New Building Update

The IHTC will move its offices on September 9, 2014 to a new stand-alone facility at **8326 Naab Road** - just a short distance from our current location on Harcourt Road near St. Vincent Hospital. The facility is south of the Max Simon Primary Care Center and west of the medical office building at 8330 Naab Road. As the sole occupant of the new facility the IHTC will provide the following opportunities for improved programs and services for our patients and families:

» Fully dedicated physical therapy rooms including one in clinic for short-term treatment and one on the second floor for full physical therapy services

» An increased capacity for the outpatient clinic, including larger family-sized rooms and a procedure room

» Enhanced infusion center with individual rooms for patient privacy and comfort

» Centralized consultation rooms to allow private discussions with our multidisciplinary team of healthcare providers

» Expanded laboratory draw space

» Improved access to the IHTC Pharmacy Program service team for medications and consultations

» Free parking with a covered drop-off pavilion

» A conference center to improve IHTC’s capacity to educate and train patients and families, staff and a wide range of healthcare providers

Importantly, the new energy efficient two-story building allows all IHTC staff to be housed within one space, while containing operating costs. If you have an upcoming appointment at the new building you will receive an appointment reminder via telephone specifying the new address. We look forward to welcoming patients to our new offices!
What if IHTC is “out-of-network” with my insurance?

IHTC will make every effort to verify benefits and coverage eligibility for services rendered by our physicians and pharmacy prior to your scheduled appointment or dispensation of medications. For this to be accomplished, please provide your current or anticipated insurance information when you schedule your appointment. If the IHTC finds that our providers are not “in-network” with your insurance provider, you may have to pay additional amounts for your deductible, out-of-pocket, and/or copay. In certain circumstances, the IHTC is able to negotiate “in-network” status with your carrier based on our specialized services or we can explore contracting with your insurance provider to become “in-network”.

What if I can’t pay the full amount I owe?

Please contact the IHTC billing service at 1-877-247-7667 (CIPROMS) to discuss payment options. If you are experiencing a financial hardship, please contact the IHTC social work team at 317-871-0011 x 553.

What if I have no insurance?

Please call the IHTC social work team at 317-871-0011, x 553 to discuss insurance matters related to your IHTC visits. If your question is about medication dispensed from the IHTC Pharmacy, please contact Jeanette Whalen at 317.871.0011, x298.

What if I have questions regarding my current insurance?

Please call the IHTC Billing team at 317-871-0011, x291 to discuss your questions.

Does IHTC bill secondary insurance?

Yes, the IHTC is dedicated to helping you receive full benefits from your insurance providers. You will be asked to provide complete insurance information upon registration. Be sure you have a copy of your insurance cards at that time. As a service to you, we will submit secondary claims along with required EOB’s (Explanation of Benefits) to your insurance provider. However, if your insurance provider doesn’t make payment within 60 days, we may ask you to contact your insurance company to assist in determining why claim payment is delayed.

The IHTC and our physicians are contracted with the following health plans:

- Medicare, including many Advantage plans
- Medicaid-including:
  - MDWise Wishard
  - MDWise St. Vincent
  - MDWise Select
  - MDWise Total Health
- Healthy Indiana Plan (HIP)
- Anthem Risk based and HIP
- Managed Health Services
- Champus/Tricare
- Choice Care
- Blue Cross Blue Shield/Anthem
- Advantage - Suburban Health
- Aetna
- Cigna
- Humana
- IU Health
- Encore
- Coventry/First Health
- Sagamore
- Multplan/PHCS
- SIHO
- United Health Care-UMR/Golden Rule/AARP
- Community Health Alliance
- Signature Care
- Multiplan/PHCS
- SIHO
- United Health Care-UMR/Golden Rule/AARP
- Community Health Alliance
- Signature Care

There are commercial or traditional health insurance plans with which IHTC does not participate. If your insurance plan does not participate with IHTC, it is difficult to predict what will be paid. You must check with your employer, health plan or other appropriate party about benefits before coming to clinic. It is important that you know your health plan benefits.
Infusion logs have become very important in hemophilia care management. They are a great tool for families to track infusion schedules, bleeds and product usage with lot numbers. This information is also important to your healthcare provider to assess trends in bleeds, infusions and to adjust dosing as needed to improve care. Some insurance companies now request logs to demonstrate infusion dates and times to monitor patient adherence.

