

Our Bleeding Disorders Newsletter

A Publication of the Regional Hemophilia and Thrombophilia Treatment Center at Ann & Robert H. Lurie Children’s Hospital of Chicago Comprehensive

Meet the Fellows

Please join us in welcoming our three new fellows who joined our team in early July. They will spend the next three years working closely with our staff as they specialize their medical training and education.



Dr. Mallorie Heneghan

Dr. Heneghan is a Chicago native who is excited to be back in this city after completing her residency at Children’s Hospital of Philadelphia. Dr. Heneghan likes to cook and travel. She is also a White Sox fan!

Dr. Kyle MacQuarrie



Originally from Boston, Dr. MacQuarrie joins us after completing his residency right here at Lurie Children’s. He has a dog named William and likes to bake, especially desserts!

Dr. Sun Young Kim



Dr. Kim comes to us all the way from Seoul, South Korea where she completed medical school and training in pediatric hematology/oncology. She then worked as a researcher at the University of Pittsburgh before completing her residency at Metropolitan Hospital in New York City.

Inside this issue:

Genetic Testing	1
Healthy Family Fair 2017	1
Announcements	1, 2
Resource Corner	2
Coping with Chronic Illness	2

Genetic Testing for Hemophilia

by Rukhmi Bhat, MD



Insurance issues may prevent a family from undergoing genetic testing.

Genetic testing for hemophilia is the process of identifying the genetic code responsible for an individual’s hemophilia. Much like a fingerprint, your genotype is unique; it can provide meaningful information about your hemophilia to you and your doctor.

Genotyping can also serve as a roadmap to greater understanding of your child’s hemophilia, and to new treatment approaches. Insurance policies don’t always cover genetic testing and the price is prohibitive for many families. For the remainder of this year—through December 2017—we have the opportunity to do genetic testing through a program of The

American Thrombosis and Hemostasis Network (ATHN) “My Life Our Future”.



Through this project, genetic testing for hemophilia patients and their families (mothers/sisters) is provided at no cost to the patient nor their insurance.

If you want to test your child/children via this opportunity, contact us now so we can arrange for testing before the program closes. Call Kristin Clemenz, our Genetic Counselor, at 312.227.4817.



Genetics of Hemophilia

- = has hemophilia
- ◐ = is a carrier of hemophilia
- = no hemophilia

Remember—we only have this opportunity until December of 2017. Please don’t delay—December will come faster than you think! 312.227.4817

Healthy Family Fair 2017



Free healthy cooking demonstrations, fitness activities, and fun were the focus of the 5th annual Healthy Family Fair held on Saturday, March 4th, 2017 for patients and families at Lurie Children’s Hospital. Over 30 community-based organizations like Chicago Park District, Joffrey Ballet, The First Tee of Greater

Chicago, Lettuce Entertain You and Kids in the Kitchen took part in the event to host booths, activities and more. The Thalassemia Action Board (TAB) also hosted a booth to promote awareness of thalassemia and the upcoming Care Walk.

Patients and families at the event were able to participate in free fitness activities that included yoga, ballet, hip-hop, boot camp and Zumba. They also met Staley Da Bear, official mascot of the Chicago Bears, who made a special guest appearance and joined in on the fun!



The Healthy Family Fair is hosted by the HOT Healthy Living Initiative (HOT stands for hematology/oncology/transplant) which promotes wellness and healthy weight management for patients and families within HOT programs.



