

the clotting times



news for patients, families and the community

winter 2017

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Carrier Testing for Hemophilia



UPCOMING 2017 EVENTS

February 10
Hemophilia of Indiana, Inc.
Hearts for Hemophilia Gala
Union Station Grand Ballroom

Month of March
Bleeding Disorders
Awareness Month

April 17
World Hemophilia Day

June 11-16
19th Annual Camp Brave
Eagle

 **INDIANA
HEMOPHILIA &
THROMBOSIS
CENTER, INC.**
helping patients thrive

Carrier testing for hemophilia is now being offered **for free** at the Indiana Hemophilia & Thrombosis Center through the *My Life, Our Future* program to females who have a son, father, brother, uncle, grandchild, or cousin with hemophilia.

According to the *My Life, Our Future website*, leaders in the hemophilia community, like the IHTC, have come together to offer free genotyping, so that you may gain a deeper understanding of your hemophilia today. Their goal is to genotype as many people as possible who are affected by hemophilia in the U.S.

Genetic carrier testing is the most accurate way for women to learn whether they are or are not carriers of hemophilia. Knowing your carrier status allows you to plan for your medical care and know your bleeding risks, and learn your choices and options regarding having a child with hemophilia.

Genetic testing could be right for you if:

- You aren't sure if you are a carrier of hemophilia, and want to know
- You know you're a carrier, but none of the men in your family with hemophilia have had genetic testing
- You had clotting factor levels in the past and were told that you were or were not a carrier based on your levels, but you would like more accurate testing

This free genetic testing will be available at the Indiana Hemophilia & Thrombosis Center for one year. If you would like to schedule an appointment to have carrier testing or would like to learn more, please contact Meadow Heiman or Kristen Dieter, the IHTC's genetic counselors.

Do You Know The Right Questions to Ask?

WHAT DO I ASK?

MY EMPLOYER

Does my insurance have any specific restrictions? Check to see if you are required to use a specific doctor, medical facility, or pharmacy.

MY INSURANCE NETWORK

Is the doctor and/or hospital in my insurance network? Many times your doctor will know, but you can always check with your health insurance provider.

ABOUT MY FINANCES

Do I have a copay? Have I met my deductible? What is my out of pocket (OOP) limit? If you have any concerns about your medical spending, call your insurance provider and get answers.

MY FAMILY

Do we know our insurance information and details? Always review your materials before an appointment. Keep records of all calls with your insurance company.

MY INSURANCE COMPANY

Do I have everything I need from my insurance company? Make sure you have an ID card from your company. Your doctor will need to confirm your benefits and coverage.

CALL US AT THE IHTC

Our Certified Insurance Navigators are always available
at 317.871.0011

Jeanette Whalen x298

DeAuntae Miller x383

Visit us at www.IHTC.org/payors

Health insurance is a complex and changing landscape and this can cause confusion and concern for many people. For this reason, the IHTC has developed an *infographic* (seen left) to remind you of smart questions to ask.

Our team of insurance experts is here to help you navigate this complicated landscape. These experts will work with you, your insurance providers, Medicaid and Medicare, to ensure you have the right coverage. Our patient insurance experts include:



Jeanette Whalen – Patient Insurance Coordinator
Jeanette is a certified Indiana Navigator for the federal insurance marketplace. She joined the IHTC in 2014 and focuses on IHTC Pharmacy Program patients with insurance questions or especially complex insurance situations. Jeanette has expertise in Medicaid and Medicare requirements.



DeAuntae Miller – Patient Insurance Coordinator
DeAuntae is a certified Indiana Navigator for the federal insurance marketplace. Joining the IHTC in 2015, her primary effort is to assist patients with insurance needs, questions, or complex insurance issues. DeAuntae excels at matching patient needs with insurance solutions. She is knowledgeable about Medicaid and Medicare requirements.

