IN MEMORIUM

Susan Kuhn

Introduction by HFNC staff Ashley Gregory

Susan Kuhn loved her community and she showed it by being present. Her presence meant that the legacy voice of the past was carried through to the present by being a board member, by being HFNC's Fresno Chair and the volunteer that ensured all the Fresno fundraisers and events happened including the holiday party that over 100 families depended on and looked forward to each year as part of their holiday traditions. Sometimes she would share with me her experiences organizing Blackbeard's, an annual family fun event or the wine fundraiser which involved a train I believe. But there is a history that begins much further back than that that still remains a mystery to me and I sought to gather that information from Susan by asking her for some kind of article, a writeup or memorialization of her experience with our community. She was so humble that she refused my copious attempts for an interview and photos. For Susan, it was always about the community, she never wanted the attention on her. I am happy to say that her daughter, Victoria Kuhn, will provide our community with a way to capture all that she embodied and to recognize her important historical contributions. I will miss her organized, focused and sage voice.

Susan A Kuhn in Memoriam

Always an empath, our Mom was fearless when it came to helping others. As an advocate, she was quick to love, quick to give her time, quick to share recipes and quick to hold space for others. She proudly wore her heart on her sleeve. There was not an organization in need that she did not support. She rooted for and supported the underdog.

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Ways to Give

GIVE NOW



DONATION OPTIONS

There are so many ways to support children, patients and families with bleeding disorders in Northern California! Your support and involvement empowers Hemophilia Foundation of Northern California to achieve our mission to provide a lifeline of support.

DONATE ONLINE

www.hemofoundation.org/support/donate/html

DONATE BY PHONE

510-658-3324

9AM-5PM Mon-Fri

DONATE BY MAIL

Hemophilia Foundation of Northern California 1155-C Arnold Drive #236 Martinez CA 94553

GIVING OPTIONS



















HFNC IS HOSTING A SPECIAL SINGLE DAY IN PERSON FAMILY CAMP ON MARCH 12, 2022 AT CAMP ARROYO IN LIVERMORE, CA.

FAMILY CAMP WAS STARTED IN 1991 TO BRING TOGETHER MEMBERS OF THE BLEEDING DISORDER COMMUNITY FOR FUN, RELAXATION, SUPPORT AND BUILDING RELATIONSHIPS WITH OTHER FAMILIES FACING SIMILAR CHALLENGES. FAMILY CAMP ALSO PROVIDES AN OPPORTUNITY FOR FAMILIES TO VISIT WITH SUMMER CAMP STAFF AND CAMPERS.

EVERYONE IS ENCOURAGED TO APPLY, BUT PRIORITY WILL BE GIVEN TO NEWLY DIAGNOSED FAMILIES AND FAMILIES WITH YOUNG CHILDREN.

SIGN UP TODAY!

FOR IMMEDIATE RELEASE

CONTACT: Norman Williams (916) 440-7660

NUMBER: 21-06 DATE: September 3, 2021 (916) 440-7660



DHCS California Dedicates \$20 Million to Support New Mental Health "988" **Crisis Hotline**

SACRAMENTO - The Department of Health Care Services (DHCS) today announced it will invest \$20 million in California's network of emergency call centers to support the launch of a new 988 hotline, an alternative to 911 for people seeking help during a mental health crisis. This federal grant funding will bolster call centers that will support 988.

"Expanded access to mental health services is a central focus of the California Comeback Plan," said Governor Gavin Newsom. "This \$20 million investment is a critical first step to ensure crisis call centers have capacity and are equipped to help all callers so we can meet Californians where they are and expand resources and support during these difficult times."

Currently, 13 call centers in California, both public and private, take calls that come from the National Suicide Prevention Hotline. Those centers will start receiving calls to 988 when the service starts in July 2022. Until then, anyone experiencing a suicidal crisis or emotional distress may call 1-800-273-8255.

