

# Updates from your HTC

News for Patients, Families and the Community.

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

### HTC Announcements

On September 24<sup>th</sup> we had our second HTC event of the year. With the help of Jhon Velasco who is a certified yoga and meditation instructor and the Manager of Education and Training at the National Hemophilia Foundation, we were able to introduce the health benefits of yoga to our patients. Yoga is one of the most ideal activities for persons living with bleeding disorders because it is low impact, builds flexibility and strengthens joints and muscles, helping to lower the amount of bleeds. Yoga helps to improve mental health by building confidence and decreasing stress. It can also help to improve coping skills with pain through breathing techniques and strength-building poses.



We would like to give a most appreciative thank you to our yoga instructor, Jhon Velasco, for taking the time to provide his support and education, to all of our patients and families who attended and participated at this event, and to Dr. Cockrell for her great ideas and efforts to help create events like this for all of our patients.

## von Willebrand Disease (vWD):

Von Willebrand disease (VWD) is a bleeding disorder in which the blood does not properly clot. There are many different proteins in the blood that are needed to help the body stop bleeding, and Von Willebrand factor (VWF) is one of these clotting proteins. People with VWD either don't have enough VWF or what they have doesn't work properly.

VWF plays two important roles in blood clotting. It allows platelets, which are cells used to build a clot, to stick to the wall of an injured blood vessel and to each other. Without it, a clot cannot be made. VWF is also called a carrier protein because it carries one of the clotting factors, factor VIII (8), with it. This means that it helps make sure there is enough factor VIII (8) in the blood and that it gets to where it is needed. Without VWF, factor VIII (8) will be broken down in the bloodstream and there may not be enough of it to stop bleeding.

### **Classifications of VWD**

Type 1	<ul style="list-style-type: none"><li>•Most common and mildest form.</li><li>•A person with Type 1 VWD has lower than normal levels of VWF and may also have low levels of factor VIII (8), which is another type of blood-clotting protein.</li></ul>
Type 2	<ul style="list-style-type: none"><li>•Body makes normal amounts of VWF but it does not work the way it should.</li><li>•Type 2 VWD is further broken down into 4 subtypes—2A, 2B, 2M, and 2N—depending on the specific problem with the person's VWF.</li><li>•Each type is treated differently.</li></ul>
Subtype 2A	<ul style="list-style-type: none"><li>•VWF levels can be normal or reduced. However, because of problem with the VWF protein, the platelets do not clump together well.</li></ul>
Subtype 2B	<ul style="list-style-type: none"><li>• VWF binds to platelets in the bloodstream, instead of binding at the injured blood vessel. Patients with this type may also have a low platelet levels.</li></ul>
Subtype 2M	<ul style="list-style-type: none"><li>•Binding of VWF to platelets is decreased.</li></ul>
Subtype 2N	<ul style="list-style-type: none"><li>•Binding of VWF to factor VIII (8) is decreased.</li></ul>
Type 3	<ul style="list-style-type: none"><li>•Most severe form of VWD; a person has very little or no VWF and very low levels of factor VIII (8).</li></ul>

## Diagnosis

Some people may have VWD for years and never know it. That's because they don't have symptoms, or their symptoms are so mild they're easily overlooked.

The signs and symptoms of VWD are similar in both men and women. Bleeding in persons with VWD usually involves the mucous membranes of the body. Many people may not be diagnosed because their symptoms are subtle, ignored, or believed to be caused by something else.

Some of these symptoms include frequent nosebleed, easy bruising, heavy menstrual bleeding (called menorrhagia) and prolonged bleeding after surgery, childbirth or dental work.

A combination of blood tests is needed to diagnose VWD. In fact, these tests may need to be repeated several times before a definitive diagnosis can be made. The amount of clotting proteins in the blood can change over time. Stress, exercise, inflammation, pregnancy, use of birth control pills, and thyroid problems can affect VWF levels.

## Treatment

Some treatments are given by injection, nasal spray, or pills. The treatment for VWD depends on the type and severity of the bleeding disorder. For minor bleeds, treatment might not be needed.

