



BLOOD LINES

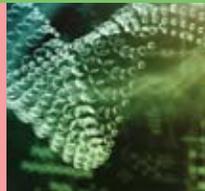
The Official Newsletter of the Hemophilia Association of San Diego County • 3550 Camino Del Rio North, Suite 105 • San Diego, CA 92108

Volume 34 Issue 3 2014



CAMP PASCUCCI 2014 – AWESOME!
YMCA Camp Whittle, Fawnskin CA, near Big Bear Lake
34 camper, 14 junior counselors - Article on page 4

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for Joint
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Ride
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DO THE 5:

- 1 Get an annual comprehensive checkup at a hemophilia treatment center.
- 2 Get vaccinated – Hepatitis A and B are preventable.
- 3 Treat bleeds early and adequately.
- 4 Exercise to protect your joints.
- 5 Get tested regularly for blood-borne infections.

NHF NATIONAL PREVENTION PROGRAM

Key steps today for giant strides tomorrow.

Collaborating with the CDC, chapters, associations, HTCs, and the community to prevent or reduce the complications of bleeding disorders.

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Since we do not engage in the practice of medicine, we always recommend that you consult a physician before pursuing any course of treatment.

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DIRECTOR'S CORNER

By Nooshin Kosar, HASDC Executive Director



GOODBYE SUMMER, HELLO FALL!

We are sad to see summer come to end but we are definitely soaking up every last moment before fall arrives. We had a great summer spending a week in Big Bear for camp, riding horses, becoming superheroes and overcoming fears. The end of camp brought the start of the annual Coastal Ride for Hemophilia where 18 riders rode down the California coast to raise awareness for bleeding disorders.

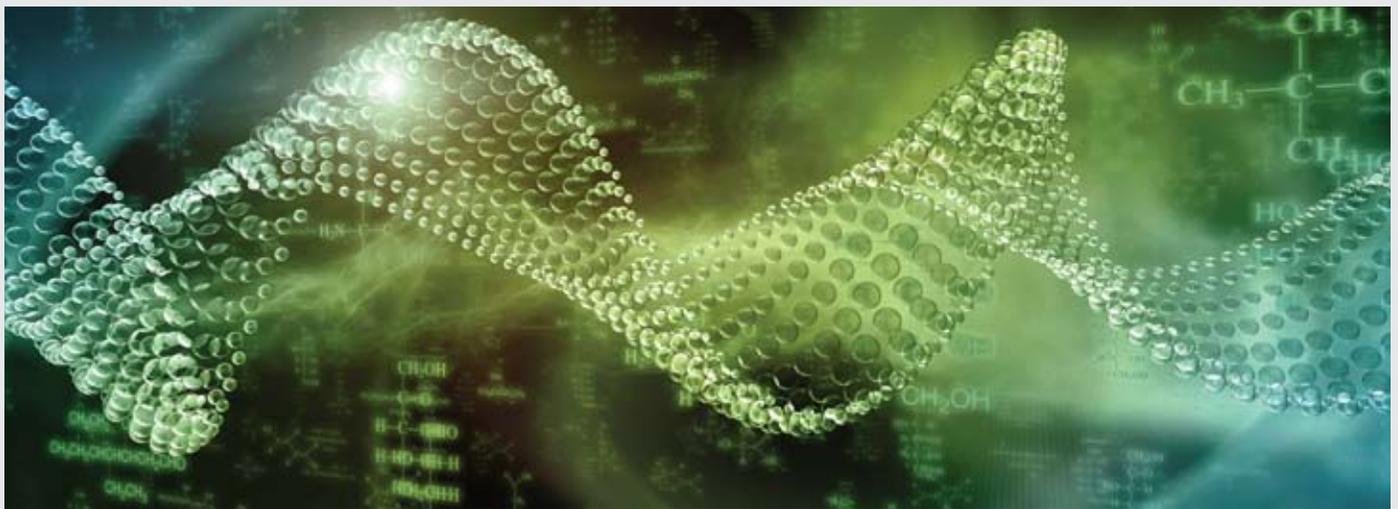
With the arrival of fall comes our 2nd Annual Hemophilia Walk. We encourage everyone to come out, participate and show support! You can register from the walk or join a team at www.hemophilia.org/walk and select San Diego. We are excited to close out the year with a festive holiday party in December. Please join us to celebrate the holidays, get a picture with Santa and of course enjoy great company. ■

¡ADIÓS VERANO, HOLA OTOÑO!

