

HEMOPHILIA ACTION



Hemophilia Foundation
of Southern California

VOLUME 20 • ISSUE 3 • SUMMER • 2023

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FAMILY INFO DAY • FAMILY RETREAT

WORLD HEMOPHILIA DAY



FAMILY RETREAT 2023
Full article on page 8!

HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

959 EAST WALNUT STREET • SUITE 114 • PASADENA, CA 91106
P 626.765.6656 • F 626.765.6657 • WWW.HEMOSOCAL.ORG • INFO@HEMOSOCAL.ORG

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HEMOPHILIAACTION is published quarterly by
THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

GENERAL

Anonymous (2) • Cliff and Gayle Adams • Alfonso Barrientos • Shyam Bhalodia and Youvanna Jimenez
Sandra Green • Perry Parker • Don and Anne Polkingharn • Timothy Van Loon

IN HONOR

Thomas Barker, in honor of Perry Parker • Harry and Juanita Boessler, in honor of Tyler, Abby and Michael
Marilyn Borowsky, in honor of Cole Warner • Claudia Borzutzky, in honor of the CHLA Coag Team
Jane Brady, in honor of Amelie Iavicoli • Brenda Gonzalez, in honor of Matteo Salcida
Mike and Kristi Grob, in honor of The Parker Family • Gloria Hernandez, in honor of Matteo Salcida
Holger Peens, in honor of Perry Parker • Mary Taylor, in honor of Cole Warner
Michele and Doug Warner, in honor of Cole Warner • Peter and Janan Whelan, in honor of Shawn Whelan
Jeffrey and Mary Lou Wright

IN MEMORY

Mary Ann Barth and Steve Yamaguchi, in support of the Christopher Mark Pitkin Memorial Scholarship
Brian Taylor, in support of the Victoria Mendoza Perez Memorial Scholarship
Peter and Janan Whelan, in memory of Bernard Warren

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2023 CALENDAR

BACK TO SCHOOL SYMPOSIUM

August 5 • Cal Poly Pomona, Pomona, CA

MUJERES ENLAZADAS POR SANGRE

August 10 • Location TBD

BRO EVENT

August 12 • Dodger Stadium, Los Angeles, CA

EMPOWERMENT WEBINAR SERIES

August 23 • Virtual Event

WOMEN'S COMMUNITY DINNER

August 31 • Solita, Huntington Beach, CA

7TH ANNUAL FAMILIA DE SANGRE

September 8 - 10 • Anaheim Marriott, Anaheim, CA

SHAKA SURF FEST & BEACH DAY

September 23 • Santa Monica Beach, Santa Monica, CA

EMPOWERMENT WEBINAR SERIES

October 18 • Virtual Event

15TH ANNUAL SOCAL UNITE WALK

November 4 • The Meadows at Whittier Narrows,
South El Monte, CA

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A LETTER FROM THE BOARD PRESIDENT

HFSC staff has been hard at work continuing to organize community events, the most recent of which was the Family Retreat held the weekend of June 2 at the Pali Retreat Center. It was wonderful seeing so many of you; our family had an unforgettable weekend creating memories while strengthening our connections with other families affected by bleeding disorders. We thoroughly enjoyed participating in many of the exciting activities offered, including creating our family banner, educational workshops, archery, tomahawk throwing, the talent show, and more! The Retreat also allowed our son the opportunity to meet his peers who will be at summer Camp.

Staff is also continuing to plan for Familia de Sangre, an educational conference held September 8-10 at the Anaheim Marriott, to empower, advocate, and educate Spanish-speaking community members. I also am looking forward to our superhero-themed 15th Annual Unite for Bleeding Disorders Walk & Health Fair, which will take place at Whittier Narrows on November 4. In order to raise even more funds in support of our community, we are planning to host an online auction this year to take place around the time of the Walk – stay tuned for more details! If you have any small items or gift cards you would like to donate, please reach out to Michele Warner at mwarner@hemosocal.org

The walk is our largest fundraising event of the year, with funds raised supporting Camp Blood Brothers & Sisters, educational programs, emergency financial assistance, scholarships, and research. Please visit www.uniteforbleedingdisorders.org/event/socal for more information on how to sign up, form a team, and start fundraising!

