Infusions
SUMMER 2021

IN MEMORIAM

Lucy Vallejo Alviso

Lucy was born on September 3, 1954.

She passed away on April 22, 2021. She was born in San Antonio, TX. Her parents are Santos Vallejo and Anita Vallejo. Her dad is deceased, but her mother is still living at 87 years of age. She has one sister named Ruth who lives in San Antonio next door to their mother. Lucy grew up in San Antonio, finished high school, and then went to work for USAA Insurance Co. In 1977 she took a job transfer to Cupertino, CA to work in a new branch office of USAA. It was at this time in October 1977 that I met Lucy. We dated for four years before getting married on April 11, 1981 in San Antonio,TX. Our first son, Daniel, was born on November 14, 1981. Daniel was born with hemophilia factor 8 deficiency. It was at that time that Lucy began educating herself about hemophilia which included talking to other mothers with hemophiliac children, Peggy Horyza and Betty Finkle. These two ladies are godsend to us because they taught us so much about raising our child. Later, on March 27, 1988 Darren was born to us without hemophilia. We were thankful to God that he did not have hemophilia, but we told ourselves that we were prepared if he had been born with it. Now Daniel is 39 and Darren is 33. Lucy's passing has been a devastating blow to the three of us. We miss her more than anyone can even imagine. We believe she is with the angels now and is looking down upon us. She still lives in our hearts and memories forever. **- Ken Alviso, loving husband**

As a sister of hemophiliac brothers, a cousin, a niece and now as a mother, I have always been a part of a hemophilia foundation. My son Stanley was being seen at Stanford Children's Hospital. I was asked by the medical staff to mentor Lucy Vallejo Alviso, my long-time sister, a truly kindred spirit, as I was one of the original Mothers of Bleeds (MOB). As first-time parents, never being touched by hemophilia, Lucy and Ken were facing the uncertainty of raising a son with hemophilia. They were open to any possibility to learn and help support the community. At first, we were a small group of south bay parents meeting at my house to bring our sons together while sharing our life's challenges. Our main objective was to help support fundraising for the yearly summer camps and start a youth group for our sons. Even though Lucy and Ken's son Daniel was young they saw the need to help with the fundraising. I must say we did everything we could think of to raise funds; sold candy bars, had a Fashion

Continued on Page 3

IN THIS ISSUE

2021 HERE WE COME!

All memorabilia has been carefully packed

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

OUR EPIC NEW LOCATION IS VIRTUAL (HOME OFFICES)

NEW MAILING ADDRESS
1155-C ARNOLD DR
#236
MARTINEZ CA 94553

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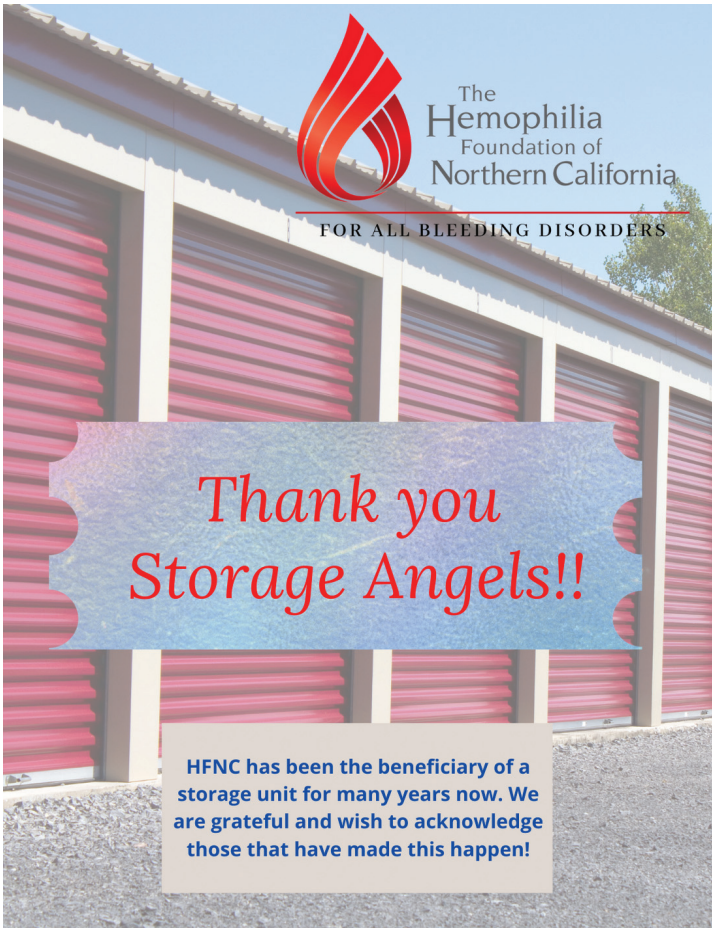
Same Website
hemofoundation.org



HFNC will be CLOSED

July 26-30, 2021

We will be busy planning next year and will RE-OPEN

August 2, 2021

Thank you for your understanding

Brothers HEALTHCARE

Continued on Page 5

"I learned how to properly use a tourniquet to swell the veins."

