

HEMOPHILIA ACTION



Hemophilia Foundation
of Southern California

70TH ANNIVERSARY
1954 • 2024

VOLUME 21 • ISSUE 2 • SPRING • 2024



Kenneth Ketchum (right), President of the Southern California chapter of the Hemophilia Foundation, delivers a supply of dried blood plasma to a United Airlines employee on a flight bound for Israel. Ketchum answered a cablegram from the Edinboro Medical Missionary Hospital in Nazareth, Israel to send plasma to aid a young child with hemophilia.

HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

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IN MEMORY

Krista and Ho Lee, in memory of David Shaw

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2024 CALENDAR

FAMILY INFORMATION DAY (HFSC ANNUAL MEETING)

May 4 • Knott's Hotel, Buena Park, CA

EMPOWERMENT WEBINAR

May 15 • Virtual

FAMILY RETREAT WEEKEND

June 1 - 2 • Pali Mountain Retreat, Running Springs, CA

SHAKA SURF FEST & BEACH DAY

June 22 • Santa Monica Beach, Santa Monica, CA

BRO RETREAT (18+)

July 13 • Ballast Point, Long Beach, CA

CAMP BLOOD BROTHERS & SISTERS

July 16 - 21 • The Painted Turtle, Lake Hughes, CA

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A LETTER FROM THE BOARD PRESIDENT

I am deeply honored to serve as the newly elected Board President, collaborating closely with HFSC's dedicated Board members and staff. I look forward to championing the Foundation's mission to enhance the quality of life for individuals with bleeding disorders, as well as their caregivers and families.

Having a background in Medical Affairs, specifically in the fields of immunology, inflammation, hematology, bleeding disorders, and rare diseases, has helped to provide me with an insight into the unique needs of our community. As I step into my new role as Board President, I am enthusiastic about utilizing my experience to contribute in every possible way to ensure that our community's needs are not only acknowledged but effectively met.

We look forward to meeting many of you and re-connecting with others at HFSC's Annual Meeting, Family Information Day, on May 4 at Knott's Hotel. Please also remember to register your children for Camp Blood Brothers and Sisters at The Painted Turtle July 16-21, so they can participate in the life-changing experience of going to a camp where they meet others like them, while receiving education about their bleeding disorders, including the life-saving technique of self-infusion. If you need help with the application, please contact Omar at omar@hemosocal.org and ask for assistance as soon as possible.

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

- Bob Numerof, Board Chair (boardpresident@hemosocal.org)

A LETTER FROM THE EXECUTIVE DIRECTOR

In a remarkable journey that began seven decades ago, we proudly celebrate the 70th anniversary of the Hemophilia Foundation of Southern California. What started as a compassionate alliance of parents has evolved into a powerhouse of support, advocacy, education and hope for those affected by bleeding disorders. What began with three families quickly blossomed into a thriving community as the visionaries organized a society of parents and neighbors. Together, they forged a united front against the trials of raising children with bleeding disorders, fostering a sense of camaraderie that would become the cornerstone of the Hemophilia Foundation of Southern California.

Serving 9 counties and more than 3,800 community members, the Hemophilia Foundation of Southern California has operated as a beacon of support, offering resources, education, and a sense of community for individuals and families navigating the complexities of bleeding disorders. As we celebrate this significant milestone, we reflect on the countless lives touched, the challenges overcome, and the enduring spirit of resilience that defines our community.

We invite you to join us in commemorating this momentous occasion. Together, let's honor the founders, celebrate the progress made, and renew our commitment to creating a future where individuals with bleeding disorders can live their lives to the fullest.

Happy 70th Anniversary to the Hemophilia Foundation of Southern California - 70 years of compassion, community, and resilience!

- Rigo Garcia, MPH



2024 INDUSTRY FORUM

HFSC held its annual Industry Forum on January 20 at Pasadena City College, featuring presentations from pharmaceutical companies, providing an in-depth understanding of current and new treatment options as well as the latest investigational therapies.

