



THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA'S

10<sup>TH</sup> ANNUAL

UNITE FOR BLEEDING DISORDERS WALK



SATURDAY, NOVEMBER 3<sup>RD</sup>, 2018 | GRIFFITH PARK

 **Hemophilia Foundation  
of Southern California**

 **Unite**  
for Bleeding Disorders

 **Shire**

## LETTER FROM THE EXECUTIVE DIRECTOR



One thing that we are incredibly passionate about are our vibrant and brave youth members of the Hemophilia Foundation of Southern California. We are committed to pouring resources into their education, support and self-esteem whether it's through our Teen Leadership Summit, legislative advocacy opportunities, or our most special Camp Blood Brothers and Sisters. Through our fabulous partnership with The Painted Turtle, our goal at camp is to empower our youth and encourage them to make new friends, try new things, build self-confidence, and become more independent in their medical care. Camp also creates a special community, a place where they feel included and not alone, where they are embraced and accepted for who they are which in turns helps them become ready to overcome challenges and embrace the new opportunities that they encounter every day. And, of course, it's all done in an environment that provides outstanding medical care and support for all the campers' needs. Youth are taught to self-infuse their medication/clotting factor which can be a life-saving technique for some, this accomplishment is then celebrated with the coveted "Big Stick Award". On behalf of all past and current campers, we thank you for your donations to enable us to host our Camp Blood Brothers and Sisters which will celebrate its 40th anniversary in 2019!

Michelle Kim, Esq.  
Executive Director

## LETTER FROM THE BOARD PRESIDENT



Friends of the Bleeding Disorders Community,

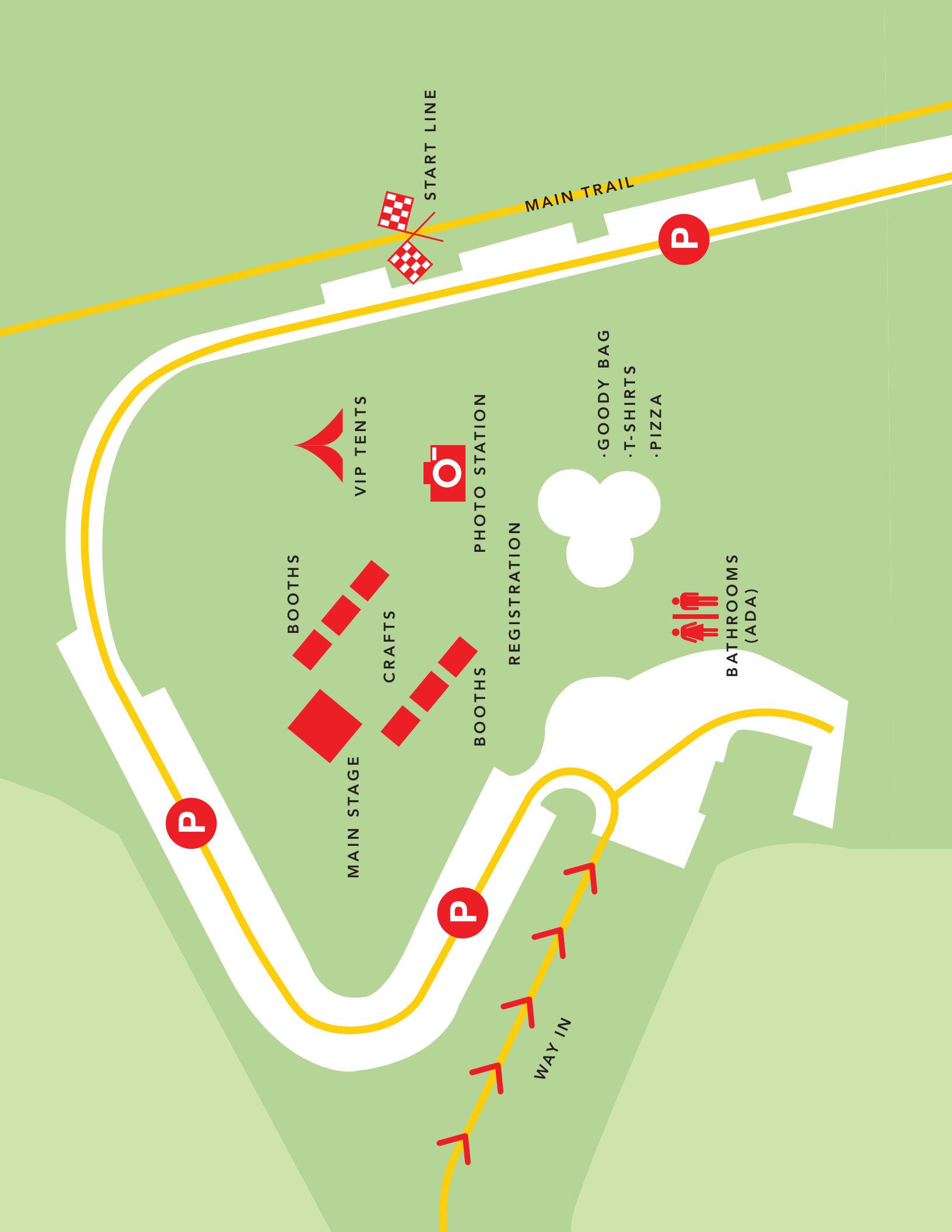
This is an incredible time in the history of bleeding disorders with changing and evolving treatments and even gene therapy in clinical trials. Despite all these potential changes, camp remains one of our most important and critical programs. Camp Blood Brothers & Sisters at the Painted Turtle has provided a safe and exciting adventure for our youth to have the camp experience with similarly diagnosed children. They encourage one another, build memories of a lifetime, learn skills to best treat their condition and have FUN! Additionally, we owe a great debt of gratitude to our doctors, nurses, pharmacists, volunteers and most of all DONORS. Without the support of our donors for over the past 39 year of camp and for our upcoming 40th year of camp these children would not have this opportunity. We can't imagine the positive impact camp has had on hundreds over the years. So, I urge all of you to dig deep, contact friends and family, use social media and together we can raise funds to ensure all of those impacted by Hemophilia and other bleeding disorders have the opportunity to attend camp.

