

MARCH IS BLEEDING DISORDERS AWARENESS MONTH



“Bleeding Disorders Awareness Month,” was approved by the U.S. Department of Health and Human Services in 2016 as a National Health Observance in March. This new health observance formalizes and expands upon the event designated by President Ronald Reagan 30 years ago as “Hemophilia Awareness Month.” This special month aims to bring together people with all inherited bleeding disorders to raise awareness of these rare conditions and their potential health problems.

The bleeding disorders community includes more than three million Americans who have hemophilia, von Willebrand disease, and other rare bleeding disorders (called rare factor deficiencies). We encourage you to spread the word about

Bleeding Disorders Awareness Month by participating in the educational campaign, posting messages on Facebook, Twitter, and Instagram, giving presentations in schools, and sharing information with your family and friends.

The Red Tie Challenge is a movement created by the bleeding disorders community and the National Hemophilia Foundation (NHF) to start a conversation about inherited bleeding disorders and support March as Bleeding Disorders Awareness Month. The red tie is a symbol of the blood ties that bind over 3 million Americans together. “Because blood ties, embodied in the color red and the tie, are what bind our community together, the red tie is the new symbol for the bleeding disorders community,”

said Val Bias, NHF CEO. “The color red also conveys strength, leadership, courage, determination and, above all, empathy and love—qualities and emotions that define our community.”

Take the Red Tie Challenge to show your support for the bleeding disorders community:

- Take a photo or record a short video that shows how you wear a red tie and pledge your support for Bleeding Disorders Awareness Month
- Post the photo or video to your social channels with #RedTieChallenge
- Encourage your fans and followers to take the Red Tie Challenge too
- Make a donation to support the bleeding disorders community at www.redtiechallenge.org



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Corner
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OFFICERS

Sean Pentz, President
aseanpentz@gmail.com

Misty McCartney, Vice President
meme4528@hotmail.com

Nicole Chen, Treasurer
nechen14@gmail.com

Shelley Flores, Secretary
hrsgrl@verizon.net

DIRECTORS AT LARGE

Renatto Medranda
Vernon Polk

STAFF

Nooshin Kosar, Executive Director
nooshin@hasdc.org

Lisa Heffernan, Director of Programs & Events
lisa@hasdc.org

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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.

Information and opinions expressed in this publication are not necessarily those of the Hemophilia Association of San Diego County, or those of the editorial staff.

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3550 Camino Del Rio North, Suite 105
San Diego, CA 92108
Tel (619) 325-3570
Fax (619) 325-4350
E-mail: info@hasdc.org

WEBSITE: WWW.HASDC.ORG



On behalf of the HASDC Board and Staff, we wish you a Happy New Year! As March approaches—now recognized by the U.S. Department of Health and Human Services as Bleeding Disorders Awareness Month—our community has the opportunity to further raise awareness of bleeding disorders.

With a new presidential administration, it is also an important time to learn about potential healthcare changes that may affect those living with a bleeding disorder.

Advocacy is the best way for our voice to be heard and has been so critically important to ensuring access to care and treatment. Become a self-advocate today and make sure your voice is heard! There are a lot of resources available to help guide your advocacy efforts.

I encourage you to visit the National Hemophilia Foundation (NHF) website or Facebook page to stay apprised of policy changes. Please respond to advocacy alerts as NHF sends them out or as we share them on Facebook. Do not hesitate to send your questions or concerns to us or directly to NHF.

If you are unable to attend NHF's 2017 Washington Days, consider how you can advocate at the state level by visiting the Hemophilia Council of California's (HCC) website, signing up to receive the Weekly Advocacy News e-newsletter or by participating in the Annual Legislative Day in May.

This is the time to come together as a community to stay informed and advocate for the programs and services that help protect those with a bleeding disorder and enable them to lead normal and healthy lives.

We look forward to seeing you at a local event or the Legislative Day in May!

Remember, you are your own best advocate and your story matters to decision makers.