I look forward to seeing you all again very soon! In the meantime, please feel free to reach out to me with any questions or if I can help in any way. - Rick Kelley, MBA

A LETTER FROM THE EXECUTIVE DIRECTOR

Joining a new company is often accompanied by a mix of excitement, anticipation, and a touch of nervousness. As I celebrate my first anniversary with the Hemophilia Foundation of Southern California, I can't help but reflect on the incredible journey I have experienced over the past year. It has been a year filled with growth, learning, and numerous accomplishments which have shaped me both personally and professionally.

From the moment I stepped through the doors, I was greeted with warmth and support. The strength of any organization lies in its people, and I consider myself fortunate to be surrounded by a team of talented and supportive colleagues. Together, we have accomplished remarkable feats and leveraged each other's strengths and pooled our collective knowledge to overcome obstacles and achieve our goals. The spirit of teamwork and collaboration within HFSC has been instrumental in our collective success.

We cannot be successful without the support and dedication of our community members. The strength of our community members is a testament to the power of unity. Each individual brings their unique skills, perspectives, and experiences, creating a diverse and dynamic network of support. We form a collective force capable of overcoming challenges, driving change, and making a positive impact. The unwavering dedication, mutual support, and shared goals of our community members are the driving force behind our accomplishments. The strength of our community lies in the bonds we have formed and the collective resilience we embody.

Celebrating my first year with HFSC fills me with a profound sense of pride and gratitude. I am grateful for the opportunities, experiences, and relationships that have enriched my life over the past year. As I eagerly look forward to the future, I remain committed to giving my best, driving innovation, and contributing to the continued success of the Hemophilia Foundation of Southern California. Here's to many more years of growth, achievements, and shared success. - Rigo Garcia, MPH



2023 WORLD HEMOPHILIA DAY

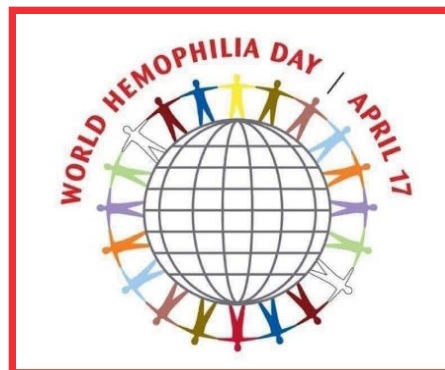
CASTAWAY, BURBANK

04.16.23

With more than 100 people in attendance, HFSC celebrated World Hemophilia Day as a community at Castaway in Burbank on Sunday, April 16, 2023. World Hemophilia Day is an opportunity for us to raise awareness and understanding of hemophilia and other rare bleeding disorders and the challenges faced by those who have bleeding disorders across the globe. The theme of the event this year was "Access for All: Prevention of Bleeds as the Global Standard of Care." Building on last year's theme, the call to action for the community in 2023 is to come together and advocate with local policy makers and governments for improved access to treatment and care with an emphasis on better control and prevention of bleeds for all people with bleeding disorders. World Hemophilia Day has been celebrated on April 17 since 1989 when the World Federation of Hemophilia chose the day to bring the community together.

At HFSC, we work hard year-round to ensure all our members have access to treatment and care. We are always available for you to be a resource for your needs.

Thank you to Sanofi for sponsoring our WHD dinner, and for their support to the World Federation of Hemophilia's Humanitarian Aid Program with their donation of factor therapy for those in need worldwide. To learn more about World Hemophilia Day, please visit: <https://wfh.org/world-hemophilia-day/>



EIGHT4NINE RESTAURANT, PALM SPRINGS

04.30.23

This year, HFSC not only celebrated World Hemophilia Day in Burbank, but we had a second celebration in Palm Springs on Sunday April 30 at Eight4Nine Restaurant. Continuing with the theme "Access for All: Prevention of Bleeds as the Global Standard of Care," HFSC wants to make sure we continue to expand our programming to all our community members. This means celebrating events like this one throughout our nine counties. Our strength as a community lies in its ability to come together as a cohesive unit, working towards a common purpose and supporting one another.