"When people are in a mental health crisis, they need to get quick help from the right place at the right time," said California Health and Human Services Secretary Dr. Mark Ghaly. "While the 911 system is dedicated to public safety emergencies, the launch of the 988 hotline next summer gives people an easy-to-remember

number to call for focused support during behavioral health emergencies."

Added DHCS Director Will Lightbourne: "There's been a great need for 988 for years, but the need is all the more pressing now, after 18 months of a global pandemic and the personal, social, and economic stresses and anxieties that accompany it. We look forward to working with California's call centers to ensure they're dialed in to implement 988."

The \$20 million investment is a first step toward building a robust statewide call center network to support 988. The Federal Communications Commission adopted rules to establish 988 as the new, nationwide 3-digit phone number for Americans in crisis to connect with suicide prevention and behavioral health crisis counselors.

"I am incredibly grateful to Governor Newsom and our coalition of sponsors, advocates, and bipartisan legislators who have come together to begin the process of creating the 988 infrastructure that will provide an alternative to police response for those suffering from mental health crisis," said Assemblymember Rebecca Bauer-Kahan. "We are taking the first, important step in ensuring that California will set up a system that will save lives and provide critical mental health care to our communities."

PRODUCT UPDATE

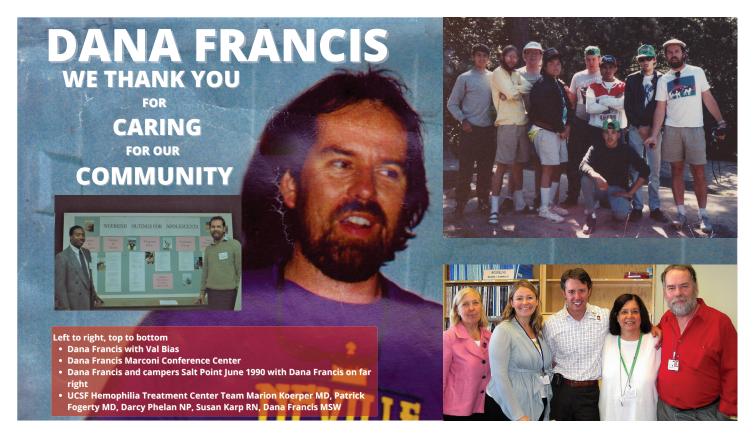
CSL Behring Biotherapies for Life'

CSL Behring has been responsible for all commercial, medical, and related distribution and product support activities for Stimate® which is owned and manufactured by Ferring Pharmaceuticals, Inc. (Ferring). We are writing to inform you that the Stimate distribution agreement between CSL Behring and Ferring has ended.

For all questions relating to Stimate, please contact Ferring at 1-888-FERRING (1-888-337-7464) - option #2 or Email: MedQueriesUS@ferring.com.

Our commitment to patient care and the bleeding disorder community remains a key priority and guiding principle for CSL Behring. We encourage patients to contact their pharmacy regarding their individual prescription and, if necessary, contact their physician about their treatment plan.

Farewell to UCSF Social worker Dana Francis



After 21 years as the social worker at the UCSF-HTC, Dana Francis has announced his intention to retire.

Dana grew up in rural Massachusetts and attended Westfield State College, in western MA. He graduated with an MSW from the University of Washington, School of Social Work in Seattle in 1980.

After working at several social work jobs, he was hired by the Hemophilia Council of California (HCC) in 1988. The HCC was, and still is, a statewide legislative advocacy organization originated by the four hemophilia foundation chapters in California and supported by the California HTC's, to meet the social work and mental health needs of people with hemophilia and HIV/AIDS and their families during the AIDS epidemic of the 1980's and 1990's.

In January 1989, he assumed the facilitation of a men's support group started by his predecessor, Jackie Fineberg. The group met in people's living rooms and grew over time until there were two support groups that met monthly for the next ten years. Dana still leads a men's support group that meets to this day, dealing with issues like challenges and triumphs of living

with a bleeding disorder, chronic pain, grief, loss, identity and relationships.