THANK YOU SPONSORS FAMILY EDUCATION DAY 2017

**A SPECIAL THANK YOU TO THE FOLLOWING SPONSORS
FOR THEIR SUPPORT OF OUR ANNUAL EVENT!**

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2017 SUMMER CAMPS

CAMP PASCUCCI

TEEN CAMP

Who	Boys and girls ages 7-14 diagnosed with a bleeding disorder (given priority), carriers and siblings.	Boys and girls ages 14-17 diagnosed with a bleeding disorder (given priority), carriers and siblings.
When	August 13-18	July 8-12
Where	YMCA Camp Whittle (FawnSkin, CA)	South Fork - American River (Lotus, CA)
What	<ul style="list-style-type: none">Gaining independence, connecting with peers, and self-infusion trainingActivities include: lake fun, horseback riding, rock climbing, high ropes course, crafts, and more	<ul style="list-style-type: none">Connecting with peers, gaining leadership skills, testing personal limits, and communing with natureActivities include: whitewater rafting, camping, cooking, and more
Notes	<ul style="list-style-type: none">Campers must independently manage all personal care and mobilityAll transportation (from HASDC office) and camper expenses coveredProfessional medical staff from both the local HTTCs on site for duration of the programExperienced and trained camp staff on site for duration of the programNote: individuals age 15+, with camp experience, can apply to be camp staff	<ul style="list-style-type: none">Campers must independently manage all personal care and mobility, and be prepared to participate in physically strenuous activitiesCampers must self-infuseCampers must be comfortable in the river and must know how to swimAll transportation and camper expenses coveredProfessional medical staff from the local HTTC on site for duration of the programTrained river guides and experienced camp staff (21+) on site for duration of the program

APPLICATION DEADLINE:

TEEN CAMP: JUNE 1

CAMP PASCUCCI: JULY 1

APPLICATION FEE:

\$25 PER CAMPER

REGISTER HERE:

WWW.HASDC.ORG/EVENTS



SPRING PROGRAMS AT UCSD HEALTH

The UC San Diego Health Hemophilia and Thrombosis Treatment Center (HTTC) is an innovative, multidisciplinary program catering to the needs of adult patients with hemophilia, von Willebrand disease, and other bleeding and thrombotic disorders. We accept most insurance and can assist with health coverage issues.

HTTC Comprehensive Services Include:

- Specialized Bleeding Disorder Physicians
- Specialized Nursing Team
- Social Worker
- Physical Therapy
- Point of Care Ultrasound for Bleed Detection
- Hemophilia Vertical

Hemophilia Vertical - New Session Starting In April 2017!

This therapeutic rock climbing program is a unique, fun, and low risk athletic activity shown to increase range of motion and overall joint health. Open to all hemophilia and bleeding disorder patients and a guest. Our adaptive climbing instructors will set personalized goals for each patient climber. Call today for more information or visit us online to reserve a spot.

A Day for Women

April 29, 2017 | 9:00 am – 1:00 pm

Women take on many roles, but when is there really time to focus on your self? The HTTC has created a day to celebrate you. This day will be filled with education, advocacy, and sharing stories with other women in the bleeding disorder community. We want to encourage and generate more support for you! Call today for more information or visit us online to register.

UC San Diego Health Hemophilia and Thrombosis Treatment Center

8929 University Center Lane, Suite 201, San Diego CA 92122

Phone: 858.657.6028

Website: health.ucsd.edu/Hemophilia

UC San Diego Health

RADY'S WELCOMES DR. HILDA DING

COURTNEY THORNBURG, M.D.
MEDICAL DIRECTOR, RADY CHILDREN'S HOSPITAL HTTC

Please help us welcome our new staff member. Dr. Hilda Ding has joined Dr. Courtney Thornburg at Rady Children's Hospital Hemophilia and Thrombosis Treatment Center. Dr. Ding moved to San Diego in 2016. She completed a fellowship program in Pediatric Hematology Oncology in 2015 and an additional fellowship in Hemostasis and Thrombosis in 2016 at Rainbow Babies & Children's Hospital in Cleveland, Ohio. She is especially interested in taking care of children and adolescents with bleeding and clotting conditions. Dr. Ding is fluent in Cantonese. Dr. Ding enjoys spending time outdoors with her husband and their dog. Please say hello to Dr. Ding during your next visit to the Treatment Center.

The Rady's team is busy. Rady Children's Hospital Hemophilia and Thrombosis Treatment Center will be hosting the Western States Region Annual Meeting for

treatment center teams from California, Nevada, Hawaii and Guam on April 2nd and 3rd. We are also looking forward to attending Camp Pascucci in August and hosting the annual Rady Children's Family Day in October.





Michael, 30 years old, lives with hemophilia A.

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Two **20-nanometer filters** used in a 5-step purification process

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Novoeight® offers the **highest storage temperature** for the **longest time^a**—up to 86°F for 12 months

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In one of the largest clinical trials of a recombinant factor VIII to date, **there were 0 inhibitors confirmed** in 213 previously treated patients^b

^aCompared with other recombinant factor VIII products.

^bPeople with previous inhibitors and those new to treatment were not included in the trial. People with hemophilia A may develop inhibitors to factor VIII.

Please see Prescribing Information for complete storage instructions.