In the past, paper logs were the standard for tracking factor infusions. Paper logs are still available in both small and large calendar sizes from the IHTC. There is also a specific tracking booklet available for patients who only infuse as needed for bleeding.

Today, there are a variety of electronic applications (apps) that can be used on either your home computer or on your mobile devices including laptops, tablets and cell phones. Each app has benefits and limitations as illustrated in our chart below.

These apps are available from the iTunes store. Advoy requires additional registration through the IHTC.

Technology will continue to advance and new methods of tracking will continue to be refined and developed. Several IHTC patients have their own favorite infusion log app. We would like to hear about your current app or method for tracking infusions.

Please address any questions or system reviews to Laura Cole at lcole@ihtc.org or Brandy Kimani at bkimani@ihtc.org. You may also call Laura or Brandy at (317) 829-7778 or (877) 633-4639.

### Which Infusion Log is For You?

<table>
<thead>
<tr>
<th>App Name</th>
<th>Iphone App</th>
<th>Android App</th>
<th>Text Logging</th>
<th>Web Profile</th>
<th>Non-Smart Phone</th>
<th>Tracks Bleeds</th>
<th>Prophy</th>
<th>Reminders</th>
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<td>Yes</td>
<td></td>
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<tr>
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<td></td>
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<td>Yes</td>
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<td>Yes - prophylactic reminders set at same dose</td>
<td>Yes - must generate an email to the IHTC</td>
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<td></td>
</tr>
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<td></td>
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</table>
In 2011, the IHTC launched the Patient Portal, a secure website where patients can communicate online with the IHTC. Among other things, patients can request an appointment or medication refill, send a message to their IHTC physician, and view information from their chart. In early 2014, a new feature was added to the Patient Portal: Enhanced Lab Results.

Enhanced Lab Results allows the IHTC physician to send a patient not only his or her lab results, but tailor these lab result reports specifically for the patient. With Enhanced Lab Results, the IHTC physician can do the following:

» write specific comments and recommendations about individual test or lab panel results. This enables an IHTC physician to directly communicate to you about what your results mean and how they might affect your plan of care.
» exclude specific lab results or lab panels from the report. This allows the physician to communicate only those lab results that require attention.
» deliver the results quickly and securely. After creating an Enhanced Lab Result Report, a physician can send this report to you through the IHTC Secure Messaging and Patient Portal system.

Enhanced Lab Results offers several advantages over calling or mailing the results:

» Speed: As soon as the physician has reviewed the lab report, he or she can send you an Enhanced Lab Report. The days of waiting for mail or playing telephone tag are over!
» Accuracy: When discussing results over the telephone, information can be either forgotten or misinterpreted. With Enhanced Lab Results, the physician’s analysis and instructions are included with the report, which you can reference at your leisure.
» Portability: Enhanced Lab Results helps make your healthcare record portable. When you see another physician, you can share this Enhanced Lab Result in a number of ways: (1) Use the IHTC Secure Messaging to send a copy to your physician; (2) Print a copy and bring it to an appointment; (3) Login to the IHTC Patient Portal at the physician’s office and share the Enhanced Lab Result report.

You can only receive Enhanced Lab Results if you sign up to use the IHTC Patient Portal. At your next appointment, be sure to tell an IHTC staff member that you are ready to join the IHTC Patient Portal Community.

Patient Portal Update

Camp 2014

Camp Brave Eagle broke a record this past June with 93 campers – the largest attendance ever!

Many campers worked towards independence with 24 self-infusing at camp and another 6 campers working on self-infusion with the assistance of a nurse. Congratulations to campers for their efforts! Campers included those with bleeding disorders, a total of 63, and many supportive siblings.

Camp Brave Eagle provides bleeding disorder children and their siblings a camp environment with traditional camp activities – swimming, climbing, tubing, basketball, canoeing, and crafting. Campers also explore concepts like team building and leadership. A highlight of camp is the awards given in honor of past leaders in the bleeding disorder community. These awards recognize campers who exemplify qualities such as generosity, leadership, perseverance, service and humility. The following campers received awards this year:

» Tony Spickelmier Award – Nick H
» Chad Beer Award – Chris L
» Billie Andreko Award – Jonathon S
» Kayla Duncan Award – Ansley J
» Tori Nakol Swoape Award – Sara J

