Volume 23 • Spring 2016

The Bear Facts

The 2016 Hemophilia Walk and Car Show!

By Your Walk Committee

Greetings, men, women, and children of the New Mexico bleeding disorders community! Have you/your children ever been to Camp Sangre Valiente, our summer camp? I sure hope so. Have you and your family attended our Patient and Family Education Weekend or maybe an advocacy event? I think maybe I saw you there. Well, all these programs take a lot of time, effort, and money to put together. That's why your chapter, Sangre De Oro, Inc. (SDO) participates in the NHF Hemophilia Walk, to raise money and awareness for these programs.

This year's hemophilia walk will take place on April 16 at Balloon Fiesta Park in Albuquerque! We will have a Mardi Gras theme. This is the day that we ask all of our community and our family members to come out and support the bleeding disorders community of New Mexico. Not only do we want you to be there that day, but we want you to help us raise money and awareness along the way. Those of you who have had walk teams in the past, know what it's like. Any of you that haven't had a team before, it's time you joined up with one, or started one yourself. It's easy! Just go to www.walk.Hemophilia.org/Albuquerque. There, you will find all of the information you need to sign your team up on-line. Don't forget to tag all your family members or send them e-mails so they can sign up and join your team too. This will be a lot of fun for you and your family and all of your friends.

This year's walk will be followed by the 2016 Hemophilia Walk Car Show. We will have tons of cars, trucks, and motorcycles on display. There will also be celebrities, fun activities (such as a dunk tank), and plenty of food. So make plans to have a full day of fun, and have your friends who couldn't make the walk join you for a taco and soda at the car show!

Just a Reminder!

The 2016 Hemophilia Walk and Car Show

Saturday, April 16, 2016
Balloon Fiesta Park
Check-in begins at 9:00 a.m., and the Walk begins at 10:00 a.m.
Distance: 1-mile fun walk

Your Walk Committee

Maria Chavez, Walk Co-Chair

Felix Garcia, Walk Co-Chair

Carnie Abajian

Steve Calderon

Lori Long

Sophia Minhas

Gary Pennington

Sangre de Oro, Inc.

Now Available!

NUWIQ®

Antihemophilic Factor (Recombinant)

Want to Learn More?

Contact your
Octapharma Representative:

KEN WAGG

PHONE | 505-414-7173

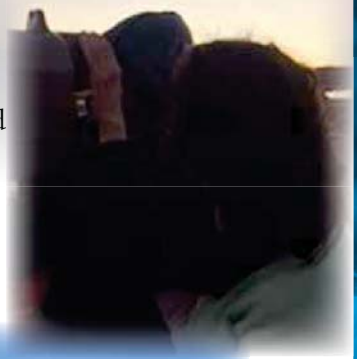
EMAIL | Kenneth.Wagg@octapharma.com

octapharma®
For the safe and optimal use of human proteins

Birds

by Roseannette Lopez

What does it take to create a tradition? I wondered this as I was taking my second trip to the Bosque De Apache with Heddy Long. The question seemed logical because that was the theme of my thought process with the holidays approaching. I wondered this as we as we pulled into the little gift shop and purchased a follow-along DVD. We stopped to see the bird count for the season. That's when I realized that this experience was more than just a "bird trip." There were nearly 20,000 ducks, 2,000 cranes, and 3,000 geese at the refuge. The magic of these birds hit me and gratitude of nature overwhelmed me. I went back to asking, "How do we become part of someone else's tradition?" I wondered this as we started on the road to circle the bird refuge. That is when the man on the audio tape explained that the refuge planned the feeding of all the birds for the entire year based on what they ate and their age. I was amazed at the detailed planning that it took to take care of these birds. As we followed the instructed direction to the next spot with a cluster of cranes the magic of bird watching reignited. I sat there taking in the moment. The birds danced around in a ceremony, hopping and flapping their wings. I have never seen so many birds in one area. The beauty of the birds was enhanced when I looked over at the beautiful Heddy, widow of Dick Long, a man with Hemophilia B, the smile on her face and excitement in her eyes made the experience of bird watching mystical.



Calendar of Events

February

25–27	Washington Days

March

	National Bleeding Disorder Awareness Month
3	Camp Dinner (Hobbs)
11	Camp Dinner (Albuquerque)
19	Blood Sisterhood Event (St. James Tea Room, 1:30 p.m.)
TBD	Board Meeting, 6 p.m., SDO Office
31–April 1	HFA Symposium in Las Vegas, NV

April

8	Camp Dinner (Albuquerque)
9	Infusion Camp (Albuquerque)
11–14	NHF Leadership Training, New Orleans, LA
15–18	Inhibitor Family Camp at The Painted Turtle, Lake Hughes, CA
16	The 4th Annual Hemophilia Walk of New Mexico, Balloon Fiesta Park
17	World Hemophilia Day
22	Camp Dinner (Santa Rosa)
23	Camp Dinner (Clovis)
24–25	MSHN Regional Meeting in Scottsdale, AZ

May

TBD	Board Meeting, 6 p.m., SDO Office
6	Camp Dinner (Grants)
7	Camp Dinner (Albuquerque)
10	Camp Dinner (Taos) (Tentative)

June

13	New Mexico Hemophilia Awareness Day
27–July2	Camp Sangre Valiente in Capitan, NM

July

TBD	Inhibitor Summit, Location TBD
TBD	Inhibitor Summit, Location TBD
TBD	Board Meeting, 6 p.m., SDO Office
16	Blood Brotherhood Event
21–26	NHF Annual Meeting/WHF, Orlando, FL
23	Blood Sisterhood Event

August

6	Caliente Classic Golf Tournament

September

TBD	Blood Brotherhood Event
TBD	Board Meeting (location TBD)

October

7–10	Inhibitor Camp at Victory Junction, Randleman, NC
21–24	Patient and Family Educational Weekend (Tentative, Location TBD)

November

TBD	Board Meeting, 6 p.m., SDO Office
TBD	Blood Sisterhood Event

December

3	Holiday Event (Tentative)

Getting in the Game

By Joe MacDonald

My youngest son competed in a golf tournament the weekend of October 23rd-25th. It was sponsored by C.S.L. Behring in Phoenix, Arizona. They did a wonderful job hosting the event, which was dedicated to the bleeding disorders community. Kids of all ages from all over the country were invited to attend. Each evening ended with a dinner and reception highlighting the achievements of the day. When all was said and done, my son won a special award for shooting his first shot closest to the hole! Pretty good considering that he had never played golf before this weekend.

The first night's festivities started with a parade of the 106 athletes competing in the competition. I did not tell my son where I was sitting in the room. Immediately, he looked around trying to find me. To him, my presence was that important. He didn't rest until we made eye contact. He stood in front of the room with complete security and pride. His daddy was there to witness all that would unfold.

I couldn't help but leave the weekend with a feeling of gratitude. The C.S.L. Reps and professional players went out of their way to make the event special and unique to each participant. I made new friends with fathers from around the country, each of us share a common story of what it is like doing the best that we can to empower our children. All of us came to the event with a mutual reason, to give our kids space to dream.

I highly recommend this event to anyone in the community. Take the challenge to learn, compete, and have a good time. You will be glad to take the time to spend with your child. It is truly a life changing experience. Go ahead, I dare you. Get in the game!

Get in the Game!

Sophie's World

By Sophia Minhas

I ask myself, "Who was I? Who am I? And who will I be?" I was Faiza, born and raised in Lahore, Pakistan. I lived with a joint family: my mom, dad, brothers (Asad, Haider, and Fahad), and sisters (Ayesha, Aleena, and Alizay), Uncle Layaqat, his wife Nasreen, second wife Uzma and their daughter Manahil. Uncle Aslam, Auntie Saeeda, and her son Badar, and Auntie Naseem. Life wasn't easy in Pakistan. I had learned that lesson at the age of 11 when I saw my father suffer from multiple health conditions, money worries, and stress. He was sick for 3 years before his body completely gave up and he passed away in December of 2003.

