

Hemophilia News and Views

Spring Edition 2016

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Chapter News

NHF Nevada has started out the year strong! Our 1st annual Winter Wine Fest was held on February 19th and was a huge success, please see page 8 for details and pictures. In March the Advisory Board of Directors met for their annual day long retreat to focus on strategic planning for the chapter. I want to thank all of them for giving up an entire Saturday to plan for NHF Nevada's future. One of the many goals set at the meeting was to grow our Advisory Board of Directors and Committees. If you are interested in serving or know someone that you think would be great, please let us know.

As we move into Spring the chapter has another inau-

gural event planned. Our first Hispanic Education Day is set for Saturday, May 7th and will be a day-long event with programming for both adults and children. We are excited to offer this new opportunity to our Hispanic families.

We have made a few changes to our spring and summer education events. Springfest is set for Saturday, June 18th and for the first time will be held on the same day as the Renee Paper Memorial picnic. In July we head up to Northern Nevada for the Reno Family Education Day and Picnic which is scheduled for Saturday, July 9th. Please mark your calendars and save the

date for these exciting events.

Our Golf 4 the Kids tournament is set for June 6th and will be held once again at Red Rock Country Club's private Mountain course. Please spread the word to all of your friends and family who would love to spend a day on the golf course. All proceeds from the golf tournament fund the many programs and events your family participates in. We hope to see you and your family at one of our upcoming events!

Helli and Arnie

RSVP Today!
Hispanic Education Day
Saturday, May 7, 2016
9:30 am-2:30 pm
Texas Station Convention Center

Please join us for our first annual Hispanic Education Day. All sessions will be given in Spanish. There will be sessions on: Bullying, Expect the Unexpected, Overcoming Obstacles and Goal Setting.

In addition, we will have a youth program that includes a talk on bullying and some fun activities.

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

April 29-30, 2016

Women's Retreat
Hilton Garden Inn, Reno, NV

May 7, 2016

Hispanic Heritage Event
Texas Station Hotel

May 13-15, 2016

Hispanic PEP
Red Rock Hotel

June 6, 2016

Golf for the Kids
Red Rock Country Club

June 18, 2016

Spring Fest/Renee Paper Memorial Picnic
Suncoast and Wet n Wild

June 25 & 26, 2016

Leader in Training Program

July 9, 2016

Reno Education Day and Picnic

July 16, 2016

Couples Event - location TBD

July 21-23, 2016

NHF Annual Meeting
Orlando, FL

August 7, 2016

Reno Ace's Baseball Game

August 16-20, 2016

Camp Independent Firefly
Big Bear, CA

September 17, 2016

Reno Walk & 5K
Bartley Ranch Regional Park

September 24, 2016

Las Vegas Walk & 5K
Floyd Lamb Park

A treatment for hemophilia B

PROTECTION* FROM BLEEDS

ALPROLIX[®]
[Coagulation Factor IX
(Recombinant), Fc Fusion Protein]

Starting with at least a week between prophylaxis infusions

Dosing regimen can be adjusted based on individual response.

*Protection is the prevention of bleeding episodes using a prophylaxis regimen.

To learn more, contact CoRe Manager Jessica Klass
at jessica.klass@biogen.com or call 623-238-0244.



INDICATIONS AND IMPORTANT SAFETY INFORMATION

Indications

ALPROLIX, Coagulation Factor IX (Recombinant), Fc Fusion Protein, is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:

- Control and prevention of bleeding episodes
- Perioperative management
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes

ALPROLIX is not indicated for induction of immune tolerance in patients with hemophilia B.

Important safety information

Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.

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 and all your medical conditions, including if you are pregnant or planning to become pregnant, are breastfeeding, or have been told you have inhibitors (antibodies) to factor IX.

Allergic reactions may occur with ALPROLIX. 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 ALPROLIX, which may stop ALPROLIX from working properly.

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

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



ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

ALPROLIX™ /all' pro liks/ [Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ALPROLIX™ 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 ALPROLIX™?

