

# 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 35 Issue 3 2015**



## BIKING FOR BLEEDERS 2015

**22 RIDERS • 7 DAYS • 572 MILES • 20 VOLUNTEERS • \$127,000 RAISED**

2015 marked the 14th year of Biking for Bleeders, a bike ride supporting those with hemophilia, von Willebrand Disease and all other bleeding disorders. Biking for Bleeders is a fitness challenge benefiting all four California Hemophilia Chapters and the Hemophilia Council of California. Recreational and semi-professional cyclists rode over 500 miles from San Francisco to San Diego in one week to support and raise awareness for the bleeding disorders community.

The ride began with a kick-off dinner on July 25 in San Francisco and concluded on August 1 with a welcome picnic in San Diego. Riders enjoyed the seven-day journey along California's majestic Highway 1 – Santa Cruz, Big Sur, Monterey, San Simeon, Pismo Beach, Santa

Barbara, and Dana Point – pedaling through the rugged mountains of the north to the bustling beach cities of the south. This beautiful coastal adventure tested and challenged each rider.

The Hemophilia Council of California (HCC) is a collaboration of the four hemophilia chapters serving California. HCC's mission is to support the four California hemophilia chapters with advocacy at the state and federal levels, leadership programs, and improve the quality of life of people living with a bleeding disorder.

Visit the website [www.bikingforbleeders.org](http://www.bikingforbleeders.org) or contact the HASDC office 619.325.3570 for information on joining the event next year as a rider or volunteer.

### In This Issue



Shelley Flores  
page 3



Save One Life  
page 4



Thinking of a Tattoo?  
page 7

# Save the Date

## Women's Educational Retreat

Saturday, November 7

9:30 am – 7:00 pm

Hyatt Regency Mission Bay

The Hemophilia Association of San Diego County will hold our first **Women's Educational Retreat** this fall. Participants will learn more about bleeding disorders, share information, gain support from their peers, and bond with other women in the bleeding disorders community. The event will include a hemophilia mom discussing the importance of being a strong advocate for your child, sessions on improving your wellness, scrumptious meals and some special pampering.

All women and girls affected by a bleeding disorder, including diagnosed, undiagnosed, carriers, family members and care-givers ages 14+ are welcome to attend.

---

Visit [www.hasdc.org/events](http://www.hasdc.org/events)  
HASDC office at 619.325.3570  
for more information

---

Event Sponsored by  
**CSL Behring**

### DISCLAIMERS

The Hemophilia Association of San Diego County (HASDC) does not endorse any particular pharmaceutical manufacturer or home care company.

**PLEASE NOTE:** The companies whose advertisements are listed herein have purchased this space, and are NEVER provided with members' names, addresses or any other personal details. Paid advertisements and paid inserts should not be interpreted as a recommendation from HASDC, nor do we accept responsibility for the accuracy of any claims made by paid advertisements or paid inserts.

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.

MATERIAL PRINTED IN THIS PUBLICATION  
MAY BE REPRINTED WITH THE EXPRESS PRIOR WRITTEN  
PERMISSION FROM THE EXECUTIVE DIRECTOR.  
NUMBER AND QUARTERLY DATE MUST BE INCLUDED.



### Officers

President: Sean Pentz  
[aseanpentz@gmail.com](mailto:aseanpentz@gmail.com)

Vice President: Yvette Bryant  
[yvbryant@yahoo.com](mailto:yvbryant@yahoo.com)

Treasurer: Nicole Chen  
[nicole.chen@tgg-accounting.com](mailto:nicole.chen@tgg-accounting.com)

Secretary: Shelley Flores  
[hrrsgrl@verizon.net](mailto:hrrsgrl@verizon.net)

### Directors at Large

Misty McCartney  
Renatto Medranda  
Vernon Polk

### Staff

Executive Director: Nooshin Kosar  
[nooshin@hasdc.org](mailto:nooshin@hasdc.org)

Program Coordinator: Lisa Heffernan  
[lisa@hasdc.org](mailto:lisa@hasdc.org)

### Graphic Design & Printing

PrintDiego  
[info@printdiego.com](mailto:info@printdiego.com)



is published quarterly by

### The Hemophilia Association of San Diego County (HASDC)

Monthly mailings and invitations will be sent in the months between newsletters when information pertinent to the bleeding disorders community is available.