2016 Patient Survey

Sustaining Excellence & Elevating the Patient Experience

The IHTC periodically conducts patient satisfaction surveys to identify opportunities to sustain excellence in our care and elevate our patient experience. We are pleased to share some highlights of the 2016 Survey.

PRC, a national organization specializing in patient satisfaction assessment, conducted confidential phone surveys of a representative sample of 320 patients with a variety of blood disorders.

Overall Quality of Care

- » 99.3% of patients rated IHTC's overall quality of care as good to excellent
- » 99.1% of patients rated IHTC's staff knowledge and skills as good to excellent
- » 98.1% of patients rated IHTC's overall teamwork as good to excellent

Topics Covered

- Appointments/Registration
- Doctor/PA/NP
- Most Involved Nurse/Staff
- Teamwork
- Staff Overall
- Environment
- Total Time Spent Waiting
- At Home Care Instructions
- Likelihood to Recommend
- Overall Quality of Care
- Comparison to Other Providers
- Outstanding Service
- Improvement Idea(s)
- Specific Services
- Ongoing Communication
- Newsletter, Website

Our Ongoing Efforts

In response to the survey results, the clinical care team meets regularly to identify specific actions to implement that will either sustain or elevate your experience at the IHTC. These focused efforts help to ensure that we will continue to meet or exceed your expectations. We welcome your input!

THANK YOU FOR YOUR PARTICIPATION!

IHTC Welcomes New Staff



Kristen Dieter, MS, Part-time Genetic Counselor on June 27, 2016

- Will see individuals with bleeding disorders, mainly hemophilia and von Willebrand disease, during comprehensive clinic, and by appointment for recommendations regarding carrier testing, preconception testing, prenatal testing, and other genetic conditions
- Received her Bachelors of Science in Biology from the University of Kansas and her Masters of Science in Genetic Counseling from Brandeis University
- Has a prenatal/preconception background, but also has offered genetic counseling focused on hereditary cancer risks and has worked at a lifespan clinic focused on a specific genetic condition called Williams Syndrome
- She has appreciation for the patient- and family-centered care model used at the center
- Kristen keeps busy in her free time with her husband and two sons



Lisa Frazier, RN, Clinic/Triage Nurse on June 27, 2016

- Patients will see Lisa in clinic, and talk to her on the telephone
- Received her Associate's degree in Nursing from Marion College
- Previously worked in Transplant and Hepatology with Hepatitis C with Dr. Paul Kwo, who has treated some IHTC patients, and was familiar with the IHTC through Carla Robinson, RN, IHTC's Pharmacy Patient Care Coordinator
- She appreciates the quality of care provided by the IHTC and the resources available to patients
- Lisa loves reading, is family-focused, enjoys exercising, and even rides her bike to work



Janet Marr, RN, Pharmacy Nurse Care Coordinator on October 24, 2016

- Patients will speak to Janet over the telephone when they call to order factor, and will assist with infusion difficulties and other needs
- Received her RN license from Muhlenberg Hospital School of Nursing in New Jersey
- A practicing nurse for 30 years, Janet's most recent work experience has been at a specialty pharmacy in St. Louis, where she worked with patients infusing at home. Janet came to the IHTC when she and her husband moved to Indiana
- Janet is impressed by the IHTC philosophy and mission of putting the patient first
- In her free time, Janet enjoys Masters Olympic weight lifting



Carla Neuhausel, RN, Adult Triage Nurse on August 1, 2016

- Interacts with adult patients predominately by telephone with some face-to-face contact
- Attended Indiana University School of Nursing where she received her Bachelors of Science in Nursing. Prior to coming to the IHTC, Carla worked for 17 years as a hepatology nurse at IU
- When looking for a new focus in nursing, Carla was excited to work with the hemophilia population because Ryan White had been a patient when she worked at IU
- Carla is very impressed with the commitment and all of the services available to the patients seen at the IHTC

