

Updates from your HTC

News for Patients, Families and the Community.

St. Joseph's Hospitals
BayCare Health System
Center for Bleeding
and Clotting Disorders

Our Team

Medical Director:
Erin Cockrell, DO

Pediatric Bleeding
Disorders Nurse
Coordinator:
Lisette Sanchez, RN

Adult Bleeding Disorders
and Pediatric
Thrombophilia Nurse
Coordinator: Candace
DeBerry, APRN-C

Social Worker:
Adrienne Abecassis, MSW

Clinical Pharmacist:
Lauren Campanella,
Pharm.D., BCOP

Research Coordinator:
Cindy Manis, RN

Data Coordinator:
Diane Telegdi, RN

Physical Therapist:
Tracey Dause, MSPT
Cassie McKee, DPT

Contact Us

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St. Joseph's HTC: What's New?

Team Member Announcements

We are so very proud to introduce you to our new HTC Pharmacist, Lauren Campanella, who will be joining the team in January of 2020.

Lauren Campanella, Pharm.D., BCOP *Clinical Pharmacist*

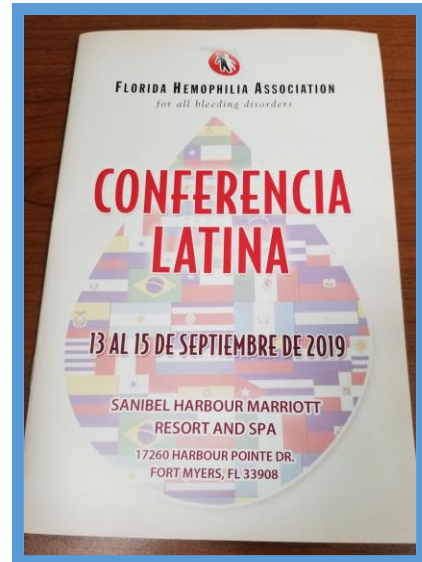


Lauren is from Tampa, FL and she was actually born in St. Joseph's Women's Hospital. She was raised in Louisville, Kentucky. She graduated from the University of Florida's School of Pharmacy in 2011. She completed her general pharmacy and oncology residencies at the University of Louisville Health Care in Louisville, KY. She has worked at BayCare since 2013, specializing in inpatient and outpatient Hematology/Oncology. She obtained her Board Certification for Oncology Pharmacy in 2014. She is most excited about working with patients in clinic, including adjusting medications, education and helping with prescription access. She is very eager to start, and help make a difference!

Your HTC has also been working closely with the Mayor's office to get a proclamation signed, which recognizes the month of March as Bleeding Disorder Awareness Month in the city of Tampa. Please stay tuned for more information on different ideas we have been working on to help advocate for the bleeding disorders community.

Recent Events

The **Florida Hemophilia Association** held their inaugural **Latin conference** from September 13- 15th at the Sanibel Harbor Marriott Resort and Spa. This was a three-day educational conference centered in educating the growing Latin community with bleeding disorders. Your pediatric nurse coordinator, Lisette Sanchez, attended this event and held a session on self- infusions. There was also a demonstration on simple exercises that help to strengthen joints, and a discussion on the differences between a 504 Education plan and an Individualized Education Program, in addition to much more. This was a great opportunity to have parents of children with a bleeding disorder meet other parents and share information, resources and life experiences. It was an amazing weekend and we are looking forward to the next one.



Thank you to all of our patients and families who also participated in the **HTC Insurance Event** that took place on Thursday, October 17th. Throughout our presentation, we discussed the benefits of helping to support our HTC's 340B Factor program, we provided information on copay and premium assistance programs, we introduced the role of a BayCare healthcare navigator (855)404-3334, and discussed insurance terminology. We also presented updated information on the different types of insurance options that are available, including Medicaid, Medicare, FL KidCare (Healthy Kids), and the Marketplace in preparation for open enrollment. We hope you found this event to be beneficial.



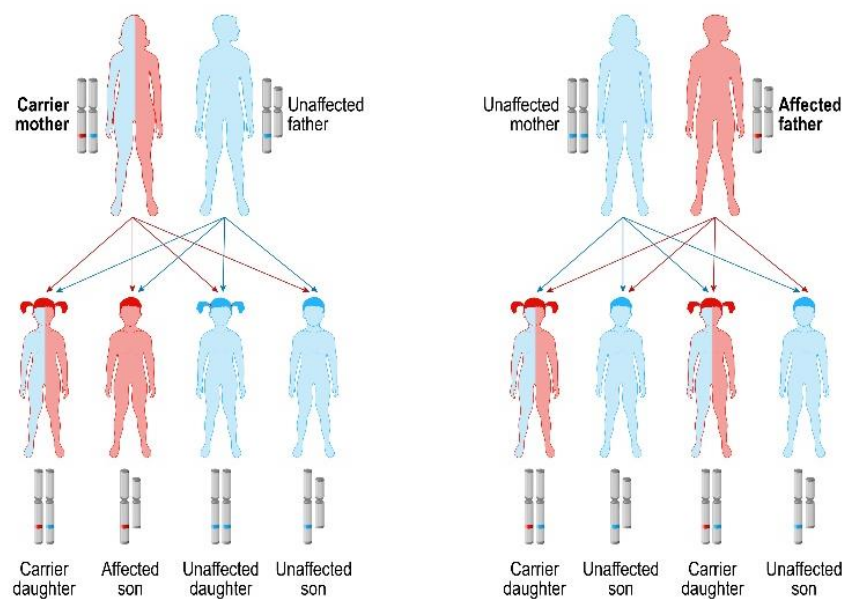
If you were unable to attend these events and/or have questions about the information discussed, please feel free to reach out to your HTC Social Worker Adrienne Abecassis at (813)870-4017.

