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

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Calendar of Events

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April 2013

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Credits

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Volume 16 • Fall 2012

The Bear Facts

Hemophilia Walk 2013

By Charlene Selbee

Dear Members of the New Mexico Hemophilia Community,

As the newly hired Walk Event Manager, I would like to invite each of you to become involved in the 1st Annual Hemophilia Walk of New Mexico. The walk will be held on Saturday, April 20, 2013 at Tiguex Park in beautiful Old Town, Albuquerque.

Like other charity walks, this event is designed to raise funds for the hemophilia community and increase the general public's awareness of hemophilia. This is your walk, and we will need your assistance and support to meet the Executive Board's fundraising goals and make the event both fun and successful. You can participate by being a walker, a donor, or a Walk sponsor, or by serving on the planning committee, or volunteering during the event. You will find a more detailed list of activities that you can become involved in on page 13.

At the Family Education Weekend in October (details on page 12), we will be holding an informational seminar to acquaint you with the walk. But you do not need to wait until then to get involved. Start now by becoming a team captain and organizing a team to participate in the Walk.

Don't forget to select a name for your team and start designing your team's t-shirt.

On page 2 of this newsletter, you will find a word search. Complete the word search and bring it with you to the Family Education Weekend. If you correctly complete the word search puzzle, your name will be entered into the drawing for spectacular prizes. You will also be able to increase your chances of winning by registering your team or teams during the Family Weekend and having your name entered into the drawing for each team you register. Names will be drawn throughout the weekend. You must be present to win.

I look forward to meeting you at the Family Education Weekend in October. If you have any questions regarding the Walk please feel free to contact me.

Yours truly,

Charlene Selbee

Hemophilia Walk

When:
April 20, 2013, 9 a.m.

Where:
Tiguex Park

Why:
Raise funds and awareness

Who:
Sangre de Oro, Hemophilia Foundation of New Mexico

Contact:
Charlene Selbee,
Walk Event Manager
505-331-7154
charlene.selbee@gmail.com

Lone Star Chapter Walk

New York City Chapter Walk

Continued on page 2.

Sangre de Oro, Inc.

Name: ____

If you would like to be contacted about assisting with the Walk please include your email address and telephone number.

Email Address: ____

Telephone Number: ____

I will walk with you.

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fundraiser
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hemophilia
joemacdonald
join
nhf
prizes
register
sangredeoro
team
tiguexpark
tshirts
walk

What is Advocacy?

by Cazandra MacDonald

ad·vo·ca·cy *n.* giving aid to a cause; active verbal support for a cause or position; pleading in favor of.

In the bleeding disorders community, when you hear the word "advocacy," you often think of legislative issues. Possibly, you think it means going to Washington, D.C. to lobby at "Washington Days" with NHF or even going to Santa Fe to speak to state legislators regarding issues right here in New Mexico.

Yes, these are acts of advocacy. But what about the advocacy that happens every day with our children and loved ones with a bleeding disorder?

- When you talk to the school nurse as your child is about to start a new school year.
- When you go to your physician's office for immunizations and you insist that shots are to be given subcutaneously (under the skin) rather than intramuscularly (into the muscle).
- When you have to deal with the insurance company because they are insisting that you change to a home care provider that does not offer 24/7 nursing.
- And even when your child takes part in extracurricular activities at school (possibly sports).

The bottom line is that advocacy is the act of speaking out for what we believe to be right.

Have you ever been scared to speak up for your child? Have you ever doubted the knowledge that you have gained while raising a child with a bleeding disorder? Never doubt! The saying "When in doubt, infuse" is a great piece of advice, but why not also change it to "When in doubt, speak out!" By sharing your knowledge and expertise, you can help educate others and help your loved one in the process.

Has there ever been a moment that changed you—when you spoke out regarding your child's or your own bleeding disorder? We would love for you to share your stories with us. Please e-mail Lori Long at sioco@msn.com to share your advocacy moments. We would like to share stories in our next issue of "The Bear Facts."

Meet Our New Walk Event Manager!

Charlene Selbee, the youngest of six, was born in Banbury, England and raised on the family's Century Farm in northeast Iowa. Charlene begin her career selling Girl Scout cookies and later selling ads as a member of her local high school year book club. Her business career continued to expand as a member of the local 4-H club where she ran club meetings, organized events, and raised funds for the club.

