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# HEMOPHILIA & THROMBOSIS TREATMENT CENTER

Spring 2018 Newsletter



Rady Children's Hospital - San Diego





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Hospital  
San Diego



## HEMOPHILIA & THROMBOSIS TREATMENT CENTER

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Rady Children's Hemophilia and Thrombosis Treatment Center cares for babies, children and teens with bleeding and clotting disorders from ages 0-21 years old.

Patients should be seen at least once per year in our Comprehensive Clinic. Call 858-966-8163 to schedule your appointment.

Our Team and the services that we provide are supported through the Rady Children's Home Care Specialty Pharmacy Program. <http://www.rchsd.org/programs-services/homecare/>

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# NEW TEAM MEMBERS



## Dr. Fady Nossair

Physician

Dr. Fady Nossair is a pediatric hematologist/oncologist who is completing a one-year fellowship in bleeding and clotting disorders. His fellowship is supported by Henry's Fund at Rady Children's, started by one of our patients with hemophilia, and the Hemostasis and Thrombosis Research Society. He lives with his family in Orange, California and speaks English, French and Arabic.



## Aura Gomez

Medical Assistant and Phlebotomist.

Aura Gomez is a medical assistant and phlebotomist. She speaks English and Spanish.



## Maira Suarez

Research Associate

Maira Suarez is a research associate and speaks English and Spanish. She has a dachshund named Slink, and her favorite color is pink.



Patients should be seen at least once a year at our HTC. Call 858-966-8163 to schedule your appointment. Most of our clinics are held on Monday afternoons. We have approximately six clinics a year in Escondido. Please let us know if you prefer to have an appointment at this location.

# HEALTH RESOURCES



## MyChart at Rady Children's

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 13 years 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/homecare>), which provides hemophilia factor products at reduced cost through a Public Service 340B Drug Program, helps support our services. Learn more in this video: <https://www.youtube.com/watch?v=WbpSggJzeik>

# EVENTS

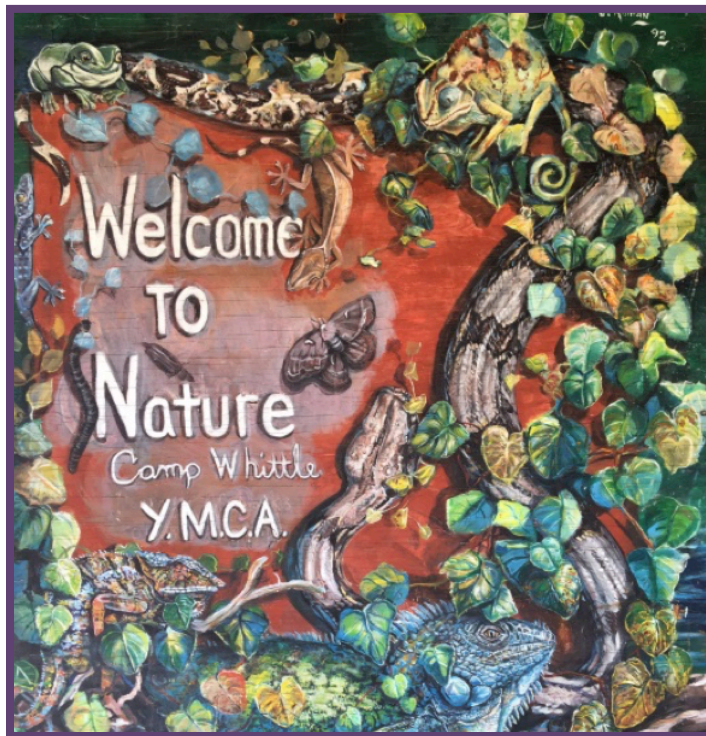
Camp Pascucci is held each year for children with bleeding and clotting disorders, ages 7-14 and their siblings. Dr. Courtney Thornburg and Dr. Fady Nossair provided medical support for the camp last August, and Rady Children's HomeCare provided nursing support.

Why go to hemophilia camp? Watch this video.  
<https://www.youtube.com/watch?v=kH9cxeur-gl>

The 2018 Camp Pascucci will be held August 11-17, 2018.

Teen Camp for ages 14-17 years will be held July 8-12, 2018.