A few weeks after losing my father I found out two of my brothers might be getting adopted by my Uncle Shaan, Sr. and Aunt Colleen (and their kids Shaan, Jr., Kaitlin, and Megan). Then I heard that my sister and I would be going also. All four of us were adopted by my uncle and aunt who became our mom and dad in July 2004 and we all four of us moved to Dallas, Texas to become part of the family. I remember going to W. T. White High School and people having hard time saying our names properly. So then we talked to our parents and they suggested changing our names to ones that will work in both Urdu and English. It was a tough decision but we all changed our names: Rayn (Asad), Adam (Haider), Jasmine (Alizay), Sophia (Faiza).

After being in the USA for a year, Rayn was diagnosed with a genetic bleeding disorder called Factor VII deficiency. After doctors confirmed his diagnosis, they tested Adam, Jasmine, and me for it also. Jasmine's and Adam's levels were borderline for the bleeding disorder, and I was mild. That was the last time time I really thought much about bleeding disorders, though I remembered to carry bandages with me in case of an emergency. As time passed, I became more interested in knowing how this condition would affect me in the long run. That was when I reconnected with SDO almost 4 years ago. I knew about SDO from getting newsletters and event invitations, and I was curious to find out about it. So I contacted SDO and spoke to Loretta who mentioned the camp for kids. She invited me to a camp dinner. My family and I attended the dinner and listened to people talk about how wonderful the camp is. Seeing pictures and video sold the older two kids and had them super excited about going. At first I thought, "Hey, I'm the one with bleeding disorder. How is this camp going to help me?" But now, when reminding them to be careful about my bleeding episodes, they understood what's happening and why. So I am thankful that they went. SDO has provided me and family with knowledge, skills, confidence, strength, and a belief that I matter. Before SDO, I didn't know much about my bleeding disorder. all I knew was no ibuprofen or Aleve for me. But with the education and multiple opportunities to learn more about hemophilia, I now can say I know what Factor VII hemophilia is and how I should treat it. I am more confident about my treatment, aware of my bleeds, and not afraid to ask for help if I'm in need. SDO also helped my family and myself financially at times when I was unable to take care of us. I am thankful for what my curiosity gave me: a family I never knew anything about. Thanks to all the support from SDO, I am a proud to be a hemophiliac!—A hemophiliac whose curiosity led her to be a Secretary of SDO and to volunteer any chance I get. I became an HFA board member this year, joined theCultural Diversity Working Group through NHF, and was asked to be the NM Ambassador for the Women's Bleeding Disorder Coalition.

I know after searching for my identity so long that I'm a mom, daughter, friend, sister, and hemophiliac, and in plain words, I'm Sophie. And this is my crazy long adventure in a short story.

COMING SOON

KOVALTRY™

Antihemophilic factor (recombinant)

Register for updates at
www.KOVALTRY.com

2015 Patient and Family Education Weekend

Continued on Page 16.

Ted R. Montoya Hemophilia Treatment Center

by Claudia MacKaron

We have had some changes at the HTC. Here is our new team!

Dr. Shirley Abraham

Dr. Abraham was born and raised in Kuwait. She received her medical school degree in India; did her pediatric residency in Long Island, New York; and did her pediatric hematology/oncology fellowship at Primary Children's Medical Center, Salt Lake City, Utah. Her husband is also a physician, and they have a 9-year-old daughter and a 5-year-old son. When Dr. Abraham has time, she enjoys cooking, reading, and painting.

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

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

Claudia MacKaron

I have been a nurse for over 20 years, primarily practicing in the acute care and oncology setting within the pediatric department at UNMH. Six years ago I was given the opportunity to move into hematology by working with the HTC at UNMH. Since then I have been assigned to be the Nurse Coordinator at the HTC. It has been a great pleasure to work at the HTC, learning daily about the world of bleeding disorders and getting to know the patients and their wonderful families. I have an admiration for the community and all their courage in facing their trials daily. I have a passion for teaching and helping others to have a better quality of life. My own passions are my family (my eight grandchildren), my dogs, and horses. I love to travel and explore new worlds and foods. Experience life to the fullest.

Yolanda Vinajeras

I am Yolanda Vinajeras, the supervising Sr. Social Worker in the Hematology/Oncology Program. I hold a master's degree in Social Work and have been with the program for the past 25 years. I have enjoyed getting to know the hemophilia community and enjoy working with the pediatric patients and their siblings in the camp environment.

My case manager, Bradley Knopp, is hard at work identifying resources offered by the various pharmaceutical companies for the adult and pediatric community. The social work component is an integral part of the HTC and works closely with the nurses and the physicians.

Bradley Knopp

My name is Bradley Knopp. I am the Pediatric Hematology/Oncology Case Manager at UNM Children's Hospital. I provide patients with comprehensive case management services, including intake assessment, benefit assessment, goal setting, long-term care plan development, progress monitoring, financial help, tenant education, advocacy, and referrals. I work closely with SDO in supplying help with resources if needed.

Kristel Wintheiser

I have been the Nurse Manager for the Pediatric Hematology/Oncology Division at UNMH for more than 3 years. You may have already talked with me on the phones at the HTC or seen me in clinic as I cover as needed for our hematology nurses, Valerie and Claudia. I have attended NHF several times along with Partners in Bleeding in my journey of understanding the community and the disease process. I graduated with my Bachelors degree in nursing over 22 years ago from Texas Women's University in Dallas.

I love spending time with my family of 8 and traveling around the world.

Valerie Lowe

I have been a nurse for 16 years and have worked with the HTC since October 2015. Prior to joining the HTC, I worked in the Newborn ICU and Pediatric Clinic. I received my Masters of Science in Nursing with an emphasis in nursing education. I love being a nurse and I am excited to be a part of the HTC medical team. In my free time, I love to spend time with family, read, and travel!

Milena Archuleta

I received a Bachelors of Science in Nursing from UNM in 2006. Upon graduation, I worked at UNMH's department

Continued on Page 14.

HTC Contacts

HTC appointments and nurse line for adult and pediatric patients: 505-272-4461
Ask for the hematology nurse (Valerie, Janet, or Claudia)

Adult and pediatric patients after hours (5 p.m.–8 a.m.): 505-272-2111
Hospital operator, ask for adult or pediatric hematologist

Adult pain medication refill/prescription: 505-925-0290

Cancer Center (adults): 505-272-4946

It is best to call the HTC nurses, and they can help you out.

Half the volume
Twice the factor*

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

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

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

Isn't it time you tried ALPHANATE?

Learn more at **alphanate.com**

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

Indications

ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) is indicated for:

- Control and prevention of bleeding in patients with hemophilia A
- Surgical and/or invasive procedures in adult and pediatric patients with von Willebrand disease (VWD) in whom desmopressin (DDAVP®) is either ineffective or contraindicated. It is not indicated for patients with severe VWD (Type 3) undergoing major surgery

Important Safety Information

ALPHANATE is contraindicated in patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components.

Anaphylaxis and severe hypersensitivity reactions are possible. Should symptoms occur, treatment with ALPHANATE should be discontinued, and emergency treatment should be sought.

Development of activity-neutralizing antibodies has been detected in patients receiving FVIII containing products. Development of alloantibodies to VWF in Type 3 von Willebrand disease (VWD) patients has been occasionally reported in the literature.

Thromboembolic events may be associated with AHF/VWF Complex (Human) in VWD patients, especially in the setting of known risk factors.

