

HEMOPHILIA ACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA
VOLUME 16 | ISSUE 1 | WINTER | 2020



UNITE FOR BLEEDING DISORDERS WALK, P.3



HOLIDAY PARTIES & SNOWFLAKE FESTIVAL, P.7

2020 CALENDAR OF EVENTS

- March 19 **Community Dinner – Emergency Preparedness**
Palm Springs, CA
- March 28 - 29 **Women's Retreat**
Orange County, CA
- April 1 **Mujeres Enlazadas por Sangre Dinner**
Pomona, CA
- April 23-25 **Hemophilia Federation of American Annual Symposium**
Baltimore, MD
- April 28 **Community Dinner**
Pico Rivera, CA
- May 1 **Women's Educational Forum and Von Willebrand Disease Dinner**
Knott's Berry Farm Hotel
Buena Park, CA
- May 2 **Family Info Day**
Knott's Berry Farm Hotel
Buena Park, CA
- May 17 **BRO Dinner**
Madre Restaurant
Torrance, CA
- May 19 **Mujeres Enlazadas por Sangre Dinner**
King's Fish House
Long Beach, CA
- May 29 - 31 **HFSC Retreat**
Pali Retreat Center
Running Springs, CA
- June 11 **Community Dinner – VWD White House | Anaheim, CA**
- July 11 **BRO Professional Training Series – Session 1**
Pasadena, CA
- July 18 - 23 **Camp Blood Brothers and Sisters**
The Painted Turtle
Lake Hughes, CA
- August 1 **6th Annual Back to School Symposium**
Brookside Golf Course
Pasadena, CA

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HEMOPHILIA ACTION

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The Hemophilia Foundation of Southern California



A LETTER FROM THE BOARD PRESIDENT

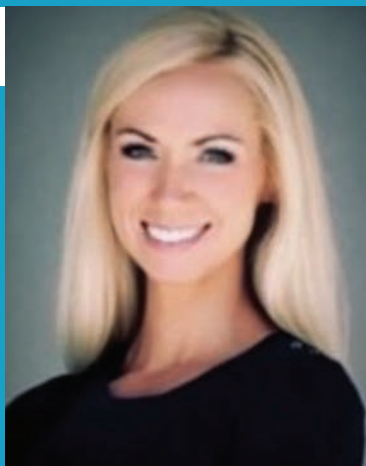
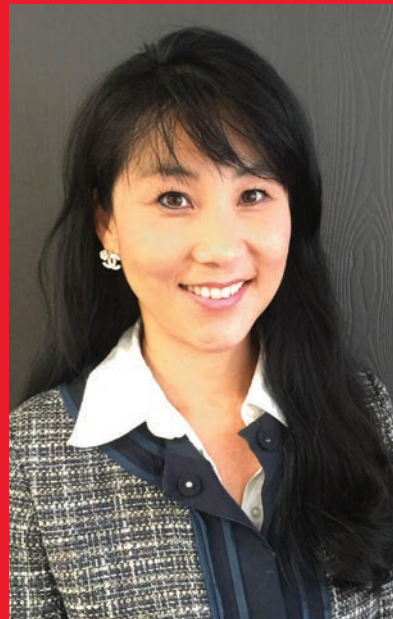
Once again, we have a lot going on at the Hemophilia Foundation of Southern California. At the end of January, we held our Industry Forum, which was a sold-out event and provided very valuable information to our community members about new and existing treatments. I would like to introduce our newest Board member, Brian Iavicoli. Brian is a nurse who works in a local school district and has experience with rare bleeding disorders. Brian's first Board meeting was at our February meeting where we met with a consultant to help us formulate a Strategic Plan. We are looking at ways to include other inherited bleeding disorders in our programming and how to work most effectively to serve our community members. If you have a specific issue that you would like to see addressed in the coming years, please reach out to us and let us know. We have many upcoming events during the spring and summer. Please make sure that you register as soon as possible; while we accommodate as many people as we can, our events tend to sell out.

