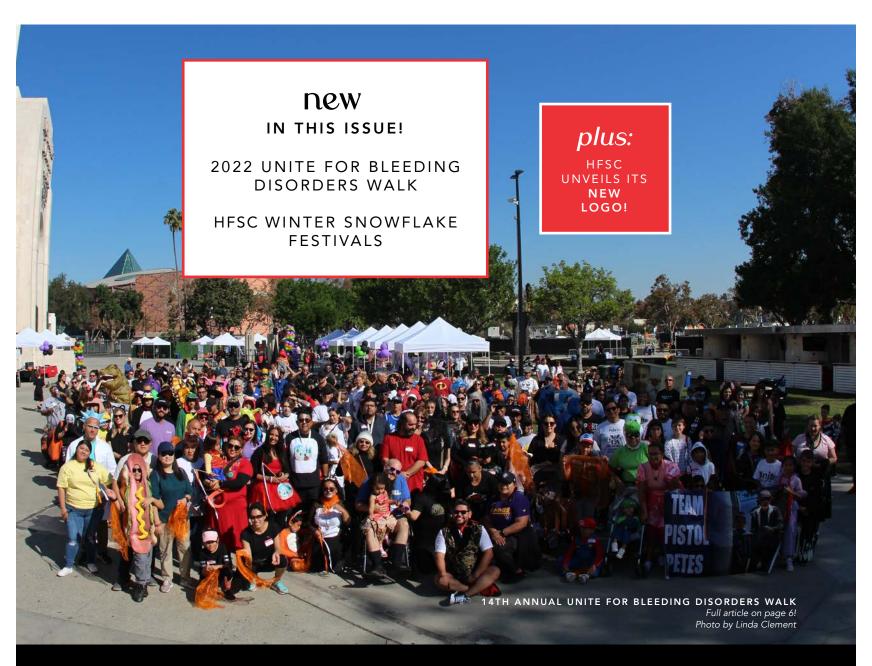
# HEMOPHILI





VOLUME 19 • ISSUE 1 • WINTER • 2023



HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

### **GENERAL**

Anonymous (2) • Richard and Shelley Aguilar • Jesus Avila • G. Beverly Bergmann • Laura and Aadip Desai Karlene Dockery • Edward and Barbara Gomperts • James A. Grove • Hector and Martha Guevara James and Kristine Hardeman • William Hartman • Tim Park • Joan Parker • Don and Anne Polkingharn Judith Rothman • Frank and Vivian Stefkovich • Jeffrey and Mary Lou Wright • Robert Zamora

### IN HONOR

Robert Bard, in honor of Richard Metz, MD • Joel Bergenfeld, in honor of Richard Metz, MD
Harry and Juanita Boessler, in honor of Tyler, Abby and Michael • Jane Brady, in honor of Amelie lavicoli
Drs. Elie M. Gindi and Pamela Schaff, in honor of Richard Metz, MD • Brenda Gonzalez, in honor of Matteo Salcida
Gloria Hernandez, in honor of Matteo Salcida • Ellen JS Greenberg, in honor of Richard Metz, MD
Barbara Lowe Fodor, in honor of Richard Metz, MD • Marc Meth, in honor of Richard Metz, MD
Robert Meth, in honor of Richard Metz, MD • Dixie Olson, in honor of Gary Olson
Michele and Doug Warner, in honor of Cole Warner

### IN MEMORY

Joy Brand, in memory of David Brand • Peter and Lana Clancey, in memory of Brian Clancey
Diane E. Haun, in memory of Don Butler • Jeanne McKay, in memory of Sidney Katz
William and Judy Metscher, in memory of Richard Katz • Mary Wallis, in memory of Michael L. Schmidt

### **GRANTS & CORPORATE GIFTS**

Anonymous • Burger Zone • The Charitable Foundation, Inc. • Colburn-Keenan Foundation Hemophilia Federation of America • Kroger • Northrop Grumman • Phillips 66 • Walmart Donations made between 10.1.22 – 12.31.22

