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# HEMOPHILIA & THROMBOSIS TREATMENT CENTER

Spring 2017 Newsletter



Rady Children's Hospital - San Diego





# Rady Children's

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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(THROMBOSIS)  
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# MEET THE TEAM



Courtney Thornburg  
Physician



Hilda Ding MD  
Physician



Kate Keese  
Nurse Practitioner



Kappi Farrow  
Nurse Case Managers



Rosalie Brooks  
Nurse Case Managers



Diana Palacios  
Social Worker



Elizabeth Hall  
Physical Therapy



Diane Masser-Frye  
Genetic Counselor



Alissa Johnson  
Dietician



Danielle Cruse  
Child Life



Jacquie Limjoco  
Research



Artemiza Pamaran  
Home Care Liaison





## WELCOME DR. HILDA DING

**P**lease join me in welcoming, Dr. Hilda Ding. She is a pediatric hematologist with special training in bleeding and clotting disorders. She recently moved from Cleveland, Ohio.

## In The Community

### NATIONAL HEMOPHILIA FOUNDATION WALK IN SAN DIEGO



**Team "Danny Boy's Biggest Fans"**

Dr. Courtney Thornburg and Ms. Artemeza Pamaran represented the Rady Children's HTC at the annual walk. There was a great turnout. Congratulations to Team "Danny Boy's Biggest Fans" for having the top individual fundraiser and to Team "Living Our Dreams" for being the top fundraising team. Funds support community events and education for individuals with bleeding disorders. The 2017 Walk is scheduled for October 14, 2017. To learn more about events in our community contact the Hemophilia Association of San Diego County at 619-325-3570; or go to website [hasdc.org](http://hasdc.org)

### RADY CHILDREN'S FAMILY DAY RECAP



The 8th Annual Family Day was held on October 22nd. We celebrated all of our Superheros including four young adults with bleeding disorders shared their stories and inspiration. Physical Therapist, Elizabeth Hall, taught how to apply Kinesiotape. Ask for a demonstration at your next clinic visit. See the enclosed brochure. The next Family Day is scheduled for October 7, 2017.

## TRANSITION MEDICINE



*Dr. Courtney Thornburg*

Our patients graduate from our HTC at age 21 years. There are many steps in the process towards graduation and in transition to adult care.

Rady Children's Hospital San Diego Hemophilia and Thrombosis Treatment Center is committed to helping our patients make a smooth transition from pediatric to adult health care. This process of transition involves working with youth, beginning at 12 to 14 years, and their families to prepare for the change from "pediatric" model of care where parents make most decisions to "adult" model of care where youth take full responsibility for decision making. This means we will spend time during the visit with the teen without the parent present to assist them in setting health priorities and support them in becoming more independent in their own health care.

At age 18, youth legally become adults. We respect that many of our young adults choose to continue to involve their families in health care decisions. Only with the young adult's consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decisions. We will assist with this transfer process by helping identify an adult provider, providing the young adult and health summary, sending medical records, and communicating with adult providers about the unique needs of our patients.

Please ask us if you have any questions about graduation from the program. Please let us know if you have any suggestions for our transition policy.

For more resources see the NHF Steps for Living Program: <https://stepsforliving.hemophilia.org/>

We are working to prepare young adults for graduation and to ensure ongoing hemophilia care. Dr. Courtney Thornburg, Mrs. Kappi Farrow and Mrs. Rosalie Brooks recently completed a year long training program in Quality Improvement focused on transition. We graduated from the program at the annual American Thrombosis and Hemostasis Network meeting in October 2016. One way to increase participation in your health care is to get access to MyChart. MyChart gives you access to your child's or your health care record and a way to communicate with the medical team. Ask about MyChart when you check at the next appointment. More info: <https://www.mychartatradychildrens.org/MyChart/login.asp>. Adolescents 13 years and older can create their own account to have the most access to their medical information.

### Women and Girls with Blood Disorders

Many girls and women have bleeding disorders with symptoms including easy bruising, nosebleeds, heavy periods and bleeding with surgery. We evaluate girls and young women with suspected bleeding disorders in the clinic and provide ongoing care.



The Foundation for Women and Girls with Blood Disorders has a website with valuable information for healthcare professionals and patients: [www.fwgbd.org/patient](http://www.fwgbd.org/patient)





Mrs. Rosalie Brooks is our thrombosis nurse specialists. She helps Dr. Thornburg and Dr. Ding manage children taking blood thinners. She is on a hospital committee to improve the safety of blood thinners. Dr. Thornburg and Dr. Ding lead a hospital committee to decrease blood clots in the hospital.

Check out this video to learn more about blood clots: [www.worldthrombosisday.org/keep-life-flowing/](http://www.worldthrombosisday.org/keep-life-flowing/) Every year, 1 in 4 people die of conditions related to thrombosis – many never knowing their risk for the condition.

The two broad classifications of thrombosis are venous (VTE) and arterial (AT), depending on whether the clot develops in the vein or an artery. VTE is a condition in which blood clots form (most often) in the deep vein of the leg (known as deep vein thrombosis, DVT) and can travel in the circulation and lodge in the lungs (known as pulmonary embolism, PE).

Although about half of us haven't heard of VTE, it's a very common condition. But this is a story of hope, not despair. In many, if not most cases, it's preventable.

Proven, accessible options exist to prevent the development of blood clots. However, many people don't realize they are at-risk for VTE and never talk with their doctor about preventive measures. A simple VTE risk assessment can help healthcare professionals decide on an appropriate action.

VTE symptoms can include:

- DVT, or blood clot in the leg: pain/tenderness often starting in the calf; swelling including the ankle or foot; redness, noticeable changes in color and/or warmth in the leg; or
- PE, or blood clot in the lung: unexplained shortness of breath or rapid breathing; chest pain (sometimes worse upon a deep breath); rapid heart rate; and/or light headedness or passing out.

While symptoms do not necessarily mean the presence of VTE, seek medical attention immediately to be evaluated.



Jacquie Limjoco is our Clinical Research Nurse. She has >15 years of experience in research.

The Center 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 the My Life Our Future project which offers free genetic testing to individuals with hemophilia. Soon we will be able to offer the testing to known or possible female carriers. 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)
- [Mylifeourfuture.org](http://Mylifeourfuture.org)



# THANK YOU!



## **Thank you**

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

Thank you to Rady Children's Homecare Specialty Pharmacy Program that coordinates our Factor Support Program and provides funding for our services.

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

## **Support the HTC**

Our Hemophilia Treatment Center receives funding through Henry's Fund which was started by one of our patients with hemophilia. The program supports medical care, genetic testing, education and games for kids in the clinic and hospital. If you are interested in donating to Henry's Fund, please contact the Rady Children's Foundation staff 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 even via web-conference.

Please save the date for the following events:

Camp Pascucci, Big Bear, August 13-18, 2017.

The camp is held each year for children with bleeding and clotting disorders and their siblings; ages 7-14 years.

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

