Upcoming Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>AUGUST 16</td>
<td>PERK UP HEMOPHILIA HALF MARATHON - PENNSBURG</td>
</tr>
<tr>
<td>SEPTEMBER 15</td>
<td>EPC GOLF CLASSIC - PHOENIXVILLE</td>
</tr>
<tr>
<td>SEPTEMBER 25-27</td>
<td>FAMILY CAMP - SCHWENKSVILLE</td>
</tr>
<tr>
<td>OCTOBER 3</td>
<td>EPC 5K - COLLEGEVILLE</td>
</tr>
<tr>
<td>OCTOBER 17-18</td>
<td>WOMEN’S RETREAT (vWD) - HARRISBURG</td>
</tr>
<tr>
<td>NOVEMBER 14</td>
<td>EPC 5K - LANCASTER</td>
</tr>
<tr>
<td>DECEMBER 5</td>
<td>HOLIDAY PARTY - PHILADELPHIA</td>
</tr>
</tbody>
</table>

Get details on all our events on our website: www.hemophiliasupport.org

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**EPC SALUTES OUR MEDICAL PARTNERS**

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Learn how a prolonged half-life may affect your infusion schedule

Meet your CoRe Manager Sue Cowell
E: Sue.Cowell@biogenidec.com  T: 609-602-6303
This information is not intended to replace discussions with your healthcare provider.

Indications
ELOCTATE [Antihemophilic 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 control and prevention of bleeding episodes, perioperative management (surgical prophylaxis), and routine prophylaxis to prevent or 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.

Common side effects of ELOCTATE are joint 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.
FDA-Approved Patient Labeling

Patient Information

ELOCTATE™ /el' ok' late/
[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?

Common side effects of ELOCTATE are joint pain and general discomfort.

Allergic reactions may occur. 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, which may stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

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.

Manufactured by:
Biogen Idec Inc.
14 Cambridge Center, Cambridge, MA 02142 USA
U.S. License # 1697

44279-01

ELOCTATE™ is a trademark of Biogen Idec.

Issued June 2014
Event Recaps – Fashion Show & Family Dinner

See more photos at www.hemophiliasupport.org/photos.html

The 36th Annual Fashion Show was held on Saturday, April 18 at Whitemarsh Valley Country Club in Lafayette Hill. Over 230 women and children of all ages enjoyed a day of food, fashion and special guest Vaughn Ripley, who had inspirational stories from his own life with hemophilia. As expected, the kids fashion show was a big hit. This long-standing event celebrates the women in our lives for their love, compassion and strength. A special “Thank You” goes to co-chairs Tina McMullen and Vickie DiCamillo for doing an amazing job!

Over 400 families, medical partners, and industry sponsors came together for the EPC Family Dinner on Tuesday, May 5 at the Hilton City Avenue in Philadelphia. Guests enjoyed a wonderful opportunity to network and learn about the latest in medical advances from Dr. Patrick Fogarty and advocacy from Patrick Collins of CSL Behring. The Chapter is very proud of the County Captains program and we were thrilled to have four of our leaders tell their stories. EPC would like to thank Lilly Diaz, Tina Marzigliano, Frank Lentini and Holly Coleman for coming near and far to make this a truly special event.
Our enduring commitment, brighter than ever.

**For more than 60 years, we’ve consistently pursued advancements in the treatment of bleeding conditions.**

Now, as Baxter’s BioScience becomes Baxalta Incorporated, this proven heritage — along with the advancements we’re making today to cultivate tomorrow’s developments — fuels our global vision and promise: Our relentless desire to make a meaningful difference in the lives of real people — one person at a time. This promise to you can be seen in all we do, and helps to make us the company we are today.

Miriam  
Caregiver, Miami, FL
Event Recaps – Million Dollar Bike Ride & Harrisburg Day

See more photos at [www.hemophiliaupport.org/photos.html](http://www.hemophiliaupport.org/photos.html)

Avid cyclists joined the EPC team “Spin Factor for Hemophilia” at the Million Dollar Bike Ride on Saturday, May 9 in Philadelphia. This event benefits rare disease research through the Penn Medicine Orphan Disease Center.

A total of 15 teams and 600 cyclists and volunteers representing various diseases participated in the day. Money raised by EPC goes exclusively to hemophilia research.

Patient advocates, health care providers, and industry partners from both the Eastern and Western Pennsylvania Chapters came together to participate in the annual Advocacy Day on Monday, April 20 in Harrisburg.