Thank you from the bottom of My Heart,

Sandy Davis

## 2018 - 2019 CALENDAR

December 1	<b>Santa Barbara Snowflake Festival</b> <i>Santa Barbara Zoo • Santa Barbara, CA</i>
December 8	<b>Santa Ana Snowflake Festival</b> <i>Santa Ana Zoo • Santa Ana, CA</i>
January 19	<b>Industry Forum</b> <i>Mount Saint Mary's University • Los Angeles, CA</i>
February 13	<b>Mujeres Enlazadas por Sangre Dinner</b> <i>Inland Empire TBD</i>
February 23 Challenge	<b>SoCal EmPOWERment Forum &amp; 4th Annual Bloody Hot Salsa</b> <i>Pickwick Gardens • Burbank, CA</i>
March 23	<b>Women's Retreat</b> <i>TBD</i>



START LINE

MAIN TRAIL

P

VIP TENTS

BOOTHs

CRAFTs

MAIN STAGE

BOOTHs

PHOTO STATION

REGISTRATION

· GOODY BAG  
· T-SHIRTS  
· PIZZA

BATHROOMS  
(ADA)

P

P

WAY IN

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### Presenting Sponsor



### Partner Sponsor



### Official Sponsors



## Local Sponsors

### Gold Sponsors



### Popcorn Sponsor



### Silver Sponsors



### Bronze Sponsor



RESTAURANT  
BREWHOUSE

### Kilometer Sponsor



# WALK AGENDA

- 8:30 AM**      **Registration, Vendor Booths & Health Booths Open, Pinwheel Distribution**  
Popcorn sponsored by Shire
- 10:30 AM**      **National Anthem**  
*(Scout Burke, HFSC Community Member)*
- Welcome**  
*(Wayne Guzman, HFSC Board Member and Michelle Kim, Executive Director)*
- Top Team Award Presented by Shire - National Presenting Sponsor**  
*(Angela Yanez, Territory Business Manager, Los Angeles and Nate Osborne, Regional Business Director, Shire)*
- Top Individual Award Presented by CSL Behring - Local Gold Sponsor**  
*(Dayami Nickel, Manager, Coagulation Products, Los Angeles, CSL Behring)*
- Largest Team Award Presented by Grifols**  
*(Willie Zuniga, President, Grifols Biologics)*
- Best T-shirt Award Presented by Ameripharma - Local Gold Sponsor**  
*(Ameripharma)*
- Factor Club Winners**  
*(HFSC Board Members)*
- Why We Walk**  
*(Benjamin Cardenas, Community Member and Camper)*
- 
- (Jordana Zeger, Chief Operating Officer, National Hemophilia Foundation)*
- Pinwheel Ceremony**  
*(Scott Carthey, Community Member)*
- Warm Up**  
*(Brooke Walsh, Master Trainer and Community Member)*
- 11:00 AM**      **Walk Begins**
- 11:45 AM**      **Walk Ends, Booths Re-Open**  
*(Complimentary Popcorn, Pizza, Speedy Dogs Food Truck available for personal purchases)*
- 12:00 PM**      **Magic Show with Robert Ramirez**
- 12:30 PM**      **Departure**