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

**Website: [www.hasdc.org](http://www.hasdc.org)**



find us on facebook



@HemophiliaSD



@hasdc



# DIRECTOR'S CORNER

By Nooshin Kosar, HASDC Executive Director



This summer has been busy with Camp Pascucci, Teen Camp, Biking for Bleeders and our first Backpacks & Bleeders event. We had a great time encouraging everyone to get outdoors and enjoy what nature has to offer. We look forward to holding more Backpacks & Bleeders events throughout the rest of 2015 and into 2016.

We would like to express a huge thank to the following Teen Camp sponsors; Baxalta, Bayer, CSL Behring, Novo Nordisk and our Kid to Camp Campaign. Without our sponsors, we would not have been able to have such a successful second year of teen camping. We look forward to expanding the program and activities in the years to come.

In addition, our summer thank yous aren't complete without thanking those riders that rode over 500 miles from San Francisco to San Diego in support of HASDC. Scott Holland, Brett Clement, Jim Redquest, Daniel Rojas, Shane McCartney, Lee Worthy and Tim Roth rode each day, some more difficult than others but always with a smile and determination to ride their best. It is not an easy week but a meaningful one as everyone works to spread awareness for the bleeding disorders community.

As we enter fall, I hope to see you at one of our remaining events this year whether it's at the walk, our new Women's Educational Retreat or our Holiday Celebration.



Scott Holland



Brett Clement



Jim Redquest



Daniel Rojas



Shane McCartney

## HASDC BOARD MEMBER SPOTLIGHT

"I love the hemophilia community and all those people who work so hard to keep it safe," shared Shelley Flores. Shelley has been active with the Hemophilia Association of San Diego County Board of Directors for more than fifteen years. She currently serves as secretary, attending board meetings, taking notes and recording board actions, in addition to making a financial commitment to the organization and assisting with committees and events.

Shelley is a Southern California girl, she was born in Los Angeles and grew up in La Habra. She and her husband Steve have been married for twenty-five years and have two sons, Adrian, age 33 and Jake, age 25. Shelley's connection to bleeding disorders

began when her oldest son was diagnosed with severe Hemophilia A at the age of two months. Both Adrian and Jake have factor VIII deficiency.

In addition to her work with HASDC, Shelley serves on the board of the Hemophilia Council of California. She also enjoys spending time with her family, walking her three Boston Terriers (who rule the house) and riding her two horses. Please say hello to Shelley at our next HASDC event.



### DESTACAMOS A MIEMBRO DE LA MESA DIRECTIVA DE HASDC

"Amo a la comunidad de hemofilia y a todas aquellas personas que hacen una gran labor para mantenerla segura," compartió Shelley Flores. Shelley ha formado parte de La Mesa Directiva de La Asociación de Hemofilia del Condado de San Diego por más de quince años. Actualmente es la secretaria, asistiendo a reuniones de La Mesa Directiva, tomando notas y documentando las acciones tomadas por los directores, además de mantener un compromiso monetario con la organización y ayudar con comités y eventos.

Shelley es una muchacha del Sur de California, nació en Los Angeles y creció en La Habra. Ella y su esposo Steve han estado

casados por 25 años y tienen dos hijos; Adrian de 33 años y Jake de 25 años. La conexión de Shelley con desordenes sanguíneos empezó cuando su hijo mayor fue diagnosticado con hemofilia A severa a la edad de dos meses. Ambos, Adrian y Jake tienen el factor deficiente VIII.

Además de su trabajo con HASDC, Shelley sirve en La Mesa Directiva del Concejo de Hemofilia de California. También le encanta pasar tiempo con su familia, caminar a sus tres Boston Terriers (quienes mandan en la casa), montar a sus dos caballos. Por favor dígame hola a Shelley en el próximo evento de HASDC.

# HASDC SUPPORTS SAVE ONE LIFE

By Lisa Heffernan, HASDC Program Coordinator

Save One Life is an international nonprofit organization that offers individuals, families, companies and organizations the opportunity to sponsor a child or adult with a bleeding disorder in a developing country. Unlike many other programs where sponsor funds are pooled, Save One Life beneficiaries receive money directly from their sponsors, with only a small percentage given to the national or local hemophilia nonprofit organization that registers and cares for them.

The Hemophilia Association of San Diego County proudly supports the Save One Life organization, sponsoring an adult in Africa living with a bleeding disorder. HASDC provides annual support to assist Zakayo and the Jose Memorial Hemophilia Society Kenya with payment for medicine, transportation to the clinic, and nutritious food.

