

Rush For Life

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Spring 2017



The mission of the RUSH Hemophilia & Thrombophilia Center is to be a premier provider of state-of-the-art, family-focused, culturally sensitive care for children and adults with bleeding and clotting disorders.

HTC STAFF

Physicians:

Mindy Simpson, MD
Lisa Boggio, MS, MD

Nursing:

John Urgo, BSN
Maria Tovar-Herrera, BSN
Colleen Tapia, BSN

Dental:

Mary Hayes, DDS

Psychology:

Jeannie Aschkenasy, PhD

Social Work:

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Pharmacy:

Heather O. Alvarez, CPhT

Physical Therapy:

Laura Mathias

Research:

Kristin Boyce, RN, BA
Beelet Dawood
Rosie Howard
Yiyong Wu

My Life Our Future Study Now Open to Potential Carriers

As we know, hemophilia is an X-linked disorder. This means that the gene or the sequence of genetic material that codes for factor VIII or factor IX is located on the X chromosome. If that sequence is damaged or missing, then the factors are not made or are not made properly and the person has hemophilia. Genotyping is the process of identifying the genetic sequence or code responsible for hemophilia in each individual. The genetic code is much like a fingerprint and your genotype can provide meaningful information about your hemophilia. For example, people with certain mutations can be at a higher risk for developing an inhibitor. Identifying the mutation in a woman who is pregnant or planning to become pregnant would help her prepare for the birth of that baby and make plans for the future. Since about a third of the mutations in hemophilia are spontaneous – do not have a family history – the mother of a boy with hemophilia may not know if she is a carrier or not and may want to be tested to see what the risk is to her other children. Sisters of boys with hemophilia also can have bleeding and low factor levels and may want to know their carrier status before having surgery or becoming pregnant. Here at Rush we have the My Life Our Future Study. This provides **free** genetic testing for persons with hemophilia and potential carriers. The potential carrier would come for a research (not clinic) appointment. This does require that a family member with hemophilia (if available) be already enrolled in the study. Please call the clinic for more information.

Rush for Life

Nigeria—Our HTC Twin

The World Federation of Hemophilia sponsors a twinning program with countries who do not have the resources to provide optimal care for patients with bleeding disorders. Dr. Lisa Boggio and John Urgo, BSN went to our 'twin' at National Hospital, Abuja, Nigeria this past fall to educate providers at that center and throughout the country about hemophilia, Von Willebrand disease, and other bleeding disorders. This was a very rewarding experience and we were able learn how providers in Africa treat patients with very few resources. We learned that many young boys in Nigeria die at the time of circumcision from bleeding and that some families had multiple babies die after circumcision. During our clinic day there we were able to evaluate 25 patients from the area and give treatment recommendations. We also brought them supplies to help in the treatment of these patients as there are very few resources (including needles, tourniquets, etc.) available. It was a great experience so see what a little education can provide to patients who need it. We are planning another visit next year to continue to support this center. How can you be involved? If you have extra supplies and want to donate, just let us know. Also, the World Federation of Hemophilia will take non-expired product to send to underdeveloped countries. Please contact us at (312) 942-3034 if you are interested in any donations.



John Urgo, BSN spoke at national symposium

Dr Oniyangi, Dr Wakama, John Urgo, Dr Oche Ogbe, Dr Lisa Boggio, PT Gili, Dr Christiana Udo



Research Spotlight

The **Rush Hemophilia and Thrombophilia Center (HTC)** is a member of **The American Thrombosis and Hemostasis Network (ATHN)**

ATHN is a nonprofit organization committed to advancing and improving care for individuals affected by bleeding and thrombotic disorders. For more information please visit <http://www.ATHN.org>.

Rush HTC supports the following ATHN research studies. For more information about any of these studies please call us at (312) 942-3034.

ATHN dataset

This is confidential database of bleeding and clotting disorders. The ATHN dataset will be used to monitor trends and address questions that haven't been answered before about bleeding and clotting disorders, inhibitors, and treatment.

