

Updates from your HTC

News for Patients, Families and the Community.



Our Team

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

HTC Announcements

In light of recent events surrounding the coronavirus disease COVID-19, we are reaching out to all of our patients and families to let you know that your hemophilia treatment center (HTC) is closely monitoring the Centers for Disease Control and Prevention (CDC) guidelines and making sure to implement safety precautions. At this time, our clinic is currently open and actively seeing patients. You can continue to contact your support team in the Center for Bleeding and Clotting Disorders, including your HTC nurse coordinator and social worker. We kindly ask that all of our patients who are scheduled to be seen by a hematologist 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. If you have an upcoming appointment, your clinic will be contacting you by phone (813)321-6820 to provide more information.

Please refer to the CDC <https://www.cdc.gov/> for daily updates on COVID-19.

We are also excited to announce that your HTC was able to connect with the office of Mayor Jane Castor and get a proclamation signed, which recognizes the month of March as **Bleeding Disorder Awareness Month** in the city of Tampa. You can see this proclamation hanging proudly on our walls when you come visit our clinic for your next clinic appointment. You can also view it online by checking out our new and improved website at <http://StJoesBleedingAndClotting.org/>.

Recent Event:

The month of March is **Bleeding Disorders Awareness Month**. March is all about movement- movement to create awareness and movement to live healthy active lifestyles.

What does bleeding disorder awareness mean to you, how do we bring about greater awareness in our daily lives, how do we create movement? Do we take time to explain to someone new what a bleeding disorder is and how it impacts an individual? Do we talk to our teachers, our neighbors, friends and other family members about bleeding disorders? Do we participate in bleeding disorder awareness walks?

On March 5th we had our first big HTC event of the year. We laughed and danced the night away at our HTC Zumba Event! Zumba *Gold* is a low impact combination of salsa and aerobics that is known to have long term health benefits, such as the improvement of strength and flexibility, range of motion, and cardiovascular fitness. Thank you wholeheartedly to all of our patients and families who attended and participated at this event.



Please feel free to reach out and share your personal experiences for how you and your family try to make a positive difference.

We would like to give a very big thank you to our fabulous Zumba instructor Terri Herrick, and to Dr. Cockrell for her great ideas and efforts to help create events like this for all of our patients. We also would like to take this time to recognize and show gratitude towards our local hemophilia support chapters- the Hemophilia Foundation of Greater Florida and the Florida Hemophilia Association- for providing your continuous support to our patients in everything that you do.

Dental Care for People with Bleeding Disorders:

Good dental habits are key to preventing dental problems for everyone. People with bleeding disorders are not more likely to have dental problems. However, they are at more risk for complications with poor dental care. Therefore, a routine of brushing, flossing and regular exams by your dentist twice a year is recommended to prevent gum disease and protect your teeth for your lifetime. Ideally, dental care should start at a young age, so a good preventative program can be set in motion from the start.

Preventing Dental Problems in Children

Dental care starts with newborns. They should have their mouths and gums gently cleaned with a soft gauze pad after every feeding. As soon as a tooth erupts, start brushing gently with water and a soft brush daily. Avoid putting your baby to bed with a bottle. When infants sleep with a bottle of milk in their mouth, it can cause tooth decay along with other medical concerns.

Since young children cannot brush their teeth well, parents should brush their teeth for them until they can do it themselves. Toothpaste should not be used until the child is able to spit it out (around 2 – 3 years old) since toothpaste should not be swallowed. At that time, you can add a pea-sized dot of fluoride toothpaste on a soft brush. Teach your child to rinse and spit the toothpaste out.

A child should see a dentist at 1 year of age to prevent dental problems and maintain a healthy mouth. Good preventative dental care can decrease the need for future procedures and dental surgeries. Tell your child what to expect before visiting the dentist, and try to make the experience fun.

Preventing mouth bleeds is challenging with babies and small children when they start to pull up and walk. Avoid play with hard plastic or metal toys. During the toddler years, injuries can occur if the child runs and falls with hard toys in their hands or mouths. In addition, children should be fed with plastic-coated spoons.

