

# Infusions

NEWS

## UCSF Benioff Children’s Hospital Hemophilia Treatment Center at Oakland Children’s Hospital

### Meet the newest team member!!

Holly Alley, RN General Hematology & Hemophilia Treatment Center at UCSF Benioff Children’s Hospital Oakland.

*From Holly,* It is a pleasure to be joining the Hemophilia and Thrombosis Community. I am a second career nurse with a background in intensive care, behavioral therapy, and global studies. I worked the past 5 years in the Pediatric ICU at UCLA Mattel Children’s Hospital, and Minnesota Children’s Hospital. I have a deep appreciation for cultural diversity and a passion to eliminate health disparities and promote equitable care to all children and families. My greatest joy is being a mom to my beautiful, brave, spunky toddler. I am grateful to be joining the hematology team at UCSF Benioff Children’s Hospital Oakland and look forward to building relationships and serving your family.



Holly (front center) with rest of Oakland HTC team: (top left to right) Maddie Pine, Clinical Research Assistant, Dr. Alison Matsunaga, Katrina Unpingco, NP, (bottom left to right) Cat Frazier, RN, Carla Ruiz, Office associate, Teresa Vazquez, MSW.

We here at HFNC are happy to introduce you to the staff at local Hemophilia Treatment Centers and will feature more of this in the future. If your Hemophilia Treatment Center would like to provide an introduction to your team, please contact HFNC; we would be happy to feature you on the cover of INFUSIONS. 🔥

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Announcement

**Bryan  
Anderson  
Associate  
Director  
is on  
Family Leave  
and  
will return  
Mid October**

*Congratulations  
to  
Bryan & Anne!*

**JIVI®  
ADYNOVATE®**

**Jivi**  
antihemophilic factor  
(recombinant) PEGylated-aucI  
LET'S GO

## PK (Pharmacokinetics) Study Data



Talk to your doctor  
about the study.



Scan the QR code to learn more  
about PK at [UnderstandingPK.com](http://UnderstandingPK.com)

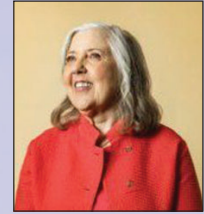
PK; Pharmacokinetics

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**Dr. Marion Koerper**  
HFNC's Medical Adviser



## QUESTIONS TO ASK WHEN ATTENDING EVENTS

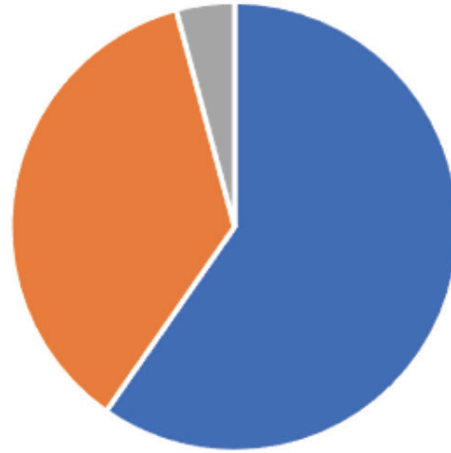
- 1. AM I VACCINATED?** If yes, great. If not CONSIDER ALTERNATIVES TO ATTENDING
- 2. IS BEING VACCINATED A REQUIREMENT TO ATTEND?** Does the host require that all attendees be vaccinated? If yes, great. If not, CONSIDER ALTERNATIVES TO ATTENDING
- 3. ARE MASKS REQUIRED?** If yes, great. If no, consider wearing a mask. If opposed to mask wearing, CONSIDER ALTERNATIVES TO ATTENDING
- 4. IS THE EVENT INDOORS OR OUTDOORS?** Outdoor air greatly reduces the risk of viral spread
- 5. HOW MANY ATTENDEES WILL BE THERE?** Covid-19 is spread by being close to an infected person and the longer you are exposed the greater the risk of infection

