

The Clotting Times

SUMMER 2008



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MARK YOUR CALENDAR

HII 2008 Calendar

- June 15 - 20
Camp Brave Eagle
- June 19
Course to a Cure Golf Outing
- August 23-24
HII Annual Meeting
- Men's Group Meetings:
 - June 26
 - July 24
 - August 28
 - September 25
 - October 23

LOGAN RICE: LIVING WELL WITH HEMOPHILIA

Achieving a personal goal is an exhilarating feeling. How much greater is the reward when additional obstacles have been overcome in the process? Logan Rice knows the excitement of succeeding despite obstacles and discouragements along the way. A



senior in high school, with years of swimming and competition behind him, he can now look back on his achievements and assure other individuals with hemophilia that they can succeed as well.

Logan was diagnosed with hemophilia as an infant. His family had a known history of hemophilia and Logan's younger brother, Quincy, also has the diagnosis. Like many individuals with a bleeding disorder, Logan has experienced his share of physical difficulties. Middle school was his most challenging time as bleeds occurred frequently in his knee and ankle leading to the development of a target joint. During these years it was not uncommon for Logan to arrive at school on crutches because of a bleed. He often grew frustrated with experiencing the same injuries again and again.

In fifth grade, Logan discovered wrestling and decided to join the school team. He was quickly disappointed to learn that wrestling was not the best sport for persons with hemophilia. He struggled with the frustration of being limited in his activities, but chose not to dwell on his disappointment. Logan realized the sooner he let go of his desire to wrestle, the sooner he could enjoy competing in another sport. Having swum for several years, Logan decided to commit himself fully to the sport; a decision he has never regretted.

"Swimming is an ideal sport for people with hemophilia," Logan says. "It is great for the joints and muscles and it keeps you lean - both of which help prevent injury and bleeds." Not only has the sport supplied Logan with superior exercise, it has helped him develop close friendships in his life as well. Swimming has provided him with the physical, mental and social

Logan Rice continued from page 1

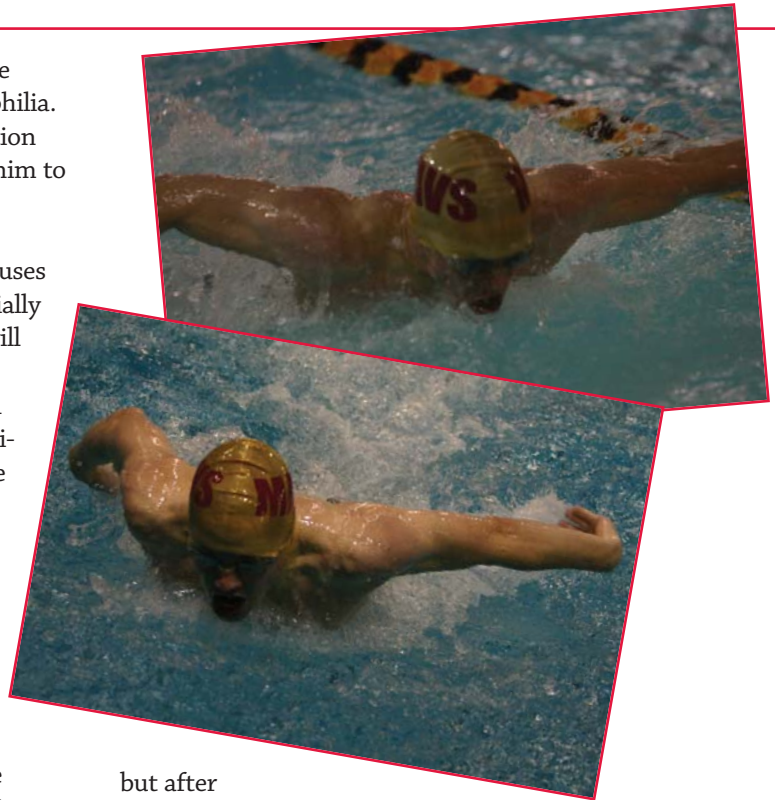
benefits of being on a team. It has also taught Logan the value of educating teammates and coaches about hemophilia. Logan's Coach, Amanda, is supportive and doesn't question his hemophilia-related needs, even if it means allowing him to sit out a practice or meet.