SAVE THE DATE!

THE FEMALE FACTOR

RETREAT

April 1-3 2022

Walker Creek Ranch Petaluma

"It made me feel alive"

"It made me feel happy and calm"

The Hemophilia Foundation of Northern California

THE FEMALE FACTOR affected and connected

FOR ALL BLEEDING DISORDERS

IN MEMORIAM *Continued from Page 1*

show (Lucy was a model at the luncheon), a Chuck E Cheese day fundraiser, Lucy sold tables of tickets for our fundraising dinner dances, gathering all their friends and family to come out to learn about hemophilia assuring them it would be an evening of dinner, dancing, and comradery. All our fundraisers were to get the word out about the hemophilia community and raising camp funds. As our little group took on the new agenda of HIV that invaded our community in the early 1980's, we had to think of a new way to support our members. Lucy was always right by my side when I was President and moved the Foundation from Oakland to San Jose. We found more ways to help support our members through this new crisis. Lucy was a guiding force in helping to start the bi-lingual community for the Hispanic and Asian communities. Lucy also got involved with National Hemophilia Foundation as one of the first chairpersons along with Cindy Bircher to start WONN retreats bringing mothers, sisters, spouses, and women bleeders together for the first time in May 1990.

Lucy was truly an amazing woman with energy like no other person I have known. Just like me she was blessed with the loving support of her husband in anything she wanted to do for the community. We both worked for Home Care Companies to ensure that our members would get that extra caring support from more than just their treatment centers. Lucy stayed in Home Care for many more years than I. Her passion for life started with her family and extended to her family of friends. Lucy's nurturing side brought love, understanding and support to hundreds of people in her lifetime. She always had time to be there for everyone, asking nothing in return. I will always treasure our lunch date and fun outings and our MOB holiday parties at Bonnie Joy's. We were blessed with sharing memories for so many years of things we did together. I only wish we could have had more time for long visits. Lucy will always hold a special place in my heart.

On April 22, 2021 Lucy floated to heaven on her angel winds. She touched so many lives by her understanding and caring personality. That quality of existence far exceeds the quantity of time in which one lives. I have always admired Lucy for her energy and drive to share her love for our hemophilia community. Her passing reminds me of the preciousness of life.

Our MOB (Mothers Of Bleeders) south bay group started before we even gave it a name in 1981. It brought us south bay mothers the security knowing we were not alone in our ups and downs of life. We have always been a phone call away for our sisters who have walked through this life with us. We have been blessed to open it up to mothers, spouses and sisters who have the need to share life with another like minded person. We shared so much of life in this very special family of friends who were brought together by hemophilia. Lucy became involved in the Holiday Party from the start in 1984. Lucky and Ken secured the Moose Lodge and the rest is history. **- Peggy Horyza**

HFNC STATEMENT ON Covid-19 VACCINE Version 21
May 11, 2021

In May 2020, As HFNC Medical Advisor and Camp Hemotion Medical Director, I made the difficult decision to cancel Camp Hemotion for the summer of 2020 due to the Covid-19 pandemic. That pandemic still exists and continues to kill people daily. In person Camp Hemotion will not be held until the number of COVID-19 infections in Northern California drops dramatically. Camp Hemotion will be held virtually June 13-19. 2021

Four mitigating strategies have been promoted by the CDC, health care providers, virologists, and epidemiologists to reduce your risk of contracting COVID-19. These are:

1. **Wear a mask**
2. **Wash your hands**
3. **Watch your distance, i.e. keep 6 feet away from others.**
4. **Get vaccinated with one of the approved COVID-19 vaccines. Attached is a chart comparing the vaccines. Note that they are not approved for children yet.**

It is the recommendation of the Northern California Hemophilia Foundation that all members of the bleeding disorders community should be immunized when offered the opportunity. This includes adults, young adults aged 16 and older, older counselors, directors, and all infirmary staff planning to attend Camp Hemotion in person in the future.

CHART ON COVID VACCINES APPROVED IN THE US
These vaccines are approved to be given intramuscular (IM) so there might be a risk of bleeding into the muscle. You should check with your bleeding disorder provider to see if you should take a dose of factor or other clotting agent before receiving the vaccine. MASAC has issued recommendation #221 regarding this issue. MASAC RECOMMENDATIONS ON ADMINISTRATION OF VACCINES TO INDIVIDUALS WITH BLEEDING DISORDERS