# ADYNOVATE

[Antihemophilic Factor  
(Recombinant), PEGylated]

ADYNOVATE® is FDA approved for children and adults with hemophilia A

PROVEN PROPHYLAXIS +  
SIMPLE,\* TWICE-WEEKLY DOSING SCHEDULE =

*moments* **YOUR WAY**

\*ADYNOVATE allows you to infuse on the same 2 days every week. Work with your doctor to determine an infusion schedule that is appropriate for you.

The pediatric study of children <12 years of age (N=66) evaluated the immunogenicity, efficacy, PK (as compared to ADVATE® [Antihemophilic Factor (Recombinant)]), and safety of ADYNOVATE twice-weekly prophylaxis (40-60 IU/kg) and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.<sup>1,2</sup>

The pivotal trial of children and adults ≥12 years (N=137) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis (40-50 IU/kg) vs on-demand (10-60 IU/kg) treatment, and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.<sup>1</sup>

†Children (<12 years) experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds.<sup>1,3</sup>

†38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds<sup>1</sup>

Talk to your doctor to see if ADYNOVATE treatment may be right for you and visit [ADYNOVATE.com](http://ADYNOVATE.com)

## ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

### What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

### DETAILED IMPORTANT RISK INFORMATION

#### Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

#### What should I tell my HCP before using ADYNOVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

### What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

### What else should I know about ADYNOVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

### What are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

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.

For additional safety information, please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.

For full Prescribing Information, visit [www.ADYNOVATE.com](http://www.ADYNOVATE.com).

**References:** 1. ADYNOVATE Prescribing Information. 2. Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2017;23(2):238-246. 3. Data on file.



# ADYNOVATE

[Antihemophilic Factor  
(Recombinant), PEGylated]

## Patient Important facts about

### ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

#### What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

#### What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

#### Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

#### How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

#### How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

#### What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

#### What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

#### What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE with other people, even if they have the same symptoms that you have.

#### The risk information provided here is not comprehensive.

To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at [www.shirecontent.com/PI/PDFs/ADYNOVATE\\_USA\\_ENG.pdf](http://www.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf) or 855-4-ADYNOVATE.

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.

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# SO, WHAT'S WITH THE PINWHEEL

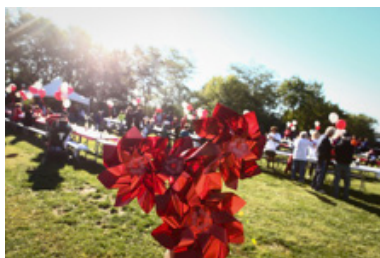
by Tracy Earll  
National Director - UNITE for Bleeding Disorders

When we started to look at rebranding the National Hemophilia Walk, one of the things that was at the top of our list was assuring that our walks across the country were tied together, UNITED if you will, around one thing - the bleeding disorders community. So, no matter where you walked in the country, if you were at a UNITE walk, you would feel our mission was present.

Many of you are seeing the pinwheel today for the first time - and hopefully after your first "Pinwheel Ceremony" today you will feel a strong affinity to it going forward. The pinwheel was chosen as our new symbol because if you really look at it, it already represents us. Each spoke of the pinwheel looks like a blood drop, something we have always associated ourselves with. But one "drop" spinning, doesn't make a pinwheel beautiful. But, like our community, if we put all our "bleeding disorder drops" together, moving in the same direction, we create something not only beautiful, but also something powerful.

The Unite pinwheel ceremony will be the height of emotion at our UNITE events. It is the moment when everyone comes together and feels the energy and passion of the entire bleeding disorder community. It is the moment our participants, sponsors and volunteers look around and realize they are not alone. They feel empowered. They feel cared for and important. They know that our organization is working every day to make their lives better, and the lives of future generations. And, they understand that, to be successful, it will take every one of us working together, united, to achieve our mission.

