Sangre de Oro, Inc.
PO Box 51494
Albuquerque New Mexico

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Credits

Volume 20 • Fall 2015

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The Bear Facts

Hemophilia Walk of New Mexico and Car Show 2015!

by Maria Chavez

On behalf of Sangre de Oro (SDO), the walk committee would like to give a huge "Thank You" to everyone who participated in our Hemophilia Walk/Car Show.

With your help we raised a total amount of $40,252. The SDO committee is super excited to announce that we will partner up again with NHF for NM Hemophilia Walk in 2016! Our team is working on details for another amazing Walk/Car Show, so be sure to check your e-mail for updates.

If any of you wonderful people are interested in helping with walk planning or volunteering to help on the Walk Day, or if you have any ideas or comments on how we can make our 2016 Walk better than 2015, please send us an e-mail at nmwalk@sangredeoro.org. We would love to hear from you.

Sign up for the walk at the Patient and Family Education Weekend or on-line after November 1 by visiting www.hemophilia.org/walk. Everyone is welcome to participate!

Sign up as a team. Choose a team name. Recruit team members from your circle of friends, family, co- workers, and neighbors.

Help us make our 2016 Walk/Car Show a great success! Volunteers are greatly appreciated before and/or during the walk.

Thank you,

Walk Chair: Maria Chavez

Walk Co-Chair: Felix Garcia

Walk Committee: Lori Long, Carnie Abajian, Roseannette Lopez, and Sophia Minhas.

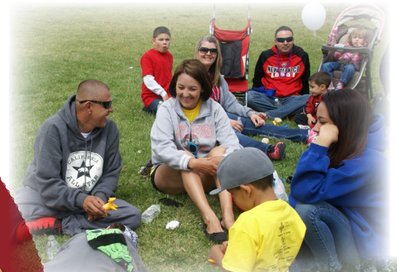
CONTACT

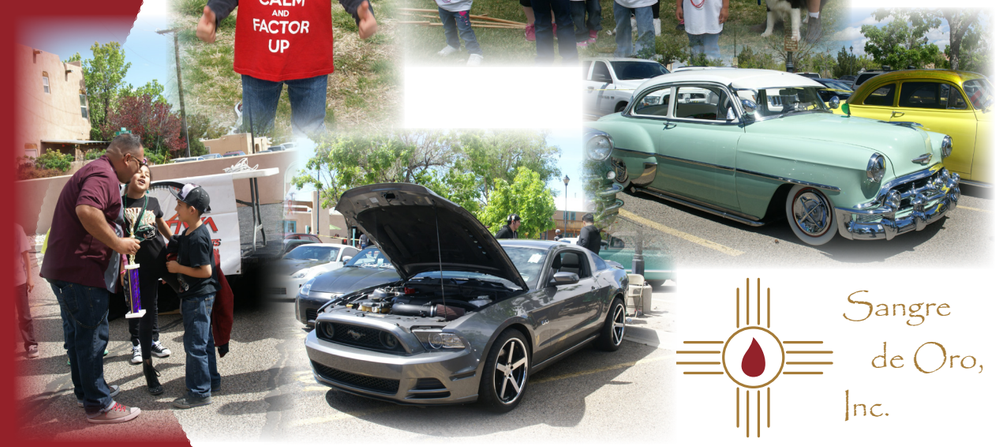
SDO Office (505-341-9321)
nmwalk@sangredeoro.org

Information

Date: 16 April 2016

Location: Balloon Fiesta Park





Sangre de Oro, Inc.

Calendar of Events

September

25	SDO Board Meeting, 6:30 p.m. (Ruidoso)
26	SDO Insurance/Advocacy Day (Ruidoso)

October

16–18	**Patient and Family Education Weekend in Albuquerque, NM**

November

13	SDO Annual Planning Meeting, 6 p.m., SDO Office

December

TBD	Holiday Party (Tentative)

February

TBD	Washington Days

March

	National Hemophilia Awareness Month
30–2 April	HFA Symposium in Las Vegas, NV

April

16	**Hemophilia Walk of New Mexico (and Car Show!) at Balloon Fiesta Park in Albuquerque**
17	World Hemophilia Day

ADVATE
[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE 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). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

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.

Who should not use ADVATE?

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.

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to

What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

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
dizziness	hematoma	abdominal pain
hot flashes	swelling of legs	diarrhea
chills	runny nose/congestion	nausea/vomiting
sweating	rash	

Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop 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.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA approved product labeling can be found at www.ADVATE.com or 1-888-4-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.

Baxter Healthcare Corporation
Westlake Village, CA 91362 USA

An Incredible Evening

By Joe MacDonald

February 28th was one of those evenings that you wish never had to end. The family and I were taken in a chauffeured limousine to the Ambassador Theater in New York City, to watch the musical *Chicago*. We were taken on a very quick backstage tour before the performance and my son, Julian MacDonald, did a sound check with the musical director. Julian had been awarded this experience by the Make-a-Wish Foundation. The final part of his wish was granted immediately after the show as he sang a song for the cast on-stage.

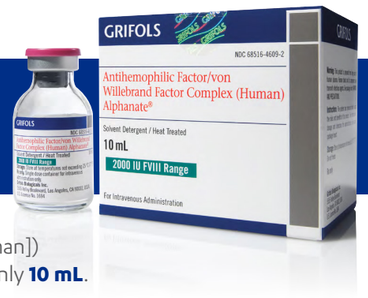
As part of our Make-a-Wish experience, we met the stage manager before the show. He was very kind and gave us a quick tour of the theater. We couldn't believe that the lead characters in the cast took the time right before the show to greet us. We had the opportunity to meet Jennifer Nettles, Carly Hughes, and several other cast members. They were all incredibly gracious and very generous as they complimented Julian's voice.

When it came time for Julian to sing after the show, many of the cast members stayed to hear him. Unknown to us, Carly Hughes (the lady who played the role of Velma Kelly) sent a text to the composer who wrote the music and the lyrics of the song Julian sang (Someone to Fall Back On, by Jason Robert Brown). Mr. Brown sent his apologies for not being present but sent his well wishes to my son (Did I mention on a Broadway stage?). Julian did a wonderful job, and I was taken aback by his demeanor and willingness to follow through and not let nerves stand in his way. After he finished singing, the cast was supportive and wonderful.

I will say that my spirit was right there with him as he sang every note. He was fulfilling a long-time dream by standing on a Broadway stage and singing. How incredible those few minutes were as he stood center stage, microphone in hand, with a spotlight shining on him for good measure. He was awesome as he simply stood there and let the music flow through his body and into the space of the theater. What a moment!

My hope is that he may remember this moment and know that it is possible to realize your dreams. When we are bombarded by the busyness of life, may we have moments like these to give us hope for the future. We will face today excited that another exhilarating moment might be around the corner. After all, what is life without looking forward to the hope that tomorrow can bring? May we all have "Broadway" moments in our lives to sustain us, comfort us, and give us a reason for the journey.