Nearly 150 community members also enjoyed the dedicated booth time where they had the chance to engage with industry partners, ask pertinent questions, and interact with representatives. Youth at the event were excited to attend The Painted Turtle Outpost, where they made crafts and played games with The Painted Turtle Staff.

Staying informed about current treatment options and emerging therapies is crucial for both healthcare professionals and community members. Industry Forum not only served as a platform for disseminating information but also as a space for fostering relationships and collaborations in our bleeding disorders community.

Thank you to all our volunteers for their help with this event and thank you to our community members for joining us!

THANK YOU TO OUR INDUSTRY FORUM SPONSORS!

PLATINUM



GOLD



2024 WOMEN'S RETREAT



On March 23 and 24, HFSC welcomed 88 women to the Sheraton Grand Los Angeles for a weekend of education, connection, and fun! The morning started with sponsor booths, followed by lunch and icebreaker activities. Women then had the opportunity to hear from Susana Escojido from Takeda, on "Emotional Health and Well-Being: Exploring the Mind-Body Connection," as well as Cynthia Lua, LMFT, who spoke on "Looking Within: Empowerment Through Feelings" and also led an art therapy activity. Both sessions also were presented in Spanish. While the women were in breakout sessions, teens ages 11-17 engaged in a rap session with Alejandra Lopez, MSW, ACSW, of Orthopaedic Hemophilia Treatment Center, and received self-care bags from Brothers Healthcare. They then took a field trip to bowl at Lucky Strike at LA Live. After the breakout sessions and checking in at the hotel, the ladies spent the early evening engaging in diamond painting crafts that complemented the connections that were forged throughout the day.

Dinner, generously sponsored by Sanofi, was led by speaker Cathy Marquez-Velasco, who spoke on "Women, Girls, and Hemophilia." Dinner was followed by a wine and dessert reception where the ladies had more time to craft, connect, and foster an atmosphere of warmth and friendship.

The Sunday breakfast, sponsored by Octapharma, included speaker Amber Federizo, DNP, who led a captivating presentation on "Understanding Menstruation and Total Body Bleeding" that sparked meaningful conversations for both women with bleeding disorders and those caring for girls with bleeding disorders.

Thank you to all our sponsors for making the Women's Retreat weekend possible! The support allowed So Cal women to have an unforgettable experience!

THANK YOU TO OUR WOMEN'S RETREAT SPONSORS!

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Hemophilia Foundation
of Southern California



The
Painted
Turtle

a serious fun camp

CAMP BLOOD BROTHERS AND SISTERS AT THE PAINTED TURTLE

JULY 16-21, 2024

**APPLY NOW AT:
[THEPAINTEDTURTLE.ORG/APPLY](https://thepaintedturtle.org/apply)**



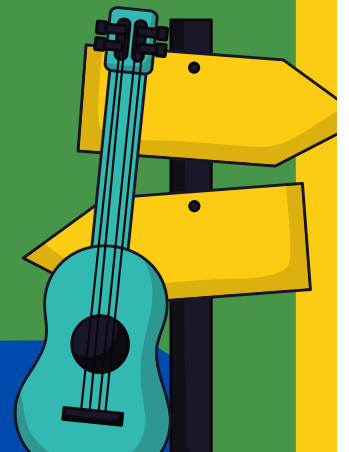
Application Checklist

- ✓ Clearance from Camper's Medical Provider
- ✓ Copy of most recent Progress Notes
- ✓ Immunization Record
- ✓ Camper Health History
- ✓ Medication List
- ✓ Allergies (if any)
- ✓ 2024 TPT Policy Forms (available on Painted Turtle website)

Questions? Contact Omar at omar@hemosocal.org



THE PAINTED TURTLE



WELCOME HFSC 2024 BOARD OF DIRECTORS

HFSC welcomes our returning and new Board Members! Please visit our website to learn more about each Board Member.



