SUMMER 2022

Infusions

COMMUNITY MEMBER SPOTLIGHT

Pedro Daniel Preciado

Being told you have Hemophilia, no matter the age, is not easy news to digest. For me, it was senior year of high school in 2014 at the age of 17 through a less than fortunate experience. Two weeks prior to finding out about my condition, I went through an event every teen goes through - wisdom tooth surgery. For me however, this surgery was anything but normal. Unlike other teens, I found my gums would not clot properly leaving me to lightly bleed throughout the day and the night. Spit, stitch, gauze, repeat. This became my anthem for two weeks until round two of care which prompted my orthodontist to send me to get tested for a bleeding disorder. After testing, I received a phone call from my doctor which would change my life forever. I was diagnosed with moderate Hemophilia A. I had always considered myself a strong person, one capable of surviving a zombie apocalypse like the idols I saw in my favorite horror movies. This news however slapped a sticker over that expectation reading "closed until further notice". Well, with my diagnosis in mind and with my mother at my side, I was able to go to the ER to receive factor VIII treatment for the first time. My clots sealed almost instantly, like magic. I was overwhelmed with joy but also anxious for what this new diagnosis meant for my future.

Life carried on fairly normally for a few months up until the two week mark before my high school graduation, (talk about perfect timing). I started to develop a weird sensation in my left knee. It started off as a light ache, but by the end of the day it really did feel like my leg was the main

Que te digan que tienes hemofilia, a cualquier edad, no es una noticia fácil de digerir. En mi caso, fue en el último año de la preparatoria en el 2014 con 17 años de edad y a través de una experiencia poco afortunada. Dos semanas antes de descubrir mi condición, pase por un evento que casi todos los adolescentes pasamos: la extracción de las muelas del juicio. Para mi, sin embargo, esta cirugía no fue nada normal. A diferencia de otros adolescentes, descubrí que mis encías no cicatrizaban correctamente, lo que me hacía sangrar ligeramente durante el día y la noche. Eso era, "escupir, suturar, poner gasa, y volver a repetir". Esto se convirtió en mi rutina durante dos semanas hasta que mi ortodoncista me envió a hacer pruebas para detectar un trastorno hematológico. Después de los exámenes, recibí una llamada telefónica de mi médico que cambiaría mi vida para siempre. Me diagnosticaron con Hemofilia A moderada. Yo siempre me había considerado una persona fuerte, capaz de sobrevivir a un apocalipsis zombi como los ídolos que veía en mis películas de terror favoritas. Sin embargo, esta noticia puso una pausa en mi sobre ese poder, con un letrero que decía, "cerrado, hasta nuevo aviso". Pues bien, con mi diagnóstico en mente y con mi madre a mi lado, pude acudir a Urgencias para recibir por primera vez el tratamiento de factor VIII. Después del tratamiento, mis encías sanaron casi al instante, como por arte de magia. Me sentí abrumado por la alegría, pero también ansioso por lo que este nuevo diagnóstico significaba para mi futuro.

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course for the undead. It was Hemophilia knocking at my door again saying hello this time in the form of an internal joint bleed. This time I began treatment much sooner but not soon enough to avoid long term problems. My knee remained swollen for the remainder of the year and put me on crutches. At the very least it allowed me to make a funny memory at my high school graduation where I almost fell off the stairs in front of the whole school. That could have been bad. Life was never boring after that. Countless trips to the doctors office and further factor VIII infusions throughout the years kept me busy for quite some time.

Early Hemophilia made me feel like a zombie instead of the survivor I had envisioned being. It wasn't until I began college that my Hemophilia turned into a tool rather than an obstruction. I've since then completely changed my perspective and feel stronger than ever. I look back at these memories with a smile because these were the moments where I believed life couldn't go on when in reality they were stepping stones for the satisfying life I would live today. At the age of 25, I can tell you that my Hemophilia has allowed me to reach my true potential as a student and an individual. I have won various scholarships for my tuition and was even accepted to a week-long leadership trip to UC Riverside for talking about overcoming Hemophilia. I've used

La vida siguió su curso con bastante normalidad por algunos meses, hasta exactamente dos semanas antes de mi graduación de la preparatoria o high school (el tiempo perfecto verdad?). En esa ocasión, empecé a sentir una sensación extraña en la rodilla izquierda. Empezó como un ligero dolor, pero al final del día, realmente se sentía como si mi pierna fuera el plato fuerte para los muertos vivientes. Era la Hemofilia tocando a mi puerta de nuevo y saludando esta vez en la forma de una hemorragia interna en la coyuntura de mi rodilla. Esta vez, empecé el tratamiento mucho antes, pero no lo suficiente para evitar los problemas que vendrían después. Mi rodilla permaneció hinchada por el resto del año y me obligo a usar muletas. Para el colmo, me permitió dejar un recuerdo vergonzoso, cuando durante mi graduación casi me caigo de las escaleras enfrente de toda la gente. Eso pudo haber sido bastante vergonzoso. La vida ya nunca fue igual después de eso: un sinnúmero de citas con el doctor y muchas más infusiones del factor VIII a través de los años me mantuvieron ocupado por bastante tiempo.