### **The most common treatments include:**

- Desmopressin acetate (DDAVP) injection: This medicine is injected into a vein or just under the skin to treat milder forms of VWD (mainly Type 1). DDAVP is the synthetic form of a naturally occurring hormone. It works by making the body release more VWF into the blood from storage sites along the blood vessel walls. This helps the body form a stable, firm clot and increase the level of factor VIII (8) in the blood
- Desmopressin acetate (DDAVP) nasal spray: This spray is the nasal form of the medication. This high-dose nasal spray is used to treat milder forms of VWD. It works by boosting the levels of VWF and factor VIII (8) in the blood.
- Factor replacement therapy: The plasma-derived clotting factor products used to treat VWD are rich in VWF and factor VIII (8). They are used to treat more severe forms of VWD or milder forms of VWD in people who do not respond well to DDAVP given either by nasal spray or injection. These clotting factor products are injected into a vein to replace the missing factor in the blood.
- Antifibrinolytic drugs: These drugs help slow or prevent the breakdown of blood clots. They are taken orally.
- Birth control pills (called oral contraceptives): The hormones in birth control pills can increase the levels of VWF and factor VIII (8) in the blood and reduce menstrual blood loss. A health care provider can prescribe these pills for heavy menstrual bleeding.

## Insurance Open Enrollment:



Open enrollment for marketplace health insurance begins Nov. 1, 2020, and continues through Dec. 15, 2020. Once enrolled, your coverage for insurance will begin Jan. 1, 2021.

Your HTC knows how important health care coverage is for you, so we wanted to put together some helpful information.

The Steps for Living website also provides a great page that gives a basic tutorial on what you need to know about insurance.

<https://stepsforliving.hemophilia.org/basics-of-bleeding-disorders/insurance/insurance-basics>

What you can do during open enrollment:

- You can renew your current individual/family health insurance plan.
- You can choose a new health insurance plan through the marketplace or through private insurance.

**If you are currently enrolled in a marketplace health insurance plan, your plan will not automatically renew itself.** You will need to go online or call the marketplace to renew your plan. However, the plan may also make changes to its provider network, copays, co-insurance and drug coverage. Your plan must send you a notice of any changes it will make for 2021.

Take time to read the notices you receive from insurance to see what it means for you.

Your prescription drug coverage could also change. The plan may no longer cover the drugs you take to manage your chronic conditions. It's important that you check your plan's drug benefits for 2021 before you allow it to renew. You may need to find a different plan for your needs during open enrollment.

Health plans must provide an online link to the list of drugs they will cover, known as formularies.

Here is the link to enroll in or renew your marketplace health insurance plan. You can contact the marketplace for questions about enrollment at 1-800-318-2596 (ext. 1, then say "representative").

<https://www.healthcare.gov/>

If you would like assistance applying for marketplace health insurance and/or learning about your other insurance options, please reach out to your HTC Social Worker Adrienne Abecassis.

## Clinical Research Update:

Our HTC has many clinical trials available for our patients, and we have just begun working on a project with American Thrombosis & Hemostasis Network (ATHN) for individuals with **Rare Coagulation Disorders (RCD)**. The goal is to work directly with ATHN affiliated HTCs and the laboratory services to document genetic data in the population of both pediatric and adult patients' with RCD. The project will enroll approximately 1,300 participants country wide. Participants must have an established RCD diagnosis, must currently receive care or have received care at an ATHN affiliated HTC, and must have opted into the ATHN dataset. After consent, one blood sample will be collected at the HTC and sent to the Center for Inherited Blood Disorders (CIBD) for genetic testing at no cost to the patient.

### ATHN 10 –Rare Coagulation Disorders that are included in this project:

- Factor I deficiency (Afibrinogenemia, Hypofibrinogenemia, Dysfibrinogenemia, Hypodysfibrinogenemia)
- Factor VII deficiency
- Factor XIII deficiency
- Bernard-Soulier syndrome (BSS)
- Glanzmann thrombasthenia (GT)

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 **HTC Research Coordinator Cindy Manis** at **813.357.0931** or [Cindy.Manis@baycare.org](mailto:Cindy.Manis@baycare.org). We are happy to discuss details with you in person or over the phone.