Dana first attended hemophilia summer camp in June 1989 as a cabin counselor and later as a roving social worker. He often brought his guitar to camp and played at campfire events and in cabins at the FOB (Flat on Bunk) time.

While working at the HCC, Dana began a monthly group for teens with hemophilia and HIV that he co-facilitated with Todd Smith. That group led to a number of weekend retreats for teens held throughout the 19190's that dealt with the challenges of living with hemophilia and HIV. Val Bias and Gail Reed helped him develop his agendas for these retreats.

In the summer of 2000, he became the social worker at the UCSF for both the pediatric and adult bleeding disorder programs. In 2006, Dana moved into the role of social worker with the adult patients after the Alta Bates adult hemophilia program closed its doors to many of its patients transferred their care to UCSF.

Continued on Page 6

IN MEMORIUM Continued from Page 1

She did HIV outreach in the 1980s-1990s at Central Valley AIDS team; she and Jon (Pace) planned many, many events for HFNC's Fresno Hemophilia Auxiliary Council (and she served on the board of Hemophilia Foundation of Northern California. She made hundreds of felt ornaments with ladies at her church's Sew-n-Sew club that benefited Saint Mother Theresa of Calcutta; she volunteered at numerous marathon registrations in the Fresno area; she was a proud board member of Fresno Rainbow Pride; she was the treasurer of numerous non-profits; and she opened many, many absentee ballots for the League of Women Voters.

Susan grew up on Long Island, New York with her parents and her favorite grandfather, until she was a pre-teen and then moved to the Fresno area. She was the older of two children to C.L. and Estelle Sullivan, where she graduated from Clovis Union High School. Mom was a competitive swimmer. During college, she met and married our Dad, William Kuhn, and together they had two kids -- and thus her hemophilia journey began though hemophilia never defined our family. Our Dad had severe hemophilia A. In the mid-1970s, our family found the HTC at LA Orthopaedic Hospital, where we received care, and compassion until our Pop unexpectedly died in 1993.

The 1980s was a scary time for our family, however we embraced - with our Mom leading the charge - AIDS education and outreach. In those days, brave outreach and education primarily came from the gay community. Susan did early advocacy with the local Act Up! Chapter in the San Joaquin Valley. She was a

voracious newspaper, magazine, and book reader about AIDS. It was common growing up for a basket of condoms to be by the door for anyone to take, no questions asked. Mom did early HIV outreach with sex workers on G Street in Fresno. She was courageous!

Our parents instilled in us the importance of education (and they sacrificed to pay for our education) so off we went to Fresno State. Robert is now a mechanical engineer and Victoria is a drug sales rep in rare cardiology. We each moved to New England, married and are now raising our children in New Hampshire and Maine, respectively. Our Mom visited us often and we enjoyed dozens of lobsters, clams, mussels, seafood, and her favorite, crab! We visited lighthouses, parks, mountains, and stayed at home gabbing it up, doing puzzles, and cooking together, too.

An amazing force of nature, Susan loved and laughed big, was a talented cook and baker, and respected and accepted all people and creatures (though she did not care for spiders!). Our sweet Mum led with her heart in all she did, filled with compassion and high expectations for herself and others. She was determined to build a better world through her volunteer efforts, her deliberate giving, and her love.

Our Mom unexpectedly passed away September 25, 2021. We will miss her like crazy, however we take comfort that she is reunited with our Pop in Heaven.

Rob and Victoria 🖔





DANA FRANCIS Continued from Page 5

Dana served two terms on the NHF Social Work Working Group from 19993 to 1997 and again from 2013 to 2017. He penned a number of articles over the years and co-edited a book entitles, "A Journey of the Heart" in 2013, which contained essays by social workers around the United States about a patient or colleague that had impacted their lives. NHF named him "Social Worker of the Year" in 1996 and "Humanitarian of the Year" in 2015.

When asked, Dana stated that he always LOVED his job and feels that he grew up professionally alongside his patients throughout his 33- year career in the bleeding disorders community. He said it was a great privilege to watch young women and men with bleeding disorders grow up to be responsible adults who could plan and manage what is now known as Camp Hemotion.