Manufacturer (6)	Type of vaccine (7)	Ages approved for (1,6)	Storage conditions (2)	#Doses/# days to repeat dose (3,4,6)	Efficacy To prevent mild to moderate infection	Efficacy to prevent moderate to severe disease, (hospitalization, death)
APPROVED in US						
BioNTech/Pfizer	mRNA	12-15 yrs. (1)	70□C	2,/21 days	95%	100%
Moderna	mRNA	18+yrs	20□C	2 /28 days	95%	100%
Johnson-Johnson /Janssen	Viral Vector	12-17, 18 +yrs	Refrigerator temperature (2)	1/none	72%	100%
NOT YET APPROVED in US						
Oxford/ AstraZeneca (.)	Viral vector	18+ years	Room Temperature	2/28 days	79%	100%

(1) NOT ALL VACCINES ARE APPROVED FOR USE IN CHILDREN under 18 years of age. Pfizer has recently gained approval for its vaccine in children aged 12-15 years. STUDIES ARE ONGOING IN ALL AGE GROUPS BY THE OTHER VACCINE MANUFACTURERS

2) A LOWER STORAGE TEMPERATURE MEANS THAT PHYSICIANS' OFFICES AND SMALLER HOSPITALS AND URGENT CARE CLINICS CAN STORE the vaccine IN REGULAR REFRIGERATORS.

3) **Full immunity is not achieved until 2-4 weeks after the second "booster" dose is received. In the meantime, one could still be infected with the virus and pass it on to others. Thus, it is important that people still wear masks and observe social distancing until 4 weeks after they receive their second dose. Persons are still encouraged to wear masks, stay 6 feet apart and wash hands frequently after receiving the vaccine. Transmission is still possible from a vaccinated person to a non-vaccinated person. The vaccinated person may experience little to no symptoms due to immunity, but the non-vaccinated person is susceptible to the full range of symptoms this virus causes.**

4) Not yet approved in the US, but FDA approval is expected soon.

5) **SIDE EFFECTS** Many people reported sore arms where the injection was given. Other side effects included fatigue, muscle aches, and headache. These indicate that your immune system is working. Some individuals had anaphylactic allergic reactions of swollen lips and tongue and difficulty speaking and breathing. These symptoms resolved with an injection of epinephrine or an EpiPen injection. The type of vaccine given was not reported.

6)A more serious type of side effect is the development of a clot in a blood vessel in the brain. These are usually preceded by a bad headache. The cause of these clots is unknown, but they seem to occur more frequently with the A_Z and Johnson-Jensen vaccine in females aged 18-45 years, so women in this age range are advised to avoid these Vaccines.

7) There are 2 **types of vaccine**:

M (messenger) RNA vaccines—mRNA carries the instructions for how to make the COVID virus's spike protein. mRNA enters the person's cells and instructs them to make the spike protein, which then sticks out from the surface of the cells. The person's immune system recognizes the spike protein as foreign and makes antibodies (like inhibitors) that attach to the spike protein. If the person is infected with COVID, the immune system then uses this antibody to destroy any invading virus cells with spike protein.

Viral vector vaccines use a harmless virus, AAV, which contains DNA instructions for making the COVID virus spike protein. The AAV virus injects the COVID DNA instructions into the recipient's cells. Those cells make the spike protein which then sticks out of the cell's surfaces. The person's immune system recognizes that the spike protein is foreign and makes an antibody (like an inhibitor) to the spike protein. When the person is infected with COVID, his immune system recognizes the foreign surface spike proteins and releases the antibodies which attach to the spike protein, and the virus is destroyed by the immune system so the person does not get sick.

8) MUTATIONS

All viruses are subject to mutation (change in genetic makeup). For example, the flu virus mutates every year. This is why we have to get a new flu shot every year.

The Corona virus that causes COVID-19 is no exception to this rule. Several different mutations have been found in various parts of the world: UK, Brazil, South Africa, and now California and New York.

Several companies, including Pfizer and Moderna, are conducting tests to see if their vaccine conveys immunity to the new variants. In the future, they may develop booster vaccines that will neutralize the variants. Thus, like the flu vaccine, we may need a new Coronavirus shot each year.

9) References

1. **Recommendation #221 MASAC RECOMMENDATIONS ON ADMINISTRATION OF VACCINES TO INDIVIDUALS WITH BLEEDING DISORDERS.**
2. **CDC website: https://www.cdc.gov/coronavirus/2019-ncov/vaccines/**

SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team

"RECOVERY WAS TOUGH, BUT I LEARNED I HAD MORE SUPPORT THAN *I THOUGHT POSSIBLE*."

