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MARK YOUR CALENDARS

- August 24-25 • Holl Annual Meeting
- September 14 • Hemophilia Walk
- October 3-5 • NHF Annual Meeting
- December 1 • Holl Holiday Party

For further information about bleeding disorders, visit www.ihtc.org and the following websites:

- National Hemophilia Foundation
<http://www.hemophilia.org>
- World Federation of Hemophilia
<http://www.wfh.org>

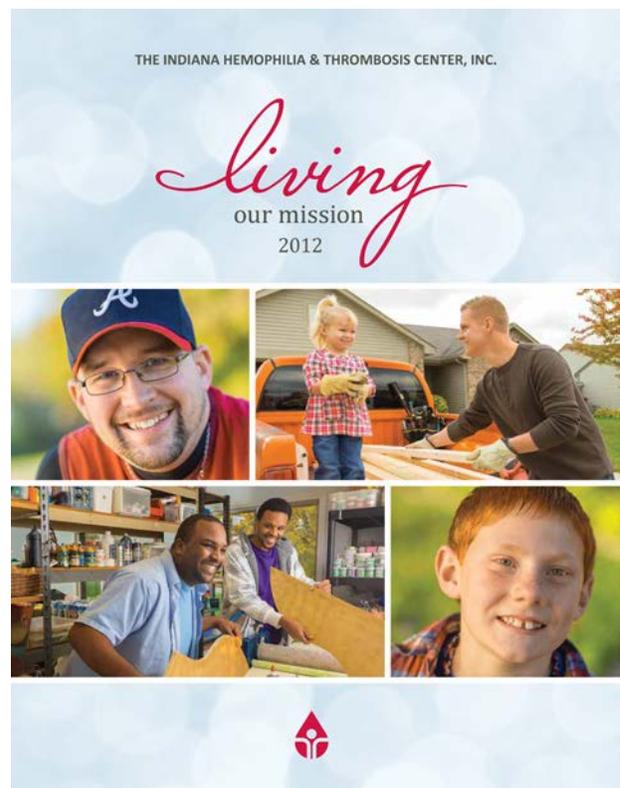
Follow the IHTC on Facebook
www.facebook.com/IndianaHemophilia

Living Our Mission

Helping patients thrive - today and tomorrow!

Did you know the IHTC is Indiana's only federally recognized hemophilia treatment center and the state's foremost bleeding disorder multidisciplinary evaluation and treatment facility? As one of the largest hemophilia treatment centers in the nation, the IHTC lives its mission to provide patients and their families with the treatment and support they need to thrive. The IHTC is nationally and internationally renowned for its leadership in bleeding disorder patient care, collaboration, education, research, and advocacy. The IHTC is your center of excellence.

Living Our Mission summarizes the IHTC's efforts to provide patients and their families with the treatment and support they need to thrive. The IHTC's large array of programs and services is highlighted in this document, including those provided by the IHTC's multidisciplinary team. Learn about the IHTC's impact through the *Living Our Mission* narrative and from *By the Numbers*, which provide meaningful statistics on IHTC efforts. Four patients share their own stories as an illustration of how the IHTC influences countless lives. Access *Living Our Mission* at <http://www.ihtc.org/2013/05/living-our-mission/>.



IHTC ZOOBILEE

Did you miss this important educational event?

Zoobilee, the IHTC's largest patient educational event, occurred on June 8, 2013 at the Indianapolis Zoo. The event was a great success with 715 people attending representing 168 patients/families from throughout the state!

The Zoobilee education pavilion included 22 educational booths and over 100 educational documents highlighting the extensive services and programs available for you through the IHTC. Patients and their families also had an opportunity to interact with IHTC physicians, nurses, pharmacy and multidisciplinary team members. In addition to the educational booths, attendees enjoyed a picnic-style lunch and activities for children. Families then spent the afternoon enjoying the zoo.

The goal of Zoobilee was to increase awareness of the IHTC's services and programs, provide important IHTC updates and receive feedback. Based on surveys completed at Zoobilee, 96% rated the overall event as excellent and 4% rated it as good.