Dana is happily married to his wife Natalie and is the father of two young men, Eli and Jamie, who are college graduates and are pursuing work, and lives, that they enjoy.

Dana is to be applauded for all his contributions to the bleeding disorder community. He will be greatly missed.

We wish him well in his retirement.





Dr. Marion Koerper

HFNC's Medical Adviser



QUESTION: WHO SHOULD GET A COVID **BOOSTER SHOT? ANSWER: IT DEPENDS**

- 1. Everyone should get the initial two shot series of COVID vaccine shots to provide immunity from serious disease with COVID. Once vaccinated, everyone who meets the eligibility criteria below should get the one shot booster. This is necessary because the immunity from the first series of shots wears off over time. The booster boosts that immunity again.
- 2. All of the approved vaccines, including Johnson & Johnson, Moderna and Pfizer have been approved for boosters. Previously it was thought that you should not mix vaccine types, but now it is felt that in some instances, it is good to mix. Especially if the first vaccine was Johnson & Johnson, THE IMMUNE RESPONSE MAY BE GREATER WITH A BOOSTER OF ONE OF THE OTHER VACCINES.

CAUTION: Women who are pregnant and women aged under 50 should not get Johnson & Johnson because of risk of blood clots.

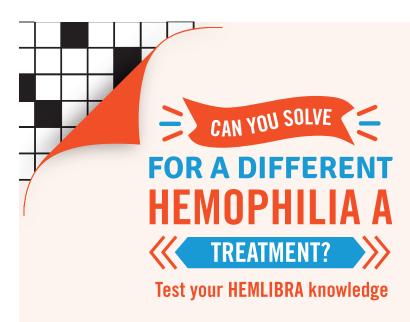
- 3. Eligibility criteria: You must meet one of the following: A. Aged 18 years and older
 - B. Aged 18+ and resident of long-term care facility
 - C. Aged 18+ and work in high-risk settings: Health Care providers, teachers and education staff, first responders, police, daycare workers and support staff, food and agricultural workers, manufacturing workers, correctional workers, US Postal Service Employees, grocery store workers, public transit workers
 - D. Aged 18+ who have underlying medical conditions:
 - 1. Pregnancy or postpartum
 - 2. Substance abuse
 - 3. Asthma
 - 4. Blood disorders, e.g. sickle cell and thalassemia
 - 5. Cancer treatment
 - 6. Heart disease/hypertension
 - 7. Pulmonary disease or COPD

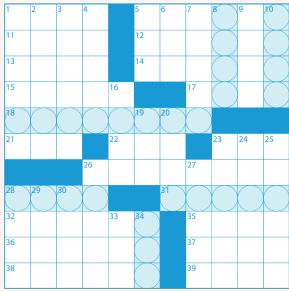
- 8. Kidney disease, hemodialysis
- 9. Cystic Fibrosis
- 10. Diabetes
- 11. Down Syndrom
- 12. Organ or stem cell transplant
- 13. Steroids and other immunosuppressive medications
- 14. Obesity
- 15. Smoking, current or former
- 16. Cerebrovascular disease
- 17. Dementia or other neurological disorders including stroke
- 18. HIV Infection
- 19. Liver Disease

If you meet any of these qualifications, you should get the appropriate COVID booster. The immunity from the original set of one or two shots declines over time, so the booster will boost it up again.

