

innovation  
belongs in every moment

## Upcoming Events

**Familia de Sangre 2019**  
**Date: September 6, 2019**  
**Location: Anaheim Marriott**  
**Register: [www.familiadesangre.org](http://www.familiadesangre.org)**

**NHF Unite for Bleeding Disorders Walk**  
**Date: October 20, 2019**  
**Location: Liberty Stations Park**  
**Register: <http://hasdc.org/events/unite-san-diego-walk/>**

**Rady Children's/UC San Diego HTTC  
 Family Day**  
**Date: October 26, 2019**  
**Location: Rady Children's Hospital**  
**Register: registration will open in the Fall**

## Hemophilia Team



Top row, left to right: Fernanda Cortez, Dr. Courtney Thornburg, Dr. Hilda Ding, Darcie Paul, Elizabeth Hall, Kappi Farrow

Bottom row, left to right: Lizandra Gilsdorf, Danielle Leonard, Rosalie Brooks, Diana Palacios, Diane Masser-Frye



Rady Children's Hemophilia and Thrombosis Treatment Center (HTC) cares for babies, children and teens with bleeding and clotting disorders from ages 0 to 21. We have approximately six clinics a year in Escondido. Please let us know if you prefer to have an appointment at this location.

Call 858-966-7918 or 858-966-8163 (Spanish) to schedule your appointment today.

## New Team Members



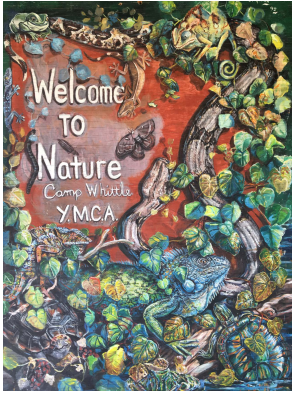
Fernanda Cortez



Lizandra Gilsdorf

Fernanda Cortez and Liz Gilsdorf are Medical Assistants and Phlebotomists for the HTC. They will call to schedule your clinic visits and may assist the nurses in returning phone calls. You will meet them in clinic as they assist in clinic and draw blood samples.

Events



**Camp Pascucci**

Camp Pascucci was held in August in Big Bear for children, ages 7 to 14, affected by bleeding disorders and their siblings. Older teens developed leadership skills as counselors in training and young adults broadened their skills as counselors. Dr. Thornburg was the camp doctor. She worked with Karen McGhee, camp nurse, to make sure that the campers got their medication.

Dr. Thornburg taught the kids about DNA (genetic instructions) as they learned to extra DNA out of strawberries and bananas.

Several campers learned self-infusion and earned their Brave Sticks for their first independent infusion, a great step towards independence.

The 2019 camp will be the week of June 22 at YMCA Camp Oakes in Big Bear. Registration is now open! <http://hasdc.org/events/camp-pascucci/>

**Indoor Rock Climbing with the Hemophilia Association of San Diego County**



The Hemophilia Association of San Diego County (HASDC) hosted an indoor rock climbing event at Mesa Rim for the community. Rock Climbing has many benefits for physical, mental and social development.

**Indoor Rock Climbing with UC San Diego**

The HTC team is collaborating with Mesa Rim and the UC San Diego HTTC to offer an ongoing rock climbing program starting in 2019. Interested patients can register with the UC San Diego Hemophilia Vertical! Call Andres Flores at 858-249-0910 or register at: <https://health.ucsd.edu/specialties/hematology/hemophilia/Pages/wellness.aspx>

**Family Day**



Rady Children's HTC partnered with the UC San Diego HTC and LA Ortho to host Family Day at the UC San Diego campus. Educational topics covered treatment center updates and new treatment options. There was a panel discussion about bleeding disorders and sports participation. Children and teens participated in breakout sessions to promote wellness. The sessions included yoga for children and with the Rady Children's HTC psychologist, Dr. Anke Reineke.

**Health Resources**



One way to stay connected to your and your child's health is to sign up for MyChart. MyChart gives you access to your or your child's medical record

and the ability to email our office. Ask us about MyChart when you check in at your next appointment. Adolescents ages 13 and older can create their own account to access their medical information. For more information, visit <https://www.mychartatradychildrens.org/MyChart/login.asp>





The Rady Children's Home Care Specialty Pharmacy Program (<http://www.rchsd.org/programs-services/home-care>), which provides hemophilia treatment products at reduced cost through a Public Service 340B Drug Program, helps support patient-centered services. Learn more in this video. <https://www.youtube.com/watch?v=WbpSggJzeik>

## New Treatment Option For Hemophilia A: Hemlibra



Hemlibra® is a groundbreaking new treatment to prevent bleeding in people with hemophilia A with and without inhibitors. Hemlibra was approved by the US FDA in 2017 for people with hemophilia A with inhibitors and in October 2018 for people without inhibitors. Hemlibra is not clotting factor. Hemlibra is a type of medication called a therapeutic antibody. Hemlibra is able to promote blood clotting without the need for factor replacement.

## New Treatment Option For Hemophilia A: Hemlibra

The HAVEN clinical trials included 373 people, including 60 children and 47 adolescents. Data from these trials led to the approval of Hemlibra. Results showed that a majority of people with or without inhibitors had no treated bleeding while taking Hemlibra and people had less bleeding compared to no prophylaxis and compared to prophylaxis with factor 8 and bypassing therapy. Hemlibra is given as an injection under the skin (subcutaneous). The medication comes ready to use and does not require mixing with saline. It takes less than 1 minute to give.



