

Updates from your HTC

News for Patients, Families and the Community.



Our Team

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Pediatric Bleeding
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Coordinator:
Lisette Sanchez, RN

Adult Bleeding Disorders
and Pediatric
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DeBerry, APRN-C

Social Worker:
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Clinical Pharmacist:
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Pharm.D., BCOP

Research Coordinator:
Cindy Manis, RN

Data Coordinator:
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Contact Us

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

HTC Announcements

What is Telehealth?

To help keep our community safe and to avoid the spread of the coronavirus, BayCare Medical Group (BMG) doctors now provide a telemedicine service through [BayCareAnywhere](#), for current patients who want its added safety and convenience benefits. Telemedicine allows you to use your smart phone, tablet or computer to visit with your doctor. Your doctor can use this service to evaluate you, just as in an office visit. If you are interested in scheduling a telehealth appointment, please download the [BayCareAnywhere](#) app first then contact our clinic at 813.321.6820 to reserve your spot.



Tips for a Telehealth Visit

- Use a 4G cellular connection or a secure Wi-Fi connection or adequate internet connection
- Be in an area with a good phone signal
- Make sure the room being used is in a private, quiet area with no potential for interruption and has plenty of light

Currently, our clinic is open for regular business hours and you have the option of scheduling an office visit or a telehealth visit. We kindly ask that all of our patients who are scheduled to be seen by a hematologist in clinic please enter through the main St. Joseph's Children's hospital entrance which is located at 3001 W. Dr. Martin Luther King Jr. Blvd., Tampa, FL 33607.

Upon arrival, your temperature will be taken and you will be given a mask to wear. Only one parent may accompany a child to their appointment. Siblings and additional supportive partners or caregivers are kindly being asked to remain at home.

If you have an upcoming appointment either by telehealth or in clinic, we will be contacting you by phone to provide more information. Please refer to the CDC <https://www.cdc.gov/> for daily updates on COVID-19.

NHF's Community Voices in Research (CVR):

My Bleeding Disorders Community (MyBDC) is now known as NHF's Community Voices in Research (CVR). This is a community-powered registry and archive created by the National Hemophilia Foundation (NHF), which provides a 360-degree view of living with a bleeding disorder from those affected while also including their unaffected family members.

It is a tool designed to encourage participants to become active partners in their healthcare.

It also helps to identify the community's research, educational and advocacy priorities.

This opportunity is available to you from the comfort of your own home by visiting this website- <https://www.hemophilia.org/Researchers-Healthcare-Providers/MyBDC>.

The first step is to click on *enroll* and take a brief 2-3 minute survey on demographics. You will then be prompted to sign the *Patient Agreement* electronically. In a few days you will be receiving an email with a customized *baseline survey* that will provide more detailed questions about living with a bleeding disorder. It is estimated to take about 20-30 minutes; however, you don't have to complete it all in one sitting. (Unaffected caregivers and children under 18 will receive their custom surveys later in 2020.) The last step of enrollment is where you will be receiving an email with a link to your personalized dashboard with educational resources, where you can see how you compare to other participants in CVR. You will also have access to a clinical trial finder. All participants remain anonymous to sponsors.



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

For more information or if you have any specific questions about CVR, please feel free to contact NHF's Research Nurse Specialist, Maria Santaella at msantaella@hemophilia.org.

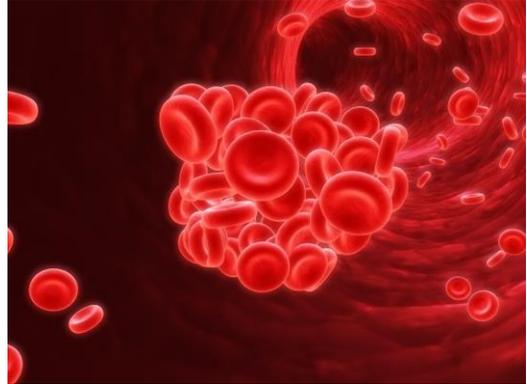
Deep Vein Thrombosis (DVT):

What is a DVT (Deep Vein Thrombosis)?

A blood clot is formed when blood turns from a liquid to a solid, in order to stop bleeding. A thrombosis occurs when a blood clot forms in a place that it is not supposed to form or gets bigger than it is supposed to. A **deep vein thrombosis** is when one of these clots forms in one of the large veins of the body, stopping the blood from passing through.