An Update on Zakayo: Zakayo Chege Wanjiku lives in Kenya, Africa and is now 25 years old. He remains unemployed at this time due to some challenges with mental illness. Zakayo had three major bleeding episodes last year, visited the clinic 15 times,

and was hospitalized three times. He had a gum and leg bleed and he broke his leg, which took a long time to heal because of his condition. There was a shortage of factor, so he did not receive infusions - he had to manage on painkillers. Throughout the year, he was vomiting blood which lead to anemia. Zakayo continues to need physiotherapy on his knee, but is not receiving treatment. Zakayo lives with his mother and two brothers. His mother works as a casual laborer to support the family and earns \$95 per month. His brother has hemophilia and most of the income goes to medical expenses. Despite their many challenges, the family was able to purchase a four room home this past year.

Caring for people with hemophilia around the world – one at a time. For under \$1 a day, you can support a person with hemophilia in a developing county and offer compassion, friendship and hope for the future. Please visit the website [www.saveonelifenet.net](http://www.saveonelifenet.net) for more information on the organization and how you can become involved.



## HASDC APOYA A SALVAR UNA VIDA

Salvar Una Vida (Save One Life) es una organización internacional sin fines lucrativos que les ofrece la oportunidad a individuos, familias, compañías y organizaciones de patrocinar a un niño o adulto con desorden sanguíneo de un país en desarrollo. A diferencia de muchos otros programas patrocinadores donde forman un fondo común, los beneficiarios de Salve Una Vida reciben el dinero directamente de sus patrocinadores con solo un pequeño porcentaje siendo dado a la organización de hemofilia sin fines lucrativos nacional o local que los inscribe y los ayuda.

La Asociación de Hemofilia del Condado de San Diego orgullosamente apoya a la organización Salve Una Vida, patrocinando un adulto en África que vive con

un desorden sanguíneo. HASDC provee ayuda anual para asistir a Zakayo y la Jose Memorial Hemophilia Society Kenya, pagando por las medicinas, transportación a la clínica, y alimentos nutritivos.

Lo más reciente sobre Zakayo: Zakayo Chege Wanjiku vive en Kenia, África y ahora tiene 25 años. Actualmente sigue sin trabajo debido a luchas con trastornos mentales. El año pasado Zakayo tuvo tres serios episodios de hemorragia, visitó la clínica 15 veces y fue hospitalizado tres veces. Tuvo hemorragias de la encía y la pierna y se fracturó la pierna, la cual le tomó tiempo para sanar debido a su condición. Hubo una escasez de factor así que no recibió infusiones – Se las tuvo que arreglar con analgésicos. Estuvo vomitando sangre durante el transcurso del año lo cual resultó en anemia. Zakayo continúa necesitando fisioterapia en su rodilla, pero no está recibiendo tratamiento. Zakayo vive con su mamá y dos hermanos. Su mamá hace trabajos laborales para mantener a la familia y gana \$95 al mes. Su hermano tiene hemofilia y la mayor parte de los ingresos



se van en gastos médicos. A pesar de todos estos retos, la familia pudo comprar una casa de cuatro cuartos el año pasado.

Ayudando a gente con hemofilia alrededor del mundo – una persona a la vez. Con menos de \$1 al día, usted puede ayudar a una persona con hemofilia en un país en desarrollo y ofrecer compasión, amistad y esperanza para el futuro. Por favor visite este sitio web [www.saveonelifenet.net](http://www.saveonelifenet.net) para más información acerca de esta organización y cómo puede ayudar.



# SAN DIEGO HEMOPHILIA WALK 2015

Help raise funds and awareness for bleeding disorders in San Diego!

10:00 am • Saturday, October 10

## Why participate?

The Hemophilia Association of San Diego County is proud to announce our 3rd annual San Diego Hemophilia Walk. Funds raised will be used to find better treatments and cures for bleeding and clotting disorders, and to prevent complications of these disorders through awareness, education, advocacy and research. The Walk is a fun event—bring the family and your dog and enjoy a beautiful morning on the San Diego Bay!

## How do I get started?

- Visit the Walk website [www.hemophilia.org/walk](http://www.hemophilia.org/walk)
- Select “San Diego” on the home page
- Register as a walker and start raising funds
- Create a walk team, start recruiting your teammates and raising funds
- Donate to a walker or team that has already registered

Walk as an individual, start a team or become a sponsor! Start now, the Walk is only 3 months away. The website Fundraising Kit includes fundraising ideas, sample letters and emails, social networking ideas, facts and figures – everything you need to be successful and raise funds for the bleeding disorders community.

