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

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Inhibitor Summits and Camps!

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

Inhibitor Summit Comes to Albuquerque!

There are two Inhibitor Education Summits planned for 2014.

They will be held:

- July 10–13, 2014 in Albuquerque, NM
- July 24–27, 2014 in Baltimore, MD

For a complete agenda or for more information, visit www.nhfinhibitorsummits.org or call 877-560-5833. You can also contact us at sdo@sangredeoro.org to let us know that you are interested, and we will be sure to keep you posted!

Inhibitor Camps

The 2014 Inhibitor Camps will happen in two locations for each coast.

- West Coast: The Painted Turtle, CA, April 11–14
- East Coast: Victory Junction, NC, October 24–27

You can register at http://www.comphealthed.com/index.php/inhib/. Contact us at sdo@sangredeoro.org if you need assistance registering.

Credits

Volume 19 • Spring 2014

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The Bear Facts

The 2014 Hemophilia Walk of New Mexico is ON!!!

By Jean Cole

The New Mexico Hemophilia Walk 2014 is ON!!

As of this writing, there are seven Walk Teams registered. A big "thank you" to each of the Team Captains for signing up your team. We have already raised $686 towards our $50,000 goal. A huge "thank you" goes to Kenneth Wagg, who is currently our Top Individual Fundraiser with $200 and to Team Bruiser (Captain Kristy Sweeney) who is currently our Top Team Fundraiser with $300!

Team Bruiser also brought the first Kilometer Sponsor for the 2014 Walk: Enchanted Smiles, LLC, donated $250. Thanks, Kristy!

The New Mexico Hemophilia Walk 2014 is shaping up to be a bigger, better, and more fun event than last year. Your Walk Committee is busy taking care of the details, but we need your help, too. If you have not yet signed up a Walk Team, now is the time! Our Walk web site is up and "walking." If you registered for the 2013 Walk and remember your user name and password, you can use them again this year. If not, you can create new ones for the 2014 Walk. Get your team members to register too. The web site address is www.hemophilia.org/walk and click on NM.

We will be sending e-mails to registered participants with tips for fundraising, team challenges, and updates about the Walk.

Walk Teams are encouraged to design team t-shirts or be creative in other ways to identify your team members, such as each person wearing a purple ball cap or a green ribbon tied to their forearm. Those attending the Walk will have an opportunity to vote on the team identity they like the best. More details about this challenge will be in the registered participant e-mails. But a secret tip: save any loose change you have and bring it with you to the Walk.

Just a reminder, New Mexico Hemophilia Walk 2014 will be on Saturday, May 3rd at Tiguex Park in Albuquerque. If you have any trouble with the Walk web site, e-mail the Walk Committee at nmwalk@sangredeoro.org, and we will assist you.

As always, thank you for your support!

Your Walk Committee

Jean Cole, Walk Manager
Joe MacDonald, Walk Chair
Carnie Abajian
Lori Long
Candace Cloud
Rea Watson

Sangre de Oro, Inc.

Loretta Cordova, January 12, 1959 to January 3, 2014. Rest in Peace and Godspeed.

by Johanna Chappelle

(The following was delivered at Loretta's funeral on January 7, 2014)

Hello, I'm Johanna Chappelle, a very good friend of Loretta's, and I had the pleasure of helping many others care for her during these past 8 months of her life. I first met Loretta more than 20 years ago, and I have shared many special moments with her since then—traveling to attend meetings and conferences and watching her support the hemophilia community through her work with Sangre de Oro, the Hemophilia Foundation of New Mexico.

She served on the board of directors for 10 years and in 2005 took on the challenge of serving as the organization's Executive Director. Loretta proved to be exactly the right person for the job. She grew the organization and worked to make sure Sangre de Oro served all people with bleeding disorders in New Mexico. Her passion and dedication to this community, along with her love for golf, led her to develop the Caliente Classic Golf Tournament and oversee its growth.

Thanks to the solid foundation she created, Sangre de Oro raised $36,000 dollars this year for its summer camp for kids with bleeding disorders in New Mexico.

Loretta helped create other programs to support this community, including the annual patient and family education weekend (which was attended by nearly 200 people this past year) and the scholarship program which helps men with hemophilia obtain a secondary education. Loretta's son, Patrick, has benefited from the scholarship program, and I'm so proud to say that he will graduate from New Mexico State University this coming May with a bachelor's degree in philosophy and plans to continue on to law school.

Some people hold a special place in our hearts, and Loretta will always hold that place for me and for our community. And if you have any question about that, just have a look around at all the faces in this packed church.

I recently heard this saying: "In the end, it's not the years in your life that count. It's the life in your years." Loretta exemplified that idea. She packed a lot of life into her years, and in doing so made a difference in the lives of so many.

Where Is Your Voice? Be Part of CHOICE!!

by Wendy Owens

What if in 20 minutes you could help improve the lives of everyone in the bleeding disorders community? It is possible if you let your voice be heard. The time is now. The CHOICE Project survey is ready. Take it online, on paper in English or Spanish. Make the CHOICE and use your voice.

Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), HFA is running the CHOICE (Community Having Opportunity to Influence Care Equity) Project. The goal of the CHOICE Project is to collect information regarding health experiences of people who have a doctor-diagnosed bleeding disorder and do not receive care at a federally-funded hemophilia treatment center (HTC). HFA is asking everyone in the bleeding disorders community to participate in this project by taking the CHOICE survey.

Together HFA and the CDC hope what is learned will help assure equity in the care received by all members of the bleeding disorders community. The more participants enrolled in this project, the more information HFA can gather. With more information, HFA has a better chance of learning what it and its chapters can do to improve the health of people with bleeding disorders. This includes possibly identifying medical and social issues that require further study. There is power in this knowledge, power to change lives, improve medical care, and help assure access to the services people with bleeding disorders need.

Since 1998, CDC has collected information on the health status of people with bleeding disorders who receive care at HTCs. Much has been learned from this information. However, a study from the mid-1990's showed that a third of people with bleeding disorders received care outside of the federally-funded HTC network. Little is known about the health experiences of people who do not receive care at federally-funded HTCs. So HFA and the CDC decided to learn more through the CHOICE Project.

HFA member organizations are a key component to the CHOICE Project's success. HFA has teamed up with seven of its member organizations in Texas, Illinois, Arizona, New Mexico, and New York to help it identify people to take the CHOICE survey. The survey itself is available in English and Spanish and takes roughly 30 minutes to complete. People can take the survey online or in paper format.

The CHOICE survey asks questions about diagnosis, bleeding history, treatment, insurance coverage, quality of life, and quality of care. The information collected from the survey will be used to understand the health of people with bleeding disorders who do not receive care at federally-funded HTCs. It will also be used to identify issues that need further understanding, such as where care is being obtained, what complications are being experienced, and what treatment is being used.

Personal privacy of the survey-takers is of the utmost importance to HFA. HFA will collect all survey information. Personal information will not leave HFA's secure, password protected database. HFA will compile paper-based surveys into this database and will shred and recycle the paper documents. HFA will share de-identified data with the CDC. Data shared with the CDC will include a unique identifier code but will not contain personal identifiers such as name or address. Information from this project may be published. However, no information will be published that could identify a survey-taker.

If you have a bleeding disorder, your voice should be heard – no matter where you get your care. You matter and it is your choice to participate in the CHOICE Project. To find out how to take part in the CHOICE project, call 800-230-9797 or go to choice.hemophiliafed.org.

Calendar of Events

February

26–28	Washington Days

March

	National Hemophilia Awareness Month
21	Board Meeting (location TBD)
24	Camp Dinner in Roswell (Peppers Grill and Bar)
25	Camp Dinner in Albuquerque (Savoy)
27–29	HFA Symposium in Tampa, FL

April

13–15	Inhibitor Family Camp in Lake Hughes, CA
17	World Hemophilia Day
24–26	Bi-Regional Meeting in Tucson, AZ

May

3	2nd Annual Hemophilia Walk of New Mexico, Tiguex Park, Albuquerque, NM
9	Board Meeting (location TBD)

June

9–13	Camp Sangre Valiente in Capitan, NM
11	New Mexico Hemophilia Awareness Day

July

18	Board Meeting (location TBD)

August

15	Caliente Classic Golf Tournament

September

17–19	NHF Annual Meeting in Washington, DC
21	Board Meeting (location TBD)

October

17–19	Patient and Family Educational Weekend in Albuquerque, NM

November

14	Board Meeting (location TBD)

Thank You to Our 2013 Sponsors!

Your support makes it possible to serve our local community

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CSL Behring
HFA
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Hemophilia Health Services
Kedrion Biopharma
National Cornerstone
Ricci & Company
Southwest Cornerstone
Walgreens

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Southwest Airlines
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Thank You to Our Volunteers!

Your hard work makes it possible to serve our local community

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Caller ID

By Cazandra MacDonald

Remember when caller ID was futuristic? I remember thinking how cool it would be if you could see who was calling before you picked up the receiver and wondering if I would ever be in a world where you could make a phone call and see the person while you spoke (Skype).

Today if a week goes by without a Skype call, it is unprecedented in our home, and the occasional "Unknown" caller on the ID is annoying.

Being able to see who is calling is normal these days. If I don't recognize the number, 9 times out of 10, I will choose not to answer the phone. And sometimes, even if I do know who is calling, I still won't answer the phone! But there are some numbers that make my heart race.

When I see a certain "891" number, I know it is the elementary school my 8-year-old, Caeleb, attends. I have a great relationship not just with his teachers, but with the ladies in the front office and especially the clinic. They all know that if they are in doubt about whether or not to give me a call regarding Caeleb, I would prefer them to call. I would rather drop in to the clinic, check him out, infuse if necessary, and send him back to class.

My husband and I are able to check on Caeleb as needed, and this has empowered the staff at his school to feel good about his care. Some families do not have flexible work schedules, and that makes it difficult when your child has issues that warrant a heightened level of attention.

