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

Table of Contents

Credits

Volume 20 • Fall 2014

Authors
Patrick Cordova
Cazandra Campos-MacDonald
Jose Duran
Matt Erdmann
Lori Long
Jordan Long-Holderried
Kyle Stephens
Rea Watson

Editor
Bryant Holderried

Coordinator
Cazandra Campos-Mac-Donald

Designer
Lori Long

The Bear Facts

Hemophilia Walk of New Mexico

by Lori Long

Sangre de Oro extends a huge "Thank You" to each of you for your incredible participation with NM Hemophilia Walk 2014!

With your help, we raised about $28,000, a decent amount for our second Walk.

The SDO Walk Committee is excited to announce that we will again partner with NFH for NM Hemophilia Walk 2015!

We are working on the details, so be sure to check your e-mail for updates. In the meantime, here is what we know now.

Date: 12 September 2015, 2:00 p.m.

Location: Tiguex Park

Walk Committee: Lori Long, Carnie Abajian, Candace Cloud, Sophia Minhas, and Rea Watson

2015 Hemophilia Walk Chairs: Carnie Abajian and Maria Chavez

Are you interested in helping with Walk planning or volunteering to help out on Walk-day? Have suggestions or comments on how to make Hemophilia Walk 2015 better than our 2014 Walk? Please send us an e-mail. We would love to hear from you.

Sign up for the Walk on-line by visiting www.hemophilia.org/walk. Everyone is welcome to participate! (Registration will open in October.)

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

Help us make our event a success. Volunteers are appreciated before and/or during the Walk.

CONTACT

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

Washington Days 2014

by Patrick Cordova

Washington Days yet again proved to be a great experience, garnering exposure for the bleeding disorders community and providing an opportunity to lobby for important legislation and funding. The major focus for the last few years has been house bill HR 460 or "The Patient's Access to Treatment Act." This bill prevents insurers from creating specialty tiers that would allow for greater cost sharing and co-payments for specialty or non-generic drugs. Since the event in February, New Mexico Representative Michelle Lujan Grisham has become a co-sponsor of the bill. This is in addition to Representative Ben Ray Lujan who has been a co-sponsor since January. The priority of the next Washington Days will likely include looking for more co-sponsors and Senator to sponsor a Senate companion bill.

Sangre de Oro, Inc.

Calendar of Events

September

12	SDO Board Meeting, 5:30 p.m.
27	Biogen Eloctate Informational Dinner

October

14	Blood Brotherhood On-Line Chat
17–19	**Patient and Family Education Weekend in Albuquerque, NM**

November

11	Blood Brotherhood On-Line Chat
13	Blood Brotherhood On-Line Chat
14	SDO Annual Planning Meeting

December

9	Blood Brotherhood On-Line Chat
TBD	Holiday Party (Tentative)

February

TBD	Washington Days

March

	National Hemophilia Awareness Month
26–28	HFA Symposium in Tampa, FL

April

17	World Hemophilia Day
18 or 25	**Hemophilia Walk of New Mexico at Tiguex Park in Albuquerque**

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).

WARNINGS AND PRECAUTIONS

Hypersensitivity Reactions

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.

The Caregiver

By Cazandra McDonald

Caregivers. When we hear the term, most of us think about someone caring for an elderly person. Maybe they are the child of an elderly parent, a homecare nurse coming regularly to care for an elderly person, or even a person who cares for a mobility-challenged individual.

"Make time to breathe ... Reach out for support."

– Mother of two sons with hemophilia A

Caregivers are everywhere.

In the bleeding disorder world we often only think about parents of children with hemophilia or von Willebrand disease. Have you taken a moment to think about the wives of men with a bleeding disorder? The husbands of women with a bleeding disorder? Or even someone caring for a family member with a bleeding disorder?

Caregivers are "people who provide direct care for someone." That definition broadens the scope of what a caregiver looks like.

