

The Clotting Times



FALL 2005

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IN THIS ISSUE

- New Medicare Prescription Drug Planspage 2
- Camp Brave Eaglepage 3
- Doug Thompson Teen Leadership Programpages 4 & 5
- IHTC Welcomes New Staffpage 5
- IHTC Career Cornerpage 6
- Hemophilia of Indiana Annual Meeting Weekendpage 7
- Advoy —
Your Bridge to Better Carepage 7
- IHTC Treatment Center and Pharmacy Movepage 8

MARK YOUR CALENDAR

October 27-28
National Hemophilia Foundation
Annual Meeting
San Diego, CA

CHANGING SEASONS

Amy Shapiro, M.D.

The summer seems to have flown by with a flurry of activity both at and outside the center and with the many programs of the IHTC and Hemophilia of Indiana. This newsletter gives you an update on Camp Brave Eagle, our longstanding camping program for children with bleeding disorders, and their siblings. The camping experience was expanded this year to include "Thompson Outpost", a leadership program for young adults performed in conjunction with CampTown and Hemophilia of Indiana. This year's inaugural program was felt to be a great success by the campers, the staff of CampTown, Hemophilia of Indiana, and the IHTC.



The end of summer brings about the beginning of the school year a time to get ready for new challenges and a fresh start. To support our patients in their educational goals we have expanded our career counselor position to full-time. Look in this edition for an article from our new career counselor Don Molter. If you, a student, or young adult in your family need some assistance, please contact Don.

In addition, staff of the IHTC in coordination with Michelle Rice, Executive Director of Hemophilia of Indiana, has worked hard on issues related to access to care throughout the state for our patients. Some of these issues include inpatient reimbursement through Medicaid for factor concentrate, use of pharmacy benefit managers by insurance companies, access to IHTC programs and services, reimbursement of factor concentrate in long-term nursing facilities and rehabilitation hospitals. These important issues impact your care and require continued efforts and vigilance to achieve our goals. Look inside for an update on the changing face of healthcare by Sally McCarty.

The IHTC is also working to make more clinic time available for comprehensive clinic. This clinic time is a critical resource given to the bleeding disorder community to improve your access to quality care. Attending comprehensive clinic has been shown to have important healthcare benefits. Not attending comprehensive clinic or not keeping your appointment in this clinic hurts our ability to deliver quality care to you and the entire community. Help us help you - keep your commitment to attend your appointment in comprehensive clinic. Come meet with our team - we are here to serve you.

NEW MEDICARE PRESCRIPTION DRUG PLANS

Starting January 1, 2006, Medicare will offer insurance coverage for prescription drugs through new Medicare prescription drug plans. Insurance companies and other private companies will work with Medicare to offer these plans. Some have referred to the plans as "Medicare Part D" but Medicare is not calling the new plans "Part D."

The plans will help Medicare beneficiaries save money on their prescription costs. Beneficiaries will be eligible to enroll even if they are not currently on a plan that offers prescription drug coverage. In order to get the new coverage, they must choose and enroll in a Medicare prescription drug plan that meets their needs. It is important to note that Medicare covers clotting factor under its medical benefits, so the new Medicare prescription drug benefits will not affect how factor is obtained.

Those Medicare beneficiaries with a limited income should receive an application from Medicare for extra help paying for a prescription drug plan. They will be eligible for extra help if they have a yearly income below \$14,355 (single) or \$19,245 (married) and they have less than \$10,000 (single) or \$20,000 (married) in resources. The lower a beneficiary's income and resources, the more help that person will receive. A Medicare beneficiary who receives an application for extra help should be sure to fill it out and return it. Millions of people will qualify for a Medicare prescription drug plan with little or no premiums or deductibles, and low co-payments.



The standard annual benefits, which must be offered by all Medicare prescription drug plans, are as follows:

- You pay a \$250 deductible.
- You pay 25% of drug costs from \$250 to \$2,250; Medicare will pay 75%.
- You pay 100% of drug costs from \$2,250 to \$5,100.
- After your total drug costs reach \$5,100, and you have paid \$3,600 in out-of-pocket costs, you pay only 5% of any costs above \$5,100; Medicare will pay the other 95%.

All insurers offering drug plans will have to provide at least the standard benefits listed above and will have to offer on their formularies at least two discounted drugs from each

therapeutic class. However, some plans may offer more coverage and additional drugs for a higher monthly premium.

Beneficiaries, who have both Medicare and full Medicaid benefits as of January 2006, will no longer receive drug coverage through Medicaid. Medicare will provide their prescription drug coverage instead of Medicaid. They will have to choose a plan by December 31, 2005, or Medicare will enroll them in one. However, they will be able to change plans at any time. Medicare beneficiaries who are not on Medicaid will only be able to change plans between November 15 and December 31 each year.

