

### NEVADA CHAPTER NATIONAL HEMOPHILIA FOUNDATION www.hfnv.org

# **Hemophilia News and Views**

### Fall Edition 2016

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Greetings! I am sure you are as happy as we are that we are finally enjoying cooler weather. Summer was the busiest the chapter has ever seen with 10 programs and events. Our Golf 4 the Kids Tournament, which was held in June, was a hot one and raised \$30,000 for programs and services, including camp! Thank you to all our sponsors and golfers!

In July we held two programs for the very first time. At our Couples Retreat, 15 couples participated in a day long workshop addressing issues specific to couples affected by bleeding disorders, as

### **Chapter News**

well as issues that are common for all adults in an intimate relationship. The retreat received high marks from the participants and will be held again in 2017.

The second new event was our inaugural "Back to School" event. One hundred adults and children received information on how to best prepare and the steps necessary to help ensure a successful school year. All school aged children received a backpack filled with school supplies. Thank you to nurse Becki from the HTC of Nevada for providing the valuable

### information!

The summer concluded with our Reno and Las Vegas Hemophilia Walks! Thank you to the over 400 walkers and runners who participated and helped raise \$62,000! We are starting to gear up for the Las Vegas Annual Education Meeting and Holiday party along with the Holiday parties in Elko and Reno. Keep a look out for the invitations.

felli and ame

Annual Meeting & Holiday Celebration Saturday, November 19th 12:30 pm – 6:30 pm City of Henderson Convention Center 200 South Water Street Henderson, NV 89015 We are in need of raffle items. If you can donate something toward the raffle please

We are in need of raffle items. If you can donate something toward the raffle please let us know. If you would like to solicit businesses you frequent, we can provide you with a request letter.

### **RSVP by November 8th**





## access solutions



Don't let insurance or financial challenges get between you and your treatment

### Free Trial Program\*

- Enroll today for up to 6 free doses<sup>†</sup>
- Delivered to your home free of charge

### Access to Therapy

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- Experience challenges getting insurance coverage for a Bayer product
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- You may be able to receive up to \$12,000 in assistance per year, regardless of income
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- · Consult with an expert in insurance
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CALL **1-800-2888-8374** 8-00 AU 8-00 PU (ET) Mondry: Friday: Spanish, speaking Case Spacialists are also available

8:00 лм-8:00 рм (ET) Monday-Friday. Spanish-speaking Case Specialists are also available.

\*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Participation in the Free Trial Program is limited to 1 time only. This program is complimentary and is not an obligation to purchase or use a Bayer product in the future. Reselling or billing any third party for the free product is prohibited by law. The Free Trial Program includes up to 6 free doses to a maximum of 5,000 IU for new patients and 40,000 IU for previously treated patients.

\*The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future product purchases. Reseiling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

People with private, commercial health insurance may receive co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.

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### Nevada Chapter of the National Hemophilia Foundation 2016-17 Program and Events Calendar

October 26, 2016 Dinner—Sponsored by Grifols Las Vegas, NV

> November 9, 2016 Education Dinner Reno, NV

November 10, 2016 Color Me Mine Fundraiser Henderson and Las Vegas

**November 19, 2016** Annual Family Conference and Holiday Celebration Henderson, NV

> December 7, 2016 Holiday Celebration Elko, NV

> December 8, 2016 Holiday Celebration Reno, NV

February 2017 Silent Auction and Wine Tasting Event Tivoli Village—Las Vegas, NV

> June 5, 2017 Golf for the Kids Red Rock Country Club

June 13-17, 2017 Camp Independent Firefly Big Bear, CA

**July 21-23, 2017** Northern Nevada Family Weekend Elko, NV

> August 24-26, 2017 NHF Annual Meeting Chicago, IL





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Wagner Lemus President Tel: 310.291.7270

Antonio Rosas Vice President Tel: 323.204.8974

### Acceso 24/7 a Farmacéuticos con Experencia

Nuestros farmacistas son especializados en el tratamiento de Hemofilia y estan disponibles para contestar sus preguntas 24 horas al día, 7 días por la semana.

### Cadena de Suministro de Factor de Coagulación Segura

Obtenemos nuestro Factor de Coagulación exclusivamente de Centros de Distribución de clase Mundial. Siempre recibirá el producto que necesita, cuando lo necesite. Calidad e Integridad de su producto está garantizado.

### Monitoreo de Cumplimiento de Normas y Programas de Adhesión

Nos mantenemos en contacto regular con usted para apoyar la adherencia a la terapia prescrita. Personal de la farmacia siempre confirmará la cantidad de medicamentos y suministros que usted tiene en la mano antes de programar su próximo envío.

### Coordinación de Servicios de Enfermería

Pacientes con Hemofilia requieren coordinación y atención de alta calidad y apoyo. Vamos a coordinar los servicios de enfermería de salud a domicilio si es requerido por su médico.