Estamos tristes de ver que el verano se termina; pero definitivamente estamos aprovechando cada momento antes de que llegue el otoño! Tuvimos un gran verano; pasamos una semana de campamento en Big Bear; montando a caballo, siendo superhéroes y superando nuestros temores. El final del campamento trajo el comienzo del Paseo de la Costa para hemofilia; en donde 18 ciclistas recorrieron la costa de California para fomentar conciencia sobre desordenes sanguineos.

Con la llegada del otoño viene nuestra 2da caminata anual para hemofilia. Alentamos a todos a que vengan, participen y muestren su apoyo! Puede inscribirse o ser parte de un equipo en www.hemophilia.org/walk y seleccione San Diego. Estamos muy entusiasmados de finalizar el año con un día festivo en diciembre. Por favor únase a nosotros para celebrar las festividades, tomarse una foto con Santa y por supuesto gozar de buena compañía! ■

GENOTYPING FOR PROGRESS IN HEMOPHILIA MY LIFE, OUR FUTURE



We are excited to announce that 1,000 people have enrolled in My Life, Our Future! The number marks a significant milestone in achieving the goal of genotyping as many people in the U.S. with hemophilia A and B as possible.

By participating, you can help our community make knowledge hereditary. Your genotype can provide meaningful information about your hemophilia today, including identifying your unique mutation. More than 61 new mutations have already been discovered

through the program. Genotyping may also accelerate the scientific breakthroughs of tomorrow. Once 5,000 people have enrolled in My Life, Our Future, scientists will be able to apply to research the data and samples.

With a quick test, you can contribute to a brighter future for generations to come. My Life, Our Future is currently available at Rady Children's Hospital and University of California, San Diego. Please visit MyLifeOurFuture.org for more information. ■



SUPERHEROES IN THE MAKING

By Nooshin Kosar, HASDC Executive Director

The mountains called and we answered. 2014 marked a change in Camp Pascucci, we moved from our home in Julian to test the waters of Big Bear, CA. Camp Whittle welcomed us with open arms, fresh mountain air and a lake that all would enjoy. Kids arrived to staff dressed up with capes and ready for what they would soon find out to be superhero week. Campers emerged from the bus amazed at the surroundings and ready to explore new territory.

Campers and staff spent the week trying new activities and facing fears. Everyone had the opportunity to ride horses, brave through high ropes courses including the much discussed leap of faith. If facing fears wasn't in the cards, campers could still enjoy time spent at the lake paddle boarding, swimming and riding The Great One. From camp activities to superhero training, campers learned about superheroes in their lives and had the chance to train to be superhero themselves. A superhero's task is not complete until they

have saved the day which is what the campers were enlisted to do. Counselors were kidnapped by the super villain network and could only be freed by the bravery and skills of their campers.