## Patient Story:

Meet Eric, Courtney and their beautiful baby boy Edison. Courtney's husband, Eric, has type III von Willebrand disease. Courtney recently shared with us that she has volunteered to train for and run in a half marathon to help raise awareness for bleeding disorders in honor of her husband. We interviewed her to find out more about what inspires her to live an active and healthy lifestyle.

1. At what point in time did you realize that you wanted to start training for marathons?

***I first heard about the Disney Princess Half Marathon in 2014, and I knew that I wanted to do something to give me motivation to lose weight- I wanted to cross the finish line!***

2. What was your motivation?

***My motivation to keep going has always been the idea of what I want my future to look like, and most importantly to be healthy for my son Edison.***



3. When does this half marathon take place and what type of half marathon is it?

***The 2021 Disney Princess Half Marathon takes place on February 21, 2021. It is 13.1 miles long and it crosses over the distance of Magic Kingdom, Epcot and Disney properties.***

4. Why did you pick this specific type of marathon?

***I want it to be my first half marathon since having the baby.***

5. How do you train for this marathon?

***I run 3 times a week (two short runs and one long run) while following the Jeff Galloway run-walk-run method! I also cross train with at-home workouts.***

6. What do you think will be some of the challenges you might face throughout the half marathon, and how do you think you might overcome them?

***February weather in Florida is super unpredictable. It might be freezing, or 85 degrees with 100% humidity.***

7. If you could pick one word to define your personal goal for the remainder of the year 2020, what would that word be and why?

***My word would be "persistent"- because I am determined to conquer this goal.***

Did you know that the Hemophilia Federation of America (HFA) also sponsors this half marathon event? If you would like to join Courtney and Eric by running for HFA's **Team Resilience**, please see the website for more information <https://www.teamhfa.org/Princess2021/>. Thank you so much, Courtney for being a shining role model and for your courage and strength in making your health a priority.

## 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 greatest impact a walk can have is that it creates awareness. It starts with one person who does not yet know what a bleeding disorder is and sees another person walking proudly with confidence while wearing a shirt that says the key words, which inspires others to ask the question- what is a bleeding disorder? It happens when an individual takes the time to talk to the community about what a bleeding disorder is-

whether it's to a teacher in school, a coach of a team, or to a young child. A seed is then planted that starts a chain reaction of events which at first may seem invisible, but in time gradually creates a profound understanding of how we can individually support one another in our differences through compassion.

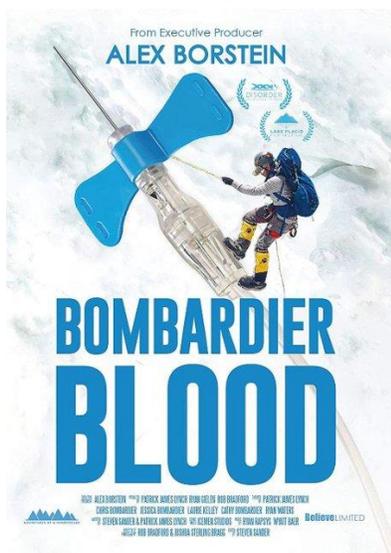
The Hemophilia Foundation of Greater Florida (HFGF) organizes a walk each year for the Tampa Bay area. Last year's walk successfully raised over \$40,000 and 91% of that revenue goes directly back towards helping to support those patients in our local HTC's. For example, our patients who are experiencing 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, those who seek one-on-one support learning how to self-infuse factor medication, 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.

Your HTC team, **The Clotting Crusaders**, are planning to participate in the walk this year virtually. You are welcome to join us online for the opening ceremony on **Saturday, November 14<sup>th</sup>**. HFGF will be sending us the link when we get closer to this event. You can pick a location nearby where you would like to walk- around your neighborhood, in a park, on the beach, or at home on a treadmill. HFGF will be giving away prizes for "**Most Creative Walk Location**", "**Most Steps Taken**", and more. You can also dress up by wearing your team t-shirts, costumes, or just show team spirit!