## COMMUNITY SURVEY RESULTS TOPIC: RETURNING TO IN - PERSON EVENTS

Thank you to all that responded! We received 73 responses to our survey from July 2 - Jul 23, 2021. See the results below. 100% of the respondents expressed being comfortable attending an outdoor event with vaccinated adults as long as a few safety measures were followed (e.g. wearing a mask). 30% of respondents were not comfortable attending an indoor event with unvaccinated people no matter what. Out of the 49% of people who said they would be comfortable attending an indoor event with unvaccinated people if certain precautions were taken, 91% said mask wearing, and 82% said proof of vaccine/negative test/family bubbles should be required, 55% said limit attendance size. We asked respondents if they were comfortable staying overnight in a shared room (e.g. the female factor retreat, family camp, etc.), only 27% said they would be comfortable, 32% said they would be comfortable if they shared with family only, 42% said they would not be comfortable at all.

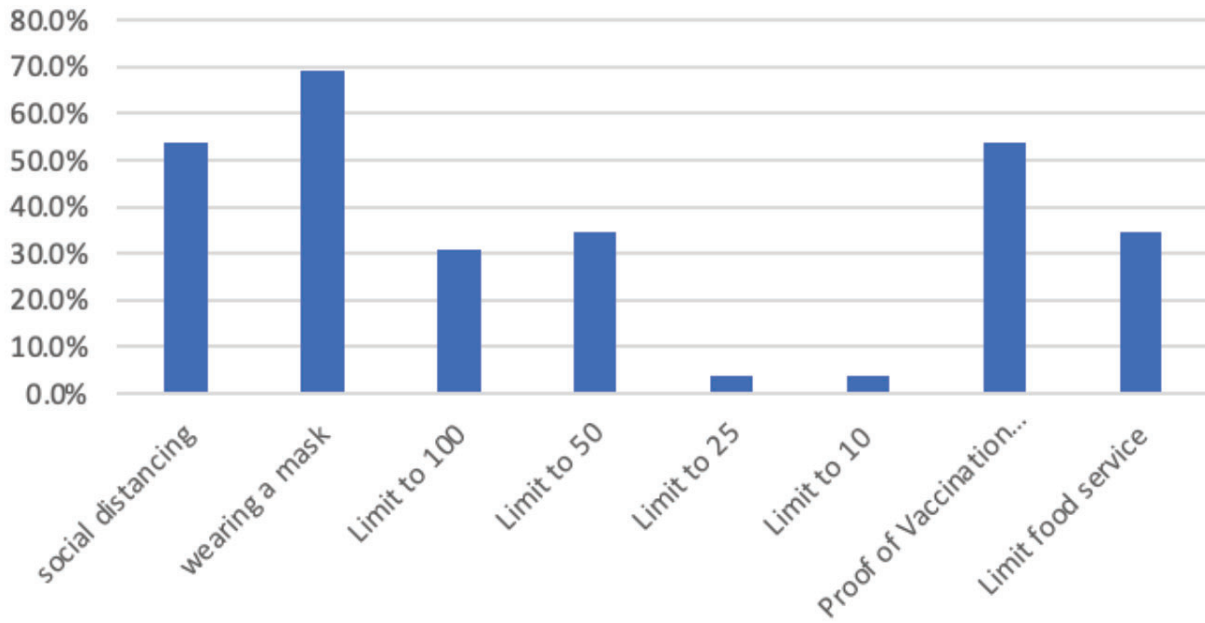
*Continued on Page 4*

### Would you feel comfortable attending an INDOOR event with VACCINATED ADULTS?

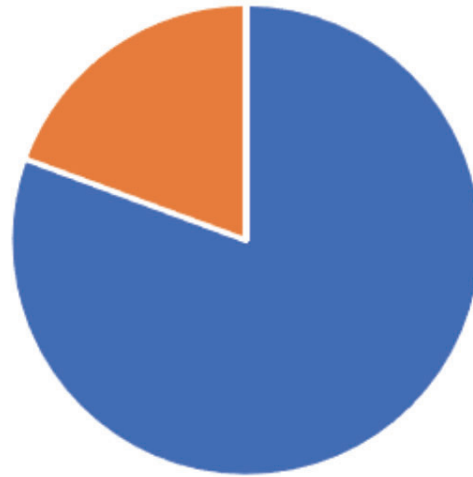


■ Yes (60%) ■ Yes, but... (36%) ■ No (4%)