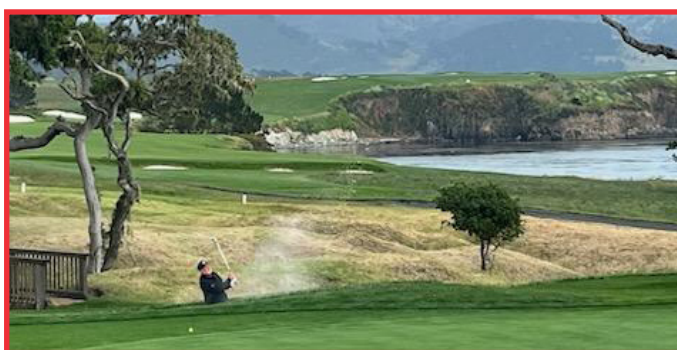
World Hemophilia Day is celebrated for the purpose of bringing awareness to local policy makers and government about not only bleeding disorders but the stories, struggles, and successes our community has endured and overcome. There are many ways we can bring attention to hemophilia and other inherited bleeding disorders. We want to make sure that we raise awareness so that there is inclusion in national and local policy. Let's keep this momentum we created during our celebration moving forward so that we as a community can make changes and have our voices heard.

Thank you to Sanofi for sponsoring two World Hemophilia dinners, and for their committed support to the World Federation of Hemophilia's Humanitarian Aid Program.

2023 REGION IX

The Western States Region IX Hemophilia Treatment Center (HTC) conference was held from April 28-30, 2023 in Manhattan Beach, CA. Over 180 Hemophilia Treatment Center professionals, community members, Clinicians, patient advocates, and industry partners joined us from throughout California, Guam, Hawaii, and Nevada. The focus of the conference was on girls, women, and women's health issues. In addition, we gained knowledge about the clinical management issues particularly affecting girls and women with bleeding disorders. Discussions took place about sexism in academic medicine and how we can do our part to make sure that there is diversity, equity, and inclusion in research of girls with bleedings disorders.

The event was kicked off with an exciting and hilarious discussion by the Emmy-award-winning actor Alex Borstein, a writer and producer who happens to be a hemophilia carrier. The time at the conference was also used to collaborate with our fellow California Chapters, the HTC's and other professionals in our field. The information provided will allow HFSC to continue to provide high quality programming in partnership with our HTC's



2023 PARKER INVITATIONAL

A heartfelt thank you to Perry Parker for hosting the Parker Invitational, a golf tournament in Pebble Beach, May 29-June 2, 2023, raising nearly \$9,000 for HFSC! 2023 marks the 6th year for the Pro-Am that included a full field of senior golf professionals from around the globe and their 3-person amateur teams. Players enjoyed a practice round on opening day, tee prizes, a welcome dinner with guest speakers and, of course, some healthy competition throughout the week!

Thank you to everyone who attended and supported this event! We are so appreciative of Perry for raising critical funds for the bleeding disorders community in Southern California. Next year's event will take place May 27-31, 2024. If anyone is interested in playing or volunteering, Perry can be reached at perryparkergolf@gmail.com.

emPOWERment WEBINAR SERIES

NUTRITION & HEALTH OUTCOMES WITH COOKING DEMONSTRATION

04.20.23

On April 20, 2023, 40 families joined HFSC's emPOWERment webinar that discussed nutrition, followed by a cooking demo presented by Rigo Garcia, HFSC's Executive Director. Rigo discussed the importance of eating healthfully in an effort to manage weight, which in turn helps remove extra strain on joints and muscles, which is particularly important for those with bleeding disorders. He then went through "Eating the rainbow" of foods, and easy substitutions for healthier choices such as replacing simple carbohydrates with whole grains to get maximum nutritional benefit, and substituting lower fat dairy options so that an individual gets the benefits of dairy products without the intake of fat that can be linked to heart disease. Rigo showed the group how to make a "Pittsburgh Salad" that features baked French fries and a simple dressing that can be made at home with standard kitchen staples.

