

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:
Lena Charafi, PharmD

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 your new HTC team members.

Cindy Manis, RN *Research Coordinator*



Cindy was born and raised in Ohio, and received her nursing degree from the Good Samaritan College of Nursing and Health Science in Cincinnati. She moved to Florida in 2013, and has been a registered nurse for over 17 years. She has earned valuable work experience in both a pediatric and adult trauma setting, in addition to a variety of different clinical areas from reproductive endocrinology to geriatrics. She has approximately 10 years of research experience, and is available to help you connect to current studies. She is very excited to join BayCare and work with such an amazing team.

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



Candace grew up in Clearwater, Florida and received her master's degree in nursing from the University of South Florida in Tampa. She is certified by the American Association of Nurse Practitioners (AANP) as a family nurse practitioner and able to treat patients of all ages. She has been a registered nurse for 14 years and a nurse practitioner for 3 years. Candace joined the Center for Bleeding and Clotting Disorders in April 2019. She is very excited about being a part of the team, and most passionate about making a positive difference in the lives of others.

Bombardier Blood Documentary Screening

Thank you to all of our patients and their family members who made great efforts to come and see the *Bombardier Blood* documentary with us. We are so grateful that you each had the opportunity to meet Chris Bombardier himself, and you all had such wonderful questions to ask him.

One of the most important messages I took from watching this film is the significance of finding your passion and letting it motivate you to work hard towards accomplishing your personal goals.



Chris Bombardier

This film also portrays what life with hemophilia looks like in developing countries where there is no access to factor medication, and leaves you with a newfound sense of overwhelming appreciation for the resources we have.

A very special thank you to the Hemophilia Foundation of Greater FL for helping to support the bleeding disorders community by planning this amazing event and giving us the platform to advocate for greater awareness of bleeding disorders.



We are also organizing a screening here for you at St. Joseph's Hospital once this inspiring and educational documentary becomes available for the general public to view. Please feel free to reach out to your HTC Social Worker if you are interested in attending our dinner/movie event.

Tampa Superhero Fun Walk

What is the purpose of attending a walk? How much of an impact does a walk have on the bleeding disorders community?

The Hemophilia Foundation of Greater Florida organizes a walk each year for the Tampa Bay area. This year's walk successfully raised over \$40,000 and 91% of that revenue will go directly back towards helping to support those patients in our local HTC's. For example, our patients who are experiencing a financial crisis, participants registered for Camp Boggy Creek, funding for those who require a Medic Alert bracelet, those who are advocating for better healthcare policies, as well as financial assistance to provide all of the amazing events that bring valuable knowledge and resources to address our most pressing issues being faced.

This year, your HTC team attended The Hemophilia Walk and were proud winners of the **Champions in Action Corporate Award** however our work is far from done and we need to continue to strive for opportunities to network by building stronger connections for the community. Our goal is to spread the word regarding our chapter organizations and educate the public on our Bleeding and Clotting Disorder community and what they can do to help in our cause.

We welcome and would truly value your feedback on this year's Hemophilia Walk and are always open to suggestions to improve attendance and participation. Please share your comments with the Hemophilia of Greater Florida or your HTC social worker.



Legislative Days

On April 17th and 18th the Bleeding Disorder Coalition of Florida along with patients and families traveled to Tallahassee to educate our new legislators on the issues that affect the bleeding disorder community.

Two important bills were discussed with the policymakers. Senate Bill 650 is very significant for our patients because it provides protections from step therapy; therefore, the Bleeding Disorder Coalition asked Florida Senators to support this bill. Step therapy is always inappropriate in the bleeding disorder context because the potential consequences of a treatment “failure” are so serious. Insurers should be required to grant exceptions to their step therapy protocols. The patient’s doctor should have the final say on which therapy is the most beneficial for the patient.



Another important bill that the Bleeding Disorder Coalition discussed with our lawmakers was House Bill 997 (Senate Bill 1422). This bill would expand short-term and association health plans. These plans are also known as “skinny” insurance plans because they do not provide adequate healthcare coverage. They also exclude patients with pre-existing conditions. The availability of “skinny” plans would lead to confusion and underinsurance; therefore, the Bleeding Disorder Coalition asked the legislators to oppose this bill.