You never know when that phone call is going to be a "little" something that you can treat with factor and a hug and a kiss, or if it is a "big" something that will change your entire day (or week) by requiring a visit to the treatment center or the hospital for further assessment and treatment.

There is nothing more frustrating than having to stop your entire day to take your child in to the clinic. You stop your workday, be it in the home or in the workplace, and you begin to assess what needs to be done. Schedules must be juggled and arrangements made for shuttling family members from one place to the other and/or getting dinner on the table, cancelling meetings...the list goes on.

But the most important thing is to get the care your child needs. Despite the frustration and anxiety of getting things handled, my top priority at that moment is my son—not the meeting I have missed, not the dinner that needs to be cooked—but getting my son the care that he needs.

The caller ID makes me crazy at times when that certain number appears on the screen, but at least I have a moment to prepare for whatever lies ahead.

Cazandra and her husband Joe live in Rio Rancho with their sons Julian (17) and Caeleb (8), both with Severe Hemophilia A. You may read more about their adventures with hemophilia and inhibitors at 2brotherswithhemophilia.blogspot.com.

"You're braver than you believe, and stronger than you seem and smarter than you think."
—Christoper Robin to Pooh

Bleeding Disorders in 2014: How Bright Is Our Future?

By Hanukkah "Rea" Watson

It has been nearly 8 years since my husband and I welcomed our oldest baby boy into the world. We knew absolutely nothing about hemophilia nor had we recalled even hearing the word *hemophilia* over the course of our lives. It was scary enough as new parents wrapping our heads around how we would cope dealing with a life-long medical condition, but what frightened us more was the fact that the pediatric hematologist, who had rescued our 3-day-old baby from nearly bleeding out from his circumcision, confessed to not knowing much about hemophilia other than what he had read.

The reality is that my story has been the story of some of you and many others all over the world. I've come to get used to the "outsiders" asking me if hemophilia is like sickle cell anemia or leukemia because there are just not many of us out there. Therefore, it is all too common to get the standard "What is that?" type of question more often than not. To add insult to injury (no pun intended), I've met more than my share of medical professionals that would conclude they knew about hemophilia, but I soon discovered they only knew the stereotypes of bleeding disorders such as hemophilia or von Willebrand's Disease (vWD), which is just as dangerous.

To the outside world, it seems that those of us affected by bleeding disorders are in a world all our own, but fortunately, it has become a world full of promise and progress. Every now and again I take a mental trip into "What if" land, and I imagine what my son's life would've been like a few decades ago. It was a totally different world back in the 1950s.

The chances of a patient with severe hemophilia surviving from a circumcision was tremendously low, considering that a blood transfusion alone may not have resolved his bleeding. Had he been born in the 1970s, there would have been a very high chance that my son would have received blood products containing the HIV virus, just like many hemophiliacs across America did in the 1980s. Sometimes, it takes a look to the past to appreciate the sacrifices made. Then I can see that all the hospital stays and surgeries that my son has endured in his 8 years really could have been worse. There have been moments when I was in tears because I was not able to access his port (before it was removed) or when I had to poke him more than once. At those times, I have often looked forward to the possibility that by the time he or his baby brother graduates from high school, there will be many more medical innovations and possibly even a cure. I've made this comment many times, and I have come to realize that it is possible, even if we still have a while to go. Please see *Where We Were* and *Where We Are Now* (left).

Where We Are Going

Gene therapies and genotyping have become the best option for researching what makes bleeding disorders unique to each individual. Understanding how our genes and bodies interact will be the catalyst for better treatment options in

Where We Were

1973 CDC put hemophilia treatment centers (HTCs) in place.

1980 50% or more of those suffering with severe hemophilia became infected with the HIV virus; many of those infected died due to the lack of promising treatments in this era.

1990 Innovative purification techniques begin to be perfected.

1992 The first official recombinant (synthetic) clotting factor to be approved by the U.S. Food and Drug Administration became available for those with hemophilia A.

1995 Reports were issued that made 14 detailed suggestions for blood safety as the NHF partnered up with governing agencies to prevent contamination. These included tougher screenings and other measures to keep us safe.

1997 Recombinant (synthetic) clotting factor (BeneFIX) became available for those with hemophilia B.

1998 The federal government acknowledged the epidemic through the Rick Ray Hemophilia Relief Fund Act. Those affected by tainted blood products received what were called "compassion payments" (but never an apology).

Comprehensive healthcare becomes available through HTCs, which are partially funded by the CDC to ensure a better quality of life for those with hemophilia, von Willebrand's disease (vWD), and other rare bleeding disorders

The CDC becomes a partner in assisting the community to achieve a better life than those who made such tremendous sacrifices just a few decades ago.

Where We Are Now

2000 Kedrion Biopharma and other manufacturers announced new purification processes for human blood products in addition to the strict screening of donors that is carried out by manufacturers today. Donors are strenuously screened several times before their blood will be considered for usage.