Intravascular hemolysis may be associated with infusion of massive doses of AHF/VWF Complex (Human).

Rapid administration of a FVIII concentrate may result in vasomotor reactions.

Plasma products carry a risk of transmitting infectious agents, such as viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, despite steps designed to reduce this risk.

The most frequent adverse events reported with ALPHANATE in >5% of patients are respiratory distress, pruritus, rash, urticaria, face edema, paresthesia, pain, fever, chills, joint pain, and fatigue.

Please see brief summary of ALPHANATE full Prescribing Information on adjacent page.

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

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

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

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

GRIFOLS

ALPHANATE®

Antihemophilic Factor/von Willebrand Factor Complex (Human)

HIGHLIGHTS OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use Alphanate safely and effectively. See full prescribing information for Alphanate.

ALPHANATE (ANTIHEMOPHILIC FACTOR/VON WILLEBRAND FACTOR COMPLEX [HUMAN])

Sterile, lyophilized powder for injection.

Initial U.S. Approval: 1978

----------INDICATIONS AND USAGE ----------

Alphanate is an Antihemophilic Factor/von Willebrand Factor Complex (Human) indicated for:

- Control and prevention of bleeding in patients with hemophilia A.
- Surgical and/or invasive procedures in adult and pediatric patients with von Willebrand Disease in whom desmopressin (DDAVP) is either ineffective or contraindicated. It is not indicated for patients with severe VWD (Type 3) undergoing major surgery.

----------DOSAGE AND ADMINISTRATION ----------

For Intravenous use only.

Alphanate contains the labeled amount of Factor VIII expressed in International Units (IU) FVIII/vial and von Willebrand Factor:Ristocetin Cofactor activity in IU VWF:RCo/vial.

Hemophilia A: Control and prevention of bleeding episodes

- Dose (units) = body weight (kg) x desired FVIII rise (IU/dL or % of normal) x 0.5 (IU/kg per IU/dL).
- Frequency of intravenous injection of the reconstituted product is determined by the type of bleeding episode and the recommendation of the treating physician.

von Willebrand Disease: Surgical and/or invasive procedure in adult and pediatric patients except Type 3 undergoing major surgery

- Adults: Pre-operative dose of 60 IU VWF:RCo/kg body weight; subsequent doses of 40-60 IU VWF:RCo/kg body weight at 8-12 hour intervals post-operative as clinically needed.
- Pediatric: Pre-operative dose of 75 IU VWF:RCo/kg body weight; subsequent doses of 50-75 IU VWF:RCo/kg body weight at 8-12 hour intervals post-operative as clinically needed.

----------DOSAGE FORMS AND STRENGTHS ----------

- Alphanate is a sterile, lyophilized powder for intravenous injection after reconstitution, available as 250, 500, 1000, 1500 and 2000 IU FVIII in single dose vials.

----------CONTRAINDICATIONS ----------

- Patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components.

----------WARNINGS AND PRECAUTIONS ----------

- Anaphylaxis and severe hypersensitivity reactions are possible. Should symptoms occur, treatment with Alphanate should be discontinued, and emergency treatment should be sought.
- Development of activity-neutralizing antibodies has been detected in patients receiving FVIII containing products. Development of alloantibodies to VWF in Type 3 VWD patients has been occasionally reported in the literature.
- Thromboembolic events may be associated with AHF/VWF Complex (Human) in VWD patients, especially in the setting of known risk factors.
- Intravascular hemolysis may be associated with infusion of massive doses of AHF/VWF Complex (Human).
- Rapid administration of a FVIII concentrate may result in vasomotor reactions.
- Plasma products carry a risk of transmitting infectious agents, such as viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, despite steps designed to reduce this risk.

----------ADVERSE REACTIONS----------

The most frequent adverse events reported with Alphanate in > 5% of patients are respiratory distress, pruritus, rash, urticaria, face edema, paresthesia, pain, fever, chills, joint pain and fatigue.

To report SUSPECTED ADVERSE REACTIONS, contact Grifols Biologicals Inc. at 1-888-GRIFOLS (1-888-474-3657) or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

----------USE IN SPECIFIC POPULATIONS----------

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

GRIFOLS

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

3041048-BS
Revised: 06/2014

2016 Walk Call to Action Dinner

Continued on Page 17.

Ted R. Montoya Hemophilia Treatment Center

of Cardiothoracic Sub-Acute Care for 6 years. I completed my Masters of Business Administration in 2010 from New Mexico Highlands University and Masters of Science in Nursing from the UNM in 2012. My background as a nurse practitioner has been in primary care and internal medicine. As a primary care provider, I worked with an underserved population in New Mexico in a federally funded health care clinic where I was also a member of the National Health Service Corp. I was fortunate to return to UNM in September 2015 with the department of Pediatric Hematology/Oncology, working with the HTC.

Genevieve Maldonado

I have been a Medical Assistant for about 9 years now. I first started in women's health for 5 years and then moved to the UNMH Pediatric clinic 3 years ago. I fell in love with pediatrics and I knew it was something that I wanted to do for a long time. When opportunity came knocking, I took a position as the first Medical Assistant for the Hematology/Oncology Department. I have been working with the HTC for about a year now, and I love it. I have learned so much by being part of a wonderful team. That is why I am continuing my education to become a nurse hopefully for Pediatric Hematology/Oncology team here at UNMH.

Janet Ratte

I am a nurse with more than 25 years of experience, 20 of which have been in the pediatric NBICU at UNMH. I have many years of experience working with the critical care neonatal patients and their families, teaching and coordinating their care. I love to teach, nurture, and care for my patients and families. In the coming months, I hope to meet you at community events and get to know the bleeding disorders community better.

Researchers Make Gene Therapy Breakthrough in Dogs with Factor VII Deficiency

In a recently published paper in the journal *Blood*, a team of researchers from the University of North Carolina (UNC) and The Children's Hospital of Philadelphia (CHOP) reported the successful application of gene therapy in dogs with factor VII (FVII) deficiency. This represents a significant advance, demonstrating the safety and efficacy of a novel therapy in large animal studies is a standard precursor to eventual clinical trials in humans.

FVII deficiency is a rare bleeding disorder with an incidence of 1 in 300,000 to 500,000, as both parents need to carry the gene in order to pass it on to their children. The condition, which affects men and women equally, is characterized by inadequate production of the FVII clotting protein. Babies are often diagnosed within the first six months of life after sustaining an intracranial hemorrhage or bleeding in the gastrointestinal tract. People with the more severe form of FVII deficiency often experience joint and muscle bleeds, easy bruising and bleeds after surgery. Bleeding can also occur in the skin, mouth, nose and genitourinary tract, while women often experience severe menorrhagia (prolonged, heavy periods). The primary treatment for FVII deficiency is recombinant factor VIIa.

The study, "Sustained Correction of FVII Deficiency in Dogs Using AAV-Mediated Expression of Zymogen FVII," was published in the February 4, 2016 issue of Blood. The senior investigator was Paris Margaritis, D.Phil., head researcher at CHOP and Penn's Perelman School of Medicine. Leading the UNC team was Tim Nichols, MD, professor of medicine and pathology at the UNC School of Medicine.

