

# 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:  
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Pharm.D., BCOP

Research Coordinator:  
Cindy Manis, RN

Data Coordinator:  
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Physical Therapist:  
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## St. Joseph's HTC: What's New?

### HTC Announcements

At this time, we regretfully announce the resignation of our HTC Social Worker, Adrienne Abecassis. She has played an integral role on our team as well as a valued resource to the patients and families of our bleeding disorder community. Adrienne has been a trusted advocate for our patients always available to help in any way she can. Her compassion and ability to connect and support our patients with such ease is what has made her truly effective in this role. We wish Adrienne all the best in her future endeavors and want her to know she will be greatly missed by her team and the HTC community. This photo of Chris Bombardier & Adrienne Abecassis was taken by Dr. Cockrell at the NHF's 70<sup>th</sup> Bleeding Disorders Conference.



With this being the season of gratitude we would also like to give thanks to all of our patients and families who participated in this year's Tampa Superhero Fun Walk held by the Hemophilia Foundation of Greater FL (HFGF) on November 14<sup>th</sup>. Because of you, we were able to raise over \$29,000 and 79% of this money will go directly towards supporting the bleeding disorders community. Our team, the Clotting Crusaders also earned recognition for having had the most donors, which really shows how much our patients care about the importance of raising awareness.

## Protect Your Health:



This fall and winter it is likely that two viruses, influenza (flu virus) and COVID-19 (coronavirus 19), will both be spreading. Hospitals and healthcare providers could become very busy and overwhelmed treating both patients with flu and patients with COVID-19. Since there is no vaccine approved for COVID-19 at this time (Fall/Winter 2020), it is very important that you get the flu vaccine. This will help protect you and others and prevent unnecessary hospitalizations.

### **How are flu and coronavirus spread?**

Both viruses are mainly spread from person to person. When people are in close contact (within about six feet) of one another, an infected person produces respiratory droplets by coughing, sneezing, or talking. These droplets can land on the mouth or nose of the other person, be inhaled into the lungs, or land on an object or surface. When a person touches a contaminated object or surface then touches their eyes, nose, or mouth, the virus is spread to them. Frequently, COVID-19 is spread by people who are infected but are not showing symptoms.

### **How to protect yourself and others**

- Stay at home when you are sick.
- Wash your hands often or use a hand sanitizer that contains at least 60% alcohol. Avoid touching your eyes, nose, and mouth with unwashed hands.
- Avoid close contact from people inside your home who are sick.
- Stay at least six feet away from other people outside your home.
- Cover your mouth and nose with a mask when in public or when around people who don't live in your household. Masks should not be put on children under the age of two, anyone who has trouble breathing, or anyone who is incapacitated or unable to remove the mask without help.

- Always cover your mouth and nose when coughing or sneezing with a tissue or use the inside of your elbow.
- Clean and disinfect frequently touched surfaces at least daily.
- Monitor your health and be alert for symptoms. Watch for fever, cough, shortness of breath and take your temperature if symptoms develop. Call your doctor if symptoms develop to find out what you need to do next.
- Get your flu shot as soon as possible.

### **Does having a bleeding disorder put me at a higher risk for contracting or having more severe effects from COVID-19?**

No, bleeding disorders alone do not put you at higher risk for contracting or having more severe effects from COVID-19. Per the CDC, people of any age with certain health conditions are at higher risk for more severe illness from COVID-19. Those comorbidities often seen in patients with bleeding disorders include HIV, chronic liver disease, and inhibitor patients who have taken immunosuppressants, like Rituximab or Cellcept, within the last 12 months. Otherwise, persons living with hemophilia or other bleeding disorders would not fall within the category of increased risk.

For updates or more information on both the flu virus and COVID-19, please go to the CDC website at [www.cdc.gov](http://www.cdc.gov). Please also be aware that BayCare Health Systems has made changes to some of their policies, including the visitation policy, so please call our office or visit our website at [www.baycare.org](http://www.baycare.org) for more information.