La hemofilia a mi temprana edad, me hizo sentir como un zombi en lugar del superviviente que siempre había imaginado ser. No fue sino hasta que empecé a estudiar en el colegio comunitario que mi hemofilia se convirtió en una herramienta en lugar de un obstáculo. Desde entonces, he cambiado mi perspectiva completamente y me siento más fuerte que nunca. Ahora miro hacia atrás con una sonrisa porque esos fueron momentos en los que yo creía que la vida no podía seguir, cuando en realidad, eran escalones o peldaños para la vida satisfactoria que viviría hoy. A mis 25 años de edad, puedo decir que mi hemofilia me ha permitido alcanzar mi verdadero potencial como estudiante y como persona. He ganado varias becas para pagar mi matrícula

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PEDRO *Continued from Page 2*

my condition to fuel me into pursuing higher education to reach a career where I may use my experience to help others overcome their own hurdles. Currently, I can look forward to the next chapter in my life where I will soon graduate with la Bachelor's degree in Psychology, begin a new job in the food industry as a food runner, and greatest of all, become involved with the Hemophilia Foundation of Northern California to help kids and their families realize that their condition does not make them any different, it simply gives them a unique road to follow to success.

escolar, e incluso fui aceptado para un viaje de liderazgo de una semana a la Universidad de California en Riverside para hablar de cómo superar la hemofilia. Yo he usado mi condición para impulsarme en estudiar una carrera universitaria y obtener una licenciatura donde pueda usar mi experiencia para ayudar a otros a superar sus propios obstáculos. Actualmente, puedo ver el siguiente capítulo de mi vida ya que pronto me graduare con una licenciatura en Psicología, acabo de empezar un nuevo trabajo en la industria de restaurante como corredor de comida, y lo más grandioso de todo, estaré involucrado con la Fundación de Hemofilia del Norte de California para ayudar a los niños y sus familias a darse cuenta que su condición no los hace nada diferente, solamente les da un camino único a seguir para tener éxito.

Can I attend Camp this year? YES!

when I meet the following:

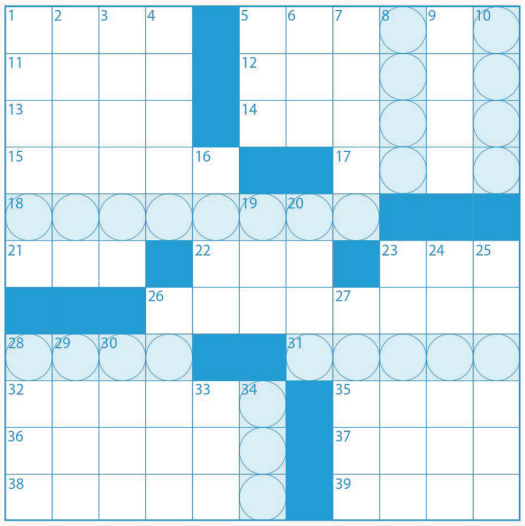
1. Age 7 years or older by 7/31/2022
2. Finishing or have finished kindergarten
3. Immunized + booster to COVID-19
4. Completed all required shots for school e.g. MMR, DPT, Chickenpox, Pneumovax
5. Test negative for COVID day before leaving for camp
6. Wear mask on bus
7. MD has filled in health form
8. Bring factor/other medication to camp
9. Not sick on 7/31. Sick = fever over 100, cough and/or sore throat, runny nose (not attributed to seasonal allergies), diarrhea or vomiting within the last 24 hours, rash etc

If you have any questions, contact HFNC at 510-658-3324 or andrea.orozco@hemofoundation.org

These precautions and requirements are to protect the health of campers, counselors and infirmary staff.

CAN YOU SOLVE FOR A DIFFERENT HEMOPHILIA A TREATMENT?

Test your HEMLIBRA knowledge



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 people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 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

†Number of people with hemophilia A treated as of October 2021.

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. More than_____ thousand patients have been treated with HEMLIBRA worldwide†

SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCs, 26. passport, 28. zero, 31. three, 32. eyelet, 35. Otoe, 36. anose, 37. tall, 38. lessen, 39. oles
Down: 1. catchy, 2. adorer, 3. serums, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

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.**

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

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.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

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

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: 12/2021

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

Genentech
A Member of the Roche Group

EXTRA! EXTRA!

READ ALL ABOUT IT!!