If you were unable to attend Zoobilee you will receive a mailing in August that includes the *IHTC Passport to Care* booklet and several additional educational documents. A web-based version of the IHTC Passport to Care will launch on-line in July. This new webpage will provide you access to many of the educational materials featured at Zoobilee. Visit the webpage at <http://www.ihtc.org/ihtc-passport-to-care/>

To get a taste of Zoobilee or reflect on the event, visit our Zoobilee photo webpage at <http://flickr.com/gp/indianahemophilia/145ShT/>



2012 Patient Satisfaction Survey Results

Sustaining Excellence in Patient Satisfaction

Thank you to everyone who participated in the 2012 Patient Satisfaction Survey. For the fourth time, the IHTC received outstanding feedback from our patients. The IHTC is pleased to share some highlights and review the survey process. 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. Over 99% of patients surveyed rated their overall quality of care as good to excellent. Over 99% of patients rated our staff's knowledge and skills as good to excellent and 98% of patients rated overall teamwork as good to excellent.

Topics Covered

- | | |
|------------------------------|-----------------------------------|
| 1. Appointments/Registration | 9. Likelihood to Recommend |
| 2. Doctor/PA/NP | 10. Overall Quality of Care |
| 3. Most Involved Nurse/Staff | 11. Comparison to Other Providers |
| 4. Teamwork | 12. Outstanding Service |
| 5. Staff Overall | 13. Improvement Idea(s) |
| 6. Environment | 14. Specific Services |
| 7. Total Time Spent Waiting | 15. Ongoing Communication |
| 8. At Home Care Instructions | 16. Newsletter, Website |

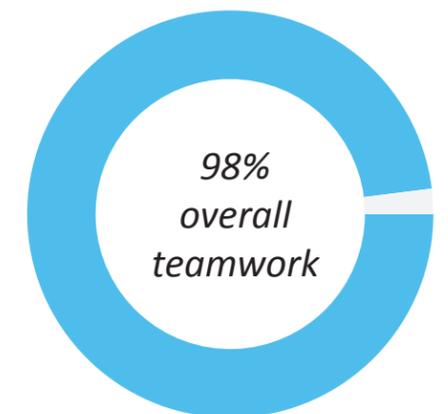
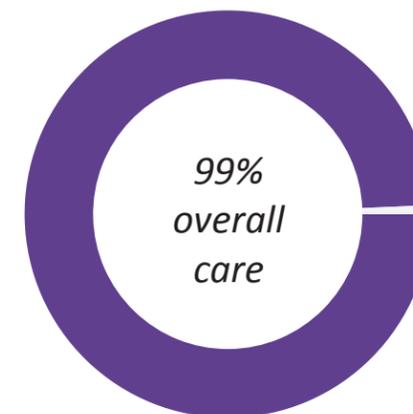
Ongoing Efforts to Sustain Excellence

Patients were also given the opportunity to verbally respond to two questions. "The IHTC is interested in recognizing excellence. During this visit, was there anything you feel was outstanding?" and "What could have been done to improve your visit?"

Although the IHTC has had four consecutive patient satisfaction surveys with outstanding results, we continue to focus on pursuing excellence. In response to the survey results, leaders of IHTC's clinical care team identify specific action plans to implement and raise the bar to improve our patient's experience, our level of services and the quality of care provided. These efforts help to ensure the IHTC will continue to meet or exceed our patients' expectations for care.

Your voice is important to us. If you were not contacted to participate, but would like to provide feedback, please contact Kelly McCarthy, Clinical Operations Director, at kmccarthy@ihtc.org or call 877.256.8837.

Rated by patients as good to excellent:



Lifestyle Change is the Key to Success

Jason's Weight Loss Story

What type and severity of hemophilia do you have? I have moderate factor VIII deficient hemophilia.

Why did you choose to pursue weight loss? I knew losing weight would reduce the stress on my joints, improve my blood pressure, and just be positive for my overall health and mobility.