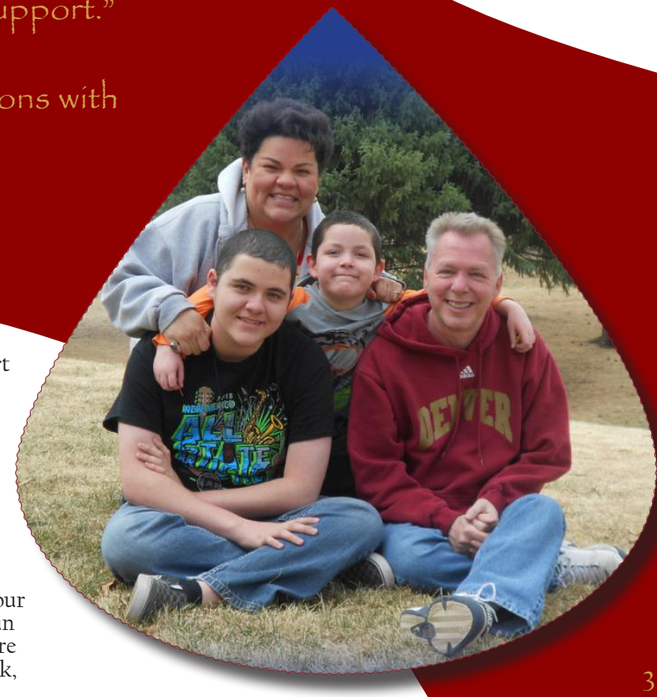
It may not look the same as someone who is providing 24/7 care for an elderly, bedridden person, but the way our community cares for individuals is very real.

While we care for a loved one with a bleeding disorder there may be times that are more intense than others. We may endure periods of constant hospitalizations and prolonged bleeds that keep our loved one homebound for days and weeks on end. Hopefully, you have a period of rest when the bleeding disorder is not "front and center."

When the bleeding disorder is the focus in your life, there are some important things you must do to take care of yourself.

- **Make time to breathe.** Even if it is only for a few minutes, take time to walk around the block and clear your mind or sit outside and listen to your heart beating.
- **Accept help.** If you have other responsibilities that a friend may help with, take them up on their offer to help! Picking up children from school, making a meal for the freezer, sitting with your loved one while you run a few errands. These are all ways to take a break, so accept help when it is offered.
- **Eat well and move.** When you are living in a hospital, good food is hard to come by. Packing lunches is not very easy when you don't have time to get to the store. Make the best choices possible. Drink plenty of water and take a walk, even if it is only to the mailbox and back (or around the hallway in the hospital in the evening).
- **Reach out for support.** Having a friend in the bleeding disorder community is extremely important. Your best friend from your school days who is not affected with a bleeding disorder may want to be there for you, but he or she won't always understand what you are going through. Social media is a great way to connect with members of the community is attending events through the Sangre de Oro chapter. Make connections.

For more information on caregiving visit The Caregiver Space at http://thecaregiverspace.org, The Caregiver Action Network www.caregiveraction.org and The Global Genes RARE Project at http://globalgenes.org.



Novo Nordisk is helping people with inhibitors realize their dreams.

changing possibilities in hemophilia™

Novo Nordisk offers financial, educational, and community support programs to people with hemophilia A or B with inhibitors so they can live more normal lives.

Find out more about how you can change your possibilities by calling **1-877-668-6777** today!

For more information, please visit **ChangingPossibilities-US.com**.

novo nordisk®

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

Reduction in bleeds when switched to prophylaxis
44 bleeds (range, 22.7-120.5)
REDUCED TO
1 bleed (range, 0-17.4)

98% reduction in bleeds[1]

ADVATE PROPHYLAXIS MAY HELP YOU PREVENT OR REDUCE THE FREQUENCY OF BLEEDS[1]

SIGNIFICANT REDUCTION IN MEDIAN ANNUAL BLEED RATE (ABR) WITH PROPHYLACTIC TREATMENT COMPARED WITH ON-DEMAND TREATMENT[1]

- **42% of patients experienced 0 bleeds during 1 year on prophylaxis[1]**
- **98% reduction in median ABR from 44 to 1 when switched from on-demand to prophylaxis[1]**

In a clinical study, after switching from 6 months of on-demand treatment to 12 months of prophylaxis with ADVATE in 53 previously treated patients (PTPs) with severe or moderately severe hemophilia A.

A clinical study that evaluated treatment efficacy (the ability to control and reduce bleeds) of 2 prophylaxis regimens—Every-Second-Day (standard) prophylaxis dosed at 20 to 40 IU/kg every 48 hours and Every-Third-Day (pharmacokinetic-driven) prophylaxis dosed at 20 to 80 IU/kg every 72 hours, targeted to maintain factor VIII trough levels ≥1%.

STRIVING FOR ZERO BLEEDS 0 WITH PROPHYLACTIC TREATMENT

INDICATIONS

ADVATE is a medicine used to replace clotting factor VIII 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, 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.