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Indications and Usage

Novoeight® (Antihemophilic Factor [Recombinant]) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

Important Safety Information

You should not use Novoeight® if you are allergic to factor VIII or any of the other ingredients of Novoeight® or if you are allergic to hamster proteins.

Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction: rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands.

Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII.

Your body can make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Common side effects of Novoeight® include swelling or itching at the location of injection, changes in liver tests, and fever.

Please see brief summary of Prescribing Information on following 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.

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

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novoeight®
Antihemophilic Factor
(Recombinant)

HEMOPHILIAC TO CLIMB MOUNT EVEREST IN 2017

Chris Bombardier, a 31-year-old Denver-based mountaineer living with severe hemophilia B, will become the first person with hemophilia to summit Mt. Everest in 2017. Believe Limited, the content agency responsible for “Stop The Bleeding!”, will create a documentary feature film and corresponding web series chronicling his adventures. In addition to spotlighting this landmark moment for the hemophilia community, the documentary and web series will also raise awareness for the hemophilia communities in developing countries.

Mount Everest is 29,035 feet high, the highest mountain (above sea level) on the planet. Approximately 4,000 people have attempted to climb Mt. Everest. Since the first successfully ascent in 1963, 660 people have successfully completed the climb. One in 10 successful climbs to the summit ends in death. Climbers burn 20,000 calories on the day of the summit climb, and an average of 10,000 a day on the rest of the climb. At Everest's highest point, climbers are breathing in 1/3 the amount of oxygen they would normally breathe due to the atmospheric pressure.

Here is a recent post from Chris's Facebook:

For the past six years I have been on an incredible journey to climb the Seven Summits, the highest mountains on each of the seven continents. To date, I have completed five, and although I've been denied access to Mt. Vinson in Antarctica due to my hemophilia—for now—I am pleased to announce that the journey is continuing....this time to the highest peak on earth, Mt. Everest!

I have dreamed of this climb for years and am so excited that this dream is becoming a reality. What will make this climb even more special is a partnership between Patrick James Lynch's production company Believe Limited and me to capture my climb and journey in Nepal for the purposes of creating a documentary feature film and online video series!



Everest lies within Nepal's borders, but the people with bleeding disorders there are unable to dream about climbing, like me. They lack the treatment that would enable them to climb. Most are lucky to live into their 20s and even those few years are full of painful untreated bleeds and constant challenges. With Believe Limited, we hope to not only capture my climb, but also highlight the drastic disparity in care between people with hemophilia in developing countries versus the developed countries.

Our ultimate goal with this film and video series is to bring awareness of hemophilia to the general population and to advocate for continued efforts that lessen the disparity in care faced by those around the world without access to treatment. I'm so excited to share this journey with you all, so please follow my page for updates as we get closer to the climb!

HEMOFÍLICO SUBIRÁ MONTAÑA EVEREST EN 2017

Chris Bombardier, un alpinista de 31 años basado en Denver que vive con hemofilia B grave, será la primera persona con hemofilia que alcanzará la cima de La Montaña Everest en el 2017. Believe Limited, la agencia responsable de este contenido para “¡Detengan el sangrado!”, creará un documental de largometraje y una serie similar para la red web creando una crónica de sus aventuras. Además de traer este momento único para la comunidad con hemofilia, la crónica y serie de web también enfocarán la atención en las comunidades con hemofilia de países en desarrollo.

La Montaña Everest tiene 29,035 pies de altura, la montaña más alta (arriba del nivel del mar) en el planeta.

Aproximadamente 4,000 personas han intentado escalar La Montaña Everest. Desde el primer intento logrado en 1963, 660 personas han logrado escalar la montaña. Uno de cada diez intentos a subir la montaña termina en muerte. Alpinistas queman 20,000 calorías en el día en que llegan a la cima y un promedio de 10,000 al día el resto de la escalada. En el punto más alto de Everest los alpinistas están respirando solo 1/3 de la cantidad de oxígeno que respiran normalmente debido a la presión atmosférica.

Aquí está la más reciente nota de Facebook de Chris:

Por los últimos seis años he seguido una increíble jornada continua página siguiente

WORLD HEMOPHILIA DAY • CLOSE THE GAP • APRIL 17

The World Federation of Hemophilia (WFH) is an international non-profit organization dedicated to improving the lives of people with hemophilia and other genetic bleeding disorders. It educates hemophiliacs and lobbies for improved medical treatment. The WFH was established by Frank Schnabel in 1963 and is headquartered in Montreal, Canada. It has member organizations in 113 countries and official recognition from the World Health Organization. Supported by the World Federation of Hemophilia (WFH), hemophilia awareness day was first established in 1989. The date of April 17th was chosen to honor Frank Schnabel, whose birthday falls on the same date.