Please share this information with family and friends, local businesses, and organizations to help reach our donation goal <https://secure.ggiv.com/event/2020tampawalk/>.

We have already started planning the walk for next year as well, and we need your help coming up with great ideas. Please contact your HTC Social Worker Adrienne Abecassis if you have an interest in joining the HFGF Tampa Walk Planning Committee or if you have any questions about the walk.

## Upcoming HTC Event:



On January 6, 2018 Chris Bombardier became the first person with hemophilia, and one of less than 500 people in the world, to climb the Seven Summits. In the spring of 2019, your HTC brought you the opportunity to meet Chris himself and see the documentary, *Bombardier Blood*, that portrays his journey of self-discovery and truly speaks to what it is like living with a bleeding disorder- shining it's radiant light of inspiration into the hearts of those who watched. This film was so meaningful to us that we wanted to give you all the opportunity to watch it with us again, this time in a drive-in movie theatre. We are planning to hold this event in the winter when the weather gets cooler outside. For more information, please reach out to your HTC Social Worker Adrienne Abecassis 813-870-4017.

## 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](mailto: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)

- October 29, 2020- November 1, 2020 (virtual)
- <https://www.hemophilia.org/Events-Educational-Programs/Inhibitor-Education/Inhibitor-Education-Summits>



**NATIONAL HEMOPHILIA FOUNDATION**

*for all bleeding disorders*

1948-2018

- **Washington Days (Advocacy)**
  - March 3-5, 2021
  - Hotel information: Hyatt Regency at Capitol Hill, 400 New Jersey Ave NW, Washington DC 20001
  - For more information, contact NHF Alla Vaynshteyn, Conference and Travel Services Manager, at [avaynshteyn@hemophilia.org](mailto:avaynshteyn@hemophilia.org)

- ***Hemophilia Federation of America***

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

- **HFA's Annual Symposium**
  - October 2021 in San Antonio, Texas
  - Registration details to be announced at <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 (Virtual)**
  - October 9-11<sup>th</sup>
  - There is no charge for this event
  - Registration details at <https://hfmich.org/oct-9-11-2020national-conference-for-women-with-hemophilia/>



- ***vWD Connect Foundation***

<http://vwdconnect.org>

- **5<sup>th</sup> Annual vWD Connect Foundation National Type 3/Severe vWD Conference**
  - Details to be announced



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

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

- **14<sup>th</sup> Annual Symposium (Virtual)**
  - Rescheduled dates are for two weekends, October 2-5<sup>th</sup> and October 9-11<sup>th</sup>
  - Register online at <https://www.hemob.org/new-events/symposium-2020>
- **BEATS Music Program (Virtual)**
  - October 23-24<sup>th</sup>, 2020
  - Register online at <https://www.hemob.org/new-events/2020/10/23/virtual-beats-music-program>



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

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

- **Jacksonville Creepy Crawl 5K and Vampire Mile**
  - October 17<sup>th</sup>
- **Orlando Creepy Crawl 5K and Vampire Mile**
  - October 24<sup>th</sup>
- **Flight For Tomorrow Golf Tournament**
  - October 26<sup>th</sup>
- **Annual Tampa Superhero Fun Walk**
  - Saturday, November 14<sup>th</sup>
- **Gator Clot Trot 5K and Fun Walk / Holiday Party**
  - December 19<sup>th</sup>
- 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](mailto:info@hemophiliaflorida.org) or 1-800-293-6527



- **Florida Hemophilia Association**

<http://floridahemophilia.org/>

- **Conferencia Latina**
  - Details to be announced
- **Lighten Up!**
  - November 15<sup>th</sup>
- Contact FHA at [admin@floridahemophilia.org](mailto:admin@floridahemophilia.org) or 305-235-0717 to register



- **Camp Boggy Creek**

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

- **Camp Boggy Creek 2021 Summer Session**
  - Details to be announced
- **Camp Boggy Creek 2021 Fall Family Retreat Weekend**
  - Details to be announced
- Applications will be available online for the Summer Session by January 1<sup>st</sup>, and for the Fall by July 15<sup>th</sup>.
  - 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.



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