- 4. How long should I wait after my vaccine series? Six months.
- 5. Can I get the flu shot at the same time? Yes, but in different arms.
- 6. How long should I wait to get the shingles shot? Six weeks after booster
- 7. Should I take factor before getting these shots? YES! Take your usual prophylactic dose.
- 8. If I already had COVID-19, do I need the booster? YES, the immunity from having the disease also declines over time, so you need to boost your immunity too.
- 9. Have the vaccines been approved for children? YES! Pfizer has been approved for children aged 5-17.
- 10. For more information, visit CDC.gov /COVID (







ACROSS

- 1. Wine barrel
- 5. Deep fissures
- 11. Mideast gulf port
- **12.** District
- 13. Ripped
- 14. Familiar with
- **15.** Mean
- **17.** Roost
- **18.** The #1 prescribed prophylaxis for hemophilia A*
 - *According to IQVIA claims data from various insurance plan types from October 2019 to November 2020 and accounts for usage in prophylaxis settings in the US.
- 21. Calendar divs.
- 22. Regret
- **23.** Banquet hosts (abbr.)
- 26. International travel necessity
- 28. Check out the ____ treated bleeds data with HEMLIBRA
- **31.** Number of dosing options HEMLIBRA offers

- 32. Small hole in lace cloth
- 35. Central Plains tribe
- 36. Melodic
- **37.** Towering
- 38. Reduce
- 39. Spanish cheers

DOWN

- 1. Memorable, as an earworm
- 2. Devotee
- 3. Medical fluids
- 4. Prepare to propose, perhaps
- 5. PC's "brain"
- 6. Owns
- 7. Concert venue
- **8.** See Medication Guide or talk to your doctor about potential _____ effects
- 9. Winter hrs. in Denver and El Paso
- **10.** HEMLIBRA is the only prophylactic treatment offered this way under the skin

- 16. Pre-Euro currency in Italy
- 19. Subway alternative
- 20. Relax
- 23. Human
- 24. New Orleans cuisine
- **25.** Mentally prepares
- 26. Collared shirts
- **27.** Instagram post
- 28. Ardent enthusiasm
- **29.** Brontë heroine Jane **30.** Old Portuguese coins
- **33.** Opposite of WNW
- **34.** _____ thousand patients have been treated with HEMLIBRA worldwide[†]

SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. totel, 14. used to, 15. cmel, 17. neet, 13. totel, 17. neet, 18. totel, 17. neet, 18. totel, 18. totel, 18. totel, 18. totel, 22. rue, 23. MCs, 25. cue, 23. three, 18. Corb, 4. kneet, 25. opelet, 25. corb, 25. corb, 25. corb, 27. three, 18. St. lessen, 35. corb, 4. kneet, 18. corb, 27. actions, 37. secums, 4. kneet, 19. corb, 27. actions, 37. decel, 36. corb, 37. corb,

Discover more at (HEMLIBRA.com/answers)

INDICATION & IMPORTANT SAFETY INFORMATION

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. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- Thrombotic microangiopathy (TMA), a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- Blood clots (thrombotic events), which may form in blood vessels in your arm, leg, lung, or head

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



[†] Number of people with hemophilia A treated as of February 2021.

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

What is the most important information I should know about

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

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:
 - confusionweakness

- stomach (abdomen) or back pain
- swelling of arms and legsyellowing of skin and eyes

use for breakthrough bleed treatment.

- 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:

 Welling in arms or less. cough up bloodfeel faint
 - swelling in arms or legs
- pain or redness in your arms or legs
 shortness of breath
- headache
- numbness in your face - eye pain or swelling
- chest pain or tightness fast heart rate
- trouble seeing

- 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
- 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.
- 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 does as prescribed.
- 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
- through 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?

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
- 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

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,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

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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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Mike's Auto Body Gives Away Two More Cars On its Way to 100 By Ed Attanasio

While many shops all over the country put their car giveaways on hold during the pandemic Mike's Auto Body never stopped giving. The COVID-19 pandemic did slow them down slightly in 2020, but later this year on December 15th, Mike's will be giving away its 100th vehicle through its nationally-known Benevolence Program.

On October 25th, Mike's Auto Body gave two fully refurbished vehicles to a pair of families through the Hemophilia Foundation of Northern California, in conjunction with NABC Recycled Rides for the fifth year to help people impacted with bleeding disorders. This year is Mike's 21st year participating in the Benevolence program.