IHTC Welcomes New Staff



Elissa O'Malley, RN, Research Coordinator on October 10, 2016

- Will interact with patients in clinic or by telephone to discuss potential research studies
- Received her Bachelors of Science in Nursing from Anderson University in 2003
- Worked for 10 years at Indiana Blood and Marrow Transplantation in Indianapolis as a research coordinator. Immediately prior to coming to the IHTC, she worked in dermatology research
- Was interested in working at the IHTC because she liked the overall mission and how the IHTC looked at the care of the patient
- In her free time, she enjoys spending time with family and friends



Natasia "Tasia" Weiss, RN, Research Coordinator on September 26, 2016

- Patients will see Tasia at outreach and comprehensive clinic, and to discuss research studies
- Received her Bachelors of Science in Nursing from Valparaiso University in 2012. Prior to joining the IHTC, Tasia worked on a cardiac floor in Michigan City. She then moved to Dallas, TX, where she worked as a research nurse in heart transplantation at Baylor University Medical Center
- Moving back to Indiana, Tasia looked for employment specifically at the IHTC because she had heard from a colleague that it was a fantastic place to work
- "It is great the way IHTC cares for the patient and family in all aspects – it really is comprehensive, and we do everything we can to help patients regardless of their circumstances."
- In her free time, Tasia likes to sing Classical and Broadway music. She also loves dogs, particularly mastiffs



Melissa Ross, RN, Pediatric Clinic Nurse on December 12, 2016

- Patients will interact with Melissa in the pediatrics clinic and over the telephone
- Attended St. Elizabeth School of Nursing in Lafayette, IN, and training at St. Joseph College. Melissa has a diploma in Nursing.
- Before coming to IHTC, she worked for Franciscan Alliance as a telephone triage nurse in an Internal Medicine office
- While working at Riley in the Emergency Room, Melissa was drawn to hematology patients
- Melissa brings experience with Pediatric patients as well personal experience dealing with a bleeding disorder at home. Melissa is a very compassionate person, and taking care of children and their families has always been her focus in nursing

IHTC Welcomes New Physicians



Nicole Randall, MD, Adult Hematologist joined the IHTC on July 11, 2016

Dr. Randall received her Medical degree from Indiana University where she also did her Internal Medicine residency. She did her Hematology/Oncology fellowship at the University of Minnesota. When asked what brought her into the field of hematology, Dr. Randall responds, "In medical school, I found the pathophysiology of hematology to be interesting and fascinating. I also enjoyed interacting with hematology inpatients who had a cancer diagnosis – explaining their diagnosis to them so that they understood what was going on. I liked the science and the patient care. It was rewarding." Dr. Randall came to the IHTC because she wanted to practice where she could focus on patients with benign and malignant hematologic illnesses in a patient- and family-centered work environment. She says it feels like people at IHTC are a very friendly, close-knit group, all with the same goal in mind – to take care of patients and families. In her free time, Dr. Randall collects fashion dolls, such as collectible Barbie®, and is in a club that meets once a month. She also enjoys spending time with her husband and her rescue dog, a rat terrier named Ozzy.



Sabrina Rainey, MD, Adult Hospitalist joined IHTC on July 11, 2016

Dr. Rainey began seeing patients in August. In her role at the IHTC, Dr. Rainey sees adult and older teenage patients if they are admitted to St. Vincent Hospital in Indianapolis. Dr. Rainey received her medical training at University of Louisville and did her residency at Indiana University. Dr. Rainey's interest in hematology stems from her fascination in learning about how the body system worked in medical school. Due to her pediatric training, she also has an interest in working in a disease state such as hemophilia that affects both children and adults, to find ways to help children grow into adults with fewer complications and greater quality of life. Regarding IHTC, Dr. Rainey states that she appreciates the integrative model of care – that we work to provide care for everyone throughout the lifespan, in addition to providing her the opportunity to work in hematology. Dr. Rainey's hobbies include baking, candy-making, archery, and anything to do with the water, such as kayaking.