#### Yes, but...(36%) \*select all that apply

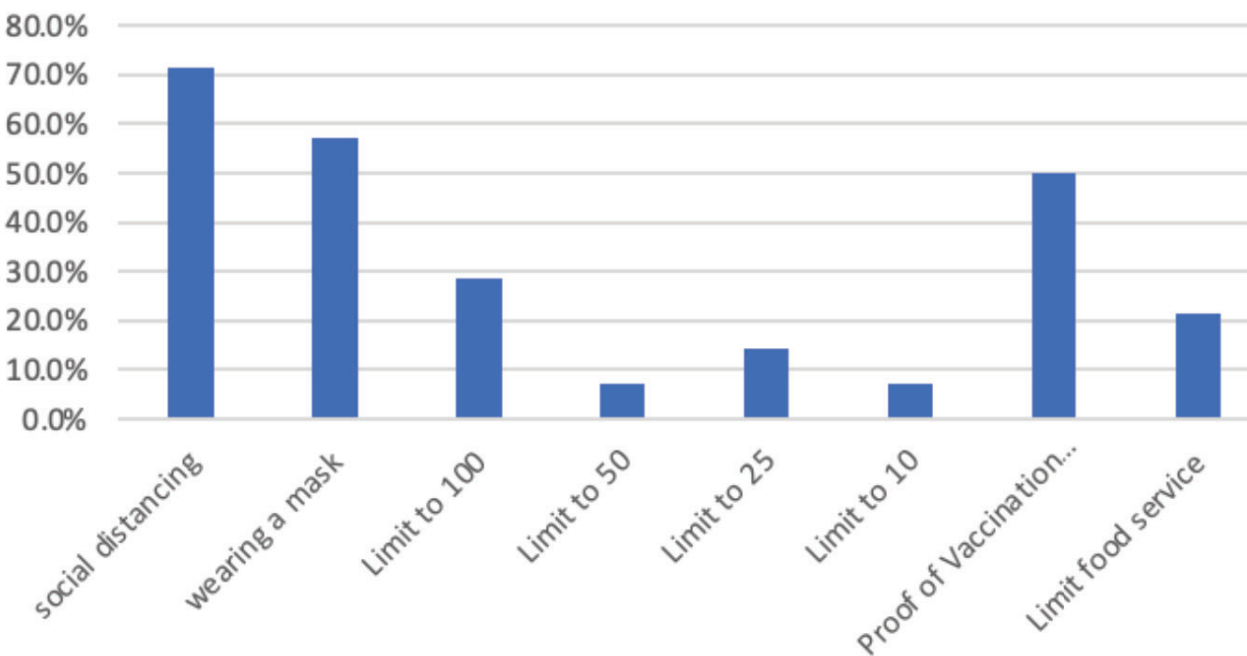


## Would you feel comfortable attending an OUTDOOR event with VACCINATED ADULTS?



■ Yes (81%) ■ Yes, but... (19%) ■ No (0%)