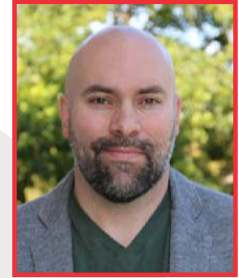
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A DREAM THAT CAME TRUE



Ladies sewing whimsical hats for an HFSC fundraiser.



North Hollywood VFW hosts a fundraiser for HFSC



HFSC Community being supported by the American Red Cross



Dr. Shelby Dietrich leads Orthopedic Hospital in Los Angeles, CA, in becoming a well-respected center for hemophilia care.

A BRIEF HISTORY OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

by Verne Hays

The first organizational meeting for families with hemophilia was called in the spring of 1952 by Mr. and Mrs. Theo Packard and Mr. and Mrs. Kenneth Ketchum, with the help of Dr. Madeline Fallon, the Foundation's benefactor and first Medical Consultant (now deceased). Others in attendance at that initial meeting were Mrs. Marvin Newman, Mr. and Mrs. Verne Hays, Mr. and Mrs. S. Fabro, Mr. and Mrs. Frank Daily, Mr. and Mrs. William Pruitt, Mr. and Mrs. L.B. Churchill, and Mr. and Mrs. Chester Eckert, and Mr. and Mrs. H. Lander.

A modest collection was taken up for rental of the meeting hall, after which Marvin Newman offered, gratis, use of his Wilshire Blvd. auction gallery for a meeting place.

Children's Hospital of Los Angeles was one of the first hospitals to help hemophiliacs and their families by administering whole blood and plasma furnished by Hyland Laboratories. Each family had to absorb the cost of treatment and also secure blood donors to replace the plasma used by the patient.

In those years, the Foundation relied on small but enthusiastic fundraisers, such as ham dinners, dances, card parties, luncheons, even Tupperware parties, all run by area groups and local sororities. The money directly aided the families and kept the office open. (We sure could have used Bingo!)

On November 30, 1953, a new Emergency Treatment Room was dedicated at the California Babies and Children's Hospital (California Hospital today). Dr. E.F. Hansen was the on-call physician in the two bed treatment room, and he did a tremendous job assisting Dr. Fallon. It was here also that Dr. Shirley Whiteman and

HISTORY

A DREAM THAT CAME TRUE

physiotherapist Donna Boone became invaluable members of the hemophilia program. The American Red Cross came to the Foundation's aid in October 1953 by supplying free of charge a new antihemophilic plasma to patients in Los Angeles and Orange Counties. In December 1953, Santa Monica Hospital was named one of the emergency centers where hemophiliacs could obtain this special plasma. Seven additional stations were set up and stockpiled with plasma provided by the Red Cross Blood Service as requested by the Foundation. These were Los Angeles County General, Orthopaedic, California Lutheran, Good Samaritan, Children's Seaside, and California Babies and Children's Hospitals.

The original families that formed the Hemophilia Foundation of Southern California did so to keep their children alive by providing and sharing information on the care and treatment of the hemophiliac. There was also the terrible financial burden that bankrupted numerous families in their fight to help their children. They had a "dream" that someday they would be able to provide the best possible care and treatment for each patient with a plan that would lift the terrible financial burden from their shoulders.

The "dream" began to come true when Orthopaedic Hospital, in 1962, became Los Angeles' first actual center for Hemophilia, under the direction of Dr. Shelby Dietrich. The "dream" continues to come true today with additional federally-funded Treatment Centers (e.g. Children's Hospital, UC Irvine, San Bernardino Medical Center).

The medical breakthrough of antihemophilic factor concentrate, home treatment, and more sophisticated physical therapy are also part of the dream, and California stands as a model regarding its aid program, the Genetically Handicapped Persons Program (GHPP), putting to work the commitment of social responsibility to people with genetic diseases.

*First published in HemophiliACTION
Volume 3, Issue 2, Summer 2004*



National AIDS Memorial Grove in San Francisco added a Hemophilia Circle to honor those we lost in the bleeding disorders community.