A liver transplant was performed on a dog with hemophilia. It was later found that the new liver "cured" this dog of hemophilia. Out of four liver transplants performed on humans with hemophilia, three were successful. Although there were many complications, this study alone gave researchers information about possible cures for hemophilia.

Parents have the option of presenting health plans to their child's schools and daycare centers and have the right to meet with administrators about their children's health concerns.

Due to the efforts of advocacy, there is growing awareness of many hemophiliacs who lack access to the factor they need to live a full life. National and worldwide programs, like free-factor programs and scholarships, offer remedies to these problems.

2013 Longer-lasting recombinant Factor IX, RIXUBIS (used for hemophilia B patients) was announced by Baxter as they continue successful trials for human usage. It is the first new treatment option in more than 15 years.

2014 A brighter future!

the years to come. Contaminants like HIV/AIDS and HCV are not an epidemic.

The medical news I've shared is really just a drop in the bucket. There are several clinical trials and research developments underway that will give us and the generations to come a better life. Not only are medical professionals looking at new products, they are also researching the complications that come along with bleeding disorders like joint issues, premature arthritis, and central lines, to name a few. All aspects of our lives are being observed. Medical professionals, physical therapists, and local chapters are now providing the education and emotional support needed to live a productive and fairly independent life.

The next time you or your loved one is dealing with the ups and downs of a bleeding disorder and feel a bit frustrated and discouraged, I hope you both will find comfort in knowing that we are not where we used to be and are definitely heading in the right direction—filled with promise and great purpose. Maybe someday, we will beat hemophilia and vWD—but we definitely have come a long way!

http://www.centerwatch.com/clinical-trials/listings/condition/379/hemophilia

http://clinicaltrials.gov/ct2/results?term=hemophiliac&Search=Search

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2965591/

http://www.hematology.org/publications/50-years-in-hematology/4737.aspx

Could You Lower the Cost of Your Internet or Phone Service?

by Miguel Sanford and Chris Fennicks

We heard that there have been a lot of Consumer Assistance Program (CAP) requests for phone and Internet service, so we have done a little digging and discovered the Internet Essentials program (www.internetessentials.com) offered by Comcast:

With Comcast Internet Essentials, low-income families can get cable internet for $10 per month.

To qualify, you must meet ALL of the following requirements:

- Comcast offers internet service in your area.
- You have not subscribed to Comcast Internet service within the last 90 days.
- You do not have an overdue Comcast bill or unreturned equipment.
- You have at least one child who is eligible for the National School Lunch Program (even if they are homeschooled, or in private or parochial school).

Customers will be accepted into Internet Essentials for 3 full school years. Any household that qualifies during the next 3 school years remains eligible as long as there is a child eligible for a free/reduced school lunch still living in the household.

There is a nice .pdf published by ConnectUp at www.solidground.org/Programs/ConnectUp/Documents/InternetProgramsBrochure.pdf, and it compares what services are available for low-income families.

It looks like CenturyLink is the way to go for SS/Medicaid recipients, while Comcast is more focused on children in low-income families.

CenturyLink has a federal assistance program called LifeLine. Information about LifeLine can be found at www.centurylink.com/Pages/Support/LifeLine/.

Lifeline is available to qualifying customers in every U.S. state. Qualifications do vary by state. States with their own programs have their own criteria. In states that rely solely on the federal program, the subscriber must participate in one of the following programs:

- Federal Public Housing Assistance
- Food Stamps
- Low-Income Home Energy Assistance Program (LIHEAP)
- Income below 135% of the Federal Poverty Guidelines
- Medicaid
- National School Lunch's Free Lunch Program
- Supplemental Security Income (SSI)
- Temporary Assistance to Needy Families (TANF)

Residents of American Indian and Alaskan Native tribal lands may qualify for up to an additional $25 of enhanced Lifeline support monthly. They may also qualify for the Link-Up program, which helps consumers pay the initial installation costs of getting telephone service. Link-Up provides a credit of up to $100 of the initial installation charges for tribal customers. An individual living on tribal lands may qualify for Lifeline and Link-Up discounts if he or she participates in one of the programs listed above, the Bureau of Indian Affairs General Assistance, Tribally Administered Temporary Assistance to Needy Families; Food Distribution Program on Indian Reservations; or Head Start (only for those households meeting its income qualifying standard).

We hope this helps.