Sandy Knight, HFSC Board President

A LETTER FROM THE EXECUTIVE DIRECTOR

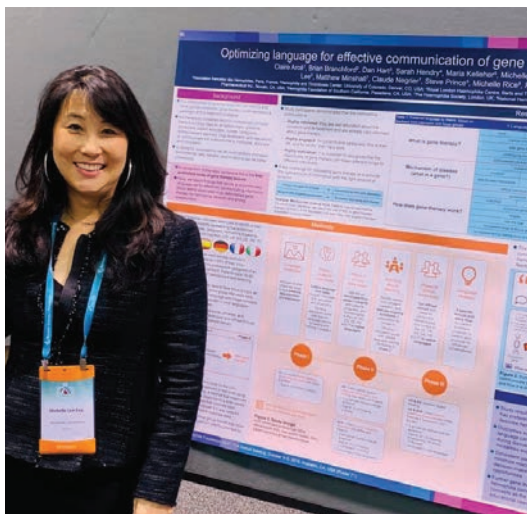
2020 is already flying by and we are well into our 2020 educational programs! HFSC is hosting many events so please make sure we have an accurate email for you to receive announcements or you can find them on our website: www.hemosocal.org. Speaking of websites, we will be working on a website overhaul this year which will provide greater resources for you! Also, we are thrilled that our community dinners have launched. We hope that local educational dinners will provide a greater sense of community and support for all of you. Finally, for high school seniors and college students, scholarship season has begun! Make sure to check out the list of available scholarships here: <https://www.hemophiliafed.org/scholarships/>. HFSC's own scholarship for community members will open on April 1st so be on the look out for that (super easy!) application by email. As always, please reach out to us for any questions or support you may need!

Michelle Kim, HFSC Executive Director



VOLUNTEER SPOTLIGHT

To kick off the new year, we want to welcome a new volunteer to the Hemophilia Foundation of Southern California team! Kellie is from Saint Louis, MO and recently moved to Los Angeles to pursue doctoral training in Health Behavior Research at University of Southern California. She is interested in examining the adult health risks associated with childhood obesity and chronic disease development in the ageing hemophilia population. A few projects she has been working on with us include developing and implementing surveys to better measure the needs of our community and writing articles for our blog to address common issues and connect those in need with helpful resources.