Reference: 1. ADVATE Prescribing Information. Westlake Village, CA: Baxter Healthcare Corporation; April 2014.

Baxter

xyntha®

Antihemophilic Factor (Recombinant), Plasma/Albumin-Free

xyntha® solofuse®

Antihemophilic Factor (Recombinant), Plasma/Albumin-Free

℞ 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 Wyeth Pharmaceuticals toll-free at 1-800-934-5556.

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.

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:

- 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.

XYNTHA contains trace amounts of hamster proteins. You should not use XYNTHA if you are allergic to hamster protein.

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 or reasonably likely side effects of XYNTHA?

Common side effects of XYNTHA are

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

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**

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), Plasma/Albumin-Free] Prescribing Information LAB-0516-3.0, revised 06/12, and LAB-0500-7.0, revised 06/12.

Wyeth®

Manufactured by Wyeth Pharmaceuticals Inc.

Marketed by Pfizer Inc.

Printed in USA/June 2012

Public Meeting on Patient-Focused Drug Development for Hemophilia A, Hemophilia B, von Willebrand Disease and other Heritable Bleeding Disorders

September 22, 2014

9:00 a.m. to 5:00 p.m.

The Food and Drug Administration (FDA) is announcing a public meeting on Patient-Focused Drug Development for hemophilia A, hemophilia B, von Willebrand's disease, and other heritable bleeding disorders, such as other factor deficiencies (including I, V, VII, X, XI) and platelet disorders.

The public meeting is intended to provide FDA with patients' perspectives on how their daily lives are affected by hemophilia A, hemophilia B, von Willebrand's disease and other heritable bleeding disorders such as those listed above. FDA also is seeking patients' perspectives on the available therapies for these disorders.

For more information visit http://www.fda.gov/BiologicsBloodVaccines/NewsEvents/Workshops-MeetingsConferences/ucm401758.htm.

Identification of Patient/Caretaker Mentors & Other Preferred Sources of Information in Bleeding Disorders; Response Requested

KOLComm, LLC, a market research company based in New Jersey, is requesting your help in completing a 10 minute survey. The purpose of this study is to understand the challenges of living with bleeding disorders and issues related to the condition and how patients and caretakers support each other. Our primary goal is to identify patients and caretakers that act as public advocates in the bleeding disorders communities within the US and Puerto Rico.

Please use the link below to take the survey:
https://www.research.net/s/PatientCaretaker

CONTACT:
Rose Ríos, MPH
P: 908-912-8980
E: rose@kolcomm.net
W: www.kolcomm.net

KOL comm

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

Patient Assistance Programs

by Lori Long

I know I've been looking at my finances pretty hard lately with changes to insurance and income. Times are changing. A lot of us are needing more assistance than we used to, and we need to be resourceful. Luckily, there are a lot of resources out there. They're a moving target, those resources. Some we used to rely on are going away (or have gone away). And there are some new ones out there.

Well, NHF just sent out an updated list* of resources, and I thought I should share it with you. Happy hunting!

No (or Limited) Income Requirements

PSI Facilitated Programs: Baxter Hemophilia Co-Pay/Co-Insurance Assistance Program
Covers a patient's OOP (out of pocket) expenses for Baxter products - 100% of co-pay costs up to $12,000 for 12 months (0%-400% FPL), or up to $6,000 for 12 months (401%-800% FPL).
Apply via PSI's website

CSL Behring "My Access" Program
May cover up to $12,000 of OOP expenses each year
www.mysourcecsl.com, 1-888-267-1440

CSL Behring Assurance Program
Allows patients to develop a product reserve in case of a gap in their private insurance coverage
www.mysourcecsl.com, 1-888-267-1440

Pfizer Factor Savings Card
Offers up to $5,000 in co-pay, co-insurance, or other OOP cost assistance
www.hemophiliavillage.com

Novo Nordisk Product Assist Program
Get up to 3 months of product assistance
1-877-668-6777, http://www.novonordisk-us.com

Novo Nordisk SevenSecure Program
Provides up to $1,500 assistance for medical expenses outside of factor, as well as access to educational grants to patients and caregivers and insurance support
1-877-668-6777, http://www.novonordisk-us.com

Grifols Alphanate® or AlphaNine® SD Savings Card Program
Covers $500 per month (up to $6000 per year) of co-insurance/co-payment costs towards prescription drug cost
http://www.grifolspatientcare.com/

