Sangre de Oro, Inc.
6301 4th Street NW, Suite 6
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Credits

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The Bear Facts

The 2015 Hemophilia Walk for Life!

By Sophia Minhas

As the 2015 Hemophilia Walk of New Mexico approaches, my heart fills with joy. I honor our sponsors, community members, families, and loved ones for taking time out of their day to come out and show their support for the bleeding disorders community. The purpose of the Walk is to raise funds for patient assistance, local programs, services, and raising awareness for our bleeding disorders community. Speaking from personal experience Sangre De Oro, Inc. (SDO) has helped me through some rough times. It's times like these that make you realize how fortunate you are to have a community full of people who are devoted to helping you, being your friend, and teaching you the importance of unity and team work. The Walk is one of most meaningful events in our community. The money we raise provides us with the opportunity to send our little ones to camp, and for all families to attend education weekend, helping us become more involved in our own health and reach out for help.

The Walk committee was able to reach out to our families during the education weekend, and it was wonderful to see how many people are committed to helping our community. I encourage everyone to sign up for the walk! It's a fun-filled morning with laughter, comfort, and encouragement. You can sign up for the Walk at http://www.hemophilia.org/walk. You can sign up as individual, join a team, or create a team of your own. The process of signing up is easy and fast. If you remember your user name and password from last year, you can avoid having to retype. If you do not remember, don't panic!!! You can create a new User Name and Password or contact the Walk committee. We will be happy to help you get all set up. Please feel free to call me or e-mail me if you have any questions at (505) 620-5836 or e-mail nmwalk@sangredeoro.org.

The Walk committee encourages to show your awesome team spirit by wearing team t-shirts or expressing your creativity. The team that shows the best spirit will get an award. Let the games begin. As always, thank you for your support.

Just a Reminder!

The 2015 Hemophilia Walk for Life

Saturday, April 18, 2015
Tiguex Park
9:00 a.m.: Check-in begins
10:00 a.m.: Walk begins
Distance: 1-mile fun walk

Your Walk Committee

Carnie Abajian, Walk Manager
Maria Chavez, Walk Chair
Shaleigh Henry
Lori Long
Roseannette Lopez
Sophia Minhas
Rea Watson

Sangre de Oro, Inc.

Ute Fennicks, 1962–2014. Rest in Peace and Godspeed.

by Johanna Chappelle

After a short 6-month battle with terminal brain cancer, Ute left us to be with the Lord on November 19, 2014. She was born in Bernkastel-Kues, Germany on August 1, 1962. She grew up on the banks of the Moselle River, which is known for its beautiful river valley, with rolling hills, grape vines and wineries, and beautiful classic German architecture. It is the home of one of the best-known wine festivals in Germany. She spoke of the beauty of the area often, and it was always close to her heart, despite living in the U.S.

In February of 1982, Ute married "Ira" Chris Fennicks, a young member of the United States Air Force (USAF) stationed near her hometown. Over the years, Ute occasionally worked as a civilian contractor in the veterinarian clinics on USAF bases, both in Germany and here in the United States. She always maintained respect for the Armed Services, and especially the Air Force.

Cindy, her oldest daughter, and her son, Christopher, were both born in Germany and currently reside in Albuquerque. Ute is also survived by three adorable grandchildren—Maryssa, 9; Ava, 7; and Tarian, 3 months. She has one brother and a mother who still live in Germany.

Ute served on the Board of Directors for Sangre de Oro, Inc./Hemophilia Foundation of New Mexico from 1988 to 2007. She served as co-camp director for the Annual Family Camp from 2000 to 2002 where she helped to plan a 4-day education event for people in New Mexico and their families affected by hemophilia and other bleeding disorders.

In the 1990s, she took her EMT-Basic Course. Not long after licensing as a Basic, she started her Intermediate EMT course at the EMS Academy. Her talent as an EMS expert led her to work at theUNM emergency department where she cared for many patients and used her experience with hemophilia to educate the ER staff. She was also able to run calls in the ambulance for the Jemez Pueblo EMS.

During her tenure at UNM, she did some part-time contract work, assisting the EMS Bureau with practical exam sites. It was here that she became intrigued with the licensing exam process. In 2004, she was hired into the full-time BLS/ILS Coordinator position with the EMS Bureau. In time, she assumed responsibility for licensing all levels of EMS caregivers, and was eventually promoted up to the Licensing Manager position. In her ten years at the bureau, she has affected thousands upon thousands of EMS caregivers. Her knowledge and passion will continue to influence New Mexico EMS for years to come.

Ute became licensed as a paramedic in 2010. She was extremely proud of this accomplishment, especially since she was diagnosed with, and subsequently vanquished, breast cancer around the same time. After getting her paramedic license and becoming the Licensing Manager position within the EMS Bureau, she became active on the national level.

Some of her favorite things in life, aside from her family, were coffee "especially Starbucks," The UNM Lobos basketball team, creamy green chili soup, Blue Moon beer, Margaritas, and watching the German soccer team win the World Cup.

She was an amazing advocate for anyone suffering from chronic and acute illness. Especially for her own family, who unfortunately has had several medical challenges, she was a self-sacrificing mountain lion. There were several instances when she drove through the night after an out-of-town board meeting or working at a test site to return to Albuquerque in order to help out a family member in need.

Nothing better illustrates the lengths she would go to in assuring the health of her family than the following story. Back in the mid-1990s, Ute's husband, Chris, developed a condition that necessitated him being placed on a kidney transplant list. After a long, unsuccessful search, Ute, who had been discouraged from doing so, insisted they test her to see if she would be a match. It is my understanding that there was significant doubt by the medical caregivers, but sure enough, Ute was a perfect match, if for no other reason than she willed it to be so. She gave a kidney to Chris, and it functioned well for longer than most donor kidneys last. In May 2014, when Ute's Brain tumor was discovered and diagnosed, she was surrounded by friends and family. We tried to return the same caring and advocacy that she had shown to so many.

She will definitely be missed by the many that she touched. May she rest in peace and be surrounded by the angels above.

Join NHF's New Inhibitor Mentor Program for Parents Like You

The National Hemophilia Foundation is pleased to announce the Inhibitor Parent Mentoring Program for parents and caregivers of children diagnosed with hemophilia with inhibitors. Parents of children with hemophilia with inhibitors face a variety of challenges in raising their children due to the complications of their condition. This peer mentoring program matches parents whose children have or had inhibitors with parents of children with hemophilia with active inhibitors who might be feeling socially isolated and seeking guidance and coaching.

The goal of NHF's Inhibitor Parent Mentoring Program is to decrease the social isolation parents of children with hemophilia with inhibitors often experience, thereby helping prevent complications of these conditions and maximizing the quality of their daily lives. This six-month program is designed to help parents comprehensively manage their child's inhibitors and maximize the quality of their daily lives through a peer-to-peer support program.

Become a Mentee

A peer support program will offer the mentee parents advice, encouragement, and support from those who have experienced such challenges in the past. The mentor will offer guidance, and coaching to reduce feelings of isolation, thereby helping to prevent complications of these conditions and to maximize the quality of their daily lives.

Eligibility

Be the parent of a child with hemophilia A or B newly diagnosed with an active inhibitor and feeling socially isolated due to the child's disorder and looking for additional support.

Become a Mentor

Through this special relationship, the mentor provides advice and support based on his or her own experience to help guide the parents of children with hemophilia A or B newly diagnosed with an active inhibitor who are facing new challenges or those who have been walking this journey for some time who are now facing new or additional challenges. The mentor provides support navigating these challenges in ways that medical professionals, family, and friends may not be able to understand.