Logan pushes himself physically in training, but he also uses caution and common sense in his activities. He is especially careful to prevent injuries, knowing an injury or bleed will keep him out of the pool. To prepare for meets, Logan performs extensive stretching exercises. He pays special attention to his ankle, a target joint that has lost flexibility. He also wears ankle braces to prevent injury when he is running or exercising.

Logan swims year round, competing on his high school team and participating in national club swimming through USA Swimming. His events include the 100 butterfly and the 200 individual medley. Logan's practice schedule demonstrates his level of dedication to the sport; year-round he practices a minimum of six times each week, during the high school season he practices eight to nine times each week. Logan's family is proud to report this training has paid off. Logan recently swam on Team Indiana for USA Swimming, representing the state. He was sectional champion in the 100 yard butterfly for McCutcheon High School in February and went on to compete in the state meet.

If you have a bleeding disorder, Logan wants to assure you it is possible to be involved in activities and sports that are both safe and gratifying. He says, "Regardless of your limitations, you can find a niche for yourself. Hemophilia isn't easy, but it is very manageable." Don't let hemophilia prevent you from setting goals!

Logan also wants to encourage others that self-infusion is an achievable goal. When Logan was a child, his family believed self-infusion was too difficult to master. For years, Logan's family traveled to medical centers and hospitals for his infusions. These experiences were often frustrating, as many times the staff was poorly educated on hemophilia. Eventually Logan's family grew tired of the time and money required to infuse at medical centers and decided to give self-infusion a chance. Learning to infuse was challenging at first,



but after finally learning the technique, both Logan and his mother feel self-infusion is simple. They both encourage others with hemophilia to try self-infusion. It has improved their lives and allows Logan to be self-reliant and proactive in managing his health. Logan's mother Becky says, "When you're ready, go for self-infusion. It will help you live an independent life!"

Becky says that the IHTC has been an important part of successfully managing their sons' hemophilia. The IHTC has been a source of reassurance for the family in the midst of confusion and frustration. The family knows that the center is available to give direction and help whenever it is needed. The annual comprehensive visit is also a great comfort to Becky and the attention that Logan and the family receive is indispensable.

Now a senior in high school, Logan is exploring various schools, and plans to swim competitively at the college level. Although his future college decision is not yet made, he has an interest in physics and computer science. Regardless of where he ends up, Logan knows good choices and self-infusion will help him reach any goal he sets.

IHTC WELCOMES NEW STAFF

Anand Tandra, MD **IHTC Hospitalist**

Dr. Anand Tandra received his medical Degree from Osmania Medical College, one of the top ten medical schools in India, and obtained his foreign medical graduate degree after coming to the U.S. Prior to coming to the U.S., he was an intern in India and worked for 2 years as a house officer. Dr. Tandra also earned his Master's in Public Health from University of Massachusetts Amherst in 2004. He finished his post-graduate residency training at Michigan State University, East Lansing; after which he joined IHTC as a Hematology Hospitalist.



Tandra

Dr. Tandra has been a physician for 7 years. His wife is a physician and his father is a dentist. He believes his father's profession inspired him to become a physician. Dr. Tandra also says that getting admitted to medical school was a challenge and he enjoys challenges. He chose to specialize in hematology because he considers it a great subject - intricate, challenging, and intellectually stimulating; an art in the form of medicine. His specific areas of interest include hemophilia, Von Willebrand's Disease, and thrombotic disorders. Dr. Tandra finds IHTC to be a great place to work with excellent resources to fulfill his goals. He greatly enjoys the people and atmosphere. He says that IHTC's mission to serve Indiana residents is noble and that he is glad to be part of it. Dr. Tandra's hobbies include cooking, reading and listening to music. We are grateful Dr. Tandra has joined our team!