The infographic is divided into two main sections: ingredients and instructions. The ingredients section is organized by cooking method: 'WASH & CHOP VEGGIES' (spinach, tomato, carrots, cucumber, red onion), 'BAKE' (french fries), 'BROIL' (chicken or other protein, garlic, Mrs. Dash), 'GRILL' (white onion, bell peppers), and 'WHISK/BLEND DRESSING' (balsamic vinegar, lemon juice, dijon mustard, olive oil, salt & pepper). The instructions section, titled 'PITTSBURGH SALAD INSTRUCTIONS', lists seven steps: 1. Wash and chop vegetables. 2. Broil chicken with garlic and spices. 3. Bake french fries. 4. Grill white onion and bell peppers. 5. Whisk dressing with balsamic vinegar, lemon juice, dijon mustard, and olive oil. 6. Build the salad with raw and cooked ingredients. 7. Serve and enjoy.

WASH & CHOP VEGGIES:
SPINACH TOMATO CARROTS CUCUMBER RED ONION

BAKE:
FRENCH FRIES

BROIL:
CHICKEN OR OTHER PROTEIN GARLIC MRS. DASH

GRILL:
WHITE ONION BELL PEPPERS

WHISK/BLEND DRESSING:
BALSAMIC VINEGAR LEMON JUICE DIJON MUSTARD OLIVE OIL SALT & PEPPER

PITTSBURGH SALAD

INSTRUCTIONS

1. WASH AND CHOP SPINACH, TOMATO, CARROTS, CUCUMBER, AND RED ONION.
2. BROIL THE CHICKEN WITH GARLIC AND SPICES.
3. BAKE FRENCH FRIES ACCORDING TO DIRECTIONS ON PACKAGE.
4. GRILL THE WHITE ONION AND BELL PEPPERS.
5. WHISK OR BLEND 1 C BALSAMIC VINEGAR, 1 TSP. LEMON JUICE, 1 TBSP. DIJON MUSTARD, AND 1/2 C OLIVE OIL. ADD SALT AND PEPPER TO TASTE.
6. BUILD THE SALAD WITH RAW AND COOKED INGREDIENTS. GENTLY STIR UNTIL ALL THE INGREDIENTS ARE WELL MIXED AND THEN TOP WITH THE DRESSING.
7. SERVE AND ENJOY YOUR DELICIOUS AND HEALTHY SALAD!

FACTOR FLUENCY: HIGHER FACTOR ACTIVITY LEVELS MATTER

05.17.23

We are delighted to share with you the highlights of the emPOWERment webinar held on May 17, 2023, titled "Factor Fluency: Higher Factor Activity Levels Matter." This session shed light on the significance of factor activity levels and their role in managing hemophilia effectively. We are grateful to Sanofi for their generous sponsorship of this event.

During the emPOWERment webinar, more than 30 participants were presented with comprehensive information about the importance of understanding and monitoring factor activity levels. The webinar emphasized that higher factor activity levels play a significant role in minimizing the risk of bleeding episodes and enhancing overall quality of life. Understanding how factor levels fluctuate, how to measure them accurately, interpreting the results, and adopting a healthy lifestyle were among the key topics covered during the event.

THANK YOU TO OUR emPOWERment SPONSORS!

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octapharma

SILVER

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2023 FAMILY INFO DAY

On May 6, 2023, 250 HFSC community members attended our annual Family Information Day at the Sheraton Cerritos Hotel. The event began with "Finding Hope," a moving talk from Reverend Cazandra Campos-MacDonald, who shared her story of raising a child with hemophilia. She was able to connect with the community in the room through shared experiences and humor.

Following the presentation, yoga instructor Cassie Roque got the audience moving with her presentation "Mind and Body Fitness." It was a reminder to take moments for yourself during the day. Cassie shared how to practice mindfulness and taught easy yoga moves anyone could do in a chair.

The lunch presentation, "Put Yourself Out There: Sharing and Advocating for Bleeding Disorders," from Annabelle Garcia, Community Education Specialist at Takeda, was beneficial for the community to learn about advocating for oneself in daily life.