ALPROLIX™ is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital Factor IX deficiency.

Your healthcare provider may give you ALPROLIX™ when you have surgery.

Who should not use ALPROLIX™?

You should not use ALPROLIX™ if you are allergic to ALPROLIX™ or any of the other ingredients in ALPROLIX™. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX™.

What should I tell my healthcare provider before using ALPROLIX™?

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

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if ALPROLIX™ may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX™ passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX™ may not work for you).

How should I use ALPROLIX™?

ALPROLIX™ should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX™ by themselves or with the help of a family member.

See the Instructions for Use for directions on infusing ALPROLIX™. The steps in the Instructions for Use are general guidelines for using ALPROLIX™. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider.

Do not use ALPROLIX™ as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX™.

What are the possible side effects of ALPROLIX™?

Common side effects of ALPROLIX™ include headache and abnormal sensation in the mouth.

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

ALPROLIX™ may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

Your body can also make antibodies called, "inhibitors," against ALPROLIX™, which may stop ALPROLIX™ from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all the possible side effects of ALPROLIX™. Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX™?

Store ALPROLIX™ vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX™ vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX™ at room temperature:

- Note on the carton the date on which the product was 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 product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:

- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX™ if the reconstituted solution is cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX™?

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

Manufactured by
Biogen Idec Inc.
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Cambridge, MA 02142
U.S. License #1697

Camp Independent Firefly



"Camp Hocus Pocus" is the theme for this summer's Camp Independent Firefly. Camp is set for Tuesday, August 16 – Saturday, August 20, 2016 and will once again be held at Camp Whittle in Big Bear, California. For the first time this year, camper applications will be completed online. All families who submitted an RSVP form should have received an email with the link to complete the camper application for their child on or around **April 1st**.

If you do not have access to a computer and/or need assistance completing the camper application, please contact our office at 702.564.4368. Camper applications are due **June 1st**.

Please keep in mind that if your child is attending another medically supervised camp this summer they will be automatically placed on our camp waitlist. This policy is in place to assure that every child with an inherited bleeding disorder has an opportunity to attend a summer camp.

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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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.

HOW DO YOU WEAR A RED TIE?



NHF | MARCH IS BLEEDING DISORDERS AWARENESS MONTH
RED TIE CHALLENGE™
REDTIECHALLENGE.ORG



WHAT IS THE RED TIE CHALLENGE?

A movement created by the bleeding disorders community and the National Hemophilia Foundation (NHF) to start a conversation about inheritable bleeding disorders **and support March 2016 as the first Bleeding Disorders Awareness Month.**



TAKE THE CHALLENGE, LOOP-BY-LOOP!



1 Accept the **Challenge** and get a



2 Get creative and show how you wear that tie!

3 Record your best tie look, pledge to support **March as Bleeding Disorders Awareness Month**, and challenge a few friends.



4 Post your video with **#RedTieChallenge**, challenge your followers, and think about making a donation at redtiechallenge.org.

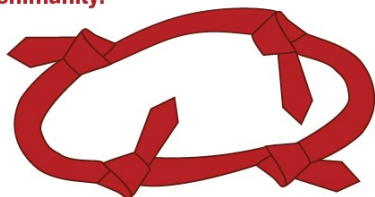


WHAT ARE INHERITABLE BLEEDING DISORDERS?

Hemophilia, von Willebrand disease and rare factor deficiencies—all of which prevent the blood from clotting normally—can result in extended bleeding after injury, surgery, or trauma, and can be fatal if not treated effectively.

WHY THE RED TIE?

Because it symbolizes the blood ties that bind **over 3 million Americans to our community.**



Thanks for taking the Challenge and check redtiechallenge.org for updates!