How has losing weight affected your bleeding disorder? I have less pain, especially in the mornings. My ankles have been a target joint ever since I can remember. Previously my morning routine consisted of getting up and limping around for about 30 minutes until my ankles warmed up. If I stopped moving during the day, they would lock up again. Now I can almost hit the ground running in the mornings! I may sometimes have more bleeding episodes from increased activity, but the bleeds are less severe and they take less factor to resolve.

It is also easier to perform my everyday tasks. I operate a sheep farm so my work is very physical. I put up hay and raise a half-acre garden for farmers market. I am usually outside working by the time the sun comes up and usually I don't come inside until after its set. My hobbies are also outdoor activities. I really enjoy shooting sports, and hunting and fishing are also favorites. Through hunting each year, I provide about 80% of my family's meat.

What have been the challenges to losing weight? Physical activity definitely helps with weight loss, so inactivity due to a bleeding episode is a significant challenge. Sometimes I gain back the weight I lost. Snacking is a definite temptation when you are laid up. Another challenge is keeping your home stocked with fresh, healthy foods. I can relate to those who sometime struggle to afford healthy snacks. When our garden isn't producing, it's easy to buy inexpensive snack foods.

What have been the most helpful strategies? I've found its best to focus on my overall weight loss rather than my week to week progress. Once I gained 6 pounds during a prolonged week-long bleed. However, at the time I was still down 30 pounds overall.

What advice or encouragement would you like to give others? Commit to changing your overall lifestyle or you will struggle to succeed. Eat healthy, fresh foods. The more processed a food is, the less nutritional value. I lose weight easier when my garden is ripe and I am primarily eating fresh vegetables and very lean meat. Most of all, if you are going to do something, commit to it fully!

A special thanks to Jason for sharing his story! If you'd like more information about weight management or how the IHTC can help you, contact the IHTC dietitian at 877-256-8837. For 10 tips for stretching your food dollars while eating healthy, visit <http://www.ihtc.org/2013/07/eatingbetteronabudget/>



Activity Based Prophylaxis

What is Activity Based Prophylaxis (ABP)?

Activity based prophylaxis is a therapy designed to prevent bleeding episodes related to activity. ABP is less intensive than primary or secondary prophylaxis; it is designed to prevent bleeding whereas on-demand therapy uses treatment after a bleeding episode has occurred. The dose utilized for ABP varies based on the planned activity and your joint status. Oftentimes ABP uses what is called your "minor dose."

When is ABP utilized?

The following are situations when ABP is commonly utilized:

- » You have a busy/active day planned and know that you are likely to experience a bleeding episode related to these planned activities, or if a bleeding episode were to occur would impact your planned activities
- » Activities that put stress on current target joints
- » Sports participation, especially with a high risk of injury such as skiing or snowboarding
- » Strenuous activity such as yard work, lifting heavy objects, etc.
- » Vacation or out of town trip
- » Exercise programs such as weight lifting or swimming where you have experienced a previous bleeding episode
- » You or your child are under the care of someone unfamiliar with hemophilia, such as grandparents, etc.

What dose of factor is used for ABP?

The goal of ABP is to prevent bleeding rather than providing treatment for a bleeding episode. The recommended dose for bleed prevention is often the dose recommended to treat "minor bleeding" episodes. The dose should be infused as close to the time of the activity as possible. Dosing may vary based on the activity and its duration, joint status, your typical response to clotting factor concentrate, etc.

What if I still have bleeding problems during or after the activity?

The recommended dose may not prevent all bleeding episodes, especially if associated with injury or in a target joint. If you think you are experiencing a bleeding episode despite having utilized ABP, you will require further therapy. Recommendations for therapy are based upon the timing and dose of the administered ABP, your level of deficiency, presence of an injury, target joint or inhibitor. Please call the IHTC for recommendations. All infusions should be recorded in your infusion log for future reference.

What if I will be active for several days?

If your planned activity lasts longer than 1 day, please call the IHTC to discuss development of an appropriate infusion plan.