During HFSC's Annual Awards, Linda Clement was awarded Volunteer of the Year, and Medical Provider of the Year was awarded to Dr. Amit Soni from the Center for Inherited Blood Disorders. Karlyn Johnson-Brown and Langston Brown were awarded Advocate of the Year awards; Fundraiser of the Year was awarded to Dr. Doris Quon of Orthopaedic Treatment Center.

Thank you to all our volunteers!

THANK YOU TO OUR FAMILY INFO DAY SPONSORS!

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HFSC ANNUAL AWARD WINNERS



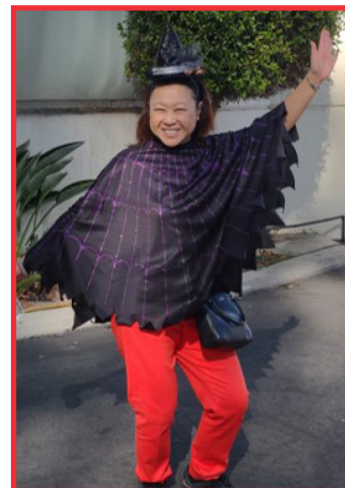
LINDA CLEMENT
Volunteer of the Year



AMIT SONI, MD
Medical Provider of the Year



**KARLYN
JOHNSON-BROWN
& LANGSTON
BROWN**
Advocate of the Year



DORIS QUON, MD
Fundraiser of the Year



**Hemophilia Foundation
of Southern California**

Happy Anniversary!



**YEARS OF SERVICE
1954-2024**

We are looking forward to celebrating our 70th anniversary with you in 2024! If you are interested in joining the committee to help us plan this milestone, please contact Rigo Garcia, Executive Director, at rigo@hemosocal.org!

2023 HFSC FAMILY RETREAT

On June 2-4, 2023, HFSC welcomed 33 families and a total of 114 attendees to Pali Retreat Center for our "Hemochella" themed retreat weekend.

As families arrived on Friday evening, participants enjoyed taking photos in front of the festival background, creating Festival Shades and "Chella Chimes," and making Family Album Covers that were presented during the weekend. The first night finished off with a campfire complete with roasting marshmallows and making s'mores.

On Saturday morning, educational sessions for the adults began with "From Clinic to Kitchen," presented by Cynthia Chavez, Community Relations & Education Core Manager at Sanofi, and self-infusion practice with Dr. Doris Quon from Orthopaedic Treatment Center (OTC). Following this session was "Haz lo que te mueve: Mantenerse activo," presented by Annabella Garcia, Community Education Specialist from Takeda. Also hosted was "Communicating for a Stronger Relationship" Couples Session led by Marvin Enriquez, and Dr. Doris Quon of OTC held a roundtable discussion for parents. Kids and teens enjoyed outside games led by Jerry Garcia as well as laser tag and archery. In the afternoon, families were free to take part in activities such as archery tag, tomahawk throwing and archery, ziplining, and the inflatable obstacle course, as well as crafts. The afternoon was rounded out with a wine and cheese reception and dinner. Following dinner, we were treated to the talents of community members at the "Hemochella Main Stage Talent Show." Thank you to all who shared their astounding talents!

On Sunday after breakfast, families said their goodbyes and headed home. Thank you to our fabulous volunteers who made the weekend possible!

A special thank you to Platinum Sponsors Sanofi and Takeda; Gold Sponsors, Genentech and HFA; and Booth Sponsor, Octapharma!



HFSC 2023 COMMUNITY DINNERS



ORANGE COUNTY WOMEN'S DINNER

05.10.23

HFSC hosted a wonderful dinner at Maggiano's Little Italy in Costa Mesa where 35 attendees learned how to practice resilience by discovering how to better adapt and manage adversity. Through interactive activities, community members explored what it means to be resilient while learning tips and tools for living a healthy lifestyle. Thank you, Annabelle Garcia and Takeda, for the informative and valuable presentation!

JOIN US FOR A COMMUNITY DINNER!

Visit hemosocal.org/events to
find a dinner location near you!