HELLO FACTOR

Read stories like James' in *Hello Factor* magazine:
BleedingDisorders.com

Takeda


Dr. Glenn Pierce
Gene Therapy
Review
Revisión de la terapia genética
Dr. Barbara Konkle
My Life/Our Future
Update
Actualización de Mi vida / nuestro futuro
Dr. Steven Pipe
New Therapies
Nuevas terapias
Clinical Trials Update list w/contact info
Actualización de ensayos clínicos
UCSF
Hemophilia Treatment Center
Keynote by Dr Len Valentino
CEO National Hemophilia Foundation
Emerging Therapies
Foro de
Terapias Emergentes
Equity within the Science
Equidad dentro de la ciencia
July 17, 2021
online
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Meal Voucher
Rifas
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Cupon de comida
Host Anfitrión
Jorge de la Riva
Past Board President
National Hemophilia Foundation
Ex presidente de la Junta de la National Hemophilia Foundation
Takeda
Pfizer
BIOMARIN
novo nordisk
The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS
Register hemofoundation.org/Events

Marion Koerper, MD

On the first day of her Pediatric internship at San Francisco General Hospital, Marion Koerper, MD, noticed a four-year-old boy "running around with cotton in his nose and his arms wrapped in elastic bandages so tight he couldn't bend his elbows." Staff in the pediatrics clinic explained that the child had hemophilia; the wrappings prevented nose-picking -- the cause of frequent nose bleeds and doctor visits.

Koerper, a Stanford University graduate whose interest in the field of hematology was sparked early in medical school at the University of California San Francisco, became his primary care doctor, later his hematologist and took off the arm splints so he could play like a normal little kid!" It was the early 1970s, when clotting factor was not yet widely used in the routine care of people with bleeding disorders. "His name was Nicky. He was my first hemophilia patient," she says, recounting the experience in vivid detail. "Every time he came to the clinic for bleeding they would call me and I would see him and treat him with cryoprecipitate."

This chance meeting launched a nearly 50-year career in pediatric hematology, packed with significant contributions, some deep sorrow, and a yearly dose of summer-camp fun. Koerper has been Director of the UCSF Hematology Treatment Center (one of the first HTCs in the US) and Professor of Pediatric Hematology at UCSF -- posts she's held since the 1970s and retired from in 2016 due to illness – as well as Medical Advisor to the National Hemophilia Foundation from 2011 through late 2018. She continues to serve as the NHF representative to the World Hemophilia Foundation's Coagulation Products Safety, Supply and Access Committee, reflecting her long interest in and significant work on the safety of blood and other products used by the bleeding disorders community.

When the harrowing and deadly toll of the HIV/AIDS crisis began affecting people with bleeding disorders in the 1970s and 1980s, Koerper co-led the NHF's successful efforts along with Val Bias, then Chief Executive Officer of the NHF, to ensure the safety of the US blood supply. "People were exposed to the virus through clotting factor from contaminated blood," she explains. "We lost a generation of people with hemophilia to AIDS." Others contracted Hepatitis B or C. Koerper, Bias and others on the NHFs blood safety working group worked with the US Food and Drug Administration to develop a required safety-risk questionnaire for all potential blood donors as well as mandatory testing of all donated blood. Since 1987, no one with hemophilia has contracted HIV from factor VIII or IX products in the US, according to the NHF.

As the NHF Medical Advisor, Koerper has led the development of over 250 Medical and Scientific Advisory Council (MASAC) recommendations used worldwide in the care of bleeding disorders – from treatment in emergency rooms to home dosing of clotting factor to the treatment of girls and women with inherited bleeding issues. She played a role in the development of the NHF sweeping My Life, Our Future (MLOF) study that has collected confidential genetic samples from about 83 percent of Americans with bleeding disorders. The data is expected to spur research on new tests, treatments and understandings of the genetic basis of bleeding disorders, Koerper says. Work on the landmark study involved plenty of informational meetings with the community, to raise awareness and answer questions. "Everyone involved with the study gave talks to every NHF chapter," she says. "I spoke throughout California, explaining the importance of the study and the safety of people's genetic information."

Sometimes, Koerper says, her life's work has also been a pure delight. In 1978, she got the idea to start a summer camp for the Hemophilia Foundation of Northern California Chapter, where she was medical advisor. With plenty of help from others, the camp (later christened Camp Hemotion) was born. Koerper was medical director for 38 years. "Kids lined up in the morning for prophylaxis and spent the day swimming, climbing and hiking," says Koerper, who visited recently for the camp's 40th anniversary. "Children as young as five learned how to mix factor and give themselves injections. We taught them about the genetics of hemophilia, so future generations could be protected from problems during pregnancy, birth, and early in life. Every kid should go to summer camp, it's too much fun to miss out on!"

Reprinted with permision, Fall 2019 Hemaware - Our Heroes; Marion Koerper MD Lifetime Achievement Award PP26-27

Hemophilia Foundation of Southern California

Central California Hemophilia Foundation

HSDC
HEMOPHILIA ASSOCIATION OF SAN DIEGO COUNTY

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

5º ANUAL

FAMILIA DE SANGRE

17-19 DE SEPTIEMBRE DE 2021

EVENTO VIRTUAL

¡Esperamos verlo en septiembre en la conferencia de desórdenes sanguíneos de habla hispana más grande del país!