Grifols Patient Care Programs-Grifols Assurance for Patient ("GAP")
http://www.grifolspatientcare.com/
BiogenIdec MyALPROLIX Free Trial Plus Program
Allows for either a 30-day supply of free Alprolix or free Alprolix for up to 1 year, if needed, until healthcare coverage begins
http://www.alprolix.com/resources-and-support/myalprolix-support.html

BiogenIdec MyALPROLIX Co-pay Program
Assists with co-pay costs for Alprolix and helps link patients to coverage resources (includes costs associated with administration of therapy)
http://www.alprolix.com/resources-and-support/myalprolix-support.html

BiogenIdec MyALPROLIX Factor Access Program
Provides access to Alprolix
http://www.alprolix.com/resources-and-support/myalprolix-support.html

Bayer Factor Solutions Assistance Programs
GAP Program – Patients who are privately insured & have a lapse in coverage can obtain a 30-day supply (based on current Rx, not to exceed 30,000U) if they have used Kogenate FS for more than 3 months (documented).
www.FactorSolutionsSupport.com

Hemophilia Federation of America's Helping Hands Program
Provides emergency assistance for people experiencing financial crisis due to a bleeding disorder, which is available one time per year
http://www.hemophiliafed.org/programs/helping-hands/

Colburn Keenan Foundation
Provides funding to assist with socio-economic and insurance needs
http://www.colkeen.org/

Sangre de Oro, Inc. (SDO)
Provides emergency financial assistance and assistance for travel for medical care
http://www.hemophilia.org/Community-Resources/Chapter-Directory

For Income 250% of the Federal Poverty Level or Lower
Grifols Patient Assistance ("GPA") Program
http://www.grifolspatientcare.com/

For Income 300% of the Federal Poverty Level or Lower
Patient Services Inc.(PSI) Assistance Programs: Premium Assistance for Hemophilia and VWD
https://www.patientservicesinc.org/

Bayer Factor Solutions Assistance Programs
PAP Program: Available to patients who are uninsured or lack third-party coverage
www.FactorSolutionsSupport.com

For Income 350% of the Federal Poverty Level or Lower
Patient Services Inc.(PSI) Assistance Programs: Premium Assistance for Hemophilia and VWD
https://www.patientservicesinc.org/

For Income 400% of the Federal Poverty Level or Lower
PSI Assistance Programs: Premium Assistance for Inhibitor Patients
https://www.patientservicesinc.org/

Sliding Scale (Based on Income, Not Specified)
PSI Facilitated Programs: Bayer's Kogenate® FS Co-Pay/Co-Insurance Assistance Program
Covers a patient's OOP expenses for Bayer's Kogenate® FS for up to 12 months
1-800-288-8374

PSI Facilitated Programs: Novo Nordisk Hemophilia Co-Pay Assistance Program
Provides co-pay assistance for individuals using Novo Nordisk hemophilia & rare bleeding disorders products
Apply on PSI website

Baxter CARE Patient Assistance Program
A 12-month assistance program under the larger "C.A.R.E." Program (Coverage, Assistance, Resources and Education) to assist with health insurance needs
1-800-288-8374

CSL Behring Patient Assistance Program
Provides free product to patients in CSL products for up to one year
www.mysourcecsl.com, 1-888-267-1440

Pfizer Rx Pathways Program
Provides co-pay assistance up to $10,000, free product, or premium assistance
www.hemophiliavillage.com (resources and support)

Federal Poverty Levels

Household #	100%	133%	150%	200%	250%	300%	400%
1	$11,670	$15,521	$17,505	$23,340	$29,175	$35,010	$46,680
2	$15,730	$20,921	$23,595	$31,460	$39,325	$47,190	$62,920
3	$19,790	$26,321	$29,685	$39,580	$49,475	$59,370	$79,160
4	$23,850	$31,721	$35,775	$47,700	$59,625	$71,550	$95,400
5	$27,910	$37,120	$41,865	$55,820	$69,775	$83,730	$111,640
6	$31,970	$42,520	$47,955	$63,940	$79,925	$95,910	$127,880
7	$36,030	$47,920	$54,045	$72,060	$90,075	$108,090	$144,120
8	$40,090	$53,320	$60,135	$80,180	$100,225	$120,270	$160,360