### Yes, but (19%). \*select all that apply

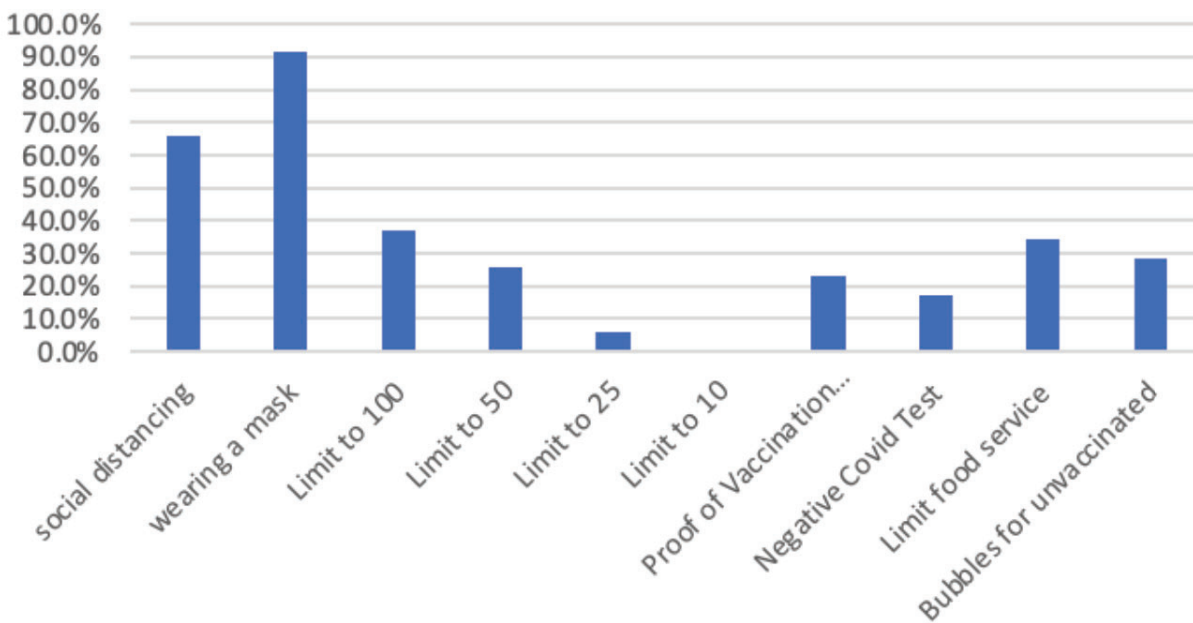


### Would you feel comfortable attending an INDOOR event with UNVACCINATED individuals including children?



■ Yes (21%) ■ Yes, but... (49%) ■ No (30%)