Hemophilia B:

Hemophilia B, also called factor IX (FIX) deficiency or Christmas disease, is a genetic disorder caused by missing or defective factor IX, a clotting protein. Although it is passed down from parents to children, about 1/3 of cases are caused by a spontaneous mutation, a change in a gene.

According to the US Centers for Disease Control and Prevention, there are about 20,000 people with hemophilia in the US. All races and ethnic groups are affected. Hemophilia B is four times less common than hemophilia A.

Genetics



The gene for hemophilia is carried on the X chromosome. Males inherit an X chromosome from their mother and a Y chromosome from their father (XY). That means if a son inherits an X chromosome carrying hemophilia from his mother, he will have hemophilia. Females inherit two X chromosomes: one from their mother and one from their father (XX). Daughters have two X chromosomes; even if they inherit the hemophilia gene from their mother, most likely they will inherit a healthy X chromosome from their father and not have hemophilia. A daughter who inherits an X chromosome that contains the gene for hemophilia is called a carrier. She can pass the gene on to her children.

Classification

People with hemophilia B often bleed longer than other people. Bleeds can occur internally into joints and muscles or externally from minor cuts, dental procedures or trauma. How frequently a person bleeds and the severity of those bleeds depends on how much FVIII is in the blood.

- Severe:
 - Factor level less than 1%
 - People with severe hemophilia B experience bleeding following an injury and may have frequent spontaneous bleeding episodes, often into their joints and muscles.
- Moderate:
 - Factor level of 1 - 5%
 - People with moderate hemophilia B tend to have bleeding episodes after injuries. Bleeds that occur without obvious cause are called spontaneous bleeding episodes.
- Mild:
 - Factor level of 6% - 49%
 - People with mild hemophilia B generally experience bleeding only after serious injury, trauma or surgery. In many cases, mild hemophilia is not diagnosed until an injury, surgery or tooth extraction resulting in prolonged bleeding. The first episode may not occur until adulthood. Women with mild hemophilia often experience heavy menstrual periods and can hemorrhage after childbirth.

Treatment

The main medication to treat hemophilia B is concentrated FIX product, called clotting factor or simply factor. There are 2 types of factor IX products, these include recombinant products and products derived from human blood or plasma. Many physicians prefer the use of recombinant factor IX because it does not contain human blood proteins. Different preparations of recombinant factor IX products are available, including standard half-life factor products and long-acting drugs that allow for less frequent administration.

These factor therapies are infused intravenously through a vein in the arm or a port in the chest. Your doctor or your HTC will help you decide which is right for you. Patients with severe hemophilia may be on a routine treatment regimen, called prophylaxis, to maintain enough clotting factor in their bloodstream to prevent bleeds.

Aminocaproic acid prevents the breakdown of blood clots. It is often recommended before dental procedures, and to treat nose and mouth bleeds. It is taken orally as a tablet or liquid. MASAC recommends that a dose of clotting factor be taken first to form a clot, then aminocaproic acid, to preserve the clot and keep it from being broken down prematurely.

ATHN Update:

National Hemophilia Program Coordinating Center (NHPCC) Patient Experience Survey

ATHN recently relaunched the Patient Experience of Care Survey. This survey aims to track improvement of the services we are providing to your child in preparation for the transition from pediatric to adult care. Our HTC is committed to addressing the transition needs of our pediatric bleeding disorder population to ensure our patients become confident and responsible in self-care. Remember, this is not an immediate change but a process that often requires taking on one skill at a time to become proficient and continuing to add responsibilities as you grow. Our HTC's role is to guide and support you through this process and this survey is a tool to measure our success and most importantly yours!

During your Comprehensive Care Clinic visit, we will be providing a short survey that we ask you and your child to complete. This survey will be repeated each year until 2022 so we can measure our improvement and continually reassess if we are meeting our patients' transition needs. Patients aged 12-17 will complete the survey with their parent's supervision and patients 18-22 years will complete the survey on their own. This survey is completely voluntary and should only take about 5 minutes to complete electronically on an iPad provided in clinic. If you would prefer a paper copy, we can provide you with a survey and envelope to complete and the sealed envelope will be collected at the end of your visit.

We appreciate your participation in this survey and your efforts to help our team improve the transition process.