### BOARD OF DIRECTORS HFSC TEAM

RICK KELLY, MBA • President
RON STAAKE • Treasurer
SHIN CHEN • Secretary
ELI ECONOMOU, ESQ. • NADIA EWING, MD
SANDY KNIGHT, ESQ. • BRIAN IAVICOLI, RN
BOB NUMEROF, PHD • PEDRO SANCHEZ, MD
SHAWN WHELAN, DO
DORIS QUON, MD • Medical Consultant

RIGO GARCIA, MPH • Executive Director
MICHELE WARNER • Director of Development
LAURA DESAI • Director of Operations
CASEY O'BRIEN • Senior Events Manager
OMAR TORRES • Outreach & Engagement Coordinator
SUSAN HALL-HARDWICK • Accounting

### 2023 CALENDAR

### **WOMEN'S RETREAT**

March 18- 19 • Marriott Irvine Spectrum, Irvine, CA

### **EMPOWERMENT WEBINAR SERIES**

March 29 • Virtual Event

### **WORLD HEMOPHILIA DAY**

April 16 • Location TBD, Los Angeles, CA

### **WORLD HEMOPHILIA DAY**

April 21 • Location TBD, Palm Springs, CA

### **FAMILY INFORMATION DAY**

May 6 • Sheraton Cerritos Hotel, Cerritos, CA

### **COMMUNITY DINNER**

May 10 • Location TBD

### **EMPOWERMENT WEBINAR SERIES**

May 17 • Virtual Event

### **MUJERES ENLAZADAS POR SANGRE**

May 20 • Location TBD

### **FAMILY RETREAT WEEKEND**

June 2 - 4 • Pali Mountain Retreat, Running Springs, CA



# A LETTER FROM THE BOARD PRESIDENT

It was wonderful to see so many of you at our most recent Halloween-themed Walk on October 29, which exceeded all past totals, raising over \$168,000 in support of advocacy and access to care, research, emergency financial assistance, scholarships, and Camp Blood Brothers & Sisters. Thank you to everyone who donated, raised funds, volunteered, and promoted awareness in support of the bleeding disorders community in Southern California! I also was grateful to have ended a fabulous year full of informative and enjoyable events at HFSC by attending the Snowflake educational dinners where I was able to celebrate the holidays with fellow community members while learning more about bleeding disorders.

We have another exciting year planned for 2023, including this year's Family Retreat, which will be held June 2-4 in San Bernardino County at the Pali Retreat Center and Camp Blood Brothers and Sisters July 16-21 at the Painted Turtle in Lake Hughes, CA. To register for any events, please visit www.hemosocal.org.

We are always looking at ways to enhance our programming and how to work most effectively to serve our community members. Recently, the Board gathered for our annual all-day retreat in person to discuss the strategic goals and vision of the Foundation. If you have a specific issue that you would like to see addressed in the coming years, we welcome your feedback. I look forward to seeing you soon! In the meantime, please feel free to reach out to me with any questions or if I can help in any way. - *Rick Kelly* 

# A LETTER FROM THE EXECUTIVE DIRECTOR

I want to start off by saying THANK YOU! Because of each one of you, we were able to have another successful year full of events and programs. We can truly say, 2022, what a year of change. This past year felt like it flew by and HFSC is very proud of the events and programs we were able to bring to you. Thank you all for your continued support, not only through the transition of Executive Directors, but also through the transition of being back in-person. As I come off having completed my first six months as your Executive Director, I truly feel we have accomplished a lot. From a successful 2022 Walk, where we surpassed our fundraising goal, to our Snowflake dinners, where I was able to meet many of you in a more intimate setting, 2022 was truly successful.