#### Yes, but (49%). \*select all that apply

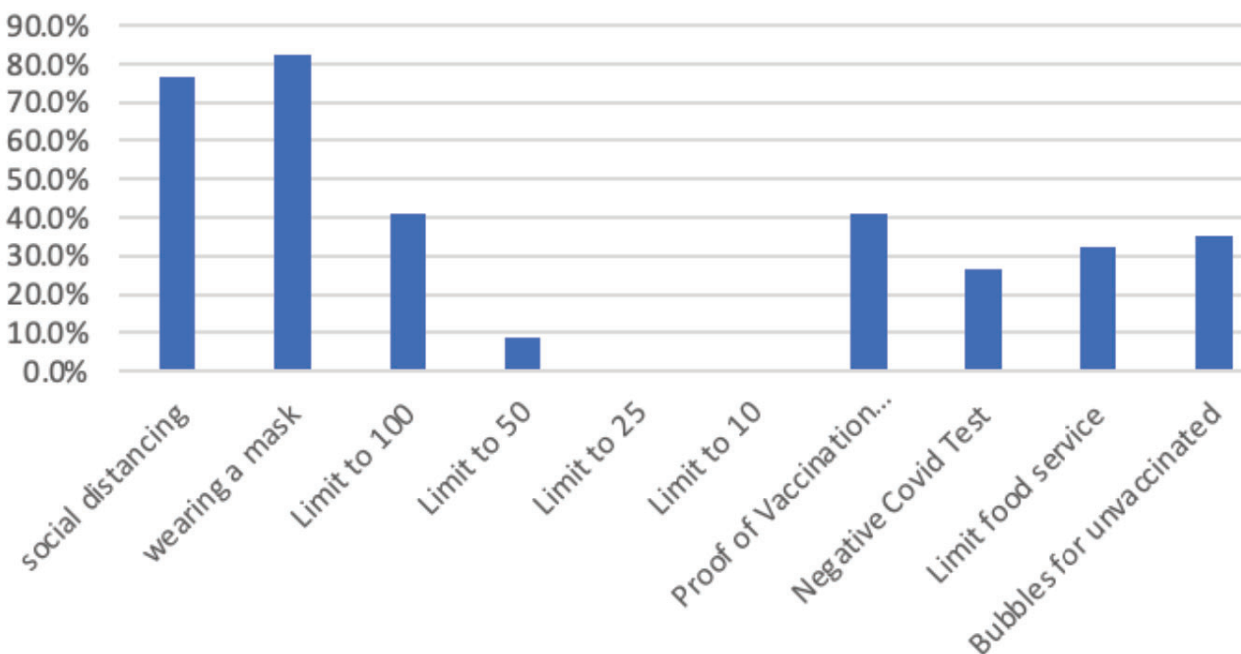


## Would you feel comfortable attending an OUTDOOR event with UNVACCINATED individuals including children?

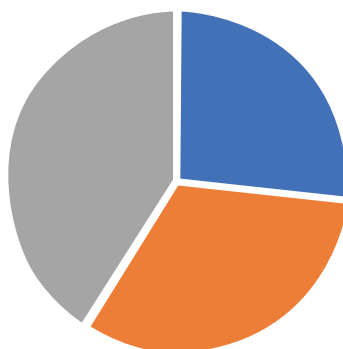


■ Yes (39%) ■ Yes, but... (47%) ■ No (16%)

### Yes, but (47%). \*select all that apply

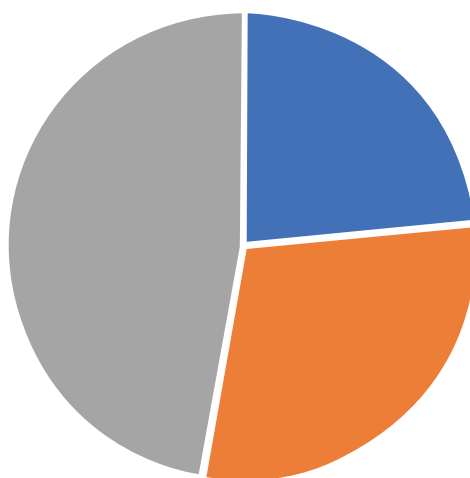


Would you currently attend an OVERNIGHT in-person event and be willing to SHARE A ROOM with another community member, E.g. The Female Factor Retreat or Family Camp?



■ Yes (27%)   ■ Yes, but only with family/choose roommate (32%)   ■ No (41%)

How far are you willing to TRAVEL to attend an in-person event?



■ Less than 1 hour (24%)   ■ Less than 2 hours (29%)   ■ More than 2 hours (47%)

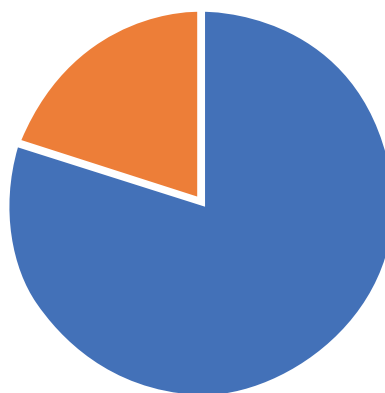


Do you feel that being vaccinated should be a REQUIREMENT to attend and in-person event, whether indoor or outdoor?



■ Yes (46%) ■ Yes for indoor only (7%) ■ Yes, but not for kids (13%) ■ No (35%)

If you were unable to attend an in-person for some reason, would you still be willing to participate VIRTUALLY?