While raising her two children, Rik and Cris, she attended Central New Mexico Community College and graduated with an Associate's degree in Business Administration. It was during her time at CNM that Charlene decided to become a community college instructor. After 15 years in the New Mexico tourism industry, Charlene is now a part-time instructor at CNM teaching hospitality/tourism and business classes. In addition, she teaches GED classes for CNM's Workforce Training Center and business classes for CNM's Small Business Development Center.

As a life-long learner, Charlene earned her BBA with a tourism emphasis from the Anderson School of Management, University of New Mexico in 1999. She recently completed her Master's degree in Tourism Administration with a focus on Sustainable Tourism Destination from the George Washington University in Washington, D.C.

Charlene's work experience in the New Mexico tourism industry includes working for the Albuquerque Convention and Visitors Bureau, REDTT, New Mexico Wine Growers Association and Acoma Business Enterprises. Charlene has also completed projects for the City of Rio Rancho, the New Mexico Department of Tourism, the Tourism Association of New Mexico, Santa Clara Development Corporation, and CRC & Associates.

As a seasoned professional, Charlene is excited to be organizing the first Hemophilia Walk of New Mexico and raising funds for Sangre de Oro.

Volunteerism: Yes, You Can Help!

By Cazandra MacDonald

Volunteering is scary. "Do I have enough time? Do I have a talent to share? Will I make a difference?" The hardest part is translating one's desire to make a difference into concrete action that will help an organization one cares about.

> The hardest part is translating one's desire to make a difference into concrete action that will help an organization one cares about.

Volunteering also depends on the "season of life" you are currently living. If you have little children, your time is extremely limited. You may be running back and forth to school or day care, working full-time and trying to keep your family at the forefront of importance. Maybe you are in school full-time and working full-time with all of your spare time spent doing homework. Even if you are retired, your life may be filled with many activities that keep you busy. We are all busy. We need to prioritize and include the things that are important to us.

In New Mexico, if you are not in the vicinity of Albuquerque, you may wonder how you can help the Sangre de Oro chapter. How in the world can you possibly help if you are hours away?

Not all volunteer opportunities require you to be in person at an event. Here are some ways you can help your chapter (as a bonus, you can do many of these tasks in your pajamas):

- Phone Calls: SDO always needs volunteers to make reminder phone calls and solicit raffle items over the phone.
- Emails: We need people to e-mail event reminders, gift basket and raffle item solicitations, and event volunteer requests.
- Mailings: Sometimes we need mailings sent out and help with labels and stuffing envelopes.
- Items: If you can donate items for raffles or baskets for silent auctions, SDO would love to hear from you.

There are many ways to help in our world of technology. Let's get creative and think about how we can bring our community together for the good of those living with a bleeding disorder. For more information on volunteering please contact Executive Director, Loretta Cordova, via email at loretta.cordova@sdoinc.org or call 505-341-9321.

HTC Update

By Lori Long

Our Hemophilia Treatment Center (HTC) is still undergoing a great deal of change. The HTC hopes that by the time the Family Education Weekend (details on page 12) rolls around, the HTC will be able to give us more information about what the future holds.

One of the major changes is that the HTC is no longer a line item on the state budget. This will force us to change our advocacy approach if we have to fight for the HTC budget again.

Another huge change is that Dr. Prasad Mathew, our pediatric hematologist, has moved on. The program is still recruiting his replacement.

In the meantime, if you have pediatric hematology needs, Dr. Jim McKinnell is the contact. You can call him at 272-4461, anytime, day or night. Before 8:00 a.m. and after 5:00 p.m. (as well as on weekends and holidays), this number provides phone triage assistance for how to reach the on-call doctor.

Another change is that our social worker, Patsy, has resigned. The program currently has the counselor/social worker position posted.

If you need a counselor's/social worker's services, you can contact Yolanda Vinajeras, who is the Social Work Supervisor for Pediatrics Hematology/Oncology. She is also available at 272-4461. If Yolanda is not available, you should ask for another social worker on staff that day.