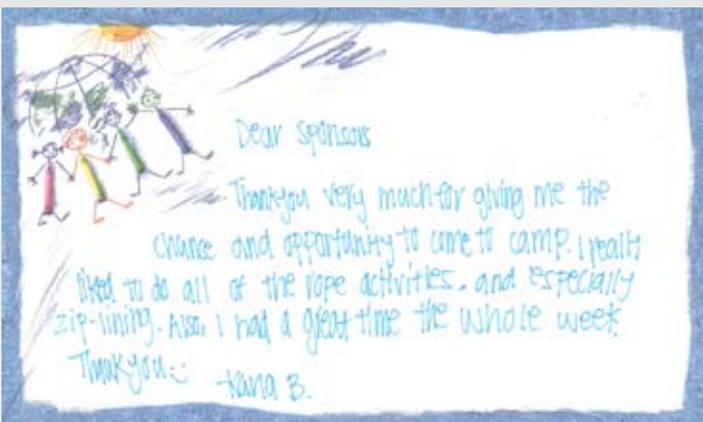
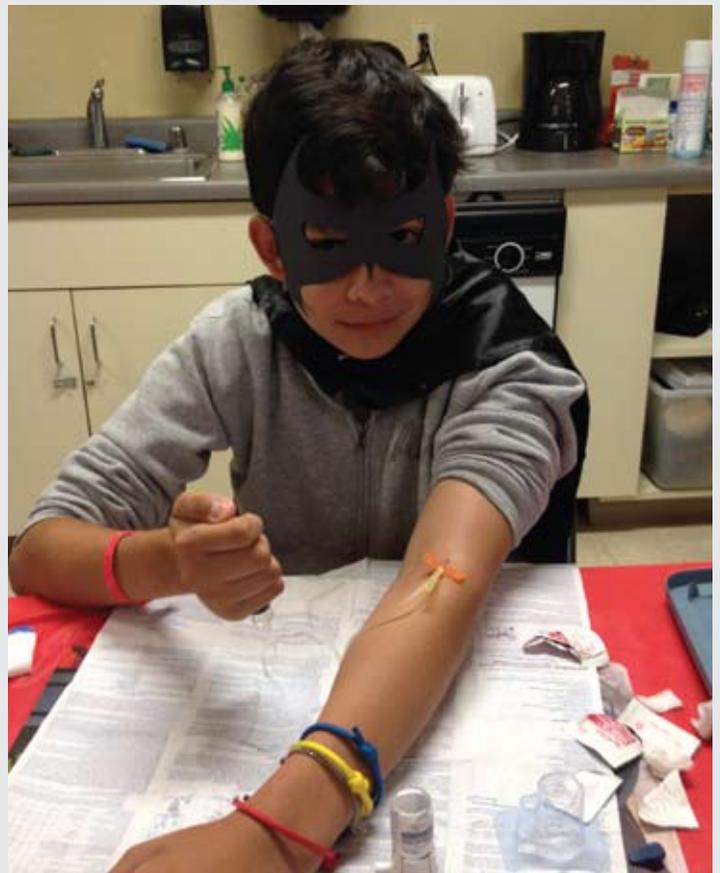
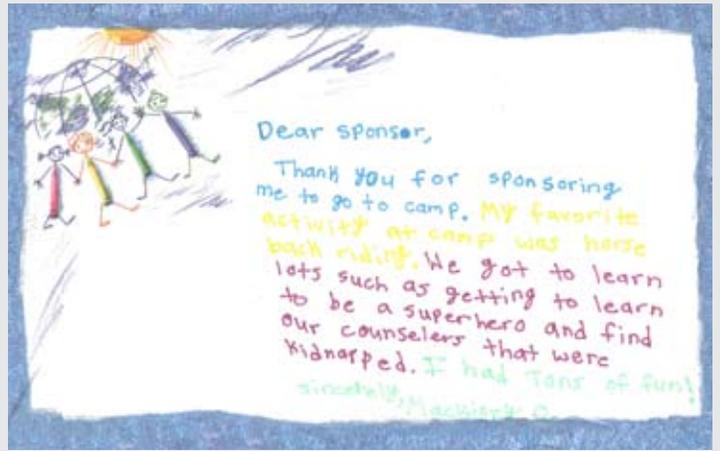
The week was packed with fun activities and many learning experiences. Camp's greatest success is when campers learn to self-infuse. Whether it was a camper, a sibling or a YMCA staffer, everyone participated and encouraged those learning for the first time.

Camp would never be a great success without our dedicated group of amazing volunteers. The enthusiasm they bring to camp is extraordinary and the Association cannot thank you enough. I would also like to thank our camp Co-Directors this year, Sean Pentz and Gabriel Rios. Your generosity and time dedicated to providing a great camp for a wonderful group of campers is greatly appreciated. It couldn't have been done without you! ■



Thank you to our generous 2014 camp sponsors!

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- ◆ Pfizer



LEARN TO ROCK CLIMB

By Alexis Sexton, UCSD HTC



The UC San Diego Hemophilia Treatment Center is launching a Rock Climbing Program in partnership with the Hemophilia Association of San Diego County at the Solid Rock Gym indoor climbing facility. Climbing sessions will take place weekly in a controlled and safe environment perfect for introducing rock climbing to beginners and honing advanced skills for future outdoor climbing excursions. Aside from being a fun way to bring the Hemophilia community together, Rock Climbing is a low risk sport for bleeding and injury. This is a unique opportunity, currently the only one in the United States, modeled after a successful program at the University of Munich, where rock climbing has shown

to increase range of motion and overall health of joints and to decrease frequency in bleeds. Participation in this program may also help the scientific community understand joint health better and lead to improved care practices for the entire hemophilia population.