■ Yes (80%) ■ No (20%)



## PAMELA LAUER

### My Hemophilia Story

My name is Pamela. My father was a hemophiliac. I remember watching my aunt give him infusions. She gave them to three of her six sons as well. I remember in fifth grade, my social studies teacher learned that my father had hemophilia. I didn't understand then why my parents were so upset that he called to ask more about my health. Had I been checked? My dad called him stupid and said he shouldn't be a teacher. Everyone knows girls can't have hemophilia.

When I was thirty four I was diagnosed with pre-cancer in my uterus. I had a hysterectomy. It was supposed to be out patient. They kept me for three days before I begged to get out of the hospital. This would become a trend for me. I was put on bed rest for a month. I was rushed to the Emergency Room as soon as I finally stood up. I just wasn't clotting. The nurses in the rural hospital had never seen anything like it. They called in the O.B.G.Y.N. She called a specialist in Vegas and together they diagnosed me over the phone as likely a hemophiliac and ordered blood work. I bled for five hours in the E.R. that day. I had 14 vials of blood taken a few days later and was told that I was a "symptomatic carrier" and to just keep that in mind.

Two years later I completely tore my ACL jumping on a trampoline while playing "School's Out" by Alice Cooper on the last day of the school year. Teachers celebrate the last day too. I spent my last day of school in the E.R. from 6pm until 6 am. I had written "hemophiliac" on my entrance paperwork and everyone at the hospital was afraid to help me. Then two days later, when I was finally able to see the orthopedic surgeon, he told me my hemophilia would ruin his reputation.

I ended up waiting three months for surgery. The hospital that would help me was two hours North of us in Portland at OHSU. The hemophilia team there finally introduced me to my new way of life. They tried to teach me to infuse myself and for the first time in my life, I had an infusion for my Factor VIII deficiency before surgery. I had a port put in and took charge of my bleeding disorder by infusing daily for a week afterward. It was a painful new way of life but it was thrilling to no longer feel the victim.

I have moved back to Northern California now. I have had to replace my ACL a second time, this time with help from the Hemo team at UCSF. I now have permanent arthritis in my knee and healing is a much slower process the second time. I am returning to teaching in the fall.

Some things in life will never be the same. I travel with factor replacement when I leave the house now. I take it hiking, biking, on long trips and into the classroom. I talk openly about my bleeding disorder. It feels good to tell others I have hemophilia. Every time I do, I empower myself and hopefully I break down stigmas about what women can have, and what women can do. 🔥



Local Silver Sponsors

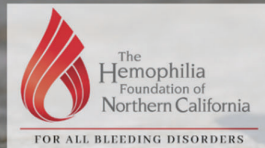


CSL Behring  
Sangamo  
THERAPEUTICS

Local Bronze Sponsor



BECAUSE OF YOU,  
KIDS GO TO  
CAMP HEMOTION



Unite for Bleeding Disorders Walk  
local sponsors 2021

**HFNC needs volunteers**

**GIVE LIFE MONEY FOOD**

**VOLUNTEERING**

**WORK HUMANITARIAN**

**GIVING**

**LOVE FRIENDSHIP HUMANITARIAN FOOD**

**LEISURE HAPPINESS UNITY SUCCESS TEAMWORK**

**COOPERATION SOCIAL FREEDOM PEOPLE**

**RELIEF DIVERSITY**

**UNITY LIFE COMMUNITY**

**CONTACT US**  
and let us  
know how  
you can help


[andrea.ozco@hemofoundation.org](mailto:andrea.ozco@hemofoundation.org)  
510-658-3324

# Why Volunteer at HFNC?

**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.


**Volunteering allows you to connect to your community and make it a better place. It can benefit you and your family as much as HFNC.**