Beneficiaries who have a Medicare-approved drug discount card can use it until May 15, 2006, or until they join a Medicare prescription drug plan — whichever comes first. Those beneficiaries who have a Medicare Supplement policy with drug coverage will receive a notice from their insurance company telling them whether or not their policies are as good as, or better than, the new Medicare prescription drug coverage. The notice will explain their rights and choices.

Beneficiaries who have prescription drug coverage from an employer or union will be notified by the employer or union about whether their current drug coverage is as good as, or better than, Medicare prescription drug coverage. If it is either, they can keep their current drug coverage. If they decide to join a Medicare prescription drug plan later, they will not be penalized for late enrollment, but may not be able to get their employer or union drug coverage back.

Those beneficiaries who are notified by their employers or by their Medicare supplement insurers that their coverage is not as good as the new Medicare prescription drug coverage should enroll in a new Medicare prescription drug plan when they become eligible. Otherwise, a late penalty of 1% for each month that passes between the enrollment deadline and the date they enroll will be added to their Medicare prescription drug plan premium for as long as they are enrolled in a plan.

More detailed information can be found at Indiana's Senior Health Insurance Information Program (SHIIP) Web site, www.in.gov/idoi/shiip, or at Medicare's Web site, www.medicare.gov.



2

The IHTC has attempted to identify and contact all of its patients who are covered by Medicare to alert them to these changes. If you or someone you know is on Medicare and did not receive our informational mailing, please contact the Center so we can add the new name to our Medicare list for any future mailings.

THOMPSON OUTPOST: One Nurse's Wilderness Experience

Jennifer Maahs, PNP

On August 7th 2005, nine of our young men with bleeding disorders and three adults began an experience that will never be forgotten. The Indiana Hemophilia and Thrombosis Center and Hemophilia of Indiana teamed up with Camptown for this year's inaugural Thompson Outpost to provide a leadership experience. The setting was in the Twin Lakes Loop at the Hoosier National Forest.

This is our story:

DAY 1- SURVIVAL TRAINING

Our experience began with an introduction to survival training in Indianapolis.



The Camptown staff met with our campers to teach them about meal planning and shopping for rations for the week ahead. Campers were expected to plan, buy, and pack all of their food for the camping trip. Careful planning was required, as everything that was bought became "cargo" in our backpacks. Many campers chose the freeze-dried meals, while others opted for beef jerky and cereal. Did you know that Doritos taste the same if they are whole or crushed into small pieces to conserve space?

DAY 2- ARRIVE AT HOOSIER NATIONAL FOREST

We started at our campsite in the Hoosier National Forest, which is a three-hour drive from Indianapolis. Our site had a fire ring and a place for our tents. It was only a short walk to the bathroom, shower, and fresh water. We did not appreciate the "luxuries" of our first campsite until we camped out in the woods for several days. We began to work on teambuilding and leadership. We learned how to pack our backpack for the next few days; each pack contained a sleeping bag, sleeping mat, food, clothes, cook stove, raincoat, flashlight, 2 water bottles, and weighed 40 pounds.



DAY 3 - JOURNEY INTO THE WOODS

Our team assembled at the lake the following morning. Those who needed to be infused did so before starting our trip. We took along emergency doses of factor in a small cooler. After securing our backpacks in the canoes, and reviewing canoe safety, we began our trip across the lake. In the hot midday sun, we arrived at the other bank, put our packs on our backs and began our journey. We hiked for several miles that day and finally came to our campsite for that night. My shower consisted of washing with a diaper wipe. I chose the freeze-dried beef stew as my first dinner, while some of the boys experimented with a burrito shell-beef jerky-Cheez Whiz® combo. Needless to say, I was dreaming of something cool like ice cream. After dinner, we built a fire, did some teambuilding activities, and then secured our camp for the night. We were all relieved to know that there were no bears in the area. The campers were really starting to work as a team. Our "support crew" hiked in with fresh water to refill our water bottles. The campers were very respectful of each other. Are these the same boys that we came with?



DAY 4 - MORE HIKING

Breakfast was freeze-dried eggs. After one bite, I opted for a granola bar. Fortunately, I was able to get one of the teens to eat my eggs. At times, having a hungry teenager around is an advantage! Many of our campers infused again. Today our "support crew" would be bringing in more fresh water and factor. We were on the trail again by 10:00. The day's hike ended at a campsite that was overgrown with weeds. This was not in the original plan, so it was on to plan B. We decided to hike a few more miles out of the woods and back to a state park campsite. We ended the day with a real shower (boy did we need it!) and a trip to the Ponderosa Buffet. The staff from Camptown was very impressed with our young men; they said that they had never seen a group work so well as a unit. I was very proud and impressed by our young men as well.