Walk length: 5K (3.1 miles) • Location: Liberty Station—2455 Cushing Road, SD 92106  
Vendor Fair • Walk T-shirt with \$20+ Donation • Give-aways • Food • Prizes for Top Fundraisers

**🔥 Register now—[www.hemophilia.org/walk](http://www.hemophilia.org/walk) 🔥**



# WELLNESS CORNER

By Lisa Heffernan, HASDC Program Coordinator

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

## STAYING HEALTHY DURING THE HOLIDAYS

The holidays are upon us, and staying healthy during this season can be challenging. While this is true for the general population, it is especially important for individuals with hemophilia or other bleeding disorders. We understand the importance that activity and a nutritious diet play in maintaining a healthy weight, decreasing the number of bleeding episodes and amount of factor needed to prevent or control a bleed.

For many of us, food represents comfort and the various smells of holidays trigger numerous joyous memories of childhood. However, studies have shown that a few extra cookies or a slice a pie each day during the holiday season can easily add 4-5 unwanted pounds in only a few short weeks.

Well, here a few tips to help you stay healthy and not overeat during the holidays:

**1. Eat Small Amounts of Those Comfort Foods You Love** – Don't deprive yourself. Enjoy a small piece of pie or one cookie, but not both. Select one item that looks yummy and that you know you will enjoy. Fill your plate with healthy vegetables, fruits, whole grain crackers, cheese and lean meats

**2. Don't Hang Around the Table or Buffet** – Mingle with friends and family. I know it is hard to resist the delicious food calling your name. Choose your items to eat, and then move to a different part of the room if you can. In most cases, you will think twice

before walking back to the table.

**3. Drink Lots of Water** – Mild dehydration can sometimes feel like hunger, so avoid this feeling and drink water. Water can also be used to slow down your eating by taking a sip or two between bites. Also have a glass or two of water before you start drinking alcoholic beverages, and have one in between drinks to slow down your alcohol consumption as well. Don't forget, cocktails add calories, so be mindful.

**4. Don't Skip Meals** – Breakfast is still very important. Don't save those calories for a big holiday meal. Not only can skipping meals make you feel tired and crabby, but it can also make you overeat when you finally have a meal. For breakfast, have a bowl of cereal or oatmeal, eat raisins and nuts for a snack, and enjoy a light salad for lunch.

**5. Stay Physically Active** – Have fun doing holiday inspired activities. Enjoy ice skating, walking the mall, going to view the holiday lights in your neighborhood, gathering pine cones or sea shells, or building a snowman out of sand!

## ESQUINA DEL BIENESTAR

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

## MANTENIENDOSE SALUDABLE DURANTE LOS DIAS FESTIVOS

Los días festivos están por llegar, y mantenerse saludable durante esta temporada puede ser un reto. Mientras que esto es cierto para el público en general, es especialmente importante para individuos con hemofilia u otros desordenes sanguíneos. Nosotros entendemos la importancia que mantenerse activo y tener una dieta nutritiva juegan en mantener un peso saludable, disminuir los episodios hemorrágicos y la cantidad de factor necesario para prevenir o controlar una hemorragia.

Para muchos de nosotros la comida representa confort, y los muchos aromas de los días festivos nos recuerdan momentos alegres de nuestra niñez. Sin embargo, estudios han demostrado que unos cuantos dulces de más o un trozo de pastel cada día durante los días festivos pueden fácilmente añadir de 4 a 5 libras no deseadas en esas pocas semanas.

Muy bien, aquí hay algunos consejos para ayudarle a mantenerse saludable y no comer de más durante los días festivos:

**1. Coma pequeñas porciones de esas comidas que le encantan** – No se prive. Disfrute de un pequeño trozo de pastel o una galleta pero no de ambos. Escoja algo que se vea sabroso y del cual sabe que disfrutará. Llene su plato de vegetales saludables, frutas, galletas de granos integrales, queso y carnes sin grasa.

**2. Aléjese de la mesa o bufete** – Circule entre amistades y familiares. Sé que es difícil de resistir esas deliciosas comidas diciendo su nombre. Escoja lo que va a comer y muévase a otra

parte del salón si puede. En general, lo pensará dos veces antes de regresar a la mesa de nuevo.