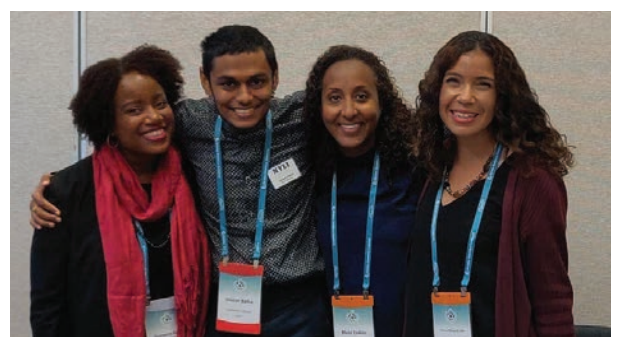


NHF BLEEDING DISORDERS CONFERENCE

ANAHEIM, CA

The National Hemophilia Foundation held its annual national Bleeding Disorders Conference from October 3-5, 2019 in Anaheim, CA. The Hemophilia Foundation of Southern CA acted as local host chapter and was thrilled to welcome hundreds of community members from all over the country. HFSC was also honored to receive five Chapter of Excellence Awards from NHF in the areas of: Advocacy and Public Policy, Board Governance, Programs and Education, Fundraising and NHF Partnerships as well as the Walk Chapter of the Year! In addition, our local medical providers were recognized for their work in the medical field: Dr. James Luck and Grace Hernandez, PT. We were equally proud of the 11 HFSC Teens who received the coveted Teen Impact Award-Great Job! HFSC Executive Director, Michelle Kim, presented a poster presentation entitled "Optimizing Language for Effective Communication of Gene Therapy Concepts: A Qualitative Study" and many HFSC community members presented in breakouts and we are very proud of the wealth of knowledge provided to the national community: Thank you for your hard work: Alejandro Barajas, Esq., Dora and Scott Burnett, KT Burns, Mia Castaneda-Layman, Cynthia Chavez, Erika Clement, Ashley Cunningham, Fel Echandi, Kristian and Silvia Garcia, Ivan Giron, Wayne Guzman, Alicia Horta, Brian Iavicoli, Esther Ibarra-Sanchez, Rick Kelly, Michelle Kim, Patrick Lynch, Christine Olivarria, Joslyn Olsen, Mickey and Tanya Price, Julie Slonaker, Morgan and Tim Stowers, Jason Walsh and Michele Warner. Finally, thank you to Board Member, Dr. Pedro Sanchez for helping to procure partial funding to sponsor the LGBTQI reception.

This year's NHF Conference will be held in Atlanta from August 6-9, 2020. Register here: <https://events.hemophilia.org/ehome/index.php?eventid=506749&>



11TH ANNUAL UNITE FOR BLEEDING DISORDERS WALK GRIFFITH PARK, LOS ANGELES



Thank you to everyone who donated, walked, and promoted awareness for HFSC's 11th Annual Unite for Bleeding Disorders Walk at Griffith Park.

More than 600 walkers donned iconic neon attire and big hair at HFSC's 80s-themed walk on November 2. Participants had the opportunity to join a Jazzercise class, watch a professional breakdance crew break it down, learn some crazy-fun dance moves, and enjoy a wide array of games, all while the DJ provided the day's soundtrack of the best 80s jams.

Thanks to the generosity of HFSC's local community, the walk raised nearly \$130,000 in support of advocacy and access to care, research to find a cure, and Camp Blood Brothers & Sisters!

Congratulations to our Top 10 Teams: We Clot This, Amelie's GT Striders, Team Joshua Kim, Cole Train, Brothers and Sisters Unite, Perry Parker's Team, Team Paul, Ortho Walkers, Thousand Oaks Globe Clotters, and Forrest's Fighters.

Congratulations to our Top 10 Individuals: Benjamin Cardenas, Michelle Kim, Michele Warner, Dr. Doris Quon, Amelie Iavicoli, Karlyn Johnson Brown, Veronica Diaz, Mariela Rodriguez, Rigo Manzo and Paul Avila

Congratulations to Best T-Shirt Award: Karlyn Johnson Brown, Team Captain, Wake Me Up Before You Hemo



Congratulations to Best Costume Award: Jessica Charlet

Thank you to our Local Sponsors! Gold: W.M. Keck Foundation. Silver: Aptevo, Brothers Healthcare, Center for Inherited Blood Disorders, CSL Behring, Fidelis, Genentech, Novo Nordisk, Santa Barbara Pharmacy, Soleo Health, and Westmount. Bronze: AltaMed, BJ's, CVS Specialty, Octapharma, Sanofi Genzyme, and Takeda.

Thank you to our National Sponsors! National Presenting Sponsor: Takeda. Official Sponsors: Bayer, Brionva, CVS Specialty, Grifols, Pfizer, and Sanofi Genzyme. Partner Sponsor Accredo.

A special thanks also to NCL Glendale and all of the volunteers who helped make this event possible! And, much gratitude to Board President Sandy Knight and Board Members Rick Kelly, Ron Staake, Shin Chen and Silvia Garcia for their help presenting during the program. Thank you to Scarlett Carmona for singing the National Anthem and to Board Member Wayne Guzman for being our emcee!

Registration is now open for our 2020 Hawaiian-themed walk, which will take place on November 7 at Griffith Park! You can sign up by visiting: www.uniteforbleedingdisorders.org/event/socal.