# Stimate® Recall: What You Need to Know

## What is Stimate®?

Stimate® is the brand name for desmopressin (also known as DDAVP). It is a medication used in both von Willebrand Disease (VWD) and mild Hemophilia A. Desmopressin works by releasing the body's natural stores of von Willebrand factor and factor VIII (8). This helps stop bleeding for minor injuries. Desmopressin is available as an IV that must be given at the hospital or a nasal spray known as Stimate®, which can be taken at home.

## Why was Stimate® recalled?

On July 21<sup>st</sup>, 2020, Ferring Pharmaceuticals and CSL Behring made a recall for all batches of Stimate® made on December 15<sup>th</sup>, 2017 or later. Testing on Stimate® batches made outside of the United States showed higher than normal amounts of desmopressin and benzalkonium chloride (a preservative). These products could cause a higher number of adverse effects related to Stimate®, including low sodium in the blood (hyponatremia), headaches, swelling (fluid retention), and facial flushing.

## Is my supply of Stimate® included in the recall?

Each bottle of Stimate® includes a Batch/Lot number, which is located on the box it came with and directly on the bottle. Below are the Batch/Lot numbers with the expiration date included in the recall. Locate the Batch/Lot number on your product and see if it is included on this list.

Batch/Lot Number	Expiration Date
N14134C	July 31 2020
N15378G	September 30 2020
N17445N	December 31 2020
P11326AA	February 28 2021
P11326C	February 28 2021
P13209L	April 30 2021
P13212H	June 30 2021
P13755A	June 30 2021
P13756P	August 31 2021
R11845A	April 30 2022
R13271A	April 30 2022
R13648A	June 30 2022
R14101A	July 31 2022
R14667A	August 31 2022
R15953C	September 30 2022



### **What should I do if my product is included in the recall?**

- Contact CSL Behring's My Source program at 1-800-676-4266.
- Provide them with the patient's name and the Batch/Lot number of your Stimate® product.
- They will send a pre-paid FedEx envelope to ship your Stimate® bottle back to CSL Behring.
- If you bought your bottle of Stimate® after January 9, 2018, you may be eligible for some refund by CSL Behring.
- If you have already thrown out your Stimate® bottle, call the My Source program as you may still be eligible for a refund if you can provide proof of purchasing the Stimate®.

### **What if I think I have had side effects from a recalled product?**

According to the Food and Drug Administration (FDA), there has not been more reporting of harmful effects from Stimate® since the recall was announced. If you think you have experienced side effects or problems with a recalled Stimate® product, please report it to the FDA's MedWatch Adverse Event Reporting program:

- Online: <https://www.fda.gov/medwatch/report.htm>
- Fax: Download form 3500B at [www.fda.gov/MedWatch/getforms.htm](http://www.fda.gov/MedWatch/getforms.htm) and submit by fax to 1-800-FDA-0178
- Regular Mail: call 1-800-332- 1088 to request a reporting form, then complete and return to the address on the pre-addressed form

### **How can I replace my recalled product?**

Unfortunately, CSL Behring states that Stimate® may not be available again until 2022 at the earliest. Since the recall involved all batches, they do not have any medication left and must make more Stimate®. Contact your nurse coordinator for alternative products to use while Stimate® is unavailable.