BayCare Medical Group Clinic Updates:



The following information only pertains to those patients who are enrolled in the Florida KidCare Program. If you are unfamiliar with Florida KidCare, it is a program that consists of low-cost health insurance plan options for children throughout FL, including Florida Healthy Kids, Medicaid, MediKids and Children's Medical Services Managed Care Plan (CMS Plan).

Our HTC would like to take a proactive stance to help our patients continue to receive care within our clinic. Beginning in 2020, our clinic will continue to accept the following FL KidCare Program plans- FL Medicaid Staywell, Staywell Kids, Sunshine Health, Sunshine Health Healthy Kids, Simply Health Care, Simply Health Care Healthy Kids, and CMS Wellcare in addition to Aetna Better Health which is a new FL Healthy Kids plan.

If you would like to receive more information on the differences between each FL KidCare plan, please contact the **FL KidCare program** at **1-888-540-KIDS**. If you are looking to change your son/daughter's insurance to a different plan our clinic accepts, please feel free to contact the office of **Medicaid Choice Counselor Help Line** at **877-711-3662** or

Please note that if you make a change to insurance before December 15th, then the change will become effective by January 1st. However if you make a change by selecting a different plan after December 15th, then the change will become effective on February 1st.

If you have any insurance-related questions, please contact your HTC Social Worker Adrienne (813)870-4017, at your earliest convenience.

Upcoming Community Events:

- **National Hemophilia Foundation**

<https://www.hemophilia.org>

- **National Youth Leadership Institute (NYLI)**

- The NYLI is a three-year program designed to assist young people ages 18-24 from the bleeding disorders community to become well-trained, recognized leaders.
 - Contact Education Specialist Marlee Whetten at mwhetten@hemophilia.org or call 212.328.3735

- **2020 Bleeding Disorders Conference**

- August 6-8th in Atlanta, Georgia
 - Registration details will be available on January 13th
<https://events.hemophilia.org/ehome/index.php?eventid=385113&>



- **Hemophilia Federation of America**

<https://www.hemophiliafed.org/>

- **HFA's Annual Symposium**

- April 23-26th in Baltimore, MD
 - Register online:
<https://www.hemophiliafed.org/our-role-and-programs/national-community-events/annual-symposium/>



- **Hemophilia Foundation of Michigan**

<https://hfmich.org/>

- **2020 National Conference for Women with Hemophilia**

- October 9-11th
 - The Westin Hotel at The Detroit Metropolitan Airport 2501 World Gateway Place, Detroit, MI 48242
 - Registration details to come



- ***vWD Connect Foundation***

<http://vwdconnect.org>

- **4th Annual vWD Connect Foundation National Type 3/Severe vWD Conference**

- June 26-29th at the PGA National Resort and Spa in Palm Beach Gardens, FL
 - Please visit website for registration details.



- ***The Coalition for Hemophilia B***

<https://www.hemob.org/>

- **14th Annual Symposium**

- March 19-22nd
 - Renaissance Orlando at Sea World
 - Apply for a Travel Grant by September 27th at <https://static1.squarespace.com/static/566b210340667a1cc1623840/t/5d7aef80ec71ca18222f2b27/1568337792976/2020+Travel+grant.pdf>



- ***Hemophilia Foundation of Greater Florida***

<http://www.hemophiliaflorida.org/>

- **Holiday Trivia**

- December 8, 2019 at 11 a.m.
 - Register by December 4th, via email info@hemophiliaflorida.org or by contacting HFGF 1-800-293-6527

- **2020 Legislative Days**

- February 18-19th
 - For more information and to RSVP contact HFGF at info@hemophiliaflorida.org or 1-800-293-6527

- **Annual Tampa Walk**

- Saturday, April 18th
 - Al Lopez Park at 4810 N. Himes Avenue, Tampa, FL 33614
 - For more information and to register for the event, contact HFGF at info@hemophiliaflorida.org or 1-800-293-6527



- **Florida Hemophilia Association**

<http://floridahemophilia.org/>

- **2019 End of Year Educational Event**

- December 15, 2019 beginning at 11 a.m.
 - TY Park in Hollywood, Florida
 - For more information and to RSVP contact admin@floridahemophilia.org or call 305.235.0717



- **Camp Boggy Creek**

<http://www.boggycreek.org/>

- **Camp Boggy Creek 2020 Summer Session**

- June 17-22nd

- **Camp Boggy Creek 2020 Fall Family Retreat Weekend**

- September 11-13th

- Applications will be available online for the Summer Session by January 1st, and for the Fall by July 15th.

- Parent(s) need to fill out the online application first, then contact HTC Social Worker Adrienne (813)870-4017 who will help to submit Medical Summary



- **Children's Cancer Center**

<http://childrenscancercenter.org/>

- This unique organization opens their arms to all of our patients and families with bleeding disorders, including Hemophilia, vWD and Sickle Cell Disease.
 - Each weekend they hold special events.
 - Please contact your HTC SW Adrienne (813)870-4017 for a list of specific events and to complete their new patient consent form.



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*We hope you enjoyed our newsletter and found the information we provided helpful. We welcome any feedback!*