Community Counts, the Centers for Disease Control (CDC) Public Health Surveillance for Bleeding Disorders Project

Remember the UDC project? That project provided free HIV, Hepatitis C, Hepatitis A and Hepatitis B information. This is a modified continuation of that project and has three parts:

- ◆ HTC Population Profile
The types of bleeding disorders cared for and their severity
- ◆ Mortality Reporting
- ◆ Registry for Bleeding Disorders Surveillance
HIV & Hepatitis C testing plus inhibitor screening all at NO COST

How you can be part of Community Counts?

ATHN, in partnership with the U.S. Hemophilia Treatment Center Network and the Centers for Disease Control and Prevention (CDC) supports Community Counts at HTCs nationwide, including the **Rush** HTC. The project is open to all patients with hemophilia A and B, von Willebrand disease, rare bleeding disorders, platelets disorders and some rare clotting disorders who are receiving care here at Rush.

My Life Our Future

This study provides **FREE** genetic testing for patients with Hemophilia A or B (Factors VIII and IX deficiencies). Carriers and potential carriers may also be tested (see page 1 article).

For any of these studies, please ask during your clinic visit or contact us at 312-942-3034

Rush for Life

Osteoporosis In Kids With Bleeding Disorders

Running, jumping, walking and weightlifting have something in common—they build bone density and strength. Hematologists now recommend some degree of bone-building physical activity for children with bleeding disorders. Nevertheless, osteoporosis, a disease usually linked to old age and old bones that become thin and brittle, is showing up in kids with hemophilia.

"In children, osteoporosis is still a rare problem, but we're finding it more often than we would like to," says Mindy Simpson, MD, pediatric hematologist/oncologist at Rush University Medical Center in Chicago. Her institution is analyzing data from a study of pediatric and adult patients. "It's a matter of trying to define what we think the prevalence is, what we think the incidence may be and who is at highest risk."

Defining at-risk patients will help pediatric hematologists devise standard protocols for screenings and preventive measures. Until then, parents can increase their awareness of pre-existing conditions or behaviors that may predispose children for osteoporosis. Understanding the body's need for calcium and vitamin D as children grow can help parents create a proactive plan for their kids so they can build better bones.

For more information, please visit: <https://hemaware.org/story/osteoporosis-kids-bleeding-disorders>

Osteoporosis en Niños con Disordenes de Sangre

Correr, saltar, caminar y levantar pesas tienen algo en común: construyen densidad y fuerza ósea. Los doctores recomiendan ahora cierto grado de actividad física para la formación de huesos en niños con trastornos hemorrágicos. Sin embargo, la osteoporosis, una enfermedad generalmente ligada a la vejez y huesos viejos que se vuelven delgados y quebradizos, está apareciendo en niños con hemofilia.

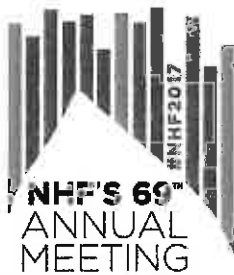
"En los niños, la osteoporosis sigue siendo un problema raro, pero lo estamos encontrando más a menudo que nos gustaría", dice Mindy Simpson, MD, hematólogo pediátrico / oncólogo en Rush University Medical Center en Chicago. Su institución está analizando datos de un estudio de pacientes pediátricos y adultos. "Se trata de definir lo que creemos que es la prevalencia, lo que creemos que puede ser la incidencia y quién está en mayor riesgo". La definición de pacientes en riesgo ayudará a los hematólogos pediátricos a diseñar protocolos estándar para exámenes y medidas preventivas. Hasta entonces, los padres pueden aumentar su conocimiento de las condiciones preexistentes o comportamientos que pueden predisponer a los niños a la osteoporosis. Comprender la necesidad del cuerpo de calcio y vitamina D a medida que los niños crecen puede ayudar a los padres a crear un plan proactivo para sus hijos para que puedan construir mejores huesos.

Para más información por favor visite: <https://hemaware.org/story/osteoporosis-kids-bleeding-disorders>

Welcoming a New Member to Our Rush HTC

Join us in welcoming Beelet. She will be working as a project coordinator here at Rush HTC. You will find Beelet during your visits at the HTC clinic when you participate in any of our studies. She graduated from University of Illinois at Chicago with a degree in neuroscience.