The aim of World Hemophilia Day is to raise awareness about hemophilia and increase the availability of treatments for this condition around the world. Unfortunately, there are many people in the world who receive poor treatment or no treatment at all for hemophilia and related bleeding disorders. According to the World Federation of Hemophilia, about 1 in every 1000 people have a bleeding disorder; many are left untreated. The slogan for World Hemophilia Day is 'Close The Gap', which reflects the difference in treatments available to people living in different parts of the world. By working together, it is hoped that we can close the gap of hemophilia care around the world.

Modern technology and social networking mean more people than ever can get involved. You can help raise awareness about this condition with minimal effort, simply like the dedicated Facebook page and email and text friends about Word Hemophilia Day. For more information visit the official website at www.wfh.org



HEMOFÍLICO SUBIRÁ MONTAÑA EVEREST EN 2017, CONTINUACIÓN

de escalar las siete cimas; las montañas más altas de cada uno de los siete continentes. Hasta ahora he completado cinco; aunque me han negado acceso a La Montaña Vinson en Antártica debido a que tengo hemofilia; por ahora, es un placer anunciarles que la jornada continúa.... ¡Esta vez a la cima más alta de la tierra, La Montaña Everest!

He soñado con esta escalada por años y estoy tan entusiasmado que este sueño se va a hacer una realidad. ¡Lo que hará esta escalada aún más especial es la asociación entre La Compañía de Producción Believe Limited de Patrick James Lynch y yo para captar mi escalada y jornada en Nepal con el propósito de crear un documental en largometraje y una serie de videos en línea!

Everest se encuentra dentro de los límites de Nepal, pero la gente de allí con trastornos hemorrágicos no puede soñar con escalar como yo. Ellos carecen de tratamientos médicos

que les permitiría escalar. Muchos tienen la suerte de vivir un poco más de veinte años; aun así esos pocos años están llenos de hemorragias dolorosas y sin tratamiento y retos constantes. Con Believe Limited tenemos la esperanza no solo de captar mi escalada, pero también de resaltar la disparidad drástica en el cuidado de la gente con hemofilia en países en desarrollo comparados con los países desarrollados.

Nuestra meta final con esta película y serie de videos es de despertar conciencia sobre hemofilia en la población general y abogar para continuar los esfuerzos para disminuir la disparidad en cuidados médicos que enfrentan aquellos alrededor del mundo sin acceso a tratamiento. Estoy muy entusiasmado de compartir esta jornada con todos ustedes; así que por favor sigan mi página que la estaré actualizando a medida que nos acercamos a la escalada.



LOOKING FOR 2017 FUTURE LEADERS!

Hemophilia Council of California's (HCC's) **Future Leaders Program** provides leadership training and advocacy tools for teens and young adults affected by bleeding disorders. Leading up to HCC's annual **Legislative Day, Future Leaders** gain insights and skills on their role in the government process, insurance, programs that support care, educational opportunities, and effective advocacy.

Participants hear from statewide and national healthcare leaders, learn self-reliance, connect with peers, meet legislators at the State Capitol, have fun and find inspiration to share their voice where it matters most. Core advocacy programming will be provided for New Future Leaders and advanced training including community-based advocacy for those returning.

How to Apply: Visit www.hemophiliaca.org/programs

Deadline: April 1, 2017

Details: Travel, accommodations and meals provided

Questions: Email info@hemophiliaca.org

HCC is a statewide nonprofit advancing access to care and quality of life for those affected by bleeding disorders. HCC represents approximately 4,000 individuals with hemophilia, more than 360,000 with Von Willebrand Disease (VWD) and countless others with related disorders.

WHAT: Future Leaders & Legislative Day

WHEN: May 8-10, 2017

WHERE: Sacramento, CA

WHO: Those affected by bleeding disorders (including carriers and siblings), ages 14-22

WHY: You want to advance access to healthcare and quality of life for those affected by bleeding disorders

BECOME A 2017 FUTURE LEADER TODAY!



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- Entertainment for the whole family
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HEMOPHILIA WALK

There's fun for everyone at the Hemophilia Walk! We walk to raise critical FUNDS for national research, local programs & services and to raise AWARENESS for the bleeding disorders community. Your support is greatly needed!

For more information, please visit NHF's Walk website:

Register online now at
**[hemophiliawalk.donordrive.com/
event/sandiego](http://hemophiliawalk.donordrive.com/event/sandiego)** 

Participate. Volunteer. Donate.