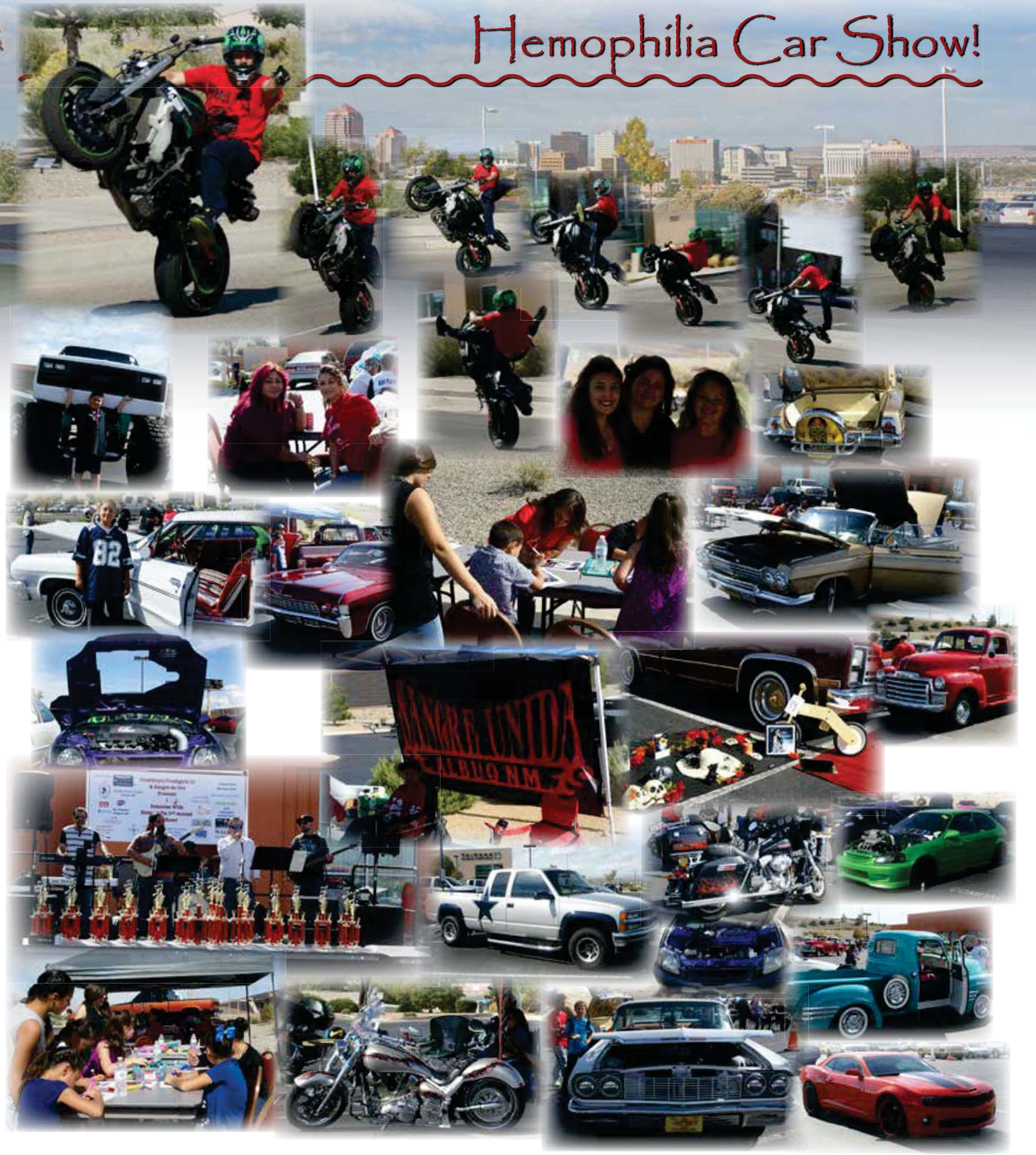
For the study, Margaritis cloned the canine factor VII gene and enclosed that genetic material inside adeno-associated viruses (AAVs). These viruses act as delivery vehicles, or vectors, to carry the genetic material into living cells to sustain therapeutic effect without causing disease or triggering significant immune responses. In this case, the AAVs are designed to elicit the production of the FVII. Nichols and his colleagues then treated four FVII deficient dogs with a single injection of the therapy, administering different amounts of AAVs in each of the animals.

They found that the amount of factor VII generated was directly proportional to the amount of AAVs given to the individual dogs. Nichols's team also monitored the dogs' progress over a period of three years and found that they all produced FVII levels that were sufficiently therapeutic – this is particularly encouraging for investigators as the amount of FVII necessary to achieve a sustained therapeutic effect in dogs correlates closely to that for humans. "This work is very exciting and promising," said Nichols. "The FVII-deficient dogs tolerated the initial gene therapy infusions very well and have had no adverse side effects over several years of follow up. In other related studies in dogs with hemophilia B (FIX), similar positive findings have translated to people with hemophilia B."

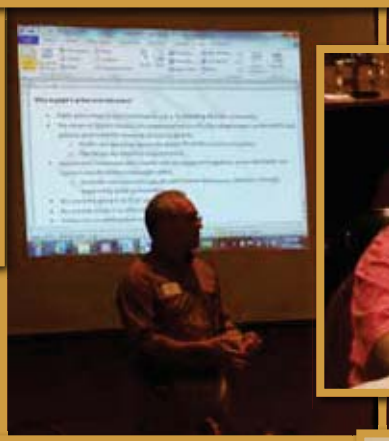
In addition, blood, kidney and liver function tests all showed that therapy was safe and did not trigger an unwanted immune response. The next step will be to conduct clinical trials in humans. "The table is now set to propose clinical trials that would treat people who suffer from FVII deficiency," concluded Nichols.

Source: *UNC Health Care news release dated January 20, 2016.*

2nd Annual I Love Someone with Hemophilia Car Show!



MORE 2016 Patient and Family Education Weekend



2016 Walk Call to Action Dinner












13th Annual Camp Sangre Valiente

By Roseannette Lopez, Camp Director

Camp Sangre Valiente 2016 will be held June 27th through July 2nd!

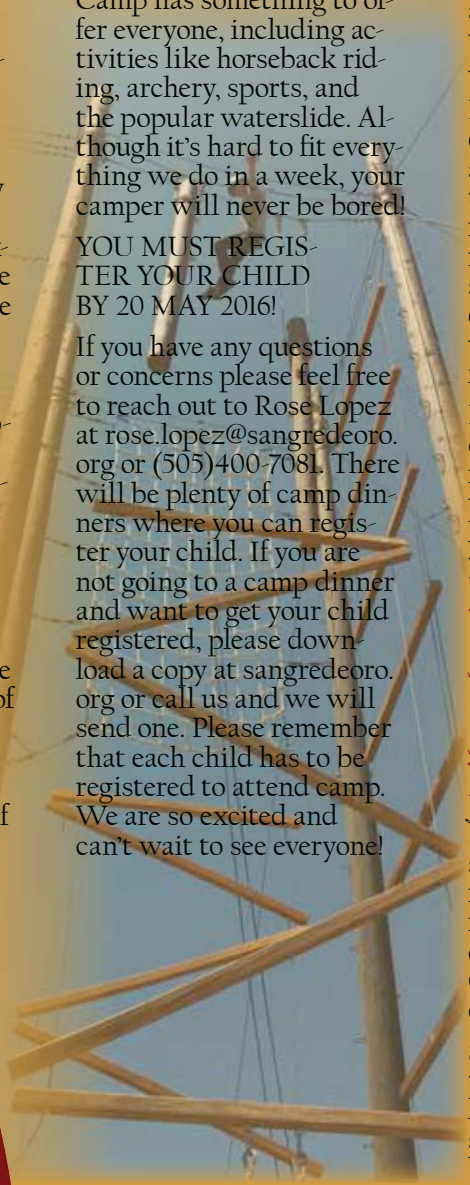
Another great summer of camp is almost here, and our camp committee and the wonderful team at Camp Sangre Valiente are very excited to welcome the kids back to what we think is going to be a great year! This year's theme is Star Wars so remember to bring anything you have that has Star Wars on it. As we eagerly prepare for this year's camp, we want to remind our families what our camp is all about.