IMPORTANT INFORMATION: ABP does not replace common sense. High-risk activities, such as hang gliding, 4-wheeling, skydiving, participation in football, hockey, and wrestling are not recommended for individuals with bleeding disorders. Life threatening injuries, including, but not limited to head injuries, must be reported immediately.

Camp Brave Eagle 2013

Camp Brave Eagle 2013 set a new record with 80 campers in attendance! 60 campers had a bleeding disorder and 42 of these had hemophilia. 23 campers self-infused or practiced self-infusion during camp.

Camp awards were a highlight as always, and a new award in memory of Tori Nakol Swoape was given. Join in us in congratulating these campers! To recognize their achievement, the IHTC has made a \$50 donation in each of their names to future camperships.

- » The Tony Spickelmier Award: Daniel M.
- » Chad Beer Award: Zach R.
- » Billie Andreko Award: Cole S.
- » Kayla Duncan Award: Macie L.
- » Tori Nakol Swoape Award: Hannah A.

To see more highlights from camp, check out the IHTC's Brave Eagle album online: <http://flickr.com/gp/indianahemophilia/Z96h20/>



The National Hemophilia Program Coordinating Center & You

In June 2012, the Health Resources and Services Administration (HRSA) awarded a grant to the American Thrombosis and Hemostasis Network (ATHN) to serve as the first National Hemophilia Program Coordinating Center (NHPCC) for the eight US Hemophilia Treatment Center (HTC) regions. The mission of the NHPCC is, "to facilitate, coordinate and evaluate the implementation of culturally sensitive activities carried out by the regional networks to optimize the health of individuals with bleeding and clotting disorders throughout their lifespan and across generations."

The NHPCC is partnering with the regional HTC networks to conduct the first national hemophilia program needs assessment and evaluation. The needs assessment will be analyzed at both the national and regional level and will provide valuable information to the NHPCC and regions to set national priorities to improve the care of persons with bleeding disorders.

The needs assessment involves two surveys. The first survey is for HTCs to assess the knowledge, tools, resources, and training needs that HTC staff require to provide services to their population. The IHTC staff will complete this HTC needs assessment.

The second survey is for patients and measures your perceptions of the care and services you receive at your HTC, and identifies strengths, gaps, and opportunities for improvement. The patient questionnaire is four pages and will take about 15 minutes to complete. You will be mailed this survey by the IHTC. The survey does not reveal your identity to the agency compiling the results or the coordinating center, and your individual responses are not revealed to the IHTC. The survey will also be available via an electronic link to a SurveyMonkey version for those individuals who prefer to complete it electronically. The IHTC will mail the surveys in September 2013 to the households of all active patients registered at the IHTC in 2012. A stamped return envelope will be included for you to mail the survey back to a third party who will compile the anonymous responses.

Look for your survey in September. We thank you in advance for your participation!

NHPCC Works with 8 HRSA Regions U.S. Federally Funded Hemophilia Treatment Centers



<http://www.athn.org/content/projects/nhpcc>

Meet the IHTC's Newest Staff



Carol Haney, LPN

Carol Haney, LPN, joined the IHTC as an Adult Phone Triage Nurse in January 2013. Carol received her nursing degree from Ball Memorial Hospital and has been a licensed practical nurse for 27 years. Prior to coming to the IHTC, Carol worked as an infusion & wound care nurse in autoimmune disorders and infectious disease. She has also worked as a surgery nurse and a histology nurse in a dermatology practice. In her spare time, Carol enjoys gardening, cooking, decorating, and making memories with her family, including her three grandchildren. Asked about her impressions of the IHTC, Carol emphasizes that this is a fabulous place to work and that she is overwhelmed by the over-achieving performance of the staff. She feels that the IHTC is truly committed to patients' best interests and to provide them excellent care.