HORARIO

VIERNES 9/17 Ceremonia de bienvenida, sala de exhibición virtual, conciertos y juegos familiares

SABADO 9/18 Sesiones educativas en vivo y sala de exhibición virtual

DOMINGO 9/19 Presentaciones de actualización de la industria, sala de exhibición virtual y sesión de clausura

TEMAS

Terapia Génica · Inmigración · Mujeres y desórdenes sanguíneos · Salud Mental

CAJAS DE LA CONFERENCIA

Cada familia inscrita recibirá: una caja de pre-conferencia llena de obsedquios del Salón de Exhibición, Programa de FDS, Camiseta de FDS y una tarjeta de Walmart de $ 150 por hogar que se enviará por correo electrónico después de la conferencia.

¡LA INSCRIPCIÓN YA ESTÁ ABIERTA! REGÍSTRESE GRATIS EN HTTP://FAMILIADESANGRE.VFAIRS.COM

5TH ANNUAL

FAMILIA DE SANGRE

SEPTEMBER 17-19, 2021

VIRTUAL EVENT

We look forward to seeing you in September at the largest Spanish-speaking bleeding disorders conference in the country!

SCHEDULE

FRIDAY 9/17 Welcome Ceremony, Virtual Exhibit Hall, Concert & Family Games

SATURDAY 9/18 Live Educational Sessions and Virtual Exhibit Hall

SUNDAY 9/19 Industry Update Presentations, Virtual Exhibit Hall and Closing Session

TOPICS

Gene Therapy · Immigration · Women & Bleeding Disorders · Mental Health

CONFERENCE BOXES

Each registered family will receive: a pre-conference box filled with goodies from the Exhibit Hall, FDS Program, FDS T-shirt, and a $150 Walmart card per household that will be emailed after the conference.

REGISTRATION IS NOW OPEN! REGISTER FOR FREE AT HTTP://FAMILIADESANGRE.VFAIRS.COM

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QUESTIONS? CONTACT CYNTHIA CHAVEZ 626-765-6656 cynthia@hemosocal.org

NATIONAL HEMOPHILIA FOUNDATION
www.hemophilia.org

MASAC Document #229
(Replaces Document #94)

MASAC RESOLUTION REGARDING CONSUMER PARTICIPATION IN THE NATIONAL PATIENT NOTIFICATION SYSTEM

This document was approved by the Medical and Scientific Advisory Council (MASAC) on September 20, 2014, and adopted by the NHF Board of Directors on September 21, 2014.

The National Hemophilia Foundation is a vigilant advocate for the safety of the nation's blood and plasma products and derivatives. MASAC supports the maintenance of the Patient Notification System (PNS), established by the PPTA, which is a voluntary notification system for reporting problems with plasma-derived and recombinant clotting factor products. MASAC acknowledges that the PNS is an important public health initiative and an essential effector mechanism of the existing systems of blood surveillance and safety. The PNS currently includes approximately 6000 registrants, which is estimated to include less than 5% of the nation's consumers of plasma-derived therapies. MASAC is concerned that the voluntary notification system has not been effectively promoted to the bleeding disorders community, including consumers and caregivers.

MASAC has previously identified participation in the PNS as one of the Standards of Service for pharmacy providers of clotting factor concentrates for home use to patients with bleeding disorders. (MASAC Recommendation #188). Pharmacy providers, hemophilia treatment centers, and distributors of plasma products and recombinant clotting factors should consider it a best practice to inform consumers about the notification system and to educate consumers that the PNS is an essential component of hemovigilance and that the effectiveness of the voluntary warning system is directly related to enrollment.

Privacy and confidentiality need to remain of paramount importance. MASAC recommends that consumers enroll in this direct notification system as the quickest and most direct way of being notified of any recalls involving product that they might have in their possession but have not yet used. The healthcare team providing care for the individual with a bleeding or clotting disorder should discuss registration in the PNS as a part of the comprehensive care visit. The discussion should include whether registrant's contact data in PNS remains current and any potential barriers to notification (including potential language and technology barriers).

MASAC urges NHF to consider how to partner with advocacy groups for consumers of blood component-derived therapeutic agents for conditions beyond bleeding and clotting disorders to achieve maximum penetration of PNS registration among all individuals exposed to plasma components.

Registration in PNS is accomplished via the following link: http://www.patientnotificationsystem.org/

This material is provided for your general information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

116 West 32nd Street • 11th Floor
New York, NY 10001
(800) 42-HANDI • (212) 328-3700 • fax (212) 328-3777
www.hemophilia.org • info@hemophilia.org

Why join our Board?

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

Here at HFNC, we make a real difference in the lives of families with bleeding disorders. We serve families with life-threatening bleeding disorders, factor deficiencies and rare clotting connections. We seek Board members that are as diverse as the community we serve.

Our Mission: Serve the needs of people impacted by bleeding disorders through enhancing quality of life by providing support, education, outreach, advocacy and research through our affiliated national foundations.

Opportunity: Work with a passionate, dedicated group of Board members and volunteers.

Mission: Impact our mission by making a contribution that matters deeply to our community.