 **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.

**Volunteering encourages people to think of others. It is the perfect way to discover something you may be really good at as you develop a new skill. Volunteering brings together a diverse range of people from all walks of life; Make new friends and strengthen existing relationships.**

 **Recognition:** Be recognized as making a valuable contribution to an organization that benefits the community.

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

**Volunteering provides a positive example to others (especially kids). It gives you the satisfaction of playing a role in someone else's life and helping people who may not be able to help themselves. It is a way of giving back to your community.**

Here at HFNC, we make a difference in the lives of persons and their families with life-threatening bleeding disorders, factor deficiencies and rare clotting conditions. HFNC's many programs and services are dependent on volunteers and are managed by volunteers such as Camp Hemotion which is run by all volunteer staff and leaders who give generously of their time and effort to deliver a life-changing program for youth in the bleeding disorders community.

**There are so many more ways to help!**

*Serve on committees for programs and events*

*Organize giveaways and handouts*

*Community outreach*

*Social media outreach*

*Data entry*

*Newsletter production*

## INTERESTED?

Contact Executive Director Andrea Orozco at 510-658-3324 or [andrea.orozco@hemofoundation.org](mailto:andrea.orozco@hemofoundation.org)



SPECIALTY WINE  
+  
CRAFT BEER  
BASKETS

SPA BASKETS

KAVAI  
VACATION PACKAGE

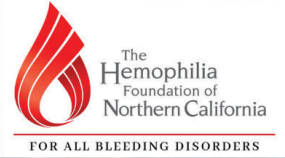
# VINES & HOPS

OCTOBER 2-24, 2021

# SILENT AUCTION

WATCH FOR DETAILS AT

[HEMOFOUNDATION.ORG/EVENTS](http://HEMOFOUNDATION.ORG/EVENTS)



JACK NICKLAUS COURSE

## Charity Golf Tournament Benefitting

### HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA

October 25 8:30 Reg opens 9:30 Putting Contest 10:30 Shotgun Start

\$625 Solo/\$2500 Foursome  
(includes bkfst/lunch/dinner)

\$95 4:30 Dinner (no golf)

- Blaster Packs
- Giveaways
- Honey Pot
- Mulligans





## GHPP: Genetically Handicapped Persons Program

**DESCRIPTION:** The Genetically Handicapped Persons Program (GHPP) is a state of California health care program for adults with specific genetic diseases including inherited bleeding disorders. GHPP helps beneficiaries with their health care costs. GHPP works with doctors, nurses, pharmacists, and other members of the health care team to provide many types of health care services. GHPP is a program for adults with certain inherited medical conditions and for children with certain medical conditions who are not eligible for CCS due to family income..

**Website:** <https://www.dhcs.ca.gov/services/ghpp>

**Phone:** 213-897-3574

**Email:** [GHPPeligibility@dhcs.ca.gov](mailto:GHPPeligibility@dhcs.ca.gov)

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## CCS: California Children's Services

**DESCRIPTION:** California Children's Services (CCS) is a state of California program for children with certain diseases or health problems including inherited bleeding disorders. Through this program, children up to 21 years old can get the health care and services they need. CCS will connect you with doctors and trained health care people who know how to care for your child with special health care needs. With CCS there are family income restrictions, so not all children may qualify on a financial basis even if they qualify medically. In this case they are referred to GHPP.

**Website:** <https://www.dhcs.ca.gov/services/ccs>

**Phone:** (916) 327-1400

\*Note: CCS is administered by each COUNTY - use this website to find your county:  
<https://www.dhcs.ca.gov/services/ccs/Pages/CountyOffices.aspx>