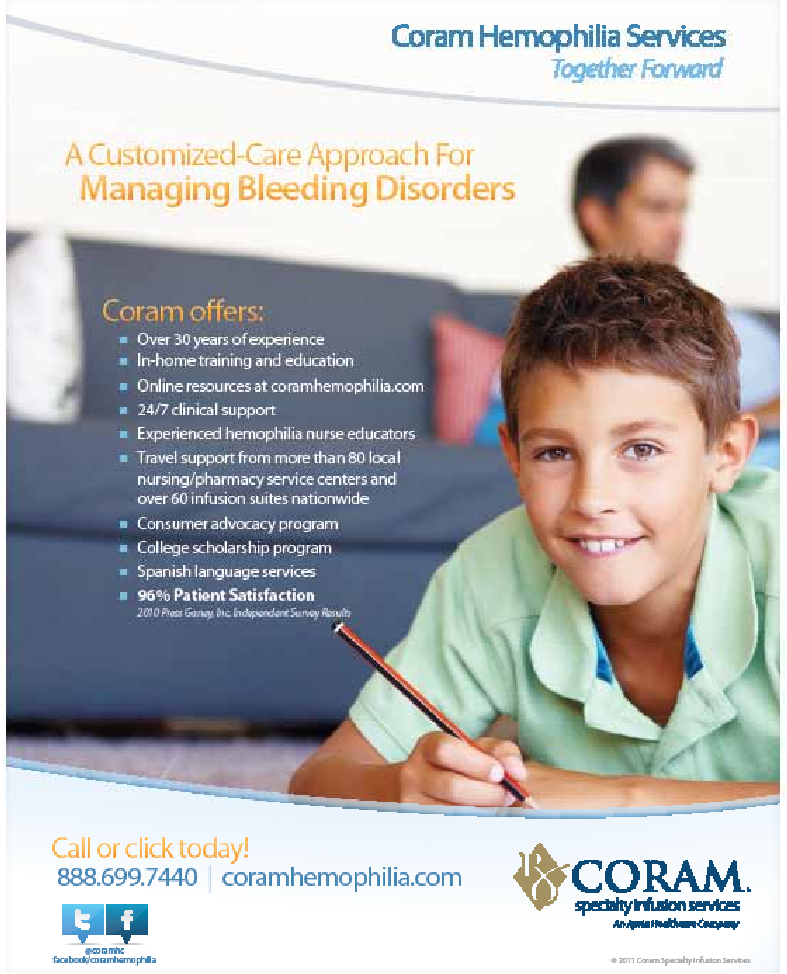
Dr. Garcia will also be leaving in November. His replacement might be Dr. Dulcinea Candelaria.

Important HTC Phone Numbers

Name	Title	Expertise	Phone
Elaine Kozlowski	RN	Pediatrics	272-0705
Claudia MacKaron	RN	Pediatrics	272-4461
Jim McKinnell	Doctor	Pediatrics	272-4461
David Garcia	Doctor	Adult	272-4946

Pediatric after hours number: 272-4461 ● Adult after hours number: 272-4946

(These numbers are turned over to the answering service at 5 p.m. on weekdays and over the weekend.)



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 male 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: Maintain 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.

Application Deadlines

Fall semester deadline: August 1st
Spring semester deadline: December 1st

Congratulations

Patrick Cordova is once again a recipient of the James Hamilton Memorial Scholarship. Great job, Patrick!

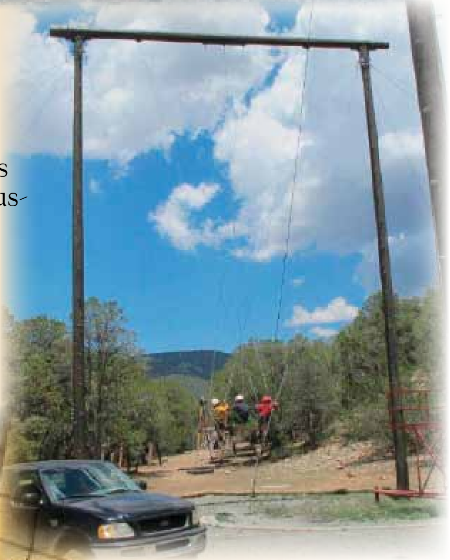
Camp Is Cool!

By Jordan Long-Holderried

Camp is fun, but the best part is the snack bar. The rifle range was pretty awesome too, but the most "darifying" thing was THE GIANT SWING. The swing goes more than two stories high. And it holds three people. We were the first cabin to be on it. It was scary at first, but after I went on it a couple of times, it wasn't too bad.

Camp to me is about having fun and learning about hemophilia. Infusions are a pain, but once they're over, it's not so bad. They obviously hurt, but you stick the needle in the vein, and it actually doesn't hurt as much as when they do it in the muscle for vaccines and stuff.

I had a good time at camp with my buddies Frankie, Mannie, and Devon, and Balthazar.



