

# 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

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Pediatric Bleeding  
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Coordinator:  
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## St. Joseph's HTC: What's New?

### Team Member Announcements

Dear patients,

It is with great sadness that we announce Lena Charafi, our HTC Clinical Pharmacist, has recently accepted a new position outside of BayCare. We are beyond grateful for the many outstanding accomplishments she has contributed to our HTC including: expansion of our 340B program, her perseverance to obtain a signed "Proclamation" by Mayor Bob Buckhorn to recognize April 17th as World Hemophilia Day, her dedication to advocacy work during Legislative Days with the Bleeding Disorders Coalition of Florida, as well as ongoing support and devotion provided to our HTC patients and coworkers.

While we are working diligently to find the best pharmacist to fill this position, we hope that you will join us in wishing Lena all the best in her upcoming endeavors.

We will also continue to work closely with the Mayor's office to get a proclamation signed which recognizes the month of March as Bleeding Disorder Awareness Month in the city of Tampa. Please stay tuned for more information on different ideas we have been working on to help advocate for the bleeding disorders community.



## Recent Events

Thank you to all of our teens and families who participated in the Hemophilia Foundation of Greater Florida's recent Teen Event from July 19<sup>th</sup>-20<sup>th</sup>. We had a great time getting to know other families throughout the community, and providing resources regarding ways to help transition your child into becoming independent in managing their health care. If you were not able to attend and would like to receive more information on transitioning, please feel free to reach out to your HTC Social Worker Adrienne Abecassis at 813-870-4017. Also, if you would like to see pictures from the event, please visit the Hemophilia Foundation of Greater Florida's website at <http://www.hemophiliaflorida.org/> and click on the link to Facebook on the top right corner.

## FYI

Speaking of transition, did you know that we created a series of transition surveys, which consist of age appropriate questions for both you and your child to answer individually? Although our center is unique in that we provide care for our patients from childhood through adulthood, we make it a priority to provide an intensive transitioning program to prepare our patients to become proficient in self-care and utilize the support and resources available to them. We start by offering this survey at around age 9 and the information gathered is utilized to help inform our medical team on which areas would be the most useful to discuss during clinic appointments. The questions are geared towards testing your child's knowledge about their bleeding disorder, and our goal is to help empower your child to gradually learn how to manage their health.



Part of the responsibility of transitioning also includes understanding the importance of having health insurance and learning how to carefully select the best plan during open enrollment.

That is why we are creating an opportunity for *all* of our patients to join us for dinner here in the Medical Arts Building of St. Joseph's Hospital at our next HTC event. We want to give you a chance to learn more about insurance, and provide education on how to choose the best plan for you and your family.

The **HTC Insurance Event** is set to take place on **Thursday, October 17<sup>th</sup>, 2019** from 5:30 p.m. - 7 p.m.!!! Please RSVP now by contacting your HTC Social Worker.

## Inhibitors:

Some people with hemophilia and von Willebrand disease (VWD) type 3 can develop inhibitors. Inhibitors make it more difficult to stop a bleeding episode because they prevent the treatment from working.

An **inhibitor** is a major complication of hemophilia. Normally the body's immune system works to fight off infections that can cause illnesses. Sometimes, however, the immune system attacks the wrong target. An inhibitor develops when the body's immune system does not recognize the infused factor as a normal part of the blood. Instead, the immune system thinks that the factor is a foreign invader, like a virus or a germ, and it develops antibodies designed to attack the factor and immediately destroy it. So even when infused, the patient with an inhibitor continues to bleed. This can lead to serious, even life-threatening bleeding episodes. Patients or parents may suspect that something is wrong, usually when a bleed will not resolve, or takes significantly longer to resolve after an infusion of factor.

Inhibitors are relatively uncommon. They occur in 15-20% of people with hemophilia A (factor VIII deficiency) and 2-5% of people with hemophilia B (factor IX deficiency). Any person with hemophilia and VWD type 3 are at risk of developing an inhibitor. Scientists do not know exactly what causes inhibitors. Multiple research studies have shown that people with certain types of hemophilia **gene mutations** are more likely to develop an inhibitor. Some studies have found other characteristics that possibly play a role in increasing the risk of inhibitor development among people with hemophilia. These include the following:



- Number of times one has used clotting factor concentrates in their lifetime,
- Increased frequency and dose of treatment,
- Black race or Hispanic ethnicity, and
- Family history of inhibitors (other family members who have had inhibitors).