SATURDAY, OCTOBER 14

Liberty Station Park

2455 Cushing Road
 San Diego, CA 92106
 9:00 AM Check-In • 10:00 AM Walk Begins
 Distance: 5K (3.1 miles)

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WELLNESS CORNER

LISA HEFFERNAN
DIRECTOR OF PROGRAMS
AND EVENTS



Wellness (wel-nis):
the quality or state of
being healthy in body and
mind, as the result of a
deliberate effort.

STRONG IS THE NEW SKINNY AND WHY THAT'S A GOOD THING

Great progress has been made in portraying what real women look like — even from where we were a few years ago. Today, Instagram is filled with women who harken back to Marilyn Monroe's wholesome figure in various yoga poses (which we love). These women are portraits of strong women, comfortable in their own skin, celebrating womanhood. And we should celebrate right alongside them.

But we should not dismiss, or worse abdicate responsibility for, our own health and wellbeing. You and you alone are responsible for your health. The editors of Cosmo are not, nor are the editors or authors on this site. Society, government, nor your friends and family can control your actions. Ultimately, the responsibility comes down to you — getting yourself to a doctor, following a healthy lifestyle, and doing the hard work of being strong.

Every body was not made equal. Not all of us were endowed by our Creator with the gifts (both physical and mental) on our wish lists. We all have things about our bodies we want to change. But being strong doesn't necessarily equate to being skinny. In most cases, being strong means weighing more, but feeling better. The bottom line is, weight aside and skinny aside, you won't be happy unless you are holistically strong: Strong in body, mind, and spirit.

Strong in Body: This can mean different things to different people. If you are a personal trainer, strong in body is going to mean something different than to someone who just wants to keep up their kids or run a local 5K. But the goal is the same — functional fitness, i.e., the ability to train your body to do what you need it to do when you need it to do it. You don't need to be skinny or to bulk up to achieve this state, but you do need to work at it and ensure you don't neglect your muscles by sitting all day, watching TV on the couch all night, and in general, being lazy. So, get up and walk to work, join a gym, take a Zumba class, or go to yoga with some friends. Every little bit helps.

Strong in Mind: You can either be the victim in your own life's play or you can take the leading part. Which do you want to be? It takes strength to walk out on stage front and center everyday, but everyone possesses the ability to take that first step. It's a choice you must consciously make and you have to have strength of mind to achieve

it. This means working out your mind as you would your body (think puzzles, such as Sudoku, reading the dictionary, or maybe even a good old-fashioned game of Scrabble). Instill in yourself the drive and temperament to access each situation to keep moving forward, even when everything around you is falling apart.

Strong in Spirit: This is how you approach life. Do you live in the dark or do you seek the revitalizing power of the light? Is your soul nourished or are you deficient in being able to express gratitude and hope? Remember the old adage — you can't take care of others until you first put on your own oxygen mask. So take the time to get to know you, your needs, your desires, your boundaries, the qualities that make up your unique soul. Then pray, meditate, chant — do whatever calls out to you — and be grateful for being you. Strong in Spirit the hardest of the three to learn, but as Oscar Wilde said, "everyone else is taken."

As you build strength, the more you'll be able to do. The more you do, the more you can enjoy what life has to offer — whether that's playing with your children or hiking the Inca trail or completing a New York Times crossword puzzle (in ink). Being strong is a gift you give to yourself.

You and you alone are responsible for your health and overall wellbeing. It is you who chooses to exercise, to not smoke, to drink in moderation, to eat healthy, to pray or meditate, to use your mind, to reflect and make adjustments, and to be the best, strongest expression of yourself... Or not. What choice will you make?

*Reprinted from Huffingtonpost.com,
written by Amy Mitchell, dated November 2015.*



ESQUINA DEL BIENESTAR

LISA HEFFERNAN
DIRECTORA DE PROGRAMAS Y EVENTOS



Bienestar:
la calidad o el estado
de estar saludable
en cuerpo y mente
como resultado de un
esfuerzo deliberado.

PORQUÉ FUERTE ES EL NUEVO DELGADO Y PORQUÉ ESO ES ALGO BUENO

Se han hecho grandes avances en la representación de como una verdadera mujer debe verse – aún de donde estábamos pocos años atrás. Hoy Instagram está lleno de mujeres que reflejan sobre el cuerpo saludable de Marilyn Monroe en varias poses de yoga (lo cual nos encanta) Estas mujeres son el retrato de mujeres fuertes, confortables en su propia piel, celebrando su condición de mujer. Nosotros debemos celebrar al lado de ellas.