American Medical ID®

Wearing a medical ID is an important action to protect your health and safety in the event you are not able to advocate for yourself. Emergency responders are trained to look for a medical ID because it can help them deliver the immediate treatment required.

Hemophilia Foundation of Northern California and American Medical ID have partnered to ensure that you or your loved ones have access to a medical ID. To qualify you must be a community member in our service area and

- be treated at one of the following Hemophilia Treatment Centers:
  - Stanford Children's Health Pediatric Center
  - Stanford Children's Health Adult Center
  - UCSF Benioff Parnassus Adult Center
  - UCSF Benioff Mission Bay Pediatric Center
  - UCSF Benioff Oakland Children's Center
  - Valley Children's Hospital Pediatric & Adult Centers
  - UC Davis Pediatric & Adult Centers
- If you are not treated at an HTC, you can reach out to Ashley Gregory who will connect you with the appropriate social worker to assist you.

What is a medical ID?

A medical Identification tag (medical ID) is jewelry that could save you or a loved one's life. It allows medical conditions, drug and food allergies, prescribed medicines, and emergency contacts to be engraved onto the surface of a medical ID bracelet or necklace.


The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS
You have the power to help
No amount is too small to give
hemofoundation.org/donate

Can you relate to this experience?

By HFNC Board Member Robert Morris

This and a few other early experiences taught me to be my own advocate and that's what's kept me alive. I'm sure I've pissed off doctors in the process, but it was my life on the line, not theirs. Now, I'm much more confident because I just tell them I've been living and dealing with this for 50+ years, so I've got much more experience than they do.

Going to an ER for a major leg bleed, I told the ER doctor what was wrong and what I needed. He replied, "it's really nice when the patient comes in to provide the diagnosis and recommend the treatment." I thought this was going to go really badly. But he called a hematologist and he agreed, so I was promptly treated. I was admitted and treated. During the night I was complaining of pain, and the doctor wouldn't give me pain medication because she didn't think it was necessary. The following day was the first time she saw me and her comment was this was really severe and I need pain meds. I replied, yes, but you should have seen it last night before the swelling went down.

I had another ER visit and the doctor was going to give me a treatment different from what I knew I needed, having just talked with my hematologist (he had given me his cell phone number). When I corrected her, she pushed back. So I just gave her my phone because I was talking with my hematologist at that moment. That cleared it up.

Just goes to show how much we have to continue the fight for proper care and don't just go along with what doctors tell us, when it is outside of norms. Every new hematologist tells me I don't have hemophilia, then they go through lots of useless tests and then come around to my side. I stick with what the first hematologist that diagnosed me told me. Figure since he found it when no one else could, he really knew his stuff. Although, I did have an initial run-in with him because he was describing everything to my parents and stopped talking when I walked in the room. I quickly corrected that, after all, I was the one that had to live with. After that, all was good.

This might seem strange, but I'm glad I have hemophilia and not something else. My case usually is very interesting to the doctors and nurses so I get lots of attention. While others are being attended, I feel that they take more care and interest in my case. Many times I've had staff come by to meet me because they worked behind the scenes and wanted to see the person behind this odd case. Also, I know how to live with it now and am successfully dealing with its many related complications. Other people are dealing with things much worse than I.

How to access care at an emergency department

by Marion Koerper MD, HFNC Board Medical Advisor

1

Call your HTC or hematologist to inform them that you are having a bleed and are going to the ER. Request that the hematologist alert the emergency room about your diagnosis and need to be seen immediately.

2

If you have clotting factor at home, take it with you to the ER.

3

If you have a letter or emergency card from your HTC or hematologist that gives your diagnosis and your treatment plan (what factor, how many units), take that with you to the ER.

4

Give the receptionist your vital information including insurance. Tell them that you have a bleeding disorder and are bleeding and need to see the nurse immediately.

5

If you have a swollen painful joint with reduced range of motion and no history of recent trauma to that area, you do not need imaging.

6

If no one comes in 5-10 minutes go out and demand to be seen by a nurse or doctor.

7

Present emergency card or letter to physician or nurse. Inform them that you have been trained in how to mix the clotting factor. Insist that they let you mix the clotting factor or that you instruct the nurse in how to mix.

8

Request that the nurse uses an appropriate size butterfly needle, not an angiocatheter or intravenous line, through which to infuse the clotting factor.

9

Once the infusion is completed the needle may be removed and the parent can apply pressure with a 2 x 2 sterile gauze. Depending on whether the patient has sensitivity to paper tape or bandages, Coban may be requested to secure the sterile gauze pressure dressing.

10

Request the lot number sticker(s) from the clotting factor bottles for your home infusion log. There is usually more than one sticker per bottle.