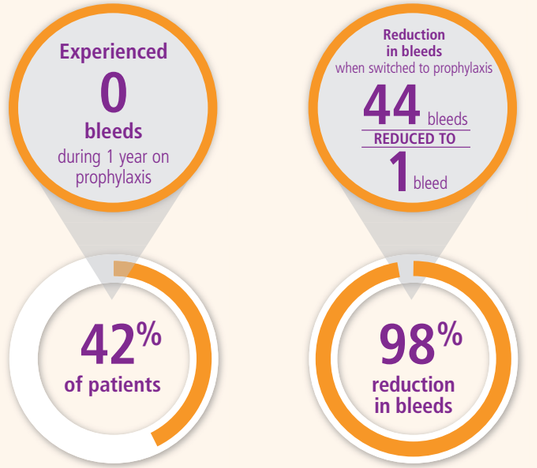
Baxter

UNLOCKING SELF-POTENTIAL

PROPHYLAXIS WITH ADVATE REDUCED BLEEDS IN A CLINICAL STUDY[1,a]

ADVATE is the only recombinant factor VIII (eight) that is FDA approved for prophylaxis in both adults & children (0-16 years)[1]

Significant reduction in median annual bleed rate (ABR) with prophylaxis treatment compared with on-demand treatment[1,a]



- 0 bleeds experienced by 42% of patients during 1 year on prophylaxis[1,a]
- 98% reduction in median annual bleed rate (ABR) from 44 to 1 when switched from on-demand to prophylaxis[1,a]
- 97% reduction in joint bleeds from 38.7 to 1 after switching from on-demand to prophylaxis[1,a]
- No subject developed factor VIII inhibitors or withdrew due to an adverse event (AE)[2,a]

[a]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 with severe or moderately severe hemophilia A.

Ask your healthcare provider if prophylaxis with ADVATE is right for you.

Detailed Important Risk Information for ADVATE

You should not use ADVATE if you are allergic to mice or hamsters or any ingredients in ADVATE.

You should tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines and dietary supplements, have any allergies, including allergies to mice or hamsters, are nursing, are pregnant, or have been told that you have 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.

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.

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

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

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 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.

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

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

References:

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

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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®

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2013 Family Education Weekend

NHF's 65th Annual Meeting

By Candice Dunlop

NHF's annual meeting took place last year in Anaheim, CA, October 3–5. It was a great meeting, both for the information presented to attendees and also for just being a really fun time! It is so healing for families in the bleeding disorders community to get together, communicat, laugh, and (in the process) learn.

The opening session started with an overview of the history of NHF, the vision of Betty Jane and Robert Henry, NHF's founders. Jorge de la Riva, NHF Board Chair, spoke of how NHF has helped families of children with bleeding disorders since 1948 and has continued right up until today, inspiring individuals and industry to fight for a better future for the bleeding disorders community.

Val Bias, NHF CEO, related how, due to an injury, he was infusing higher levels of factor product. This diminished his pain and raised his energy level. Yet, normally, he is restricted by his treatment plan and insurance coverage to only a certain amount of factor—an amount that keeps him alive but does not allow him to feel his very best. Bias included that perhaps those of us with bleeding disorders should play a larger role in the decision-making process. He challenged the audience to adopt a slogan made popular in Central European politics: "Nothing about us, without us." We, as a community, need to communicate our needs and expectations, as related to our own well-being.

Bias's next point was that it is our responsibility to contribute to the data currently being collected about those with bleeding disorders, thereby showing how adding value to our lives reduces cost in the long run. One option for participating is NHF's national genotyping initiative, called "My Life, Our Future." In 2013, the program was started in 11 pilot sites across the country, with more than 200 people taking part. Soon it will be available nationwide for all who want to participate, giving researchers the tools they need to make advancements for our care.

Alex Borstein is NHF's new spokesperson for genotyping. Alex is an actress and comedienne. She is the voice behind Lois Griffin on FOX's "Family Guy." She and her daughter are carriers of hemophilia. Alex closed the opening session of NHF's Annual Meeting with a performance, and we all had a good laugh!

Some of the ladies were treated to more time with Alex Borstein later that same evening at the Girls' Night, presented by the Victory for Women initiative. Along with many other women who have bleeding disorders, the president of Sangre de Oro, Lori, and I had a blast. We ate, danced, laughed, and shared our stories. That night was definitely a highlight for us. After the reception, we continued on to the opening night of the exhibits. As usual, industry outdid themselves. There was so much information being given and activities in which to take part, it was definitely overwhelming. I can't imagine how much fun the children must have in the exhibit hall.

During the next 2 days, there were sessions addressing many topics related to different bleeding disorders. Different aspects of von Willebrand's Disease were covered, as well as several different sessions on communication.

Updates on treatments for HIV and hepatitis C were presented. Other topics included aging with hemophilia, gene therapy clinical research trials, healthcare reform, and World Federation of Hemophilia updates.

On the last night of the meeting, everyone was treated to a night at the Magic Kingdom. After dinner at the hotel, we were transported to Disneyland in buses. It was a beautiful, warm evening. The shows on the water and at the castle were, of course, magical!

If you have never attended an annual NHF meeting, you are eligible to apply for a scholarship to pay for your family's expenses to attend the meeting. If you are interested, go to NHF's web site this spring and print out the paperwork necessary to apply for a scholarship. The meeting this fall will be held in Washington, DC on September 18–20.

Patient Notification System

for the plasma-derived and recombinant analog industry

The Patient Notification System is a free, confidential, 24-hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.

The system was created to provide consumers with a single, convenient, and confidential source for up-to-date withdrawal and recall information.

Please visit us at:

www.patientnotificationsystem.org

to register. You will be notified automatically of any recalls or withdrawals.