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

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

YOU MUST REGISTER YOUR CHILD BY 20 MAY 2016!

If you have any questions or concerns please feel free to reach out to Rose Lopez at rose.lopez@sangredeoro.org or (505)400-7081. There will be plenty of camp dinners where you can register your child. If you are not going to a camp dinner and want to get your child registered, please download a copy at sangredeoro.org or call us and we will send one. Please remember that each child has to be registered to attend camp. We are so excited and can't wait to see everyone!



Executive Board Members

Jessica Hernandez, President

Jose Duran, Vice President 1

Eric Marquez, Vice President 2

Sophia Minhas, Secretary

Carnie Abajian, Treasurer

Lori Long, Past President (Non-Voting)

Johanna Chappelle, Past President (Non-Voting)

Board Members

Maria Chavez

Gary Louis DeSoto

Gary Pennington

Carlos Sanchez

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

Dear Community,

Well, my term as your president is over, and I hope you have been pleased with the direction in which I've moved SDO. It has been a humbling learning experience, and I feel more a part of the SDO family than ever before.

I have had good moments and bad moments. Seeing my blood brothers in those infusion sessions filled my heart with joy! But saying good-bye to Loretta Cordova and Ute Fennicks broke it. Watching my blood sisters support each other out there in the world filled it with joy again. Watching the kids come back from camp, filthy, grimy, and ridiculously happy... well, that's priceless.

You won't miss me because I'll still be around. I'm still doing the newsletter. I'm still on the Walk Committee. And I will be chairing the Governance Committee. Of course, I will still plan education weekend for you. I'm hoping we can head north to Buffalo Thunder this year!

I am very impressed with our new board. They are going to do great things for us! I figured I'd give you the low-down on them in case you don't know them yet.

Your new President: Jessica Hernandez (who prefers to be called Jess or Jessie).

Jess is not affected by a bleeding disorder (though she does have a cousin with hemophilia). She is a local business owner who has supported our Caliente Classic golf fundraiser for many years.

She joined our board at the beginning of 2015. Her leadership is fantastic, and she has shown herself to be smart, level-headed,

(Past) President's Corner

and creative at problem-solving. She has a fabulous sense of humor to boot. In other words, she's "all that and a box of chocolates."

If you haven't met her yet, you will at an upcoming event. I hope you welcome her with open arms and an open heart. She is an incredible person, and you will be better for knowing her.

Jose Duran, Vice President 1

Jose has been with us since 2014. He has served as both board Secretary and Vice President. He is our IT specialist, and in addition to getting the Blood Brotherhood going, he got our office hooked up with computers, Internet, and phone service. He was also instrumental in preparing the office to function, helping with flooring, demolition, and painting.

Eric Marquez, Vice President 2

Eric has been with us for more than 5 years and has served as both Treasurer and Vice President. Although he is quiet, he is also incredibly smart. When he speaks, I always pay attention because he is usually bringing us all back to the point and reminding us what is important.

Carnie Abajian, Treasurer

Carnie has been with the advisory board for 3 years and joined the board in 2015. She has also served as Walk Manager and Treasurer. She has been instrumental in getting our finance policies and procedures up and running. Carnie is the one to always ask the hard questions. She keeps us honest!

Sophia Minhas, Secretary

Sophia is our blood sister. She has been on our board for 2 years and served as Secretary. She volunteers in several capacities and has represented us at the national level with HFA, NHF, and the Women with Bleeding Disorders Coalition.

Maria Chavez, Board Member

Maria joined the board in 2014. My first memory of Maria is that she said she wanted to "help" with getting raffle items for Golf. I figured any help would be great. She went out and got us more raffle items in less than a week than we had all been able to get combined! I was astounded! I never cease to be amazed at Maria's incredible energy and willingness to serve!

Gary Louis DeSoto, Board Member

I've known Gary Louis for years. Gary is always willing to laugh and is great at keeping the mood light. He is also a business owner and brings us business process expertise. Gary Louis was elected to the board this past January. I look forward to seeing what he can do!

Gary Pennington, Board Member

I met Gary at a dinner program back in 2013. I am so grateful he chose to get involved and support SDO! He joined the board in 2015. Along with advising us on parliamentary procedure, Gary always seems to be there when something needs doing. He volunteers frequently and works very hard the whole time at any task asked of him. I am so glad he has chosen to join our family!

Carlos Sanchez, Board Member

Carlos joined our board in January. I have found him to be intelligent, practical, and creative. His budget and finance experience will be invaluable to us as we build our business.

In 2013, the board set out to develop in number and diversity. We now have blood brothers, blood sisters, hemo parents, and unaffected community members on our board. We also have business owners, a PhD, a budget and finance expert, an IT expert, an auditor/investigator, and a carpenter. We have gone from having 5 board members to having 9 or 10 consistently for the last few years. I'd say we met our goal. I can't wait to see what's in store for SDO!

I look forward to seeing you all at the next event!

Land Softly,

Lori Long, Past President

Go to www.hemophilia.org to apply for a scholarship to attend the 68th NHF Annual Meeting in Orlando, FL, July 21–23. Scholarships are offered to first-time attendees (and some others), and this is a great conference. If you haven't attended, please apply!

Meet Your Hemophilia Community Specialist

Your HCS is a valuable resource to help you manage life with hemophilia. Whether you need information about living with hemophilia, Novo Nordisk products, or financial assistance and reimbursement programs, Jessica is there to help. Arrange a one-on-one meeting today!

Jessica Steed

JCSD@novonordisk.com
602-615-6974
ChangingPossibilities-US.com

About Jessica

Jessica is a community builder who believes that connecting with people, creating communities, and advocating for important causes is the key to her mission as an HCS.

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

novo nordisk®

FDA Approves Octapharma's NUWIQ® for the Treatment of Adults and Children with Hemophilia A

NUWIQ® is the first B-domain deleted recombinant Factor VIII derived from a human cell-line, not chemically modified or fused with another protein, designed for the treatment of patients with Hemophilia A

HOBOKEN, N.J. (September 15, 2015) – Octapharma USA today announced the U.S. Food and Drug Administration (FDA) has approved NUWIQ®, Antihemophilic Factor (Recombinant), an intravenous therapy for adults and children living with Hemophilia A. The NUWIQ® approval includes on-demand treatment and control of bleeding episodes; routine prophylaxis to reduce the frequency of bleeding episodes; and perioperative management of bleeding.

NUWIQ® is the first B-domain deleted recombinant Factor VIII (FVIII) derived from a human cell-line, not chemically modified or fused with another protein, designed for the treatment of patients with Hemophilia A, congenital FVIII deficiency. Hemophilia A impacts the lives of up to 16,000 individuals in the U.S. and their caregivers. Although present therapies for Hemophilia A treatment exist in the U.S., significant challenges still remain, including development of inhibitors and the need for multiple infusions on a prophylactic basis. Octapharma USA is a subsidiary of global human protein products manufacturer Octapharma AG, which develops and manufactures high-purity recombinant and plasma-derived coagulation factor concentrates for patients with bleeding disorders.

"Octapharma has been committed to the bleeding disorders community for many years and its decade-long drive to find solutions for Hemophilia A challenges has never wavered," said Octapharma USA President Flemming Nielsen. "Early development strategies were integral in the development of NUWIQ® and these initial goals have been realized with the FDA approval. NUWIQ® has demonstrated safety and efficacy in global clinical trials and has the potential to positively impact patients' quality of life in the years ahead. Octapharma is dedicated to providing life enhancing and saving therapies for Hemophilia A and looks forward to bringing NUWIQ® to the U.S. marketplace."

The European Commission first approved the therapy in August 2014. NUWIQ® is currently approved in many countries, including the United Kingdom, Australia, Canada, Germany, Italy, Sweden and Argentina.