### Comprensión de los Beneficios De Seguro

Le ayudamos a comprender cómo obtener el máximo provecho de sus beneficios de seguro y reducir los costos de su propio bolsillo lo más bajo posible. Ofrecemos la confirmación inicial de cobertura, incluyendo beneficios de farmacia y médica.

### Llene su receta hoy



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### Stretch It Out

Simple movements provide daily benefits for people with bleeding disorders

### By Matt McMillen | 07.15.2016

Stretching is a low-impact form of exercise that encourages movement, relieves stiff joints and supports recovery after a bleed.

"When you have a muscle bleed, you lose flexibility in that muscle. You need to stretch to get it back," says Heidi Lane, PT, DPT, PCS, a physical therapist at Intermountain Hemophilia and Thrombosis Center in Salt Lake City, Utah. Plus, stretching is a feel-good activity. "You feel more mobile, flexible, and free when you stretch."

Stretching also can help you return to activities that you may have given up. For example, if you no longer ride a bicycle because you can't bend your knee fully, a successful stretching program may help you regain enough range of motion to take a spin around the block again.

### The basics and benefits

Stretching involves putting controlled, moderate pressure on your muscles and joints until you feel a slight tension. You then hold that position for about 20 to 30 seconds. "Don't bounce," says Lane. "Instead, gently hold it steady."

To understand how a stretch should feel, bend your index finger backward, says Cindy Bailey, PT, DPT, OCS, SCS, a physical therapist with the Orthopaedic Hemophilia Treatment Center at the Orthopaedic Institute for Children in Los Angeles. "There's discomfort, but it's not injurious," she says. "You want to feel that level of tension, but no more on your hamstring, shoulder or whatever you're stretching."

The key to a good stretch is to engage the muscle or joint until you reach the end of its range of motion. "The motion you have, you want to keep," says physical therapist Nancy Durben, PT, of the Mountain States Hemophilia Center at Oregon Health and Science University in Portland. When you stretch, you also promote joint health. Stretching through your full range of motion stimulates the production of synovial fluid inside the joint's lining. That fluid helps protect and preserve the shock-absorbing, friction-reducing cartilage found at the ends of your bones. "Synovial fluid is the grease for our joints," says Bailey. "Without it, cartilage starts to deteriorate."

### Form matters

Before stretching, warm up. Do a few minutes of light aerobic exercise, such as a brief ride on a stationary bicycle. Your muscles will be a little more elastic, and that will allow them to stretch more easily. "It helps to get some blood flowing before you stretch," says Durben.

Stretching requires precise movements and proper form. If you stretch incorrectly, you risk muscle and joint injury, including strains, pulls, and bleeds. This is especially true if you have target joints. Before you start any new exercise, no matter how gentle it may be, talk with your physical therapist. "You need instructions on how to be safe when you stretch that joint so that you don't create a bleed," Bailey says.

Practice your stretching routine with your PT, who can correct any mistakes in form. A common error occurs when people try to stretch their hamstrings, Lane says. People sit on the floor with their legs stretched out in front of them. When they reach forward to touch their toes, they wrench their backs rather than engage their hamstrings. "You need proper technique and good alignment," says Lane. "That means keeping the back straight and bending forward at the hips."

Alternately, Lane suggests, lie on your back in front of an open doorway. Raise one leg and place your heel against the wall with your knee slightly bent. Rest your other leg on the floor and extend it through the doorframe as much as necessary. This allows you to keep one leg straight while you stretch the muscles in your other leg. Carefully straighten your raised leg until you feel slight tension. Hold that position for 20 to 30 seconds to stretch your hamstring, then switch legs. Work with your PT to be sure you do this correctly.

Your stretching program should be tailored to your needs and abilities, but should give your whole body a workout. That includes your leg muscles, hip flexors, arms, shoulders, abs and more. No matter what your routine, make stretching a daily practice. "It doesn't have to be difficult," Durben says. "Feed your muscles with movement every day and throughout the day."

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### Gettin' in the Game

The Chapter had the opportunity to send 2 kids and a parent to CSL Behring's "Getting in the Game". Gettin' in the Game was developed by CSL Behring to help children with bleeding disorders exercise, play sports, and learn more about their disease state. The kids meet ath-



letes, who themselves have been diagnosed with bleeding disorders such as hemophilia and von Willebrand dis-

ease. These athletes hold clinics to help educate children and their families about the fundamentals of golf, baseball and swimming, and provide support to encourage participants to remain active as part of managing their condition.