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

NHF is a 501(c)(3) nonprofit organization dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. Established in 1948, NHF has 51 chapters throughout the country. Learn more about NHF at www.hemophilia.org.
7 Pennsylvania Plaza #1204, New York, NY 10001 | T (212) 328-3700 | redtiechallenge@hemophilia.org

NHF: The Bleeding Disorders Community's Advocate™

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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



"Su farmacia preferida especializada en hemofilia para la comunidad latina"

Hemophilia Walk & 5K Registration is now open!



2 Dates and Locations!

Reno Area: Bartley Ranch Regional Park Saturday, September 17th

Las Vegas: Floyd Lamb Park Saturday, September 24th

Register yourself and your team at www.hemophilia.org/walk

Winter Wine Fest

Our inaugural Winter Wine Fest had over 200 people attending and raised \$30,000 to support the Nevada Bleeding Disorders Community! The event included food, wine, fabulous silent auction items and a wine pull! A huge thank you goes out to our wine committee for all of their hard work: Sonia Arevalo, Kelly Gonzalez, Doug May, Anne McGuire and Katrina Nicosia.



Thank you to Tivoli Village, Brio and Leon Café for donating the space and the food. We also want to thank our incredible sponsors: Baxalta, Biogen, CSL Behring, Bayer Healthcare, Emergent Bio-Solutions, Factor Support Network Pharmacy, Novo Nordisk, Octapharma and Pfizer.





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Free Trial Program*

- Enroll today for up to 6 free doses[†]
- Delivered to your home free of charge

Access to Therapy

We might be able to provide treatment at no cost if you[‡]:

- Experience challenges getting insurance coverage
- Are uninsured or underinsured
- Are between jobs and are experiencing a gap in insurance coverage

\$0 Co-pay Program[§]

If you have private insurance, you may be eligible for the \$0 Co-pay Program.

- You may be able to receive up to **\$12,000 in assistance** per year, regardless of income
- **Assistance is awarded per patient.** Multiple members of the same household can apply
- Enrollment can be completed in **one short phone call**

Live Helpline Support

- Consult with an expert in insurance
- Spanish-speaking Case Specialists are also available

CALL
1-800-288-8374

8:00 AM-8:00 PM (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. Reselling 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.

Swim Time

Pools can provide safe workouts

By Matt McMillen



Swimming provides equal parts fun and good-for-you physical activity. It is one of the safest ways to be active for people with bleeding disorders. “The beauty of water is that it is supportive. It decreases the weight on your joints, making it easier to move with less pain,” says physical therapist Nancy Durben, PT, of the Mountain States Hemophilia Center at Oregon Health and Science University in Portland.

Lap swimming

As with any new exercise, first consult your hemophilia treatment center (HTC) team and then start slowly. “If you plan to swim laps, start with just a few at a time to build up your endurance,” says Christine Rowell, MSPT, the physical therapist at Lucille Packard Children’s Hospital Hemophilia Treatment Center in Palo Alto, California.

What stroke you do is up to you, says Durben. But keep in mind that it will depend on what your joints can handle. “The breast stroke involves a kick/whip at the knee, and if someone has limited knee extension, this could aggravate it,” Durben says. “The butterfly is a particularly demanding stroke,” says Rowell. Save it until the others are perfected, she says. Be forewarned that some people cannot master this difficult stroke.

No matter what strokes you prefer, use the proper form. A swim coach can help you with that. Tell your coach about any joint problems and physical limitations, says Durben. If you have limited range of motion in your arms, try using a kickboard. Or if kicking is a problem, place a pull buoy, a squishy piece of foam, between your legs to give your arms a workout.

Swimming laps provides an excellent workout, but it’s not for everyone. Some people find them dull. Others lack the range of motion to perform all of the movements needed. For these folks, there are plenty of other options for pool workouts.

Walk it off

Water walking is a good exercise for everyone, and especially for beginners who don’t know how to swim. If you can’t swim, play it safe and wear a life vest while in the pool, Durben cautions.

To work different muscles, walk forward, backward and sideways, says Durben. “Even in water that is not deep, you get resistance to your muscles as you walk,” she says.