If you are interested in participating in Legislative Days next year, please email Leah Nash at leahnash@hemophiliaflorida.org.



Proclamation



Bob Buckhorn, Mayor

Earlier this year, Mayor Bob Buckhorn signed the Proclamation recognizing April 17th, 2019 as a **World Hemophilia Day** in the city of Tampa. This amazing achievement can help bring awareness to the Tampa Bay community about hemophilia and other bleeding disorders.

World Federation of Hemophilia (WFH) was established in 1963 by Frank Schnabel to improve treatment options and overall care for hemophilia patients worldwide. The organization established the month of March as **Hemophilia Awareness Month** to shine a light globally on this serious condition and to find ways to assist these patients. WFH also created **World Hemophilia Day** held each year on April 17th, in recognition of the founder, Frank Schnabel's birthday.

Michelle Phillips from the Mayor's office has been extremely helpful with the proclamation process. She has a family member who has severe hemophilia A, so she is well aware of all the challenges patients with hemophilia might face and the importance of raising awareness of this disease state.

Next year our HTC will work closely with the Mayor's office to get a proclamation for the month of March as a Hemophilia and Bleeding Disorder Awareness Month in the city of Tampa.

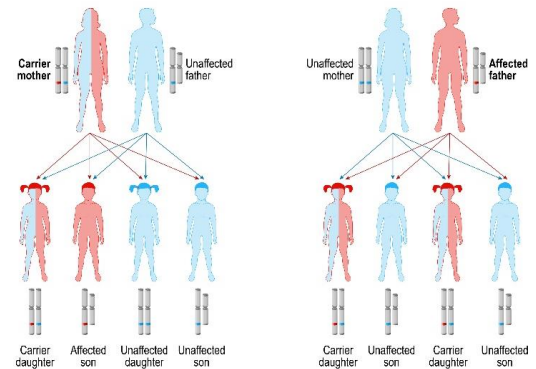


Hemophilia A

Hemophilia A, also called factor VIII (FVIII) deficiency or classic hemophilia, is a genetic disorder caused by missing or defective factor VIII, a clotting protein. All races and ethnic groups are affected. 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.

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 A 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 A 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 A 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 A 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

- Factor VIII concentrates:
 - Available as recombinant factor products (developed in a lab) and plasma-derived factor products (contain human plasma proteins). Majority of the hemophilia community use recombinant FVIII products.
 - Different preparations are available, including standard half-life factor products and long-acting drugs that allow for less frequent administration.
 - These factor therapies are infused through a vein in the arm or a port in the chest.
 - Your doctor or your HTC will help you decide which factor 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.
- Hemlibra (emicizumab):
 - Monoclonal antibody that is used for prophylaxis in adult and pediatric patients with and without inhibitors (alloantibodies) to Factor VIII.
 - It has been shown to significantly reduce bleeding episodes in patients with inhibitors.
 - This medication is given subcutaneously (under the skin).
- DDAVP (desmopressin acetate):
 - Synthetic version of vasopressin, a natural antidiuretic hormone that helps stop bleeding.
 - In patients with mild hemophilia, it can be used for joint and muscle bleeds, for bleeding in the mucous membranes of the nose and mouth, and before and after surgery.
 - It comes in an injectable form and a nasal spray.
- 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. It is recommended 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.

Clinical Research Updates:

Our HTC has so many exciting clinical trials available for our patients. Pediatric Hematology-Oncology Specialists Erin Cockrell, DO, Dana Obzut, MD, and research coordinators Jennifer Manns, RN, and Cindy Manis, RN, are working on a **gene therapy trial in individuals with severe hemophilia A**. The goal of gene therapy is to allow the person's own body to make a working form of factor VIII, the blood-clotting protein that is missing or not working efficiently in a person with hemophilia A.

"It's very exciting to see the advancements in treatment options that have become available to our patients," Manns said. "Some of the results we've seen in patients include fewer infusions, a reduction in the number of bleeding episodes and improvements in the quality of life."

eTHINK is another new and exciting study that our Hemophilia Treatment Center is participating in. This study is looking to see if hemophilia has any effect on learning. The study will include a neurocognitive assessment, which is a series of questions conducted by your hematologist, Dr. Erin Cockrell, as well as a neuropsychologist. This testing can be useful to help with school performance by looking at different ways patients learn best, and the results can be shared with the school at each patient's request.