**3. Tome mucha agua** – Un leve caso de deshidratación algunas veces se siente como que si tuviese hambre; tome agua para evitar sentirse así. También puede usar el agua para retrasar lo que come; tome sorbos entre cucharadas de comida. Tome uno o dos vasos de agua antes de empezar a tomar bebidas alcohólicas y tome agua entre bebidas para retrasar el consumo de alcohol. ¡No se olvide, cocteles añaden calorías, tenga cuidado!

**4. No deje de comer** – El desayuno es muy importante. No guarde esas calorías para una inmensa comida festiva. El dejar de comer una comida no solo la(o) hace sentirse cansada(o) y de mal humor, pero también termina comiendo de más cuando al fin decide comer. Para el desayuno, coma un plato de cereal o avena, de merienda, coma pasas y nueces, disfrute de una ensalada liviana en el almuerzo.

**5. Manténgase activa(o) físicamente** – Diviértase haciendo actividades inspiradas por las festividades. Disfrute patinando en hielo, caminando por el centro comercial (mall), yendo a ver las luces festivas en el vecindario, recogiendo conos de pinos o conchas de mar, o construyendo un hombre de nieve hecho con arena!



# ONE WOMAN'S STORY

By Raeann Purnell, Oceanside resident, age 21

I have always been so proud to be a part of the San Diego bleeding disorder community, and what better way to that show that pride than getting a tattoo of the Association's blood drop? Growing up in Southern California I always wanted a beach related tattoo. Knowing others with bleeding disorder themed tattoos, I knew I wanted my tattoo to help express my pride to the world. Having a bleeding disorder is something to be proud of! The bonds you make within this community are lasting. I wanted to have a permanent reminder of what it meant to me to be a

part of this amazing San Diego bleeding disorders community.

I researched the guidelines, took the necessary precautions and got inked! As the writer Jack London so profoundly said "show me a man with a tattoo and I'll show you a man with an interesting past." If you are over 18 and want a tattoo, be smart and talk to your doctor, your hemophilia treatment center and your tattoo artist to make sure a tattoo is healthy and safe for you.



## LA HISTORIA DE UNA MUJER

Siempre he estado muy orgullosa de ser parte de la comunidad de desórdenes sanguíneos de San Diego, y que mejor manera de demostrar ese orgullo que tatuándome la gota de sangre de La Asociación. Creciendo en el Sur de California siempre quise un tatuaje relacionado con la playa. Al conocer a otros desplegando tatuajes de desórdenes sanguíneos, supe que quería que mi tatuaje ayudara a expresar mi orgullo al mundo. ¡Tener un desorden sanguíneo es algo de lo cual se debe estar orgulloso! Los vínculos que formamos dentro de esta comunidad son duraderos. Quería tener un recuerdo permanente de lo que significa ser parte de esta maravillosa comunidad de desórdenes sanguíneos de San Diego.

¡Investigue las pautas a seguir, tome las precauciones necesarias y me tatué! Como el escritor Jack London tan profundamente dijo "muéstrame a un hombre con un tatuaje y te mostrare a un hombre con un pasado interesante" ("show me a man with a tattoo and I'll show you a man with an interesting past.") Si eres mayor de 18 años y quieres un tatuaje, se inteligente y habla con tu doctor, tu Centro de tratamiento para hemofilia y tu artista de tatuajes para asegurarte de que un tatuaje es sano y sin peligros para ti.

## ONE MISSION. ONE PASSION.



We know hemophilia because we live it. Our president and CEO, his son and even some of our team and their families have hemophilia.

## Hemophilia Homecare. It's what we know. It's all we do.

Our over twenty years of providing a personalized service model has led us to be considered one of California's premier hemophilia homecare service providers. Patients receive their care from pharmacists experienced in bleeding disorders, local hemophilia field care specialists, and reimbursement professionals who provide education on co-pay and resource assistance.

Superior customer service is the standard at Herndon Pharmacy. We strive to make a difference in your life by coordinating a comprehensive care plan between you, your physician and our clinical team.

We are Herndon Pharmacy, and we have only one priority—you.

 **HERNDON**  
PHARMACY  
1827 E. Fir, Suite 101, Fresno, Ca 93720  
Toll Free (877) 432-6250  
www.herndonpharmacy.com

Employment opportunities available. Contact us by phone or website.



## JOIN OUR VOLUNTEER TEAM!

We invite you to join the HASDC team as a volunteer. Many volunteer opportunities are available to contribute back to the community in a very special way.