Pero no debemos descartar, peor aún, abdicar responsabilidad por nuestra salud y bienestar. Tú y solamente tú eres responsable de tu salud. Los editores de Cosmo no lo son, tampoco los editores o autores en este sitio. La sociedad, el gobierno, tampoco tus amigos y familia pueden controlar tus acciones. Ultimadamente, la responsabilidad cae sobre ti – yendo al doctor, siguiendo un estilo de vida saludable, y haciendo el difícil trabajo de ser fuerte.

No todos los cuerpos fueron hechos iguales. No todos fuimos dotados por nuestro creador con regalos (ambos, físicos y mentales) en nuestra lista de deseos. Todos tenemos cosas acerca de nuestro cuerpo que queremos cambiar. Pero el ser fuerte no necesariamente es igual a ser delgado. En la mayoría de los casos, ser fuerte significa pesar más, pero sintiéndose mejor. Lo importante es, poniendo el peso a un lado y delgado a un lado, tú no serás feliz al menos que seas fuerte en tu totalidad: Fuerte en cuerpo, mente y espíritu.

Cuerpo fuerte: Esto puede significar diferentes cosas a diferentes personas. Si tú eres un entrenador personal, fuerte de cuerpo significará algo diferente que a alguien que solo quiere correr detrás de sus hijos o correr 5K al nivel local. Pero la meta es la misma – condición funcional, i.e., la habilidad de entrenar tu cuerpo para que haga lo que tú necesitas que haga cuando quieras que lo haga. No necesitas ser delgado o tener músculos grandes para alcanzar éste estado, pero si tienes que trabajar en ello y asegurarte de que no vas a descuidar tus músculos sentándote todo el día, mirando televisión en el sillón toda la noche y en general, ser un perezoso. Así que, levántate y camina al trabajo, ve al gimnasio, toma clases de Zumba o ve a clases de yoga con tus amistades. Cada cosa que hagas por pequeña que sea, siempre ayuda.

Mente Fuerte: Tu, o puedes ser la víctima en el drama de tu propia vida o puedes tomar la parte del personaje principal. ¿Cuálquieres ser? Se necesita fuerza para salir al escenario, al frente y centro todos los días, pero todos tienen la habilidad de tomar ese primer paso. Es una decisión que tienes que hacer conscientemente y tienes que tener la fuerza mental para obtenerla. Esto quiere decir ejercitarte tu mente como haces con el cuerpo (piensa rompecabezas, como Sudoku, leer el diccionario, o quizás un juego de Scrabble). Inculca en ti mismo el dinamismo y temperamento para obtener acceso a cada situación para seguir hacia adelante, aun cuando todo a tu alrededor se está desmoronando.

Espíritu Fuerte: Así es como abordas la vida. ¿Vives en la oscuridad o buscas el poder revitalizante de la luz? ¿Está tu alma alimentada o está deficiente en la habilidad de expresar gratitud y esperanza? Acuéstate del viejo refrán – no puedes ayudar a otros hasta que no te pongas tú la máscara de oxígeno primero. Así que tomate el tiempo para conocerte a ti mismo, tus necesidades, tus deseos, tus límites, las cualidades que forman tu alma única. Entonces reza, medita, canta – haz lo que tu alma te pide – y se agradecido de ser tú. Fuerte en espíritu, la más difícil de las tres para aprender, pero como dijo Oscar Wilde, “todos los demás has sido escogidos.”

Mientras más fuerza desarrolles, más podrás hacer. Mientras más haces, más gozarás de lo que la vida ofrece – ya sea jugando con tus hijos, caminar los senderos del Inca o completar un crucigrama en el New York Times (con pluma). Ser fuerte es un regalo que tú te das a ti mismo.

Tú y solo tú eres responsable por tu salud y bienestar total. Eres tú quien escoge hacer ejercicios, no fumar, tomar en moderación, comer saludable, rezar o meditar, usar tu mente, reflexionar y hacer ajustes, y ser el mejor, la expresión más fuerte de ti mismo... O no. ¿Qué selección harás?

Reimpresa de Huffingtonpost.com,
escrito por Amy Mitchell,
con fecha de noviembre del 2015.



LIVING!
with HEMOPHILIA

Looking for a new, fresh perspective on living with hemophilia?

Introducing your all NEW guide to **Living With Hemophilia**

Discover the new online destination for learning about hemophilia, living a healthy life and even leading in the hemophilia community. It's all at the new LivingWithHemophilia.com. Our site has been totally redesigned to give you more of the information you want and less of the stuff you don't want.

See What's New at

www.LivingWithHemophilia.com



Save up to \$12,000 in 2016!

Eligible patients can save up to \$12,000 annually
on co-pay, deductible, and coinsurance costs
with the Pfizer Factor Savings Card.