Derek Sim

I am a scientist by training. I started my journey in the study of blood clotting and the coagulation cascade during graduate school. After completing my graduate training, I continued pursuing my interest in this area and did further research in platelet biology and thrombosis. Currently, I am working in a biotech start-up based in Berkeley. For many years, I worked on the research and development of therapeutics for hemophilia and bleeding disorders, including hemophilia A, hemophilia B, as well as inhibitor projects. Besides replacement therapies, non-factor therapies and gene therapies were also development programs that I had worked on. It was through my scientific career that I learned about hemophilia and bleeding disorders, as well as the medical needs and issues that persons and families with bleeding disorders must face every day. Importantly, I also had the opportunity to speak to some of the patients over the years. One conversation that had made a particularly lasting impression on me was on Camp Hemotion. One summer quite a few years ago, we had a person with hemophilia working as an intern in our department. He shared with me how wonderful and important Camp Hemotion had been to him and the community. He told me that the camp was the place where he had learned self-infusion when he was a kid. When he got older, like many other kids, he was back at the camp to help the younger kids learn how to perform self-infusion. This story was just so beautiful to me. It is a wonderful illustration of how the community comes together to help each other and the huge impact of the events being held by HFNC. While it was through my scientific interest I learned about hemophilia, it was through my conversations with persons with hemophilia I learned about all the great work that HFNC is doing for the community. To be able to help and support these activities and events which are so impactful to the community is my main motivation for joining the foundation. I am honored to be a board member of the foundation and I look forward to serving the community.

Which type of support animal is right for you?

As we make our way through the world questions can arise about traveling with your service animal. Here is a helpful excerpt from https://www.ada.gov/regs2010/service_animal_qa.html

Q: Can I charge a maintenance or cleaning fee for customers who bring service animals into my business?

A: No. Neither a deposit nor a surcharge may be imposed on an individual with a disability as a condition to allowing a service animal to accompany the individual with a disability, even if deposits are routinely required for pets. However, a public accommodation may charge its customers with disabilities if a service animal causes damage so long as it is the regular practice of the entity to charge non-disabled customers for the same types of damages. For example, a hotel can charge a guest with a disability for the cost of repairing or cleaning furniture damaged by a service animal if it is the hotel's policy to charge when non-disabled guests cause such damage." According to https://service-dog.org/faq/ (accessed March 30, 2022) these are the differences between Service, Emotional Support and Therapy Animals.

	Service Animal	Emotional Support Animal	Therapy Animal
Definition	trained to do work or perform tasks for people with disabilities	provide emotional well-being of for people with disabilities	trained to provide comfort to individuals in specific environments
Applicable Federal Laws	ADA (Americans with Disabilities Act)	ACAA (Air Carrier Access Act) FHA (Fair Housing Act)	Only State & Local Laws Apply
Type of Animal	Dog or Miniature Horse	Any Animal (with some exclusions)	Any Animal
Should Be Certified or Registered	✓	✓	✓
Must Have Documentation Identifying the Disability	✓	✓	✗
Travel in the Cabin of an Airplane	✓	✓	✗
Live in No-Pet Housing	✓	✓	✗
Able to Have in Public Places	✓	✓	✗
Animal Must Be Leashed or Tethered at All Times	✓	✓	✗
Must Wear a Leash or Vest Identifying the Animal	✓	– Not Always Required	✗

Comcast Free Internet - Do you qualify?

Get help with your Internet bill

As part of our ongoing commitment to keep you connected, Comcast is proud to participate in the Affordable Connectivity Program (ACP).

ACP offers long-term financial assistance to qualified households of up to $30/month toward Internet service.

How to apply in 3 steps:

STEP 1

Check eligibility for ACP. Complete the National Verifier form.

Check Eligibility

STEP 2

Apply for Internet Essentials online or call 855-8-INTERNET

Apply Now

STEP 3

Complete the Xfinity ACP enrollment form to receive your credit. For this step, you'll need the application ID you received from the National Verifier when you were approved. Start ACP enrollment.

Start ACP Enrollment

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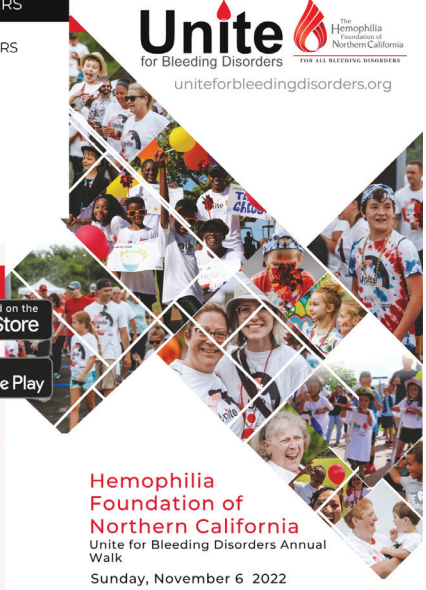
Takeda