Half the volume
Twice the factor*



ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) is now available in a **2000 IU FVIII vial** with a reconstitution volume of only **10 mL**.

*That's **TWICE** the amount of factor of the largest vial available for other FVIII/VWF products,[1-4] so patients may require:

- **Less volume**
- **Less time**
- **Fewer syringes**

Isn't it time you tried ALPHANATE?

Learn more at **alphanate.com**

Alphanate®
Antihemophilic Factor/von Willebrand Factor Complex (Human)

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.

References: 1. ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) Prescribing Information. Grifols. **2.** CSL Behring. Humate P Package Insert. August 2013; **3.** Octapharma. Wilate Package Insert. January 2012; **4.** Kedrion. Koate-DVI Package Insert. August 2012.

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

Grifols Biologicals Inc.
5555 Valley Boulevard, Los Angeles, 90032 CA - USA Tel. 888-GRIFOLS (888 474 3657)
www.grifols.com

GRIFOLS

UNLOCKING YOUR SELF-POTENTIAL

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

ADVATE SUPPORTS YOU BY IMPROVING YOUR PERSONAL INFUSION EXPERIENCE WITH THE BAXJECT III SYSTEM

The reconstitution process with the BAXJECT III system is easier, faster, and designed for you*

- An all-in-one, connected design[1]
- Broad selection of doses, providing opportunities for single-vial options[1]
- One-step activation with fewer steps for **faster** reconstitution—just press, swirl, flip and withdraw*[1,2]
- **Straightforward** pooling process if more than 1 vial is needed—no additional supplies required[1]

1/2 the time

Reconstitute ADVATE in about **half the time***[2]

*As compared with the BAXJECT II needleless transfer device.

Watch the ADVATE with BAXJECT III system reconstitution video and see how it all comes together at **ADVATE.com**

Share your experience using the ADVATE with BAXJECT III system at **www.BAXJECT3Survey.com**

ADVATE [Antihemophilic Factor (Recombinant)] Important Information

Indications

ADVATE 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.

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, 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 following page for Brief Summary of ADVATE full Prescribing Information.

xyntha®

Antihemophilic Factor (Recombinant)

xyntha® solofuse®

Antihemophilic Factor (Recombinant)

℞only

Brief Summary

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

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

What is XYNTHA?

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

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

What should I tell my healthcare provider before using XYNTHA?

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

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

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

How should I infuse XYNTHA?

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

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

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

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

What are the possible side effects of XYNTHA?

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

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

Common side effects of XYNTHA are

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

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

How should I store XYNTHA?

Do not freeze.

Protect from light.

XYNTHA Vials

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

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

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

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

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

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

XYNTHA SOLOFUSE

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

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

Throw away any unused XYNTHA SOLOFUSE after the expiration date.

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

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

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

What else should I know about XYNTHA?

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

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

This brief summary is based on the Xyntha® [Antihemophilic Factor (Recombinant)] Prescribing Information LAB-0516-5.0, revised 10/14, and LAB-0500-9.0, revised 10/14.

Pfizer U.S. Pharmaceuticals

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 ----------

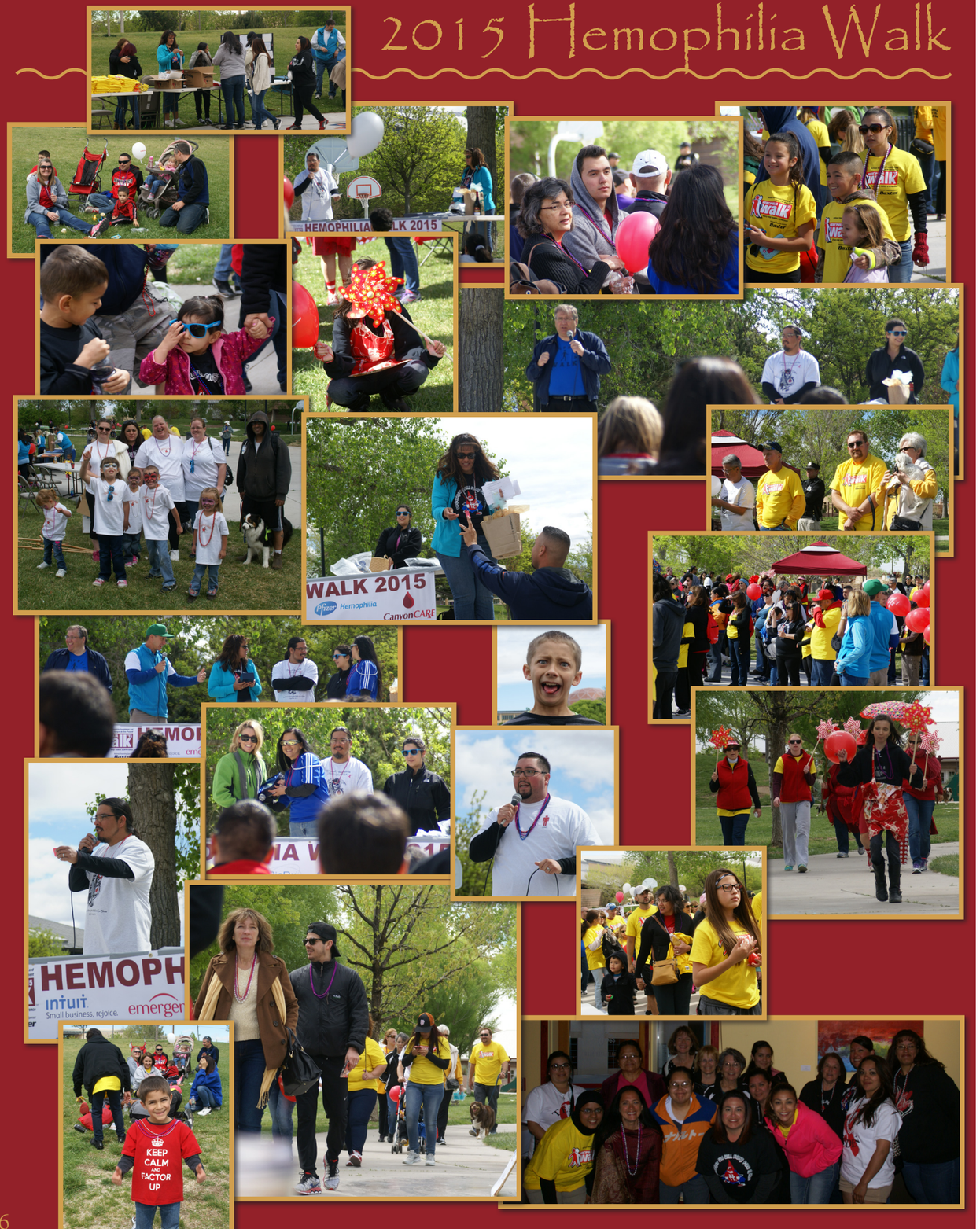
- Pregnancy: No human or animal data. Use only if clearly needed.
- Pediatric Use: Hemophilia A - Clinical trials for safety and effectiveness have not been conducted. VWD - Age had no effect on PK.