Congratulations to each recipient! In recognition, the IHTC made a $50 donation towards a future Brave Eagle campership in each of their names.
Meet the IHTC’s Newest Staff

Adrianna Williamson, BSN, MA, Research Coordinator

The IHTC welcomed Adrianna Williamson as a Research Coordinator on March 17, 2014. A native of Flint, Michigan, Adrianna moved to Grand Rapids during her junior year of high school and then to Muncie, Indiana for college. Adrianna has her Bachelor’s degree in pre-med and Biology and her Master’s degree in Physiology from Ball State University. In her position as a Research Coordinator, Adrianna likes having variety and especially enjoys auditing studies. Prior to coming to the IHTC, Adrianna worked at Baxter in quality assurance. In her free time, Adrianna is an avid cook, crochets, and loves tennis. When asked her initial impressions of the IHTC, Adrianna said, “IHTC is an extraordinary center, focused on the health of the entire person, not just a specific condition. It’s a great place to be able to meet patients, assist in their treatment and make a lasting impression on their lives. I’m truly honored to be able to work with individuals who are so passionate about the work we do every day.”

Jeanette Whalen, Patient Insurance Coordinator

On April 7, 2014, Jeanette Whalen joined the IHTC as the Patient Insurance Coordinator. A certified Indiana Navigator for the federal insurance marketplace, Jeanette is available to assist IHTC Pharmacy Program patients with insurance needs. Jeanette comes to the IHTC from the pediatric dentistry field where she served as a manager for 25 years. Jeanette currently lives in Fountaintown; she was born and raised in Indianapolis and graduated from Warren Central High School. She has been married for 30 years and has two children and two grandchildren. When she’s not working, Jeanette loves to be outside and especially enjoys Nascar racing, live music, hiking, and spending time with family and friends. Jeanette always strives to be a compassionate person who enjoys helping people. She reports learning much since joining the IHTC and is happy to be a part of the center.

Gina Bindley, BSN, RN, Phone Triage Nurse

Gina Bindley became an IHTC Phone Triage Nurse on May 28, 2014. Gina is an experienced emergency room nurse with her bachelor’s degrees in nursing from Marion University and business and sociology from Indiana State University. In her spare time, Gina enjoys camping with her family and participating in youth sports with her three children. Gina says that as an ER nurse, she gained a unique perspective of the IHTC as she came to know some of the IHTC’s patients and heard inspiring feedback from them about the IHTC and their love for the center. “Everyone here is so positive,” Gina says. “I like that.”

Erin Wiles, Research Coordinator

Erin Wiles, RN, BSN joined the IHTC as a Research Coordinator in March 2014. Erin grew up in rural Indiana, describing her home as a “one stop sign” town. She still enjoys a small town feel, now living in Brownsburg with her husband and one year old daughter. Erin completed her Health Sciences major at Purdue University. After college she worked for a biopharmaceutical company in Arizona for almost 4 years and then moved to North Carolina to earn her BSN from Duke School of Nursing. Prior to coming to the IHTC, Erin worked at St. Vincent Women’s Hospital in labor and delivery and high-risk maternity services. Erin feels research is an ideal fit for her interests and her desire to continually learn and grow. She also enjoys the administrative aspects of being a research coordinator. She says the IHTC “felt like home from my first week.” She appreciates the helpfulness of her coworkers and how staff operates like a family. In her free time, Erin enjoys being in the outdoors with her family. Erin also plays volleyball and enjoys outdoor photography and scrapbooking as hobbies.

Mark Heiny, M.D., Ph.D, Pediatric Hematologist

Mark Heiny, M.D., Ph.D. joined the IHTC as Pediatric Hematologist in 2013. Dr. Heiny attended medical school at the Indiana University School of Medicine and completed his Pediatric Residencies at Riley Hospital for Children and St. Louis Children’s Hospital. He completed his Pediatric Hematology/Oncology Fellowship at Washington University School of Medicine. Following his fellowship, he returned home to Indiana, working at Riley Hospital for Children for over 15 years. In addition, Dr. Heiny earned a doctorate in Biochemistry from Indiana University. Dr. Heiny’s interest in medicine began at an early age as his mother worked in the office of a small town doctor. As a pre-med college major, he traveled on a medical trip to Honduras. After seeing him care for and interact with children on the trip, Dr. Heiny’s professor encouraged him to go into pediatrics. Dr. Heiny has a special interest in sickle cell disease, specifically stroke risk and prevention and transfusion therapy, as well as hemostasis and thrombosis. Dr. Heiny enjoys boating, skiing and collecting Indiana books and art. Dr. Heiny is pleased to work at the IHTC, noting how welcoming staff were to him and helpful in acclimating him to the IHTC.