Angeli Rampersad, MD **Pediatric Hematologist**

In February of this year, Dr. Angeli Rampersad became the newest pediatric hematologist at the IHTC. She comes to the center from New York City where she completed her Pediatric Hematology and Oncology Fellowship as part of the Memorial Sloan Kettering and New York Presbyterian Cornell program. Dr. Rampersad attended medical school at the University of the West Indies and worked in pediatrics for four years in Trinidad. She served her pediatric residency at SUNY Brooklyn and stayed for an additional year when she was asked to be Chief Resident.



Rampersad

Dr. Rampersad was born in Anguilla, an island in the Caribbean. From the time she was a child, she knew she would become a doctor. She was determined to use medicine to positively impact people's lives; this passion and care for people is evident to those who meet her.

Dr. Rampersad's interest in hematology began after meeting a distant cousin in Trinidad during her medical school training. This cousin had beta thalassemia major, a disorder in which the body fails to produce hemoglobin normally. If a transplant is not possible, the only treatment for this disorder is frequent blood transfusions every few weeks. After watching her cousin cope with this disorder, Dr. Rampersad decided to specialize in hematology in an effort to provide individuals like her cousin the best medical care possible.

When Dr. Rampersad finds free time in her schedule, she enjoys reading fiction, photography and dining out to experience different types of cuisine. She also enjoys traveling and seeing Broadway shows and musicals and she makes sure to see one when she returns to New York for visits.

Dr. Rampersad is enjoying her new home at the IHTC and is joining in the camaraderie she notices among staff. She has been impressed with the knowledge level and self motivation of every staff member and is inspired by their dedication to each patient's well-being. We are grateful to have Dr. Rampersad as a part of our team!

Lisa Bowman, RN, CRRN **Pediatric Triage Nurse**

Lisa Bowman graduated from Purdue University as a registered nurse with her Associate's of Science in Nursing. She is also a Certified Rehabilitation Registered Nurse. Prior to coming to the IHTC, Lisa worked at the Rehabilitation Hospital of Indiana for nine years. She has also worked in adult critical care, the Riley Hospital emergency room, and home care infusion therapy. Lisa started out in Business school at IUPUI and in her free time volunteered at Riley Hospital. While volunteering, Lisa says that she fell in love with the children and was inspired to become a nurse. In her early impressions of the IHTC, Lisa has been impacted by the level of professionalism and by the collaborative efforts in caring for patients. She also enjoys the family atmosphere. Lisa has been married to her husband, Steve, for 19 years and has two children, Zach, 16, and Josie, 11. As hobbies, Lisa enjoys boating, reading, going to flea markets and antique stores, and selling items on eBay. Her family also owns a restored vintage tin can camper that they enjoy using whenever possible.



Bowman

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DENTAL PROTOCOL REVIEW

A recent survey of persons with bleeding disorders revealed confusion regarding dental health and general recommendations. The following is a review of important dental guidelines.

Dental Disease:

Plaque is a sticky film that builds up on teeth daily and causes dental disease if not removed effectively. The most effective way to remove plaque is by brushing and flossing every day. Flossing is the only method that removes plaque between teeth. Even in persons with bleeding disorders, healthy gums should not bleed. During manipulation such as teeth cleaning, bleeding should be limited. Red, swollen, or irritated tissues are signs of dental disease and will bleed easily during dental treatment. This condition is not caused by a bleeding disorder, but by poor oral health. The IHTC encourages all patients to find a general dentist to address these issues, as they will improve with routine care.

Dental Procedures:

There are several specific dental treatments that require special precautions. Patients should contact the IHTC before procedures that require block anesthesia (numbing), dental extractions, or periodontal surgery. These procedures require additional factor replacement, Stimat, or Amicar. If a patient is following a prescribed prophylaxis regimen, it is best to plan appointments on days when infusion is scheduled. Additionally, patients with certain heart conditions, joint replacements, or a central venous device (port) may need antibiotics before invasive dental procedures. It is best to contact the IHTC for recommendations before scheduling treatment.

Fluoride:

Fluoride is necessary to prevent decay. If a family is utilizing well water and there are children in the home whose permanent teeth have not finished erupting, the fluoride content of their water needs to be analyzed. While permanent teeth are developing, fluoride helps increase future resistance to decay. This water analysis can be completed with a simple water test that is available through your local dentist or the IHTC. Additional fluoride, available in chewable tablets, can be prescribed if necessary.