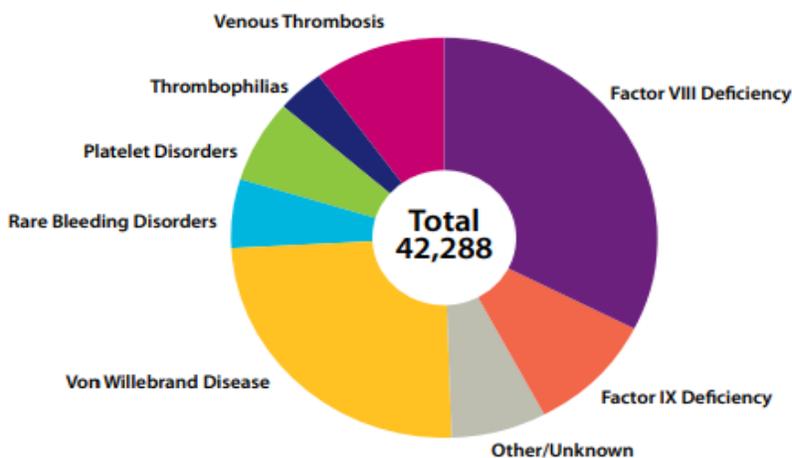
## ATHN Update:

St. Joseph's Hospital Center for Bleeding and Clotting Disorders is part of a group of Hemophilia Treatment Centers (HTC's) across the country called ATHN affiliates. There are over 135 HTC's that have teamed up with ATHN with the goal of improving the quality of life for people with bleeding disorders. ATHN provides a safe and secure national database following all HIPAA privacy guidelines to protect your confidentiality. Patient's names or identifying information will never be used in any reports produced as a result of studies or research using this data. Our HTC makes it a priority to approach and educate our patients about ATHN and its importance in research and improving patient outcomes.

In March of 2020, ATHN provided a research update which shows the growth in the ATHN Dataset participants since 2010. Additionally, demographic breakdowns were provided to give a snapshot of the patient populations we care for.

We want to share with you some of the results of this report to help you understand the importance of what the ATHN Dataset can provide to our researchers.