To learn more information  
or volunteer please contact  
**Lisa Heffernan**  
lisa@hasdc.org  
619.325.3570

## FROM THE UCSD HEMOPHILIA & THROMBOSIS TREATMENT CENTER

By Moniqa Diaz, Administrative Assistant; Sally Holle, RN, Hemophilia Administrative Nurse & Annette von Drygalski, MD, Director

Greetings from the UC San Diego Hemophilia and Thrombosis Treatment Center: After patiently waiting for walls to be constructed and flooring installed we are excited to announce that we have moved! Our new space was not the only thing under construction! We are also undergoing many changes as we continue to build our program and expand services to the bleeding disorders community.

Our team strives to vigorously attend to our patients. Taking care of their medical needs, assisting with social and insurance matters, enable clotting factor prescriptions and infusions to ensure overall well-being. Growing demands from our community, patients and families means adjustments to our personnel and services. Expect to meet new staff, expanded services and experience more innovations as we continue to give you the best.

Initiated last fall, "Hemophilia Vertical", is a rock climbing program for patients with hemophilia in collaboration with the Hemophilia Treatment Center at the Ludwig Maximilians University at Munich, Germany. This personalized goal-directed curriculum offers, upon successful completion, muscular strength, flexibility, concentration and dexterity. This motivating experience creates a sense of responsibility for self and other climbers. Next session is anticipated to start in October 2015.

Our Infusion Classes and personal Infusion Services were successful in training over 50 patients and family on how to infuse. Mike, our dedicated home infusion nurse will meet you wherever you need to be infused. Along with HASDC and Rady Children's Hospital we hosted the first ever-community sponsored infusion class. We have since held more classes, also in El Centro and at Camp Pascucci. New classes start in the fall. We invite you to train, re-train and rotate your veins. Private lessons available.

Our Physical Therapy program with Colleen remediates impairments and promotes mobility, function and quality of life through examination, diagnosis, and physical intervention. Colleen assists with post-surgical joint recovery and provides exercises for any condition. Come build up your muscles with her!

Our center also offers rapid bleed detection and diagnosis of synovitis and other painful joint conditions with high resolution musculoskeletal ultrasound. A leader in this modality, we share our expertise by providing courses to hemophilia providers all over the world. This hands-on musculoskeletal ultrasound training course is the only one of its kind. We thank our volunteer patients for sharing the insights of their joints with the international hemophilia provider community. More to come on this wonderful innovation to care.

## FROM RADY CHILDREN'S HOSPITAL HEMOPHILIA & THROMBOSIS TREATMENT CENTER

By Courtney Thornburg, MD

### BLOOD CLOT PREVENTION

We take care of many children with a bleeding disorder where the blood does not clot well enough. We ALSO take care of children who have too much blood clotting. Sometimes the blood clots so much that it blocks blood flow. If this occurs in a vein (tube that takes blood back to the heart), then the leg can swell and be hot and painful. People who have blood clots are prescribed blood thinners.

### WHO GETS BLOOD CLOTS?

Blood clots are more common in adults than children, but anyone can get a blood clot.

### WHAT INCREASES THE RISK OF BLOOD CLOTS?

Smoking, obesity, immobility, trauma, surgery and severe infection.

Some families have a predisposition to blood clots due to changes in the blood clotting genes.

### WHAT ARE WE DOING TO PREVENT CLOTS?

Dr. Thornburg is working with doctors and nurses at Rady Children's Hospital to prevent clots in hospitalized children. Strategies that we use to prevent blood clots include the following: walking, compression devices (worn on the leg to keep the blood flowing) and blood thinners.

More information about blood clots can be found at [www.clotconnect.com](http://www.clotconnect.com) and [www.stoptheclot.com](http://www.stoptheclot.com).

### STAFF SPOTLIGHT - ROSALIE BROOKS, RN

Rosalie Brooks is the Nurse Case Manager for children with blood clots at Rady Children's Hospital San Diego. She has been a part of the Hemophilia and Thrombosis Treatment Center since 2009. She provided nursing care and education at Camp Pascucci in Big Bear this year. Rosalie lives in Escondido with her husband and two children. Rosalie and her husband stay very active- leading their children's Girl Scout and Boy Scout troops and attending their children's band and orchestra events. Rosalie also enjoys crochet, photography, archery, watching movies and attending Comic Con. She looks forward to helping you at your next appointment!