A first-person perspective shot from someone standing on a wide set of stone steps. In the foreground, a pair of hands holds an open brochure with text and images. In the background, a woman in a white shirt and yellow shoes is walking up the steps, and two children are further ahead. At the top of the steps is a large, light-colored stone building with a prominent circular window, likely a church or historical site. The sky is clear and blue.

GO SEEK. GO EXPLORE. GO AHEAD.

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Discover your sense of go. Discover **HEMLIBRA®**.

What is **HEMLIBRA**?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about **HEMLIBRA**?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. **HEMLIBRA** may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; **FEIBA®**), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (**FEIBA®**) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (**FEIBA®**) total.

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



HEMLIBRA®
emicizumab-kxwh | 150
mg/mL
injection for subcutaneous use

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 - confusion
 - weakness
 - swelling of arms and legs
 - yellowing of skin and eyes
 - stomach (abdomen) or back pain
 - nausea or vomiting
 - feeling sick
 - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs
 - pain or redness in your arms or legs
 - shortness of breath
 - chest pain or tightness
 - fast heart rate
 - cough up blood
 - feel faint
 - headache
 - numbness in your face
 - eye pain or swelling
 - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018



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Mujeres Enlazadas por Sangre gathered at beautiful Maggiano's Restaurant in Costa Mesa on Tuesday, December 2, 2019. Edgar Vega engaged the ladies in attendance to share about their own struggles and feelings with being diagnosed with a bleeding disorder. The women shared their emotions and received support from each other! All attendees, received a beautiful "Mujeres Enlazadas Por Sangre" t-shirt! Thank you, Sanofi, for sponsoring dinner!

MUJERES ENLAZADAS POR SANGRE



Mujeres Enlazadas por Sangre gathered at the Sheraton Hotel in Cerritos on Wednesday, September 25, 2019 to learn how to become better advocates! Hector Grisalez shared his inspiring story as he taught us how to be better advocates for the bleeding disorders community. Many thanks to CSL Behring for its support and sponsorship.



Camp Blood Brothers and Sisters

• APPLICATION DUE JUNE 19 •

JULY
18-23

The Painted Turtle
Lake Hughes, CA

- Child must be between the ages of 7 and 16 prior to session start date
- Minimum developmental age of 5 years
- Must be able to function and participate in a group setting
- Must be able to communicate needs independently
- Able to be away from family members for a limited period of time

.....

<https://www.thepaintedturtle.org/apply>

Questions? Call Cynthia at the HFSC Office at 626-765-6656



FESTIVAL OF LIGHTS AT THE MISSION INN | RIVERSIDE, CA

On December 18, members attended the Mission Inn Snowflake Dinner in Riverside. During a fantastic dinner, attendees participated in an interactive presentation from Sanofi Genzyme, "Spotlight on Unaffected Siblings." Attendees came in their best tacky outfits to enter the "Tacky Holiday Attire" contest and got into the holiday spirit by singing popular holiday songs in our sing-along. Gifts and gift cards were received after an appearance and special dance by Olaf. The evening concluded with families enjoying the beautiful Festival of Lights at the Inn. Thank you to Sanofi Genzyme for your support of this event!

Thank you to all our volunteers who helped wrap gifts and assisted at all our Snowflake Festival events!



SANTA BARBARA & SANTA ANA SNOWFLAKE FESTIVAL

HFSC hosted three Snowflake Festival events in December to celebrate the end of 2019, serving nearly 700 community members! On December 7, members gathered at the Santa Barbara Zoo and participated in fun crafts and games, followed by an eye-opening presentation, "Food for Thought," from Takeda. After a delicious lunch, the day ended with a special visit from Santa, gifts, and a visit to the zoo. Thank you to Takeda for supporting this event!