Eligibility

Be the parent of a child with hemophilia with an inhibitor (active or tolerized) who is at least 2 years old; feels comfortable sharing his/her experience parenting a child with a bleeding disorder with other parents; have the capacity (time, emotional stability, no major health crisis, etc.) to commit to mentoring for at least 6 months; have regular and consistent access to the Internet, email and long-distance phone service. The following characteristics are not minimum criteria for mentors, but will be considered to ensure no conflicts of interest or for the best match: languages spoken; membership in NHF or its chapters, staff of NHF or its chapters, board members of NHF or its chapters.

For questions, please email mgallagher@hemophilia.org.

Supported by an Educational Grant from Novo Nordisk

Inhibitor Summits and Camps!

Inhibitor summits and camps are free for those families who have inhibitors. Here is some information on upcoming opportunities!

There are two Inhibitor Education Summits planned for 2015. They will be held:

- July 9–12, 2015 in Denver, CO
- July 16–19, 2015 in Atlanta, GA

Registration will open in March. See more at http://www.hemophilia.org/Events-Meetings/Inhibitor-Education-Summits. For a complete agenda or for more information, call 877-560-5833.

You can also contact us at sdo@sangredeoro.org to let us know that you are interested.

The 2015 Inhibitor Camps will happen in two locations for each coast.

Spring Session

Location: The Painted Turtle, Lake Hughes, CA

Scheduled: April 10–13, 2015

Registration opens January 9th (9am, EST).

Fall Session

Location: Victory Junction, Randleman, NC

Scheduled: October 16–19, 2015

Registration opens July 1st (9am, EST).

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?
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.

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Issued June 2014

Meet Betty Schroll

by Candice Dunlop

After moving to Carlsbad, NM a few years ago, my husband and I finally settled into a house in a small retirement community. One of the first people I met there was Betty Schroll, who attended the same yoga class I had joined. I was so impressed by this woman, who, at 86 years young, was doing yoga and swimming regularly. She and her husband, Ron, (who is 88), play pool often at the senior center and still go out dancing! They competed in the Senior Olympics in Roswell in 2013, and both brought home medals.

At some point, I mentioned something about hemophilia, and Betty said that she has a family history of hemophilia. I became interested and decided to investigate this history. Betty has given me permission to write this article and all of my information comes straight from her. Betty, herself, is an asymptomatic hemophilia A carrier, but her family history of hemophilia is remarkable. Unfortunately, it is marked here and there with sadnesses related to hemophilia. I have agreed not to use names.

Betty's immediate family consisted of five girls and two boys. Of these, four of the girls were carriers and one of the boys had hemophilia. The family lived in Connecticut, and Betty's mother was instrumental in starting a hemophilia organization in that state. Her mother had come over from England as an infant, and Betty is not aware of any research having been done further back than her mother's family. After Betty's brother was diagnosed within the first couple years of his life, it then became apparent that one of her uncles on her mother's side should be tested. The uncle was then diagnosed, but he did live quite a long time. Betty remembers that he was in a wheelchair near the end of his life due to a fall.

Betty's brother had been diagnosed because he had bitten his tongue and it wouldn't stop bleeding. He lived into his 60s, but did die of AIDS, due to contaminated factor. Betty does remember many traumatic times related to her brother's bleeding episodes. In fact, Betty had seen her brother suffer so much, that she planned to never have children, even without knowing if she was a carrier or not.

Three of Betty's sisters had boys with hemophilia A (who I shall call Sister #1, Sister #2, and Sister #3). Sister #1 took her child to be tested when he was 4 months old. The baby died that night, due to internal bleeding caused by the blood draw. Sister #2 had two boys and no girls. One of the boys had hemophilia. He lived into his early 30s before he succumbed to AIDS.

Sister #3 had one son with hemophilia and adopted another boy with hemophilia when she heard he had been put up for adoption. The two boys were only 4 months apart. Both of the boys received contaminated factor and both died of AIDS in their early 20s, within the same year. Betty remembers that her nephew asked to go home to die, and since she was a nurse, she had made plans to go to help care for him at home. However, he passed away within hours of arriving home. As I am writing this, I feel overcome with sadness, knowing what so many went through during that era.

Sister #3 also had a daughter who had a boy with hemophilia. Betty saw him recently at a reunion. He is about 4 years old and is extremely active. She was amazed how much differently he is treated than her brother was as a child. Progress has been made for these little guys!

Now, back to Betty. She did decide to have children before she ever got tested for being a carrier. She ended up having three girls. Betty actually was tested sometime in the 1960s and was told she was not a carrier. However, this was disproved when her second daughter had a boy with hemophilia. He has done fairly well and is now in his 20s. He has severe hemophilia and is on prophylaxis. Betty also has two granddaughters from her first daughter. To her knowledge, neither the mother nor the daughters have been tested. Her youngest daughter has not had any children.

That is Betty's story. I have enjoyed learning about it and writing about it. As I said, I was first drawn to Betty because of her active life. I only hope I have half of her stamina at 86. Keep dancing, Betty and Ron! We welcome you into our New Mexico hemophilia family.

Calendar of Events

February	
25–27	Washington Days
March	
	National Hemophilia Awareness Month
6	Teen Event (tentative)
13	Camp Dinner (Albuquerque)
14	Camp Dinner (Roswell)
20	Board Meeting (SDO office, 5:30 p.m.)
21	Blood Sister Event: Jamberry Nails and Lunch, 11:30 a.m.–2:30 p.m., SDO Office
26–28	HFA Symposium in St. Louis, MO
April	
10	Camp Dinner (Albuquerque)
10–13	Inhibitor Family Camp in Lake Hughes, CA
11	Camp Dinner (Santa Fe)
17	World Hemophilia Day
18	The 3rd Annual Hemophilia Walk of New Mexico, Tiguex Park
23–25	Bi-Regional Meeting in Spokane, WA
May	
1	SDO Board Meeting, 6 p.m., SDO Office
2	Insurance Event, Northern New Mexico (Tentative)
11–14	NHF Leadership Training, Tempe, AZ
June	
6	Hemophilia B Symposium, Albuquerque, NM
9	New Mexico Hemophilia Awareness Day
9–13	Camp Sangre Valiente in Capitan, NM
20	Blood Brotherhood Event (Tentative)
27	Blood Sister Event: "The Courage to Soar," All Day, Venue TBD
July	
9–12	Inhibitor Summit, Denver, CO
16–19	Inhibitor Summit, Atlanta, GA
17	Board Meeting, 6 p.m., SDO Office
24	Teen Baseball Game
August	
8	Caliente Classic Golf Tournament
12–15	NHF Annual Meeting, Dallas, TX
29	Blood Brother Event (Tentative)
September	
17–19	NHF Annual Meeting in Washington, DC
21	Board Meeting (location TBD)
October	
16–19	Inhibitor Camp, Randleman, NC
17–19	Patient and Family Educational Weekend in Albuquerque, NM
November	
13	Board Meeting, 6 p.m., SDO Office
December	
4	Holiday Event (Tentative)

Thank You to Our 2014 Sponsors!

Your support makes it possible to serve our local community

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Being Grateful in the New Year

By Cazandra MacDonald

The New Year is here, and for many it is a time of starting over. It can also be a time filled with hope that "this year will be better than the last." When you live with a bleeding disorder, there are times, or "seasons," in your life that can be extremely complicated, with problems like extra factor, clinic appointments, hospital stays, crutches and wheelchairs, physical therapy ... the list continues. And hopefully, it is not a season that will last very long.