Meetings with House and Senate Representatives focused on two areas – funding for the seven PA hemophilia treatment centers and support of Senate Bill 841, which addresses co-pay and cost-sharing issues for medication.

As a community, we will need to keep SB 841 in front of our representatives. Please let us know if you would like to become more involved with the Chapter’s advocacy efforts by calling Curt Krouse at 215-393-3611.
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Holly Coleman
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*Counties*: Potter, Clinton, Centre, Huntingdon, Fulton, Tioga, Lycoming, Mifflin
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It comes with all-in-one reconstitution. It’s XYNTHA.

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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 small 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 (2%), and cough (1%). 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 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 1-800-710-5739 or write us at XYNTHA Trial Prescription Program Administrator, MedVal Inc., PO Box 5735, Sioux Falls, SD 57117-5735.

The chemically defined cell culture medium in which the Chinese hamster ovary (CHO) cells are grown contains recombinant insulin but does not contain any materials derived from human or other animal sources.

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

Need help accessing Pfizer medicines? Pfizer’s RxPathways program may be able to help. Call 1-888-327-7787 or visit www.PfizerRxPath.com.
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 diluted 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 pre-filled 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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Counties: Lehigh, Northampton
What is HPPS?

Hemophilia Patient and Program Support (HPPS) is a 501 (c) (3) charitable and educational organization created by the Eastern Pennsylvania Chapter of the National Hemophilia Foundation. HPPS was founded to provide funds for community outreach, education and resources to individuals with hemophilia and von Willebrand Disease residing within the geographic boundaries served by the Eastern Pennsylvania Chapter. HPPS is dedicated to ensuring that patients continue to receive the highest quality of care and services at affordable costs. Working in collaboration with the Eastern Pennsylvania Chapter, HPPS will provide additional funding to help the Chapter meet patient and program needs.

Participating Companies –
Accredo, CVS/Caremark, NCHS, Walgreens provide:

- a full range of services to meet your needs (pharmacy, delivery, support, financial counseling, etc.)
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- financial help for patient life needs, when need is determined
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INFORMATION IS EMPOWERING.
At Accredo, we believe the more you know about your condition and available options, the better. We provide educational materials and a team of dedicated professionals. We're here to help you make informed decisions about your care. A personal touch from people who know bleeding disorders.

Jim Seagrave-Daly | (484) 225-3788
JASegrave-Daly@express-scripts.com

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www.CVSCaremarkSpecialtyRx.com

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Many of you know Donna Gallegos and Kim Bayer, longtime members of the bleeding disorders community. For more information, please contact them Donna at 1.877.505.4697, or Kim at 1.877.505.4697

Or, for more information:
www.nc-hs.com • customerservice@nc-hs.com
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We're there to extend your care.

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Walgreens Infusion Services
Bodyweight Basics

USING SIMPLE EXERCISES TO BUILD MUSCLE, BURN CALORIES

By Matt McMillen | 05.12.2015

Skip the gym, now you can exercise the do-it-yourself way at home using bodyweight exercises. Bodyweight exercises, which include pushups and situps, build muscle, burn calories and boost your heart health. Plus, your workout won’t cost you a dime. Such exercises require only the weight of your own body, rather than barbells or other weight training equipment. These are all good reasons why the American College of Sports Medicine predicts that bodyweight training will be the No. 1 fitness trend in 2015.

For people with bleeding disorders, bodyweight exercises can be beneficial. They increase strength, and the stronger your muscles, the better they can protect your joints from bleeds.

FOLLOW YOUR PT’S LEAD

Before beginning a bodyweight exercise program, check in with your health team at your hemophilia treatment center (HTC), especially your physical therapist (PT). The staff can help you plan a workout that matches your abilities and won’t tax your joints.

“Your PT knows you and knows whether, for example, squats are going to be difficult for you because of knee or ankle problems,” says Kim Baumann, MPT, of the Center for Bleeding and Clotting Disorders at the University of Minnesota Fairview Medical Center in Minneapolis. You will also learn how to do each exercise correctly. “You need to practice proper body mechanics to avoid injury,” she says. “For example, if you do a squat and let your knees go past your toes, you’re putting tremendous pressure on your knees. Such pressure can cause joint injuries or even bleeds.

There are many different bodyweight exercises you can do, each of which can be modified to match your fitness and abilities. First, focus on exercises that are comfortable for you. “As you adapt to your new workout, you can vary it to make it more challenging,” says Heidi Purrington, PT, of the Hemophilia and Thrombosis Center at Phoenix Children’s Hospital in Arizona. For example, if you’re new to exercise, you may need to start with functional exercises. These include sit to stand, reaching into cupboards, stepping sideways along the counter in the kitchen, or leaning forward and to the sides and back while sitting. Your PT can help you decide how many to start with and what goals you should set.