Hemlibra is first given once weekly for four weeks to increase the drug level in the body to the level that we know prevents bleeding. In order to keep the level up, doses are continued either once weekly, once every two weeks, or once every four weeks. Since the drug levels stay steady in the blood, extra doses of Hemlibra or clotting factor are not needed before activities. If breakthrough bleeding occurs, then bleeding is treated with factor 8 for people without inhibitors and with bypassing therapy for people with inhibitors. For people with inhibitors, the preferred treatment for bleeding is NovoSeven, because treatment with FEIBA may increase the risk of blood clots from too much bleeding.

If you would like to learn more about the medication, please contact the Rady Children's HTC.

## Ultrasound



Ultrasound can be used to look inside of joints for signs of bleeding. Many HTC's are now using ultrasound in the clinic to look at joints to make decisions about treatment. Drs. Thornburg and Ding, Kate Keese and Elizabeth Hall completed training to do musculoskeletal ultrasound in clinic.



## NHF Unite for Bleeding Disorders Walk

The annual NHF walk got a new name this year: Unite for Bleeding Disorders. Dr. Ding, Elizabeth Hall, and Artemiza Pamaran walked along with families and friends to raise awareness and funding for bleeding disorders. Save the date for the 2019 UNITE WALK in San Diego, October 20, 2019 at Liberty Station Park.

[www.uniteforbleedingdisorders.org](http://www.uniteforbleedingdisorders.org)

## Recipe: Mean Green Chocolate Milk Shake



### Ingredients

- 1 cup spinach
- 2 frozen ripe bananas
- 1 cup unsweetened almond milk, or milk alternative of choice
- ¼ cup low fat vanilla yogurt
- 3 Tbsp cocoa powder
- 2 Tbsp honey (optional)
- 1 cup ice (optional, for a more slushy smoothie)

### Directions

1. In order: add spinach, ice (opt.), banana, yogurt, honey, cocoa powder, and milk to blender.
2. Blend, pulsing until mixture is smooth.

### Serves 4

Smoothies are a quick and easy way to fill you up on the go, while providing nutrition from fruits and vegetables. They can be an excellent meal because they are easy and allow you to customize the recipe to your taste.

Experiment by freezing different types of overripe fruit to add to your smoothies. Different vegetables can be easily hidden in your smoothies. The flavor from the fruits you use can disguise the taste of the veggies you add and you will still get all of the benefits from the veggies!

Experiment with adding spinach, kale, avocado or zucchini for a nutritious and filling meal.



## Exercise Tip



The President's Council on Fitness, Sports, and Nutrition has General Fit Facts and Tips for Specific Populations, including information for people with chronic medical conditions. According to the Physical Activity Guidelines for Americans, "Most health benefits occur with at least 150 minutes (2 hours and 30 minutes) a week of moderate-intensity physical activity, such as brisk walking. Additional benefits occur with more physical activity."

Here are some more tips:

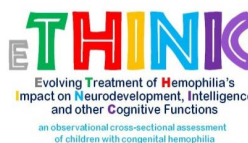
- It's a good idea to write down your plan. Tell how to do each exercise and the number of times to do it.
- Start with a few exercises that use different movements. At first, only do a few of each exercise and don't work out too long. Your muscles will be sore in the beginning. As your program becomes easier, slowly add more of each exercise. Your program should include exercises that make you stronger (strengthening), more flexible (stretches), and able to do things longer (endurance).
- You will get the best results if you exercise at least three times a week.
- When you stop your exercise program for any reason, you may find it painful or even have a bleed if you start back at the same level. It's better to start back at a lower level and then work up to where you were before.
- Unless you are told not to by your doctor or physical therapist, you need to move your joints every day. This is especially important for joints that have been damaged. Bend, flex, and stretch each joint through all its movements.

Exercising when you've had a bleed

It is not a good idea to exercise a muscle or joint if it is bleeding. You should exercise the other parts of your body

while the joint or muscle is healing. Exercise of the part that bled should begin as soon as you can do it without pain. The longer you wait to begin, the more likely it is that the joint will be stiff or that the muscle will have shrunk. After a serious bleed, ask your doctor how long you should wait before starting your exercises again.

## Research Corner



There are some new research opportunities for children with hemophilia.

### eTHINK study

Evolving treatment of hemophilia's impact on neurodevelopment, intelligence and other cognitive functions

The purpose of this study is to find out how boys with hemophilia develop into young men and specifically how their brain develops over childhood.

### ATLAS studies

Phase III study of fitusiran in patients with hemophilia A or B, with or without inhibitory antibodies to Factor VIII or IX

The purpose of this study is to see if the study drug, fitusiran, can prevent or reduce the number of bleeds subjects experience over time. Fitusiran is a monthly subcutaneous injection that reduces antithrombin in the body.

### ATHN 8 study

(PUPs Matter) US Cohort Study of PUPs with Congenital Hemophilia

The purpose of this study is to determine the incidence and risk factors associated with inhibitor development in previously untreated patients (PUPs) with hemophilia.

## Thank you



Thank you to all of the patients and families who support our HTC and attend community events.

Thank you to Rady Children's Homecare Specialty Pharmacy Program, which coordinates our 340B Factor Program and provides funding for our services.

Thank you to Henry's Fund, which provides financial support for our center.

### **Support the Rady Children' HTC Community**

We receive funding through Henry's Fund at Rady Children's. The program supports medical care, genetic testing, education and games for kids in the clinic and Hospital. If you are interested in donating to the fund, please contact the Rady Children's Foundation at 858-966-7878 or visit the Grateful Families website: <https://www.radyfoundation.org/give/ways-to-give/grateful-families/grateful-families>

### **We Want Your Input**

Please let us know if you have ideas for the HTC and/or if you would like to be part of a parent/patient advisory committee. The committee could meet in person or via web conference.