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 or visit them on the Web at www.patientservicesinc.org.

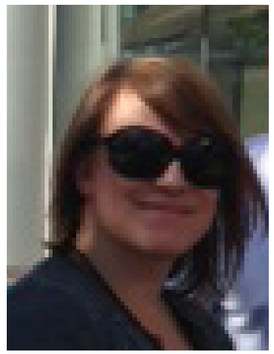
Presbyterian Pediatric Hematology/Oncology Clinic

by Shawna Montano

Presbyterian Pediatric Hematology/Oncology clinic is now accepting patients with bleeding disorders. We have two physicians, a family nurse practitioner, and a team of clinical and ancillary staff to care for patients of all ages. Our board-certified physicians, Dr. Jeffrey Hanrahan and Dr. Samuel Esparza, are welcoming new patients of all ages. We recently opened a new Pediatric Infusion Center attached to Presbyterian Hospital. Our office phone number is 505-563-6530.

Ted R. Montoya Hemophilia Treatment Center

by Brie Johnson, RN



Brie Johnson, RN

I've been at the HTC for just about a year now, and I absolutely love it! The first years of my nursing career were spent in the Newborn ICU and from there I spent a short time in the Emergency Room before coming here. This opportunity was unexpected, but I'm glad I took it.

I was not quite sure I was ready to leave bedside nursing when I did, but this has been the best opportunity in my career so far. I've met so many amazing people. Working for the HTC gives me the opportunity to do what I love. It allows me to develop long-lasting relationships with our patients and provide the kind of care that they deserve. I enjoy getting to know each and every one of you in the clinic as well as outside of the hospital setting. I've made great memories in my short time here and look forward to many more!

HTC Contact Information

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

Claudia MacKaron, RN

My name is Claudia MacKaron, and I have been a nurse for more than 19 years. I graduated from the UNM nursing program and started with my first job on the Peds acute care unit at UNMH. I moved to the hematology/oncology outpatient division 13 years ago, primarily working with the oncology program. Then 3 years ago I had the opportunity to work with the bleeding disorders population, and it hit; I fell in love with the bleeding disorders. At this point of my life I am settled and have no intention of changing my focus anytime soon.

In my spare time I love to spend time with my husband, three grown children and six grandchildren.

I have two dogs and two horses that I have enjoyed taking care of.

When I first started working with the HTC, I had no idea in what I was getting myself into. Since then I have learned so much of the disease process and how it affects our patients and their families in every aspect of their lives. I have grown to love this community. The complexities of each patient's needs and how I can help facilitate an answer has been a fulfilling experience for me. I have grown to respect and admire what each person affected by this disease has gone through to strive for a normal and productive life.

One love I have is camp. I see children that live with their struggles daily. Yet they come to play and grow with confidence to go forward looking to the future for a better life then what they have experienced. It is a thrill for me to see this unfold with the support of their peers. I hope to continue to be a support to this special community. Thank you for allowing me to be part of it.

Shynia Litzau, RN

I have worked for the HTC for a little over a month. Prior to joining the HTC I worked as a staff nurse in the clinic that provides care for many of the HTC patients. I have really enjoyed my time with the HTC. I love the fact that I am part of a team that is able to provide our patients with a well-rounded care experience.

Yolanda Vinajeras, MSW

Yolanda Vinajeras is the senior social worker on the UNM interdisciplinary team of pediatric hematology/oncology providers. Her expertise spans a variety of fields including inner city work Chicago and Kansas City. More recently, her primary interest has been in the area of hemophilia. She earned her MSW from Highland University and has served on a number local and national boards, including the National Association of Pediatric Oncology Social Workers. She also brings many years of camping expertise as a co-director for New Mexico's Camp Enchantment and Camp Super Stars serving childhood cancer patients and their siblings.

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

Rest in Peace, Angela

by Johanna Chappelle

On February 10, 2014, Angela Mathew, daughter of our beloved former pediatric hematologist, Dr. Mathew, was killed in a traffic accident. She was attending Harvard and majoring in Neurobiology.

Angela and her brother, Raji, were at several SDO events over the years, so many of you may have met her or known her. She graduated from the Albuquerque Academy in 2012. She was a brilliant and beautiful young lady, and quite a track runner. Her friends remember her as an energetic debater with a magnetic personality.

She was in a van returning from a mock trial event when the accident happened.

Our hearts go out to Prasad, Susan, and Raji Mathew.

ring in the larger chapters and happy that we don't have those problems. I attribute it to the fact that we are a small community and have a small board. That in itself is a problem because of the lack of manpower necessary to provide to the community. I see the need for our community at large to become more engaged and contribute to our small and growing family.

Board Development

This was about training the board members on what is expected of them, their roles and responsibilities, how to run board meetings, and how to participate in board meetings to keep them efficient and on-time.

Managing Multiple Projects

This basically discussed how chapter boards take on multiple projects and the need for setting priorities and deadlines all in accordance with the chapter goals.