The Leader in Training (LIT) Program

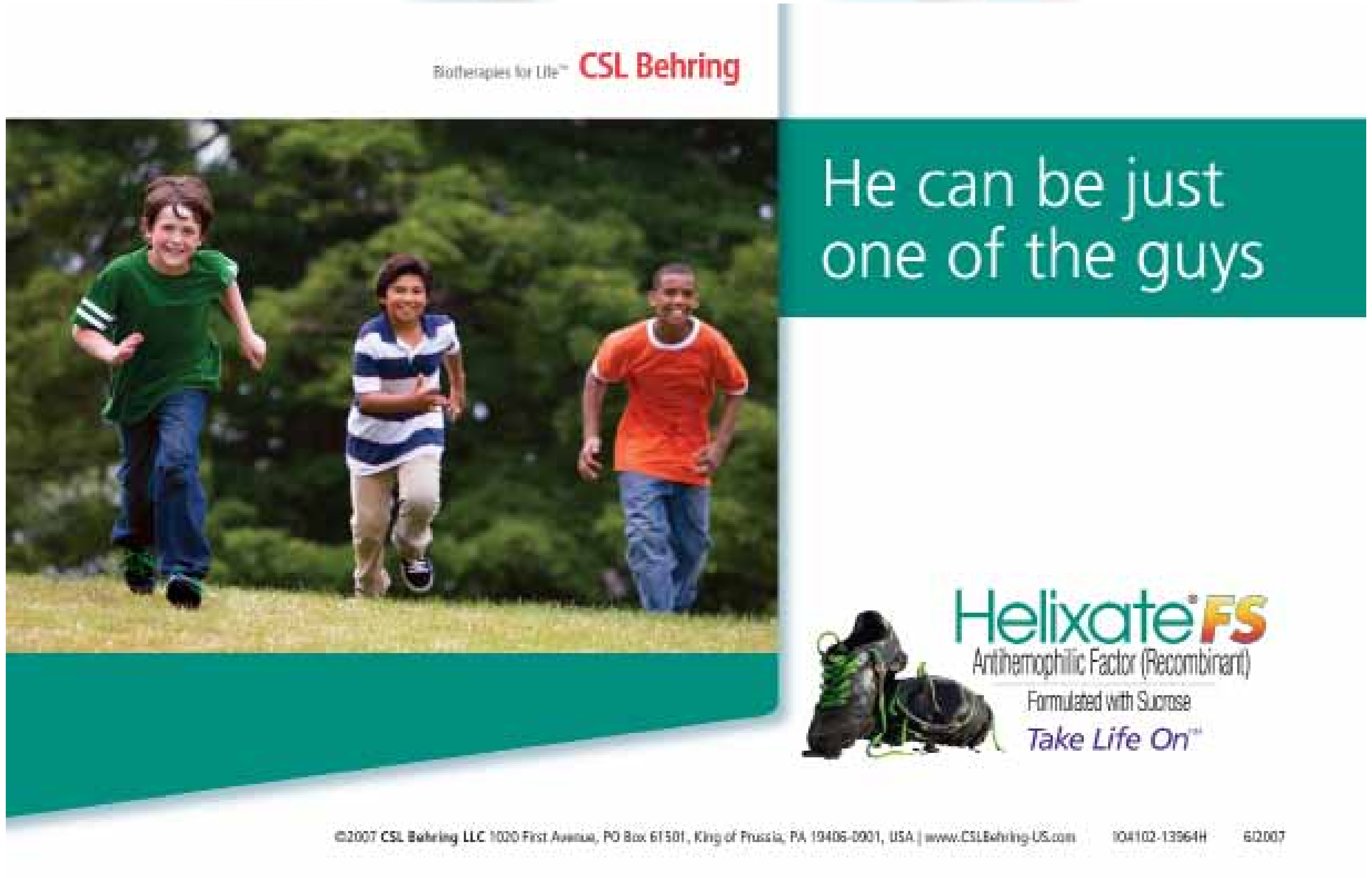
By Alex King

I first joined the Leaders In Training (LIT) Program at camp when I was 14. The LIT Program is a leadership program for young adults who are going to live in the world independently and want to learn the skills needed to treat and live successfully with their bleeding disorder. The LIT Program has taught me how to be a leader and how to manage my factor independently. It has given me the skills to become a leader and a role model for younger kids with a bleeding disorder. The LIT Program is a leadership program, but it is also a way for people to become leaders themselves.

The LIT Program is great because it teaches young people with hemophilia how to be independent when they grow up and how to be a leader. It teaches you how to take care of your factor orders and your insurance. These two things are essential for people with hemophilia because without these two things, it is difficult to live well with your hemophilia. You need to know how to order your factor so that you are able to live independently and successfully. It is very important to know how to take care of your insurance because without it, you will become dead broke with the expenses of the factor and unhappy because you will have no factor to take care of bleeds or do prophylaxis; you will be unable to do many of the things that you want to do.