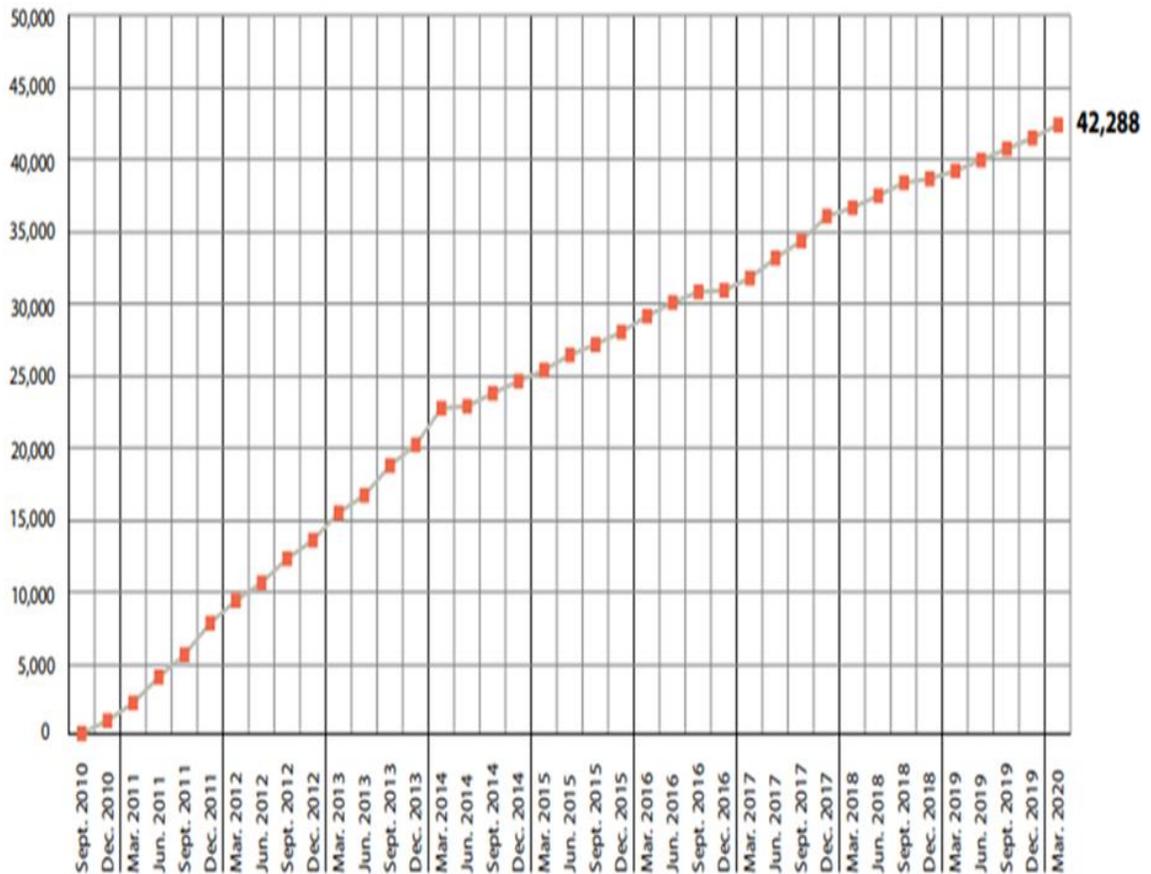
*Figure 1: Breakdown of Patient*



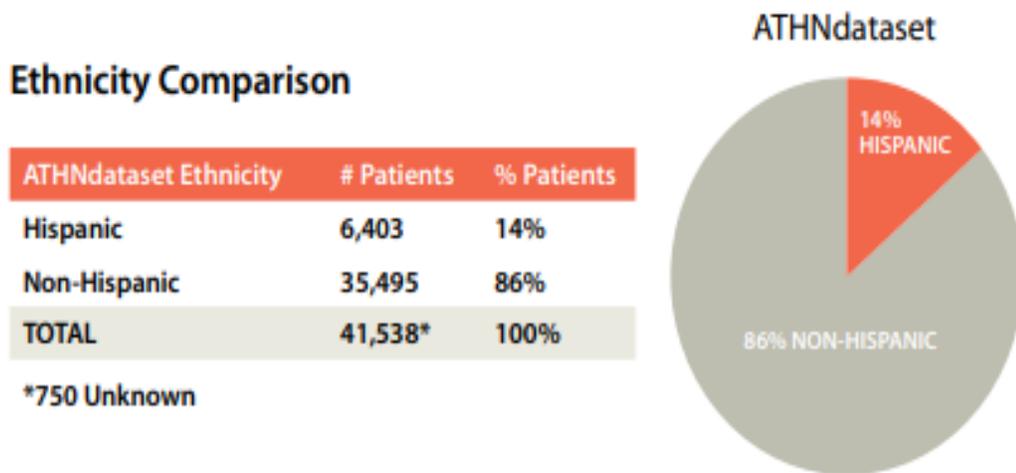
PRIMARY BLEEDING OR CLOTTING DISORDER	% ATHNdataset
Factor VIII Deficiency	32.53%
Factor IX Deficiency	9.80%
Von Willebrand Disease	24.60%
Rare Bleeding Disorders	5.63%
Platelet Disorders	6.54%
Thrombophilias	3.67%
Venous Thrombosis	9.93%
Other/Unknown	7.30%
<b>TOTAL</b>	<b>100%</b>