GRIFOLS

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

3041048-BS
Revised: 06/2014

2015 Hemophilia Walk



Genetics: Old Topic, New Information

by Gary Pennington

In attempting to understand hemophilia, we have all listened to the biology teachers as they explained the sex-linked traits and dominant and recessive genes. We learned that a male Y chromosome would allow a dominate trait on the woman's X chomosome to produce a male child with hemophilia. It all seemed simple. But it was harder to understand how a child could develop a bleeding disorder without a family history. The pure hereditary charts we became familiar with were suddenly in question.

How could my child have hemophilia without "grandpa" exhibiting the same symptoms? Could something be wrong with our charts? The answer is no. The charts were not wrong. They simply did not apply. The fact is that hemophilia is a deficiency in the factor needed to produce the proper clotting of the blood after an injury, either internal or external. If something goes wrong with the development of the fetus and the gene that produces this particular factor is not properly developed, then a mutation occurs, and the offspring develops hemophilia.

Scientists now know that some cases of hemophilia can be NOVO. That is the mutation of a gene that will produce the same symptoms and thus allow the hemophilia gene to now be passed on to future generations. In fact, one third of all type A and fifty percent of all type B hemophilia cases are now thought to be genetic mutations and not simply an inherited trait.

Geneticists are now aware that carriers often exhibit bleeding risks. While for years doctors dismissed young women who claimed to be bleeders by saying that only men could be hemophiliacs, we now know that 10% of all carriers have factor levels >35%. Often mistakenly diagnosed with von Willebrands, it was not clear why women did not have more complications during childbirth. We now know that factor 8 levels increase during pregnancy to protect the mother while factor 9 levels do not.

Through genetic testing, scientists have confirmed that 100% of all the daughters of a man with hemophilia will be carriers. What is shocking to the old school doctors is that sometimes the X chromosome of a woman carrier that is supposed to be the dominant gene and protect her from the X chromosome possessing the hemophilia trait, can be damaged or weak). This allows the trait to develop into the true symptoms of hemophilia. Also the genetic mapping has shown that it is possible for the female to posses the X1 X1 that results in a true female hemophiliac. Ladies you have been vindicated by the science most of you hated in school.

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

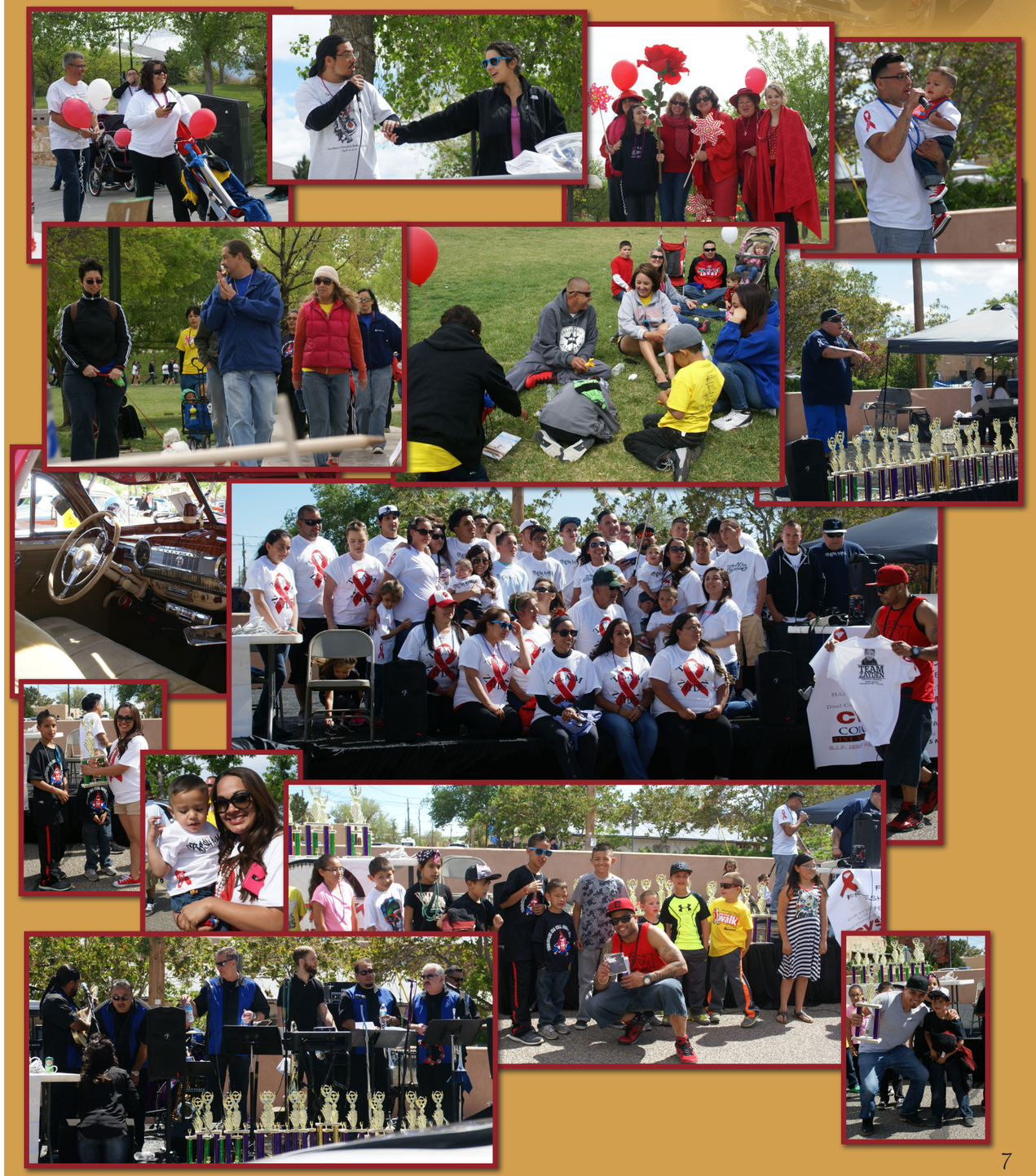
- Provide evidence of satisfactory academic progress by maintaining a minimum 2.5 GPA out of a possible 4.0 to be considered for scholarship renewal. Official transcript showing final, current grades must be submitted when requesting a renewal of this scholarship. **If your GPA falls below a 2.5, you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

Application Deadlines

Fall semester deadline: August 1st

Spring semester deadline: December 1st

# of New Mexico and Car Show!



Camp Sangre Valiente LIT Program

By Matt Erdmann

As a kid growing up with severe hemophilia, I looked forward to attending hemophilia camp every summer. Camp was awesome. It was a place to have fun and try new things in an environment where people around you knew and understood what having a bleeding disorder was about. Where else could you get that? Maybe that's why people came back year after year. It certainly is a big reason I did and because of that I was very excited to be part of Camp Sangre Valiente again in 2015. Below are a couple of my highlights from this year's camp:

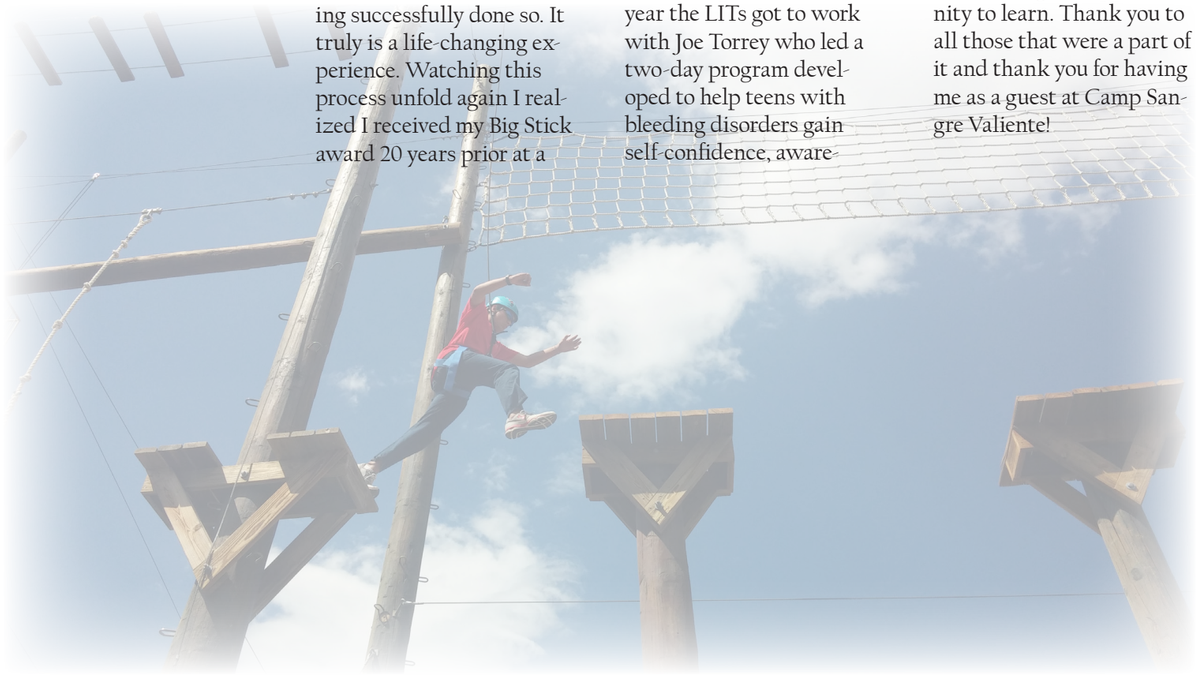
The Big Stick Award

The famous Big Stick Award. A major goal of camp is to help those with a bleeding disorder learn to self-infuse—a major step in gaining independence while living with a bleeding disorder. What impresses me year after year is how encouraging everyone involved in this process at camp is—the nurses, counselors, fellow campers, etc. Some campers arrive at the start of the week and have no intention of poking themselves, but by the end of the week they leave with confidence having successfully done so. It truly is a life-changing experience. Watching this process unfold again I realized I received my Big Stick award 20 years prior at a camp like this one. Where would I be if I didn't receive the support and encouragement to own this part of living with a blood disorder? I'm not sure, but I am so grateful for this major focus of camp and for the support from the medical staff and fellow campers and volunteers!

Working with the Leaders In Training (LITs)

The Leaders In Training, commonly called LITs, are the group of campers typically 13-17 years old that are learning life skills to become independent. This year the LITs got to work with Joe Torrey who led a two-day program developed to help teens with bleeding disorders gain self-confidence, awareness, and understanding of individual power and responsibility for their self-treatment of their bleeding disorder. To learn various concepts Joe had everyone participate in off-the-wall games, some of which included a rubber chicken, to help the campers learn to approach challenges in a different way. If you are a parent of an LIT, perhaps you are now playing some of these games with rubber chickens too! Ask an LIT to tell you more.

Another successful week came and went, but the memories will not be forgotten. What a neat experience and great opportunity to learn. Thank you to all those that were a part of it and thank you for having me as a guest at Camp Sangre Valiente!



HFA 2015 Continued

by the members present.

Luncheon Theme: "Give Back"

- Opening report was the last year the HFA returned 94% of funding back into programming. The anticipation this year is that number will be closer to 95%.
- Noted that the "Food Outreach" is a food drive for the St. Louis area that helps community members. They have 2,100 clients with HIV or hemophilia. Program hopes that by keeping a family fed and healthy you can keep them out of the hospital.
- *Tracy Cleghorn HFA board president states there are 48 board members. A video resume was required for board nominations. The son introduced his mother. HFA president gives a speech on motherhood. Encourages people to get involved and stay connected.
- HFA Communications director, Rich Pezzillo, introduces Emily Craner a teacher.
- There was a video and discussion on the history of hemophilia.
- Take action: Lori Long and the Care Access Working Group (CAWG) introduced the "Bleeders Bill of Rights."

Awards

Terry Lamb Award: Vaughn Ripley

Tea Award: Robert Sidonio, Jr.

Michael Davon Award: Lori Long

Ron Neiderman Award: Michelle Burg

Charles Stanley Hamilton Award: David Huskie

Volunteer of the Year award: Maryann May

President's Award: John Reed

Hepatitis C Advocacy and Choice for Treatment Meeting

John Reed, pharmacist, presents the medications and treatment plans for curing hepatitis C.

Genotype Medications available:

- Lidipasvir
- Harvoni
- Viekera Pak
- Sovaldi
- Sovaldi and Riavarin
- Sovaldi and Lidipasvir

*Herbs such as St. John's Wort blocked the absorption of Sovaldi.

*There is a new drug called Lidipasvir.

*Seven new drugs expected in 2015

Literature on People with Bleeding Disorders and HCV

Congress expected to introduce and pass major FDA reform legislation this year. Please put your comments on the bills through the web site. 21st century cures can be found at http://energycommerce.house.gov/cures.

Hepatitis C is the leading cause of death among hemophilia patients.

Mt. Sinai in NY has started new trials just for patients with bleeding disorders.

Ledipasvir- No Ribavarin or interferon.

170,000 patients expected to take Sovaldi this year. Some specific studies are with patients who have bleeding disorders.

Information at clinicaltrials.gov: Gilead GS-us-334-1274. Results expected in November 2015.

Gilead help at www.mysupportpath.com 1-855-769-7284.

Insurance Meeting

Hosted by Cora Walker, Professor at St. Louis Law School.

Outlines: New Law, Strengthening Medicare, and consumer choice in coverage and care.