Signs/Symptoms of a DVT:

- Swelling in the arm or leg where the blood clot is located
- Red or discolored skin
- Low-grade fever
- Warm or hot skin
- More visible surface veins
- Aching or dull pain, tightness, or tenderness in the arm or leg where the blood clot is located
- Rapid heart rate



Risk Factors for forming a DVT:

- Inherited condition that increases risk (i.e. Factor V Leiden Mutation, Positive Lupus Anticoagulant, Prothrombin Mutation)
- Surgery
- A long period of bed rest or sitting/traveling for a long time
- Birth control pills or hormones
- Pregnancy
- Personal or family history of having a clot
- Central venous catheter

How is it diagnosed?

If your doctor suspects a DVT, they may order one of these tests: Doppler or Venous Ultrasound, MRI (Magnetic Resonance Imaging), or Venogram.

Depending on your risk factors, your doctor may also order bloodwork to find out if an inherited condition is present.

How is a DVT treated?

The type and length of treatment for a DVT will be determined by your doctor based on the different factors involved with the diagnosis.

The goal of treatment is to prevent the clot from growing, to prevent another blood clot from forming, and to ensure that the clot doesn't break off and travel to other parts of the body, including the lungs (i.e. pulmonary embolism).

Types of DVT Treatments:

- Medications: blood thinners (Enoxaparin (Lovenox), Warfarin (Coumadin). For patients over 18 years of age: Xarelto or Eliquis)
- Thrombolysis or "clot busting" is the breakdown of blood clots through infusion or using a catheter to actually break up or remove the clot directly

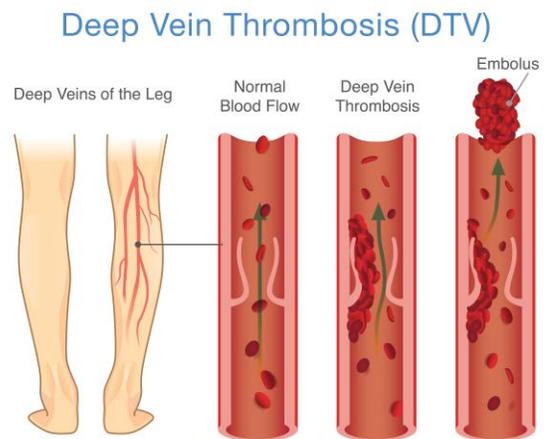
- Vena cava filter serves as a “clot catcher” placed in the vena cava (large vein which returns blood from the body to the heart)
- Removal of central venous catheter if DVT is related

Complications:

A DVT can be a serious threat to your health if it goes untreated or is not effectively treated.

One complication is that the blood clot could become so large that it blocks blood flow into the vein, causing the blood to back up. This may cause swelling, pain, and permanent damage to the arm or leg, which is called post-thrombotic syndrome.

Another complication is called a **pulmonary embolism**. This happens when a piece of the clot breaks off and travels through the bloodstream to the lungs. It can be fatal and should be treated immediately. Symptoms include: sudden shortness of breath, chest pain, anxiety, dizziness/ lightheadedness, low blood pressure, and palpitations.



If these symptoms occur, go immediately to the Emergency Department and contact your Doctor or thrombosis team.

Ways to prevent DVT:

- Taking blood thinners as prescribed by your doctor. Blood thinners may be prescribed during or after surgery to patients with a history of clotting to prevent DVT.
- Wearing elastic stockings to reduce swelling and promote circulation
- Stretching or walking every hour during long trips or long periods of sitting
- Adequate hydration

Precautions to take if you have a DVT:

Keep your entire care team informed of your diagnosis or your history of DVT.

Keep your entire care team informed if you are on blood thinners. It is especially important to let your thrombosis team know about upcoming surgeries or procedures.

Avoid estrogen containing birth control.

Avoid long periods of sitting. If it is necessary, be sure to exercise or stretch every hour.

Follow precautions involved with taking blood thinners.

Watch for signs/symptoms of any new clots forming and notify your doctor immediately if this occurs.

Always wear your MedicAlert bracelet/necklace. This keeps others informed of your diagnosis and medications.

Patient Story:



A **MedicAlert** is a bracelet or necklace which alerts first responders that there is an individual with a medical and/or cognitive diagnosis. When first responders contact MedicAlert, they will be provided with the person's name, diagnosis, medication, and dosing. This information is vital for the first responders to be able to properly care for the person wearing the MedicAlert.

Additionally, the MedicAlert company will notify your emergency contact listed, expediting the reunification and support to the wearer.