After covering weekends for the past two years, Dr. Brandon Hardesty joined the IHTC as an Adult Hematologist in July 2013. Dr. Hardesty received his Bachelors of Science in biochemistry from Miami University and his Doctor of Medicine from The Ohio State University. Prior to working at the IHTC, Dr. Hardesty completed a residency and fellowship at Indiana University as well as working as a Hospitalist at IU Health West from July 2009 to June 2010. Asked what inspired him to become a physician, Dr. Hardesty says that his mother was a nurse; he was introduced to medicine at a young age and always found it interesting. He has chosen to pursue benign hematology specifically because he finds the clotting cascade and benign hematology itself to be interesting and challenging. In his free time, Dr. Hardesty enjoys wood-working, reading, and spending time with his wife and two sons, ages 2 and 5 years old. With regard to his impressions of the IHTC, Dr. Hardesty feels that this is a very collegial group in which everyone seems to have mutual respect. He finds the IHTC to be an efficient care center with highly skilled staff caring for patients.



Brandon Hardesty, M.D.



Treg Harris, RPh

The IHTC welcomes Treg Harris, RPh, as our new Pharmacist. Treg started at the IHTC in January 2013. Treg graduated with his Bachelor of Science degree at Purdue University in 1993. He grew up in southern Illinois, where he discovered in high school that he was interested in chemistry. Treg had a Sunday school teacher who was a pharmacist and guided Treg by telling him that pharmacy offered an opportunity to learn more about and work with chemistry. Treg has two daughters, ages 12 and 14, and two pet boxers. In his free time, he is interested in sports, including golf and basketball. When asked about his impressions of the IHTC, Treg says that he sensed during the interview process that it was a good workplace with a sense of family among the employees. His experience has shown that IHTC does indeed have a family atmosphere. Treg says his work is challenging and provides the opportunity to continue to learn. He welcomes patients to call with questions about medications or clotting factor concentrate.

After working as a Data Specialist at the IHTC since May 2011, Kat Rees, RN, became a full-time Research Coordinator in May 2013. Kat received a Bachelor's degree in Public Health from Purdue University and graduated with an Associate's degree in Nursing from Ivy Tech in 2013. Kat has extensive experience working as a phlebotomist during college and at the Indiana Blood Center in blood collection. When asked what inspired her to enter the health field and become a Registered Nurse, Kat says that she has always been personally interested in wellness, nutrition,



Kat Rees, RN

and fitness. Through family illnesses, Kat has seen doctors and nurses provide excellent patient care and has been inspired by these professionals to help others. Kat reports that she is happy to be in the IHTC research department as she is curious about research studies, frequently reading research articles and study reports. Kat has been a violinist since age 12. She and her husband are interested in movies, video games, camping, and nature. Kat says that she loves working at the IHTC and feels lucky to have the opportunity to work at the center full-time. She feels the IHTC provides amazing patient care.

Cindy Schroeder, MSW, LCSW, LAC, joined the IHTC in May 2013 as the Social Worker Supervisor. Cindy received her Masters of Social Work at Indiana University in Indianapolis. She is also a licensed clinical social worker and a licensed addictions counselor. Prior to working at the IHTC, Cindy worked at the Tara Treatment Center, Reach for Youth, and Gallahue Behavioral Health. As a child, Cindy had a tendency to protect other children and this grew into a passion for standing up for the marginalized. After an early career in business, Cindy began making episodic mission trips with her church until she was able to attend school for social work, allowing her passion for helping others to become a vocation. Cindy has two daughters and four granddaughters. She enjoys hiking, kayaking, and writing. Asked for her impressions of the IHTC, Cindy notes the staff is forward thinking. She is impressed by the IHTC's involvement in research and the center's partnerships to advance care for both current and future generations. Cindy looks forward to getting to know many patients in the years to come.



Cindy Schroeder, MSW, LCSW, LAC



Shawna Thayer, CPhT

The IHTC welcomed Shawna Thayer in March 2013, as a Pharmacy Technician. Trained on-the-job, Shawna has been a pharmacy technician for 14 years. Prior to working at the IHTC, Shawna worked at the Indiana University Simon Cancer Center Outpatient Pharmacy. Shawna's family is from Greenfield, Indiana, although she grew up in a Navy family and as a result has lived in many different places. Shawna was inspired to become a pharmacy technician by her mother, who was also a pharmacy technician. Shawna has three children – one boy and two girls. When her children were little, she entered pharmacy as it provided an opportunity to work part-time. In addition to her three children, Shawna has three dogs. She says that she loves how the IHTC cares for its patients, and that she has never known an employer to be so interested in the well-being of its employees.