HEMOPHILIA ALLIANCE

Unite
for Bleeding Disorders

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

uniteforbleedingdisorders.org



DOWNLOAD
OUR MOBILE APP

Simply search by
Unite
for Bleeding Disorders

Download on the App Store

GET IT ON Google Play

(you must first register for a walk at www.uniteforbleedingdisorders.org and then you can activate your mobile app)

Hemophilia Foundation of Northern California

Unite for Bleeding Disorders Annual Walk

Sunday, November 6 2022
Start: 9am-12
Check-in: 8am-9
Lake Merritt Amphitheater
Oakland CA 94607
contact
ashley.gregory@hemofoundation.org or
call 510-658-3324

ABOUT NHF

Along with our 53 chapters nationwide, the National Hemophilia Foundation (NHF) is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research.

HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA

The Hemophilia Foundation of Northern California (HFNC) serves 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.

UNITE FOR HOPE.
UNITE FOR COMMUNITY.
UNITE TO MAKE A DIFFERENCE.

The Unite for Bleeding Disorders walk brings our community together. It UNITES families with bleeding disorders and chapters with family, friends, neighbors and coworkers to support important programs and services to help people with hemophilia, von Willebrand disease, and other rare bleeding disorders in our community.

WE ARE WITH YOU EVERY STEP OF THE WAY!

- One on one fundraising coaching with chapter staff.
- Personal walk website to tell your story and ask for donations.
- Sample letters/emails to recruit your family and friends.

PLEASE CONTACT US FOR MORE INFORMATION OR SUPPORT

Contact Ashley Gregory at 510-658-3324 Email her at ashley.gregory@hemofoundation.org

REGISTER TODAY AT WWW.UNITEFORBLEEDINGDISORDERS.ORG

Spark THERAPEUTICS

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At Spark® Therapeutics, we are committed to discovering, developing and delivering gene therapies.

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- **Want to know more about gene therapy clinical trials?**

Discover more about gene therapy research

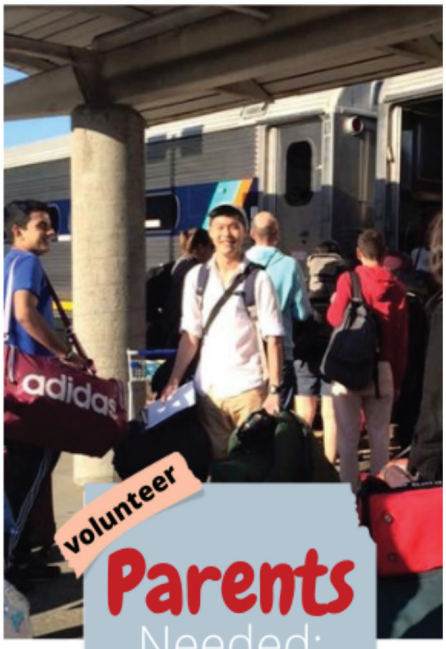
Volunteer Opportunity!

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

CAMP HEMOTION 2022

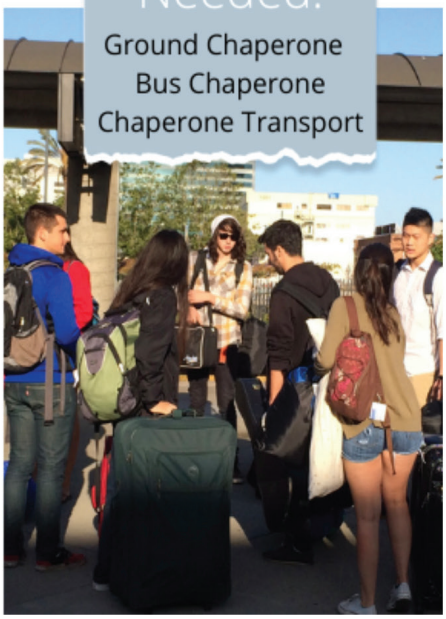
contact ashley.gregory@hemofoundation.org



volunteer

Parents Needed:

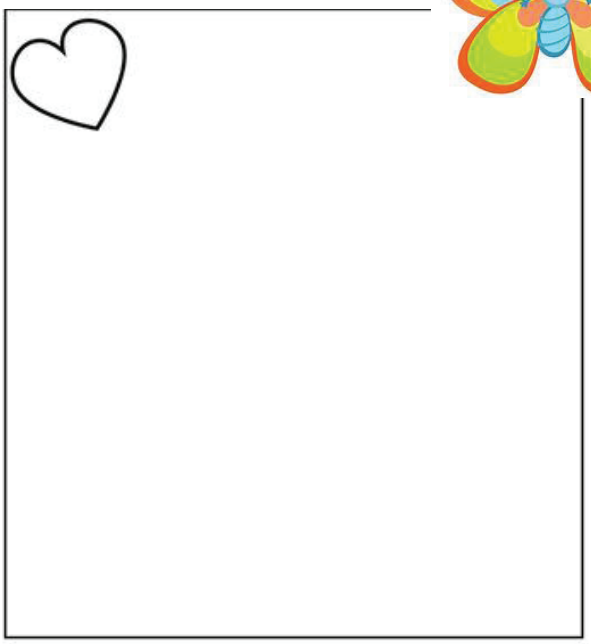
Ground Chaperone
Bus Chaperone
Chaperone Transport



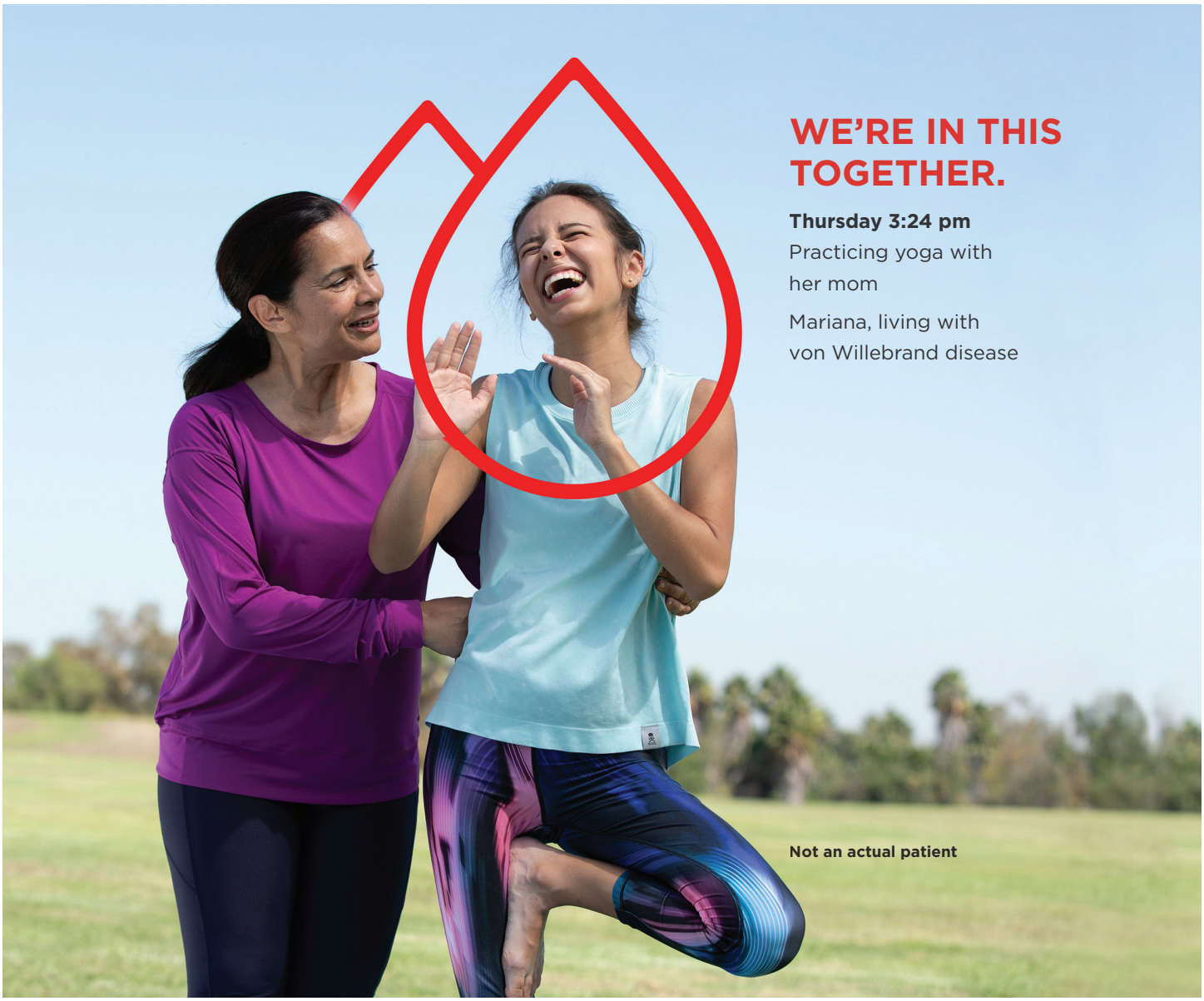
Kid's Page

SPRING SCAVENGER HUNT

	Items To Find	What I Found
1.	A yellow flower	
2.	Easter decorations	
3.	A watering can	
4.	A baby animal	
5.	Sidewalk chalk	
6.	A tricycle	
7.	Green lawn furniture	
8.	A sprinkler	
9.	A playground with a swing	
10.	A skipping rope	
11.	A basketball	
12.	A person jogging	
13.	A duck	
14.	A water hose	
15.	Someone planting flowers	
16.	A "Garage Sale" sign	
17.	A lawnmower	
18.	An umbrella	
19.	Someone doing spring cleaning	
20.	Rubber Boots	