Meet Dominic. He is 15-years-old, and has hemophilia A. Dominic loves archery and playing golf, and wants to be an auto mechanic. He chooses to wear his MedicAlert necklace at all times. We interviewed him recently after he was involved in a serious car accident.

1. What is the importance of wearing a MedicAlert?

It is important to wear a MedicAlert bracelet or necklace in case you are involved in an accident or an emergency, and there is no one present who knows about your medical condition. Wearing a MedicAlert will help you to get the right treatment and medication you need if you are unable to speak. As Lisette (HTC pediatric nurse coordinator) always says, "You don't ever leave the house saying to yourself, today is the day I will have an emergency."



2. Dominic, can you please tell me about a time when your MedicAlert was beneficial?

My dad and I were recently driving home from dinner after celebrating my birthday, when another car hit us while we were turning at a light. I don't remember every detail because it happened so fast. But thankfully the paramedic noticed my MedicAlert necklace and was able to contact the hospital I was being sent to by ambulance ahead of time to let them know that I have hemophilia A and what type of medications I use. If I had been by myself or unable to speak, or if something worse happened to my dad, then my MedicAlert could have saved my life. In this case, my MedicAlert helped to accelerate services for me.

3. What motivates you to keep wearing your MedicAlert?

I am motivated to keep wearing my MedicAlert because I cannot predict the next time I will be involved in an emergency. I plan on attending college after graduating from high school, and I want to make sure that I am doing everything I can to protect myself while becoming more independent.

Thank you so much, Dominic for being a shining role model and for making smart choices by wearing your MedicAlert at all times!

MedicAlert:



people with bleeding disorders since 1996.

If you have not yet obtained a MedicAlert, you can receive one for free through your HTC with the help of the Hemophilia Foundation of Greater Florida (HFGF). The Hemophilia Foundation of Greater Florida, a chapter of the National Hemophilia Foundation, has been serving

We encourage all of our patients to obtain a Medic Alert and wear it at all times for your safety. You can contact your HTC social worker or HFGF directly to submit an application for a MedicAlert. Choose your own MedicAlert and HFGF will cover anything \$29.99 or under. To view a list of options, please visit the website for MedicAlert at <https://www.medicalert.org/>. In order for HFGF to cover the cost of your MedicAlert, the application must be submitted to your HTC social worker or HFGF directly.

Once you receive your MedicAlert, it's crucial to keep the information that you provide to MedicAlert updated including your diagnosis, medications, and emergency contact. If at any point in the year this information changes, please contact MedicAlert at 800.432.5378 to provide an update.

MedicAlert also needs to be renewed annually. The only time that you should be receiving mail from the company itself is when they are notifying you that your MedicAlert renewal is approaching. **Please do not disregard this notice! If it is not renewed, MedicAlert will not be able to assist in the event of an emergency.** Please contact your HTC social worker at 813.870.4017 or HFGF 407.629.0000 directly in order to renew your account, and if you have any questions.



Find Your Voice:

What does it mean to find your voice? It means having the courage to muster up every ounce of strength you have within to face a challenging issue by speaking your truth and sharing your story. It means knowing that your words carry high importance and value. It means understanding that your vulnerability is not your weakness. It means knowing that true strength is gentle. It means understanding the power of your words.

To quote Jane Goodall, “Every individual matters. Every individual has a role to play. Every individual makes a difference.”

How can you use your voice to become an advocate with insurance? Please take a moment to ask yourself these questions. Are you are having an issue with your insurance company not covering your bleeding disorder medication? Has your insurance company told you that you can no longer utilize your HTC’s 340B program?



We are here to tell you that it is your right to appeal your insurance company's decision to deny your medication coverage. You have the right to contact your insurance company and voice your concern. You can ask to speak with a supervisor or a pharmacy benefits manager’s supervisor, and you can be persistent in making multiple calls. We realize that this takes time-- a lot of time being placed on hold, and being transferred to more than one person. We understand that most people whom you will speak to throughout insurance do not realize the impact of their decision not to cover a medication or support the growth of your 340B program. We realize that the appeal process is not always a guarantee and it takes time. However, when more people make the effort to use their voice, we are more likely to see a change.

For those of you who are not familiar with what a 340B program is, it is a way for your HTC to purchase bleeding disorder medication at a reduced cost (mandated by the government) and supply our patients with the medication they need. The cost is reduced even more than what any commercial specialty pharmacy is able to negotiate. We are then able to save a tremendous amount of money for the insurance plan. It is also a way to provide all necessary services to our patients within the realm of the HTC and in turn adds to the comprehensive care model that has been a priority of the healthcare system.