**Mail:** Children's Medical Services

MS 8100, P.O. Box 997413

Sacramento, CA 95899-7413

**Fax:** (916) 327-1106

Thanks  
for the love



**2021 WINNER**  
ZIGGY DOUGLAS  
INNOVATION IN YOUTH  
PROGRAMMING

**2021 WINNER**  
NHF WALK  
CHAPTER OF THE YEAR



CALIFORNIA LE DA LA BIENVENIDA  
APOYANDO A NUESTROS HIJOS



LA 5A CONFERENCIA ANUAL DE FAMILIA DE SANGRE



17-19 de septiembre de 2021  
Registrar aquí: <https://famiadiasangre.vfairs.com>



# Kid's Page

## FALL CROSSWORD PUZZLE



### Outdoor Scavenger Hunt Fall

- Yellow Leaf
- Orange Leaf
- Brown Leaf
- Flower
- Pine Cone
- Bug
- Something to Climb
- Stick
- Animal
- Flat Rock
- Find something Special
- Spider Web
- Bird



Bonus: Pumpkin



#### Across

2. The seed of an oak tree.
4. A team game played with a brown oval ball.
6. The parts of a tree that change colors in autumn.
8. A large bird that is cooked for dinner on Thanksgiving.
9. A common round red or green fruit that is made into pie or cider.
12. The first day of fall when the sun crosses the celestial equator.
13. A ride in a wagon carrying hay.
14. A very large yellow flower that can grow over 6 feet tall.

#### Down

1. A figure set up in a crop field to scare away birds.
3. An outer layer of clothing worn to keep warm on a chilly day.
5. A colorful fall tree that is grown for its sap that is made into syrup.
7. A large round fruit that is carved with faces for Halloween.
10. A grain plant that yield kernels set in rows on a cob.
11. A yard tool used to gather and pile leaves.



## INDOOR SCAVENGER HUNT

Find something that:

- is Red
- can Beep
- is Flat
- has Four Legs
- Floats
- can Hold Other Things
- is Soft
- is Bright
- is Two Inches Long
- Makes you Smile



GO SEEK. GO EXPLORE.  
**GO AHEAD.**

PEOPLE LIKE YOU. STORIES LIKE YOURS.  
Explore more at [HEMLIBRAJourney.com](https://HEMLIBRAJourney.com)



**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. 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**.



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

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan  
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For more information, go to [www.HEMLIBRA.com](http://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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A Member of the Roche Group

## CALENDAR

### SEPT

9/5/21	Labor Day	Holiday HFNC closed
9/6/21	<b>HFNC closed</b>	Holiday HFNC closed
9/14/21	Board Meeting	Virtual
9/17/21-9/19/21	Familia de Sangre	Virtual

### OCT

10/2/21-10/24/21	Vines & Hops 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 HFNC closed
11/30/21	Giving Tuesday	Virtual

### DEC

12/1/21	World AIDS Day	AIDS Memorial Grove, Golden Gate Park, SF, CA
12/4/21	Oakland Winter Gathering	TBD
12/11/21	South Bay Winter Gathering	TBD
12/?/21	Fresno Winter Gathering	TBD
12/24/21-12/31/21	<b>HFNC closed</b>	Holiday HFNC closed
12/24/21	Christmas Eve	Holiday HFNC closed
12/25/21	Christmas Day	Holiday HFNC closed

### JAN 2022

1/1/2022	New Year's Day	Holiday HFNC closed
1/3/2022	HFNC opens for 2022	Remote
1/17/2022	MLK Jr Day	Holiday HFNC closed

Do you know someone in the bleeding disorders community that needs an automobile?



Hemophilia Foundation of Northern California

&

Mike's Auto Body  
Present



Invitation

to  
Apply

Giveaway  
10/25  
Must possess  
current  
CDL & insurance

Giveaway  
will be live  
and in person  
in Pleasanton

Deadline 9/24

These vehicles are refurbished and 100% safe!

contact your HTC social worker to apply

HEMOPHILIA FOUNDATION  
OF NORTHERN CALIFORNIA  
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Martinez, CA 94553

PRSR STD  
U.S. POSTAGE  
**PAID**  
PERMIT NO. 316  
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