If premiums at a job are greater than 9.5% of salary the individual can deny coverage and get a personal policy.

NOTE: Make sure the information on the computer screen is the same as what the insurance actually covers. Take a copy to insurance.

Discussion was held on the difference between pharmacy and medical benefit coverage

Managing Arthritis with Hemophilia: Prevention and Treatment

Orthopedics

Hemophilic Arthropathy

Subclinical bleeding occurs when a bleed takes place, but shows no symptoms that are similar to a regular bleed. There are two types of damage from bleeding in a joint: osteoarthritis and rheumatoid arthritis.

ITIS=Inflammation

OSIS=Degenerative changes have taken place.

Cartilage is a complex sugar.

Bleeding in a joint may lead to possible iron toxicity causing continued joint problems.

**It was noted that rock climbing appears to be beneficial for joint health.

*Hemathrosis=blood in the joint

*Synovitis=swelling of the synovial area

*Ankles can develop osteophytes/spurs

* Some people are helped by synovial embolisations. The tissue in the synovial sac is cleaned of damaged tissue.

*Steroid and Lidocaine injections relieve the swelling and pain caused by the damage to cartilage and synovial areas.

Blood Brotherhood Meeting

Veil of secrecy invoked. A lot of people talked about a lot of stuff.

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, i 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

Issued June 2014

HFA
Hemophilia Federation of America™

SAVE THE DATE!

SYMPOSIUM 2016
LAS VEGAS

March 31 – April 2, 2016

For more information go to:
www.hemophiliafed.org

Do you know about the blog "Infusing Love: A Mom's View?" The HFA is hosting this new blog written by mothers of children with a bleeding disorder. New Mexico is represented by Cazandra MacDonald who will be a guest blogger. Visit www.hemophiliafed.org and check out the "News & Stories" tab.

HTC Update: A Letter from the Director

Dear Community,

I have been at UNM since October of 2011, and I took over as the HTC Director in October of 2014. We have a great team! Dr. John Kuttesch has been our Division Chief since 2013, and he has been very supportive in all our endeavors. Dr. Dulcinea Quintana has been our adult hematologist since 2013. Kristel Wintheiser has been our nurse manager since 2012. Claudia Mackaronn RN, BSN, CPON, has been our nurse since 2010, and Brie Johnson, RN, has been with us since 2012. I am happy to inform you that we will have two additions to our team this year, Milena, NP and Valerie Lowe, RN. Our CRA for the hematology projects is Jacqueline Torrez, and our medical assistant, Genevieve Lucero helps with data entry. Yolanda Vinajeras is our social work supervisor, and Bradley Knopp works as our case manager. Our physical therapists are Vincent Amendolagine and Heather Messier.

Since I took over as Director, I have ensured that we are maximizing the services and support for our patient and families. We have been able to schedule regular comprehensive clinics at UNM and the CTH outpatient clinic. Our weekly comprehensive meetings to discuss patient labs and follow up are attended by all members of the team. We also had a great camp experience this year. It was attended by 39 campers, and we had 15 camp volunteers. Two nurses from the HTC and I attended as well. It was amazing to see our children in a different setting. I have been truly impressed by the courage and endurance that they have demonstrated in learning to self-infuse and in the various fun activities there.

My goal in the coming years is to be able to expand the services provided to our patients at the comprehensive visits. We also strive to improve counseling and education for our patients and hope to reach out to more communities and locations in New Mexico. We want to be advocates for our patients and families as well as empower them to be their own advocates. I am optimistic that we can accomplish these goals with funding through a 340B program. Currently, we are in the process of establishing this program for our HTC. My hope is that, as we move forward, we can work hand-in-hand with SDO and the community to better serve our patient population.

Yours Truly,

Shirley Abraham, MD
HTC Director

DON'T MISS OUT—MARK YOUR CALENDAR NOW!

SDO Education and Family Education Weekend
October 16–18, 2015
Embassy Suites Hotel

HFA's 22nd Symposium
March 31 to April 2, 2016
Las Vegas, NV

HFA Symposium is an annual community-centered educational event. Symposium draws more than 800 patients and families, more than 100 exhibitors, more than 20 speakers, and more than 50 community volunteers from almost every state!

HFA awards more than 100 travel scholarships to first-time attendees each year for families who need financial assistance. The meeting is a place where community members come together to share information and build a network of support in a relaxed environment.

The 12th Annual Caliente Classic Golf Tournament

Title Sponsor: DMC Logistics

By Roseannette Lopez

Many thanks to our generous sponsors:

- DMC Logistics (Platinum Title sponsor)
- Aerolynx
- Bayer
- Novo Nordisk
- AA Auto and Air Conditioning
- Biogen Idec
- Cornerstone-NCHS
- Payday
- Southwest Capital
- Factor Support Network
- Accredo
- Bank of the West
- Baxalta
- Bruckner's Truck Sales
- Canyon Care
- Emergent
- Koch Construction
- Morgan Stanley
- Parts Plus
- Pfizer
- Reliance Factor
- Ricci & Co. CPAs
- The Noel Company
- US Bank
- The Payroll Company
- AJ Gallagher Insurance
- Auctoris
- BioRX
- Hub Insurance Company
- Linton and Associates
- Octapharma
- RAKS Building Supply
- REDW
- Grifols
- Advanced Pest Control
- Aviall
- Campos Quality Care
- Christian's Automotive
- DTA Insurance Company
- Elemental Risk Management
- Elite Medical Transport
- Enterprise Holdings
- Health Insurance Plans (All Ages)
- JLM Auto Sales
- Johanna Chappelle
- Leadership NM
- Manzano Day School
- Masterpiece Medical Massage
- Mighty Auto Parts
- Soleo
- The Long Family
- Zimmerbiomet
- John Jay (Western Assurance)
- Legacy Mortgage
- Quality Aircraft Accessories
- Western Assurance
- Mercedes-Benz of Albuquerque.

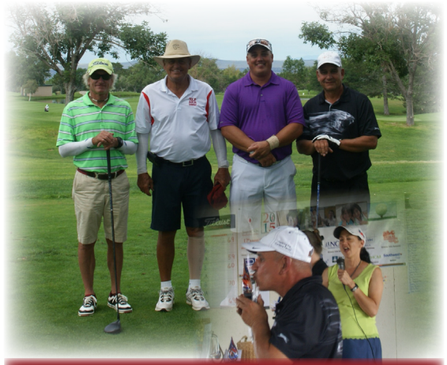
Sangre de Oro, Inc. (SDO), held a very special event this August, the 12th Annual Sangre de Oro Caliente Classic 2015. Held at Arroyo del Oso Golf Course, the event helps fund Camp Sangre Valiente for children with bleeding disorders living in New Mexico. Camp Sangre Valiente is SDO's annual New Mexico camp for bleeding disorder patients and their siblings, ages 7 to 17. Participants are able to enjoy camp life and learn about managing life with a bleeding disorder, including how to infuse themselves.