We all get to the point during these hard times where we think it will never get better. But most of the time it does; you just have to hang on. Our family went through one of these seasons recently, where hemophilia simply ruled our lives. I remember sitting in the hospital night after night thinking I would never spend a 24 hour period at home again. It was months before that happened with my entire family under one roof, and then it took months to breathe again.

You are never completely "out of the woods" with a bleeding disorder because you never know what will happen. But we have to live in the moment and not let ourselves become consumed by fear, anxiety, and "what if."

This year has already found me being grateful for things to which most other people would not give a second thought.

- Dropping my 9-year-old off at the curb and seeing him walk into school is a tremendous event, considering he spent over a year in a wheelchair.
- Missing three days of school due to a *cold*, not a bleed!
- Parking in a regular space (not handicapped) and not having to load a wheelchair.
- Seeing my son run (despite a limp) and keep up with his friend on the playground.

I bet you can find something to be extremely grateful for this year. Try not to let it be something that you wait to recognize at the end of hte year, but recognize the amazing things around you each and every day.

You will be amazed.

This year has already found me being grateful for things to which most other people would not give a second thought.

New Drugs Offer Hope, Barriers for Hepatitis C Patients

By Laura Weiss, Inquirer Staff Writer, Summarized by Lori Long

POSTED: January 4, 2015

Hepatitis C is a viral disease that is transmitted through the blood and is now spread largely through injection drug use. It scars the liver, sometimes leading to liver cancer or necessitating a transplant. About 3.2 million Americans are thought to be infected, most of them baby boomers. But symptoms may not appear for decades, and many carriers are unaware they carry the virus.

For patients with hepatitis C, the last year has brought great hope: new drugs, such as Sovaldi, that are highly effective with few side effects. But their high cost has led Medicaid officials in Pennsylvania and other states to put up barriers for patients, treating only the sickest ones and leaving many others to wait.

"This is an unprecedented approach we've had to take with these drugs," said Terri Cathers, pharmacy director for Pennsylvania's Office of Medical Assistance Programs. "We've not done this before for other treatments as long as I've been in the business." To get the drugs in Pennsylvania, Medicaid now uses prior authorization guidelines, which require patients to be assessed for treatment compliance, show the amount of damage to their liver or virus in their systems, and prove they are abstinent from drugs and alcohol through tests and a confirmation of six months of sobriety from a doctor, Cathers said. Generally, only patients with significant liver damage get approval. The state also asks if patients have been treated before, and if so, why it failed. Patients who are denied the drugs must wait for prices to go down or their disease to progress, or try to get free or discounted medication through a drug company patient assistance program, if they qualify. The approach, she said, is a direct result of the cost (up to $150,000 per patient). But some doctors who treat hepatitis C say the state's effort is discriminatory and shortsighted. "We providers feel like this is really not the way that we need to be allocating health care," said Stacey Trooskin, who specializes in hepatitis C. "We know that people who are treated earlier respond better to treatment." She says private insurers also deny coverage but are amenable to appeals. Not Pennsylvania Medicaid. The state's hepatitis C policy is disproportionately harming the poor, she said. Pennsylvania's is one of 35 state programs placing barriers on the drugs.

Doctors say they have to go to great lengths to get Medicaid patients approved, generating up to four denials before a final rejection. They say that employees must spend eight to 12 hours to get a patient drug approval. Sovaldi, an effective hepatitis C treatment, costs $84,000 for 12 weeks of the daily pills containing sofosbuvir. Harvoni, a sofosbuvir and ledipasvir combination pill, costs $94,500 for a full 12-week course, but some patients with less liver damage can be cured with a $63,000, eight-week treatment. Sovaldi is used in combination with other drugs such as Janssen Pharmaceuticals' pill Olysio, pushing the cost up to $150,000 for 12 weeks.

The new drugs change the game for hep C, offering daily pills with cure rates of more than 90 percent. The treatments are well tolerated, with minor side effects of fatigue and headaches. Older treatment relied on a combination of pegylated interferon and ribavirin. Patients were often deterred by interferon's weekly injections, severe side effects, and lower success rate. Trooskin warns her patients up front about the difficulty of getting the new pills, particularly if they are on Medicaid. She said that Medicare has been covering them but that private insurance companies sometimes reject them the first time and then generally relent. She called new hep C treatments "the greatest public health accomplishment of our generation." But it's not enough to have a cure. Anyone who needs it has to be able to get it, she said. Trooskin receives grant funding from Gilead and sat on hepatitis C advisory boards for the company.

A Gilead spokeswoman said in a statement that the pricing of Harvoni and Sovaldi reflects their value and will save the nation's health system over time, since the average cost of a liver transplant was $577,100 in 2011. Responding to the drug restrictions, the spokeswoman wrote that starting therapy earlier has produced a higher cure rate in studies, which would cut future costs of treating advanced liver damage. Paul Yabor, 52, of Juniata, had moderate liver damage from hepatitis C when he was first denied the drugs by his private insurer. Then he got approval, thanks to advocacy, he said. He began treatment, which he found free of side effects, in June and finished in September. Now he has no hep C virus detectable in his system.

"Behind this medication are sick people who are dying," he said. "We're dealing with a system that basically says: Is it more affordable to let someone die than to live? Or how little can we give out to make the most profit?" Carl Grant, 64, of South Philadelphia, hasn't been so fortunate. More than two decades with the infection has left him with severe liver damage, but he said he avoided the old treatment because of its severe side effects. Grant's cirrhosis puts him at risk for liver cancer or needing a transplant. He was prescribed two of the new drugs in July. His Medicaid HMO, Keystone First, denied the $150,000 cost. Months after his doctor first prescribed the drugs for him, Grant attended a first appeal hearing on Dec. 9. Joining him were nurse practitioner Jody Gilmore, coordinator of the viral hepatitis program at Penn Presbyterian Medical Center, and Lance Haver, director of the city's Office of Consumer Affairs. Both spoke on his behalf to a company-employed doctor hearing the appeal.

"We have a cure, so let me have that cure," Grant said beforehand. "As a United States citizen, I feel like I'm being cheated." When Grant was first denied Sovaldi and Olysio, Keystone First suggested that he try a cheaper regimen of Sovaldi, pegylated interferon, and ribavirin, Gilmore said. But when she applied for those drugs, Grant was denied again. Keystone First wouldn't discuss Grant's case with a reporter, but said its protocols are approved by Pennsylvania Medicaid and are subject to "a rigorous review process" based on evidence. "About 80 percent of hepatitis C patients don't experience a progression of their disease," the company said in a statement. "For those that do, we have developed protocols to put them on the path to wellness as quickly as possible."

Grant is awaiting a decision that Gilmore said will likely depend on the results of a new scan to confirm the extent of his liver damage. The nurse practitioner said all her Medicaid patients are getting denials, generally at least two to four times, for the new hep C drugs. The process, she said, takes months.

Weiss, Laura. "New drugs offer hope, barriers for hepatitis C patients," 4 January 2014, Philly.com.Copyright 2015.

ADVATE [Antihemophilic Factor (Recombinant)]
Lyophilized Powder for Reconstitution for Intravenous Injection
Brief Summary of Prescribing Information: Please see package insert for full Prescribing Information.

INDICATIONS AND USAGE

ADVATE [Antihemophilic Factor (Recombinant)] is a recombinant antihemophilic factor indicated for use in children and adults with hemophilia A (congenital factor VIII deficiency or classic hemophilia) for:

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

ADVATE is not indicated for the treatment of von Willebrand disease.