Parents shouldn't pull loose baby teeth. If there is significant bleeding from a loose tooth, please notify your HTC for treatment if a plan has not already been discussed.

Treating Mouth Bleeds

The gums (called gingiva), which are soft tissue, cover the bones surrounding the roots of the teeth. One of the early stages of gum disease (called periodontal disease) is gingivitis, a swelling of the gums caused by bacteria. One of the first signs of gum disease is spontaneous bleeding.

Gum disease is a much more difficult problem for people with bleeding disorders because they will bleed longer. Treating the bleed with clotting factor or other therapies may temporarily stop the bleeding but not the underlying gum disease; therefore, emphasis on prevention with flossing and brushing is imperative to prevent gum disease.

With a minor injury to the lips, gums or tongue, sucking on ice or a popsicle may help to stop bleeding. Bleeding from the mouth should be reported to the HTC since clotting factor and an anti-fibrinolytic medication may be required to stop bleeding.

If needed, the HTC will order an anti-fibrinolytic medication (such as Amicar or Lysteda) to have at home to use to treat mouth bleeds. An anti-fibrinolytic medication will help to maintain the clot until healing occurs. A clotting factor infusion may be needed to stop bleeding from a mouth injury.

Pain should be controlled with acetaminophen (Tylenol). **Avoid aspirin products or nonsteroidal anti-inflammatory drugs (NSAIDs, like ibuprofen, Motrin, Advil, Aleve) since these may cause bleeding.**

Call or go to the emergency room right away:

- If you or your child has bleeding from the tongue, cheek or from under the tongue that does not stop.
- If you or your child has significant trauma causing swelling or bruising on or under the tongue, cheek, throat or neck.
- If you or your child has difficulty breathing or swallowing.

Finding a Dentist

It is important that your dentist knows your diagnosis and the severity of your bleeding disorder along with the HTC contact information. They will also need to know about any allergies, your clotting factor replacement product, your other medications, and whether or not you have an inhibitor. Your HTC nurses are happy to help you find a dentist that knows about bleeding disorders. The HTC team can give your dentist information about your bleeding disorder.

If dental procedures are required, your dentist and hematologist can work together. Some dental procedures require pre-treatment with clotting factor or DDAVP and an anti-fibrinolytic medication (such as Amicar or Lysteda). Please contact your HTC in advance so that a plan of care can be made before your dental procedure or appointment.

ATHN Update:



Sisterhood App

Bleeding disorders such as Von Willebrand's disease and certain factor deficiencies can cause menorrhagia, which is heavy or prolonged menstrual bleeding. This can prevent you from performing your usual activities because you have so much blood loss and cramping.

The Sisterhood App is a tool and informational resource for women of all ages with bleeding disorders to track their monthly period cycles, symptoms, and treatment. This app will assist women in recording their cycles and communicating with their providers in order to receive the best possible treatment.

We are happy to announce this family-friendly app created by the Hemophilia Federation of America for women and teenagers with bleeding disorders has teamed with ATHN to provide our HTC patients who are enrolled in ATHN, the ability to share the information entered in the Sisterhood app with their ATHN Clinical Manager account.

If you are interested in utilizing the Sisterhood App and wish to share the data you have entered with ATHN, we have step-by-step instructions that can be provided at your next appointment. You can also request this information by email SJCHHTC@baycare.org and we can send the instructions electronically.



Patient Story:

Camp Boggy Creek is a unique camp designed and created with the intention of giving children with a medical condition between the ages of 7 and 16, the opportunity to have a true camp experience while under the care of medical supervision. Families are invited to join their child at camp in the fall, and our patients have the chance to spread their wings and become more independent during the summer.

Please meet McKenna! She is 8-years old and recently attended Camp Boggy Creek for the first time with her family during the Fall Family Retreat Weekend.