BDAI upcoming Events

Camp Warren Jyrch

August 6th-12th at Camp Benson
in Mount Carroll IL

Hemophilia Walk

September 16: 10:00AM -
12:00PM Lincoln Park Chicago

Check out their calendar at

www.bdai.org

The National Hemophilia Foundation

is holding their 69th Annual Meeting in Chicago, "Exploring the New Frontier", August 24-26 featuring three days of educational sessions, networking, Awards Luncheon and the entertaining Final Night Event. To sign up, Go to www.hemophilia.org

How to reach us:

Emergencies
Hematologist on Call
312.227.4000

To make or change your child's appointment: 312.227.4814

Physicians

Alexis Thompson, MD, MPH
Rukhmi Bhat, MD
Robert Liem, MD, MS
A. Kyle Mack, MD
Sherif Badawy, MD

Advance Practice Nurses
Susan Gamerman MS. PNP-BC
312.227.4814

Anna Dickson, APN
312.227.4815

Kristin Clemenz, MS
Genetic Counselor
312.227.4817

Karolina Lieponis, LCSW
Social Worker
312-227-3346

Do you have something you'd like to share in the next newsletter? Contact Faith V. Gately, Outreach Coordinator, 312.227.4830 or email fgately@luriechildrens.org

Chronic Illness in the Family by Faith V. Gately**Having a child with chronic illness puts stress on the whole family.**

The stress of a chronic illness such as hemophilia affects everyone in the family, each parent, each sibling, and extended family as well as the patient. Illness in the family puts stress on a marriage and on sibling relationships, and may add financial stress as well, as medical bills, insurance deductibles and co-pays build up.

At your Hemophilia Treatment Center, we want to see you thrive as a family—not just survive. We are here to help you navigate the ups and downs that come with chronic illness.

To thrive, a family must utilize many resources and strategies.

- **Knowledge**

Knowledge is a powerful tool. Read about your child's illness, learn about treatments, therapies and options. Talk to your medical team, ask them questions. Meet with other families who have children with hemophilia.

- **Teach your child**

Help prepare your child for what is to come, and teach them about their illness in stages as they grow. Teach siblings too, so they can understand what's happening, and why. Involve them if possible, so they don't feel pushed aside by their sibling's illness.

- **Self care**

The demands on parents of a child with hemophilia may feel constant and endless. It is important to carve out some time for one's spouse and one's personal interests.

- **Seek out help**

Seek help—there are local and national organizations that assist hemophilia families such as Bleeding Disorders Alliance, IL

www.bdai.org

National Hemophilia Foundation

www.hemophilia.org

**The Resource Corner****Bounce Children's Foundation**

Bounce Children's Foundation is an organization that works to strengthen and build community for families who have children with chronic illness. In fact, that's their mission:

"Build community for chronically ill children and their families enabling transformation from surviving to thriving -- until cures are found."

Bounce was established in 2015 and aims to expand their programs and capacity to help families thrive with chronic illness. With values such as "a child's work is play" and "no child should lose their childhood to the medical system" Bounce works to infuse families with fun, reduce frustrations and build both virtual and real life connections. To accomplish this they have five Programming Pillars:

Bounce Net

Provides a safe on-line space

where families can network and give and receive support.

Bounce Bash Family Adventures

Provide face to face get togethers in a safe environment focused to give families a fun and much needed break

Bounce Back Kits

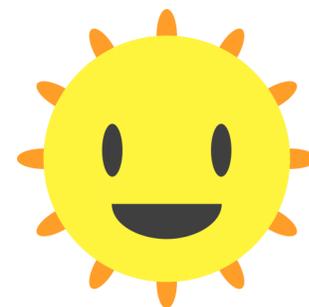
Fun filled kits sent to families during medical crisis or to acknowledge milestones

Bounce it Forward

Tickets for sporting events, theatre, movies...provides some unexpected fun!

Bounce Academy

Bounce back academy is launching this summer! It will provide education and support for parents and caregivers with child care on site. "For parents, improving one's ability to find positive solutions to their unique struggles, and being able to teach this to their children, is a game changer in both the short and long run."

**Need some cheer? Go to:**

www.bouncechildrensfoundation.org Click on "join" at the very top and fill out a family application. You can put Karolina Lieponis, LCSW as your referral source. If you have no computer or need assistance, call Karolina at 312-227-3346.