On December 14, the Snowflake Festival was held at the Santa Ana Zoo with crafts, games, and sponsor booths. Everyone enjoyed the Habit Truck serving burgers and were thrilled by the animal presentations offered by the Zoo. Santa stopped by for pictures and to say hello, and Olaf, Anna, and Elsa made a surprise visit. Gifts and gift cards were distributed to all kids and teens, and families were able to enjoy the Santa Ana Zoo for the rest of the afternoon! Thank you to all of our sponsors!

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CONGRATULATIONS, MICHELLE KIM!



On December 4, 2019, Senator Anthony J. Portantino awarded HFSC Executive Director Michelle Kim with the prestigious *Women in Business Award* which celebrates exceptional women whose professional skills and commitment to their community have made them outstanding leaders and role models. We are so proud of Michelle! The Awards luncheon was held at the Castaway Restaurant in Burbank, CA with over 600 attendees. Thank you Senator Portantino for supporting the accomplishments of women in business!

BAKERSFIELD COMMUNITY DINNER



HFSC hosted an exciting meeting in Bakersfield on Wednesday, October 23, 2019 to talk about self-advocacy! Thank you to Rose Cardenas for kicking off her role as the Bakersfield Community Liaison and our sponsor Pfizer. So much love and support for each other filled the room and we love our Bakersfield families!

FUNDRAISING & UNITE YOUR WAY

Many of you have asked how to turn your hobbies, as well as your participation in activities and events, into a way to raise funds for HFSC. Well, we are excited to share that we are now rolling out Unite Your Way, which is our Do It Yourself (DIY) fundraising platform!

Unite Your Way lets you turn your passion into a fundraiser – however, wherever, whenever you want. With an online platform dedicated to the fundraiser you choose, and many resources to empower you, you can create your own personal or group fundraiser in a matter of minutes.

Events can be created year-round and can be as big (or as small) as you design them to be. Examples can include “donating” your birthday (asking for donations on your birthday to benefit HFSC), an organized bike event to raise funds, game night with your friends, working with a local gym to organize a spin event, or even a baking contest to support our local bleeding disorders community.

Participants can register online and make a contribution, as well as invite their friends and family to sign up for or donate to their fundraising efforts.

Questions? Please contact Michele Warner, Director of Development, at mwarner@hemosocal.org

The logo features the word "Unite" in a large, bold, black sans-serif font. Above the letter "i" is a red graphic of a blood drop with a white outline. Below "Unite" is the phrase "YOUR WAY" in a bold, red, sans-serif font. A thick black horizontal line is positioned below "YOUR WAY".The logo consists of a red graphic on the left, made of three vertical bars of increasing height from left to right, with a stylized 'H' shape formed by the top bars. To the right of this graphic, the text "Hemophilia Foundation" is stacked above "of Southern California" in a bold, black, sans-serif font.

Visit <https://www.uniteyourway.org/event/SouthernCal> to learn more and get started today!

Let's get together to talk about IXINITY[®]

“My mission in life is to work at removing barriers for people in order to help them live to their highest potential. Helping to remove barriers for those in the rare bleeding disorders community fulfills this purpose.

—Samuel Gbadebo, your resource for all things IXINITY



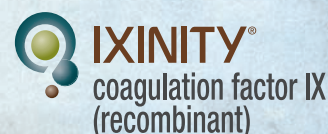
► Contact Samuel at 562-234-8531 or gbadebos@apvo.com



Aptevo BioTherapeutics LLC, Berwyn, PA 19312

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BRO GOES TO THE RAMS GAME



On December 29, 2019 our BRO group (Bleeders Reaching Out) ushered in the New Year by attending the LA Rams game versus the Arizona Cardinals. Thank you to our Community Liaison Rigo Manzo for assisting with organizing the event, and the Colburn Keenan Foundation for their support!