The IHTC welcomed Carla Timm, RN, as a Research Coordinator in February 2013. Carla received her Bachelor's degrees in biochemistry and nursing from Purdue. Prior to working at the IHTC, she worked as a medical surgery floor nurse and, more recently, as an occupational health nurse at Subaru. When asked what inspired her to go into medicine and research, Carla says that she simply wanted to help people. In her free time, Carla enjoys running, playing with her daughter, reading, fixing up her house, and doing anything outdoors. Carla sees the IHTC as a friendly place to work where patients are the top priority.



Carla Timm, RN

IHTC Research & Your Bleeding Disorder Community

Clinical research brings improved therapies to market and provides an opportunity for patients to contribute to advance care and treatment. Clinical research may also improve overall understanding of bleeding and clotting disorders, increase knowledge of genetics, and provide ongoing safety information of therapy. Clinical research studies may offer patients and payors substantial treatment and genetic testing-related cost savings.

The IHTC has a long standing history of leadership in clinical research. The IHTC performed the first in the world human infusion of the following products:

1. genetically engineered factor IX concentrate
2. long-acting genetically engineered immunoglobulin fused factor IX concentrate
3. genetically engineered von Willebrand factor concentrate
4. genetically engineered bio-similar factor IX concentrate

The IHTC is a leader in clinical research with 45 currently active studies available to eligible patients. The IHTC independently evaluates the need for a specific study weighing how it may impact future patient care; above all the safety of the project is critically evaluated. There are a variety of different clinical research categories including pharmaceutical, investigator initiated, quality of life analyses and studies with national funding including the Centers for Disease Control and Prevention (CDC) or National Institute of Health (NIH).

The IHTC research coordinators connect patients to available studies and provide ongoing follow-up and coordination for the duration of the study for those enrolled. Below is a list of some of the important current studies related to the bleeding disorder community.

Studies Open to All

The IHTC Biorepository was established as part of the IHTC commitment to research. The Biorepository is a collection of biological samples such as plasma and DNA voluntarily provided by patients and family members. These de-identified samples are used to advance the management and outcomes of bleeding and clotting disorders.

ATHNdataset is a national HTC and ATHN project to monitor trends, address unanswered questions, gain a better understanding of bleeding and clotting disorders, inhibitors, and treatment, develop cost effective care, and monitor the safety of therapies.

My Life Our Future is an initiative from NHF, ATHN, Puget Sound Blood Center and Biogen Idec. The aim is to genetically test individuals with factor VIII or IX deficiency in the US. Genotyping is free. In the future they will offer carrier testing as well.

Cardiovascular Disease in Hemophilia is a study to determine the history of stroke, prevalence of heart disease and symptoms of atherosclerosis in men aged 54-73 years with severe or moderate hemophilia. The study seeks to understand the similarities and differences in risk factors for heart disease, stroke, and atherosclerosis between men with hemophilia and a group of US men of similar age without hemophilia.

The CDC Public Health Surveillance Project/HTC Population Profile will delineate the demographics, diagnoses and health service utilization of a population of patients that receive care through federally funded hemophilia treatment centers across the US. The study will assess, by comparison across years, what proportion of the annual HTC census is comprised of “new” or “infrequent” service users versus those who use services routinely or repeatedly.

Hemophilia A Studies

Long Acting Products have the potential to improve treatment due to less frequent infusions, and improve compliance and

quality of life. The IHTC has one long-acting factor VIII fusion product study open for enrollment.

Development of Inhibitors in Mild Hemophilia during Surgical Procedures compares two currently established methods of administering factor VIII concentrate during procedures to determine their effect on subsequent inhibitor development. The study evaluates the immune system to investigate markers of inhibitor development to help predict or prevent inhibitor formation.