This year's event is the most profitable to date, grossing $79,000. We are supported by local companies such as DMC Logistics, Aerolynx Air Charter, and AA Auto. Event host and title sponsor DMC Logistics and its President and CEO, Steve Griego, was also recognized by the National Hemophilia Foundation (NHF) as Philanthropist of the Year for the third consecutive year. NHF recognized DMC Logistics and Mr. Griego in part for contributions and fundraising efforts associated with SDO.

The 2015 golf tournament raised enough funds to cover costs. Because of this year's participation SDO will be able to fully fund camp in 2016. Our goal now is to reach out to find children with this disorder throughout New Mexico that have yet to hear about camp.

Both our first- and second-place winners donated their winnings back to SDO. Thank you AA Auto and DMC Logistics!

We look forward to the event each year and send our thanks to all sponsors, participants, and volunteers. It took an amazing group effort to put on this event and we sincerely appreciate all those that contributed. We look forward to seeing you all next year.



Our First Place Winner: AA Auto and Air Conditioning

Our Second Place Winner: DMC Logistics

Special thanks to DMC Logistics, our Title Sponsor, for the past 12 years, for making a difference in so many lives!

To Friends and Supporters of "People with Bleeding Disorders and HCV"

Dear Friends and Supporters,

Over the last two years, we have seen incredible advancements in the treatment of hepatitis C with new regimens including Sovaldi, Olysio, Viekira Pak and Harvoni. We now have effective, "gentle" treatment (meaning all oral, high cure rates, low side effects) for people with genotypes 1A, 1B and 4. This covers about 70% of our population .... but it leaves everyone in our community with genotypes 2 and 3 reliant on therapies that are longer, much less tolerable, and probably less effective.

People with Bleeding Disorders and HCV has been vigorously pursuing alternative treatment options, and talked with more than one manufacturer and the FDA in May 2015 to prepare our testimony at an expected hearing on approval of the drug Daclatasvir. We were very pleased with our conversations concerning the following:

- Possibilities just around the corner
- New options available today for those most at risk in our community.

As regards the newest available options, we emphasize that we are not advocating a particular treatment regimen; that is a matter between you and and your physician. As you can see below, access to the new options MUST be initiated by your physician and there are criteria that must be met. Yet, we are excited that there are two closely related options, both sponsored by Bristol-Myers Squibb (BMS), which may provide, today, access to gentle and effective therapy for those who most need such options. We feel obligated and excited to share these options with you.

The online request form for both BMS programs can be found at:

http://bms.com/clinical_trials/investigator_sponsored_research/Pages/expanded-accessprogram.aspx

1. The Daclatasvir Expanded Access Protocol (EAP) clinical trial is called AI444-257 and can be found on Clinical.Trials.gov at https://clinicaltrials.gov/show/NCT02161939.

This protocol is open to patients with chronic hepatitis C and decompensated cirrhosis, as well as post liver transplant patients with F3/F4 or fibrosing cholestatic hepatitis. It is run by the HCVTARGET consortium, which serves as the BMS Clinical Research Organization (CRO) for this trial. See the link above for active sites and the point persons.

2. The EAP 'Named Patient Program' for Daclatasvir, requires a healthcare professional (HCP) to request the drug from BMS for each patient individually and under an individual IND (Investigational New Drug) application filed by the HCP with FDA. Those requests are reviewed internally by BMS on a case-by-case basis according to specific criteria:

- Adult patients with compensated liver disease secondary to chronic hepatitis C viral infection
- Genotypes 1, 2, 3 or 4, and
- Urgent need for effective treatment, and a life expectancy ‹12 months
- Meet additional criteria related to intolerance of or ineligibility for P/RBV containing regimens.

Please feel free to distribute this information to others in our community who might be helped by additional curative HCV treatment options.

Best to you all,

John Reed, Mark Antell, Paul Brayshaw, and Carl Weixler, for "People with Bleeding Disorders and HCV"

11th Annual Camp Sangre Valiente

Special thanks to Alyssah Leon for our fabulous camp pictures!

HFA 2015: A Simple Synopsis of the St. Louis Symposium in Simple Sentences

by Gary Pennington

Thursday March 26th

Blood Brotherhood Coordinator Meeting

This event was open to facilitators, family members and chapter coordinators. No veil of secrecy was invoked.

- Discussion on bringing patients together for 2 or 3 day therapeutic retreats, i.e., camping trips and yoga classes.
- Virginia chapter has now begun to open up the age range to include men between 18 and 60. They are planning a retreat that includes both the older and the younger men but is split up into separate events. Then the last day of the event, they will bring the men together so the older men can mentor the younger ones.
- Discussion of the on-line rap sessions.
- Discussion of working more with the Blood Sisterhood.
- In Northern California, the 18 to 30 age patients there have their separate sessions.
- The group discusses compelling events to unite the age groups. White water rafting and fishing trips.
- Seattle shares information and general topics to escape the issues of hemophilia. Have fun and feel a part of the community.
- North Carolina: the lady states that it is difficult to get the men to attend strict structured events.
- Virginia Coordinator: Create events to bring more people to the chapter such as fishing trips, pizza tours, and camping.
- Oregon has recently done indoor skydiving.
- Montana has taken trips to Chico Hot Springs, and brought sled dog teams and snow machines to the national parks.
- Northern California uses community members as experts and treatment center clinicians to share their expertise on hepatitis C.
- Virginia suggested using home care rep specialists as speakers.
- Discussion on events: If you cannot take exotic trips then just find a good restaurant that everyone likes.
- New Jersey: Often new members are located and recruited by information provided by the social workers or the home health care reps. Northern California adds that the home health care rep can at least relay the information to new patients.
- Discussion on Inclusion: Montana asks if dads can be included. Virginia does include a lot of others. Northern California says no. That the women have a strong group of their own. It is allowed to bring guests as translators. Michelle, who works with Lauren, explains the original grant parameters. The original proposal was for men with hemophilia aged 25 and up. It has now evolved to include 18-year-olds. Lauren discusses spouse inclusions. A young men's group has been established in some states for ages up to 24. Lauren says, 18 is acceptable. Virginia has accepted 21.
- Discussion on including pharmacy reps. There must be a distinction between presentations and sales. Pennington states that in this day and age the patient is not easily swayed by a sales pitch. We are informed and can make educated decisions on our own. If they want to wine and dine us or sponsor events the let them. Northern California does not allow any reps at all.
- Michelle from NHF wants to keep the Blood Brotherhood unbiased and industry to keep their endorsements out to avoid conflicts with grants. To avoid this NHF will work on making speakers more available. The group evaluations are very important. She can arrange more conference calls or Webinars. Northern California: Make physical therapist or fitness trainers your presenters.

I asked about funding and the increase of support as the membership numbers increase. Michelle stated that they are revamping the grant applications with the CDC and hoping for the increase in funding. As the program grows, the funding becomes more diverse and challenging. There are 700 blood brothers in 23 groups. That has grown from just 16 in 2014.