The Benevolence Program Director at Mike's Auto Body is Sal Contreras. Sal admits he has seen every car presentation since the program's inception, but never grows tired of them. "It has been so rewarding for the past 21 years, presenting these cars to deserving individuals and organizations who are working to improve their skills and become independent. We always say that at Mike's, we are providing a hand up as opposed to a hand out. These two people are living amazing lives and all they needed was the gift or transportation to continue the journeys."

Student Jonathan Zhang received a 2012 Volkswagen Sport Wagon in collaboration with State Farm Insurance. The car was completely refurbished by the crew at Mike's Pittsburg location under the direction of Manager Kent Osborn, Production Manager Mike Lister and Office Manager Angelina Yuen.

Zhang is studying at Skyline Community College and will transfer to UC Davis for the spring semester majoring in Mechanical Engineering so his new VW will enable him to get to school and back from his home. Retired State Farm Agent Mike Stoiber and State Farm Agent Jeff Chaput gladly presented the keys to Jonathan. His mother Lian Poh Lee and his two siblings were on hand to share the moment with Jonathan.

The other car recipient Rocio Orozco Chavez, was presented with a 2013 Toyota Corolla in collaboration with Farmers Insurance. When Rocio was notified, she was selected as the recipient of the Benevolence car, she shouted out, "I am doubly blessed today, it is my birthday today". The car was completely refurbished by the crew at Mike's Antioch location under the direction of Manager Nick Thorne and Office Manager Cheryl Arvizu. Farmers District Manager Daniel Brown was on hand to present the keys to Rocio.

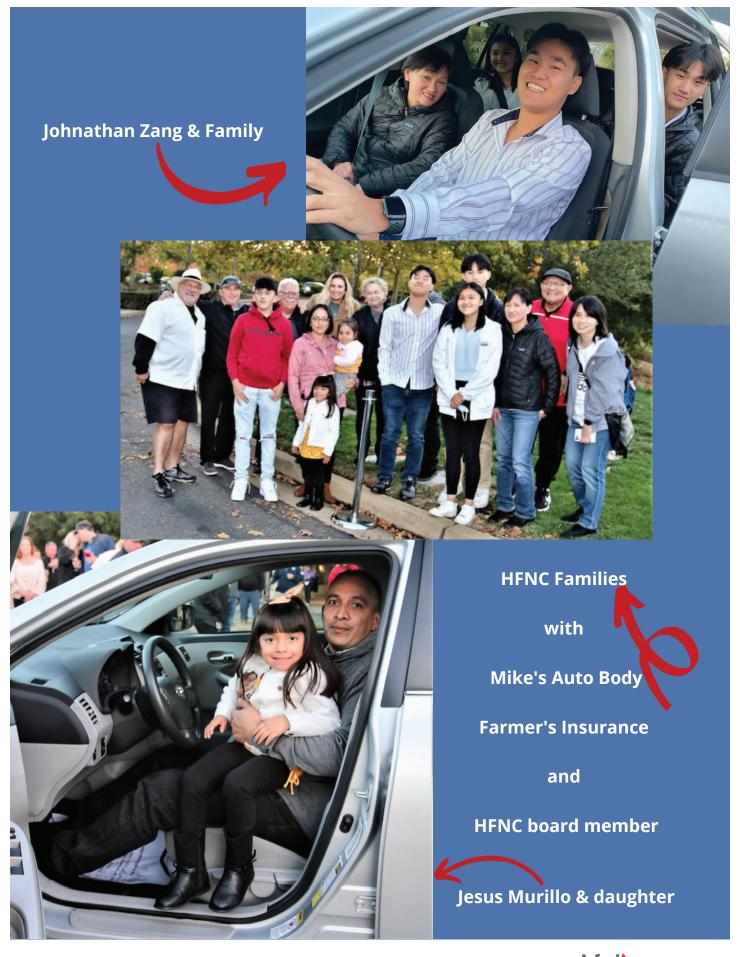
The Chavez family of Antioch, CA has a daughter named Brisa who suffers from a homozygous Factor XII deficiency, which requires two trips every week to the doctor in Oakland, CA. Her "refurbished" Corolla will enable the family to transport Brisa and the rest of her family safely. Also in attendance were Rocio's husband Jesus and their son, Jesus, Jr.