SAN LUIS OBISPO

05.23.23

HFSC hosted a community dinner at Cafe Roma in San Luis Obispo on Tuesday, May 23, where we explored aspects of resilient behavior and thoughts. Following the presentation on "Raising Resilience," attendees engaged in a group discussion on how one can reframe setbacks as opportunities for growth, and how the power of the mind can change not only your emotional state, but the trajectory of the outcome. Participants were reminded that resilience is important for mental health and well-being and that, luckily, everyone can learn to be resilient. Thank you to Sanofi for sponsoring this dinner!

BAKERSFIELD

06.08.23

On June 8, 2023, HFSC hosted a wonderful community dinner at Frugatti's Restaurant in Bakersfield, CA. The event, sponsored by Novo Nordisk, brought together 32 community members for an evening focused on mental well-being. It was an invaluable opportunity to address the importance of mental health and its significance for individuals living with a bleeding disorder.

The theme for the evening, "A Focus on Mental Well Being," aimed to highlight the interconnectedness of mental health with our overall well-being. The dinner provided a safe and supportive space for individuals to come together and openly discuss mental health, sharing personal experiences, insights, and coping strategies. Through informative discussions and heartfelt conversations, participants explored ways to nurture their mental well-being while managing the unique aspects of living with a bleeding disorder. Attendees had the opportunity to learn about various approaches to managing stress, building resilience, and seeking support when needed. We extend our sincerest gratitude to Ian Corona and Novo Nordisk for their generous sponsorship of this event.



2023 FAMILIA DE SANGRE

Familia de Sangre: Inscríbase ahora a la mayor conferencia nacional totalmente en español sobre trastornos hemorrágicos!

Estamos encantados de anunciar que está abierto la inscripción para Familia de Sangre (FDS), la mayor conferencia sobre trastornos hemorrágicos en español del país. Marque sus calendarios para el 8-10 de septiembre de 2023, FDS regresa al Anaheim Marriott. Este evento educativo de tres días está diseñado para empoderar, defender y educar a los miembros de la comunidad hispanohablante. Con una impresionante lista de diversos presentadores que cubren una amplia gama de temas, Familia de Sangre promete ser una experiencia enriquecedora para todos los asistentes.

En FDS, creemos en la creación de un ambiente donde las familias puedan reunirse, conectarse con otros, y sentir una sensación de comodidad y seguridad. Es una oportunidad única para que las personas y las familias no sólo obtengan información importante, sino también para que establezcan relaciones duraderas con sus hermanos y hermanas de sangre. Estas conexiones pueden servir como un valioso recurso de apoyo, aliento y amor.

Detalles Importantes:

8-10 de septiembre de 2023 • Anaheim Marriott • Visite famiadiadesangre.org para inscribirse y asegurar su lugar.



¡INSCRÍBASE HOY!

Para la conferencia de desórdenes sanguíneos mas grande en el país completamente en Español

Familia de Sangre: Register Now for the Largest National All-Spanish Conference!

We are thrilled to announce that registration is open for Familia de Sangre (FDS), the largest, all-Spanish bleeding disorders conference in the nation! Mark your calendars for September 8-10, 2023, as FDS returns to the Anaheim Marriott. This three-day educational event is designed to empower, advocate for, and educate Spanish-speaking community members. With an impressive lineup of diverse presenters covering a wide range of topics, Familia de Sangre promises to be an enriching experience for all attendees.

At FDS, we believe in creating an environment where families can come together, connect with others, and feel a sense of comfort and safety. It is a unique opportunity for individuals and families to not only gain important information but also to form lasting relationships with their blood brothers and sisters. These connections can serve as a valuable resource of support, encouragement, and love for one another.

Key Details:

September 8-10, 2023 • Anaheim Marriott • Visit famiadiadesangre.org to register and secure your spot!

THANK YOU TO OUR SPONSORS!