**Full NHF source document can be found at http://www.hemophilia.org/Cloud/Public-Policy-Updates/PPU1408-Patient-Assistance-Programs.pdf*

Walk of New Mexico

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. Being able to meet up with other kids my age with similar bleeding disorders was the best. Camp was filled with opportunities to try new things, overcome challenges, and have a lot of fun. So I knew the chance to work with the LIT (Leaders in Training) group in 2014 at Camp Sangre Valiente was going to be a blast and it certainly was. Here are some of the highlights of the week:

Independence with Managing a Bleeding Disorder

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 was most impressive to me was the action taken by the LITs to help their peers with this process without passing judgment. This allowed for a safe environment through what can be a very challenging task. It was great to see campers overcome their fears and earn their "Big Stick" awards with the encouragement of their peers and the medical staff.

Life/Leadership Skills Development

This year, the LIT group was very fortunate to have Pat Torrey lead a two-day program that he 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. Through the experiential learning activities Pat led, the LITs gained real-life skills that they began applying at camp and can use while in pursuit of their life goals beyond camp. I think the most popular skill the group discussed was the importance of having a positive mental attitude.

About Pat Torrey – Pat is a nationally recognized facilitator who has developed programs specifically for kids with bleeding disorders who are transitioning from camp to future challenges. He participates and trains in programs at more than 20 camps across the country.

Opportunities to Try New Things (...even if they're hard)

Throughout the week there were many fun and physical activities the LITs participated in, some more challenging than others. The activity where I saw the LITs come together most and apply the skills learned from Pat's program (as mentioned above) was on the four-story ropes course. Yes, I said four stories! I had no idea I was afraid of heights until this experience. This was true for some of the other LITs too. Regardless, we helped each other tackle this course. We saw LITs who initially had no plan to participate get up and try it out and conquer new challenges. It was a rewarding experience and great to see LITs achieve their goals and try new things.

By the end of the week, new friendships were made, challenges overcome, and a lot of fun was had. Thanks for letting me be a part of it, Camp Sangre Valiente!

Blood Brotherhood!

By Lori Long and Jose Duran

New Mexico has become a Blood Brotherhood site! Jose Duran, our board secretary, is our site coordinator, and we recently had our first event with Barry Haarde.

It was a great event! We all had dinner, and Barry told us about his story in a presentation called, "Get off Your Aspirations." His story was so inspiring! He went from "staying under the radar" to riding his bike across the country to support his blood brothers and sisters around the world. Once he was done, we broke into two groups and had some really great rap sessions!

Here is Barry's bio:

Barry Haarde is a 43-year-old severe hemophiliac who lives and works in Houston, Texas. He participates in many local cycling events including the MS150 bike tour from Houston to Austin. He receives medical treatment at the Gulf States Hemophilia Treatment Center and would like to acknowledge the hard work of its dedicated staff and brilliant physicians. He would also like to thank the CDC, HFA, and Baxter International Inc. for their development and support of the "Blood Brothers" initiative that has been responsible for "bringing him back" to the bleeding disorders community. He invites others to visit his bike team website at tlsports.org.

Blood Brotherhood is a program for men over 18 who have a bleeding disorder. Events throughout the year provide educational information and support from others with bleeding disorders. We will also have adult events through Blood Brotherhood that the Blood Sisters can attend! To register, contact Jose Duran, our Site Coordinator at Jose.Duran@sangredeoro.org or 505-341-9321.

Please join us for the next event! We had a great time with Barry and during our second event, a discussion of fitness with Michelle Morath, a local personal trainer, who showed us how to work out with whatever's handy at home.

HTC Update

By Claudia Mackaron, RN

Much has been going on since we last talked to the community.

In June we had the wonderful opportunity to spend a week with your children at Camp Valiente at Fort Lone Tree in Capitan, NM. Camp was a great success. We had many new campers this year along with the returning campers. Our focus at camp is not only to keep your kids safe and healthy but to teach them how to self-infuse.

Every morning we spent time with our affected campers teaching them to infuse by reinforcing technique, building confidence, and cheering them on with every little step toward the end result of self- infusion. We witnessed courage and determination in getting it right no matter how many pokes it took. One non-affected brother wanted to know how his brother felt and decided he needed to learn. Every day he came into the session and infused saline into himself. We had two other boys that were first year campers. They never came to camp because they were terrified to infuse. This year they both had the courage and determination to get it done. How exciting it was to watch them succeed with joy and tears. Their lives will be more fulfilling and satisfying as they will be able to care for themselves and be independent. I have to say that we were very proud of how the older, more experienced campers offered great support to the inexperienced. They shared techniques and continued to encourage the young campers. It was a great time of bonding in the young community of bleeders.