Friday March 27th

Chari Yoga: Presented by Cory

(Could be used at the beginning or end of each Blood Brotherhood meeting.)

Blood Brothers and Spouses

No veil of secrecy invoked.

Topic was how a relationship is affected by pain and discomfort caused by bleeding. Spouses asked to share how they cope with men feeling pain and wanting to be left alone.

Personal Note: Room poorly set up. A big circle with not enough room for men to feel comfortable.

General discussion that marriage counseling may help to develop a better physical relationship.

I spoke on sharing the information about bleeding episodes and treatment (whining) with families and friends to get past the issues and to get treatment and help when needed.

*The rest of the discussions were private issues shared

Continued on Page 24

An Amazing Opportunity

By Cazandra Campos-MacDonald

The morning of June 12th I received one of the best e-mails ever.

"Dear Cazandra, Congratulations! You have been selected as a 2015 TEDxABQ speaker!"

Oh my goodness! I was selected!

I have always enjoyed listening to TED Talks during my workday. TED, which stands for "Technology, Entertainment, and Design," is all about "ideas worth spreading" and after the year my family survived with Caeleb's inhibitor complications I felt like I had a story to tell.

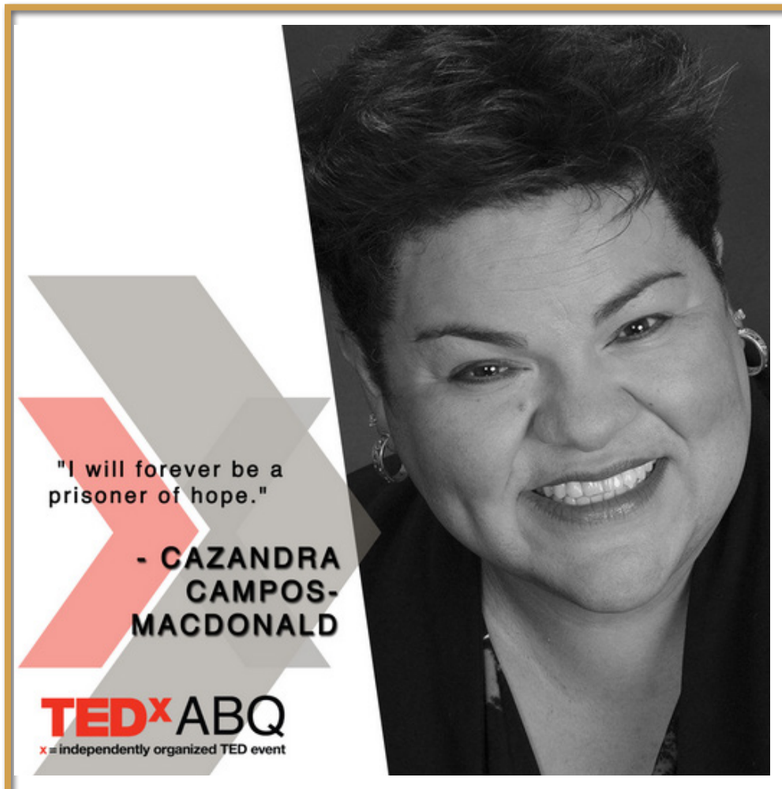
On Saturday, September 12th at Popejoy Hall I had the honor of delivering my talk, "A Prisoner of Hope" on the TEDxABQ stage.

In a time frame of approximately 8 minutes, I shared a story, briefly telling the audience about hemophilia, inhibitors, and the generation of individuals we lost to HIV. I provided a message about living with despair but choosing hope and making it to the other side. Yes, all in 8 minutes!

The TED process has been exciting, challenging, and even brutal as each of the speakers participates in a coaching program through the weeks before the event. The coaches help you craft your talk into more of a "conversation" and not a "presentation."

I simply want to share a message of hope to those living with chronic illness. And if someone happens to hear about hemophilia when they browse talks online, then this process will have been more than worth my time and passion.

To learn more about TED visit www.ted.com and www.tedxabq.com.



From the ted.com Web Site

It is easy to become overwhelmed with feelings of despair when a loved one is faced with a chronic medical condition. The fight to maintain your own identity while providing the care they need is long and difficult, but hope is a choice that can be made even in the worst of times. Hope brings with it meaning, comfort, and strength. Cazandra Campos-MacDonald is the mother of two sons with hemophilia and a Patient Advocate with Option Care. Cazandra lost a brother due to complications from hemophilia and is passionate about sharing with those who live with chronic illness.

Hemophilia B Symposium on the Road

By Lori Long

On 6 June 2015, the Coalition for Hemophilia B hosted their Symposium on the Road. It was wonderful! We had programming similar to the SDO Patient and Family Education Weekend, with some extra programming added.

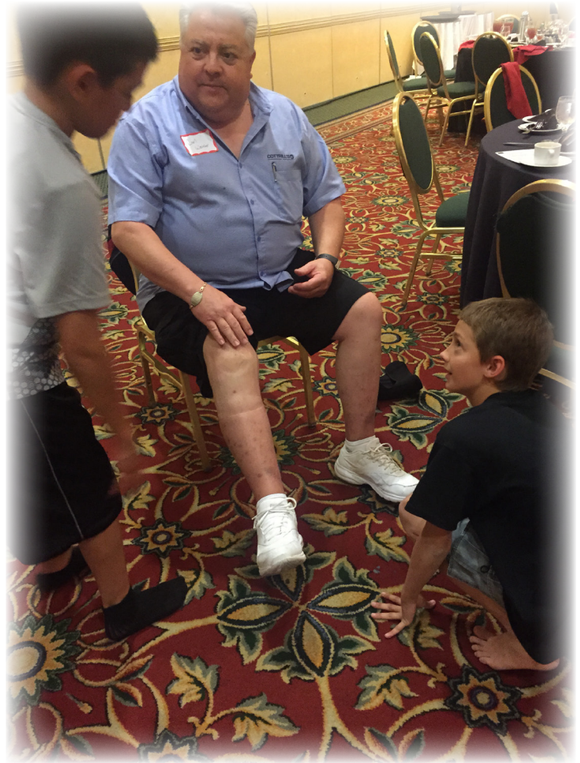
I very much enjoyed the one session I didn't think I wanted to attend: Taiji-fit. What fun stuff! We all got lost in it and had a great time. It was over before we knew it, and none of us wanted to stop!