Sugar:

Soda consumption is detrimental to oral health. Most people are aware of its high sugar content, but they often do not realize that diet and regular soda is also high in acid. Acids eat away at the hard surface enamel of teeth and continue to do so 30 minutes after the last sip. This can cause generalized decay and sensitive teeth. In recent years, soda consumption has steadily increased in people's diets, with children experiencing the largest increase. It is best to limit daily soda intake and to drink it only with a meal, switching to water between meals.

The IHTC has two dental hygienists ready to assist you with questions or concerns. They consult with dentists throughout the state to address issues related to your oral health. It is helpful to contact the hygienist at least one week prior to a procedure so that recommendations can be in place before your scheduled appointment.



New staff continued from page 3

Tamara Guynn, RN - Adult Triage Nurse

Tamara Guynn graduated from Indiana State University in Terre Haute with a degree in Nursing. When asked why she chose to go into nursing, Tamara states she decided at the age of twelve to become a nurse and followed through with this plan into adulthood. Prior to starting at IHTC, Tamara gained extensive experience in case management, disease management, and home care nursing. She became a Certified Medical/Surgical Nurse through the American Nursing Association, with a designation of RN-C for many years. Tamara has found working at the IHTC to be "like working with a family" where employees share a "bond like brothers and sisters." Tamara is the proud mother of two sons, Stephen, 25, and Jermaine, 22. In her spare time, Tamara is an aspiring author who has loved writing her entire life. She is an ordained minister who enjoys working with people in the community. Tamara also calls herself the "biggest adult roller-coaster enthusiast in the world!"



Guynn

R.I.C.E. REVIEW

You call the treatment center to discuss a recent injury. You are told by the nurse to infuse as prescribed and to also use R.I.C.E. As you hang up the phone, you pause. You are clear about infusing, but how does rice help? Do you need to eat the rice? If so, how much and how often? Is brown rice better than white rice? Do you just apply cold rice to the joint like a salve? With so many questions, you decide to call the treatment center to verify exactly how to use "rice" therapy. This is what you learn:

R.I.C.E is an acronym for Rest, Ice, Compression and Elevation. These four components are prescribed by health professionals for the early treatment of injuries. R.I.C.E. therapy is not meant to replace infusion, but used as a supplement to help decrease bleeding, and relieve symptoms.

- **REST:** Resting an area of the body involved in a bleed will reduce the chance of re-bleeding into the injured joint or muscle. If you are having a bleed, reduce or stop using the injured area for 48 hours. If you have a leg injury, you may need to stay off it completely. Crutches, splints or slings are often helpful if you need to remain active.

- **ICE:** Ice causes blood vessels to constrict, therefore limiting blood flow to an injured area. Place an ice pack on the injured area for 20 minutes at a time, four to eight times per day. You may use an ice bag, cold pack, or a plastic bag filled with crushed ice that is wrapped in a towel.

- **COMPRESSION:** Compression of an injured ankle, knee, or wrist may help limit or reduce swelling. Compression aids include bandages such as elastic wraps, special boots, air casts, and splints. If you are using an elastic wrap, remember to start below the injured area and progress upward. If you feel throbbing, or if the wrap feels too tight, remove the bandage and rewrap the area so the bandage is looser. Ask your medical provider which type of compression is best for you.

- **ELEVATION:** Elevating an injury reduces swelling. Proper elevation means keeping the injured area elevated above the level of the heart. You may want to use a pillow to elevate an injured limb.

R.I.C.E. can relieve pain, limit swelling, and protect injured tissue- all of which help speed the healing process. Quicker healing can translate into decreased time missed from school or work and can lead to better health outcomes.

So remember - follow each injury-related infusion with a side dish of R.I.C.E.!



RICE RECIPES

ICE BAG RECIPE

2 Cups of Water	1 Cup Rubbing Alcohol
2 Gallon Size Ziploc Bag	1 Thin Towel

1. Pour water and rubbing alcohol into the Ziploc bag, squeezing out most of the air. (NOTE: You may want to double bag to prevent leaks.)
2. Place in the freezer until the mixture is slushy.
3. Place a thin towel between the ice bag and area of skin to be iced.
4. Leave on for 15-20 minutes.
 - a) You can repeat this procedure but use **no more than once every two hours.**
5. Return the ice bag to the freezer for refreezing.