"We are pleased that the treatment options for adults and children with Hemophilia A continue to advance with ever more innovative therapies being approved for the U.S.," said Val Bias, chief executive officer of the National Hemophilia Foundation (NHF). "The continued commitment to develop life-enhancing products for the bleeding disorders community is absolutely vital. Empowering patients and providers with treatment options, as well as education and support programs, is extremely important to people living with Hemophilia A."

The initial global clinical study program for NUWIQ® commenced with a pharmacokinetic (PK) evaluation in an open-label, multi-center clinical trial of 22 (20 adults, 2 adolescents) previously treated patients (PTPs). In this study, NUWIQ® demonstrated a mean half-life of 17.1 hours using a one-stage clotting assay in adults. NUWIQ® was also evaluated in children using a one-stage clotting assay with a mean half-life of 11.9 hours for ages 2 to 5; and a mean half-life of 13.1 hours for ages 6 to 12. These PK results for mean half-life were longer than earlier generations of recombinant FVIII products currently available in the U.S.

The second set of global clinical studies for NUWIQ® also evaluated overall efficacy and tolerability in three prospective, open-label clinical studies in PTPs with severe Hemophilia A. Across all clinical studies, a total of 135 patients with Hemophilia A were treated with NUWIQ®, including 74 adults, 3 adolescents between ages 12 and 17, and 58 pediatric patients between ages 2 and 11. These 135 patients were treated with a total of 16,134 infusions over 15,950 exposure days using NUWIQ®.

In a study of 32 adults, overall prophylactic efficacy of NUWIQ® for spontaneous bleeds was rated as excellent or good in 92% of patients. In a study of 59 children, prophylactic efficacy for spontaneous bleeds was rated as excellent or good in 97% of patients. The mean annualized bleeding rates (ABR) for spontaneous bleeds during prophylaxis were approximately 1.5 in children and 1.2 in adults. For Hemophilia A patients receiving NUWIQ® prophylaxis compared to on-demand treatment, the ABR was reduced 96% for adults and 93% for children. Treatment of breakthrough bleeds during NUWIQ® prophylaxis was rated as excellent or good in 30 of 30 (100%) bleeds in adults and for 89 of 108 (82%) bleeds in children. For on-demand treatment with NUWIQ® in 20 adults and 2 adolescents, efficacy for the treatment of bleeds was excellent or good in 931 of 986 (94%) bleeds. Overall efficacy in surgical prophylaxis was rated excellent or good in 32 of 33 (97%) procedures using NUWIQ®.1

In all clinical studies, NUWIQ® had a total of 7 reported adverse events. Each of these adverse events occurred one time with a rate of 0.7% across all 135 patients. These events were parathesia, headache, injection site inflammation, injection site pain, back pain, vertigo, and dry mouth.

As part of its continuing commitment to the bleeding disorders community, Octapharma USA will offer Hemophilia A patients educational and support services in connection with the introduction of NUWIQ®. Octapharma USA aims to have NUWIQ® available in the U.S. marketplace by early 2016.

About NUWIQ®

NUWIQ®, Antihemophilic Factor (Recombinant) Lyophilized Powder

Continued on Page 23.

Be Part of HFA's Advocacy Team!

By Katie Verb, JD
HFA Government Relations and Policy Director

Two summers ago, HFA launched an internship program based in its Washington, DC office for young adults interested in advocacy, policy, and government relations. Opportunities for young people to become involved abound within the bleeding disorders community. At HFA however, we are specifically seeking to develop a passion in individuals for health care policy and self-advocacy, so that they return home committed to continuing their advocacy leadership.

Advocacy is at the core of HFA's mission and we strive to educate our future leaders about the issues that affect our community. We want our interns to follow along the path of the many advocates who came before them and accomplished amazing things, like securing the passage of the Ricky Ray Hemophilia Relief Fund Act or successfully working with the FDA to implement procedures that greatly improved the safety of the blood supply. Our intern program truly speaks to one of the main adages of HFA: "Honoring Our Past, Building Our Future!"

Last summer, two members of the bleeding disorders community spent 10 weeks at the HFA office in Washington, DC participating in, and contributing to, all of the efforts of our policy and government relations team. Specifically, the interns:

- Received legislative, policy, and advocacy training.
- Built communication and media skills.
- Attended congressional hearings and made visits to offices on Capitol Hill.
- Collaborated on activities with partners and coalitions including the National Organization for Rare Disorders (NORD), American Plasma Users Coalition (APLUS), Coalition for Accessible Treatment (CAT), and Plasma Protein Therapeutics Association (PPTA).
- Authored at least one policy work paper or issue brief.
- Supported staff on activities including HFA's advocacy blog Dear Addy, Action Alerts, and social media outreach.
- Assisted a local member organization in planning their 2016 legislative day.
- Assisted a local member organization in reading and analyzing state legislation.
- Gained valuable exposure to the workings of state and federal government.
- Developed a comprehensive understanding of HFA's programming and services, and how it serves the national bleeding disorders community.
- Improved skills, knowledge, and abilities in order to participate actively in the public policy process.

Over the past two years, we have been delighted to have had four remarkable interns and are currently looking for two young adults to participate in the 2016 program which runs from June 2016 to August 2016. If you know of any current or recently graduated college students who are community members and have an interest in health advocacy, please encourage them to apply!

SUMMER INTERNSHIP

Apply for our summer advocacy and government relations internship!

DEADLINE MARCH 15

Apply today at **www.hemophiliafed.org**

HFA Hemophilia Federation of America

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

for Solution for Intravenous Injection is a recombinant antihemophilic factor [blood coagulation factor VIII (Factor VIII)] indicated in adults and children with Hemophilia A for on-demand treatment and control of bleeding episodes; perioperative management of bleeding; and routine prophylaxis to reduce the frequency of bleeding episodes. NUWIQ® is not indicated for the treatment of von Willebrand Disease.

Important Safety Information

NUWIQ® is contraindicated in patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components. Hypersensitivity reactions, including anaphylaxis, are possible. Should symptoms occur, discontinue NUWIQ® and administer appropriate treatment. Development of Factor VIII neutralizing antibodies (inhibitors) may occur. If expected plasma Factor VIII activity levels are not attained, or if bleeding is not controlled with an appropriate dose, perform an assay that measures Factor VIII inhibitor concentration. Monitor all patients for Factor VIII activity and development of Factor VIII inhibitor antibodies.

The most frequently occurring adverse reactions (0.7%) in clinical trials were paresthesia, headache, injection site inflammation, injection site pain, non-neutralizing anti-Factor VIII antibody formation, back pain, vertigo, and dry mouth. For full prescribing information on NUWIQ® please visit www.octapharmausa.com.

About the Octapharma Group

Headquartered in Lachen, Switzerland, Octapharma is one of the largest human protein products manufacturers in the world and has been committed to patient care and medical innovation since 1983. Its core business is the development and production of human proteins from human plasma and human cell-lines. Octapharma employs approximately 6,000 people worldwide to support the treatment of patients in over 100 countries with products across the following therapeutic areas: Hematology (coagulation disorders), Immunotherapy (immune disorders) and Critical Care. The company's American subsidiary, Octapharma USA, is located in Hoboken, N.J. Octapharma operates two state-of-the-art production sites licensed by the U.S. Food and Drug Administration (FDA), providing a high level of production flexibility. For more information, please visit www.octapharmausa.com.

REFERENCES

1 – Octapharma, Data on file. 2015.

Forward-looking Statements

This news release contains forward-looking statements, which include known and unknown risks, uncertainties, and other factors not under the company's control. The company assumes no liability whatsoever to update these forward-looking statements or to conform them to future events or developments. These factors include results of current or pending research and development activities and action by the FDA or other regulatory authorities.