Just recently our community of patients with inhibitors had the opportunity to participate in the Inhibitor Summit offered by NHF. I was able to attend the sessions and mingle with the nationwide community of bleeders. There were experts from the field that taught so much about the difficulties of treatment and everyday life that these families experience. Scientifically, I knew what our families faced with this difficult trial in their lives, but watching and listening to them was an eye-opener. It was a good experience to rub shoulders and elbows with those that attended.

This month, our team in the hematolgy/oncology world welcomed a new member to the practice. Dr. Jodi Mayfield has joined our team of seven doctors. Soon you will be able to get to know her in the clinic and (heaven forbid) in-patient setting. She will be covering both the hematology and oncology practice. Welcome aboard, Dr. Mayfield.

We look forward to seeing you and sharing some classes at the Patient and Family Education Weekend in October.

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 Mac-Donald who will be a guest blogger. Visit www.hemophiliafed.org and check out the "News & Stories" tab.

HFA Symposium is an annual community-centered educational event. Symposium draws more than 600 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.

PSI

PSI, Inc.

Patient Services Incorporated (PSI), a 501(c)(3) non-profit, charitable organization, is the ground-breaking premium and co-payment assistance foundation for the chronically ill.

If you would like more information about the financial help available from PSI, please call 1-800-366-7741.

Hemos Unite!

A new site has recently been launched that provides inspiration, support, and information for the bleeding disorders community. Matti Vann, mother to a child with hemophilia, lives in southern California and has launched a site that will feature a new podcast monthly. Stop by and visit Hemos Unite! at www.hemosunite.com.

DON'T MISS OUT—MARK YOUR CALENDAR NOW!

SDO Education and Family Education Weekend
October 17–19, 2014
Embassy Suites Hotel

HFA's 21st Symposium
March 26–28, 2014
St. Louis, MO

11th Annual

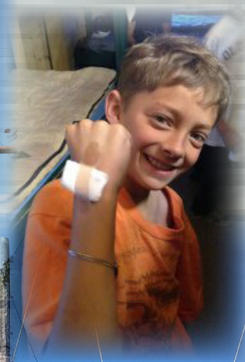
by Kyle Stephens

Basically, my Sangre Valiente experience came about accidentally. was contrived off a whim. That being said, it was without a doubt a blessing in disguise. My name is Kyle Stephens. I am a senior at Eastern New Mexico University, and my major is biology with a premed emphasis. Like many of my peers, I was searching for shadowing opportunities over the summer. My main interest in medicine at the time was oncology. This led me to ask my advisor about any possibilities to learn more about oncology. It just so happened that my advisor knew Dr. McKinnell, and he contacted him on my behalf to see if he was willing to mentor an undergraduate student aspiring to shadow an oncologist.

Dr. McKinnell gladly took me under his wing. After only meeting with him once, before I began shadowing, he asked me if I would like to go with him to a camp for kids with hemophilia. According to his description, my duties would entail observing him and possibly being a "floating counselor." Naturally, I accepted, only to realize at the camp how quickly those responsibilities could escalate.

Admittedly, I did pursue the opportunity to help infuse because I am a phlebotomy technician. However, the staff must have perceived that I was willing to do it all because I was put on the spot in more the one occasion! Much to my surprise I was made a red team leader at the beginning of the week. I definitely felt out of my comfort zone, but I remember thinking that this was for a cause greater than me. My main goal was to encourage the kids to have as much fun as possible by being uncommonly enthusiastic. Honestly, this came much easier than I expected because I was probably having more fun than the kids in many circumstances. We bonded with ease, and I am so grateful for the experience now.

The children may be preoccupied with the zip-lines and high rope courses, but the main



Three Blood Sisters go to HFA 2014

by Lori Long and Rea Watson

Lori and Sophia: Walking with a Blood Sister

Sophia and I barely knew each other getting ready to leave on this trip. We had met, of course, at camp drop-off and pick-up and at education weekend. And there was a flurry of e-mails as we made arrangements to get ourselves there.

I'm an introvert, and I was worried. What if we couldn't think of anything to talk about on the long flight to Tampa? Well, we had plenty to talk about, and I got a new friend. We were blood sisters from the get-go!