She is enthusiastic and excited about getting involved in our various studies and projects.



EXPLORING THE NEW FRONTIER

CHICAGO | AUGUST 24-26, 2017

The Annual Meeting of the National Hemophilia Foundation will be held here in Chicago in August.

Individuals and/or families with bleeding disorders are encouraged to attend the meeting. For more information, call NHF or **Visit this site:** <https://events.hemophilia.org/ehome/annualmeeting/>

Bleeding Disorders Alliance Illinois may also have opportunities to participate. Preference is given to first time attendees. Call BDAI 312-427-1495 for more information.

La Reunion Annual de la Fundacion De Hemofilia Nacional es aqui en Chicago en Agosto.

Individuos y/o familias con disordenes de sangre se anima a asistir a la reunión annual. Para mas información, llama o visita **este sitio:** <https://events.hemophilia.org/ehome/annualmeeting/>

Es posible que la Bleeding Disorders Alliance Illinois puede tener oportunidades para participar. Se dará preferencia a los primeros asistentes de tiempo. Llamme a BDAI 312-427-1495 para mas información.



Rush for Life

Clinic Visit Letters

Rush will no longer be routinely mailing out clinic notes to patients. If you require a visit note, please notify us. Notes will automatically be sent to your primary care provider (internist or pediatrician). If you want to receive your labs and notes via email, please sign up for MyChart at www.mychart.rush.edu. Unfortunately teens are not eligible for MyChart due to privacy laws, so please notify us if you will need a copy of the note. Remember, that you can receive a copy of our clinic recommendations at the end of every clinic on your After Visit Summary. These are given at check out so please be sure to ask for this.

Rush HTC Fun



CAMP

Camp Warren Jyrch, established in 1973, is an annual, one-week resident camp program for persons with hemophilia or other hereditary symptomatic bleeding disorders between the ages of 7-17. You will need to have a physical examination for camp, so make your comprehensive clinic appointment early as spots fill quickly.

This year camp is planned for August 6-11, 2017 at YMCA Camp Benson in Mount Carrol, IL.

If you are interested in attending camp, get an application from BDAI at <http://bdai.org/camp> or call 312-427-1495. Applications are usually available in April and due July 1st.



Hematology Clinic Renovations

The clinic in Chicago—Suite 710 at 1725 W Harrison Street—is currently being renovated. There will be new flooring and say goodbye to the sailboat wallpaper! During this time there will not be as many rooms available to see patients and you may need to shuffle rooms during clinics. We will have all blood draws and research procedures performed in our new infusion area on the 3rd floor. We apologize in advance for any inconvenience this may cause but the result will be fabulous and we are sure that it will make your future clinic days much more comfortable.

Renovations should be completed by April, so make sure to come back after April to see the new space. As you know, comprehensive clinic is essential for persons with bleeding disorders and those who attend comprehensive have better health and longevity. Clinic times are very full in Chicago, so, despite the renovations, please come to clinic on time as there are not openings again for several months.



Infusion Classes

Clases de Infusion

Clinic: (312) 942-3034

Office: (312) 942-8114

Fax (312) 942-8975

www.rush.edu

Held At / Ubicacion

Rush University Medical Center Chicago 4/25/17 6-8 pm

More dates coming soon in: / Mas fechas vienen pronto a:

Hoffman Estates

Rush-Copley, Aurora

This program provides one-on-one attention and teaching for patients/families/caregivers to ensure comfort, knowledge, and effective technique for infusions

Este programa proporciona atención persona a persona enseñando a pacientes/familias/cuidadores asegurar comodidad, conocimiento, y técnica con eficaz para infusions.

Space is limited and you **MUST RSVP**. Please call 312-942-3034 and ask for Colleen, John or Maria to schedule the class or if you have any questions.

Espacio es limitado y usted **tiene que confirmar** su lugar. Por favor llama al 312-942-3034 y pregunta por Colleen, John o Maria para programar una cita para la clase o si tiene preguntas.

Postage

Label