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.

xyntha®

Antihemophilic Factor (Recombinant)

xyntha® solofuse®

Antihemophilic Factor (Recombinant)

℞ only

Brief Summary

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

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

What is XYNTHA?

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

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

What should I tell my healthcare provider before using XYNTHA?

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

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

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

How should I infuse XYNTHA?

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

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

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

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

What are the possible side effects of XYNTHA?

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

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

Common side effects of XYNTHA are

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

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

How should I store XYNTHA?

Do not freeze.

Protect from light.

XYNTHA Vials

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

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

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

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

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

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

XYNTHA SOLOFUSE

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

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

Throw away any unused XYNTHA SOLOFUSE after the expiration date.

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

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

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

What else should I know about XYNTHA?

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

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

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

Skilled Pharmacists.
Experienced Infusion Nurses.
Dedicated Patient Experience Team.

Soleo Health provides a team approach to bleeding disorder therapy management. To learn more about programs in New Mexico, call **Edmund Merino** at **866.665.1121**

www.soleohealth.com

Consumer Assistance Program

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

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

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

...for the human factor®

At Accredo, we believe the more you know about your condition and available options, the better. We provide educational materials and a team of dedicated professionals. We're here to help you make informed decisions about your care.

A personal touch from people who know bleeding disorders.

Bonnie Webb | 801.598.1260
bonnie.webb@accredohealth.com

accredo®
Specialty Pharmacy

Ready to help you **define your IXperience™**

Your IXINITY® Product Specialist, Steve Calderon

"I am honored to connect with and motivate the future leaders of my community. It is my goal to show every member of this community that they are not alone."

— Steve Calderon

Let's talk about IXINITY and how you can get the most out of Emergent-sponsored programs, including the **Generation IX Project** and the **B More™ Scholarship Program**.

Contact Steve at 214.886.4035 or calderons@ebsi.com

emergent biosolutions®

IXINITY.com

IXINITY® coagulation factor IX (recombinant)

Baxter Initiates Voluntary Recall of Two Lots of IV Solutions due to Potential Presence of Particulate Matter

By U.S. Food and Drug Administration

Deerfield, Ill. - Baxter International Inc. announced today it is voluntarily recalling two lots of intravenous (IV) solutions to the hospital/end user level due to the potential presence of particulate matter. The particulate matter in each case was determined to be an insect and was identified as a result of a customer complaint. The matter was identified prior to patient administration and there have been no adverse events associated with this issue reported to Baxter to date.

Injecting a product containing particulate matter, in the absence of in-line filtration, may result in blockage of blood vessels, which can result in stroke, heart attack or damage to other organs such as the kidney or liver. There is also the possibility of allergic reactions, local irritation and inflammation in tissues and organs.

This recall affects the lots in the table below.

0.9% Sodium Chloride Injection, USP, 250 mL VIAFLEX Plastic Container is intended for IV use as a source of water and electrolytes and may also be used as a primary solution in hemodialysis procedures. 70% Dextrose Injection (2000 mL) USP is indicated as a source of calories and waterfor hydration.

The lots being recalled were distributed to customers and distributors in the United States between June 6, 2015 and December 16, 2015. Baxter is directing customers not to use the product from the recalled lots. Recalled product should be returned to Baxter for credit by contacting Baxter Healthcare Center for Service at 1-888-229-0001, Monday through Friday, between the hours of 7 a.m. and 6 p.m., Central Time. Unaffected lots of product are available for replacement. This recall is not expected to affect current supply and product remains available for current customers.

Customers with questions regarding this recall can call Baxter at 1-800-422-9837, Monday through Friday, between the hours of 8 a.m. and 5 p.m. Central Time, or email Baxter at onebaxter@baxter.com (mailto:onebaxter@baxter.com?subject=Recall). Consumers should contact their physician or healthcare provider if they have experienced any problems that may be related to using these drug products.

Adverse reactions or quality problems experienced with the use of these products may be reported to the FDA's MedWatch Adverse Event Reporting program either online, by regular mail or by fax.

- Complete and submit the report on-line: www.fda.gov/medwatch/report.htm (http://www.fda.gov/MedWatch/report.htm)
- Regular Mail or Fax: Download form www.fda.gov/MedWatch/getforms.htm (http://www.fda.gov/Safety/MedWatch/HowToReport/DownloadForms/default.htm) or call 1-800-332-1088 to request a reporting form, then complete and return to the address on the pre-addressed form, or submit by fax to 1-800-FDA-0178.

Baxter is voluntarily conducting this recall with the knowledge of the U.S. Food and Drug Administration.

Product Code	Product Description	Lot Number	Expiration Date	NDC
2B1322Q	0.9% Sodium Chloride Injection, USP, 250 mL VIAFLEX Plastic Container	C980227	11/30/2016	0338-0049-02
2B0296H	70% Dextrose Injection (2000 mL) USP	C985150	7/31/2016	0338-0719-06

Are You Safe in Cyberspace?

By Lori Long

Most of us use the computer everyday, whether it's to get on Facebook, check e-mail, or comment on Twitter. Here are some assumptions you should make when you get online, along with some recommendations for keeping yourself a little safer. Some of the recommendations are bit extreme because they are geared toward active duty military, but it's all just food for thought. (I get tagged in posts all the time and don't mind at all!)

Assumptions

- Once something is posted on a social network, it can quickly spread. No amount of effort will erase it – the Internet does not forget.
- You are not anonymous on the Internet.
- There are people on the Internet who are not who they purport to be and could take advantage of you.
- Participating in more social networking sites increases your vulnerability and overall risk.
- Everyone on the Internet can see what you post, from where you post it, who your friends are, friends' comments, and your replies.
- An embarrassing comment or image will come back to haunt you.
- There is a complete record of your online activity...somewhere.

Recommendations

- Do not post anything you would be embarrassed to see on the evening news.
- Do not accept friend/follower requests from anyone you do not know; independently verify identities.
- Avoid using third-party applications or don't give them access to your social networking accounts, friends list, or address books.
- Do not post personally identifiable information.
- Be cautious about the images you post. What is in them may be more revealing than who is in them. Images posted over time may form a complete mosaic of you and your family.
- Do not allow others to tag you in images they post. Doing so makes you easier to locate and accurately construct your network of friends, relatives and associates.

Excerpted from "Cyber Crime Prevention Flyer," 20 May 2015, U.S. Army Criminal nvestigation Command, Computer Crime Investgative Unit.

COAGULATION

Heritage

At CSL Behring, we are committed to providing treatments and supportive services that make a meaningful difference in the lives of people with bleeding disorders and those who care for them.

We set out on this journey with you more than a century ago, starting with the development of treatments for those with rare and serious diseases.

Community

As we look to the future, we see the promise of new innovations and opportunities—just as we always have.

Over the years, we have never lost sight of what matters most: you and the countless others who inspire our efforts every day.

Innovation

Thank You to Our 2015 Sponsors!

Your support makes it possible to serve our local community

$10,000 +

DMC Logistics
Novo Nordisk
Hemophilia Alliance
Bayer
Baxter
NHF

$5,000–$9,999

AeroLynx
HFA
Octapharma
Pfizer

$1,000–$4,999

AA Auto and Air Conditioning
BioRX
Biogen Idec
CVS
CSL Behring
Express Scripts
Falcon Executive Aviation
Grifols
Kedrion Biopharma
National Cornerstone
Ricci & Company
Southwest Cornerstone
Walgreens
Bruckner's Truck
Christian's Automotive
Enterprise Holdings
Payday
Ryder Systems, Inc. Team Mercedes-Benz of Albuquerque
The Payroll Company
US Bank
The Noel Company
Select Staffing
Parts Plus

$100–$999

Arroyo del Oso Golf Course
Black Duck
Chappelle Family
Chevron Mining
Daniel Maulkin
International Indoor Soccer
Jeffry Duran
Jose and Elvira Guillen
Linton and Associates
Long Family
Ken Wagg
New Mexico Gas Co.
Koch Construction
Majestic Forms
MediaWorks
NSPA
One Stop Aviation
Southwest Airlines
W. Lawrence Pfeiffer
Weck's

Thank You to Our Volunteers!