Experience: Interact with a diverse community and people from a variety of backgrounds and practice ways of working toward a common goal.

Recognition: Be recognized as making a valuable contribution to a Foundation that benefits the community.

Satisfaction: Contribute to the community in a meaningful way by giving two of your most valuable assets: time and experience.

What can I do?

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

HFNC has been looking for someone like you...

Every person can make a difference. That's why we don't start with strictly defined job descriptions. Instead, we look for people who want to use their skills to make a difference and match them with the opportunities we have. The examples below are flexible and include opportunities such as:

MANAGE

Your work background can be put to good use as a **Project Manager!** We are always in need and can match you with some projects or programs that fill your heart! Time estimate: two - three hours per month increasing slightly during budget preparation and year-end close. Total time commitment is approximately six hours per month. Note: No limits on what you can accomplish alone or as part of a team.

FINANCE

Your financial background can be put to great use as **Treasurer**. You'll be responsible for financial oversight of our QuickBooks with support and day-to-day work done by our bookkeeper, Executive Director and consulting services from the former Treasurer. Time estimate: two - three hours per month increasing slightly during budget preparation and year-end close. Total Board commitment is approximately six hours per month. Note: HFNC uses a calendar year accrual-base accounting system in QuickBooks. Books are in excellent shape and include an extensive library of reports. No major overhaul is necessary.

MARKET

Your marketing background can be out to great use as a **Marketing Specialist** analyzing the way we market over a dozen events per year to ensure that we are reaching our target audience. Time estimate: two - four hours per month depending on your availability and your project interests. Total Board commitment is approximately six hours per month. Note: HFNC uses Facebook, email, snail mail and some others. We would love to learn how to expand our reach.

INFORM

Use your creative skills as a **Communications Specialist** to help us prepare collateral materials for events, social media posts and educational materials. Time estimate: two-four hours per month depending on your availability and your project interests. Total Board commitment is approximately six hours per month. Note: HFNC uses Microsoft Office Suite, Google docs, Canva, Airtable and numerous other applications.

PLAN

Your business background will help us in **General Business** to develop and manage our operations and communications to best inform Board members and stakeholders. For example, we want to revise our Board meeting format including content and presentation as well as determine what type of "dashboard" might be most helpful to report on grants, donations, etc. Time estimate: two - four hours per month depending on your availability and your project interests. Total Board commitment is approximately six hours per month. Note: You will work closely with the Board President and Vice President on this project.

FUND

Fundraising is likely the scariest word when considering Board membership! HFNC always needs help ensuring our fundraising efforts are effective. Any prior experience in this area OR a general willingness to train to use our tools to advance our efforts will ensure that families get needed services. Time estimate: two - four hours per month depending on your availability and your project interests. Note: Don't be intimidated! For example, you might be interested in attending our annual Walk Rally. This two-day rally held in various locations around the country, is paid for by sponsors with the intention of teaching local organizations how to effectively raise funds through our annual Unite for Bleeding Disorders Walk.

www.hemofoundation.org | (510) 658-3324 |infohfnc@hemofoundation.org

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

MASAC Recommendation #266
(Replaces Document #244)

MASAC RECOMMENDATIONS REGARDING THE TREATMENT OF VON WILLEBRAND DISEASE

The following recommendations were approved by the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF) on February 20, 2021, and adopted by the NHF Board of Directors on March 4, 2021.

von Willebrand disease (VWD) is the most common inherited bleeding disorder and affects males and females equally in up to 1% of the general population. (1,2) VWD is associated with mucous membrane bleeding, excessive bruising, and bleeding from cuts. It can result in excessive bleeding with invasive dental work, during surgical procedures, and after accident or injury. In women, heavy menstrual bleeding is often the major symptom. Women with VWD are also at risk of postpartum hemorrhage, particularly delayed postpartum hemorrhage.

The following are current recommendations for treating bleeding in individuals with VWD. They are adapted from the ASH, ISTH, NHF, WFH 2021 VWD guidelines. (3)

Refer to Connell et al for suggested definitions for desmopressin response, prophylaxis, heavy menstrual bleeding (HMB), post-partum hemorrhage. (4)

Desmopressin (DDAVP) [5-9].

1. Persons with type 1, 2A, 2M, and 2N VWD may be treated with the synthetic agent desmopressin (DDAVP Injectable or Stimate Nasal Spray for Bleeding, 1.5 mg/ml) if they have been shown by a DDAVP trial to be responsive. This is particularly important for patients with type 1 VWD and VWF <=30% and types 2A, 2M, and 2N who may not have sufficient response. Response should be assessed one and four hours after DDAVP; the one-hour assessment is particularly important for patients suspected of having type 1C VWD. A desmopressin response requires an increase of at least >2 times the baseline VWF activity level and a sustained increase of both VWF and factor VIII (FVIII):C levels >0.50 IU/mL for at least 4 hours.