NOTE: Your skin should be pink and feeling numb. Your sensation should return within 20-30 minutes

HOT PACK INSTRUCTIONS

1 Hand Towel	2 Gallon Size Ziploc Bag
Microwave	2 Large Towels

1. Wet the hand towel and wring it out until it is almost dry.
2. Fold the hand towel and place it in the Ziploc bag. *Partially* zip the seal, leaving the bag open one half to one inch to allow for escaping steam.

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IHTC RECEIVES OUTSTANDING FEEDBACK FROM PATIENT SATISFACTION SURVEY

The IHTC is happy to report excellent results of our most recent patient satisfaction survey. Around November 2007 the IHTC conducted its second patient satisfaction survey to evaluate the level of service we offer and identify areas where we can improve.

Over 91% of patients surveyed reported having an excellent or very good overall experience with the IHTC. These results were consistent with the positive feedback we received from the previous year's survey.

One area identified last year as having the potential for improvement was waiting time in the reception area and exam room. After making some scheduling adjustments and modifying our clinical work flows, a higher percentage of patients rated the time spent in the waiting room and the time needed to complete the visit as excellent or very good.

When asked why patients rated the IHTC so highly, some responses were:

- "They have taken excellent care of me every time I have been there."
- "I just felt very comfortable there with how they presented everything and how they discussed and answered all of my questions. It was very thorough. I could definitely not give it a lower score."

Thank you to everyone who participated in the survey - we are grateful for your feedback and take all of your recommendations to heart. We look forward to continuing to fulfill our mission of providing the best care possible to persons with bleeding and clotting disorders and their families.

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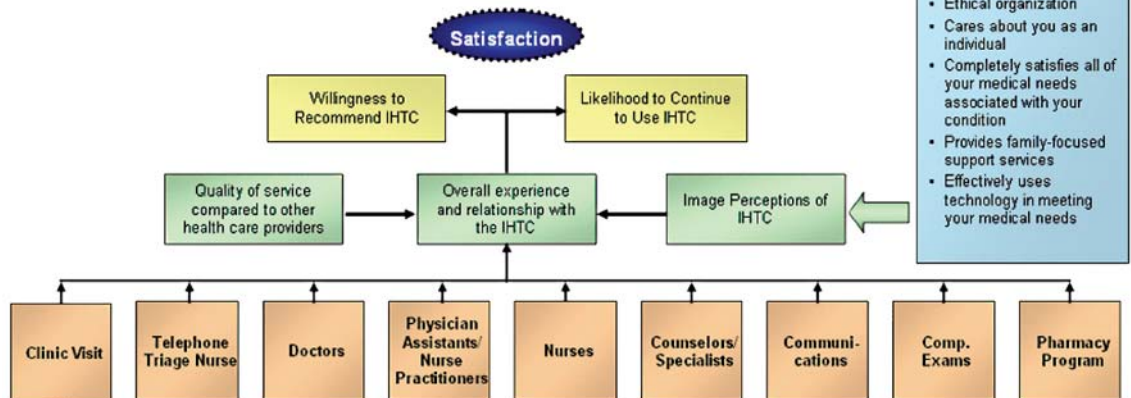
3. Place bag in the microwave and heat on full power for 2 to 2 1/2 minutes.
4. Remove that bag from the microwave and seal the bag completely. The contents will be *very hot*.
5. Wrap the bag in 2 larger dry towels and place it on the area to be warmed.
6. Leave the bag on the area for 15-20 minutes.

The wrapped hot pack should feel warm and not hot. If it is too hot, put more towels around it. Do not use the hot pack if you have diabetes, poor circulation, loss of sensation, or swelling in the area where you would be applying the hot pack.