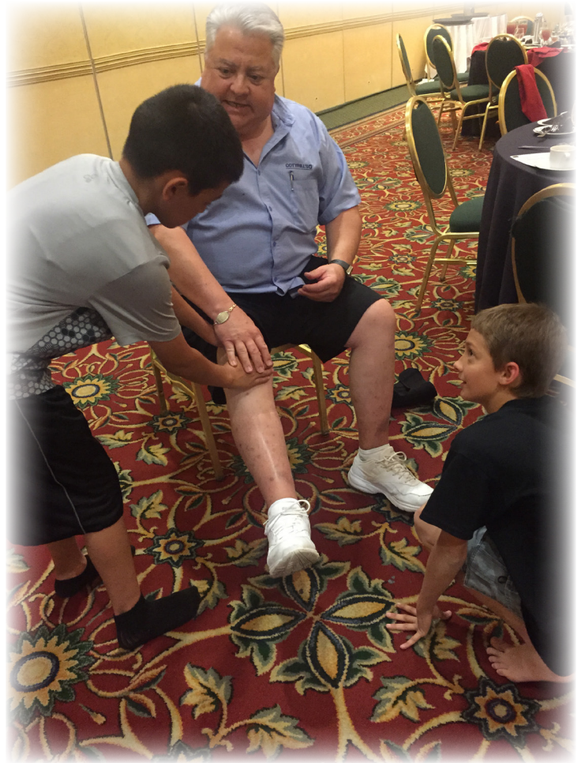
The most important session was the Factor Nine Family Meeting. This is a meeting for just families affected by Factor IX deficiency. Dr. David Clark provided us with an update of upcoming products and the results of products that have recently hit the market. It was educational and fun! Dr. Clark has a special way of explaining this stuff so that we all understand it.

At the end of the day, we had a nutrition and fitness program given by our blood brother, Brian Rodgers, and our very own Michelle Morath. It was great! I learned a few important things:

- Portion out snacks into smaller containers so that you only eat a serving.
- Which exercise is the best? The one you like because you'll do it!

My favorite part of the day was watching our blood brother, Carl Weixler, schooling some of our young boys on what happens to our joints when we don't take care of them with infusions (pictured here). He demonstrated the creakiness of his own joints by having the boys place their hands on his knee and bending and straightening the joint so they could feel what happened. It made quite an impression on my son! I have to say that compliance with infusions has become a bit easier in our household. Sometimes, what we learn at these events isn't learned during programming. Sometimes, we learn from each other. I think that was the most important thing my son learned that day.





The 2015 Family Education Weekend

By Lori Long

Our 2015 Patient and Family Education Weekend will be held October 16–18 at the beautiful Embassy Suites in Albuquerque.

You can register to attend on our web site at www.sangredeoro.org. **Online registration must be completed no later than October 2nd to guarantee a room.**

Be sure to also download and fill out the registration forms for your children if they will be attending. You can turn them in when you check in for the weekend. We will have fun activities and programming for them!

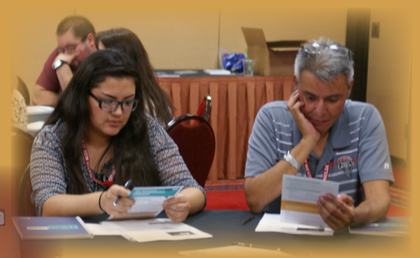
Check-in starts Friday, October 16 at 4 p.m. The event runs through Sunday, October 18. We will have some great presenters and speakers and opportunities for visiting with old friends.

We hope to see you there!

October 16–18, 2015

Where: Embassy Suites, 1000 Woodward Place NE, Albuquerque, NM 87102

What: A chance to learn about bleeding disorders and catch up with old friends



The SDO Board

Executive Board Members

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Jose Duran, Vice President

Sophia Minhas, Secretary

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Past President, Johanna Chappelle

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Johanna Chappelle

Maria Chavez

Jessica Hernandez

Gary Pennington

Sarah Trawinski

If you wish participate on the board, please call 341-9321 or contact us at sdo@sangredeoro.org.

President's Corner

Dear Community,

I hope you all had a wonderful summer, with lots of time in the sun and plenty of chances to escape it on really hot days!

It has been a fabulous 6 months since my last report to you. We have done amazing things! We hired an Executive Director. I would like to personally welcome Roseannette Lopez to our team. She has already done amazing things, and I look forward to what she will accomplish in the future. We had our third Hemophilia Walk. And we had an amazing turnout for our golf tournament fundraiser!

We had a good Hemophila Walk and made about $42,000. This is more than the previous two years, and our Walk committee did an amazing job! Thanks to everyone who participated! We had a great time, and we're hoping to have a bigger Walk in 2016! We will be changing venues to Balloon Fiesta Park, and we will have the Walk and Car Show at the same place. It's going to be a wonderful whole day of fun!

Maria Chavez and Felix Garcia will co-chair our 2016 Walk. Thanks, Maria and Felix! There are still plenty of ways to participate. Have a team! Volunteer! Donate! Every penny we earn will remain in New Mexico to support our blood brothers and sisters here.

In August, we had our 12th Annual Caliente Classic Golf Tournament. Our wonderful Past President, Johanna Chappelle, was our Golf Chair, and she did it again! We had a very successful tournament, raising more than ever. More importantly, the bulk of the funds raised came from local businesses. This is very important because part of the board's strategy is to diversify our funding sources to ensure that we can keep having events into the future.

Our Platinum Sponsor, Steve Griego from DMC Logistics brought in a lot of that local funding, and our gratitude can't be measured. In addition, Jessica Hernandez and her father, Steve Hernandez, from AA Auto and Air Conditioning brought in close to $9,000. I'd like to say a special THANK YOU to Jess and Steve for supporting us with so much effort!

We had a fabulous camp in June. Two more campers self-infused for the first time. It's life-changing, I tell you. In addition, in June, the Coalition for Hemophilia B hosted its "Symposium on the Road" here in Albuquerque, and Inalex Communications provided the women of our community with an amazing day of programming called "Courage to Soar." It was a beautiful day. I am sorry to say that the man who made this program possible, Joe Caronna, passed away on 10 September 2015 at the age of 55. We will be forever grateful to Joe for the warmth, hope, and education he has brought to our community. Rest in peace, my friend.

We sent Roseannette Lopez, Shaleigh Henry, and Alfonso Jaramillo to represent us on Capitol Hill. They did a great job an were even pictured in HFA's *Dateline* magazine. Thanks, you three!

HFA will have its Symposium March 31 to April 2, 2015 in Las Vegas, NV. HFA sponsors patients to attend, especially first-time attendees, so watch their web site (www.hemophiliafed.org) and apply for support to attend.

We had wonderful Blood Brother and Blood Sister events after the Walk and Car Show in April.

We also had an amazing Insurance/Advocacy Day at Buffalo Thunder in July, and we have another one planned for 26 September in Ruidoso. I am so excited about our community's response to these events! We anticipated attendance of approximately 30 at each event, and both events had a registration of more than double that!

October 16–18, we will have our 2015 Patient and Family Education Weekend. We hope to see you all there for some learning, networking, and fun!

If you haven't been to an event at our new office, I hope you get to attend one soon. It's a great little place! Our new address is 6301 4th Street NW, Suite 6, Albuquerque, NM 87107.

Have a safe and happy holiday season, and watch for upcoming events!

Land Softly,

Lori Long
President