These two things are very important, and the LIT Program teaches you how to live independently and take care of yourself.

The LIT Program is also very important because it teaches you how to be a leader. It teaches you how to take charge of yourself and of a group when it needs direction. I think that the LIT Program lives up to its name very well. It teaches you how to help others when they need support during a tough time, no matter how short, and when to let others do their own thing. You sometimes need to show the group in what direction they should go and how they can get there. These things are all attainable with the LIT Program because it shows young adults how to be a leader in the community.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He can be just one of the guys
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Antihemophilic Factor (Recombinant)
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ADVATE

[Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method]

Brief Summary of Prescribing Information. Please see package insert for full prescribing information.

INDICATIONS AND USAGE

Control and Prevention of Bleeding Episodes

ADVATE [Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method] is an Antihemophilic Factor (Recombinant) indicated for control and prevention of bleeding episodes in adults and children (0-16 years) with Hemophilia A.

Perioperative Management

ADVATE is indicated in the perioperative management in adults and children (0-16 years) with Hemophilia A.

Routine Prophylaxis

ADVATE is indicated for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children (0-16 years) with Hemophilia A.

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

CONTRAINDICATIONS

Known anaphylaxis to mouse or hamster protein or other constituents of the product.

WARNINGS AND PRECAUTIONS

Anaphylaxis and Hypersensitivity Reactions

Allergic-type hypersensitivity reactions, including anaphylaxis, are possible and have been reported with ADVATE. Symptoms have manifested as dizziness, paresthesias, rash, flushing, face swelling, urticaria, dyspnea, and pruritus. [See Patient Counseling Information (17) in full prescribing information]

ADVATE contains trace amounts of mouse immunoglobulin G (MuIgG): maximum of 0.1 ng/IU ADVATE and hamster proteins: maximum of 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

Carefully monitor patients treated with AHF products for the development of Factor VIII inhibitors by appropriate clinical observations and laboratory tests. Inhibitors have been reported following administration of ADVATE predominantly in previously untreated patients (PUPs) and previously minimally treated patients (MTPs). 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]

Monitoring Laboratory Tests

The clinical response to ADVATE may vary. If bleeding is not controlled with the recommended dose, determine the plasma level of Factor VIII and administer a sufficient dose of ADVATE to achieve a satisfactory clinical response. If the patient's plasma Factor VIII level fails to increase as expected or if bleeding is not controlled after the expected dose, suspect the presence of an inhibitor (neutralizing antibodies) and perform appropriate tests as follows:

- 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 (2) in full prescribing information]
- 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 drug reactions (ADRs) seen with ADVATE are hypersensitivity reactions and the development of high-titer inhibitors necessitating alternative treatments to Factor VIII.

The most common ADRs 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 studies in previously treated patients (PTPs) and one ongoing study 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 128.0 (range: 1 to 598).[1]

The summary of adverse reactions (ADRs) with a frequency ≥ 5% (defined as adverse events occurring within 24 hours of infusion or any event causally related occurring within study period) is shown in Table 1.

No subject was withdrawn from a study due to an ADR. There were no deaths in any of the clinical studies.

IMMUNOGENICITY

The development of Factor VIII inhibitors with the use of ADVATE was evaluated in clinical studies 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 (2.0 [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).[1,2] No Factor VIII inhibitors were detected in the 53 treated pediatric PTPs.

In clinical studies 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.[1] Four patients 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 patients, 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 muIgG protein antibodies. Of these, 10 showed an upward trend in anti-muIgG 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.

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 2 represents the most frequently reported post-marketing adverse reactions as MedDRA Preferred Terms.

Table 1
Summary of Adverse Reactions (ADRs)[a] with a Frequency ≥ 5% in 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] ADRs are defined as any Adverse Event that occurred within 24 hours after being infused with investigational product OR all Adverse Events assessed related or possibly related to investigational product OR 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 study in PUPs as of 27 March 2006.

[c] MedDRA version 8.1 was used.

Table 2
Post-Marketing Experience

Organ System [MedDRA Primary SOC]	Preferred Term
Immune system disorders	Anaphylactic reaction* Hypersensitivity*
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

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

References: **1.** Shapiro A, Gruppo R, Pabinger I et al. Integrated analysis of safety and efficacy of a plasma- and albumin-free recombinant factor VIII (rAHF-PFM) from six clinical studies in patients with hemophilia A. Expert Opin Biol Ther 2009 9:273-283. **2.** Tarantino MD, Collins PW, Hay CR et al. Clinical evaluation of an advanced category antihaemophilic factor prepared using a plasma/albumin-free method: pharmacokinetics, efficacy, and safety in previously treated patients with haemophilia A. Haemophilia 2004 10:428-437.