2. Desmopressin is a potent antidiuretic agent, and fluid retention is a potential complication of this drug. Both parenterally administered DDAVP (IV and SQ) and Stimate® Nasal Spray have been associated with the development of hyponatremia and seizures. To minimize this risk, the following precautions should be observed when this drug is used at home and in the hospital:
   a. DDAVP and Stimate should be administered no more often than once every 24 hours.
   b. DDAVP and Stimate should be used for no more than three consecutive days unless directed to do so by Hemophilia Treatment Center medical staff.
   c. DDAVP and Stimate should not be used in children under the age of two years.
   d. DDAVP and Stimate should be used with caution in the elderly and in individuals with a history of heart disease, hypertension, or stroke.
   e. If a patient is treated with DDAVP before surgery, the anesthesiologist should be advised to avoid fluid overload and dilutional hyponatremia.
   f. DDAVP should be used with caution in pregnant women in the peripartum and immediate postpartum period, with careful attention to fluid management to avoid hyponatremia.
   g. Oral fluids should be restricted to maintenance for 24 hours following treatment.

3. VWF Replacement
   Persons with type 2B and type 3 VWD, and those with type 1, 2A, 2M, and 2N who have been shown to be nonresponsive to DDAVP, should be treated with a factor VIII/VWF concentrate that is known to contain the higher molecular weight multimers of von Willebrand factor and that has been virally attenuated to eliminate transmission of HIV and hepatitis A, B, and C. Human plasma-derived products Alphanate, Humate P, and Wilate have been approved by the FDA for use in VWD. A recombinant VWF concentrate, Vonvendi, has also been approved. Another plasma-derived product, Koate DVI, may also be effective in these patients, but it has not been approved by the FDA for use in VWD. For further information, see MASAC Document #263, "MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders."

   Because of the increased risk of HIV and hepatitis A, B, and C transmission, cryoprecipitate should not be used except in an emergency situation when none of the above-mentioned products are available and delay of treatment would be life- or limb-threatening.

4. Antifibrinolytics

   Adjunctive treatments for mucous membrane bleeding include the antifibrinolytic agents aminocaproic acid and tranexamic acid. These agents can be given orally or intravenously. (See MASAC Document #263, "MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders.")

5. Management of Heavy Menstrual Bleeding - See MASAC Document #264.

6. Prophylaxis

   In patients with VWD with a history of major and frequent bleeds, the ASH ISTH NHF WFH guideline panel suggests using long-term prophylaxis with factor replacement rather than no prophylaxis.(3) Prophylaxis in VWD is defined as a period of at least 3 months of treatment of VWF concentrate at least once weekly, or for women with HMB, use of VWF concentrate at least once per menstrual cycle.

7. Perioperative Management

   Prior to surgery in a patient with VWD, consultation should be obtained with a pediatric or adult hematologist who specializes in the management of individuals with inherited bleeding disorders. This consultation should cover risk of bleeding with procedure and duration of risk. Treatment plan should be developed including such issues as the need for a DDAVP trial; type of fluid replacement or fluid restriction; dose and duration if DDAVP is to be used; appropriate dose, timing, and duration of factor replacement therapy; and use of adjunctive medications (antifibrinolytics and topical agents).
   The ASH ISTH NHF WFH 2021 guidelines on the management of VWD suggest the following:
   - Desmopressin should not be used for major surgery.
   - Factor replacement the panel suggests targeting both FVIII and VWF activity levels of 0.50 IU/mL for at least 3 days after surgery (conditional recommendation based on very low certainty in the evidence of effects).

Remarks:
- When it is possible to keep both trough levels at 0.50 IU/mL for at least 3 days or as long as clinically indicated after the surgery (instead of choosing only 1), this should be the preferred option.
- The specific target levels should be individualized based on the patient, type of procedure, and bleeding history as well as availability of VWF and FVIII testing.
- The duration of the intervention can vary for specific types of surgeries.
- In patients undergoing minor surgery or minor invasive procedures, the panel suggests increasing VWF activity levels to 0.50 IU/mL with desmopressin or factor concentrate with the addition of tranexamic acid over raising VWF levels to 0.50 IU/mL with desmopressin or factor concentrate alone.
- The panel suggests giving tranexamic acid alone over increasing VWF activity levels to 0.50 IU/mL with any intervention in patients with type 1 VWD with baseline VWF activity levels of 0.30 IU/mL and a mild bleeding phenotype undergoing minor mucosal procedures.