Get your card online now...



Scan the QR code or visit
PfizerFactorSavingsCard.com
to download your card today.*



Beginning in 2016 (follow these steps):

1. Get your prescription for a Pfizer factor product from your doctor.
2. Visit PfizerFactorSavingsCard.com and fill out a brief registration form.[†]
3. Save and print your card right from your computer. The card is now activated.
4. Keep your card and use it for every purchase until the maximum benefit has been reached or the card has expired, whichever comes first.

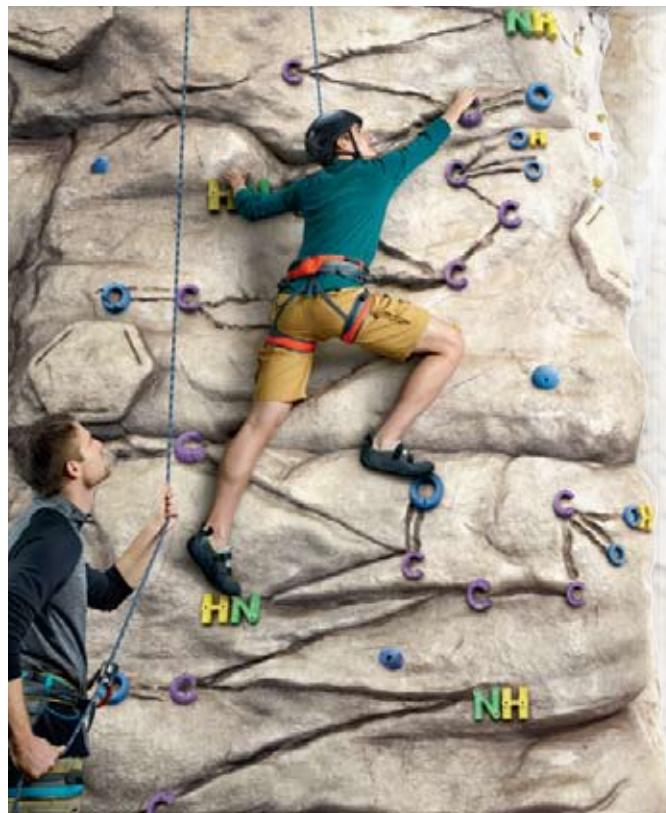
This card will be accepted only at participating pharmacies. This card is not health insurance.

No membership fees. You will receive a total benefit of \$12,000 per calendar year, or the amount of your co-pay over one year, less a patient financial responsibility of \$10 per month, whichever is less.

If you have any questions about the use of the Pfizer Factor Savings Card, please call 1-888-240-9040 or send questions to: Pfizer Factor Savings Program, 6501 Weston Parkway, Suite 370, Cary, NC 27513. The Pfizer Factor Savings Card cannot be combined with other offers and is limited to one per person.

*Terms and conditions apply; visit PfizerFactorSavingsCard.com for complete terms and conditions. For commercially insured only. Medicare/Medicaid beneficiaries are not eligible.

[†]You can also request a card from your doctor, or by calling 1-855-PFZ-HEMO.



For adults and children with hemophilia A

REACH HIGHER

With the Long-lasting Protection of AFSTYLA

**2X
WEEKLY
AVAILABLE**

FDA-approved for
dosing 2 or 3 times
a week

**ZERO
BLEEDS
(median ASR*)**

In clinical trials,
whether dosed
2 or 3 times a week

**COMPARABLE TO
NATURAL
FACTOR
VIII**

Identical to
natural Factor VIII
once activated

**Zero inhibitors observed—Low incidence
of side effects in clinical trials**

In clinical trials, dizziness and allergic reactions
were the most common side effects.

Visit AFSTYLA.com to sign up for the latest news

*Annualized spontaneous bleeding rate in clinical trials (interquartile range [IQR]=0–2.4 for patients ≥12 years; 0–2.2 for patients <12 years).

Important Safety Information

AFSTYLA is used to treat and control bleeding episodes in people with hemophilia A. Used regularly (prophylaxis), AFSTYLA can reduce the number of bleeding episodes and the risk of joint damage due to bleeding. Your doctor might also give you AFSTYLA before surgical procedures.

AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition.

Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

Immediately stop treatment and contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against FVIII, which could stop AFSTYLA from working properly. You might need to be tested for inhibitors from time to time. Contact your healthcare provider if bleeding does not stop after taking AFSTYLA.

In clinical trials, dizziness and allergic reactions were the most common side effects. However, these are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

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 the following brief summary of full prescribing information on the adjacent page, and the full prescribing information, including patient product information, at AFSTYLA.com.