My Family

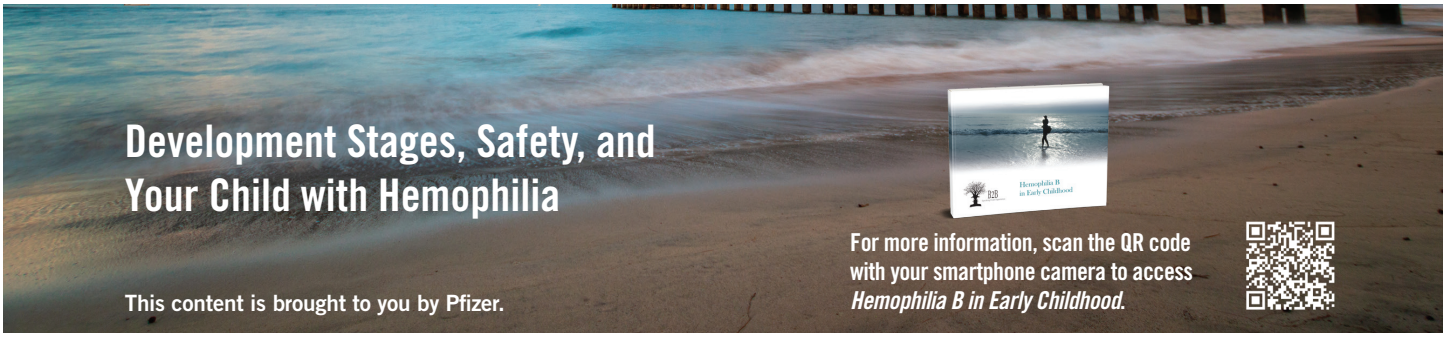


Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to adult patients with von Willebrand disease is stronger than ever.

Not all activities are appropriate for all individuals.
Consult your doctor prior to engaging in any activity.

bleedingdisorders.com | Takeda



Parents and caregivers are a child's primary nurturers, teachers, and protectors. Parents and caregivers of a child with hemophilia may find it easier to care for their child if they understand the stages of physical, emotional, and mental growth all children go through and how these stages can impact hemophilia care.

At every developmental stage, there are special considerations for children who live with hemophilia. When a child is about 6 months old, they can start to become more mobile, which may increase the chances for bruising or bleeding. While it's important to allow a child to explore and expand their newly acquired mobility, it's also important that their environment is safe. These are challenging times for caregivers, as there may be a tendency to be overprotective.

Knowing ahead of time how to prepare for a growing child with hemophilia may help in gauging the types of safety measures needed during these life stages. The following are some special considerations and safety suggestions to consider for a child living with hemophilia, but at all ages, be sure to consult with a child's treatment team when making health and safety decisions or in the treatment of injuries.

Infants 6 to 12 Months[1]

- Bleeding episodes that need factor concentrate seldom occur during the first year
- Crawling and walking are important for muscle development despite the possibility for a bleeding episode
- Frequent playpen use is discouraged
- Infants with hemophilia may experience more bruising than infants who do not live with a bleeding disorder
- Head injuries should be reported to a health care provider immediately

The Toddler Years

- Lower the crib mattress to its lowest level to discourage climbing out, or consider putting the mattress on the floor[2]
- Discourage unsupervised climbing and jumping from high places or off furniture[1]
- Always use an approved car seat according to your state's laws[1]
- Avoid excessive roughhousing[2]
- Use a helmet when skating, biking, or riding a scooter[2]

The Preschool Years

- Use ice to help reduce bruising and ease discomfort[2]
- Encourage a well-balanced diet to assist with staying fit and trim in order to avoid joint stress from excess weight[2]
- Promote regular flossing and brushing teeth with a soft brush[2]
- Talk to the dentist about your child's hemophilia diagnosis[2]
- NHF recommends the hepatitis B vaccine (recommended for all children) and the hepatitis A vaccine (above 2 years old)[3]

Parenting infants, toddlers, and preschoolers can be a challenge for any family. Families may benefit from the extensive resources offered in the hemophilia community, including printed materials, family get-togethers, educational conferences, emotional support, and comprehensive hemophilia care at a local hemophilia treatment center.