As we move into 2023, we, the bleeding disorders community in Southern California, need to continue to work with not only our hemophilia treatment centers, but with all our partners in the bleeding disorders community. We have a great calendar of events for 2023. This year, we will continue to provide high quality events and programming, with a focus on advocacy, mental health, Spanish programming, and relaunching our new families program. We also will focus on strengthening programming for our teens, women, men, LGBTQ+, and older populations. Soon, you will be getting phone calls from one of our HFSC staff members to update your information. We want to make sure you receive all communications regarding our upcoming programs. As always, please reach out to our office if you have any questions, comments, or concerns or need any help with issues you are facing with your bleeding disorder. Thank you once again, and I will be seeing you at one of our events. - *Rigo Garcia* 

# We are excited to announce the launch of our new logo as part of the ongoing evolution of HFSC!



After many creativity sessions, we have chosen a new logo that is modern with key elements that convey our mission and orientation for growth, while remaining true to our longstanding commitment to serve those with bleeding disorders in Southern California!



### THANK YOU, MICHELLE!

The Hemophilia Foundation of Southern California thanks Michelle Kim for completing her role as Special Advisor to the Executive Director. We are grateful for Michelle's eight years as Executive Director; full of inspiration, determination, and guidance, in service of those in the rare bleeding disorders community.



APPLY NOW!

# CAMP BLOOD BROTHERS AND SISTERS

CNVFILLM F

**JULY 16 - 21** 

AT THE PAINTED TURTLE

23 Francis 2025

CANVA STORIES

27

### **APPLICATIONS NOW OPEN!**

Spots limited, apply today!

Must be fully vaccinated to attend.

### Apply:

https://www.thepaintedturtle.org/apply

# 14TH ANNUAL UNITE FOR BLEEDING DISORDERS WALK

HFSC was excited to share the Halloween spirit with more than 350 attendees at the Unite for Bleeding Disorders Walk at the LA Coliseum on October 29, in support of those with bleeding disorders in Southern California. We are extremely grateful to everyone who donated, raised funds, volunteered, and promoted awareness for HFSC's Walk. We loved seeing everyone's Halloween costumes! Participants had the opportunity to play a wide array of Halloween-themed games at the event, visit sponsor and activity booths, enter a raffle, and enjoy the post-walk entertainment by Tiger Squadron, a precision formation flying and aircraft display team, sponsored by Fidelis!

HFSC is so thankful to everyone who donated; this year we raised the most yet, totaling over \$168,000 in support of advocacy and access to care, research, emergency financial assistance, scholarships, and Camp Blood Brothers & Sisters. A special thank you to Daniel Cruz, Fiach Echandi, Carrie Davidson, Annabelle Garcia, Albert Maffei, The Painted Turtle, and HFSC's Board for presenting at this event! And much gratitude to Talan Carthey for singing the National Anthem, Vicky Michua and Grace Hernandez for serving as Co-Chairs for the walk, and to all of our community for their participation! A shout out also goes to NCL Glendale and all of the volunteers who helped make this event possible!

Congratulations to our Top 10 Teams: Perry Parker's Team, Team Kim Family, Amelie's GT Striders, Cole Train, Team Avila, Ortho Walkers, Super C, Langston Brown's The Walking Red, Team Wild at Heart, and The Newbies.

Congratulations to our Top 10 Individuals: Perry Parker, Michelle Kim, Jesus Avila, Doris Quon, Michele Warner, Erika Clement, Brian O'Keefe, Richard Metz, Shin Chen, and Amelie Iavicoli.

Congratulations to Best T-Shirt Award: Langston Brown, and to Best Costume Award: Sterling Hubbell!

Thank you to our Local Sponsors! Gold: Design Science. Silver: Bayer, Center for Inherited Blood Disorders, CSL Behring, CVS Specialty, Fidelis Specialty Pharmacy, Genentech, Grifols, InfuCare Rx, Novo Nordisk, Octapharma, Optum, Soleo Health, and Specialty Care Rx. Bronze: Brothers Healthcare, Profusion Specialty Pharmacy, Sam's Club, Tito's Handmade Vodka, Walmart, and Westmount.

Thank you to our National Sponsors! National Presenting Sponsors: Takeda and Hemophilia Alliance. National Community Partners: BioMarin and Sanofi. National Partners: Ascella Health, Bayer, and HEMA Biologics.









Registration is now open for our 2023 Superhero-themed walk! Sign up today!