Your hard work makes it possible to serve our local community

Alfonso Jaramillo
Alyssah Leon
Andrea Harper
Angelie Garcia
Anna Cheshire
Anthony Padilla
Bonnie Webb
Bryant Holderried
Carla Smith
Carlos Sanchez
Carnell Chappelle
Carnie Abajian
Catie Cheshire
Cazandra MacDonald
Charity Marquez
Cherise Trujillo
Chris Fennicks
Dawn Bodenner
Dayna Duran
Donald Azure
Donna Gallegos
Elvira Guillen
Eric Faulring
Eric Harper
Eric Marquez
Felix Garcia
Gary Pennington
Heber Ramos
Iktemal Jaber
Jess Hernandez
Jessica Steed
Joe MacDonald
Johanna Chappelle
Jordan Long-Holderried
Jose Guillen
Jose Duran
Jose Hernandez
Julianne Parrish
Karen Prieto
Ken Nead
Ken Wagg
Kyle Stephens
Laura Katcher
Lisa Cheshire
Lori Long
Lorraine Duran
Lynette Francisco
Maria Chavez
Melissa Farias
Michelle Bloodworth
Miguel Sanford
Mike Parish
Mirella Hernandez
Monique Trujillo
Patrick Wagner
Prospero "Pops" Chavez
Rea Watson
Robb Williamson
Robert Farias
Roseannette Lopez
Sarah Trawinski
Sergio Guillen
Shaleigh Henry
Shannon Duran
Sherri Trujillo
Sophia Minhas
Steve Griego
Steve Hernandez
Tania Hake
Willette Francisco

ELOCTATE®
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

THE FIRST FACTOR VIII WITH A PROLONGED HALF-LIFE

Learn how a prolonged half-life may affect your infusion schedule

Meet your CoRe Manager Jessica Klass
E: jessica.klass@biogen.com T: 623-238-0244

Indications

ELOCTATE [Antihemophilic Factor (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency) for: control and prevention of bleeding episodes, perioperative management (surgical prophylaxis), and routine prophylaxis to prevent or reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

Important Safety Information

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.

Allergic reactions may occur with ELOCTATE. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

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

Common side effects of ELOCTATE are joint pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.

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

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

This information is not intended to replace discussions with your healthcare provider.

Biogen

FDA-Approved Patient Labeling

Patient Information

ELOCTATE™ /el' ok' tate/
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

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

What is ELOCTATE?
ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ELOCTATE when you have surgery.

Who should not use ELOCTATE?
You should not use ELOCTATE if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ELOCTATE?
Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

How should I use ELOCTATE?
You get ELOCTATE as an infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

What are the possible side effects of ELOCTATE?
Common side effects of ELOCTATE are joint pain and general discomfort.

Allergic reactions may occur. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.

Your body can also make antibodies called, "inhibitors," against ELOCTATE, which may stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

How should I store ELOCTATE?

- Keep ELOCTATE in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated (2°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- When storing at room temperature:
  - Note on the carton the date on which the product is removed from refrigeration.
  - Use the product before the end of this 6 month period or discard it.
  - Do not return the product to the refrigerator.

Do not use ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution (mixing with the diluent):

- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

What else should I know about ELOCTATE?
Medicines are sometimes prescribed for purposes other than those listed here. Do not use ELOCTATE for a condition for which it was not prescribed. Do not share ELOCTATE with other people, even if they have the same symptoms that you have.

Manufactured by:
Biogen Idec Inc.
14 Cambridge Center, Cambridge, MA 02142 USA
U.S. License # 1697

44279-01

Issued June 2014

Having a Child with a Bleeding Disorder

By Roseannette Lopez

Having a child with a bleeding disorder can be highly emotional. I feel like I am on an emotional roller coaster at times and not sure how to flip the switch off. There are many times we are told to put our brave face on, advocate, stand-up for yourself and your child, but there isn't a place to yell " %^$# you, Hemophilia!" However, the moment that sentence pops into my head so do reminders of all the little joys that pull at my heart. I get to have one of the largest families with all my blood brothers and sisters, and I have the peace of mind that my son will too. I never go a day feeling like I am alone through this process. I know that every decision and path that I take will look completely different from anyone else's, and I will have nothing but support and love on this journey.

These were the thoughts that were going through my head as the sun beat on my face and I watched my son, who had just turned 13, reel in a shark from the middle of the ocean in Key West, Florida. I watched my boy gleam with joy as he struggled with a pole three times his size, his smile of pure joy filled with pride, encouragement, and strength. I began to imagine the man he will be, and I wondered if this will turn into his life passion. Will he want to live close to the ocean? Will he plan boating trips with his friends? And one day, will he be standing over his own son pulling a shark out of the ocean?

The thoughts overwhelmed me with gratitude for the opportunity to go on this week-long voyage. I knew that without Make-a-Wish my son would not be spending his 13th birthday catching sharks. As tears welled up in my eyes my thought was broken with calls of "Mom, mom, hurry! Come look at this!"

Inhibitor Summits and Camps!

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

There are two Inhibitor Education Summits planned for 2016. We are waiting for NHF to announce exact dates and locations, which usually happens in March.

See more at http://www.hemophilia.org/Events-Meetings/Inhibitor-Education-Summits. For a more information, call 877-560-5833.

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

The 2016 Inhibitor Camps will happen in two locations, one on each coast.

Spring Session

Location: The Painted Turtle, Lake Hughes, CA

Scheduled: April 15–18, 2016

Registration opened January 8th.

Fall Session

Location: Victory Junction, Randleman, NC

Scheduled: October 7–10, 2016

Registration opens July 1st.

Sangre de Oro, Inc.
6301 4th Street NW, Suite 6
Albuquerque, New Mexico 87107

Table of Contents

The 2016 Hemophilia Walk and Car Show! 1
Birds 3
Calendar of Events 4
Getting in the Game 5
Sophie's World 6
2015 Patient and Family Education Weekend 8
Ted R. Montoya Hemophilia Treatment Center 10
2016 Walk Call to Action Dinner 13
Researchers Make Gene Therapy Breakthrough in Dogs with Factor VII Deficiency 14
2nd Annual I Love Someone with Hemophilia Car Show! 15
MORE 2015 Patient and Family Education Weekend 16
13th Annual Camp Sangre Valiente 18
SDO Board 18
[Past] President's Corner 19
Consumer Assistance Program 20
FDA Approves Octapharma's NUWIQ® for the Treatment of Adults and Children with Hemophilia A 21
NHF's 67th Annual Meeting 22
James Hamilton Memorial Scholarship Fund 23
PSI, Inc. 24
Baxter Initiates Voluntary Recall of Two Lots of IV Solutions due to Potential Presence of Particulate Matter 29
Are You Safe in Cyberspace? 30
Thank You to Our 2015 Sponsors! 32
Thank You to Our Volunteers! 32
Having a Child with a Bleeding Disorder 35
Inhibitor Summits and Camps! 35

Credits

Authors

Carnie Abajian
Maria Chavez
Felix Garcia
Lori Long
Roseannette Lopez
Claudia MacKaron
Joe MacDonald
Sophia Minhas

Editor

Bryant Holderried

Coordinator

Lori Long

Designer

Lori Long