Audrey Taylor, NP, Nurse Practitioner

Audrey joined the IHTC as Nurse Practitioner in March 2014. Audrey earned her Master’s of Science in Nursing from Rush University. Following her degree, she worked in pediatric critical care for 10 years at Rush Medical Center, and at the Rush Hemophilia & Thrombophilia Center for 16 years. She has a special interest in hemophilia and Von Willebrand Disease. While working in the Pediatric Critical Care Unit (PICU) she developed a passion for caring for children with bleeding disorders. As a result she left the PICU to work as an HTC nurse coordinator at the Rush Hemophilia & Thrombophilia Center. Audrey is a Board Certified Family Nurse Practitioner, and has managed patients in the hospital during acute bleeds and surgeries, as well as outpatient. Audrey enjoys attending church, reading and spending time with her family, especially her 26 year old son, Clyde. Enjoying her time at the IHTC so far, she appreciates the IHTC staff’s warm welcome, collaborative model and expertise. Audrey says “the staff’s expertise, care and concern extend not only to patients and caregivers, but to other staff. Coworkers are always eager to go above and beyond their job description to help each other.”
Bob Louden, LCSW, Social Worker

Bob Louden joined the IHTC as social worker in July 2014. He earned his Bachelor and Master of Social Work degrees from Indiana University School of Social Work. Bob comes to the IHTC from Health and Hospital Corporation, the parent company of Wishard Hospital, now Eskenazi Health, and the Marion County Public Health Department. For 5 years, Bob was the social worker for the HIV-STD Clinic at the health department. Following this, he was the HIV social worker at the hospital for 8 years. Asked why he went into social work, Bob says he wanted to work directly with people. He originally planned to be a psychologist, but found social work to be a better fit. His experience with HIV and history in public health led him to medical social work specifically. Born and raised in Indianapolis, Bob attended Scecina Memorial High School. He has two pugs, Pickle and Puck. In his free time, he enjoys watching movies, particularly documentaries. He also likes to travel. Bob went to Curacao in February 2014 and is planning another big trip for 2015. Bob is excited to work with the bleeding disorder population and at the IHTC, a center of excellence.

Longer-Lasting Agents

Exciting new hemophilia factor products hold promise to change the way we treat hemophilia. Some of these new products are now available!

The new factor products are recombinant, meaning no human or animal materials are used during development or purification. Some have longer half-lives than current factor products. A longer half-life means the product is available in the body for a longer time. This may mean that fewer infusions are needed. The new products use several different methods to increase the half-life.

With some of the new FVIII and FIX products, a chemical called polyethylene glycol, or PEG, is added to the factor. PEG protects the drug from being broken down by the body’s normal degradation process.1

Other products achieve a longer half-life by attaching the factor molecule to natural proteins in the body. Proteins like albumin2 or immune proteins3,4 are in the circulation longer than other proteins and have proven to extend clotting factor half-life. These are called fusion proteins. Fusion proteins for hemophilia A and B were recently approved by the FDA for use!

Other Products

New products for persons with inhibitors are currently being studied. Pig, or porcine, FVIII is similar to human FVIII but is not inactivated as much by human FVIII inhibitors. It can be useful in people with acquired hemophilia who have FVIII inhibitors.

Finally, a recombinant von Willebrand factor, or rVWF, is in development. This will be the first recombinant product to treat von Willebrand disease!

### Advances in Hemophilia Treatments: Longer-Lasting & Other New Agents

#### POPULATION AGENT MANUFACTURER DESCRIPTION STATUS

<table>
<thead>
<tr>
<th>FVIII</th>
<th>Bayer</th>
<th>rFactor VIII</th>
<th>Phase 3</th>
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<tr>
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<tr>
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<td>Baxter [Inspiration]</td>
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<td>Recombinant VWF</td>
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</table>

**References:**

Upcoming Events

September 8
IHTC Offices Move to New Location
*See page 1 for more information

September 13
Hemophilia of Indiana - Hemophilia Walk

September 18-20
NHF Annual Meeting

December 7
Hemophilia of Indiana - Holiday Party