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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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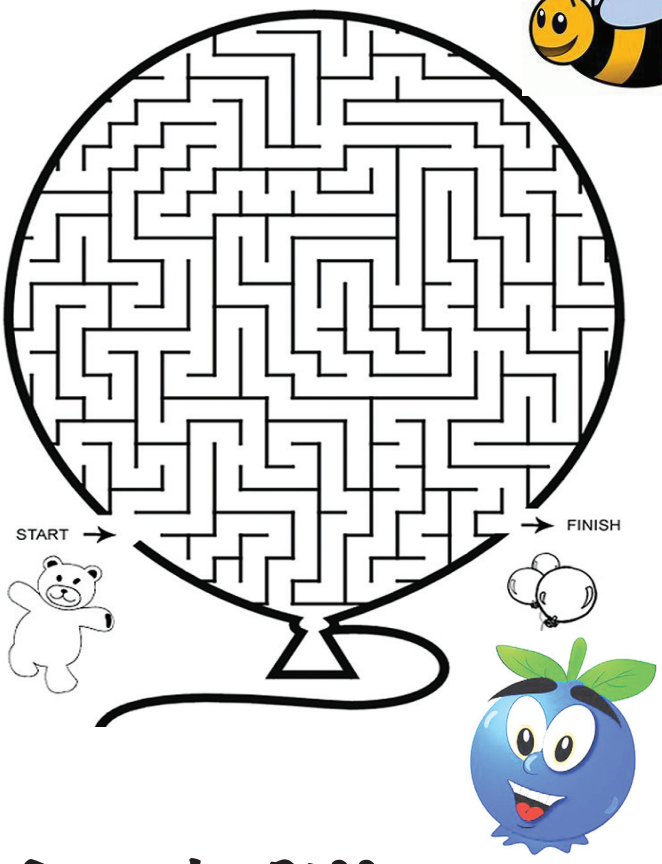
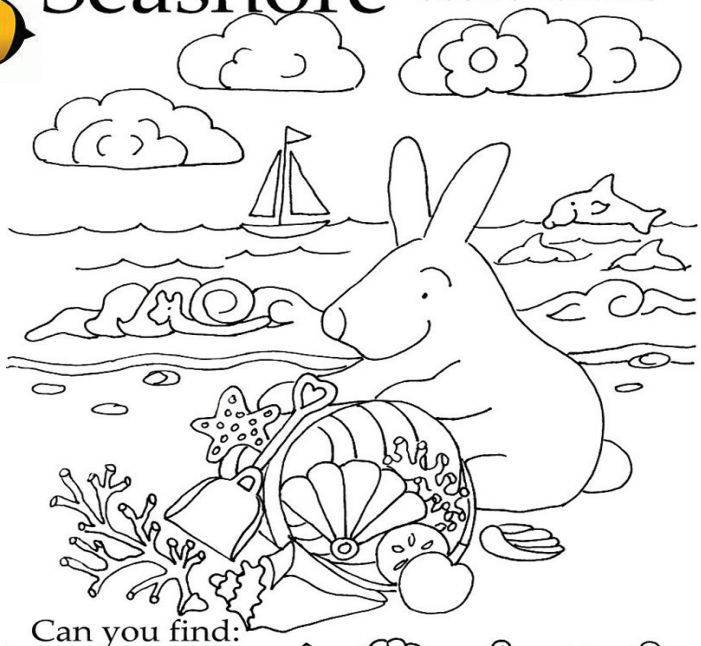
Kid's Page

Show Benny the bear the way to his balloon



Seashore Seek and Find



Can you find:

a snail, an apple, a fan, a bell, a heart, and a flower?

Spot the Difference

Word Search

cab pad wag jam man
nap rat bag ram cat

f g h y t r e w p l n k
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l o v w u a k h b g e e
a l y a o t n e n b z f
r t h g y p a n a t x z
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CALENDAR

JUN		
6/13/21-6/19/21	Camp Hemotion	Virtual
JULY		
7/4/21	Independence Day	
7/13/21	Board Meeting	Virtual
7/17/21	Emerging Therapies	Virtual
7/26/21-7/30/21	**Strategic Planning/HFNC CLOSED**	In person*
AUGUST		
8/10/21	Board Meeting	Virtual
8/26/21-8/28/21	Bleeding Disorders Conference National Hemophilia Foundation	Virtual
8/29/21	Unite Walk	Virtual
SEPT		
9/5/21	Labor Day	
9/14/21	Board Meeting	Virtual
9/17/21-9/19/21	Familia de Sangre	Virtual
9/25/21	Asian Infusion Community Cooking Demo	Virtual

OCT		
10/2/21-10/24/21	Silent Auction	Online
10/12/21	Board Meeting	Virtual
10/18/21-10/28/21	Hemophilia Federation of America Annual Symposium	Virtual
10/25/21	Golf Tournament	In person
NOV		
11/9/21	Board Meeting	Virtual
11/25/21-11/26/21	Thanksgiving Holiday	
11/30/21	Giving Tuesday	Virtual
DEC		
12/1/21	World AIDS Day	
12/?/21	Fresno Holiday Party	To Be Determined
12/4/21	Oakland Holiday Party	To Be Determined
12/5/21	Posada	To Be Determined
12/24/21-12/31/21	**HFNC closed**	
12/24/21	Christmas Eve	
12/25/21	Christmas Day	

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