Safety first

While swimming in a pool is generally considered safe, there are some precautions that you should take. Ask your physical therapist to help you design a program for your specific needs. Find out if you should infuse before you swim. “It is a low-impact activity, but you are working hard,” says Durben. “Why risk a bleed?”

If you’re a lap swimmer, wear goggles so you can better judge the distance to the wall; otherwise, you risk colliding with it and causing a bleed. Further, goggles protect your eyes from chlorine, an irritant.

Other equipment to consider:

- Ear plugs, which reduce the risk of ear infections
- Swim caps, which protect your ears from water and your hair from chlorine
- Swim fins, which help you swim more efficiently
- Water shoes, which help prevent cuts and abrasions in and out of the pool

Finally, don’t forget to hydrate. You may be in water, but you still need to drink plenty to prevent dehydration. Durben recommends 20 ounces of water each hour that you are in the pool.



Another successful Washington Days is in the books! 350 participants from around the nation attended to advocate for the community. We met face to face with lawmakers and staff who shape national healthcare policy. We asked our Nevada legislators to do three things:

1. Participate in the Red Tie Challenge by doing a one-minute floor speech in honor of Bleeding Disorders Awareness Month or posting a photo wearing the red tie on their social media channels.
2. Support funding for the hemophilia programs at CDC and HRSA in their appropriations requests.
3. Co-sponsor the Access to Marketplace Insurance Act (House) or introduce companion legislation (Senate).



NHF's annual Washington Days empowers individuals in the bleeding disorders community to impact the legislative process.

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pioneering spirit

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www.grifols.com

Nevada Yellow Dot Program Provides Vital Service



The Yellow Dot Nevada Program is a free, life-saving program that alerts first responders at a vehicle-incident scene that an occupant may have medical issues. This information is vital in the “golden hour” following an accident or roadside medical episode. Through knowledge gained from this information, emergency workers can increase the chance of survival or lower the risk of error for an incident victim who may be incapacitated.

A yellow dot decal on the rear window of the driver's side of the vehicle alerts first responders to check the glove compartment, where a Yellow Dot kit contains vital medical information about the driver and/or passengers.

A Yellow Dot kit contains the following:

- ◆ A Yellow Dot decal
- ◆ Name and emergency contact information
- ◆ List of allergies or medical conditions for the participant(s)
- ◆ Name and contact information of the participant's physician and preferred hospital, if any
- ◆ Information, if any, about the participant's health insurance

Once information is compiled and complete, the kit should be stored in the car's glove compartment, while the Yellow Dot decal should be affixed to the car's rear window on the driver's side.

Kits are available from the Hemophilia Treatment Center and at local libraries.

For additional information about the program, visit rtcsnv.com/yellowdot



DESIGNED TO PREVENT AND CONTROL BLEEDS—
A FACTOR VIII THAT HELPS PREPARE YOU TO LIVE ACTIVELY

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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 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.

*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, Sioux Falls, SD 57117-5736.

†This card will be accepted only at participating pharmacies. This card is not health insurance. No membership fees.



Save on XYNTHA[®]
Terms and conditions can be found at XYNTHA.com.

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Need help accessing Pfizer medicines?
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Call **1-888-327-7787** or visit www.PfizerRxPath.com.



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September 2015

Pfizer RxPathways is a joint program of Pfizer Inc and the Pfizer Patient Assistance Foundation™.



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 10/14, and LAB-0500-9.0, revised 10/14.



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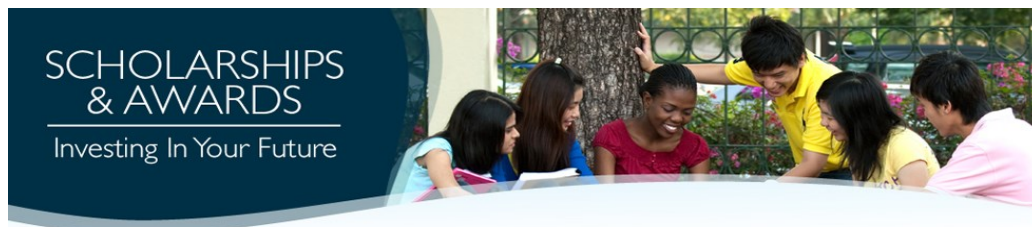
As one of the nation's leading providers of specialty pharmaceuticals, we understand it can be difficult to cope with a chronic or complex condition. That's why our dedicated therapy teams work diligently to coordinate solutions for the challenges our patients face.