**Figure 2: Growth in ATHN Dataset participants**

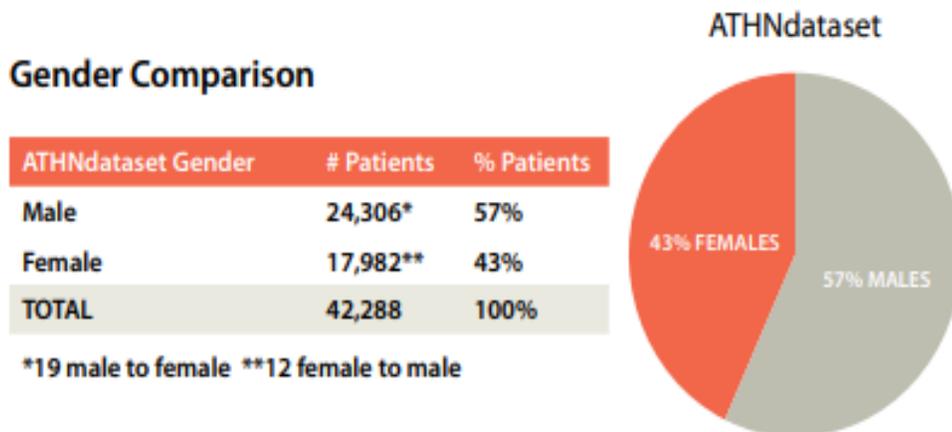
ATHNdataset	PATIENT ACCRUAL OVER TIME (AS OF MARCH 31, 2020)
The ATHNdataset is a HIPAA-compliant limited data set under the stewardship of ATHN.	
Participating hemophilia treatment centers across the U.S. abstract data from the medical record.	
Patients choose to "opt in" by signing a patient authorization.	
No special lab tests or clinic visits are required.	
Patient identity is protected through the use of a unique system-generated identifier.	
Since December 2010, the ATHNdataset has grown to include 42,288 patients.	



*Figure 3. Ethnicity Comparison*



*Figure 4. Gender Comparison*



The St. Joseph's Hospital Center for Bleeding and Clotting Disorders clinical team wish to thank you for consenting to the ATHN Dataset and making it a priority in your care so we can utilize this information to improve patient outcomes.

## Patient Story:

Meet Kim. Both Kim and her beautiful son Alex each have hemophilia. Kim recently shared with us that she has trained for and ran in the 2020 Gasparilla Distance Classic to help raise awareness for bleeding disorders. We interviewed her to find out more about what inspires her to live an active and healthy lifestyle.

1. In what ways does having a bleeding disorder impact your life? How did you train for the Gasparilla Distance Classic? (e.g. diet, physical activity, specialists, resources)

*Having a bleeding disorder plays a significant roll in how I approach my physical activities. I must be conscientious about everything that affects my body, including the mind. We must not forget how important the mind is when participating in events and in life. I know that I must listen to my body and understand my specific needs.*

*Getting the proper nutrition to feed my muscles and also stay at a healthy weight to make moving easier on my joints is very important, especially with moderate hemophilia. This is one of the biggest challenges for me, having grown up with a very different way of thinking about food. I have really worked on (and continue to work on) changing my mindset about food. The phrase that 'should' come to mind before eating is: "How will this benefit my body?" I still do struggle with this, but I am certainly doing much better than in the past.*

*Of course, while having hemophilia, another extremely important thing to know is when to infuse factor. I grew up in a time of "on-demand" treatment, only infusing after knowing a bleed was happening. I am now well aware of when I need to use factor prior to physical activity. Prophylactic treatment is beneficial to keeping healthy joints.*

*Taking care of our emotional and mental well-being is one of the most important things we can do for ourselves. If we have the right mindset, we can make better choices for our physical bodies. I believe we should take care of our minds prophylactically as we do our physical bodies. We have (or should have) regular check-ups with our physicians for our physical well-being, but often disregard our mental well-being. I find it very helpful and important to talk with a therapist on a regular basis.*

2. At what point in time did you realize you wanted to start training for marathons? What was and is your motivation?

*In 2009, my husband and I decided we needed to make some changes to our lifestyle to become healthier people, not only for ourselves, but also for our son who is our motivation. Our son has many special medical needs so; we must make it a priority to take care of ourselves in order to be able to take care of him.*



***I started training with swimming and eventually added cycling and running as I felt my joints could handle it. I started with 5K races and worked my way up in mileage very gradually. My first Half Marathon (13.1 miles) was the Melbourne Music Half Marathon in February 2012. The first and only Full Marathon (26.2 miles) to date was the Walt Disney World Marathon in January 2015. I have now completed 23 Half Marathons, with a few on the books in the upcoming months.***