BRO: "BLEEDERS REACHING OUT"

NOVEMBER 10, 2019



BRO, "Bleeders Reaching Out" kicked off its inaugural dinner on Sunday November 10, 2019. Laughter, support and a delicious dinner was followed by the movie "Midway" at the Alamo Drafthouse Theater. BRO Community Liaison, Rigo Manzo, did an amazing job organizing this event! A special thanks to Aptevo for their generous support and Nike for their athletic sock donation!



We're Listening



At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team

GETTIN' IN THE GAME!



HFSC Member Representing Southern California!

The annual Gettin' in the Game Junior National Championship hosted by CSL Behring was held in Phoenix, AZ from November 8-10, 2019. HFSC was excited to have two young members, Sophia Horta (Swimming) and Jonathan Jackson (Golf) represent HFSC! Congratulations!

HFSC WELCOMES ITS FIRST FURRY COMMUNITY MEMBER!

Vini Paik is a 7-year-old dog with Hemophilia A. He lives in Murrieta, CA. He was diagnosed when he was a year old after he had surgery for a mass under his tongue that was not healing. He had three blood transfusions before he was diagnosed with Hemophilia. Vini receives treatment with Cryoprecipitate on an as needed basis. He gets anywhere from 3 to 5 bleeds a year but otherwise lives a pretty normal life. He gets walked once a day and lives with 2 other dogs, 3 cats, and a tortoise.



IRVINE COMMUNITY DINNER



HFSC hosted its first community dinner in the beautiful city of Irvine on Thursday, October 17, 2019. Edgar Vega presented on the role of unaffected siblings in families with rare blood disorders and there was much lively interactive discussions and laughs with input from siblings that brought this educational dinner to life! Families enjoyed a delicious Cantonese Chinese dinner! Thank you to Sanofi for your generous support.

MASAC RECOMMENDATIONS REGARDING GIRLS AND WOMEN WITH INHERITED BLEEDING DISORDERS

The following recommendations were approved by the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF) on October 23, 2016, and adopted by the NHF Board of Directors on November 3, 2016

Inherited bleeding disorders are under-recognized as causes of bleeding in girls and women. However, recent data have documented that 50% of girls and women who are carriers for hemophilia A or B have factor VIII or IX levels below 50%, putting them in the category of mild hemophilia and causing them to have an increased risk of bleeding, especially during menstruation and at the time of an accident, surgery, or delivery. Moreover, up to 1% of all girls and women may have laboratory evidence of inherited von Willebrand disease (VWD). and may also have heavy bleeding during menstruation, surgery, or labor and delivery. (2)

With this information in mind, MASAC recommends the following:

A. MANAGEMENT

1. Von Willebrand Disease (VWD) and other inherited bleeding disorders should be considered in the differential diagnosis of all girls and women presenting with menorrhagia, and an appropriate workup should be undertaken. Initial testing should include a CBC, PT, PTT, and a TT or fibrinogen. Additional testing specifically for VWD should include factor VIII activity, ristocetin cofactor, Von Willebrand antigen, and Von Willebrand multimers. This workup should be done in consultation with a hematologist who is well versed in the diagnosis of inherited bleeding disorders.
2. The above laboratory evaluation should be considered in all girls and women scheduled for endometrial ablation and/or hysterectomy for menorrhagia or dysfunctional uterine bleeding who also have mucous membrane bleeding and/or a family history of bleeding.
3. If there is a positive family history of a bleeding disorder, girls and women should have the appropriate factor activity level determined as soon as feasible and definitely prior to any planned surgical procedure regardless of age.
4. For bleeding, trauma, and before and after any surgical procedure, or labor and delivery, females with a factor VIII level less than 50% may be treated with recombinant factor VIII or DDAVP (if DDAVP trial has shown her to be responsive).
5. If a female with a factor IX level below 50% has a clinically significant bleeding episode, she may be treated with recombinant factor IX.
6. For clinical bleeding episodes, females with abnormal Von Willebrand studies may be treated with DDAVP, antifibrinolytics (Amicar or tranexemic acid) or a virally inactivated factor VIII product that contains Von Willebrand factor (Alphanate, Humate P, Koate DVI, Wilate). Alphanate, Humate P, and Wilate are approved by the FDA for treatment of VWD. A recombinant VWF clotting factor product Vonvendi is also available. (See MASAC Document #246, MASAC Recommendations Regarding the Treatment of Von Willebrand Disease, for specific details.)
7. Cryoprecipitate and fresh frozen plasma should not be used unless the patient is at risk of life-threatening bleeding and a Factor VIII/Von Willebrand Factor concentrate is not rapidly available. (See MASAC Document #246, MASAC Recommendations Concerning the Treatment of Hemophilia and Related Bleeding Disorders, Revised October 23, 2016).