So, we hope you take your pinwheel home today and place somewhere you will see it. And on those days between today and next year's walk when you give it a glance, we hope you remember how UNITED you felt surrounded by this community, how empowered to give back you felt, and you will be looking forward to next year's walk and the impact we are making on the bleeding disorders community.



**Stop by the HFSC Unite Booth to grab a pinwheel and some Unite gear! This year, the Unite brand was created to encompass and support all bleeding disorders.**

**Be sure to take a pinwheel for the Pinwheel Ceremony and celebrate the community coming together to unite in support for everyone with a bleeding disorder.**





We are the Cardenas Family and we are excited to be participating on our very first Walk. We have benefited from the services and support groups our hemophilia chapter provides, so we would like to give back by fundraising for this great event.

On November 3rd, we will walk to empower our son Benjamin; we will walk so that he may see that he is not alone in this journey, but most importantly, we walk because as parents we desperately want a cure.



# CONGRATULATIONS 2018 FACTOR CLUB WINNERS\*

Paige Antonio  
Langston Brown  
Karlyn J Brown  
Rose Cardenas  
Rebecca Carmona  
Jacqueline Ceja

Sandra Davis  
Veronica Diaz  
Michelle Dotson  
Julia Grove  
Elena Iavacoli  
Michelle Kim

Corinne Love  
Richard Metz  
Christina Olivarria  
Doris Quon  
Michele Warner  
Willie Zuniga

\*as of October 26th, 2018

# HIGHLIGHTS OF 39TH ANNUAL CAMP BLOOD BROTHERS AND SISTERS

From July 18-22, 2018, HFSC sponsored a record 108 campers who attended the 39th Annual Camp Blood Brothers and Sisters held at The Painted Turtle in Lake Hughes, CA. Campers had a blast and participated in many activities including archery, ropes course with zip line, talent show and of course the famous Silly Olympics! HFSC is so proud of the Big Stick Award Winners: Jefferson "Steven" Reyes, Jonathan Moreno, Elizabeth Villanueva, Julian Alvarado, and Jason Slonaker Jr. Also, new for 2018 is a category called "All Star Access Award" for two boys that learned to self-infuse via a port and subcutaneous injection! Congratulations to Jeffrey Kasinger and Jeremiah Kasinger! HFSC is particularly thankful for our major camp donors Shire, Novo Nordisk, Bayer, Bioverativ, a Sanofi company, CSL Behring, CVS, Grifols and Pfizer. Thank you also to our many volunteers: camp could not run without you!



*Thank you donors and board members!*



## Congratulations 2018 Big Stick Winners!

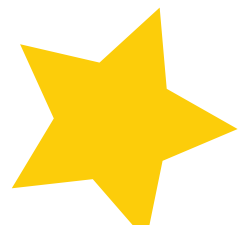


Jefferson "Steven" Reyes  
Jonathan Moreno  
Elizabeth Villanueva  
Julian Alvarado  
Jason Slonaker Jr.

## Congratulations All Star Access Award Winners!



Jeffrey Kasinger  
Jeremiah Kasinger







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**Wagner Lemus**  
Co-Founder

**Antonio Rosas**  
Co-Founder

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Our pharmacists are specialty trained in hemophilia treatment and are available to answer your questions 24 hours a day, 7 days a week.

### Secure Pharmaceutical Supply Chain

Our pharmacies only source blood clotting factors from the top pharmaceutical distributors, each with world-class distribution centers. The quality and security of your drug product is guaranteed.

### Compliance Monitoring & Adherence Programs

We stay in regular contact with you to support adherence to your prescribed therapy. Pharmacy staff will always confirm the amount of medication and supplies you have on hand before scheduling your next shipment.

### Home Nursing Services Coordination

Hemophilia patients require high-quality care coordination and support. We will coordinate home health nursing services if required by your prescriber.

### Understanding Insurance Benefits

We help you understand how to get the most out of your insurance benefits and make out-of-pocket costs as low as possible. We'll provide upfront confirmation of coverage, including pharmacy and medical benefits.