WWW.UNITEFORBLEEDINGDISORDERS.ORG/EVENT/SOCAL



# HFSC 2022 COMMUNITY DINNER

### DIA DE LOS MUERTOS

11.01.22

### Patrocinado por Takeda

El 1 de noviembre de 2022, el grupo Mujeres Enlazadas se reunió en el hermoso Hotel Mission Inn y Spa! Fue un placer ver a todas las pacientes, madres, abuelas y cuidadoras. Tuvimos la oportunidad de aprender a manejar situaciones estresantes. Annabelle García hizo una excelente presentación. ¡Gracias a Takeda por su apoyo a esta cena educativa!



# HFSC 2022 COMMUNITY DINNER

### ORANGE COUNTY COMMUNITY DINNER

11.09.22

Sponsored by Bayer, HFSC hosted a wonderful dinner at Maggiano's Little Italy in Costa Mesa where attendees learned how to rediscover goals related to their careers, education, and passions. Thank you, Erika Bocanegra and Bayer, for the informative and interactive presentation!

# OCTOBER emPOWERment WEBINAR SERIES



### CA INSURANCE PROGRAMS

10.12.22

On October 12, 2022, HFSC hosted a webinar as part of its emPOWERment Webinar Series on California Insurance Programs.

Annabelle Garcia, BCH, discussed insurance programs specific to California, including California Children's Services (CCS), marketplace insurance options, and the Genetically Handicapped Persons Program (GHPP). Thank you so much to Takeda for your support!

# NOVEMBER emPOWERment WEBINAR SERIES



### THE POWER OF YOUR STORY

11.16.22

On November 16, 2022, HFSC hosted the final webinar of the year in the emPOWERment Webinar Series on "The Power of Your Story."

Reverend Cazandra Campos-MacDonald, a mother of children with a bleeding disorder, gave a powerful presentation about learning to share your personal stories during life-changing moments. Attendees learned how to empower themselves in everyday situations by identifying significant experiences to share and develop into their story.

### THANK YOU TO OUR emPOWERment SPONSORS!

**PLATINUM** 

GOLD

SILVER













### **HFSC 2022 SNOWFLAKE DINNERS**



### **BAKERSFIELD**

11.30.22

On November 30, HFSC hosted 25 community members for an Italian dinner in Bakersfield, CA. Tyra Holland, Gene Therapy Patient Resource Navigator for CSL Behring, gave an overview of the basics of Gene Therapy. After the talk, participants played a White Elephant gift exchange game. Thank you so much to our sponsor, CSL Behring, and to Fidelis Specialty Pharmacy for providing our families with crafts and gingerbread houses.











### REDLANDS

11.30.22

On November 30, HFSC hosted more than 50 community members at the Redlands Snowflake Dinner at The Old Spaghetti Factory. Attendees enjoyed an informative and fun video "Challenge Accepted," where we followed a young adult with a bleeding disorder learning to take control of his life. Following the video, attendees participated in a brief discussion and completed a bleeding disorders crossword puzzle. The night ended with a fun game of White Elephant. Thank you to Genentech for sponsoring this holiday gathering and everyone who attended to celebrate the season! Thank you also to Brothers Healthcare for their donations and to Paul and Linda Clement for volunteering at this event.



12.01.22



On December 1, HFSC hosted 30 community members at the Lancaster Snowflake Dinner. The dinner took place at Gino's Italian Restaurant, sponsored by Bayer. The presentation for the night was "And Now Back to You," where we were given tips on how to focus on ourselves. So many times, we focus our attention on others and forget about ourselves. It was wonderful to be able to connect with families and their children who had not attended an event in some time, as well as with community members who now have families of their own.

### HFSC 2022 SNOWFLAKE DINNERS



### **NEWPORT BEACH**

12.01.22

More than 45 attendees enjoyed a fun-filled evening at The Old Spaghetti Factory in Newport Beach, including celebration, great company, and an informative and interactive presentation from Nick Self, "Bleeding Disorder Family Feud," where members answered questions about bleeding disorders, competing against one another for the correct answers. Thank you to our sponsor, Octapharma, for your support! Thank you also to Soleo for their donation and to volunteers Karla Reynado Arce and Mauricio Reynado for your help!