**Baxalta**

**THE  
COUNTDOWN  
HAS BEGUN.**

For more information  
and updates, sign up at  
**ADYNOVATE.com**

  
**ADYNOVATE**  
[Antihemophilic Factor  
(Recombinant), Pegylated]

# Start saving today.

Save up to \$5000 with the Pfizer Factor Savings Card.\*

Eligible patients can save up to \$5000 annually on co-pay, deductible, and coinsurance costs with the Pfizer Factor Savings Card.

## How the card works:

1. Get your prescription for factor from your doctor
2. Visit [PfizerFactorSavingsCard.com](http://PfizerFactorSavingsCard.com) and fill out a brief registration form. You can also request a card from your doctor, or by calling **1-855-PFZ-HEMO**
3. Save and print your card right from your computer
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

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. This card will be accepted only at participating pharmacies. This card is not health insurance. No membership fees apply.

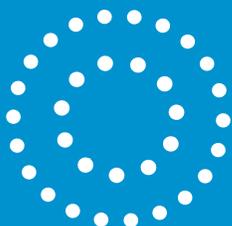
\*Terms and conditions apply; visit [PfizerFactorSavingsCard.com](http://PfizerFactorSavingsCard.com) for complete terms and conditions. For commercially insured only. Medicare/Medicaid beneficiaries are not eligible.



Get your card online now...



Scan the QR code or visit [PfizerFactorSavingsCard.com](http://PfizerFactorSavingsCard.com) to download your card today.





## 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.

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

# Meet Maria, your CoRe Manager



Hello! I'm Maria Perez, and I am a bi-lingual registered nurse. I'm also a CoRe Manager for Biogen. It is my job to connect you with others in the community, share insights taken from my personal experience, introduce our educational programs, and to support you on your journey. I am here so we can take action together!

.....

*Contact me!*

Maria.Perez@biogen.com | 323.236.1257

.....



Get to know us: [BiogenHemophilia.com/CoRes](http://BiogenHemophilia.com/CoRes)

© 2015 Biogen. Printed in U.S.A. 03/15 HEM-US-0156

 /BiogenHemophiliaCoRes

 /BiogenHemCoRes

INTRODUCING

# Grifols Pay As Little As \$0 Copay Programs

SAVINGS AVAILABLE IMMEDIATELY UPON ENROLLMENT



Call



1-877-264-1405  
AlphaNine SD Savings Card Program  
Help Desk

OR

Visit



[www.alphaninecard.com](http://www.alphaninecard.com)  
AlphaNine SD Savings Card Program  
Website

Call



1-877-255-4829  
ALPHANATE Savings Card Program  
Help Desk

OR

Visit



[www.alphanatecard.com](http://www.alphanatecard.com)  
ALPHANATE Savings Card Program  
Website