"It was a great weekend, my son had a lot of fun and he hasn't stopped talking about it since we've been home. The experience is

truly a once in a lifetime. He had the opportunity to perfect his skills in baseball while making new friends. The encouragement he was given and the sportsmanship he was taught will stay with him forever. The educational session for the parents was very informative and useful. Jonathan is hoping to have the chance to get to do Getting' in The Game again soon! We thank CSL Behring for this opportunity. It was amazing."

-Lisa Cervantes



"Maddie was so grateful to be selected for CSL's Gettin' In The Game program for golf. Although a beginner golfer, Maddie learned so much with the teams and especially her new buddy Perry Parker. Friday started with golf lessons and then some game room time with other youth and finished off with a dinner and some fun activities. On Saturday, Maddie went to the golf competition and had her own caddie! She was partnered up with a young golfer, Quinn from Maine. The kids had a blast. After the golf competition, the kids had a little down time to play in the resort's pool and water park. Then there were kids "rap sessions" while adults went to some adult sessions as well. The night finished off with dinner, awards, a dance party and of

course an ICE CREAM BUFFET! Maddie

was so thrilled for such a wonderful weekend!

This program was a wonderful experience which really allowed Maddie to get involved with other youth with bleeding disorders and for parents to relax and learn some important things in session for people with bleeding disorders like: insurance and details about starting school. Thank you Nevada Chapter of NHF for selecting Maddie and thank you CSL for sponsoring such an amazing weekend!"



-Kelly Gonzalez

Biotherapies for Life\* CSL Behring



### 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 harnster 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 LHe® is a registered trademark of CSL Behring LLC.

©2016 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussis, PA 19406-0901 USA www.CSLBehring-us.com www.AFSTYLA.com AFS16-05-0084 5/2016 **OAFSTYLA**°

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 dotting 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 harnster 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

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## 2016 Hemophilia Walk and 5K! Thank you for your support!

























NHI Nevada Walk 5







### Welcome Johnson to the Hemophilia Treatment Center

Johnson Shao has joined the Hemophilia Treatment Center as a

Social Worker. "I am absolutely stunned to work alongside such skilled and compassionate efforts to help some of Nevada's most vulnerable patients, says Johnson. Prior to working at the Hemophilia Treatment of Nevada, I worked as a trauma social worker at UMC and Sunrise Hospital. Now, I am looking forward to working in an entirely different, yet joyfully special, capacity with the Hemophilia Treatment team and aspire to build upon the innumerable milestones my predecessors have achieved before me. Thank you."



### HEMOPHILIA TREATMENT CENTER OF NEVADA

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### 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

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

### 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.

### **Contacts:**

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

### Join our 340B Program Today!

Benefits of enrolling in HTCNV 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

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



### NYLI is Now Recruiting!

Tomorrow's leaders in the bleeding disorders community are being shaped today. That's why the National Hemophilia Foundation (NHF) recruits young adults each year for its **National Youth Leadership Institute** (NYLI).

The <u>three-year program</u> builds individual and professional skills in three areas: advocacy, outreach and nonprofit development. As a part of NYLI, you will attend NHF's Annual Meetings, participate in Washington Days on Capitol Hill, and deliver educational workshops for teens and adults at the local level.

If you are 18-22 years old, have a bleeding disorder or a have sibling with one, and are looking for a unique leadership opportunity to effect change and positively influence others, <u>now's your time to apply</u>! Applications are due by **Monday**, **October 31**, **2016**.

Learn more about the NYLI Eligibility & Selection Process and apply today! Go to www.hemophilia.org and search **NYLI**.

For more information, please contact Marlee Whetten, Education Specialist 212.328.3735 or mwhetten@hemophilia.org

If accepted, all expenses (e.g. travel, hotel, meals) for any NYLI event are covered and/or reimbursed by NHF.

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### Indications

ELOCTATE [Anthemophilic Factor (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency) for: on-demand treatment and control of bleeding episodes, perioperative management of bleeding, and routine prophylaxis to reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

### Important Safety Information

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.

Allergic reactions may occur with ELOCTATE. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called, "inhibitors," against ELOCTATE, which may stop ELOCTATE from working properly.

The most frequently occurring side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.

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 full Prescribing Information on the next page.

This information is not intended to replace discussions with your healthcare provider.

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### FDA-Approved Patient Labeling Patient Information ELOCTATE\*/el' ok' tate / [Antihemophilic Factor (Recombinant), Fc Fusion Protein]

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

### What Is ELOCTATE?

ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ELOCTATE when you have surgery.

### Who should not use ELOCTATE?

You should not use ELOCTATE if you had an allergic reaction to it in the past.

### What should I tell my healthcare provider before using ELOCTATE?

Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

### How should I use ELOCTATE?

You get ELOCTATE as an infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

### What are the possible side effects of ELOCTATE?

You can have an allergic reaction to ELOCTATE. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.

Your body can also make antibodies called, "inhibitors," against ELOCTATE. This can stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

Common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.