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**Wagner Lemus**  
Co-Founder

**Antonio Rosas**  
Co-Founder

**Hablamos Español**

### Acceso 24/7 a Farmacéuticos con Experiencia

Nuestros farmacistas son especializados en el tratamiento de Hemofilia y están disponibles para contestar sus preguntas 24 horas al día, 7 días por la semana.

### Cadena de Suministro de Factor de Coagulación Segura

Nuestras farmacias solo obtienen el factor de Coagulación de los mayores distribuidores farmacéuticos, exclusivamente de Centros de Distribución de clase Mundial. La calidad e Integridad de su producto está garantizado.

### Monitoreo de Cumplimiento de Normas y Programas de Adhesión

Nos mantenemos en contacto regular con usted para apoyar la adherencia a la terapia prescrita. Personal de la farmacia siempre confirmará la cantidad de medicamentos y suministros que usted tiene en la mano antes de programar su próximo envío.

### Coordinación de Servicios de Enfermería

Pacientes con Hemofilia requieren coordinación y atención de alta calidad y apoyo. Vamos a coordinar los servicios de enfermería de salud a domicilio si es requerido por su médico.

### Comprensión de los Beneficios De Seguro

Le ayudamos a comprender cómo obtener el máximo provecho de sus beneficios de seguro y reducir los costos de su propio bolsillo lo más bajo posible. Ofrecemos la confirmación inicial de cobertura, incluyendo beneficios de farmacia y médica.



**"Su farmacia preferida especializada en hemofilia para la comunidad latina"**



The Iavicoli Family cannot wait until November 3rd when their daughter Amelie will lead a team of family and friends during their second hemophilia walk. Amelie's GT Striders strives to educate others about Glanzmann's Thrombasthenia, while also raising awareness and funding for the entire bleeding disorders community. Glanzmann's Thrombasthenia is a platelet function disorder affecting the abnormality of a protein receptor found on platelets. As the receptor is absent or improperly working, the platelets do not stick together at the site of injury, making it difficult for the blood to clot. Glanzmann's Thrombasthenia is estimated to affect one in one million individuals worldwide.

The Iavicoli Family hosted a fundraiser at their local Chipotle in July to raise awareness and support for Amelie's GT Striders. They raised almost \$200 for their team!

"The Hemophilia Foundation of Southern California has meant everything to our family, opening its doors to a diagnosis that would otherwise have no home," said Elena Iavicoli. "For this reason, we give back to the family that relates to us in a way few others could. In doing so, we hope to empower Amelie beyond her platelet abnormality, as she walks, runs, and likely even skips, towards a future free of hospital stays and needle sticks."

## THANK YOU VOLUNTEERS\*

Enrique Arevalo  
Laura Arevalo  
Nayeli Arevalo  
Ivan Arevalo  
Claudia Capria  
Mathew Casas  
Shin Chen  
Erika Clement  
Paul Clement

Linda Clement  
Randy DeSantis  
Allison Dsouza  
Kathy Dunam  
Fiach Echandi  
Fel Echandi  
Laura Echandi  
Elizabeth Garman  
Josh Garman

Mollie Heiser  
Judy Mangione  
Yatzared Michua  
Arely Michua  
Kelly Murray Rodriguez  
Gabi Navarro  
Lori Strauss  
Patti Rubio  
Jessica Rubio

Giankarlo Rubio  
Hector Rubio  
Jenny Rubio  
Victor Rubio

\*as of October 26th, 2018





When my daughter, Brooke, was diagnosed at age 13 with a bleeding disorder, we were thrown into a storm. Her Hematologist/Oncologist gave her a lot of numbers and a list of activities that she could no longer participate in. She could no longer run on the track team, compete as a high jumper, take karate class, or play basketball. I was instructed to purchase an SUV for her to be safely transported, and the school removed her from PE class and said that she would be sent to the library to write reports in order to receive credits for the class.

She fell into depression and verbalized that she didn't know who she was. She felt like she was an athlete, not a "sick" girl. She was overwhelmed by all the restrictions. At our next follow up appointment, I asked her Hem/Onc for a referral to a support group. The Doctor made a face at her and asked her why she needed support. She pointed to the bald children getting chemotherapy and told my daughter that she should be grateful to have von Willebrand's Disease instead of Cancer. I left the office with my daughter choking back tears.

When I got home from the appointment, I opened my phone book and found the Hemophilia Foundation of Southern California. I told them that my daughter was just diagnosed, and I was looking for a support group. They told me that they had a family camp coming up the following weekend and invited us to attend.