DAY 5 - COLLECTING THE CANOES

Today we had to collect the canoes that we had left in the woods on our first hiking day. Hiking was much easier as we no longer had to carry our 40-pound packs. It was great to be back in civilization. We did more team building and life-skills games. We were all appreciating the fact that we had flush toilets again. Don't ask what we did before that!



DAY 6 - HOMEWARD BOUND

Time to pack up and leave. What a great trip! The boys had a hard time saying good-bye to each other. It was well-worth all of the sore muscles and sweat!

DOUG THOMPSON

The Doug Thompson Teen Leadership Program, "Thompson Outpost," was developed in memory of our beloved friend and colleague. Doug graduated from Indiana University School of Social Work in 1995. At 35 years old, he was not a traditional college graduate. Like many people with bleeding disorders, Doug's life did not run the typical course. At a young age he faced many difficulties and challenges that most people would not encounter until they were much older. Later in life, however, he accomplished and enjoyed things that many people experience when they are younger. During the sometimes chaotic unfolding of his life, Doug developed a character and personality that was rich in compassion, empathy, humor, determination, and, most essential to his being, optimism. Doug's testament to life was his ability to triumph over his disorder and live a full, loving, productive life, and his wish for us was to do the same.



IHTC WELCOMES NEW STAFF

LORIE GLENN • Research RN

Lorie has been in the health care field for over 10 years with two degrees from Indiana University in Nursing and Public Health. She has also worked in wellness programs in California, and returned to Indiana working in research and pediatrics. Lorie enjoys taking research on the road with IHTC's outreach team, who provide services to patients throughout the entire state.



WILLIAM WANFIELD • Clinical RN

William brings a wealth of knowledge to the IHTC clinical team. In addition to 16 years experience in hospital nursing, William also worked 2 years as an Army medic and has 2 years of dialysis experience. William enjoys intellectual, innovative medical approaches to accomplish a successful outcome with patients.



LINDA MCCORMICK • R.Ph.

Linda recently came on board with IHTC after working for us intermittently through a pharmacy-staffing agency. She has thirty years of diverse experience working for well-established pharmacy programs such as CVS, Marsh and Methodist Medicine Shoppe Pharmacy. Linda's excellent work ethic will be a valuable contribution to the IHTC Pharmacy's mission of providing the best possible pharmaceutical care to our patients.



DONALD MOLTER Career Counselor

Don comes to IHTC with years of invaluable experience in career and personal counseling. In addition to 11 years as a career counselor at Purdue University, Don has worked with elementary and high school students in West Lafayette and Lebanon. Don will be offering his expertise to help our high school students apply for college scholarships and financial aid, complete college applications, and a wide range of other services.



IHTC CAREER CORNER

Don Molter, M.S., IHTC Career Counselor

"What makes me unique? What am I good at? Why don't I do as well as my friends in school even though I study?"



These and other questions can be a real source of frustration for students as they seek to establish their own identities in school and among peers. At the IHTC I hope to help answer some of these perplexing questions in my role as the new career counselor.

My name is Don Molter and I am a graduate of Purdue

University with a Bachelor's degree in Public Relations and a Master's degree in Counseling and Personnel Services. I spent 11 years in Purdue's Office of the Dean of Students, specializing in career and personal counseling/testing, academic advising, leadership training, and special education issues. For the last 13 years, I worked in two Indiana School Corporations as an elementary and high school counselor. I am a father of three residing in Lebanon, Indiana along with two greyhounds. I enjoy attending my children's activities, music, church, and volunteering for our local greyhound rescue.

My vision for the coming year is to establish a positive working relationship with each student, and to offer personal, educational and career support through home, school, and office visits. Career counseling is so much more than helping to find a good job. Understanding what motivates you, accepting responsibilities, and developing a life-time action plan, among other things, will aid in development of positive self-esteem and a better sense of self-worth. My main focus for this year will be to identify and support current junior and senior students. It is crucial that they understand the requirements for graduation, and the many prerequisite steps required when looking at a post-secondary education.



Another focus this year will be current seventh and eighth grade students and their families. Did you know that income-eligible 7th and 8th graders who enroll in the Twenty-first Century Scholars Program and fulfill a pledge of good citizenship to the state are guaranteed the cost of four years of college tuition at any participating public college or university in Indiana? There are strict income guidelines for eligibility, so not every student and family will qualify; but it is my goal that every IHTC 7th and 8th grader fills out an application this year.

Career information and self-actualization activities are crucial to the empowering process for each person affected with a bleeding disorder. It is very important throughout a person's life to realize what they can and cannot do.

This is a true sign of maturity. Not all careers are attainable; although many young boys dream of a professional sports career, very few will realize this goal. Interest in sports does not have to be limited to being a professional athlete. There are other opportunities available for people with this interest, such as a sports writer, agent, or trainer. It is also very important for those affected with a bleeding disorder to look at potential future positions that allow them access to insurance. Starting to explore options early will help direct your goals into serious possibilities.