Comparison of Secondary Prophylaxis Versus Episodic (On Demand) Treatment in adults evaluates the number of bleeding events that occur yearly and their consequences in severe hemophilia A individuals who were not treated with prophylaxis prior to study entry. This study helps to establish whether prophylaxis in adults previously treated with on-demand therapy can prevent or reduce bleeding events, and improve joint preservation and other aspects such as cost and quality of life.

Hemophilia Inhibitor PUP Study (HIPS) evaluates immune factors related to inhibitor development in children. There are a variety of factors that impact development of an inhibitor including the individual immune system, environmental factors, and the genetic defect. This study evaluates the link between the immune system and inhibitors. This information could be used in the future to predict and/or prevent inhibitors.

Hemophilia Inhibitor Genetics Study (HIGS) identifies genetic factors associated with inhibitor formation in patients with hemophilia A. Mutations within the factor VIII gene are known to affect inhibitor development, a serious obstacle in hemophilia. This study focuses on the relationship between genetic factors and inhibitors and hopes to predict and/or prevent inhibitor development in the future.

Hemophilia B Studies

Long Acting Products have the potential to improve treatment due to less frequent infusions, and improve compliance and quality of life. The IHTC has two long-acting factor IX infusion products with studies open to enrollment.

Hemophilia Costs and Impact of Disease Study (HUGS) documents the financial and psychological cost of Hemophilia B. This study examines joint disease, quality of life, and financial impact on patients. The study combines patient interviews and chart reviews for individuals in four states.

Von Willebrand Disease

The Composite Score Test has been shown to be highly predictive of VWD in children. The study validates how well the composite test performs in a group of children undergoing VWD testing. Scoring questions based on bleeding symptoms, anemia, family history and early childhood bleeding may predict the likelihood of diagnosis and are compared to the standard clinical and laboratory testing for VWD.

PPG-VWD Study links the relationship between genetic changes causing VWD and the clinical impact on the diagnosis and management of bleeding disorders in families diagnosed with VWD. The study uses bleeding symptoms, standard laboratory tests, and genetic testing to determine if other genes or proteins contribute to bleeding symptoms or abnormal VWD testing. Definitive diagnosis impacts how to deliver treatment to prevent or minimize bleeding during surgery or severe trauma, thus testing family members is important.

Investigator Initiated Projects

Female Carriers of Hemophilia B is a data collection study to explore the relationship of “modifier” genes and environmental factors in the expression of factor IX to better understand the causes of variation in levels. Information regarding medical and bleeding history is obtained, in addition to blood tests, to determine factor IX levels and genetic analysis.

Intracranial Hemorrhage (ICH) in Children with severe hemophilia is a collaborative study with Malmo University in Sweden. This study strives to determine whether prophylaxis treatment versus on-demand therapy can prevent or reduce the occurrence of intracranial hemorrhage and related quality of life.



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IHTC Kenya Program Update

Watch our new video about the Kenya Program!



In a recent issue of the Clotting Times, we provided an update about the IHTC's partnership with the Indiana University School of Medicine and Moi Teaching and Referral Hospital (MTRH) in Eldoret, Kenya. This partnership was formed to establish western Kenya's first comprehensive HTC and advance care for individuals with blood disorders. In 2011, a year after the partnership began, the IHTC and the newly formed HTC at MTRH were recognized as official twinning partners through the World Federation of Hemophilia's Twinning Program. In addition, the Novo Nordisk Hemophilia Foundation supports the program. The IHTC recently created a video to inform the public and bleeding disorder community about the program. You can find the video on the IHTC website at www.ihtc.org/2013/06/kenya-video/

Most recently a team from IHTC traveled to Kenya from May 2-16, 2013 to continue to train healthcare professionals and advance care for individuals with hemophilia or sickle cell disease. The team conducted three outreach clinics and enhanced the process and efficiency of the newborn screening laboratory for sickle cell disease.