Treating people with an inhibitor is complex and remains one of the biggest challenges in hemophilia care today. Inhibitors that persist can increase the risks associated with bleeding episodes because factor therapy is less effective. Some treatments for people with inhibitors include the following:

- **High-Dose Clotting Factor Concentrates:** People with low titer inhibitors may be treated with higher amounts or increased frequency of factor to overcome the inhibitor and yet have enough left over to form a clot.
- **Bypassing Agents:** Special blood clotting products, called bypassing agents, are used to treat bleeding episodes for people with high titer inhibitors. Instead of replacing the missing factor, they go around (or bypass) the factors that are blocked by the inhibitor to help the body form a normal clot.
- **Products that mimic Factor VIII:** This type of product works by replacing the function of factor VIII (8) without being affected by inhibitors, and can be used to prevent bleeding episodes in people with hemophilia A. This treatment product can be given by injection under the skin.
- **Immune Tolerance Induction (ITI) Therapy:** The goal of ITI therapy is to stop the inhibitor from blocking factor in the blood and to teach the body to accept factor as a normal part of blood. With ITI therapy, people receive large amounts of factor every day for many weeks or months.

Treating bleeds for someone with an inhibitor may be very frustrating for the patient and family because it may require a variety of treatments and much time. It is extremely important that patients and parents work very closely with the HTC to manage bleeding episodes and treatments. The team can offer both medical advice and emotional support for dealing with this major complication.



## ATHN Update:

St. Joseph's Hospital Center for Bleeding and Clotting Disorders is committed to improving and providing optimal patient care to the individuals affected by bleeding and clotting disorders. Our HTC is a center of excellence providing multidisciplinary care and we believe partnering with ATHN as an affiliate has been instrumental in research aimed at improving the quality of care of our bleeding and clotting disorder community.

When our HTC team approaches you in regards to participation in ATHN, we are inviting you to join in a national effort to collect information which can help advance our knowledge and understanding of bleeding disorders. This valuable information can be utilized to focus on research studies, genetics, clinical and socioeconomic issues involved with these disorders as well as impacting the safety of FDA approved medicines for our patients. When you consent to participate in ATHN, rest assured your HTC follows all HIPPA privacy guidelines to protect your confidentiality thus identifying information will never be used in any reports generated as a result of using this data.

Participation is the key to achieve these goals... as one of our HTC physicians stated "Participation defines a database's success: the more the community supports it, the more it can give back." Our HTC is excited to report our patient participation in ATHN continues to grow and that is because of you and your involvement in this effort. In 2013, 21% of our active patient population consented to participate in ATHN. Today, with the growth of our patient population as well as our HTC team, an estimated 81% of our active patient population is now consented for ATHN, which is an amazing achievement! We commend you for being part of the solution to improve clinical outcomes.



## Clinical Research Updates:

As you know, our HTC has so many exciting clinical trials available for our patients.

The **ATHN 7: Hemophilia Natural History Study (ATHN 7)** is a new observational, minimal risk study that will enroll approximately 280 subjects and follow patients with hemophilia A or B, as they receive hemophilia treatment for 4 years.

The primary objective is to determine the safety of non-factor products, bypassing agents or clotting factor replacement products when used for people with hemophilia with or without inhibitors. The total study duration is planned for 6 years. Safety will be measured by those events listed in the European Hemophilia Safety Surveillance (EUHASS).

The treatment regimen will be at the discretion of the patients' HTC caregivers. No treatment products are being provided by the study nor will the participants be paid. However, inhibitor titer testing will be provided at no cost to patients by the Center for Disease Control and Prevention (CDC). Participants that participate in this study, will co-enroll into the ATHN dataset study.

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



## BayCare Medical Group Clinic Updates:

The following information only pertains to those patients who have FL Medicaid Children's Medical Services (CMS) Wellcare.

You may already be aware that CMS as of February 1, 2019 is now operated by Wellcare. However, our clinic was just recently informed that **we will no longer have a contract with CMS** as of September 30, 2019. Our HTC would like to take a proactive stance to help our patients continue to receive care within our clinic. If you would like to change your son/daughter's insurance to a different plan our clinic accepts, and receive information on the difference between each plan, please feel free to contact the **Medicaid Choice Counselor Help Line at 877-711-3662.**

Our clinic will continue to accept the following Medicaid plans year round- FL Medicaid Staywell, Staywell Kids, Sunshine Health, Sunshine Health Healthy Kids, Simply Health Care, and Simply Health Care Healthy Kids. Please note that if you make a change to insurance before October 15<sup>th</sup>, then the change will become effective by November 1<sup>st</sup>. However if you make a change by selecting a different plan after October 15<sup>th</sup>, then the change will become effective on December 1<sup>st</sup>.