3. What dates did the Gasparilla Distance Classic take place and what type of race was it?

***The Gasparilla Distance Classic in 2020 was February 22 & 23. The Gasparilla Distance Classic is a weekend of 4 races (Saturday includes a 15K & 5K, Sunday includes a Half Marathon & 8K) and there are many different challenges to choose from. Runners can decide to run in 1 or multiple races.***

4. Why did you pick this specific type of marathon? Throughout the Gasparilla Distance Classic 2020, what were some of the challenges you faced and how did you overcome them?

***In the previous 3 Gasparilla weekends I have participated in, I have opted for the challenge that includes the 15K & 8K (1 race each day). For the 2020 Gasparilla Distance Classic, I opted to undertake all 4 races (30.5 miles running in 2 days). I am not a fast runner, so finishing the first race of each day to start the second race on time was something I had to defy, especially on Sunday, as the Half Marathon was before the 8K. After having run 12.4 miles the day prior, it was certainly difficult for me to complete the Half Marathon in the allotted time. I did it, but with only about 5 minutes to spare.***

***This was something I wanted to prove to myself I could accomplish, if I set my mind to it. I do not feel competitive with other people, but I do like to see what I am able to do myself. Many doctors from my past have tried to set limits, but I always wonder if I am able to overcome them? Is my body able to accomplish something if given the right circumstances, fed the right foods for the physical part, fed the right attitude for the mental part?***



5. What is the significance of the words "functional" and "athlete" for you personally throughout this year?

***I like to use the term "functional athlete" because to me, it means whatever it takes for me to keep moving and have less bleeding. My body must be "functional" to perform any task I am expecting of it. Being an "athlete" to me, means I am doing my best to be strong, which naturally leads to being "functional". I must eat foods that fuel my body appropriately. I must think with positivity to continue on the path of expansion and well-being.***

(Left): Kim running her first 5K with her amazing son Alex. Thank you so much, Kim for being a shining role model and for your courage and strength in making your health a priority.

Did you know that the Gasparilla Distance Classic is scheduled to take place February 20-21, 2021? Please see the website for more information <https://rungasparilla.com/>. If you or a loved one would be willing to share your inspirational story, please feel free to reach out to your HTC Social Worker.

## 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>

- **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**

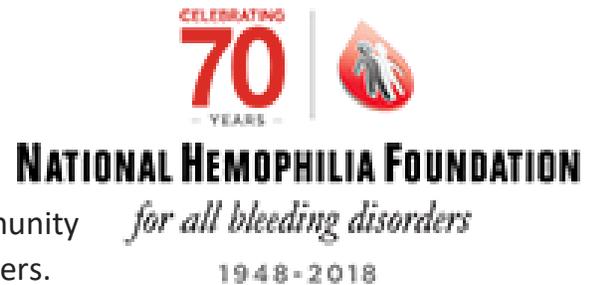
- October 2021 in San Antonio, Texas
- Registration details to be announced at <https://www.hemophiliafed.org/our-role-and-programs/national-community-events/annual-symposium/>

- **Hemophilia Foundation of Michigan**

<https://hfmich.org/>

- **2021 National Conference for Women with Hemophilia**

- Details to be announced



- ***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)**
  - Details to be announced



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

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

- **Virtual Family Bingo Night**
  - December 17<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/>

- **Details on events for 2021 to be announced**
- Contact FHA at [admin@floridahemophilia.org](mailto:admin@floridahemophilia.org) or 305-235-0717



- **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**
  - September 11-13 virtual retreat
- Accepting applications now online for the Fall Family Retreat Weekend!
  - Parent(s) need to fill out the online application first, then contact the HTC Social Worker (813)870-4017 who will help to submit a 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 (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!*