The goal of this program is to create a fun and innovative way to provide joint therapy to our patients with hemophilia. The Program is open to all males with hemophilia, ages 17-50. For more information, contact Alexis Sexton at the UC San Diego HTC: 619-471-0375 or arsexton@ucsd.edu. ■

RIDING WITH HEMOPHILIA FOR HEMOPHILIA

By Matt Erdmann



As a person with severe hemophilia A, I have always been very active. I love the outdoors, sports, and I try to maintain a lifestyle with some form of daily exercise. When I learned about the 500 mile California Coastal Ride for Hemophilia it hit me—time to try cycling! I consulted with my healthcare team and received guidance of how to approach this goal safely and then started training for the big ride.

The actual ride experience was amazing to say the least and if given the opportunity to ride again I would in a heartbeat! I was impressed by the comradery among the riders and the encouragement from the support crew. The views were incredible and combined with the satisfaction that came from riding for hemophilia, I was able to reach my goal of completing this year's ride. Thank you to the Hemophilia Council of California, local California chapters, the sponsors, as well as a special thanks to those that came out to cheer us on for such a great experience and cause! ■



GUARDAR LA FECHA



Evento Del Mes Sobre La Cultura Hispana

**SÁBADO, 8 DE NOVIEMBRE
EN OLD TOWN!**

**ÚNASE A NOSOTROS PARA:
EDUCACIÓN, ENTRETENIMIENTO Y COMIDA**

This educational program in celebration of Hispanic Heritage Month will be presented solely in Spanish for our Spanish speaking community.

NICOLE CHEN, TREASURER



Nicole Chen is an Accounting Manager at TGG Accounting, an outsourced accounting department for small and mid-sized businesses. Nicole's business focus is on delivering timely, accurate, easy-to-understand financial information to business owners. Nicole joined the HASDC Board of Directors in 2012. Along with her quick wit and fun personality, Nicole brings a wealth of accounting experience and has been integral in helping the board with financial analysis and management.

she was the founder and president of the Undergraduate Accounting Society. Nicole was born and raised in Orange County. She came to San Diego for college and now can't imagine calling any other city "home". Nicole enjoys staying active with activities such as hiking, boot camp fitness classes, and runs along the bay. You can expect to see Nicole at the upcoming HASDC events. ■

Nicole earned her Bachelor's Degree in Management Science from the University of California, San Diego (class of 2011) where

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GENERAL DONATION: General Donation: \$ _____

This donation is in honor/memory (circle one) of _____

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Or fax this form with credit card donations to: HASDC @ (619) 325-4350.



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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)

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July 2014

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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.