References: 1. Hemophilia of Georgia. Safety Issues. http://www.hog.org/handbook/section/5/safety-issues. Accessed July 8, 2020. **2.** National Hemophilia Foundation. Caring for your child with hemophilia. https://www.hemophilia.org/sites/default/files/document/files/Caring%20for%20Your%20Child.pdf. Accessed May 10, 2020. **3.** National Hemophilia Foundation. MASAC recommendations for hepatitis A and B immunization of individuals with bleeding disorders. https://www.hemophilia.org/Researchers-Healthcare-Providers/Medical-and-Scientific-Advisory-Council-MASAC/MASAC-Recommendations/MASAC-Recommendations-for-Hepatitis-A-and-B-Immunization-of-Individuals-with-Bleeding-Disorders. Accessed May 10, 2020.

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

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CALENDAR

JUN		
6/14/2022	Board Meeting	Virtual
6/17/22-6/19/22	Disabled Adventure Outfitters Family Camp	Trinity River, Junction City CA
6/20/22-6/23/22	Disabled Adventure Outfitters Teen Camp	Trinity River, Junction City CA
JULY		
7/4/22	Independence Day	Holiday HFNC closed
7/12/22	Board Meeting	Virtual
7/30/22	Camp Hemotion staff arrive	Camp Oakhurst, Coarsegold CA
7/31/22-8/6/22	Camp Hemotion	Camp Oakhurst, Coarsegold CA
AUGUST		
8/9/22	Board Meeting	Virtual
8/15/22-8/19/22	Strategic Planning/ HFNC closed	In person*
8/20/22	Asian Infusion	San Mateo Central Recreation Center
8/25/22-8/27/22	Bleeding Disorders Conference National Hemophilia Foundation	Houston, TX
SEPTEMBER		
9/5/22	Labor Day	Holiday HFNC closed
9/13/22	Board Meeting	Virtual
9/23/22-9/25/22	Familia de Sangre	Anaheim, CA
OCTOBER		
10/11/22	Board Meeting	Virtual
10/15/22	Family Camp (in-person)	Camp Arroyo TTFF
10/24/22	Golf	Ruby Hill G.C. Pleasanton
NOVEMBER		
11/6/22	Walk	Lake Merritt Amphitheatre, Oakland
11/8/22	Board Meeting	Virtual
11/14/22-11/17/22	NHF Chapter Leadership	Scottsdale, AZ
11/24/22-11/25/22	Thanksgiving Holiday	Holiday HFNC closed
11/29/22	Giving Tuesday	Campaign
DECEMBER		
12/1/22	World AIDS Day	AIDS Memorial Golden Gate Park San Francisco, CA
TBD	Winter Gatherings	Fresno, South Bay, East Bay
12/26/22	Christmas Day (Observed)	Holiday HFNC closed
12/26/22-12/30/22	HFNC Office Closed	Holiday HFNC closed
JANUARY		
1/2/23	New Year's (Observed)	Holiday HFNC closed

HFNC Hemophilia Foundation of Northern California
https://www.hemofoundation.org/

AFFILIATED ORGANIZATIONS

NHF National Hemophilia Foundation
https://www.hemophilia.org/
NHF Chapters (See full list at NHF):

HFSC Hemophilia Foundation of Southern California
http://www.hemosocal.org/

HASDC Hemophilia Association of San Diego County
http://hasdc.org/

CCHF Central California Hemophilia Foundation
https://www.cchfsac.org/

AHA Arizona Hemophilia Association
https://www.arizonahemophilia.org/

HFO Hemophilia Foundation of Oregon
http://hemophiliaoregon.org/

HFA Hemophilia Federation of America
http://www.hemophiliafed.org/

HCC Hemophilia Council of California
https://www.hemophiliaca.org/

WFH World Federation of Hemophilia
https://www.wfh.org/

HEMOPHILIA TREATMENT CENTERS HTC's

Hemophilia Treatment Centers:
Stanford University Medical Center
https://www.stanfordchildrens.org/en/service/hematology
University of California at Davis
https://www.ucdmc.ucdavis.edu/hemophilia/
University of California San Francisco
https://www.ucsfhealth.org/clinics/hemophiliatreatment_center/
UCSF Benioff Children's Hospital Oakland
https://www.childrenshospitaloakland.org
Valley Children's Hospital
https://www.valleychildrens.org/

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

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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.

Information and opinions expressed in this publication are not necessarily, those of the Hemophilia Foundation of Northern California, or those of the editorial staff.

Hemophilia Foundation of Northern California is a 501(c)(3) non-profit. Donations are tax-deductible, much needed and appreciated.

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If you would like to advertise in the next issue, please contact the foundation.

Infusions

is published quarterly by **Hemophilia Foundation of Northern California**

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Shelley Jajeh

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