For a simple exercise you can do every day, Purrington recommends stand-up/sit-downs. With your hands at your sides, sit in a chair, stand up and then sit back down. Repeat. You can vary the difficulty by using a higher or lower chair, not using your arms to help and increasing the number of repetitions you perform.

“You can also use bodyweight exercises to improve your balance,” says Baumann. Single-leg stands involve lifting one foot, bending your knee and holding your foot a few inches off and perpendicular to the floor for a half-minute or so. Once you feel comfortable doing them on a solid surface, try standing on a pillow. For a real challenge, do them with your eyes closed. You can even do single-leg stands while brushing your teeth.

MODIFYING AND ADJUSTING

Bodyweight exercises can also be modified to work...
ALPHANATE is the preferred plasma-derived FVIII product for the treatment of hemophilia A among hematologists practicing in HTCs.*

*Results are statistically significant with a 95% confidence interval with a 6.3% margin of error and are based on a blinded national survey of 75 HTC-based Hematologists from a list of federally and non-federally-funded HTCs within the US, conducted and validated by a reputable, independent third party, Advo Associates LLC, on behalf of Grifols USA from October 2014 - January 2015. In order to qualify to complete the survey, Hematologists were rigorously screened according to market research standards having the necessary experience in the relevant treatment segment. Respondents were asked to assume no difference in terms of availability, cost, and reimbursement when indicating their most preferred plasma-derived FVIII brand.

HTC=Hemophilia Treatment Center; pdFVIII=plasma-derived factor VIII

**Indications**
ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) is indicated for:

• Control and prevention of bleeding in patients with hemophilia A

• Surgical and/or invasive procedures in adult and pediatric patients with von Willebrand disease (VWD) in whom desmopressin (DDAVP®) is either ineffective or contraindicated. It is not indicated for patients with severe VWD (Type 3) undergoing major surgery

**Important Safety Information**
ALPHANATE is contraindicated in patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components.

Anaphylaxis and severe hypersensitivity reactions are possible. Should symptoms occur, treatment with ALPHANATE should be discontinued, and emergency treatment should be sought.

Development of activity-neutralizing antibodies has been detected in patients receiving FVIII containing products. Development of alloantibodies to VWF in Type 3 von Willebrand disease (VWD) patients has been occasionally reported in the literature.

Thromboembolic events may be associated with AHF/VWF Complex (Human) in VWD patients, especially in the setting of known risk factors.

Intravascular hemolysis may be associated with infusion of massive doses of AHF/VWF Complex (Human).

Rapid administration of a FVIII concentrate may result in vasomotor reactions.

Plasma products carry a risk of transmitting infectious agents, such as viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, despite steps designed to reduce this risk.

The most frequent adverse events reported with ALPHANATE in >5% of patients are respiratory distress, pruritus, rash, urticaria, face edema, paresthesia, pain, fever, chills, joint pain, and fatigue.

Please see brief summary of ALPHANATE full Prescribing Information on adjacent 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.

For more information Grifols Biologicals Inc. Tel. 888-GRIFOLS (474-3657)

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GRIFOLS
ALPHANATE®
Antihemophilic Factor/von Willebrand Factor Complex (Human)

HIGHLIGHTS OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use Alphanate safely and effectively. See full prescribing information for Alphanate.

ALPHANATE (ANTIHEMOPHILIC FACTOR/VON WILLEBRAND FACTOR COMPLEX [HUMAN])
Sterile, lyophilized powder for injection.
Initial U.S. Approval: 1978

-------------------------------INDICATIONS AND USAGE-------------------------------
Alphanate is an Antihemophilic Factor/von Willebrand Factor Complex (Human) indicated for:
• Control and prevention of bleeding in patients with hemophilia A.
• Surgical and/or invasive procedures in adult and pediatric patients with von Willebrand Disease in whom desmopressin (DDAVP) is either ineffective or contraindicated. It is not indicated for patients with severe VWD (Type 3) undergoing major surgery.

-------------------------------DOSEAGE AND ADMINISTRATION-------------------------------
For Intravenous use only.
Alphanate contains the labeled amount of Factor VIII expressed in International Units (IU) FVIII/vial and von Willebrand Factor:Ristocetin Cofactor activity in IU VWF:RCo/vial.