These are not the only possible side effects of ELOCTATE. Tell your healthcare provider about any side effect that bothers you or does not go away.

### How should I store ELOCTATE?

- Keep ELOCTATE in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated (2°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- When storing at room temperature:
- Note on the carton the date on which the product is removed from refrigeration.
- Use the product before the end of this 6 month period or discard it.
- Do not return the product to the refrigerator.

Do not use ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution (mixing with the diluent):

- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible.
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

### What else should I know about ELOCTATE?

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

### 44279-02

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We are saddened by the sudden loss of David Heath Ostrove on 10/08/16. David was an avid volunteer and advocate for the Nevada Bleeding Disorder Community. He will be greatly missed. Our condolences to his family.

xuntha<sup>e</sup>solofuse

Antihemophilic Factor (Recor

Designed to prevent and control blocks A factor VIII that helps prepare you to live actively

> Visit XYNTHA.com and see if you're eligible to get a one-time, 1-month supply up to 20,000 IU at no cost.\*

### XYNTHA SOLOFUSE brings together all-in-one reconstitution and proven efficacy in a portable travel-ready kit.

### 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.
- Pfizer

PP-XYN-USA-0177-01 © 2016 Pfizer Inc. All rights reserved. August 2016  XYNTHA is an injectable medicine administered by intravenous (IV) infusion. You may experience local irritation when infusing XYNTHA after reconstitution in XYNTHA<sup>®</sup> SOLOFUSE<sup>®</sup>.

Please see brief summary of full Prescribing Information for XYNTHA and XYNTHA SOLOFUSE on the next 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.

### Consolidated support with Pfizer Hemophilia Connect

- One number with access to all of Pfizer Hemophilia's financial resources and support programs
- Get matched with the financial support programs that best fit your needs
- Learn about community support resources and materials like HemMobile<sup>TM</sup>, Patient Affairs Liaisons, and the CNE series'



Contact Pfizer Hemophilia Connect at 1.844.989.HEMO (4366)

"You must be currently covered by a private (commercial) insurance plan. If you are not eligible for the trial prescription program, you may find help accessing Pfizer medicines by contacting Pfizer's RxPathways program. For questions about the XYNTHA Trial Prescription Program, please call 1-800-710-1379 or write us at XYNTHA Trial Prescription Program administrator, MedVantx, PO Box 5736, Sloux Falls, S0 57117-5736. \* Eligibility may be required to participate.



Antihemophilic Factor (Recombinant)

## xyntha<sup>•</sup>solofuse<sup>•</sup>

### Antihemophilic Factor (Recombinant)

### Ronty

#### **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 to free at 1-800-873-3477.

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 ite my healthcare provider before using XYNTHA?

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

- have any allergies, including allergies to harmsters.
- · 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 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 bood 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

RUS706211



- Prescribing Information LAB-0516-5.0, revised 10/14, and LAB-0500-9.0,

How should store XYNTHA?

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.

### 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 weste 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 prefiled 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 containe

#### What else should 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\* [Antihemoph∎c Factor (Recombinant)] revised 10/14.



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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.

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Smith's Food & Drug has a new **Smith's Community Rewards** program that lets customers select the charities Smith's will donate to, based on dollars they spend in stores. Please link your Smith's Rewards Card to our unique Community Rewards number **48291**. Once linked, every time you swipe your Smith's Rewards Card or enter your phone number, the Nevada Chapter of the National Hemophilia Foundation will receive a quarterly donation from Smith's based on the dollars spent.

There is no cost to enroll, and enrollment will not affect your fuel points or coupon discounts.

To Enroll in the Smith's Community Rewards program go to:

www.smithsfoodanddrug.com

Sign In if you already have an account; otherwise click **Register** and create an

account.

After you are logged in, click on My Account (top right corner).

Scroll to the bottom where is says **Community Rewards**.

Add our Community Rewards #: 48291

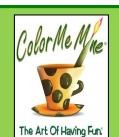
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ACT—Access to Care Today Achieve a CURE Tomorrow



Painting for the Holidays Fundraiser! Get a Head Start on your Holiday Gifts! Thursday, November 10<sup>th</sup> 5:45pm – 8:45pm

Join us at COLOR ME MINE to make one of a kind gifts! You Pick It! You Paint It! We Fire It and (about 5 – 7 days later) You Take It! **Invite your friends and neighbors!** 

50% of proceeds will support NHF Nevada to help provide holiday gifts for our kids!

### Event will be held at both Color Me Mine Locations:

The District in Green Valley Ranch 2255 Village Walk Drive #13 Henderson, NV 89052 Village Square 9350 W. Sahara Ave, # 120 Las Vegas, NV 89117

To RSVP: amcguire@hemophilia.org or 702-564-4368