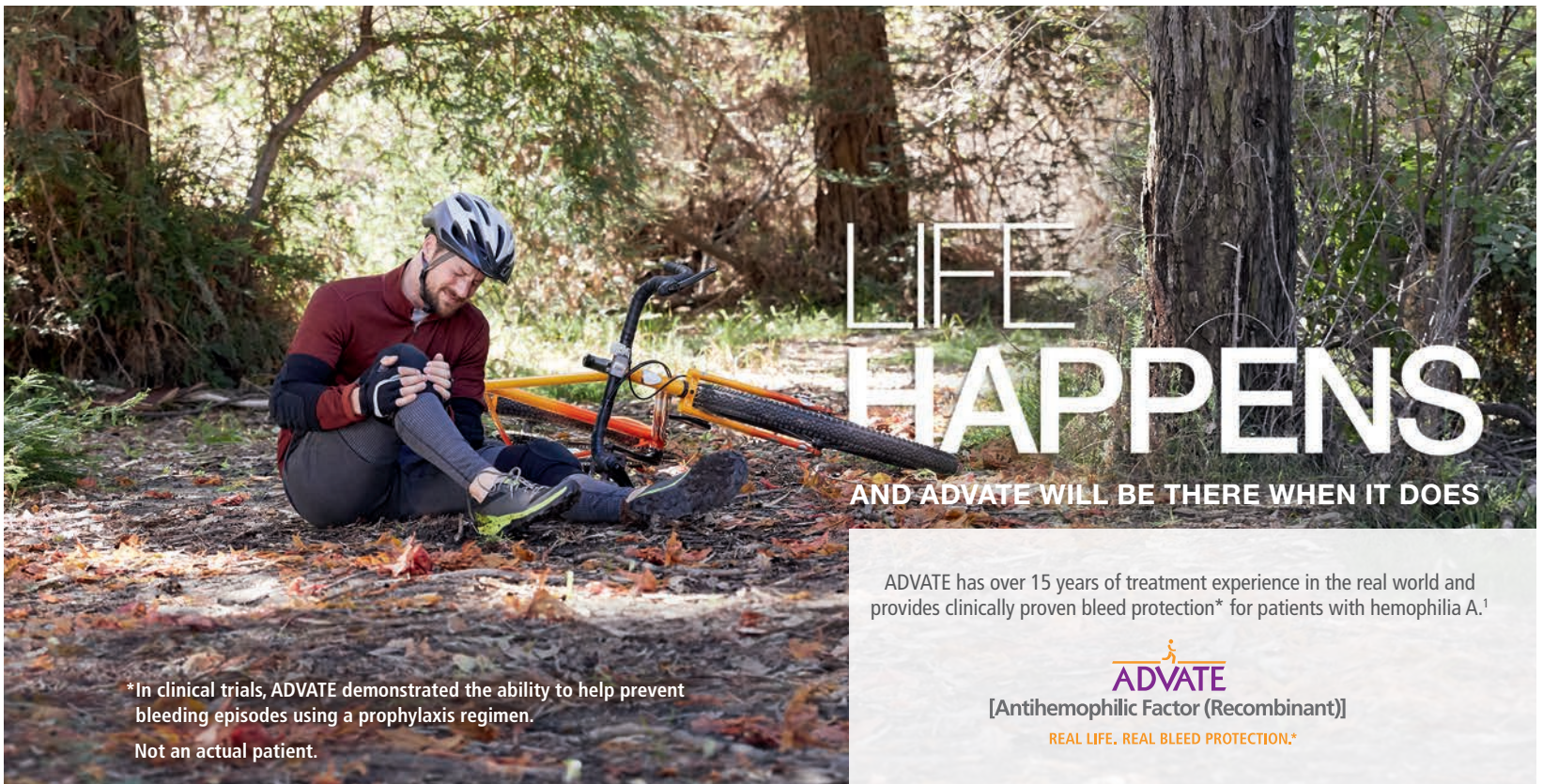
Two boys learn to self-infuse at a 2017 Camp Kickoff Lunch.