Hemophilia A: Control and prevention of bleeding episodes
• Dose (units) = body weight (kg) x desired FVIII rise (IU/dL or % of normal) x 0.5 (IU/kg per IU/dL).
• Frequency of intravenous injection of the reconstituted product is determined by the type of bleeding episode and the recommendation of the treating physician.

von Willebrand Disease: Surgical and/or invasive procedure in adult and pediatric patients except Type 3 undergoing major surgery
• Adults: Pre-operative dose of 60 IU VWF:RCo/kg body weight; subsequent doses of 40-60 IU VWF:RCo/kg body weight at 8-12 hour intervals post-operative as clinically needed.
• Pediatric: Pre-operative dose of 75 IU VWF:RCo/kg body weight; subsequent doses of 50-75 IU VWF:RCo/kg body weight at 8-12 hour intervals post-operative as clinically needed.

-------------------------------DOSAGE FORMS AND STRENGTHS-------------------------------
• Alphanate is a sterile, lyophilized powder for intravenous injection after reconstitution, available as 250, 500, 1000, 1500 and 2000 IU FVIII in single dose vials.

-------------------------------CONTRAINDICATIONS-------------------------------
• Patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components.

-------------------------------WARNINGS AND PRECAUTIONS-------------------------------
• Anaphylaxis and severe hypersensitivity reactions are possible. Should symptoms occur, treatment with Alphanate should be discontinued, and emergency treatment should be sought.
• Development of activity-neutralizing antibodies has been detected in patients receiving FVIII containing products. Development of alloantibodies to VWF in Type 3 VWD patients has been occasionally reported in the literature.
• Thromboembolic events may be associated with AHF/VWF Complex (Human) in VWD patients, especially in the setting of known risk factors.
• Intravascular hemolysis may be associated with infusion of massive doses of AHF/VWF Complex (Human).
• Rapid administration of a FVIII concentrate may result in vasomotor reactions.
• Plasma products carry a risk of transmitting infectious agents, such as viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, despite steps designed to reduce this risk.

-------------------------------ADVERSE REACTIONS-------------------------------
The most frequent adverse events reported with Alphanate in > 5% of patients are respiratory distress, pruritus, rash, urticaria, face edema, paresthesia, pain, fever, chills, joint pain and fatigue.
To report SUSPECTED ADVERSE REACTIONS, contact Grifols Biologicals Inc. at 1-888-GRIFOLS (1-888-474-3657) or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

-------------------------------USE IN SPECIFIC POPULATIONS-------------------------------
• Pregnancy: No human or animal data. Use only if clearly needed.
• Pediatric Use: Hemophilia A - Clinical trials for safety and effectiveness have not been conducted. VWD - Age had no effect on PK.

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Bodyweight Basics

around problem joints. “There are lots of ways to do strength training, even if you have limitations,” says Baumann. For instance, if you like pushups but have bad elbows, adjust how low you go or do them against the wall. The same goes for how low you squat.

Go slowly when you get started. Together with your PT, plan when to take each exercise to the next level. Too much too soon may cause an injury that knocks you out of commission.

If you have the time, do a whole workout every other day. Otherwise, do a little bit of your routine every day; dividing it into chunks of time that fit your schedule. Try alternating between upper-body exercises like shoulder shrugs, lower-body exercises such as squats and core exercises, which include situps and planks, says Baumann.

Work some variety into your workout. That way, you keep things interesting as you continue to challenge yourself. Purrington shares pages of exercises with some of her patients. She recommends they choose one or two exercises from each page for each session. Just be sure to give each major muscle group at least a day between workouts.

Although bodyweight exercises require no special equipment, you will need a good pair of shoes. Running or cross-training shoes provide joint support and prevent falls. Also, consider a yoga mat, especially if you like to exercise outdoors or on a slippery hardwood floor.

Look for the first signs of progress in just a few weeks. Soon you’ll be doing a few more repetitions of each exercise. In addition, everyday activities like walking to the park with your kids will become noticeably easier. In a few months, exercise will become a more natural part of your daily routine, says Purrington. Plus, your mental health will improve. “The more you exercise, the better you will feel about things in general,” she says.
Having issues with co-pays or gaps in coverage for your hemophilia A treatment?

We may be able to help.