The technicians from Mike's Auto Body who worked on the vehicles include Jason Tebbet, Jason Tebbet Jr., Zack Hodges, Miguel Gomez, Marcos Lopez, Oscar Hernandez, Hugo Medina, Nick Parks, Carlos Ortiz, Raul Avila, Romeo Rhones, Jose Padilla, Thomas Mendoza, and Abel Mendoza. Vendor partners include Big O Tires in Pittsburg, Delta Dealer Services, Dirito Brothers W/C, Livermore Toyota, MAB Towing, and PPG Automotive Refinish. Special thanks goes out to Board of Directors Vice President, Peter Barbounis, Executive Director, Andrea Orozco, and Associate Director, Bryan Anderson from the Hemophilia Foundation of Northern California.

The Mike's Benevolence Program is an ideal charity model for body shops because it involves the insurance companies, local non-profits. Everything is donated, the cars, parts, paint, mechanical inspections, tires, and Mike's pays for one full year of insurance. The body and paint technicians donate their time and talents. "We are grateful this year to have Farmers Insurance®, State Farm Insurance and Recycled Rides collaborating with Mikes in presenting two refurbished cars to two deserving families sponsored by the Hemophilia Foundation," Contreras said. "We have now given away 96 cars over 21 years to deserving families, individuals, and non-profit organizations."

Each year the collision repair industry comes across cars that are "written off" by either the owner or the insurance company. Often, these are older vehicles that just need some mechanical and body work to get them back on the road and perfectly safe to drive. Because the people at Mike's strongly believe that these cars are going to waste when there are people out there who really need them, this MSO with 17 locations in Northern California's East Bay decided to do something about it starting back in 2000.

"We feel very fortunate to be involved with such a wonderful program and are very excited to be able to give back to the area communities that have supported us for the past 49 years," Owner Mike Rose said. "After receiving hundreds of applications over the years and reading the heartbreaking stories, we only wish that we could do more. But hopefully with increased publicity of our Benevolence Program other shops will adopt a similar program of their own." 🛝







instacart

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conveniently?

Use these Apps: Safeway Delivery PostMates GrubHub Instacart





is
nominal
average
\$4/delivery
+ bag fees



lf you are able, tip the delivery person

JIVI® ADYNOVATE®



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thank you

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WE COULDN'T DO IT WITHOUT YOU!











octa pharma





































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HEMOPHILIA A IS A PIECE OF YOU.

NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week. $^{1.2}$

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

No actual patients depicted.

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds²

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)²

- <u>Children Under 12 Years</u>: This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment²
- During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median[†] overall ABR[†] of 2.0
- 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

*Median is defined as the middle number in a list of numbers arranged in numerical order.

*ABR=annualized bleed rate, the number of bleeds that occur over a year.

*Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE Important Information What is ADYNOVATE?

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

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

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

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

What should I tell my HCP before using ADYNOVATE?

Tell your HCP if you:

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

- Adolescents and Adults 12 Years and Older: This study evaluated the efficacy of
 ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic
 regimen with on-demand treatment and determined hemostatic efficacy in the treatment
 of bleeding episodes in 137 patients. These adolescents and adults were given either
 ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand
 treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal
 was to compare ABR between the prophylaxis and on-demand treatment groups²
 - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
 - 0 bleeds in 40% (40 out of 101 per-protocol[§] patients) during 6 months on twice-weekly prophylaxis

What important information do I need to know about ADYNOVATE?

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

What else should I know about ADYNOVATE and Hemophilia A?

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

What are possible side effects of ADYNOVATE?

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

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.

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

References: 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. Haemophilia. 2014;20(5):607-615. 2. ADYNOVATE Prescribing Information.

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Patient Important Facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

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

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

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

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

What is ADYNOVATE?