Over the years, we have not only received support from a community that has become like family, but we have been educated, equipped with education and advocacy, and empowered to not live in constant fear of injuries, but to seek normalcy with accommodations. We received the help we needed to navigate the storm.

Brooke did not write reports for PE credit. She swam laps every morning. She competed throughout high school, and went on to teach swim lessons, and coach swimmers on stroke refinement. She graduated high school having participated in team sports and positive memories of being the athlete that she has envisioned herself as, in her youth.

Now that Brooke is 25 years old, she works as a "Master Trainer" for 24 Hour Fitness. She has shared her story, and her mission to modify exercise to be inclusive to those with limitations. She is currently also a fitness model that demonstrates movements in exercise. She is an athlete.

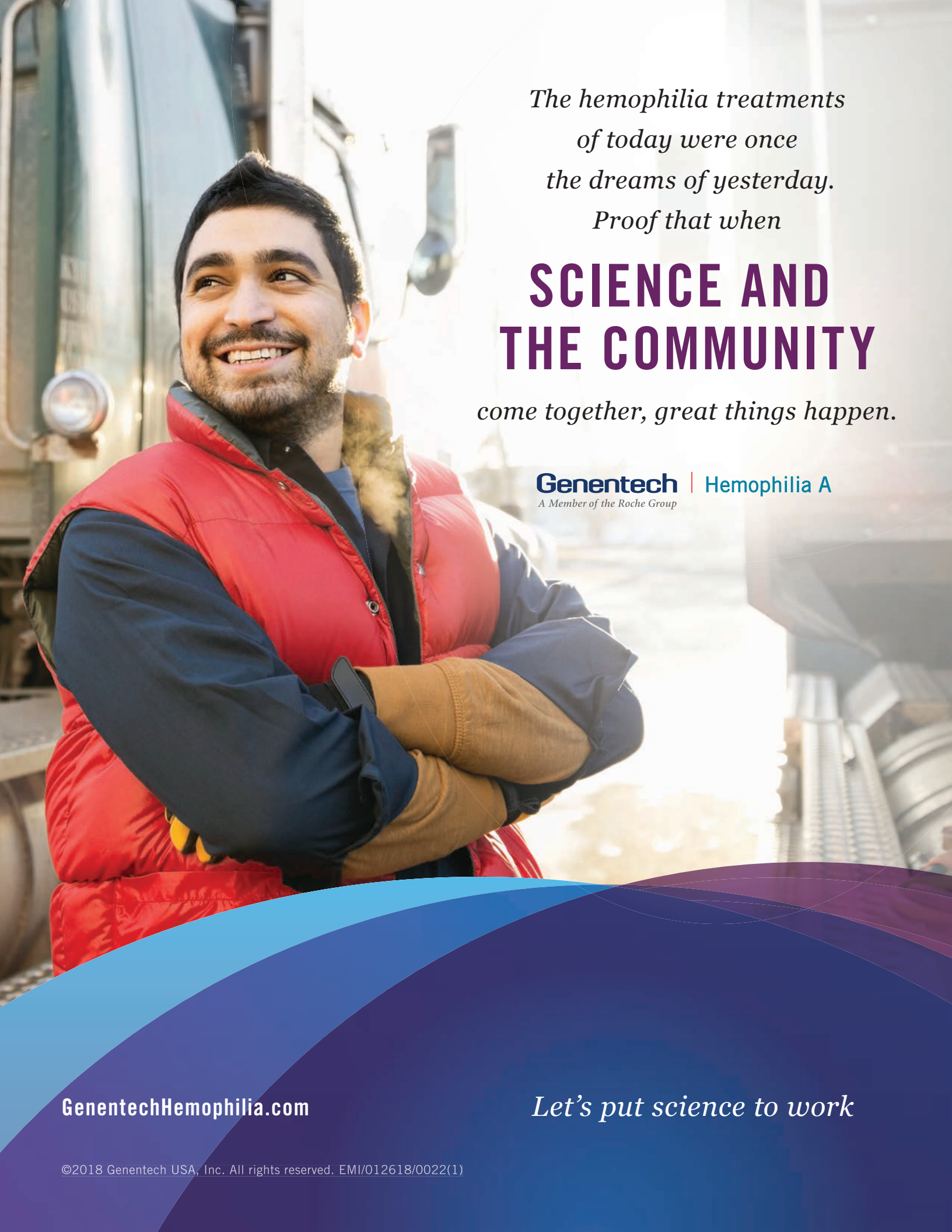
Brooke, along with the rest of our family, are so thankful to HFSC for equipping us to pursue goals.