Bayer offers a range of programs that can help you navigate insurance questions about your hemophilia A treatment. If you’re having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call 1-800-288-8374 and press 1 to speak to a trained insurance specialist!
BBQ Cook-Off 4 a Cure Recap

See more photos at www.hemophiliasupport.org/photos.html

The storms held off, and the 6th Annual BBQ Cook Off for a Cure and Horseshoes for Hemophilia Tournament, June 20th, was bigger and better than ever. Twenty-eight BBQ competition teams from the Mid-Atlantic Region competed for trophies, cash and of course, bragging rights for the best barbeque! This year’s new People’s Choice category was a great success, with participating teams creating their best bite of “Anything Bacon”. Savoring the “all you can eat” bbq prepared by our event chair person, John Roberts and his team, hundreds of people from the local and hemophilia communities enjoyed the country feel of The Little Red Rooster Blues Band. With our good friend Dave Neill at the helm, the Horseshoe Tournament continues to grow each year. Dozens of spectators, eyes glued to the pits, watched the fierce competition between twenty-two participating teams. An enormous thank you to John and Dave for their hard work and dedication, and to the very special volunteers who help make this event such a great success!
Community Spotlight: Mount Carmel Area Elementary School

120 students from 5th and 6th grade, as well as faculty and staff of Mount Carmel Area Elementary School under the direction of Jolene Scicchitano – Mom of three young men with hemophilia, teacher and County Captain – raised an amazing $1,220 for EPC at their annual dance and talent show on Thursday, June 4. The staff sold chances for a $25 American Eagle gift card, $50 GameStop gift card, Two $25 iTunes gift cards, and a $25 Pepe’s Ice Cream gift card. They also sold chances for a “pie in the eye” contest in which 11 faculty and staff members (including Jolene) volunteered to have a student pie them in the face. The dance had a “Glow in the Dark” theme. Each student was given a glow in the dark bracelet when they entered the dance. There were glow in the dark balloons, a glow in the dark ring toss game, and glow in the dark prizes that were given out for the limbo and hula hoop contests. Food and refreshments were sold at the dance. Pizza was donated by two local restaurants - Scicchitano Buono Pizza and Hollywood Pizza. Boyer’s Supermarket donated a gift card used to purchase snacks.

EPC Men’s Group – Save the Dates

Men’s Group (South Central) meetings will occur on Wednesday, September 9 and Wednesday, November 11. More information will be coming! To join this group or to start one in a different region of EPC’s coverage area, please contact Curt Krouse at (215) 393-3611.

Stay informed. Stay involved. Stay connected.

Like us on Facebook: www.facebook.com/EPCNHF
Follow us on Twitter: https://twitter.com/hemophilia_epc
Check out our official website: www.hemophiliasupport.org
Delivering on our promises is what we do.

Unlocking the promise of biotherapies is how we do it.
The Winning Spirit
Summer 2015

You’ve Got the Beat
Sing loud and play along

Boom, chaka chaka, boom!

Hear that? That’s the sweet sound of your pain going away.

See, pain from bleeds happens. Even if you get medicine to help with pain, sometimes you still hurt. But, after you’ve told Mom and Dad about it, you might not feel it so bad if you lean back, close your eyes and listen to your favorite songs. Here’s why: Your brain is like a really powerful computer—but one that can only open one window at a time. That’s why when you listen to music, your brain can’t “hear” the pain signals coming from your joints, your port or from a needle stick. So whether it’s Thomas the Tank Engine songs, Broadway musicals or hip hop, music can help you when you hurt.

The best part? You can enjoy music anywhere! Play some tunes at home or in the car. Your family may find a professional music therapist who can teach you how to use music to deal with the pain. Either way, all you need is to tune in, sing loud and play along.

Tune In

Tune in to the music you like and that makes you feel good all over. Mom and Dad might put a few rules around it, like how loud the music can be or they may even say no to certain bands. But other than that, if it gets your toes tapping and your body moving, it’ll help drown out the pain.

Ask Mom and Dad to help you create a playlist of your absolute favorite songs. If you listen to them when you are chilling out—like when you’re getting ready for bed—your brain will know that it’s music to help you relax. Then when you play that music when you’re in pain, it will calm you even faster.

Sing loud and play along

Listening to music is great for pain relief, but singing and playing along are even better! That’s because your whole body and brain are involved, putting a “Go Away, Pain!” sign out that sends the pain signals packing in a hurry. The pain will still be there, but you won’t notice it as much.

Don’t own an instrument? That’s OK. Do you have fingers? Toes? Snapping and stomping and drumming out the beat on your chest or leg can get you in the groove. Now’s the time to pull out Rock Band, karaoke CDs or your air guitar. If your parents have a tablet personal computer, they might have an app that turns it into a musical instrument. All you have to do is swipe a finger across the screen, and you’re in the band!

Musical Healing

No matter how you engage with the music, humming your favorite tune or just listening can make healing from a bleed or sitting through an infusion more fun—and less painful.