When to Call the IHTC

We love hearing from you!

Often, we hear from patients and families that they do not know when they should call the IHTC with questions or when they should make treatment decisions independently. One of the benefits of modern clotting factor concentrates is that they enable patients to treat at home and to be independent. While we are glad that you are confident in managing your own bleeding disorder, there are often times when we need to talk to you.

Hopefully these guidelines will help you know when to call:

- **Call to report every bleeding episode.** You may or may not need medical advice, but we need to document every bleeding event in your medical record. This enables us to watch bleeding patterns over time and identify concerns such as the development of joint issues
- **Insurance companies are increasingly requiring documentation of bleeding events before they approve the shipment of additional medication/factor to your home.** Without the appropriate documentation, your care can be negatively impacted
- **Call before you go to an emergency room (ER) for care.** The IHTC will contact the ER before your arrival and give recommendations as to how your bleeding disorder will impact your care upon your arrival
- **Call before all surgeries, procedures or dental work.** It is best to call us a week or two before interventions, even if they seem minor, because we will coordinate care, provide treatment recommendations, and prescribe medications to prevent complications that may be associated with an intervention
- **Call to discuss any injury or symptom of concern.** Based on your situation, we will determine treatment and length of therapy
- **Call before you run out of your medication/factor/supplies.** We want to help you have adequate treatment available at home at all times

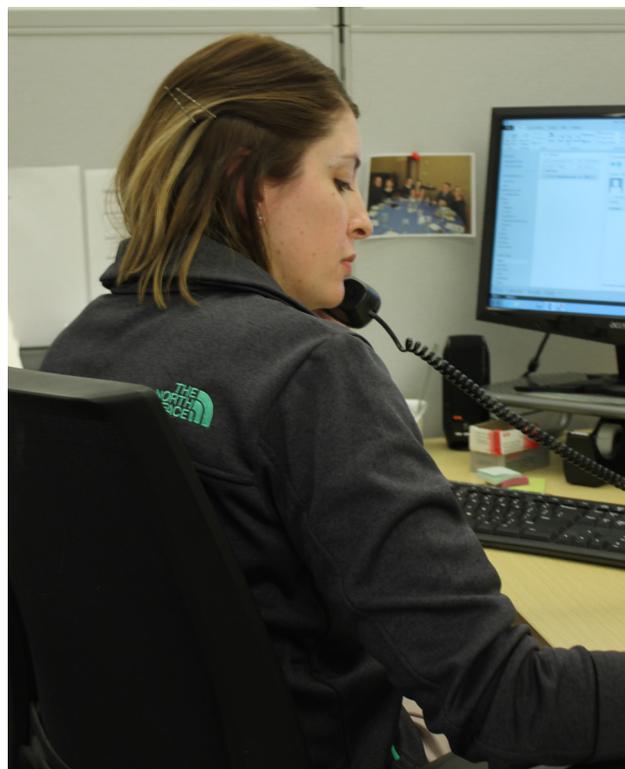
You never inconvenience us! While some may not know the appropriate time to call, others report not calling because they don't want to inconvenience us. We may not hear about many events until the once-yearly comprehensive visit, when patients report everything that happened to them in the past year. This is not ideal as it limits our ability to intervene early for optimal outcomes. We want you to call us as it helps us help you!

For urgent issues, we are available 24/7 to answer your calls.

For non-urgent issues or other concerns, call anytime during regular office hours to discuss your question or concern.

1-877-256-8837 (1-877-CLOTTER) or 317-871-0000

In 2015, the IHTC added two Patient Service Coordinators. Their role is to answer the nursing triage telephone line which limits the need to leave a voice mail. If you do need to leave a voice mail, they will assure that you are called back promptly.





8326 Naab Rd
Indianapolis, IN 46260



*If you have any questions, please contact the IHTC
at 317.871.0000 or www.ihtc.org*