Sylvia Garcia, HFSC Board Member

- **JOIN HFSC FOR A RIVETING DAY TO GAIN KNOWLEDGE ON NEW PRODUCTS AND TREATMENTS!**
- **FREE PARKING AND CHILDCARE**
- **BREAKFAST AND LUNCH INCLUDED**
- **SOLD OUT LAST YEAR—REGISTER NOW!**

**INDUSTRY FORUM!**  
 MT. SAINT MARY'S UNIVERSITY  
 12001 CHALON RD, LOS ANGELES, CA  
 January 19, 2019  
 9am-3pm

**CALL CYNTHIA TO REGISTER: 626-765-6656 OR CYNTHIA@HEMOSOCAL.ORG**



*The hemophilia treatments  
of today were once  
the dreams of yesterday.  
Proof that when*

# SCIENCE AND THE COMMUNITY

*come together, great things happen.*

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A Member of the Roche Group

**GenentechHemophilia.com**

*Let's put science to work*

# THANK YOU TO OUR LOCAL BUSINESS SPONSORS



W. M. KECK FOUNDATION



Our son Langston has Hemophilia, but we consider him lucky. Why? Langston was diagnosed at birth because I knew I could be a carrier and he has had excellent treatment his entire life. He plays soccer, baseball, and basketball and is the fastest 5th grader you've ever met. He is a true superstar. We Walk for Langston.

My grandfather also had Hemophilia and died from complications in the 70's. We walk for my grandfather who didn't have the same treatment available. Last year, my sweet cousin Charles Gilbert died from complications of his hemophilia. Charles was in his 30's and suffered from arthritis and other ailments. Shortly after Charles' death my son asked me if he was going to die, too. He told me that everyone he knew with Hemophilia was dead and that made him sad. I told him that's not true! I reminded him of his campmates and camp counselors and the other folks he's met on the walks. There is strength in community. We walk for Charles and our community.

Last year we were finally able to take a family vacation because of Langston's port. We love his port because of the freedom it gives us for travel and care. While vacationing, we met a woman who was celebrating with her family because she had just finished her third round of chemo. She told us about her port and we told her about Langston's. The response was immediate and overwhelming. She had never met a child with a port. He had never met an adult with one. She told us she wears hers as a badge of honor. "Warriors have ports," she exclaimed!

It was on that trip that we got the idea for our walk theme for last year: "Heroes have capes, but warriors have ports." We walk for my grandfather and for my cousin and for my son – for all those who suffer from bleeding disorders – for the strength they gather by being together, for the freedom that early diagnosis and care brings, and for the families who support them.

Thank you for your support and together, we will make a difference.

Karlyn Johnson Brown and "Langston's Star Walkers"





959 East Walnut Street  
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## 5 REASONS TO GIVE TO



### GUARDING THE U.S. BLOOD SUPPLY



80% of all people with severe hemophilia were infected by blood based medicine tainted by HIV in the 1980's. Thousands died. Due to this tragedy, we remain prime advocates and watchdogs of the blood supply to ensure blood safety nationwide.

### RARE DISEASE ADVOCATES



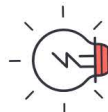
1 in 10 Americans are affected by a rare disease the majority of whom are children. Hemophilia Patient Advocacy groups are one of the most well-organized and when we fight for our rights such as access to rare disease specialists, all those in the rare disease community benefit!

### HEALTH INSURANCE ACCESS



HFSC advocates for access to health insurance on both the federal and state level. We constantly have a handle on proposed legislative changes that affect all. As a result of this hard work, all people who need and care about health insurance access can benefit!

### GENE THERAPY AND INNOVATION



Gene Therapy may be the key breakthrough in providing a cure to many rare conditions that have no treatment. Gene therapy trials in hemophilia are well underway and this research can provide answers for other diseases.

### HELPS EARN RESPECT



Donations can help you earn respect in many areas. Philanthropy is a noble act that only people with a good heart can fall into and it also earns you a lot of respect from your peers and society in general. Other than that, it will also earn you the undying respect of the people or organizations that you donate to.