Once we got to Tampa, we found Rea, and our girls' weekend of learning, supporting, and networking started. It was wonderful!

We all attended different sessions (and a few of the same) and then compared notes. It was like I had tripled my brain strength!

I wouldn't trade our long talks (and long walks, despite all of us having leg bleeds at the same time) for the world. It reminded me that we blood sisters have a bond, and it's there from the moment we're together. I need my blood sisters from time to time, and they're always there for me.

Rea: My First Symposium (Sort of.....but, not really)

When my son was born about 8 years ago, our family experienced a moment that many of you may be able to identify with. We were thrown into the world of hemophilia by way of a horrific circumcision that our then 3-day-old son underwent all the way in Japan. I felt guilty and came to believe that his suffering had been all my fault. I was angry that I had not heeded the signs of all the bleeding issues that the women in our family had experienced through the years, and covered in a sense of hopelessness when I tried to imagine the type of future we could face. These were only the beginnings of some of the feelings that my husband and I had, and our son had not even been here on this earth but for a few months.

Long story short, we made our way to New Mexico by the gracious acts of the U.S. Air Force to receive care from the local hemophilia treatment center and start our new lives. We were fortunate to be bombarded with a wealth of support and resources, one of which was Sangre De Oro, Inc. and an awesome medical team that took us under their wing immediately as we started this new journey. If I remember anything else from the roller coaster of emotions we felt at this time, it was how we attended the Hemophilia Federation of America's Symposium because it would be held here in Albuquerque. The date (which was a blur as well, but thanks to Google) was March, 1-4, 2007 and over 600 people attended this grand affair. It was then that we not only met families that had experienced what we had, but who were able to offer hope to us. I cried and cried. I laughed and laughed. I met families that I continue to keep in touch with. My husband still remembers his encounter with Carl Weixler, whom we had no idea was the HFA president at the time. He spoke to him as if he was his long-lost brother who was just getting reacquainted with. It was a time that I only remember bits and pieces of due to the overwhelming amount of emotion (or just lousy memory), but it gave us the strength we needed to go on as a family, knowing that we were a part of a much bigger family of other bleeders like my son and carriers like me.

This year, the HFA Symposium was very profound to me (and not only because it was held in Tampa, Florida, and I got to see more water and trees than I had in a long time), but because I was able to see my growth as a parent who was once hopeless. We were able to enjoy tracks for all walks of life. Whether you were a mom, dad, teen, carrier, or caregiver, there was an appropriate session for everyone. My favorites were...well, all of them! We were all enlightened as we sat in a panel discussion that spoke of our history as a bleeding disorder community. We were able to see the visual representation of that history—the good, the bad, and the ugly—in the first-ever History room. We were able to draw our feelings, our challenges, hopes and dreams in a session of Art Therapy and speak our heart in the Rap Session for carriers. As consumers, we were educated on our legal rights and the breakthrough research that could change hemophilia and inhibitors forever. And that was only a few of the sessions filled with so much great information! Some of the distinguished pioneers of our community were awarded for their services at the Annual Awards Luncheon. We ended the symposium with a celebratory, barbeque-style dinner as we said our goodbyes. This experience was quite different from my first, for this time I was coming in as a board member and was able to encourage others as others had encouraged me. And just to think that the little baby that I was so worried about is now 8 years old and thriving. He has hemophilia and hemophilia does not have him. I am not so alone anymore. I amtruly am a part of the family. So, in a nutshell, this was my first Symposium, sort of... but, not really.

The 11th Annual Caliente Classic Golf Tournament

Title Sponsor: DMC Logistics

By Jordan Long-Holderried

Many thanks to our generous sponsors:

- DMC Logistics
- AA Auto and Air Conditioning
- Aerolynx
- Bayer
- Baxter
- Novo Nordisk
- National Cornerstone
- Pfizer
- The Payroll Company
- Linton and Associates
- The Noel Company
- Biogen
- CSL Behring
- CVS
- New Mexico Gas Co.
- Parts Plus
- Bruckner's Truck
- Christian's Automotive
- Enterprise Holdings
- New Mexico Gas Co.
- Payday
- Ryder Systems, Inc. Team
- Mercedes-Benz of Albuquerque
- Ricci & Co. CPAs
- US Bank
- Koch Construction
- Weck's

We had our tournament on 15 August.