HEATING PADS

Care must be taken when using heating pads to help relieve pain. Incorrect usage can lead to burns. Heating pads should be used on low heat and should be placed on the affected area. Use this form of heat for twenty minutes at a time. Do NOT sleep on a heating pad. Use great care when using a heating pad if you have diabetes, poor circulation, or loss of sensation. Inspect the skin under the heating pad to check for redness or blistering. Do not use heating pads in areas where there is swelling.

NEVER USE HEAT DURING AN ACUTE JOINT OR MUSCLE BLEEDING EPISODE!



- Leader in the treatment of bleeding and clotting disorders
- Focused on the needs of the patient
- Easy to work with
- Professional organization
- Ethical organization
- Cares about you as an individual
- Completely satisfies all of your medical needs associated with your condition
- Provides family-focused support services
- Effectively uses technology in meeting your medical needs

HOOSIER WOMEN ATTEND NHF WASHINGTON DAYS

Judy Moore, longtime IHTC Social Worker, and Judy Rich, the mother of a young man with hemophilia, represented the Indiana bleeding disorders community at the National Hemophilia Foundation's (NHF) Washington Days event, held this past March in Washington, D.C.

Rich began the three-day experience at an orientation session for first-time attendees where she learned the basic skills required to promote an agenda on Capitol Hill. Both representatives benefited from the NHF briefing session for the more than 200 attendees. At the briefing, NHF staff reviewed the issues to be presented during the visits to House and Senate offices on the next day.

The targeted issues at the annual event included the Medigap Legislation (H.R. 1282), which helps Medicare beneficiaries under the age of 65 purchase Medicare Supplement policies. This bill requires insurers to offer these beneficiaries the same 6-month open enrollment period available to individuals who are 65 or older. Other Washington Days issues included additional funding for hemophilia treatment centers and a call for support for S2706, a bill that requires insurers to raise minimum lifetime caps. This bill would phase in minimum lifetime caps for private insurance plans to \$10 million with an annual inflationary index.

On the morning of March 6, the Washington Days group assembled on Capitol Hill to honor Senator Byron Dorgan of North Dakota, the author of the lifetime caps bill. Dorgan offered words of encouragement to the group before they began a day of visits to their respective Congressional delegations. Following the session, Moore and Rich visited the offices of Senators Bayh and Lugar, as well as Representative Dan Burton. They also accompanied the Illinois delegation on a visit to the office of Senator Barack Obama.

While visiting the various congressional offices, Rich was able to recount how her family nearly reached the lifetime cap on



two different group insurance policies. She was fortunate in that her employer changed insurers on each occasion just before the cap was reached. Rich brought EOBs and pictures of her son to help tell her story. Her personal experience gave a face to the lifetime cap issue plaguing the bleeding disorder community and provided strong support for the need for legislation.

Moore's years of experience with the IHTC enabled her to make a persuasive case regarding the need for additional funding for hemophilia treatment centers.

She described the IHTC's many outreach efforts and the broad range of services provided to the Indiana bleeding disorders community. Moore explained that the growth of the center's patient population, especially the increasing number of women with Von Willebrand Disease, makes it necessary to obtain additional federal funding to support the center's efforts and those of similar HTC's around the country.

Both Moore and Rich found the Washington Days event to be educational and productive. They are confident that their participation contributed to the advancement of the bleeding disorders agenda on Capitol Hill. While much work remains, events like Washington Days provide an important reminder to federal legislators that the needs of the bleeding disorders community are significant and must be addressed.



DON'T MISS OPEN ENROLLMENT IN THE DELTA DENTAL INSURANCE PROGRAM!

Many of our patients have taken advantage of a great opportunity - subsidized dental insurance! The IHTC and Hemophilia of Indiana collaborated with Delta Dental to offer a group dental insurance plan to the bleeding disorders community in Indiana. The plan provides 100% payment for covered services when provided by a Delta Dental network dentist, and includes coverage for two check-ups and cleanings per year, as well as a number of other dental services. Claims for covered dental services are paid up to a maximum of \$1,000 per calendar year for each covered individual.

One low monthly premium covers all family members within a household. Premium assistance is available from Hemophilia of Indiana at varying levels, based on the family income.

For more information, please contact Rea Rhodes at the IHTC (877-256-8837) or Hemophilia of Indiana (800-241-2873).