If you wish to learn more information about the studies currently open or you would like to be a candidate for one of the studies, please contact your new research coordinator Cindy Manis at Cindy.Manis@baycare.org. We are happy to discuss details with you in person or over the phone.



Patient Story: Meet Tyron

Last summer, we held an exclusive Health and Wellness event where we invited our nutritionist, physical therapist and head Chef of St. Joseph's Hospital to help demonstrate how to prepare healthy yet delicious meals, and educate our patients on the importance of living an active lifestyle. We also held a Fitbit challenge and gave away a reward to the team that achieved the most steps within a three month time frame.

We have a patient who attended this event and has since then gone above and beyond to work towards accomplishing his personal health goals. We wanted to send him a huge HTC Shout Out for all of his dedication. He also self-enrolled in the competitive eight week NHF Make Your Move program, and joined a local gym to help keep the momentum going. We are highlighting his story in hopes that it might also inspire you in the same way that it did for us.



Please meet Tyron! He is 33-years old and from Dominica. Tyron was diagnosed with hemophilia at age four. He recently moved to Florida two years ago and married his beautiful wife/teammate Pheona whom he met in college. Tyron was recommended to have knee replacement surgery and encouraged to lose at least 20 lbs. prior to his procedure.

1. What did you find to be the most helpful thing about our HTC Health and Wellness Event?

I learned about how to eat healthier, and how you can make healthy foods taste delicious.

2. How do you stay motivated? In other words, what motivates you?

I try to be the best I can be and not let hemophilia control my life, but instead I control it. I'm also inspired by helping to motivate others to accomplish their goals even if it's not someone in the hemophilia community.

3. How much weight have you lost since the HTC event in June, and what is your overall goal?

I've lost 13 lbs. since the event and my overall goal is to get to 260-270 lbs.

4. What advice do you have for other adults who are considering whether they have

what it takes to live a healthy and active lifestyle?

The journey begins with a single step. Don't let anything hold you back. I never thought I would be able to go to the gym due to the fact that I have hemophilia and because I received no treatment when I lived in Dominica. Now I'm in the gym 5-6 times per week. My favorite line is- trust the process. Once you start, don't give up.

5. How often do you exercise each week, and how has your diet changed?

I work out 5 days a week for at least 30 minutes, and 1 hour a week with my personal trainer. If I don't go to the gym, then I try and swim for at least 20 minutes. I have completely cut out breads and rice from my diet, and eliminated other starchy foods.

6. What is your favorite recipe to cook? What are the main ingredients?

My favorite recipe was Shrimp Alfredo and I used to make my own sauce. But now that I've eliminated carbs from my diet, it's been lentil and kale soup. The main ingredients are lentil, kale, carrots, celery, and chicken.

7. What is your favorite smoothie to make?
Ingredients?

My smoothies consist of whatever fruits I have in the fridge. But my favorite go-to recipe consists of pineapple, watermelon and a berry mix with some water blended and an amino acid powder to help with my muscle recovery.



8. What is your favorite type of exercise to do? And why?

I love lifting weights. I really like being able to challenge myself. While lifting weights I can increase the weight amount gradually, which feels like a small victory for me because I can see the actual difference. I also love swimming because it is a great way to get a good cardio workout.

Thank you so much for sharing your story, Tyron! Keep up the great work!

If you know someone throughout the bleeding disorders community who would be willing to share their inspirational story, please feel free to reach out to your HTC Social Worker.

Teen Retreat

One of our goals collectively is to be able to help support our patients by teaching them how to become more independent in managing their own health.

“Research shows that many young adults are likely to struggle with adherence issues. One 2016 study by researchers at the Northern Regional Bleeding Disorder Center in Michigan revealed that while 17% of study participants between ages 13 and 17 were nonadherent to their prescribed treatment regimens, that number jumped to 47% for participants ages 18 to 25” (*HemAware*, 2019).