Thank you so much for your overall patience during this transition.

If you have any insurance-related questions, please contact your HTC Social Worker at your earliest convenience.





## Patient Story: Amelia

Last October, we held an exclusive HTC Health and Wellness event where we invited a very well-known and highly respected member of the bleeding disorders community and Tai Chi instructor Rick Starks to join our physical therapy team and help educate our patients on the importance of living an active lifestyle.

We have a patient who attended this event and has since then gone above and beyond towards accomplishing her personal goals. We wanted to send her a huge HTC Shout Out for all of her hard work and dedication. She has recently been accepted by a competitive summer internship program on June 1, 2019 and learned how to become an advocate for the bleeding disorders community. She also earns high academic scores while attending college at the University of South FL and continues to maintain her honors level scholarship.

Please meet Amelia! She is 20-years old and from Tampa, Florida.

1. What year are you in school? What is your area of focus in school? What scholarship(s) have you been approved for?

*I am currently in my senior year of college, pursuing a bachelor's in science in Cellular and Molecular Biology along with a minor in psychology. I have been approved for the USF Directors academic award (4-year) and the Bright Futures Academic scholarship (4-year).*

2. How did you find out about this summer internship opportunity? How many other candidates did they select for that program?

*I found out about this internship from a pharmacy representative centered in Florida along with research on the program within the company's website. Only two other young adults were selected to participate in the internship.*





3. How many days in total was the internship, and what was the agenda?

*It was an 8-week internship program and the hours were from 9 a.m.-5 p.m. at the corporate headquarters in New Jersey. Travelling also occurred, during weekdays and some weekends.*

4. Where did you travel to, and can you tell us about what you learned in each place?

*I travelled to Dallas, Texas to the state chapter hemophilia symposium. I observed different company booths and assessed their methods to promote awareness of the bleeding disorder community. This helped me to understand competitive assessment and the ways different companies advertise their product.*

*I was then able to go to Boston and meet with members of the New England Hemophilia Association chapter and the Save One Life organization. This was a valuable look into the life and issues of leaders within the Hemophilia community. I was informed about different leadership roles and decision-making challenges. I was even given inspirational advice to help guide me for future career goals and personal accomplishments. For example, I was shown how Save One Life aims to increase global awareness. So many people around the world are not being diagnosed due to a lack of healthcare and treatment options. Some parts of the world do not even have basic essentials such as ice. When I become a health care professional, I hope to help travel to other countries and treat others (or even help with raising awareness).*

*I took several trips to New York City and met with NHF (National Hemophilia Foundation), and visited the advertising agency for their company. It was there that I viewed competitive assessments (specifically on social media) and discussed the process of making advertisements and reaching out to the bleeding disorder community.*

*Lastly, I travelled to Washington D.C and met with HFA (Hemophilia Federation of America) and discussed the history of HFA, current work in the community, the HFA annual meeting in San Diego this past April, and the multiple programs offered to the youth and families affected by hemophilia.*

5. What was the most valuable lesson you took from this opportunity?

*The most valuable lesson that I learned from this internship is to take advantage of opportunities that are given to me, along with not letting others influence my decisions. This experience gave me the chance to work with individuals from different*

*professional backgrounds and experiences (ranging from marketing to STEM), allowing me to understand the significance of using different perspectives to solve problems and assess situations.*

*\*STEM is an educational curriculum based on the four principles of science, technology, engineering and math.*