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How Does the Individual Mandate Work?

By Lori Long

One of the most controversial elements of the Affordable Care Act (ACA) is the "individual mandate." So, what is it, and how does it affect those of us in the bleeding disorders community?

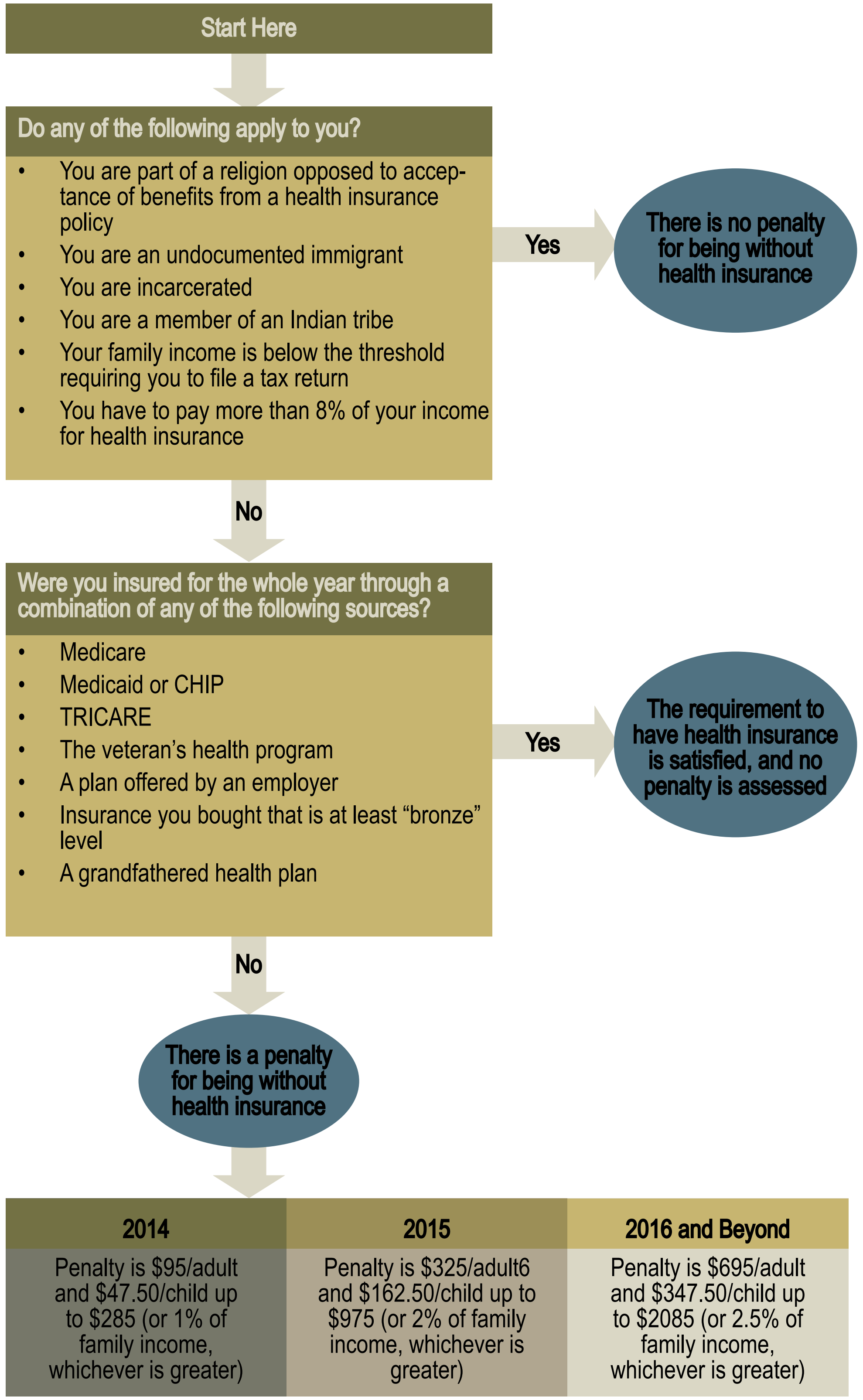
The individual mandate means that most individuals in the United States will be required to purchase health insurance. (Exceptions are described in the graphic to the right. The information in this graphic was obtained from www.kff.org.) A lot of folks didn't like this idea of being forced to purchase health insurance (and a many other things about the ACA), so they took the issue to the U.S. Supreme Court. (As a side note, New Mexico was one of the states supporting the ACA.)