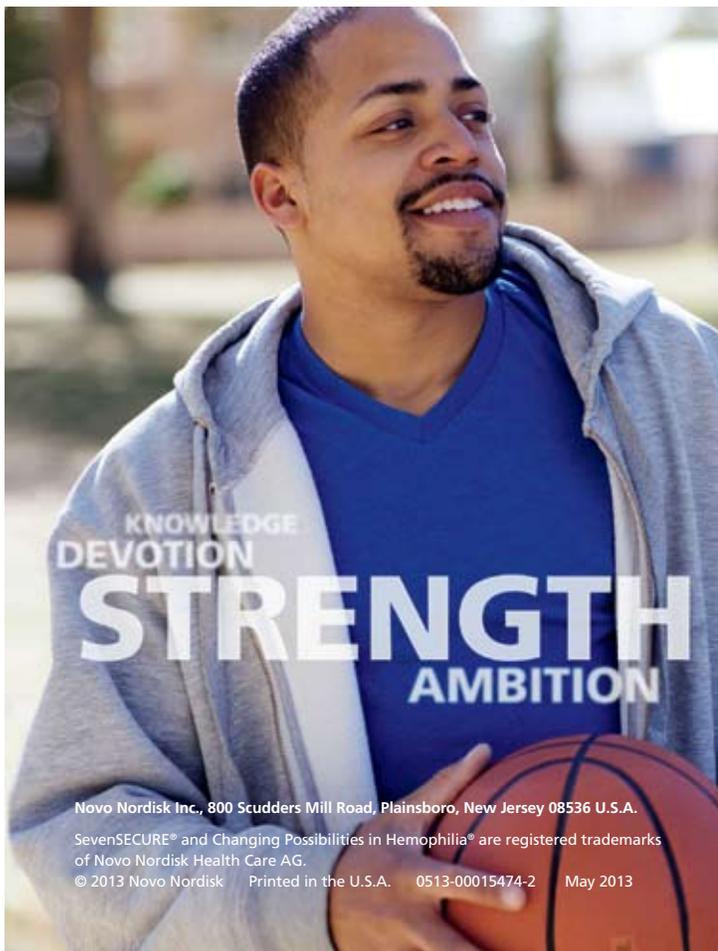
USE IN SPECIFIC POPULATIONS

- 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.

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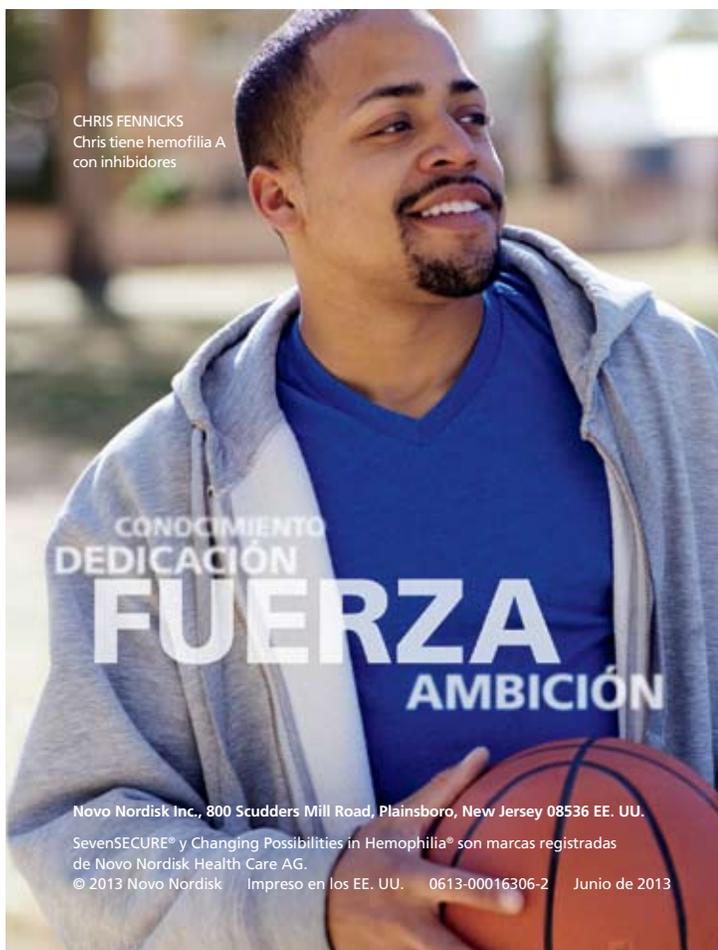
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UPCOMING EVENTS

- San Diego Hemophilia Walk** • October 4 • NTC Park, Liberty Station • 9:00 am
- Hispanic Heritage Event** • Saturday, November 8 • Hacienda Hotel • Old Town San Diego
- Toy Drive** • November • Details TBD
- Holiday Celebration** • Sunday, December 14 • Handlery Hotel • San Diego

Advanced registration is required for all events. Please contact the HASDC office for details.



REGISTER NOW SUPPORT HASDC

Saturday, October 4, 2014

Registration Check-In Time: 9:00 am

Walk Start Time: 10:00 am

Distance: 5K (3.1 miles)

Location: Preble Field-NTC Park

Liberty Station
 2455 Cushing Rd.
 San Diego, CA 92106

The 2nd annual San Diego Hemophilia Walk is fast approaching! Join us in our dedication to promote healthy, normal lifestyles and meet the needs of everyone affected by bleeding disorders. Make a donation, walk as an individual, join a team or become a captain and create your own team with co-workers, friends and family members. Register now and help us reach our fundraising goal of \$50,000!

For more information, please visit www.hemophilia.org/walk or info@hasdc.org.

www.hemophilia.org/walk

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