CONTRAINDICATIONS

ADVATE is contraindicated in patients who have life-threatening hypersensitivity reactions, including anaphylaxis, to mouse or hamster protein or other constituents of the product (mannitol, trehalose, sodium chloride, histidine, Tris, calcium chloride, polysorbate 80, and/or glutathione).

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Allergic-type hypersensitivity reactions, including anaphylaxis, have been reported with ADVATE. Symptoms include dizziness, paresthesia, rash, flushing, facial swelling, urticaria, dyspnea, and pruritus.

ADVATE contains trace amounts of mouse immunoglobulin G (MuIgG) ≤0.1 ng/IU ADVATE, and hamster proteins ≤1.5 ng/IU ADVATE. Patients treated with this product may develop hypersensitivity to these non-human mammalian proteins.

Discontinue ADVATE if hypersensitivity symptoms occur and administer appropriate emergency treatment.

Neutralizing Antibodies

Neutralizing antibodies (inhibitors) have been reported following administration of ADVATE predominantly in previously untreated patients (PUPs) and previously minimally treated patients (MTPs). Monitor all patients for the development of factor VIII inhibitors by appropriate clinical observation and laboratory testing. If expected plasma factor VIII activity levels are not attained, or if bleeding is not controlled with an expected dose, perform an assay that measures factor VIII inhibitor concentration. [see *Warnings and Precautions*]

Monitoring Laboratory Tests

- Monitor plasma factor VIII activity levels by the one-stage clotting assay to confirm the adequate factor VIII levels have been achieved and maintained when clinically indicated. [see *Dosage and Administration*]
- Perform the Bethesda assay to determine if factor VIII inhibitor is present. If expected factor VIII activity plasma levels are not attained, or if bleeding is not controlled with the expected dose of ADVATE, use Bethesda Units (BU) to titer inhibitors.
  - If the inhibitor titer is less than 10 BU per mL, the administration of additional antihemophilic factor concentrate may neutralize the inhibitor and may permit an appropriate hemostatic response.
  - If the inhibitor titer is above 10 BU per mL, adequate hemostasis may not be achieved. The inhibitor titer may rise following ADVATE infusion as a result of an anamnestic response to factor VIII. The treatment or prevention of bleeding in such patients requires the use of alternative therapeutic approaches and agents.

ADVERSE REACTIONS

The serious adverse reactions seen with ADVATE are hypersensitivity reactions and the development of high-titer inhibitors necessitating alternative treatments to factor VIII.

The most common adverse reactions observed in clinical trials (frequency ≥10% of subjects) were pyrexia, headache, cough, nasopharyngitis, vomiting, arthralgia, and limb injury.

Clinical Trial Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in clinical trials of another drug and may not reflect the rates observed in clinical practice.

ADVATE has been evaluated in five completed clinical trials in previously treated patients (PTPs) and one ongoing trial in previously untreated patients (PUPs) with severe to moderately severe hemophilia A (factor VIII ≤2% of normal). A total of 234 subjects have been treated with ADVATE as of March 2006. Total exposure to ADVATE was 44,926 infusions. The median duration of participation per subject was 370.5 (range: 1 to 1,256) days and the median number of exposure days to ADVATE per subject was 128 (range: 1 to 598).[3]

The summary of adverse reactions with a frequency ≥5% (defined as adverse events occurring within 24 hours of infusion or any adverse event causally related occurring within the trial period) is shown in Table 3.

No subject was withdrawn from a clinical trial due to an adverse reaction. There were no deaths in any of the clinical trials.

Table 3
Summary of Adverse Reactions[a] with a Frequency ≥5% (N = 234 Treated Subjects[b])

MedDRA[c] System Organ Class	MedDRA Preferred Term	Number of ADRs	Number of Subjects	Percent of Subjects
General disorders and administration site conditions	Pyrexia	78	50	21
Nervous system disorders	Headache	104	49	21
Respiratory, thoracic, and mediastinal disorders	Cough	75	44	19
Infections and infestations	Nasopharyngitis	61	40	17
Gastrointestinal disorders	Vomiting	35	27	12
Musculoskeletal and connective tissue disorders	Arthralgia	44	27	12
Injury, poisoning, and procedural complications	Limb injury	55	24	10
Infections and infestations	Upper respiratory tract infection	24	20	9
Respiratory, thoracic, and mediastinal disorders	Pharyngolaryngeal pain	23	20	9
Respiratory, thoracic, and mediastinal disorders	Nasal congestion	24	19	8
Gastrointestinal disorders	Diarrhea	24	18	8
Gastrointestinal disorders	Nausea	21	17	8
General disorders and administration site conditions	Pain	19	17	8
Skin and subcutaneous tissue disorders	Rash	16	13	6
Infections and infestations	Ear infection	16	12	5
Injury, poisoning, and procedural complications	Procedural pain	16	12	5
Respiratory, thoracic, and mediastinal disorders	Rhinorrhea	15	12	5

[a] Adverse reactions are defined as all adverse events that occurred (a) within 24 hours after being infused with investigational product, or (b) all adverse events assessed related or possibly related to investigational product, or (c) adverse events for which the investigator's or sponsor's opinion of causality was missing or indeterminate.

[b] The ADVATE clinical program included 234 treated subjects from 5 completed studies in PTPs and 1 ongoing trial in PUPs as of 27 March 2006.

[c] MedDRA version 8.1 was used.

Immunogenicity

The development of factor VIII inhibitors with the use of ADVATE was evaluated in clinical trials with pediatric PTPs (<6 years of age with >50 factor VIII exposures) and PTPs (>10 years of age with >150 factor VIII exposures). Of 198 subjects who were treated for at least 10 exposure days or on study for a minimum of 120 days, 1 adult developed a low-titer inhibitor (2 BU in the Bethesda assay) after 26 exposure days. Eight weeks later, the inhibitor was no longer detectable, and *in vivo* recovery was normal at 1 and 3 hours after infusion of another marketed recombinant factor VIII concentrate. This single event results in a factor VIII inhibitor frequency in PTPs of 0.51% (95% CI of 0.03 and 2.91% for the risk of any factor VIII inhibitor development).[3,4] No factor VIII inhibitors were detected in the 53 treated pediatric PTPs.

In clinical trials that enrolled previously untreated subjects (defined as having had up to 3 exposures to a factor VIII product at the time of enrollment) , 5 (20%) of 25 subjects who received ADVATE developed inhibitors to factor VIII.[3] Four subjects developed high titer (>5 BU) and one patient developed low-titer inhibitors. Inhibitors were detected at a median of 11 exposure days (range 7 to 13 exposure days) to investigational product.

Immunogenicity also was evaluated by measuring the development of antibodies to heterologous proteins. 182 treated subjects were assessed for anti-Chinese hamster ovary (CHO) cell protein antibodies. Of these subjects, 3 showed an upward trend in antibody titer over time and 4 showed repeated but transient elevations of antibodies. 182 treated subjects were assessed for mulgG protein antibodies. Of these, 10 showed an upward trend in anti-mulgG antibody titer over time and 2 showed repeated but transient elevations of antibodies. Four subjects who demonstrated antibody elevations reported isolated events of urticaria, pruritus, rash, and slightly elevated eosinophil counts. All of these subjects had numerous repeat exposures to the study product without recurrence of the events and a causal relationship between the antibody findings and these clinical events has not been established.

Of the 181 subjects who were treated and assessed for the presence of anti-human von Willebrand Factor (VWF) antibodies, none displayed laboratory evidence indicative of a positive serologic response.