Day 3

Healthcare Reform, the Final Countdown

This was an update on what is to happen this Fall and into 2014 with the roll-out of the ACA. They basically reiterated that open enrollment begins on 1 October 2013 and goes through 31 March 2014. The Kaiser Family Foundation site (www.kff.org) is a good resource on the ACA. A more detailed explanation on what the ACA entails is provided in this newsletter.

Acceptance and Diversity in Chapter Programming

The title pretty much describes the substance of the discussion. We need to be more accepting of our diverse community members.

Awards Luncheon

This working luncheon was actually a 3-hour meeting (with lunch) where recognition was given to healthcare providers, chapter staff volunteers, and best practices within the bleeding disorders community.

NHF Final Night Event at Disneyland Park

I did not attend, preferring dinner with my daughter and her husband.

In attending these Chapter meetings, I was pleasantly surprised to find out about all the resources available from NHF to train and help our SDO chapter organization become more efficient and better at fundraising.

SDO is not only a hemophilia support organization; it is a bleeding disorders support organization. So I challenge the community to get involved and see what you can contribute to help our community with your skills and talents.

Attending the 65th NHF Annual Meeting, October 3–5, 2013

By Jose Guillen

I have been fortunate to attend three NHF Annual Meetings. Twice with my family in a consumer role (Dallas, TX and Denver, CO) and this one in Anaheim, CA as an SDO Chapter representative.

I was privileged to attend a special NHF Recognition Dinner for NHF Chapter Philanthropists hosted by Val Bias, CEO of NHF. It was held on the evening of 2 October. NHF selected three Philanthropists of the Year from chapter nominations. These individuals have significantly helped the bleeding disorders community in their area. This year, NHF recognized just three: two from Northern California, and one from New Mexico. The awardee from New Mexico was Steve Griego from DMC, who has been the primary sponsor and fundraiser for the SDO Annual Caliente Classic Golf Tournament. Steve has been doing this for the past 10 years (a lot longer than the 2 or 3 years he expected). In his words, "I told Loretta [Cordova], I would help for 2 or 3 years to get the golf tournament off the ground and then you [SDO] could take over." In attendance with Steve was his wife Lydia, his nephew Patrick Cordova, our SDO Past President, Johanna Chappelle, and myself.

The actual meeting program was jam-packed with 3 full days of meetings. It started with CEO Val Bias presenting NHF Chapter Update from the NHF Staff. I attended the Chapter Staff track, which covered the following topics for each day:

Day 1

Chapter Staff Organization (CSO)

I was surprised to find out the CSO was initially set up to provide a unified voice on behalf of the grassroots organizations (chapters) to advocate for better support from the national organization (NHF). It also provides skills training to chapters outside of the NHF: training for chapter board member development, like who should be on the board and who shouldn't, training in writing grants, scholarship applications; a web site as a template to be used by all chapters.

Chapter Design on a Budget

This was about defining the chapter's mission statement and how to communicate it to multiple audiences to raise funds. The discussion started out by focusing on simplicity, having a clear focus and an exact, intriguing, and authentic vision to share with multiple audiences by knowing who you are, defining the problem, and planning how to accomplish your vision. Tools (beginner and advanced) were even suggested that are free and/or low-cost to set up your chapter web site.

Social Media

This was about how to activate your supporters, why we (as a chapter) should be using social media to reach our stockholders and community members, establish relationships, engage in conversation, and provide insight into our community's needs.

On-Line Fundraising

This discussion addressed the issue of getting more for less—the secret of on-line fundraising. This started off as basically setting a goal for fundraising for the next year and then setting up a web site that tells a story.

- Mission, goal, objective, and work
- Use of the donated money.

Provide timely, relevant and specific e-mails to donors that are more personal. Web site locations to examine were suggested like Google for Non-Profits.

The last three sessions here are all interrelated. SDO does have a web site, but it is not used as these sessions suggest to reach our fundraising potential. Maybe someone in the SDO community can help in this endeavor?

Day 2

Healthcare Reform

This was about the 10 essential health benefits required under the Affordable Care Act (ACA): no pre-existing conditions, no lifetime caps, coverage to age 26 under parents policy, etc.

Lessons Learned from Dave (Getting along within your chapter)

I was surprised to learn about the problems occur-

Continued on Page 16.

10th Annual Camp Sangre Valiente

By Patrick Wagner, Camp Director

Summer's coming! Yes, it is time once again to start thinking about Camp Sangre Valiente 2014. Our friends at our campsite are eagerly awaiting our return, and our camp committee is hard at work preparing for what is sure to be the best camp year yet!

Just about every year, we get asked by some folks, "What is camp all about?" Camp is the place where kids and siblings of kids with bleeding disorders can come together for a week of fun, challenges, and education in a safe, controlled, and caring environment. Kids can "just be kids" for a week without worrying about their bleeding disorder and some of the issues that come along with it.