**AlphaNine<sup>®</sup> SD**  
Coagulation Factor IX (Human)

**Alphanate<sup>®</sup>**  
Antihemophilic Factor/von Willebrand  
Factor Complex (Human)

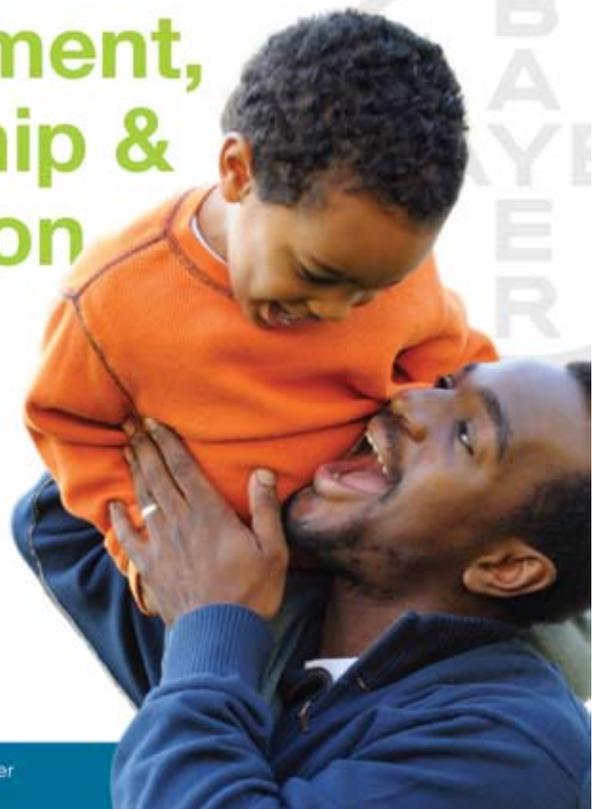
US/A8/0315/0011

## GRIFOLS

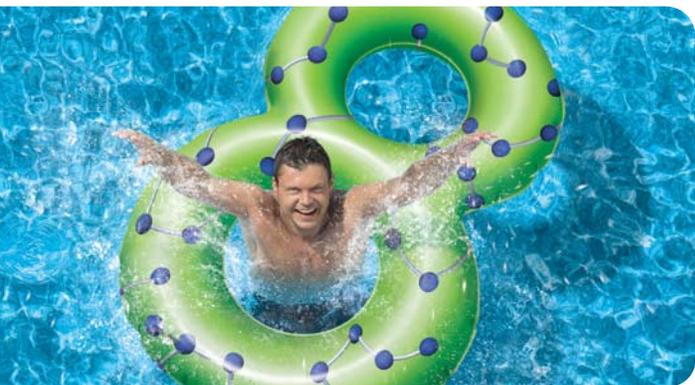


BAYER HEALTHCARE AND THE HEMOPHILIA COMMUNITY

**commitment,  
leadership &  
innovation**



For information on Bayer's Educational Patient and Community Resources, contact your Hematology Account Executive by calling **1-888-79-BAYER**.



Michael, 30 years old, lives with hemophilia A.

An injectable medicine used to control and prevent bleeding in people with hemophilia A

# Novoeight® — designed to fit into your world

## ✓ Purity

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

## ✓ Portability

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

## ✓ Reliability

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

<sup>a</sup>Compared with other recombinant factor VIII products.

<sup>b</sup>People 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.



Terms and conditions apply.

Visit [Novoeight.com](http://Novoeight.com) today to learn more.

## 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](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

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

Novoeight® is a registered trademark of Novo Nordisk Health Care AG.

© 2015 Novo Nordisk All rights reserved. 1114-00024070-1 April 2015



**novoeight®**  
Antihemophilic Factor  
(Recombinant)

# Our enduring commitment, brighter than ever.

**Baxalta**

**For more than 60 years, we've consistently pursued  
advancements in the treatment of bleeding conditions.**

Now, as Baxter's BioScience becomes Baxalta Incorporated, this proven heritage — along with the advancements we're making today to cultivate tomorrow's developments — fuels our global vision and promise: Our relentless desire to make a meaningful difference in the lives of real people — one person at a time. This promise to you can be seen in all we do, and helps to make us the company we are today.

**Miriam**  
Caregiver, Miami, FL

# HASDC 2015 CALENDAR OF EVENTS

Subject to change. Advance registration is required for all events. Please contact HASDC office for event details.

<b>September</b>	<b>Hispanic Education Day</b> <b>Día Educativo Hispano</b> (presented only in Spanish, sponsored by Baxalta)	September 19 Best Western Hacienda, Old Town
<b>October</b>	<b>San Diego Hemophilia Walk</b> <b>Paseo de Hemophilia de San Diego</b>	October 10 Liberty Station, San Diego
<b>October</b>	<b>Educational Dinner Program</b> <b>Programa Educativa y Cena</b> (sponsored by Baxalta)	October 15 Phil's BBQ, Point Loma
<b>November</b>	<b>NHF Regional Inhibitor Conference</b> <b>Conferencia Inhibitor Regional de NHF</b> (www.hemophilia.org/Events-Educational-Programs)	November 6-8 San Diego <i>National Hemophilia Foundation Event</i>
<b>November</b>	<b>Women's Education Retreat</b> <b>Retiro Educativo de las Mujeres</b> (new event, sponsored by CSL Behring)	November 7 Hyatt Regency Mission Bay
<b>November</b>	<b>Annual Toy Drive</b> <b>Coleta Annual de Juguetas</b>	October & November Drop donations @ HASDC by Dec 4
<b>December</b>	<b>Educational Dinner Program</b> <b>Programa Educativa y Cena</b> (sponsored by Novo Nordisk)	December 8 Gordon Biersch, Mission Valley
<b>December</b>	<b>Holiday Celebration</b> <b>Celebración de Navidad</b>	December 13 Handlery Hotel, Mission Valley

Please visit our website for event details and online registration.

[www.hasdc.org/events](http://www.hasdc.org/events)