The detection of antibody formation is highly dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to ADVATE with the incidence of antibodies to other products may be misleading.

Post-Marketing Experience

The following adverse reactions have been identified during post-approval use of ADVATE. Because these reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

Among patients treated with ADVATE, cases of serious allergic/hypersensitivity reactions including anaphylaxis have been reported and factor VIII inhibitor formation (observed predominantly in PUPs). Table 4 represents the most frequently reported post-marketing adverse reactions as MedDRA Preferred Terms.

Table 4
Post-Marketing Experience

Organ System [MedDRA Primary SOC]	Preferred Term
Immune system disorders	Anaphylactic reaction[a] Hypersensitivity[a]
Blood and lymphatic system disorders	Factor VIII inhibition
General disorders and administration site conditions	Injection site reaction Chills Fatigue/Malaise Chest discomfort/pain Less-than-expected therapeutic effect

[a] These reactions have been manifested by dizziness, paresthesias, rash, flushing, face swelling, urticaria, and/or pruritus.

Steve Griego: a Great Philanthropist!

by Lori Long

On September 27, 2014, I was honored to attend a recognition dinner hosted by NHF for philanthropists who support individual chapters. NHF selected four Philanthropists of the Year from chapter nominations. These individuals have significantly helped the bleeding disorders community in their area.

The awardee from New Mexico was Steve Griego from DMC Logistics. Steve has been the primary sponsor and fundraiser for the SDO Annual Caliente Classic Golf Tournament for the past 11 years (a lot longer than the 2 or 3 years he expected). In his words, "I told Loretta [Cordova], I would help for 2 or 3 years to get the golf tournament off the ground and then you [SDO] could take over." In attendance with Steve was his wife Lydia, our SDO Past President, Johanna Chappelle, and myself.

Philanthropists often make significant contributions to NHF chapters, which allows the chapters to provide vital programs and services to people affected by bleeding disorders. These individuals have exhibited exceptional generosity through their direct financial support, exemplified outstanding civic and charitable responsibility, and encouraged and motivated others in their own philanthropy. We congratulate these individuals who have made such significant contributions to their chapters, especially our own Steve Griego.

Thank you, Steve and Lydia for your years of support! You have changed our lives!

NHF 2014 Philanthropists of the Year

Pete Barbounis: Hemophilia Foundation of Northern California

Steve Griego: Sangre de Oro, Inc., Bleeding Disorders Foundation of New Mexico

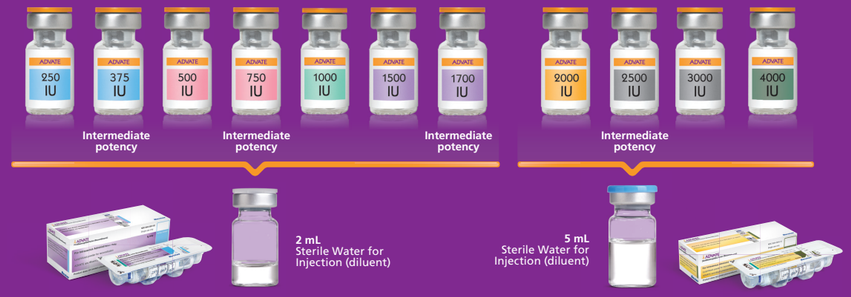
Innovating Worthy Projects Foundation: Hemophilia Association of the Capital Area

The J. Willard and Alice S. Marriott Foundation: Hemophilia Association of the Capital Area

2014 Patient and Family Education Weekend

PERSONALIZATION WITH A BROAD SELECTION OF ADVATE OPTIONS

CUSTOMIZED CONVENIENCE WITH 2 ML OR 5 ML DILUENT VOLUME



- **11 potencies provide more options for single-vial infusions—more than any other FVIII product[1,3]**
- **7 different potencies available with 2 mL diluent volume, up to 1700 IU[1]**

DETAILED IMPORTANT RISK INFORMATION (continued)

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

You can have an allergic reaction to ADVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash.

Tell your healthcare provider about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Brief Summary of ADVATE Prescribing Information on the following page.

References: 1. ADVATE Prescribing Information. Westlake Village, CA: Baxter Healthcare Corporation; April 2014. **2.** Valentino LA, Mamonov V, Hellmann A, et al. A randomized comparison of two prophylaxis regimens and a paired comparison of on-demand and prophylaxis treatments in hemophilia A management. *J Thromb Haemost*. 2012;10(3):359-367. **3.** Data on file. Westlake Village, CA; Baxter Healthcare Corporation.

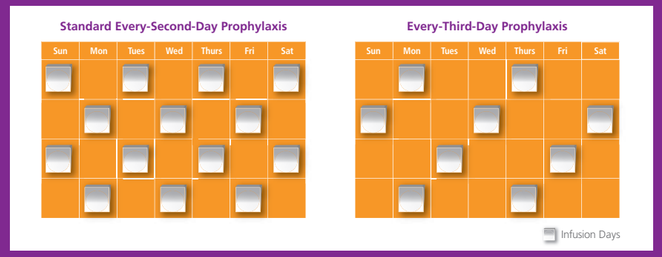
ADVATE
[Antihemophilic Factor (Recombinant)]
There's more to life.

Baxter

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

ADVATE DOSING CAN BE PERSONALIZED FOR YOU

EVERY-SECOND-DAY AND EVERY-THIRD-DAY DOSING OPTIONS WITH ADVATE PROPHYLAXIS WERE BOTH SHOWN TO BE EFFECTIVE IN A CLINICAL TRIAL[1]



60 POTENTIAL FEWER INFUSIONS PER YEAR
WHILE MAINTAINING EFFICACY[1,2]

You may be a candidate for Every-Third-Day Dosing if

- **Your treatment is on-demand and your bleed frequency is 4 to 6 times per month or more, and you want fewer bleeds with fewer scheduled infusions[1]**
- **Your current prophylaxis treatment regimen is 3 times per week or more, and you want fewer scheduled infusions**

Talk to your healthcare provider to see if Every-Third-Day Dosing is right for you.

- **You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADVATE so that your treatment will work best for you**
- **You must be willing to have blood tests to help determine your appropriate starting dose (as it may be higher than your current dose)**

INDICATIONS

ADVATE [Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method] is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

Please see Detailed Important Risk Information continued on the following page.

Continued on Page 16.

NHF's 66th Annual Meeting

By Jose Guillen

Attending the 2014 National Hemophilia Foundation Annual Meeting as an SDO Chapter representative was an honor and a privilege. The previous three NHF Annual Meetings I have been fortunate to attend were great experiences, and this one was no different. NHF Annual Meetings are a whirlwind experience that move at a rapid pace. You meet outstanding, dedicated community members from across the country who are making a difference in their communities, and it feels great to be part of that group.

The meeting started off on Wednesday evening after a long day of travel from Albuquerque to Washington D.C. At the Chapter Leadership Reception, we mingled over hors d'oeuvres with chapter leaders from across the country.

The entire Meeting Program was jam-packed with 3 full days of meetings. The Annual Meeting is structured such that there are presentations for different audiences, such as Consumers and New Families, MDs, Nurses, Physical Therapists, Social Workers, Chapter Staff, and Teens. I primarily attended the Chapter Staff meetings and mixed in a couple of Consumers and New Families presentations.

The Annual Meeting started in a huge ballroom with the NHF Chapter Update presentations from the NHF Staff.