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

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE $^{\circ}$ [Antihemophilic Factor (Recombinant)]

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

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

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

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

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

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

How should I use ADYNOVATE? (cont'd)

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

What should I tell my healthcare provider before I use

You should tell your healthcare provider if you:

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

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

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

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

What else should I know about ADYNOVATE and Hemophilia A?

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

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-TAKEDA-7.

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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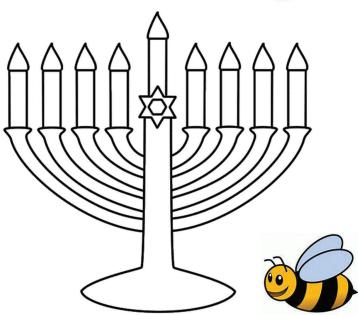
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Diwali Wordsearch



e	i	v	×	u	9	f	u	r	f
f	e	s	t	i	٧	a	t	t	i
h	b	h	α	i	d	0	0	j	r
i	Z	w	1	n	y	s	9	r	e
n	d	e	d	i	w	a	1	i	w
d	i	y	a	u	e	e	Ь	1	0
u	l	a	k	5	h	m	i	m	r
i	f	c	l	i	9	h	t	5	k
S	r	а	n	9	0	ι	i	i	5
m	q	j	n	v	m	a	w	u	r

Bhaidooj	Diwali	diya	
festival	fireworks	Hinduism	
Lakshmi	lights	rangoli	

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Color this Hanukkah Menorah



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WINTER 2021



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HFNC wishes YOU AND YOURS

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wonderfully warm winter & holiday season! Whatever you celebrate,



CALENDAR

DEC 12/1/2021 12/4/2021 12/23/2021-12/31/2021 12/24/2021 12/25/2021 12/31/2021	World AIDS Day Winter Cheer Event HFNC Office Closed Christmas Eve Christmas Day New Year's Eve	AIDS Memorial Grove, Golden Gate Park, SF, CA Virtual HFNC Office Closed Holiday HFNC Office closed Holiday HFNC Office closed Holiday HFNC Office closed
JAN 2022 1/1/2022	Now Year's Day	Haliday HENC closed
	New Year's Day	Holiday HFNC closed Virtual
1/11/2022	Board Meeting	
1/17/2022	MLK JR Day	Holiday HFNC closed
FEB 2022		
2/21/2022	President's Day	Holiday HFNC closed
2/28/2022	Rare Disease Day	TBD
MARCH 2022		
TBD	HCC Health Summit	TBD
3/1/2022-3/31/2022	Bleeding Disorders Awareness Month	Month Long Activity
TBD	NHF Washington Days	TBD
3/8/2022	Board Meeting	Virtual
3/12/2022	Family Camp	The Taylor Family Foundation, Camp Arroyo, Livermore CA
3/27/2022-3/29/2022	Future Leaders Program HCC	TBD
TBD	Asian Infusion	TBD
APRIL 2022 4/8/2022-4/10/2022 4/17/2022 4/17/2022 4/20/2022-4/23/2022 TBD	The Female Factor Retreat Easter World Hemophilia Day Hemophilia Federation of America Annual Symposium LEG Day	St. Clare's Retreat, Soquel CA Holiday HFNC closed TBD San Antonio, TX Virtual
MAY 2022		
5/10/2022	Board Meeting	Virtual
5/13/2022-5/15/2022	Region IX Meeting	San Francisco CA
5/22/2022	Spring Fest (Family Education/ Walk Launch/Emerging Therapies)	TBD
5/30/2022	Memorial Day	Holiday HFNC closed
JUNE 2022 6/12/2022-6/18/2022	Camp Hemotion	Camp Oakhurst, Coarsegold CA

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Since we do not engage in the practice of medicine, we always recommend that you consult a physician before pursuing any course of treatment.

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HFNC is going green! Starting in 2022, all issues except our Winter issue will be electronic! We are eliminating our print versions of Spring, Summer and Fall.

Visit our website at www.hemofoundation.org for important information. If you would like to advertise in the next issue, please contact the foundation.