Once the Supreme Court decided that the case was within their jurisdiction, they decided that the individual mandate is a constitutional exercise of Congress's power to tax.

They covered some other issues (expansion of Medicare, etc.) as well. In the end, they decided to uphold the ACA. For a detailed description of how the Supreme Court came to their decision, you can view the slides from the webinar offered by HFA on July 11th. You can find the webinar by going to www.hemophiliafed.org and searching for "webinar."

Because most of us with bleeding disorders go to great lengths to be insured in order to pay for our medication, we are less likely to be affected by the individual mandate. Those who are affected will hopefully have the option of purchasing insurance through the state health insurances exchanges that should be established across the country by 2014.

If you want to get more involved and know more about what is going on in legislature, consider joining the SDO Advocacy Committee! Contact Lori Long at sioco@msn.com if you are interested.



Start Here

Do any of the following apply to you?

- You are part of a religion opposed to acceptance of benefits from a health insurance policy
- You are an undocumented immigrant
- You are incarcerated
- You are a member of an Indian tribe
- Your family income is below the threshold requiring you to file a tax return
- You have to pay more than 8% of your income for health insurance

Yes

There is no penalty for being without health insurance

No

Were you insured for the whole year through a combination of any of the following sources?

- Medicare
- Medicaid or CHIP
- TRICARE
- The veteran's health program
- A plan offered by an employer
- Insurance you bought that is at least "bronze" level
- A grandfathered health plan

Yes

The requirement to have health insurance is satisfied, and no penalty is assessed

No

There is a penalty for being without health insurance

2014	2015	2016 and Beyond
Penalty is $95/adult and $47.50/child up to $285 (or 1% of family income, whichever is greater)	Penalty is $325/adult6 and $162.50/child up to $975 (or 2% of family income, whichever is greater)	Penalty is $695/adult and $347.50/child up to $2085 (or 2.5% of family income, whichever is greater)

SANGRE DE ORO WOULD LIKE TO THANK THE FOLLOWING TOP SPONSORS OF CALIENTE CLASSIC 2012

TITLE

DMC

LOGISTICS *Evolved*™

PLATINUM

novo nordisk®

SILVER

PAYROLL COMPANY

your community partner, your business partner.

BRONZE

Pfizer Specialty Care

aa auto & air conditioning & LUBE too!

Prophylaxis with ADVATE delivers 44 to 1

ADVATE IS THE **ONLY** RECOMBINANT FACTOR VIII (EIGHT) THAT IS

PROPHYLAXIS WITH ADVATE

THE POWER TO REDUCE YOUR ANNUAL BLEED RATE (ABR)

Significant reduction in ABR[1]

After switching from 6 months of on-demand treatment to 12 months of prophylaxis with ADVATE in 53 previously treated patients with severe or moderately severe hemophilia A:

- **Median ABR of 1** while on either prophylaxis regimen[1]
  - prophylaxis every second day (20-40 IU/kg)
  - prophylaxis every third day (20-80 IU/kg, targeted to maintain FVIII trough levels ≥1%)
- **42% of patients experienced zero bleeds** during 1 year on prophylaxis[1]
- **No subject developed factor VIII inhibitors** or withdrew due to an adverse event (AE)[1]

Indication for ADVATE

ADVATE [Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method] 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 people with hemophilia A. Your healthcare provider may give you ADVATE when you have surgery.

ADVATE is not used to treat von Willebrand Disease.

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.

TALK TO YOUR HEALTHCARE PROVIDER TO SEE HOW PROPHYLAXIS

The 9th Annual Caliente Classic Golf Tournament

Title Sponsor: Distribution Management Corporation (DMC)

By Joe MacDonald

Many thanks to our generous sponsors (top sponsors listed on page 10):

- Bank of the West
- Baxter BioScience
- Bayer HealthCare
- SW CornerStone
- CSL Behring
- Don Chalmers Ford
- Koch Construction & Mechanical
- Majestic Forms
- MediaWorks
- Pepsi Beverages Co.
- Ricci & Company
- Southwest Airlines
- US Bank
- Weck's

Congratulations to our winners, **Steve Hernandez of AA Auto and Air Conditioning, Stan Hockerson, Danny Ottman, and Matt Wisely**! Thanks to the AA Auto and Air Conditioning team for generously donating their winnings to support camp!