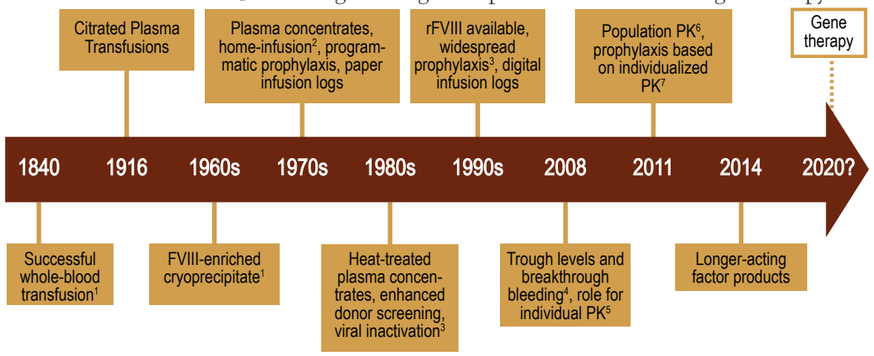
- Joe Klieber spoke about the establishment of a Chapter Intranet to be used to provide help to chapters with HR administration, fund raising, professional development, board development, and nhf chapter membership registration. he also mentioned that chapter Charter Agreements need to be renewed in 2015 and referred to Chapter Services for those chapters that have issues with the agreements for resolution.
- Jorge de la Riva spoke about the Board of Directors and his experience on how a small group of determined people can change the world.
- Kristin Hokoyama spoke about the NHF Walk Program and how the monies raised get used.
  - Monies raised locally stay local
  - Monies raised nationally greater than $1M go back to NHF to a revenue sharing pot for Walk training, which took place in Las Vegas right after NACCHO training in 2015
  - Walk training program will be expanded
  - Baxter initiated a Hemophilia Walk for Research matching grant program.
  - The NY Chapter donated $10K to this JGP research program. This NHF fellowship program named for Dr. Judith Graham Pool who discovered a method of obtaining clotting factor from human plasma to make cryoprecipitate. Her research led to the newer recombinant factor therapies that many with bleeding disorders use today. Chapters are encouraged to make a donation to this program since no corporate money is accepted for its research.
- Alain Weill from the World Federal of Hemophilia provided the following update:
  - 20 million IUs of factor were donated by pharmaceutical companies after the Melbourne Congress in 2014. They commited to further donations in the future.
  - Community donations were also encouraged. NHF will match these donations up to $50K.

I have summarized two meetings that were significant for me.

Chapter Staff Organization (CSO) Business Meeting and Luncheon

During the short business meeting, new executive directors were recognized. This was followed by an exciting update on the new factor drugs in the pipeline. The following figures in this article were provided by Dr. Steven W. Pipe, M.D., Professor of Pediatrics and Pathology, and Director of Pediatric Hematology at the University of Michigan in Ann Arbor.

Figure 1 illustrates just how far hemophilia care has progressed, from blood transfusions in 1840 to today's longer-lasting factor products and tomorrow's gene therapy.



1 ABB. Available at http://www.aabb.org/resources/bct/Pages/highlights.aspx
2 National Hemophilia Foundation. Available at http://www.hemophilia.org/NHFWeb/Mainpgs/MainNHF.aspx?menuid=178&contentid=6.3
3 Hemophilia-information.com. Available at http://www.hemophilia-information.com/history-of-hemophilia.html; accessed 17 May 2013
4 Collins, et al., *J Thromb Haemost*, 2009;7(3);413-420
5 Collins, et al., *J Thromb Haemost*, 2010;8(2);269-275
6 Bjorkman, et al., Blood, 2012; 119(2):6112-618
7 Valentino, et al., *J Thromb Haemost*, 2012;10(3);359-367

Figure 1. Evolution of Hemophilia Care

Continued on Page 13.

BeneFix®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

℞ only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-934-5556.

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

What is BeneFix?

BeneFix 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 or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor 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.

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

- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

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

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

Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE BeneFix. BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Store the diluent syringe at 36° to 86°F (2° to 30°C). Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

Different storage conditions are described below.

Product labeled for Room Temperature Storage
Store at 2° to 30°C (36° to 86°F).
If you have the product kit labeled for room temperature storage, it can be stored at room temperature (below 30°C or 86°F) or in the refrigerator (2° to 8°C or 36° to 46°F).

Product labeled for Refrigerator Storage
Continuous refrigeration
[2° to 8°C (36° to 46°F)]
If you have the product labeled for storage in the refrigerator (2° to 8°C or 36° to 46°F) and you have not taken the kit out of the refrigerator, then the expiration date printed on the package still applies. You can store the product at room temperature (below 30°C or 86°F) for up to 6 months or until it has reached its expiration date, whichever comes first.

If you have taken the product kit labeled for storage in the refrigerator out of the refrigerator and stored it at room temperature (below 30°C or 86°), then use the product within 6 months from the time you took the product out of the refrigerator or until it has reached its expiration date, whichever comes first. If you cannot remember when you took it out of the refrigerator, then subtract one year (12 months) from the date that is printed on the end flap of the carton package. The date you get is your new expiration date. Throw away any product that has gone over the new expiration date.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

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

If you would like more information, talk to your doctor. You can ask your doctor for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® Coagulation Factor IX (Recombinant) Prescribing Information LAB-0464-8.0, revised November 2011.

Wyeth®

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Marketed by Pfizer Inc.
July 2012

Pfizer

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.

----------DOSAGE 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.

GRIFOLS
Grifols Biologicals Inc.
5555 Valley Boulevard
Los Angeles, CA 90032, U.S.A.
U.S. License No. 1694

3041048-BS
Revised: 06/2014

In Figure 2, Dr. Pipe presented the outcome of a study on the prophylactic use of clotting factor. He presented data from two separate years (2011 and 2009) in which the number of bleeds per year were basically the same when patients treated on demand. The number of bleeds per year dropped to two (-0 bleeds/mo.) when patients were treated prophylactically. He noted that in children, prophylaxis prevents joint bleeding, overall bleeding and joint disease, and in adults it prevents joint and overall bleeding. He recommended that patients be started on prophylaxis as early as 12 months to improve and preserve bleeding control and joint function. He described prophylaxis regimens in Sweden, Germany, the U.S., and Italy where higher dosage regimens are being advocated for hemophilia A (one to three times per week) and for Hemophilia B (once or twice per week).

Dr. Pipe presented an extensive look at the many biologic products for hemophilia in the clinical trial pipeline. Certain hemophilia A and B products have demonstrated significant half-life extensions.

Now, products from Baxter, Bayer, Novo-Nordisk, and Biogen Idec have extended half-lives 1.3 to 1.5 times the current half-lives with no inhibitors, antibodies, or other adverse reactions. Hemophilia B products demonstrated half-lives of 84 to 110 hours, depending on product used, with no inhibitors and no drug-related adverse events.

I have provided an abbreviated list of trial results:

Y855: PEGylated rFVIII (Baxter)

Phase I and III results (patients, age 12 to adult)

- Half-life extension to 1.5 times longer than Advate
- Twice weekly dosing vs. on-demand for 6 months
- 95% reduction in median annual bleed rate (ABR), 1.9 vs. 41.5
- 96% of bleeds controlled with 1 or 2 infusions
- No inhibitors, no AB to PEG, and no allergic reactions

N8-GP: PEGylated rFVIII (Novo Nordisk)

Phase III trials (patients, age 12 to adult)

- Half-life of 18.4 hours
- ABR 1.3 (median) on prophylaxis

BAY94-9027: PEGylated rFVIII (Bayer)

Phase I study (patients, severe hemophilia A, ages 21 to 58)

- 19 hours half-life vs. 13 hours for rFVIII-FS
- No treatment-related adverse events, no inhibitors or antibodies directed against PEG or BAY94-9207

rFVIII:Fc (Biogen Idec), FDA Approved

Phase I trials (adult men with severe hemophilia A)

- No serious adverse events, including no inhibitors
- 1.5- to 1.7-fold longer half-life compared to rFVIII
- Phase III trials (patients, severe hemophilia A, age 12+ years)
- Individualized prophylaxis: 1.6 ABR
- On-demand: 33.6 ABR
- No inhibitors and no drug-related serious adverse events.