DIAMOND



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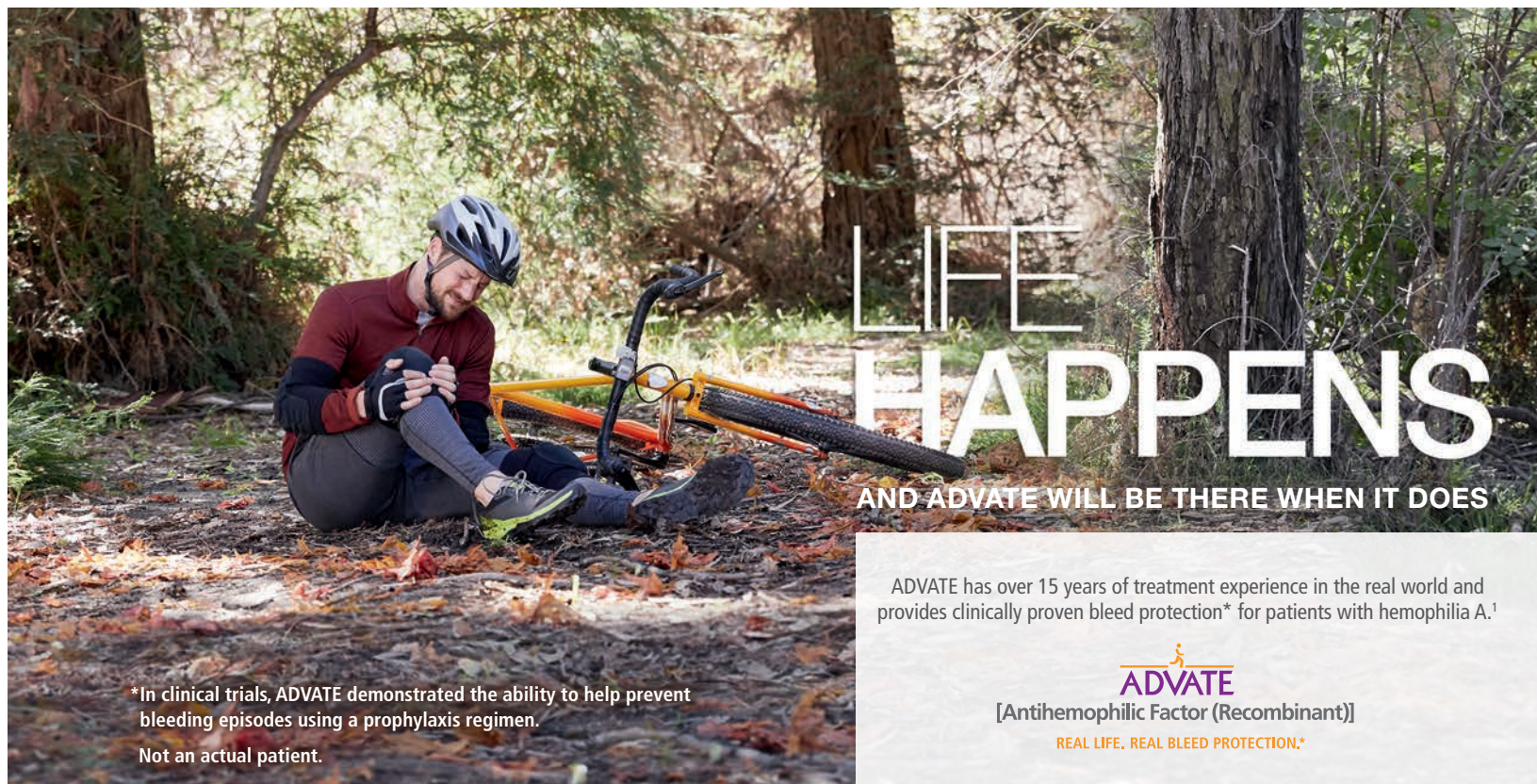


SILVER



BRONZE





LIFE HAPPENS
AND ADVATE WILL BE THERE WHEN IT DOES

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.¹

ADVATE
[Antihemophilic Factor (Recombinant)]
REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

*In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.
Not an actual patient.

Prophylaxis with ADVATE prevented bleeds¹

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment. 53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.[†] This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

[†]Median is the middle number in a group of numbers arranged from lowest to highest.

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

What should I tell my HCP before using ADVATE?