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www.CSLBehring-us.com www.AFSTYLA.com AFS16-05-0084 5/2016

AFSTYLA®
Antihemophilic Factor
(Recombinant), Single Chain

HASDC 2017 CALENDAR OF EVENTS

March 4	Children's Hospital Los Angeles Hemophilia Family Day	Los Angeles, CA
March 8-10	National Hemophilia Foundation's Washington Days	Washington, DC
March 18	Family Education Day	San Diego Zoo
April	Educational Dinner Program (sponsored by Bayer Healthcare)	Location TBD
April 6-9	Hemophilia Federation of America Symposium	Providence, RI
April	Charity Spin Class	Rush Cycle – Carmel Valley
April	Backpacks & Bleeders	Location TBD
April 17	World Hemophilia Day	---
April 28-30	NOW Conference (National Outreach for VWD)	Phoenix, AZ
May 8-10	Hemophilia Council of California's Future Leaders Program	Sacramento, CA
May 10	Hemophilia Council of California's Legislative Day	Sacramento, CA
May 23	Charity Golf Tournament	The Crosby at Rancho Santa Fe
June	Backpacks & Bleeders	Location TBD
June	Women's Educational Retreat	Location TBD
July 8-12	Teen Camp on the American River – South Fork	Lotus, CA
July	Educational Dinner Program (sponsored by CSL Behring)	Location TBD
July 22-29	Hemophilia Council of California's California Coastal Ride	Sacramento to San Diego
August	Summer Beach Party	Location TBD
August	Educational Dinner Program (sponsored by Pfizer Hemophilia)	Location TBD
August 13-18	Camp Pascucci at YMCA Camp Whittle	Fawnskin, CA
August 24-26	National Hemophilia Foundation's Annual Meeting	Chicago, IL
September 15-17	Familia de Sangre 2017	Anaheim, CA
September	UC San Diego Health HTC Patient Wellness & Education Day	Location TBD
October 14	San Diego Hemophilia Walk	Liberty Station Park
October	Backpacks & Bleeders	Location TBD
October	Rady Children's Hospital HTC Family Day	Rady Children's Hospital
October 26	Educational Dinner Program (sponsored by Bioverativ)	Location TBD
November	Industry Symposium	Location TBD
November	Holiday Toy Drive	---
December	Educational Dinner Program (sponsored by Novo Nordisk)	Location TBD
December 9	Holiday Celebration	Handlery Hotel, Mission Valley

Subject to change. Advance registration is required for all events.
Please visit our website for event details and online registration - www.hasdc.org/events



Hemophilia Association of San Diego County
3550 Camino Del Rio North, Suite 105
San Diego, California 92108

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RED TIE CHALLENGE™ HOW DO YOU WEAR A RED TIE? REDTIECHALLENGE.ORG

WHAT IS THE RED TIE CHALLENGE?

A movement created by the bleeding disorders community and the National Hemophilia Foundation (NHF) to start a conversation about inheritable bleeding disorders and support all people living with bleeding disorders around the world.

WHAT ARE INHERITABLE BLEEDING DISORDERS?

Hemophilia, von Willebrand disease and rare factor deficiencies—all of which prevent the blood from clotting normally—can result in extended bleeding after injury, surgery, or trauma, and can be fatal if not treated effectively.

WHY THE RED TIE?

Because it symbolizes the blood ties that bind over 3 million Americans to our community.

TAKE THE CHALLENGE, LOOP-BY-LOOP!

- Accept the Challenge and get a Red Tie.
- Get creative and show how you wear that tie!
- Record your best tie look, pledge to support the bleeding disorders community, and challenge a few friends.
- Post your video with #RedTieChallenge, challenge your followers, and think about making a donation at redtiechallenge.org.

[Twitter icon](#) [Facebook icon](#) [YouTube icon](#) [Instagram icon](#)



"This has been the healthiest year of my entire life."

—Peter

Peter suffers from severe hemophilia. An immigrant from the Phillipines, he was not aware of the resources available in the US to help him and spent many long, frustrating hours at the hospital in order to receive the factor he needed. In 2016 he searched the internet, found Herndon Pharmacy and is now receiving the medication and attention he desperately required.

As a Bleeding Disorder Specialty Pharmacy, we believe there are underserved patients amongst us.

And we have a **passion** for service! We only hire people who believe what we believe! In what will be a lifetime of treatment, we look forward to partnering with our patients to provide the best care possible.

"Thank you Herndon Pharmacy, for changing my life."



ONE MISSION. ONE PASSION.

1827 E. Fir, Suite 101, Fresno, Ca 93720

Toll Free (877) 432-6250

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