We try our best to educate our patients on the importance of taking their medication as prescribed to prevent long-term joint damage from musculoskeletal and functional abnormalities, avert the development of chronic pain, and to maintain healthy factor levels in the event that they experience an injury.

But you know just as well as we do, that if our teens feel like they are being lectured to, then they are less likely to be receptive to sharing and learning.

HFGF has teamed up with your HTC Social Worker to organize a fun yet educational event with the help of **Gut Monkey** which is scheduled to take place on Friday evening of July 19th, and Saturday morning of July 20th. Your teenager who is affected by hemophilia or von Willebrand disease will get the opportunity to stay one night in a hotel on Madeira Beach and learn how to become better advocates for their own healthcare. You are also more than welcome to join them as there is a separate (optional) meet-up for the caregiver(s) that takes place that Saturday morning.

To learn more about Gut Monkey, please visit their website at <http://www.gutmonkey.com/>.

Please feel free to reach out to your HTC Social Worker if you are interested in attending this event.



Stewart, Kathryn Anne. “6 Ways to Help Your Kids Move to Adult Care.” *HemAware*, NHF, May 2019, <https://hemaware.org/life/6-ways-help-your-kid-move-adult-care>. Accessed on 22 May 2019.

Upcoming Community Events:

- **National Hemophilia Foundation**

<https://www.hemophilia.org>

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

- Leadership opportunity for youth ages 18-24
 - Contact Education Specialist Marlee Whetten at mwhetten@hemophilia.org or call 212.328.3735

- **Inhibitor Education Summits**

- June 6-9th in Indianapolis
 - June 27-30th in Seattle
 - August 1-4th in Boston
 - Contact Nikole Scappe at nscappe@hemophilia.org or call at 646-483-5896

- **2019 Bleeding Disorders Conference**

- October 3-5th in Anaheim, California
 - Registration is now open
<https://events.hemophilia.org/ehome/index.php?eventid=385113&>

- **Hemophilia Foundation of Greater Florida**

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

- **Ready-Set...Transition**

- June 1st at Sea World Orlando
 - Hosted by Michael Rosenthal, Bleeding Disorder Education and Fun Specialist
 - RSVP by sending email to info@hemophiliaflorida.org or call 800-293-6527

- **Teen Retreat**

- July 19th-20th in the Marriott hotel of Madeira Beach, FL
 - Hosted by Gut Monkey
 - RSVP by sending email to info@hemophiliaflorida.org or call 800-293-6527



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders
1948-2018



- **HFGF Adventure Island Retreat**

- August 17th
- RSVP by sending email to info@hemophiliaflorida.org or call 800-293-6527

- **Florida Hemophilia Association**

<http://floridahemophilia.org/>

- **Annual Teen and Young Adult Retreat**

- June 13th-June 16th in West Palm Beach, FL
- For ages 15-25
- Transportation assistance available
- For more information and to RSVP send email to admin@floridahemophilia.org or call the office at 305-235-0717

- **Dolphin Day Camp**

- June 28th & July 12th in Island Dolphin Care Center in Key Largo FL
- For ages 6-18
- Transportation assistance available
- For more information and to RSVP send email to admin@floridahemophilia.org or call the office at 305-235-0717

- **36th Annual FL Bleeding Disorders Conference**

- July 26th-29th
- Transportation assistance available
- For more information and to RSVP send email to admin@floridahemophilia.org or call the office at 305-235-0717

- **23rd Annual Flight for Tomorrow Invitational Golf Tournament**

- October 28th
- East Lake Woodland Country Club at 1055 E Lake Woodlands Pkwy, Oldsmar, FL 34677
- For more information and to RSVP contact Rhonda McDonald at 727-638-6979 or rhonda@brmgroupp.us



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

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

- **The Beats Music Program**

- July 31-August 4, 2019
 - Gaylord Opryland Hotel
 - Register at www.hemob.org/thebeatsmusic2019



- ***Camp Boggy Creek*** <http://www.boggycreek.org/>

- **Summer Session**

- June 19-24, 2019
 - Application will be available by January 1, 2019

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

- September 20-22, 2019
 - Application will be available by January 1, 2019
 - 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 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!*