HFSC brings the Teen Leadership Council to Washington Days in D.C. in 2019.



Ladies at the 2024 Women's Retreat chatting while making crafts.



*In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

Not an actual patient.

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.*

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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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MARCH IS BLEEDING DISORDERS



Thank you to all who donated, in honor of
**BLEEDING DISORDERS
AWARENESS MONTH!**

Because of your generous support, we
raised over **\$4,500** to help us provide
SCHOLARSHIPS for our community members!

Anonymous (2) • Matt and Hazel Borowsky • Marilyn Borowsky • Betsy Cook • The Desai Family
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CALIFORNIA LEGISLATIVE DAY



HFSC participated in the Hemophilia Council of California's Legislative Day on March 18. Community members spoke with Senators, Assemblymembers, and their staff to advocate on issues including protecting patient assistance programs. This year, a teen from the Future Leaders Program and a set of parents held all their visits completely in Spanish. This was significant to ensure our elected officials hear firsthand from all constituents they represent with nothing lost in translation, as well as understanding the added struggles the Spanish community faces within the bleeding disorders community.

PROCLAMATION FROM THE CITY OF BELL



The Hemophilia Foundation of Southern California thanks the City of Bell for issuing a proclamation on behalf of our community and for promoting awareness of those living with rare bleeding disorders. The Bell City Council also provided time during their session to learn about HFSC and bleeding disorders.

AWARENESS MONTH!

2024 WASHINGTON DAYS

In my dual role as a member of the bleeding disorders community and as the Community Outreach & Engagement Coordinator for HFSC, attending Washington Days for the first time was an enriching experience.

HFSC was well represented by dedicated community members who took time out of their busy schedules to advocate passionately on behalf of our community. Together, we championed our community's needs, focusing on HR 830/S 1375, the HELP Copays Act, and urged Congress to sign the Essential Health Benefits letter. This letter urges the US Department of Health & Human Services to enforce regulations requiring healthcare plans to cover medical treatments for all disease states, rather than lumping all different bleeding disorders into one broad category, ensuring comprehensive care for all. The dialogues and stories shared were truly impactful and will greatly benefit our blood brothers and sisters.

We extend a heartfelt thank you to all the California Congress Members, Senators, and their dedicated staff for engaging in these meaningful discussions about improving access to care. Working together, we can continue to make strides towards better healthcare for all.

- Omar Torres (Bleeding Disorder Community Member & HFSC Outreach Coordinator)



MEDICAL UPDATES

Are Bleeding Disorder Patients Getting the Most Out of Physical Therapy (PT)?

by Vita Staff

For those who live with bleeding disorders, joint problems can reduce their mobility and keep them from being active. When blood doesn't clot as it should, bleeds can occur inside joints, causing pain. Older patients are especially affected because they didn't benefit from treatment advances until later in life. Then they experience the compounding effects of age-related joint problems, like arthritis.

That makes physical therapy an important aspect of health care delivered at Hemophilia Treatment Centers, which are comprehensive clinics that take a holistic approach to the patient's overall health and well-being. A survey from the National Bleeding Disorders Foundation (NBDF) looked at how closely physical therapists at HTC are following treatment guidelines from the foundation's Medical and Scientific Advisory Council (MASAC). The council issues annual recommendations for treatments that are evidence based, meaning that research has shown their usefulness and effectiveness.

The current guidelines for physical therapists include frameworks for managing joint health and rehabilitating patients after major bleeds. The guidelines also advise on how best to use cold packs to reduce swelling and when shoe inserts and braces can be most helpful.

But it can take up to 17 years for these guidelines to be implemented and only 14% of interventions are impacting the intended patient population, physical therapist Lena Volland said at a recent NBDF webinar. She has hands-on experience providing PT at hemophilia treatment centers and she's also NBDF's Director of Education.