Glycopegylated FIX

First human dose trial in hemophilia B (patients, adult men with hemophilia B)

- Half-life of 93 hours, which is 5 times that of rFIX
- Better plasma recovery than rFIX

N9-GP: PEGylated rFIX

Phase III results (74 subjects following a 12-month prophylaxis regimen)

- 40 IU/kg. weekly
- 99% of bleeds treated with a single infusion
- Two-thirds reported complete resolution of target joints
- Half-life of 110 hours
- No inhibitors.

rFIX:Fc (Biogen Idec), FDA Approved

Phase III results

- Half-life of 82.1 h
- No inhibitors.

Dr. Pipe also mentioned that novel products that are hemo-type agnostic (non-protein therapies) are being investigated to clot blood. So the future is looking very bright for hemophilia products.

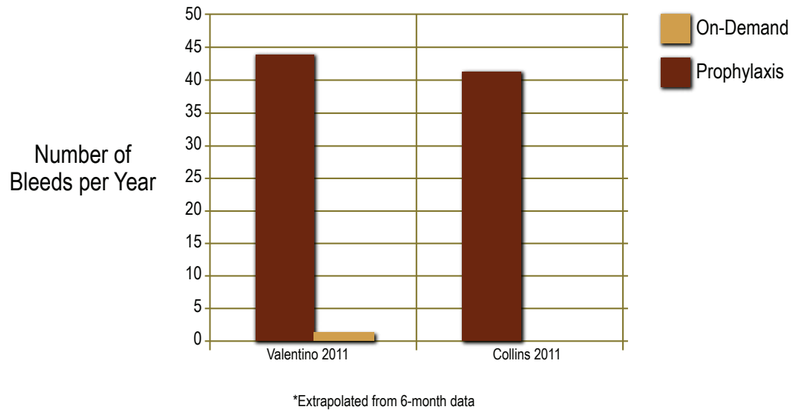

Figure 2. Outcome of Prophylaxis

Continued on Page 23.

Ted R. Montoya Hemophilia Treatment Center Gets a New Director!

by Cazandra Campos-MacDonald

The Ted R. Montoya Hemophilia Treatment Center has announced Dr. Shirley Abraham as the new Director of the Hemophilia Program. Dr. Abraham was born and raised in Kuwait. She received her medical school degree in India, performed her Pediatric residency in Long Island, New York and Pediatric Hematology/Oncology fellowship at Primary Children's Medical Center, Salt Lake City, Utah. Her husband is also a physician and they have an 8-year-old daughter and 4-year-old son. When Dr. Abraham has time she enjoys cooking, reading, and painting.

As Dr. Abraham comes in as the Director of the HTC, she finds her biggest challenge to be obtaining all of the necessary resources under one umbrella that will provide a comprehensive, multidisciplinary clinic for patients. This will include physical therapy, dental services, pharmacy, and various ancillary services.

Dr. Abraham wants to develop a program that will provide exemplary care as well as educational and clinical services to patients and their families. In the short term, providing comprehensive services for all patients, encouraging patients and families to become actively involved in education, and supporting active participation in regional activities are her goals for the program. Her future goals include becoming a nationally recognized HTC that provides state-of-the-art services with a staff that will pioneer efforts to improve the care of those in the bleeding disorder community.

Congratulations to Dr. Shirley Abraham! The community is grateful to have a leader for the program that will champion the needs of those affected by bleeding disorders.

HTC Contacts

Brie ---------- 272-4088
Claudia ------- 272-3264
Shynia -------- 272-0705
Adult on-call after hours:
272-4946
Pediatric on-call after hours:
272-4461
Mail:
MSC10 5590
1 University of New Mexico
Albuquerque, NM 87131

James Hamilton Memorial Scholarship Fund

In order to be considered, the applicant must provide evidence of the following by submitting pertinent copies of personal records to the scholarship committee chair or designee.

Scholarship Eligibility Criteria

- Be a person with hemophilia
- Be a New Mexico resident
- Be a U.S. citizen or an eligible non-citizen

Other Requirements

- Provide a valid social security number
- Provide proof of application for student aid (FASFA)
- Demonstrate financial need, as evidenced by the FASFA form
- Provide evidence of application to two additional sources of financial aid assistance
- Provide a copy of a high school diploma or GED
- Provide evidence of enrollment or acceptance for enrollment as a regular student working toward a degree or certificate in an eligible program
- Submit completed scholarship application form to Sangre de Oro, Inc.
- Submit a letter of reference from someone, other than a family member, who knows you
- Have a personal interview by the scholarship committee or chairperson
- Must meet deadline for semester of request

Scholarship Renewal Requirements

- Provide evidence of satisfactory academic progress by maintaining a minimum 2.5 GPA out of a possible 4.0 to be considered for scholarship renewal. Official transcript showing final, current grades must be submitted when requesting a renewal of this scholarship. **If your GPA falls below a 2.5, you can reapply the following semester!**

Application Deadlines

Fall semester deadline: August 1st

Spring semester deadline: December 1st

NHF's 66th Annual Meeting

Is that OK? Ethical Dilemmas in Our Community by the Ethics Advisory Committee

The hemophilia community has unique ethical situations that need to be examined for the good of all the community. NHF has a multi-disciplinary Ethics Advisory Commitee (also known as the ethics working group [EWG]) that reviews and examines situations, problems, and issues that affect the entire community. The EWG consists of a nurse, two doctors, a philosophy and ethics professor, and a parent from the community.

These individuals are volunteers (typically service 2- or 3-year terms). They hold monthly meetings by phone and meet in person bi-annually. They review cases regarding ethical behavior by the medical, pharmaceutical, and home care professions that impact our community.

A couple of examples of this are:

- History of contaminated products
- Industry volunteers at camp who have access to minor information.

So why have an EWG?

- 1998: a problem was identified
- 2002: a group was formed to review the problem
- 2008: a committee was formed to address ethical concerns over a longer period of time
- 2014: a permanent group was formed at NHF

So what is ethics? It is the moral correctness of conduct. A guideline or rule that helps you determine right from wrong and influences your behavior.

Review of a situation starts off with a couple of questions:

1. What is the good?
2. What should I do? vs. Who should I be?

They use an Ethical Decision Making Process with the following steps:

1. **Clarify** the ethical situation
2. **Identify** all stakeholders and their values
3. **Investigate** and understand the circumstances regarding the ethical conflict
4. **Discuss** all perspectives.

At this point, you may have to return to step 1 to refine and pinpoint the ethical situation more clearly.

1. **Identify** the best recommendations
2. **Share** by making recommendation statements
3. **Measure** behavior changes over time

They presented the following three cases as examples to discuss. These were actual situations that the EWG was asked to consider:

1. A physician prescribes cryoprecipitate rather than factor for an operation.
2. An adult homecare representative initiates contact with a minor who has hemophilia without parental permission.
3. A homecare representative wishes to be on local bleeding disorders board of directors.