<http://hasdc.org/en/events/teen-camp/>



## Rady Children's Family Day

Our Rock & Roll Family Day, held Oct. 7, was a fun-filled event with music, food, fellowship and education about physical activity and clotting factor.

# National Hemophilia Foundation Walk in San Diego

Dr. Courtney Thornburg and Artemiza Pamaran represented our HTC at the National Hemophilia Foundation annual walk, which had a great turnout. Congratulations to the winning teams: Anaya's Trot for the Clot, Super Brothers, and Walk for a Walker. Funds raised support community events and education for individuals with bleeding disorders. To learn more about events in our community, contact the Hemophilia Association of San Diego County at 619-325-3570 or visit [hasdc.org](http://hasdc.org).

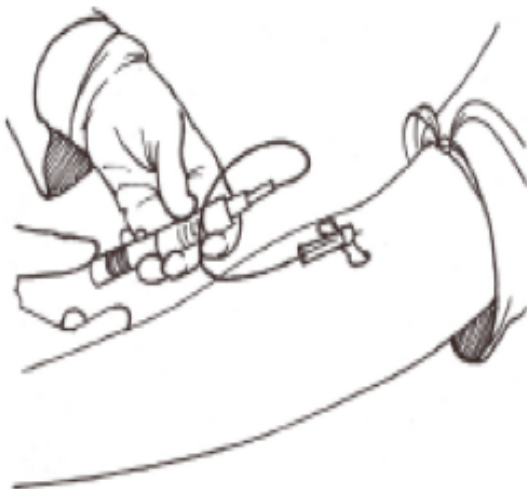
## NEW FOR 2018! Self-Infusion Training

Many children with hemophilia and von Willebrand disease receive clotting factor to treat and prevent bleeding. The factor is infused into the veins. Factor infusion is a skill that takes time, patience and practice to learn. It can be challenging, but parents and patients can learn infusion with the right education and support.

Being able to infuse clotting factor gives children more independence and freedom. It's empowering – and a big step!

Here are a few of the benefits:

- It treats bleeds more quickly and prevents bleeds.
- Your child can avoid trips to the emergency room, hospital and clinic.
- Your child can infuse factor when away from home.



Usually, parents and other caregivers learn how to infuse factor for their children. By age 7, many children are ready to learn how to do it themselves. (They may start learning self-infusion at hemophilia camp.) Teenagers may want to learn so they can infuse factor when away from home (at camp or on vacation) and when they go to college.

When You Are Ready for Self-Infusion

- IF YOU:
  1. Complete house chores and do homework without a reminder.
  2. Know the name of your bleeding disorder and how you treat it.
  3. Can stay calm when someone is accessing your vein to infuse factor.
- YOU may be ready for PERIPHERAL FACTOR INFUSION
- WHY? Because it puts you IN CONTROL.
- HOW can YOU get started:
  - WATCH someone get INFUSED CAMP is a great place to LEARN
  - WRITE all the STEPS down → ASK a lot of QUESTIONS
  - PRACTICE makes perfect → DON'T GIVE UP
- WHAT do YOU need?
  - Factor with its diluent → MIX FACTOR AHEAD OF INFUSION
  - Syringe & Butterfly needle → NEVER REUSE OR SHARE NEEDLES
  - Alcohol wipes, gauze & Band-Aid
  - Tourniquet
  - Sharps container → PUT USED NEEDLES IN THIS CONTAINER

Additional Resources:

- Steps for Living – [Hemophilia.org](http://Hemophilia.org)  
<https://stepsforliving.hemophilia.org/next-step-kids/treatment-kids/self-infusion-kids>

# RESEARCH CORNER



Our HTC is active in clinical research, participating in national studies of hemophilia and other bleeding and clotting disorders. We are collaborating with the American Thrombosis and Hemostasis Network and the Centers for Disease Control and Prevention to learn more about hemophilia and other bleeding disorders. We are participating in clinical trials to evaluate new ways to treat children with blood clots.

For information about current research studies, please call Rady Children's at 858-966-5877 or visit the following websites:

- [Athn.org](http://Athn.org)
- [Clinicaltrials.gov](http://Clinicaltrials.gov)

# 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 Our HTC

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 858-966-5950.

## 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.