MASAC's strategies have their roots in research and expertise, but putting these guidelines into action is not always a straightforward task.

"There are many compounding factors that will prevent something from being implemented in the clinical practice," said Volland. For MASAC's recommendations to be fully effective, a well-planned and executed strategy for implementation is necessary.



Barriers to Implementation

NBDF surveyed physical therapists at HTCs about barriers that prevent the application of best practices recommended in the MASC guidelines. The survey found a high percentage of alignment with MASC guidelines – 82%. But an analysis of survey results also identified reasons why the treatment guidelines aren't always followed. They included patient preference, limitations of the physical space in therapy areas, a lack of funding and problems with health insurance coverage.

Continuing education programs are necessary to spread specialized information, according to Volland. Experienced professionals can share their skills through mentorship programs, she said. Volland also noted that providing financial support for full-time physical therapist positions helps address staff limitations in hemophilia treatment centers.

emPOWERment WEBINAR SERIES

On February 7, HFSC hosted the first emPOWERment Webinar of the year, "Medi-Cal Updates: What You Should Know." Patricia Lopez, Health Insurance Program Manager at the Venice Family Clinic educated community members on important changes to Medi-Cal.

In 2024, Medi-Cal will update annual redeterminations after a break from 2020-2023. It is important to update information such as address and household income. Medi-Cal is sending these out in yellow envelopes.

If Medi-Cal terminates your coverage due to not submitting a redetermination form, you will have 90 days to reactivate your coverage.

As of January 2024, Medi-Cal Expansion has changed so an individual of family is eligible regardless of immigration status. Anyone who applies and meets the income requirements will receive full-scope benefits.

THANK YOU TO OUR SPONSORS!

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SILVER



ADVOCACY CORNER

The Hemophilia Council of California's have chosen their 2024 Future Leaders and Advocacy & Access Ambassadors. The Advocacy and Access Ambassadors are volunteer leaders who help establish and build a strong grassroots network of bleeding disorders advocates in California. Most importantly, the Ambassadors lead as advocates on legislative and health policy initiatives that are important to the bleeding disorders and rare disease community.

Returning Ambassadors

Carson Knight
Leslie Guevara
Rigo Manzo
Trevor Messerly
Jack Russek
Karina Piu
Naomi Giron

New Ambassadors (for 2024)

Daniel Cruz
Diego Horta
Haylee Slonaker
Mathew Casas
Mia Castaneda-Layman
Meredith Wolfe



The Future Leaders Program provides leadership training and develops advocacy skills for teens affected by bleeding disorders. The program teaches young adults, grades 9-12, to be effective advocates for themselves and their families and attend Legislative Day, where they tell their stories to legislators.

2024 Future Leaders

Natalie Cardenas, Bakersfield; Braedon Criner, Santa Clarita; Logan Dawes, Tustin; Heidi Agama Jimenez, Laguna Niguel; Langston Brown, Los Angeles; Isaac Pinto, Bakersfield; Renatto Medranda, Temecula; Marcantonio Medranda, Temecula; Andrea Ramirez, San Luis Obispo; Ivan Giron Jr, Indio; Sophia Horta, Downey



**Hemophilia Foundation
of Southern California**

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If you would like a copy of this newsletter in Spanish, please contact the HFSC office at 626-765-6656 or info@hemosocal.org, and we would be happy to send one to you!

¡Si desea una copia de este boletín de noticias en español, por favor póngase en contacto con la oficina de HFSC al 626-765-6656 o info@hemosocal.org!



Hemophilia Foundation
of Southern California

HFSC Family Information Day

**May 4, 2024
Knott's Hotel
8:30am - 2:00pm**

Hemophilia, von Willebrand, and Rare Disease
Breakouts

Tickets to Knott's Berry Farm for all in attendance
Childcare spots limited: register today!



 REGISTER




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June 1-2 | Pali Retreat