Exhibit Hours

- Thursday, August 13 Platinum Preview Lounge 1:00 p.m.–4:00 p.m.
- Exhibit Hall Reception Opening 6:30 p.m.–9:30 p.m.
- Friday, August 14 9:00 a.m.–6:00 p.m.
- Saturday, August 15 8:30 a.m.–1:00 p.m.

Accommodations

Rooms are available at the Gaylord Texan Resort & Convention Center Hotel.

NHF room rates are $184.00 single/double, including a $15 mandatory resort fee, and are subject to applicable taxes. Resort fee includes: wired and wireless high- speed internet access in guest rooms; two bottles of water per day in guest rooms; local telephone calls; discounted shuttle bus to designated locations; admission to two to Glass Cactus nightclub (21+ only; restrictions apply); admission to Paradise Springs water park (four per standard room and six per suite).

Please note rooms are limited. The deadline for the NHF rate at the Gaylord Texan Resort & Convention Center Hotel, located at 1501 Gaylord Trail, Grapevine, TX, is Friday, July 10, 2015 based on availability. To reserve a room, please call: 877.491.5138 and mention NHF's 67th Annual Meeting or visit: https://resweb.passkey.com/go/NHFACAttendees

Please note that requests for room blocks of 5 or more rooms are subject to NHF approval. In an effort to accommodate all consumer hotel needs, NHF is grateful to the Annual Meeting sponsors and exhibitors for housing their staff off site.

Wheelchair Accessibility

The hotel is wheelchair accessible. We have reserved handicap-accessible rooms on a first-come, first-serve basis. If you require a special room or have any other special needs, you must call the hotel directly. The hotel does not provide wheelchairs. Annual Meeting participants who need to rent wheelchairs or other equipment should note this in the special needs section of the registration form and submit it on or before Monday, July 6, 2015.

Emergency Care

NHF has advised the local hemophilia treatment center (HTC) of our group's arrival to help facilitate any emergency treatment that may be necessary.

Special Requests

Sharps containers: NHF will not provide sharps containers during the Annual Meeting.

Refrigerators: the hotels will make every effort to provide refrigerators to hotel guests who require them for medicine storage. You must request a refrigerator through the hotel when making your room reservations.

First-Ever I Love Someone with Hemophilia Car Show!

Continued on Page 21.

MORE 2015 Patient and Family Education Weekend

Consumer Assistance Program

Did you know that SDO has more than one form of assistance? If you need financial assistance to get yourself or your child to a medical appointment, our Consumer Assistance Program(CAP) can assist you with meals, hotel, or fuel.

If you need assistance to attend an SDO event, you can likely get support from our Communications and Outreach fund. This fund can assist with travel funds, such as fuel and hotel.

If you would like to know more about either of these programs, please contact us at 505.341.9321 or sdo@sangredeoro.org.

The SDO Board

Executive Board Members

Lori Long, President

Jose Duran, Vice President

Sophia Minhas, Secretary

Eric Marquez, Treasurer

Board Members

Johanna Chappelle

Maria Chavez

Robert Farias

Jessica Hernandez

If you are interested in participating on the board, please call 505/341-9321 or e-mail sdo@sangredeoro.org.

11th Annual Camp Sangre Valiente

By Jose Duran, Camp Executive

Another great summer of camp is almost here, and our camp committee and the wonderful team at Camp Sangre Valiente are very excited to welcome the kids back to what we think is going to be a great year! As we eagerly prepare for this year's camp, we want to remind our families what our camp is all about.

Camp is the place where your children will not only have tons of fun but also gain a great educational experience. Our goal is for the kids to become comfortable with their bleeding disorder and become independent while enjoying the company of friends and siblings. Our friends from the HTC will be at camp to ensure that your children are in a safe and healthy environment while they are enjoying the great activities our camp has to offer!

SDO is providing camp free to kids between the ages of 7 and 17 with a bleeding disorder, their siblings, and children of an affected parent (including carriers). Campers ages 13 to 17 are put in the Leaders in Training (LIT) program where they presented with different challenges and are encouraged to take charge of their care and the responsibilities that come along with it. Camp has something to offer everyone, including activities like horseback riding, archery, sports, and the popular waterslide. Although it's hard to fit everything we do in a week, your camper will never be bored!

YOU MUST REGISTER YOUR CHILD BY 1 MAY 2015!

If you have any questions or concerns please feel free to reach out to Jose Duran at sdo@sangredeoro.org or 505.341.9321. There will be plenty of camp dinners where you can register your child. If you are not going to a camp dinner and want to get your child registered, please contact the SDO office at sdo@sangredeoro.org or 505.341-9321 and we can send you a camp registration packed either by mail or email. Please remember that each child has to be registered to attend camp. We are so excited and can't wait to see everyone!

President's Corner

Dear Community,

We have had another momentous year, haven't we?

We lost Ute Fennicks, our blood sister. We will miss her, and may she rest in peace.

We have also had some triumphs. We had our second Hemophilia Walk with about 300 people attending. We raised more than $25,000! I hope you all plan to sign up and walk again. It was so fun (page 1)! Also, if any of you know folks who own businesses, we do have sponsorship levels for business that allow them some marketing opportunities. Please contact us at nmwalk@sangredeoro.org if you can help us out there.

We just about doubled the number of community members attending our education weekend again this past October! It was a fun weekend. My favorite session was the Blood Sisterhood session. It was so fun to enjoy some girl time! This year's education weekend will be October 16–18 at Embassy Suites in Albuquerque. I hope I see you all there!

Directly after our education weekend, we had our first annual I Love Someone with Hemophilia Car Show. It was FANTASTIC! Please see the photos on pages 15 and 21.

Jose Guillen has stepped down as Vice President and rolled off the board, and Jose Duran has taken his place. I want to send a special thanks out to Jose, who has worked tirelessly for SDO for more than a decade. His service will continue because he is still chairing our Policies and Procedures committee and our Governance committee. We also welcome Sophia Minhas as board secretary and Jessica Hernandez and Maria Chavez as new board members.

We got office space! Watch for events being held at our new digs, and if you have an event in mind, please e-mail me! I will do my best to make it happen!

We do have a number of events planned for 2015, so please check out the calendar on page 4.

We have hired staff! Roseannette Lopez joins us as Executive Assistant with plans to develop into our Executive Director. Welcome, Roseannette!

We are sending a New Mexico contingent to Washington Days this year: Alfonso Jaramillo, Roseannette Lopez, and Shaleigh Henry will all attend to represent us on Capitol Hill. Thanks for your support!

In addition to continuing our current services, we have the following goals for 2015:

- Additional programming, especially for adults, including parents
- Continuing to strive toward more local funding and less industry funding
- Hiring an additional staff person to support Roseannette
- Completing our updated policies and procedures on all fronts
- Starting a scholarship fund that is for all of us with bleeding disorders.

We have events planned for the blood sisters! I am still working on funding for women's retreat, but the next event is on 21 March at 11:30 a.m. We'll have a bit of programming, some lunch, and do our nails with Jamberry nail products. Come on out for some GIRL TIME!

Last, but not least, we have become a Blood Brotherhood site! Watch the calendar on the web site for events!

I hope you are all having a wonderful 2015 so far. I hope I see you in April at the Walk or at an event before then!

Land Softly,

Lori Long, President

Go to www.hemophilia.org to apply for a scholarship to attend the 67th NHF Annual Meeting in Dallas, TX, August13–15. Scholarships are offered to first-time attendees (and some others), and this is a great conference. If you haven't attended, please apply!