSTYLA?

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

Please see full prescribing information, including full FDA-approved patient labeling. For more information, visit www.AFSTYLA.com

Manufactured by:
CSL Behring GmbH
35041 Marburg, Germany

for:
CSL Behring Recombinant Facility AG
Bern 22, Switzerland 3000
US License No. 2009

Distributed by:
CSL Behring LLC
Kankakee, IL 60901 USA

National Hemophilia Foundation
Nevada Chapter
7473 W. Lake Mead Blvd. Suite 100
Las Vegas, NV 89128

NON-PROFIT ORG.
U.S. POSTAGE PAID
LAS VEGAS, NV
PERMIT NO. 447

Phone: 702-564-4368
website: www.hfnv.org

ACT—Access to Care Today
Achieve a CURE Tomorrow



Golf 4 The Kids
Benefiting Cure 4 The Kids Foundation
and the Nevada Chapter of the
National Hemophilia Foundation

Our goal is to raise funds for the life-saving treatment, educational and outreach efforts provided to children with cancer and rare diseases as well as those with life-threatening inherited bleeding disorders.

Date: Mon., May 1, 2017	Location: Red Rock Country Club	Reg: 9:30 AM	Shotgun Start: 11:00 AM
-----------------------------------	---	------------------------	-----------------------------------

Longest Drive Contest **Closest to The Pin** **Putting Contest & More**