While we had many challenges with the new site for our golf tournament (the UNM Championship Golf Course), our fundraising efforts were still quite successful. We raised close to $40,000. Many members of our community helped ensure that this tournament would be a complete success. Our sponsors once again rose to the challenge and donated their time and money to the Chapter. The manufacturers and home care companies' continued participation in our event ensured the future of our summer camp experience for children and youth. To add in an extra display of encouragement, members from the Hemophilia Treatment Center came and participated.

The Caliente Classic plays an important role in the life of the Sangre De Oro Chapter. Without the funds raised from this event, many of the members of our bleeding disorders community would not be able to attend summer camp. This camp is the "life blood" (so to speak) to those who live with bleeding disorders. It is at camp that many of our children meet and form lifelong relationships with those who share the experience of having a bleeding disorder. Children learn that they are not alone and that they have a resource to help them manage and treat their respective bleeding disorders.

Many of the people who participated in the event, either as players or volunteers are actually members of our community. I send my profound appreciation to these mighty men and women who continue to give back to their community. Fundraising efforts proved more than just a financial means to an end. The golf tournament brought together our unique community.

I have participated in this event for approximately four years now, and I can honestly say that each year I am very humbled when I see the amazing men and women who give of their time and energy to support our community. There is a connection to something that is greater and bigger than who we are alone. I am grateful to all of the volunteers who dealt with my endless e-mails and constant changing of the schedule. Thank you for sharing your time to make my sons' lives a little easier.

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

The SDO Board

Executive Board Members

Johanna Chappelle,
President

Lori Long,
Vice President

Jose Guillen,
Secretary

Chuck Boberschmidt,
Treasurer

Loretta Cordova,
Executive Director

Board Members

Robert Farias

Joe MacDonald

Eric Marquez

If you are interested in participating on the board, please contact Loretta Cordova at 341-9321.

The 2012 Family Education Weekend

October 19–21, 2012

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

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

By Lori Long

Our 2012 Family Education Weekend will be held at the beautiful Embassy Suites in Albuquerque.

You can register to attend on our web site at www.sangredeoro.org. **On-line registration must be completed no later than October 5th to guarantee a room.**

Be sure to also fill out registration for your children if they will be attending. We will have fun activities for them!

Check-in starts Friday, October 19, at 4 p.m. The event runs through Sunday, October 21. We will have some great presenters and speakers and opportunities for visiting with old friends.

We hope to see you there!

How Can You Be Involved in the 2013 New Mexico Hemophilia Walk?

- Become a Team Captain and organize a team. Register your team at the Family Education Weekend (details on page 12). Each Team Captain who registers their team at the Family Education Weekend will have their name entered in a drawing. Register more than one team, and your name will be entered in the drawing for each team you registered over the weekend. Names will be drawn throughout the weekend for a variety of prizes. You must be present to win.
- Make a cash donation of $10 or more during the Family Education Weekend and have your name entered into a drawing. Names will be drawn throughout the weekend for prizes. You must be present to win.
- Volunteer to serve on the walk committee. Contact Charlene Selbee, Walk Event Manager, at 505-331-7154 or charlene.selbee@gmail.com if you are interested in serving on the committee.
- Add your name to the walk e-mail list to receive current information on the walk. E-mail Charlene Selbee at charlene.selbee@gmail.com if you would like to be added to the mailing list.
- Attend an informational seminar at the Family Education Weekend to learn how you can play a starring role in the 2013 Hemophilia Walk of New Mexico.
- Donate items or services for drawings that will be held during the Family Education Weekend.
- Suggest possible businesses to the Walk Event Manager that would be interested in sponsoring the Walk.
- Volunteer to help at the walk.
- Share your ideas with the Walk Committee, the Walk Event Manager, and the Walk Chair.

President's Corner

Dear Community,

Thanks to all our sponsors for making this year's camp and golf tournament a huge success. Camp was at a great new location, and all the kids and LITs truly enjoyed themselves, learned a lot, and grew by learning more about bleeding disorders. Many thanks to all the volunteers who joined us at the golf tournament. Without you, we just couldn't make it happen. Thanks to all who donated wonderful gifts for the silent auction and the raffle. All in all, the tournament was a success, and it continues to provide the funding for our annual youth camp.

We need some help at the Family Education Weekend with the younger kids this year. If you know someone over the age of 18 who would like to volunteer on Saturday providing programming and fun for these kids during the adult sessions, please let Loretta know.

Blessings to all, and see you soon at our October meeting.

Kindest Regards,

Johanna Chappelle,
President