As the IHTC supports me in this new career counseling adventure, I hope to likewise support, direct, and offer promising and exciting career possibilities to our patients of all ages. Whether you are searching for a college, struggling to improve grades, or need assistance with a career change, please call me and let me be a resource for you.

Career inventories are available and appropriate from kindergarten to adulthood, and many of our resources may be taken on loan. To contact me, Don Molter, call (317) 871-0011 ext. 352 or toll-free at (877) 256-8837. You can also email me at dmolter@ihtc.org.

AUGUST 27 & 28TH MARKED 11TH ANNUAL WHEELS FOR WINNING MEETING & HEMOPHILIA OF INDIANA'S ANNUAL MEETING

According to Michelle Rice, "approximately 200 consumers and some 25 industry representatives, including representatives from both the National Hemophilia Foundation and the Hemophilia Federation of America were on hand for this year's annual meeting weekend."

The meeting began Saturday the 27th at 10:00 a.m., with a general session titled "Healthy Living with Hemophilia - Exercise & Fitness." A series of breakout sessions provided helpful information to family and friends on such topics as Dental Facts, Dads in Action, First Steps, Medicare Part D and more. National and local speakers, including Sally Crudder of the Centers for Disease Control and Prevention and Dr. Amy Shapiro, presented topics ranging from "The Obesity Epidemic - The hemophilia community is not immune" to "How to Avoid Problems in the ER." The programs and activities were a tremendous success thanks to the hard work of Michelle Rice and the staff of HII. Perhaps the biggest hit (at least for the kids!) was "Caribbean Cove," the Holiday Inn's indoor water park.



Dr. Amy Shapiro discussing "How to avoid problems in the E.R." at the annual meeting.



Sunday's 11th annual "Wheels for Winning" biking and walking event at the Indianapolis Motor Speedway was another success story. The day of activities promoting a healthy lifestyle, including biking and walking around the Formula One track, made this Sunday one of the most enjoyable days of summer for over 200 attendees.

ADVOY — YOUR BRIDGE TO BETTER CARE

The IHTC has been training patients for almost a year on Advoy — the web-based infusion and bleeding log system that helps you and your doctor track, share and access your important treatment information.

Though only patients who were participating in IHTC's Disease Management Program were enrolled in the past, the IHTC is proud to announce that we are now offering the Advoy system to the rest of our patients. Advoy is a fast, easy, accurate way to record bleeding and infusion details. In addition to eliminating the need for paper records, Advoy has a complex alert system that allows the IHTC nurses and physicians to intervene early to prevent target joints or other related medical conditions.

Date of Treatment	Date of Blood	Treat. Type		
11/9/2004 3:30 PM	11/9/2004 3:30 PM	Bleed		\$28 Co
11/9/2004 7:30 PM	11/9/2004 7:30 PM	Bleed	4	\$28 Co
11/9/2004 4:15 PM		Prophylaxis	4,268.00	\$28 Co
11/9/2004 7:00 PM		Prophylaxis	38,056.00	\$28 Co
11/2/2004 12:45 AM	11/2/2004 12:45 PM	Bleed	4,282.00	Elbow - Right \$28 Co

Infusion and treatment information has proved to be an invaluable resource to the health care providers at IHTC. A good example of how Advoy can improve patient care came not too long ago, when a patient came to clinic with a recurring thigh bleed. After carefully reviewing the patient's bleeding and treatment patterns on Advoy, it was decided that the patient should temporarily switch from on-demand to prophylactic infusion. This change in treatment regimen not only resulted in a better clinical outcome, as the patient's recurrent thigh bleed resolved, but the ability to interpret the clear and concise bleeding and treatment graphs also provided a sense of empowerment and control for the patient.

Patients interested in using or learning more about Advoy should contact Lariann Lowe at (317) 871-0011 x 218. Patients that choose to enroll in Advoy will be provided with access to the Advoy website and a training session will be offered. After 3 months of successful data entry into the Advoy website, patients will be offered a handheld PDA, free of charge, to record their bleeds and infusions. Alternative arrangements are readily available for patients who do not have access to the Internet.



8402 Harcourt Road, Suite 500
Indianapolis, IN 46260

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IHTC TREATMENT CENTER & PHARMACY TO MOVE



Because of the growth in the IHTC patient base, we will be moving up to the 5th floor in the St. Vincent Professional Building in December 2005. Construction and renovation has already begun, and should take the majority of the next three months to complete.

The new area will have a check-in desk with a separate nursing area, more exam rooms, and a larger reception area - with an area for adults and a play/education area for kids.

Stay tuned for more details - we will be sending out a reminder with the specific date of the move and all pertinent details this fall.