### **MONTEBELLO**

12.06.22

On December 6, HFSC hosted more than 50 community members at the Montebello Snowflake dinner, which took place at Montebello Quiet Canon. Thank you to Takeda for sponsoring this event, where they presented on "What is Healthy Aging?" The presentation covered what does it really mean to "age gracefully" or, rather, "age healthfully?" We discussed how to reduce the risk of disease and related disabilities, how to preserve and improve physical and mental functioning, and how to actively engage in life. We would like to thank our volunteers Rosie Villalpando, Vicky Michua, and the Clement Family for their assistance that evening. Thank you also to Optum for their donations.





### DOWNEY

12.07.22

On December 7, HFSC hosted more than 60 community members at the Downey Snowflake Dinner at the Embassy Suites by Hilton Los Angeles Downey. Attendees were given an informative presentation on gene therapy, followed by an exciting game of "Gene Therapy Jeopardy!" The event closed out with a fun round of White Elephant, with many great gifts received! Thank you to BioMarin for sponsoring this holiday gathering and everyone who attended to celebrate the season! Thank you also to Specialty Care Rx for their donations.



### RIVERSIDE

12.08.22

On December 8, HFSC hosted nearly 60 community members at the Snowflake Dinner at Mamma Mia Restaurant and Bar in Riverside. Attendees participated in an interesting discussion, "Living Well with Hemophilia," where they gained a better understanding of hemophilia and how to manage physical and emotional challenges through their interactions with other people who also have a bleeding disorder. Thank you to Novo Nordisk for sponsoring this special evening and all who joined us for the informative presentation and celebration. Thank you also to Profusion Specialty Pharmacy for their donations and to volunteers Karla Reynado Arce and Mauricio Reynado for your help! It was so wonderful seeing everyone!



### SANTA BARBARA

12.13.22

On December 13, HFSC hosted 50 community members at the Snowflake Dinner at Stella Mares in Santa Barbara. Attendees listened to an informative presentation on gene therapy, followed by splitting into teams for an entertaining game of "Unlock the Science of Investigational Gene Therapy for Hemophilia." The event closed out with a fun round of White Elephant, with many great gifts received! Thank you to Spark Therapeutics for sponsoring this holiday gathering and everyone who attended to celebrate the season! Thank you also to InfuCare Rx for their donations.



### POMONA

12.08.22

HFSC hosted more than 50 community members at our Pomona Snowflake dinner on December 8 at the Pomona Mining Company. Thank you to Sanofi who sponsored the event and provided a very nice and thoughtful presentation titled "Gratitude Nation." The conversation covered finding out why practicing gratitude may be good for people living with a chronic condition and learning how to leverage gratitude in our own life. All community members were invited to write down and share what they were grateful for and place it on the gratitude tree. The tree was very full by the end of the night! We would like to thank the Clement Family for volunteering at this event. Thank you also to Guided Alliance for their donations.



BRO (BLEEDERS REACHING OUT)
12.18.22

GOOOOAAAALLLLLLLL....was the only thing on our minds when HFSC hosted the BRO Group Snowflake Luncheon on December 18. The event took place at Goals in Covina, a soccer facility, appropriate since the World Cup Championship took place on this same day. Bleeders Reaching Out (BRO) was established to help meet the needs of adult men in the bleeding disorders community and includes dads, siblings, and spouses who meet every other month for support on various topics. The day included community members enjoying lunch and a fun gift exchange. Thank you to all who attended this event!



### 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 bothal remedice.
- 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.

### 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.





### 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.

©2020 Takeda Pharmaceutical Company Limited. 300 Shire Way, Lexington, MA 02421. 1-800-828-2088. All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda Pharmaceutical Company Limited. ADVATE is a registered trademark of Baxalta Incorporated, a Takeda company.