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 ADVATE passes into your milk and if it can harm your baby.

Reference: 1. ADVATE Prescribing Information.

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What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP 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 ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE 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 ADVATE 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 ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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 Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.





[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. 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 ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

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 ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE 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 ADVATE by themselves or with the help of a family member.

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

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

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

What should I tell my healthcare provider before I use ADVATE?

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 ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

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.

Side effects that have been reported with ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

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 ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE 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 ADVATE 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 ADVATE for a condition for which it is not prescribed. Do not share ADVATE 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 ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

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.

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MEDICAL ARTICLE SPOTLIGHT

HOW TO KEEP SUMMER ACTIVITIES SAFE FOR KIDS WITH BLEEDING DISORDERS

by Donna Behen • Posted: June 29, 2021, Updated: July 19, 2021

It's summertime, and kids are out of school and excited to have fun in the great outdoors. After a year of remote learning, social isolation and so much uncertainty, probably more than ever! But if you're the parent of a child with hemophilia or another bleeding disorder, your eagerness for your child to get outside and be active is tempered by the concern that the sport he is playing or another activity he's doing might put him at risk for a serious injury. What can you do to help make this summer an enjoyable and active one for your child while also keeping him or her safe from injuries?

For advice about hemophilia and sports, we turned to Alice Anderson, PT, DPT, PCS, a co-author of the National Hemophilia Foundation's (NHF's) *Playing It Safe: Bleeding Disorders, Sports and Exercise* guide. Here's what she recommends.

Check with Your HTC

A good first step is to talk to your child's hemophilia treatment center (HTC), Anderson says. "You can find out if they recommend that your child be on prophylaxis, and if your child has a problem joint, you can determine if there are specific sports that would be safer for them than others," she says. You can also talk about any measures you can take to make the sport or activity safer. "Clearly, it's a no-brainer that everybody should use the appropriate safety gear for each sport," she adds.

Steer Clear of Activities with a 3 Rating

In the *Playing It Safe* guide, sports that are rated 3 for "high risk" include BMX racing, boxing, tackle football, rugby and wrestling. "These are sports that can be dangerous for anyone, regardless of whether they have a bleeding disorder, because they are considered high velocity and/or at high risk for collision," Anderson says. "The most important thing we want to prevent is a blow to the head, which at the very least can cause a concussion and at the very worst, a head bleed."

Be Cautious with Trampolines

Sales of backyard trampolines jumped last summer as families looked for ways to keep their kids occupied at home during the pandemic. But the American Academy of Pediatrics strongly discourages the use of home trampolines for any child, citing the high rate of injuries that can occur, including fractures and dislocations. In the *Playing It Safe* guide, trampoline use has a 2.5 to 3 rating. "If you choose to allow your child to be on a trampoline, the things that are going to make it safer are ensuring there's adult supervision and no flips or somersaults and, most importantly, having only one child jump at a time," Anderson says. "You want to avoid the risk of two heads hitting each other really hard."

Don't Overlook Neighborhood Pickup Games

While tackle football is a definite high-risk sport, what about a friendly neighborhood game of touch football? Anderson says these kinds of impromptu pickup games can often be a lot riskier than you realize, because there's usually little to no adult supervision. "With league play or a game at the Y, you're going to have refs that are watching, but if it's just a bunch of kids playing up the street, it's possible that a player could go rogue and do something really dangerous," she says.

Keep Your Child's Interests in Mind

Don't make the mistake of limiting your child's activities to only those rated 1 for "low risk," Anderson says. It's important to allow kids to have a say in the sports or activities they're interested in. Some activities are actually less risky for kids with bleeding disorders than parents might think. Take rock climbing, for instance. While outdoor rock climbing gets a 2 to 3 rating in the *Playing It Safe* guide, indoor rock climbing, with proper safety equipment such as ropes and harnesses, is 1.5 to 2. "Back in the day before we had such good treatment, every kid was encouraged to swim because it's not a high-impact sport, but what if your kid doesn't like swimming?" Anderson says. "Forcing your kid to do a level 1 sport they hate is not helpful, and they're not going to get any fun out of it."



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