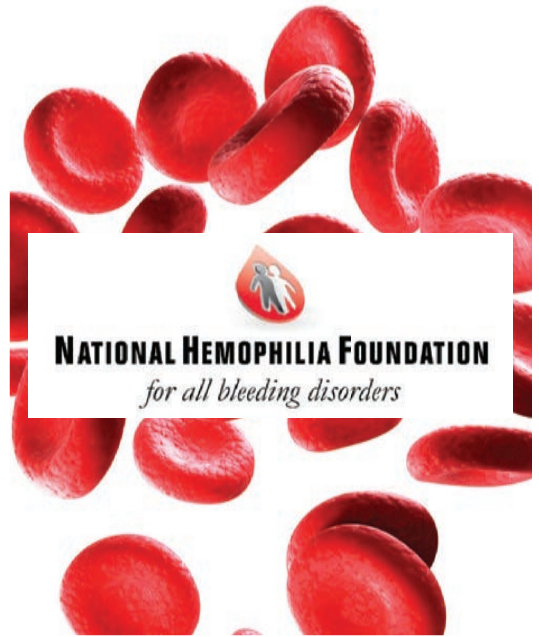
B. RECOMMENDATIONS

1. Much progress has been made in increasing awareness of girls' and women's bleeding disorders by both the general public and clinicians who are primary care providers for girls and women. Nonetheless, the national outreach and education program should be continued. The target audiences should be health care professionals (e.g. pediatricians, hematologists/oncologists, internists, OB/GYN, family practitioners, emergency department personnel and dentists as well as nurse practitioners in these fields), women's health advocates, and the general public.
2. NHF should continue to work with NHLBI and CDC to develop a national research agenda on women's bleeding disorders.

References

1. Trigg DE, Stergiotou I, Peitsidis P, Kadir RA. A systematic review: The use of desmopressin for treatment and prophylaxis of bleeding disorders in pregnancy. *Haemophilia* 2012; 18: 25-33.
2. James AH, Kouides PA, Abdul-Nadir R, et al Evaluation and Management of Acute Menorrhagia in Women with and without underlying bleeding disorders: consensus from an international expert panel, *Eur J Obstet Gynecol Reprod Biol.* 2011 Oct; 158(2): 124-34

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Dive in at the
HFSC Retreat
May 29-31, 2020
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Register Here:
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Join your bleeding disorders family for a fun weekend in the beautiful San Bernardino Mountains! Enjoy a campfire with s'mores, zip line, and a talent show!

Registration Open!
Women's & W/D Educational Forum
Friday, May 1, 2020
Knott's Berry Farm Hotel

All are invited; participate in educational roundtables! Please join us after dinner for an evening of karaoke.
Room block available for \$129
Limited Friday night hotel scholarships available for those who live 40+ miles away. Please contact HFSC Office.

Family Information Day
Saturday, May 2, 2020
Knott's Berry Farm Hotel, Buena Park, CA

 Educational Speakers,
Youth and Teen Programs,
Breakout Sessions, and Sponsor Booths

REGISTER:
<https://familyinfoaday2020.eventbrite.com>