SDO provides camp free of charge to children and young adults with a bleeding disorder, their siblings, and any child of a parent affected by a bleeding disorder. Camp is for kids between the ages of 7 and 12 years, and the camp Leader in Training (LIT) program is for kids 13 to 17 years of age. The LIT program includes education, experiential activities, and challenges to help the kids prepare to take charge of their future by becoming more involved in their own care.

Our camp is held in Capitan, New Mexico between the beautiful Capitan and Sacramento mountains at Fort Lone Tree. The camp site is a fantastic facility that is staffed by a trained, accredited, paid camp staff as well as some of our own bleeding disorders community members. The camp has some amazing things for the kids to do, such as horses, archery, sports, a water slide, and many other activities. We often find it hard to fit everything in during the week we spend there!

I know some of you out there may have questions or concerns about camp, and I encourage you to reach out to Johanna Chappelle at sdo@sangredeoro.org or 505/341-9321 with any of those. You will be able to register for camp at the camp dinners this year. If you are not attending a camp dinner, please contact Lori Long at sdo@sangredeoro.org, and she will get you registered. Each child must be registered in order to attend.

Don't wait until it is too late! Sign up your kids now for camp and bring on the summer!

Executive Board Members

Lori Long, President

Jose Guillen, Vice President

Jose Duran, Secretary

Eric Marquez, Treasurer

Board Members

Johanna Chappelle

Jean Cole

Robert Farias

Chris Fennicks

Joe MacDonald

Sarah Trawinski

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

President's Corner

Dear Community,

We have had a momentous year, full of tragedies and triumphs, haven't we? I have reflected a number of times on our history, so I've included an SDO time line (bottom) in case you are curious too!

We lost our beloved Executive Director, Loretta Cordova (pages 2 and 3). Our former HTC Director, Dr. Mathew, lost his daughter, Angela, to a tragic traffic accident. And we lost two of our blood brothers, Barry Stein and Darrell Johnson. May they rest in peace and remain in our hearts.

We have also had some triumphs. We had our first-ever Hemophilia Walk last April with about 300 people attending. We raised more than $35,000! I hope you all plan to sign up and walk again. It was so fun (page 1)! Also, if any of you know folks who own businesses, we do have sponsorship levels for business that allow them some marketing opportunities. Please contact us at nmwalk@sangredeoro.org if you can help us out there. Our Walk Call to Action (CTA) meeting will happen over dinner at Embassy Suites on March 15, so save the date for that!

We doubled the number community members attending our education weekend this past October! It was a fun weekend. My favorite session was the infusion session for adults, where our wonderful HTC nurses, Brie and Claudia, went over how to infuse, and then everyone practiced with Baycuffs. I put one photo from the kids' field trip to the zoo on this page (lower left) because it strikes me as the epitome of what the weekend is all about: have some fun, learn something new, and bond with our blood brothers and sisters and fellow caretakers. Of course, the additional attendance means that our costs doubled (to nearly $60K), so we need to earn a lot more on this year's Walk! This year's education weekend will be October 17–19 at Embassy Suites in Albuquerque. I hope I see you all there!

We also doubled the size of our board and quadrupled the number attending board meetings! Joe MacDonald has stepped down as VP, and Jose Guillen has taken his place. I want to send a special thanks out to Joe, without whom I'm not sure I would have survived the last year! We welcome Jose Duran as our new secretary and Jean Cole, Chris Fennicks, and Sarah Trawinski as new board members. We also thank Chuck Boberschmidt for his years of service on the board. He has stepped down but will continue to run our camp LIT program and participate on our advisory board.

We are getting office space! We will be asking everyone to pitch in with cleaning, painting, and a little bit of building. This will give us a place to gather—for board meetings, for events, as a community. Watch for events being held at our new digs, and if you have an event in mind, please e-mail me! I will do my best to make it happen!

Last year, Loretta and the HTC had several camp dinners where folks could come and learn about camp. Our next few dinners are March 24 in Roswell and March 25 in Albuquerque. Claudia is working hard to get all of the registration paperwork done at the camp dinners, so please do attend one if you can!

We are sending a New Mexico contingent to Washington Days this year: Robert and Melissa Farias, Jose Duran and Alyssah Leon, Patrick Cordova, and Cazandra MacDonald will all attend to represent us on Capitol Hill. Thanks for your support!

Last, but not least, we are hoping to become a Blood Brotherhood site! This will allow us (and provide some funding) to have adult events, especially for the men. (Don't worry, ladies! I'll make sure we have events too!)

I hope you are all having a wonderful 2014 so far. I hope I see you in March at the Walk CTA meeting or in May at the Walk itself!

Land Softly,

Lori Long, President

1980	1989	1990	2001	2002	~2004	2014
	Volunteer Operated					
First Organized	Incorporated	Received Non-Profit 501(c)3 status	Hired first Executive Director	Became NHF Chapter	Became HFA Member Organization	Looking at a Bright Future!

Go to www.hemophilia.org to apply for a scholarship to attend the 65th NHF Annual Meeting in Washington, DC, September 18–20. Scholarships are offered to first-time attendees, and this is a great conference. If you haven't attended, please apply!