1. What did you think about Camp Boggy Creek overall, McKenna?

I loved it a lot, a lot. There were tons of activities, there were tons of people to make new friends, and I loved my pal who made sure that I was comfortable.

2. What activities did you participate in?

I got to participate in archery, the talent show, board games, fishing out on a paddle boat in the lake, and making crafts at the wood shop (such as a picture frame, coaster, and unicorn). I learned new songs too.

3. Did you meet/make any new friends?

Yeah! I got to meet Danielle who was a medical student and liked to play games with me. She was my pal who I got to hang out with for the entire weekend. I also got to meet a boy named Colter that was the same age as me and I got to do crafts with him, eat lunch with him, and do archery with him. He was my hopper buddy which is when you hop to get the food for the table. I also got to see him again outside of Camp Boggy Creek at an HFGF event.

4. Was there anything that worried you about going to Camp Boggy Creek? If so, what helped you to get rid of your worry?

I was shy at first because I wasn't sure I was going to make any friends because I didn't know anyone who was going. If I didn't have any friends, I didn't know who I was going to play with. Danielle and the activities helped me make new friends. The other thing that helped was participating in the icebreaker on the first night, because most kids didn't know one



another either.

5. Are you happy you attended Camp Boggy Creek?

Yes, I'm happy. On a scale of 1-10, it was a 10. I was really bummed when I had to leave.

6. Would you want to attend the Summer Session?

Positively, yes because I had so much fun at the other session.

Please meet McKenna's mom for her perspective on attending Camp Boggy Creek for the first time.

1. What did you think about Camp Boggy Creek overall?

It's super beneficial for kids with special needs to show them that they can still have fun with their disorder. I had a great time, it was an opportunity for our family to make memories together.

2. What activities did you most enjoy participating in?

I thoroughly enjoyed making crafts with my daughter and going out on the boat in the early morning and watching the excitement of my daughter catching a fish.

3. Did you meet/make any new friends?

Yes, I also became close with McKenna's pal, Danielle.

4. Was there anything that worried you about going to Camp Boggy Creek? If so, what helped to resolve those concerns?



I wasn't worried, I was just looking forward to a fun weekend.

5. Are you happy you attended Camp Boggy Creek?

Yes, it was a blessing to be able to go and get away from the regular daily stress.

Thank you both so much for taking the time to share your experience!!!

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)

- ***Applications for Inhibitor Education Summits are currently closed and summit dates will be postponed. Please visit the website for more information.***

- May 29th- 31st Denver, CO

- October 16th-18th Denver, CO

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

- **2020 Bleeding Disorders Conference**

- August 6-8th in Atlanta, Georgia

- Registration 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**

- ***Symposium is currently postponed.***

- April 23-26th in Baltimore, MD

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



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders
1948-2018



- **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**
 - Rescheduled dates are June 6th-9th
 - 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/>

- **Superhero Fun Walk Registration Party at Lightning Game is cancelled.**
- **Gene Therapy Information and Session Dinner in Tampa**
 - Tentatively scheduled for April 14th at 6 p.m.
 - Brio International Plaza



- For more information and to register for the event, contact HFGF at info@hemophiliaflorida.org or 1-800-293-6527

- **Annual Tampa Superhero Fun Walk**

- Re-scheduled for Saturday, September 26th
- 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/>

- **All March & April events are currently being postponed.**

- **Lighten Up Program**

- Fun, informative cooking and nutrition program
- April 19th at Johnson & Wales in North Miami, FL
- For more information and to RSVP contact admin@floridahemophilia.org or call 305.235.0717

- **2020 Unite for Bleeding Disorders Walk**

- May 3rd at 8 a.m.
- Tradewinds Park in Coconut Creek, Florida
- For more information and to RSVP contact admin@floridahemophilia.org or call 305.235.0717

- Stay connected for more information on the (B)LEAD: Action League of Bleeders- Teen and Young Adult Retreat July 2-5, and the Florida Bleeding Disorders Conference July 24-26.



- **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.



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