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We are pleased to announce two awards available beginning in the Spring of 2016.

The **Advocacy Award** is open to any individual with a bleeding disorder or a caregiver, who invests time and volunteers to better the Nevada bleeding disorder community. A monetary gift is given to the recipient of this award.

The **Educational Scholarship** will be available for any individual with a bleeding disorder who is accepted to a secondary school, part or full-time, in the fall of 2016.

You can request applications by emailing amcguire@hemophilia.org. The deadline to apply is June 1, 2016.

Are you headed to college next year? Now is the time to start looking for scholarships that are available to those with bleeding disorders. For more information on scholarships please either visit the website below, contact our office or contact Jay Hill at the Hemophilia Treatment Center. www.kelleycom.com/scholarships.html



Do you shop at Smith's Grocery Store?

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. **We currently have 24 families signed up.** If you have not already, 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 it says **Community Rewards**.

Add our Community Rewards # : **48291**

Please call with any questions or if you need help linking your card!

Build a Better Breakfast Kid-friendly options abound

Cold cereal with milk provides good nutrition for kids at breakfast time, but it's not the only way to break the fast. Nowadays, nutritionists give the green light to everything from wholesome smoothies to whole-wheat wraps and bagels with nut spreads. One thing they agree on: Breakfast is a must. Studies show that -students who eat breakfast concentrate better in school, have higher test scores and have more muscle coordination.

If you're flummoxed about breakfast foods for your kids, try:

- Oatmeal with raisins, dried cranberries, dates or nuts
- Whole-wheat pita with hard-boiled egg slices and low-fat shredded cheese
- Low-fat milk smoothie with frozen strawberries or peaches
- Leftover pizza with a whole-grain crust and veggie toppings
- Nutritious mini-muffins packed with shredded carrots and zucchini
- For kids or teens on the go, try homemade trail mix or granola
- Whole-wheat tortilla with peanut, almond or hazelnut spread, topped with dried fruit
- Fruit parfait, layered with Greek yogurt, chopped fruit and granola

Source: fda.gov

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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.

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Benefits of enrolling in HTCNV 340B

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 - ◆ Family retreats & summer camp
- ◆ Full time Nurse Practitioners
- ◆ Full time Social Worker
- ◆ Full time Physical Therapist
- ◆ Dental Assistance Program

Contacts:

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340 B Compliance
702-732-1956

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

Jamilah Hill Named Social Worker of the Year!



Congratulations goes to Jamilah Hill of the Hemophilia Treatment Center for being named **State of Nevada Social Worker of the Year!** The National Association of Social Workers - Nevada Chapter honored her with the award -- Congratulations Jay!

From Jay: I just want to thank the most amazingly awesome team for nominating me for this award. It's not everyday that you work with people that value you and uplift you. Social work is very unique and we are often faced with challenges. Our providers understand social work practice and allow me to do my job with autonomy and support. They are the best!

I don't look at myself in the same light, because I humbly accepted the charge of a lifetime of service when this career path was chosen for me. I am forever indebted to the families that give me the honor to work with them when they are faced with adversity or challenges. It is not always easy to allow someone into your personal space or your lives; however, I am truly appreciative of every opportunity. I am continually searching for ways to improve the quality of life for our patients and families and will continue to do so. I am so grateful.

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Nevada Chapter
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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., June 6, 2016 **Location:** Red Rock Country Club **Reg:** 7:30 AM **Shotgun Start:** 9:00 AM

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