6. What do you hope to do for a career long-term?

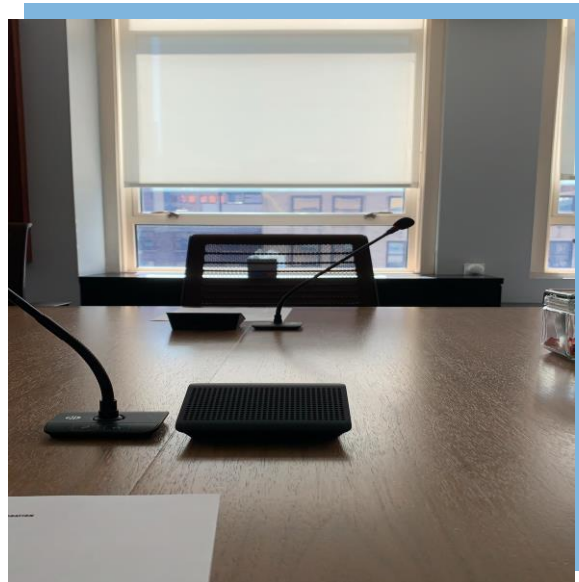
*I hope to attend medical school in the near future and become a physician. I am not currently sure what specialty; however, I am very interested in hematology-oncology and pediatrics.*

7. What advice would you give to someone else who is considering doing a similar internship as well?

*To always be confident in yourself and to not be scared of saying your opinions and different perspectives. Additionally, I learned the importance of taking advantage of the opportunities offered within the internship, especially in situations that allowed myself to gain knowledge and experience.*

Thank you so much for sharing your story, Amelia! 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.



## Upcoming Community Events:

- **National Hemophilia Foundation**

<https://www.hemophilia.org>

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

- The NYLI is a three-year program designed to assist young people ages 18-24 from the bleeding disorders community to become well-trained, recognized leaders.

- Applications are due by October 31<sup>st</sup> at

- <https://www.hemophilia.org/Events-Educational-Programs/NYLI>

- Contact Education Specialist Marlee Whetten at [mwhetten@hemophilia.org](mailto:mwhetten@hemophilia.org) or call 212.328.3735

- **2019 Bleeding Disorders Conference**

- October 3-5<sup>th</sup> in Anaheim, California

- Registration is now open

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

- **Red Tie Runners for 2019 TCS New York City Marathon**

- November 3<sup>rd</sup> in NYC

- 26.2 mile marathon

- Contact Dilber Karamanci at [dkaramanci@hemophilia.org](mailto:dkaramanci@hemophilia.org) or call 212.328.3731

- Register online at <https://www.hemophilia.org/How-You-Can-Help/2019-TCS-New-York-City-Marathon>

- **Hemophilia Foundation of Michigan**

<https://hfmich.org/>

- 2019 National Conference for Women with Hemophilia

- November 1st-3<sup>rd</sup>

- The Westin Hotel at The Detroit Metropolitan Airport 2501 World Gateway Place, Detroit, MI 48242

- Register online by October 4<sup>th</sup> at

- <https://form.jotform.com/82285355483161>



- **Hemophilia Foundation of Greater Florida**

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

- **Jacksonville Creepy Crawl**
  - October 12<sup>th</sup>
  - Register online at <https://secure.ggiv.com/event/201jacksonvcreec/>
- **Orlando Creepy Crawl**
  - October 26<sup>th</sup>
  - Register online at <https://secure.ggiv.com/event/201orlcrecra/>
- **23<sup>rd</sup> Annual Flight for Tomorrow Invitational Golf Tournament**
  - October 28<sup>th</sup>
  - 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](mailto:rhonda@brmgroupp.us)



- **Florida Hemophilia Association**

<http://floridahemophilia.org/>

- **Health Insurance Roadmap**
  - September 26<sup>th</sup> from 6:30 p.m. to 8:30 p.m.
  - Dolores Lolita at 1000 South Miami Avenue, Miami, FL 33130
  - For more information and to RSVP contact Caitlin Losa at 305.243.0834 or [CSL70@med.miami.edu](mailto:CSL70@med.miami.edu)
- **Guy's Day Out at Topgolf**
  - September 29<sup>th</sup> at 1:45 p.m.
  - 17321 NW 7<sup>th</sup> Avenue, Miami Gardens, FL 33169
  - For more information and to RSVP contact [admin@floridahemophilia.org](mailto:admin@floridahemophilia.org) or call 305.235.0717



- **The Coalition for Hemophilia B**

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

- **14<sup>th</sup> Annual Symposium**
  - March 19<sup>th</sup>-March 22<sup>nd</sup> 2020
  - Renaissance Orlando at Sea World



- Apply for a Travel Grant by September 27<sup>th</sup> at <https://static1.squarespace.com/static/566b210340667a1cc1623840/t/5d7aef80ec71ca18222f2b27/1568337792976/2020+Travel+grant.pdf>

- **Camp Boggy Creek**

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

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

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