Congratulations to our winners. First place went to **Steve Griego, Tony Hildago, Fernando Baca, and Casey (ADO Pro)** and second place to **Steve Hernandez of AA Auto and Air Conditioning, Stan Hockerson, Matt Wisely, and Kevin Lintal.** Thanks to the first and second place winning teams for generously donating their winnings to support camp!

Here is the speech I delivered at the tournament:

Hello, my name is Jordan Long-Holderried, and I have hemophilia B. I wanted to tell you about how your support for Sangre de Oro (SDO) has changed my and a lot of my friends' lives.

As you probably know, hemophilia is a bleeding disorder that keeps my blood from clotting. The treatment for hemophilia is a shot of clotting factor in the vein. When I was 5 or 6, I was really scared of needles. Going to camp helped me destroy that fear. This June at camp, I gave myself an infusion of clotting factor for the first time and began taking control of my life as a hemophiliac.

Throughout the course of a hemophiliac's life, it is very important that he knows how to self-infuse. So let's put you in a hemophiliac's shoes. One reason why it's important to know how to self-infuse is that if you ever want to go on a camping trip with a couple of your friends, you need to know how to give yourself a shot if you slip and hurt your knee.

This is why camp is important because you have trained medical staff helping you learn to self-infuse. Therefore, by donating to SDO, you are helping hemophiliacs lead better lives.

Special thanks to DMC Logistics, our Title Sponsor, for the past 9 years, for making a difference in so many lives!

Camp Sangre Valiente

goal of this camp is to educate them on self-infusing in hope of them gaining their independence. One camper in particular seemed to trust my guidance so I worked with him throughout the week. The day after I infused him, we were working diligently on self-infusion. But poking himself with a needle was just too daunting, and without further deliberation Dr. McKinnell interjected, "Why don't you just infuse Kyle today with saline to help you practice?" Believe me, the thought of such a young boy using a butterfly on me was unnerving. He missed on the first try, but was successful on his second attempt. Again, another unexpected beneficial situation was presented. Now we really had developed a trusting relationship. The following day he self-infused successfully on his first attempt! That was one of the most rewarding feelings, one I will never forget. The patience involved was immense, but it proved to be worth it in the end.

Between "ultimate knock out" to the treasure hunt and all the other events in between, the 14-hour days passed by quickly. I took advantage of the slide and all the other camp activities. I had a blast, and am looking forward to next year!

The SDO Board

Executive Board Members

Lori Long, President

Jose Guillen, Vice President

Jose Duran, Secretary

Eric Marquez, Treasurer

Past President, Johanna Chappelle

Board Members

Johanna Chappelle

Robert Farias

Jean Cole

Christopher Fennicks

Sarah Trawinski

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

The 2014 Family Education Weekend

By Lori Long

Our 2014 Patient and Family Education Weekend will be held October 17–19 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 3rd 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 17, at 4 p.m. The event runs through Sunday, October 19. We will have some great presenters and speakers and opportunities for visiting with old friends.

We hope to see you there!

October 17–19, 2014

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

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

Jess Hernandez and her golf team

Washington Days (and the new HFA office)!

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 another crazy 6 months since my last report to you. We have done amazing things! We had our first two Blood Brotherhood events. We had another adult event, where we learned about joint health. We had our second Hemophilia Walk. And we had an amazing turnout for our golf tournament fundraiser!

We had a good Hemophila Walk and made about $28,000. This is less than 2013, but still good. Thanks to everyone who participated! We had a great time, and we're hoping to have a bigger Walk in 2015!

Carnie Abajian and Maria Chavez will co-chair our 2015 Walk. Thanks, ladies! 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 11th 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 $8,000. 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. My own son infused himself for the first time and has continued to infuse himself (and me!) ever since. It's life-changing, I tell you.

We sent quite a contingent to Washington Days: Patrick Cordova, Jose Duran and Alyssah Leon, Robert and Melissa Farias, and Johanna Chappelle all went to represent us on Capitol Hill. Thanks!

HFA will have its Symposium March 26–28, 2015 in St Louis, MO. HFA sponsors patients to attend, especially first-time attendees, so watch their web site (www.hemophiliafed.org).

October 17–19, we will have our 2014 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

Eric Marquez, our board treasurer volunteering at the golf tournament. We sure work our volunteers hard!

Jose Guillen, our vice president, and his family volunteered at the golf tournament.

Several community members came out to golf!