Patented: see https://www.takeda.com/en-us/patents/

U.S. License No. 2020 Issued: 12/2018

US-ADV-0030v1.0 02/20



# MEDICAL ARTICLE SPOTLIGHT

### CULTURAL COMPETENCE IN HEALTHCARE: A WORTHY DISCIPLINE

### **FORBES**

February 7, 2023 by Hugh Lytle

While there is no single way to define "cultural competence," one prevailing explanation, shared by Georgetown University's National Center for Cultural Competence, is "A set of congruent behaviors, attitudes, and policies that come together in a system, agency or among professionals and enable that system, agency or those professions to work effectively in cross-cultural situations."

Cultural competence is critical to successful health outcomes. When care is delivered with sensitivity to and understanding of cultural influences and differences, it can improve the experience and outcomes for all stakeholders, including people, communities, healthcare staff, insurers/payers and the entire U.S. healthcare ecosystem.

Cultural diversity manifests in different cultural beliefs, which can be barriers to the one-size-fits-all U.S. healthcare system. Social and cultural backgrounds influence beliefs, motivations and decision-making with regard to healthcare.

Health equity goes hand in hand with cultural competence. When we achieve health equity, every individual has the opportunity to achieve his or her full health potential, with no one left behind due to social or socioeconomic circumstances. Health inequities can be measured through differences in length and quality of life; rates of disease, disability and death; severity of disease; and access to treatment.

Training for cultural competence enables providers to have a better understanding of the values of the community that is being served in order to achieve a better outcome. Cultural competence benefits the patient, the provider and the healthcare system. It improves understanding, communication and respect by fostering trust and faith in whatever care plan is indicated.

### CULTURAL COMPETENCE IN VALUE-BASED CARE

A number of organizations in the U.S. healthcare industry are exploring changes in the way care is delivered and funded. For years, the standard has been the "fee-for-service" (known as the "FFS") model. FFS is a volume game wherein healthcare providers are paid based on the services they deliver.

Through my company's work helping primary care practices adopt a value-based care model, I'm seeing more players in the industry shifting to alternative payment models, including VBC. In the VBC delivery model, providers, such as hospitals, physicians and other clinicians, are compensated based on patient health outcomes; they're rewarded for helping patients improve their health. Still, there remains a need for healthcare organizations (providers and payers) to actively prioritize health equity in their value-based models. For VBC to chip away at inequities, more payers and providers must incorporate health equity—and cultural competence—into their VBC program designs and approaches.



### IMPROVING CULTURAL COMPETENCE IN HEALTH ORGANIZATIONS

What I've found physicians often lack are practical methods needed to embed unique cultural preferences into their work with diverse cultural groups.

Cultural care training can provide a heightened consciousness about cultural values, beliefs and preferences, as well as provide guidance on how to tactically embed cultural care approaches at point-of-care to improve outcomes and decrease costs. Ideally, these trainings should take place in person and involve the entire practice. Everyone in the practice has a role to play in making a patient's visit inviting, inclusive, respectful, personable and customer-centric.

Takeaways from these trainings might include an understanding of population health and strategies for improving overall health status; recognition of how patient health behaviors affect the financial risks of patient populations; identification of community and state-specific health disparities; and an identification of the socioeconomic challenges and community risk factors faced by underserved populations. Ideally, providers will gain insight with regard to leveraging the short amount of time they spend with patients to embed respect, trust and a personal approach into point of care.

Collectively, it's critical for the healthcare industry to encourage and incentivize the delivery of care that is culturally competent, addresses health disparities and improves health equity. Today, that means whole-person care that comprehensively addresses an individual's needs, including healthcare needs, social needs, mental health needs, environmental needs and economic needs.

These same principles and considerations apply to any industry or profession. Whether you're a physician, medical assistant, nurse, attorney, engineer or accountant, you must do more than deliver quality service. We all win when we endeavor to understand the social and cultural constructs within which we practice our given professions.

Hugh Lytle is founder and CEO, Equality Health, a Value Based Care leader helping independent primary care practices make the shift to VBC.

Article provided by NHF



NON PROFIT US POSTAGE PAID PASADENA CA PERMIT 562

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!



# family information day

SAVE THE DATE!

May 6, 2023 Sheraton Cerritos Hotel 8:30am - 1:30pm



Lunch Provided Knott's Berry Farm Tickets for ages 3+