Your HTC has a 340B program available through our specialty pharmacy called **BayCare Homecare** (BCHC). You have a right to advocate for your HTC by calling your insurance and telling them what a 340B program is and why it is beneficial to you or your family to support a 340B program. If you have commercial insurance and would like more information about 340B, or if you would like to see whether you are eligible to switch to using BCHC pharmacy, please contact your HTC pharmacist Lauren at 813.554.8292.

We are here to help, in addition to your local chapter organizations (the Hemophilia Foundation of Greater FL & Florida Hemophilia Association) who have formed a committee called The Bleeding Disorders Coalition of Florida (BDCF). BDCF is also doing a lot of work to reach out to your Florida state legislators about issues affecting the bleeding disorders community. But we need your help as well. Let’s work together to help make a positive difference.

Upcoming Community Events:

- **National Hemophilia Foundation**

<https://www.hemophilia.org>

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

- The NYLI is a two-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 or visit the website for details at <https://www.hemophilia.org/Events-Educational-Programs/NYLI>

- **Inhibitor Education Summit** (for Hemophilia A/B patients with inhibitors)

- ~~Friday, May 29 – Sunday, May 31, 2020: Denver, CO – Summit~~
postponed to November 20-22, 2020

- October 16-18, 2020: Denver, CO

- [Applications are open for both dates.](#) Applications close July 17th.

- <https://www.hemophilia.org/Events-Educational-Programs/Inhibitor-Education/Inhibitor-Education-Summits>

- **2020 Bleeding Disorders Conference**

- Transitioned to a virtual Bleeding Disorders Conference from August 1st through August 8th

- Registration and schedule details are available at

<https://events.hemophilia.org/ehome/index.php?eventid=385113&>

- **Hemophilia Federation of America**

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

- **HFA's Annual Symposium**

- Transitioned to a virtual conference

- ~~April 24-26th in Baltimore, MD~~ August 24-29, 2020

- Registration and schedule details are available at

<https://www.hemophiliafed.org/our-role-and-programs/national-community-events/annual-symposium/>



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- **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**
 - Event is in the process of transitioning to a virtual conference
 - June 26-29th
 - The foundation will also be hosting a virtual 5-week series of social, educational and support sessions using Zoom



- **The Coalition for Hemophilia B**

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

- **14th Annual Symposium**
 - Rescheduled dates are October 2nd-5th
 - Renaissance Orlando at Sea World
 - Register online at <https://www.hemob.org/symposium2020>



- **Hemophilia Foundation of Greater Florida**

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

- **Scavenger Hunt**
 - June 4th (via Zoom)
- **Bleeding Disorder Coalition of Florida legislative webinar**
 - Understanding the Committee Process
 - June 11th (via Zoom)



- **Star Search**
 - June 18th (via Zoom)
- **Annual Tampa Superhero Fun Walk**
 - Saturday, September 26th
 - Al Lopez Park at 4810 N. Himes Avenue, Tampa, FL 33614
- **Jacksonville Creepy Crawl 5K and Vampire Mile**
 - To be announced
- **Orlando Creepy Crawl 5K and Vampire Mile**
 - October 24th
- **Flight For Tomorrow Golf Tournament**
 - October 26th
- **Gator Clot Trot 5K and Fun Walk / Holiday Party**
 - December 19th
- Each week the foundation will also be hosting a series of social, educational and support sessions by using Zoom. For more information and to register for these events, contact HFGF at info@hemophiliaflorida.org or 1-800-293-6527

- **Florida Hemophilia Association**

<http://floridahemophilia.org/>

- **Dolphin Day Camp**
 - June 26th & July 10th
- **Florida Bleeding Disorder Conference**
 - July 24th-26th
- **10th Annual Unite for Bleeding Disorders Walk**
 - Sunday, September 13th
 - Tradewinds Park in Coconut Creek, Florida
- **Conferencia Latina**
 - October 2nd-4th
- **Lighten Up!**
 - November 15th
- For more information and to register for these events, contact FHA at admin@floridahemophilia.org or 305-235-0717



- **Camp Boggy Creek**

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

- **Camp Boggy Creek 2020 Summer Session**
 - ~~June 17-22nd~~ Transitioned to a virtual program beginning June 1st
- **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 virtual events.
- Please contact your HTC SW Adrienne (813)870-4017 for a list of specific events and to complete their new patient consent form.



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

