The Clotting Times

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Mark Your Calendar

May 5
Racing for Hemophilia

June 18
Camp Brave Eagle

June 22
Course to a Cure

IHTC Physicians Among Indy's "Top Docs"

Drs. Amy Shapiro and Anne Greist have served Indiana's bleeding disorder community for more than 17 years. In its December 2005 issue, Indianapolis Monthly Magazine recognized the doctors' dedication and achievements by naming them among Indiana's "Top Docs." All of those associated with the Indiana Hemophilia & Thrombosis Center are honored to congratulate Dr. Shapiro and Dr. Greist for this prestigious recognition.

Dr. Amy Shapiro is a board-certified pediatric hematologist-oncologist. She received her medical degree in 1980 from the New York University School of Medicine and went on to complete her pediatric internship and residency, as well as a pediatric hematology/oncology fellowship, at the University of Colorado Health Sciences Center. In 1987 she became an Assistant Professor of Pediatrics at the Indiana University School of Medicine, and the Medical Director of the Indiana Hemophilia Comprehensive Center. In 1993, Dr. Shapiro was promoted to Associate Professor with tenure. Dr. Shapiro has served on the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation since April 1997, and is active in many local, regional, national, and international medical organizations. The National Hemophilia Foundation named her "Physician of the Year" in 2001. She left the University to open the IHTC with Dr. Anne Greist in July of 1998.

Dr. Anne Greist is a board-certified hematologist-oncologist. She received her MBBS degree in 1977 from the University of London and Associate of King's College, and then completed an internship in London. She was a Family Practice resident at St. Joseph's Hospital in South Bend, Indiana, followed by an Internal Medicine residency at the Indiana University Medical Center. She completed a fellowship in Hematology and Medical Oncology at Indiana University and was a Clinical Lecturer in Hematology-Oncology there from 1984 to1986. In 1986, she became an Assistant Professor of Medicine in Hematology-Oncology at Indiana University. In 1993, Dr. Greist was promoted to Clinical Associate Professor of Medicine at I.U., a position she held through June 1998, when she left to open the IHTC with Dr. Amy Shapiro. Her special areas of interest include coagulation disorders, sickle cell disease, and hematologic complications of HIV disease.

Enroll in Medicare Part D By May 15, 2006 to Avoid Costly Penalty

Despite the program's rocky beginnings, it is important that all Medicare recipients who are not enrolled in a Medicare Part D Prescription Drug Program plan do so by May 15. Those not enrolled by that date will be penalized 1% of the normal premium for each month that passes between May 15, 2006, and the month in which they enroll. For example, if someone does not enroll until July 15, 2006, that person will always pay a premium that is 2 percent higher than others with the same plan. The only people who will be exempted from this penalty will be those who are enrolled in a prescription drug plan (usually an employer or retirement plan) that has been deemed by Medicare to be as good as or better than Medicare Part D. Don't assume that you are exempt because you are on an employer group or retirement plan. Check with your plan administrator to be sure.

Those recipients who qualify for assistance ("Extra Help") with their Medicare Part D premiums or deductibles should have been notified about their eligibility last summer, and should now be assigned to a Medicare Part D plan. If you are single with an income of $14,355 or below, or if you are married with an income of $19,245 or below, and you have not received notice that you qualify for "Extra Help," you should call the Social Security Administration at 1-800-772-1213 to obtain an application. If, after contacting that office, you learn that you are only eligible for partial help with your Medicare Part D costs, you may be eligible for help from Indiana's Hoosier Rx program. For questions about Hoosier Rx, call 1-866-267-4679 after you determine if you are eligible for "Extra Help."

There are 43 different Medicare prescription drug programs available to Indiana Medicare beneficiaries. Before choosing a program, you should make sure that the program's formulary includes the prescription drugs you take. You might want to look at several plans to compare prices and coverage. Insurers offering Medicare Part D plans should be eager to answer questions and provide informational materials. Many of them have increased their customer service staffs to accommodate this enrollment period.

The Medicare Part D Prescription Drug Program went into effect on January 1, 2006, amid a great deal of confusion and error. Some Governors have gone so far as to offer state funds to seniors who can't pay for their prescriptions until their eligibility issues are straightened out. Once you are enrolled in a plan, you can attempt to avoid these problems by taking your plan card or other documentation of enrollment, along with your Medicare card, with you to the pharmacy when you are purchasing prescriptions or refills.

If you have questions or problems, the Department of Insurance's Senior Health Insurance Information Program (SHIIP) can be very helpful. You can reach a SHIIP counselor by calling 1-800-452-4800. Other agencies that may be helpful are the Indiana Area Agencies on Aging (1-800-986-3505); or the Centers for Medicare and Medicaid Services (1-800-633-4227). Also, Judy Moore, IHTC Social Worker, is ready to help with any problems you might encounter. Judy can be reached toll free at 1-877-256-8837.

Dr. Jakica Tancabelic Joins IHTC

Dr. Jakica Tancabelic, (pronounced yakeetza tantzabelich, or "Dr. T") recently joined the Indiana Hemophilia and Thrombosis Center, becoming our 5th physician.

Growing up, Dr. Tancabelic was interested in studying Biology, but her father persuaded her to give some thought to a career in Medicine. By the end of her studies, she had discovered an affinity for Medicine, one that she says some of her classmates who wanted to study Medicine from the start didn't always necessarily share!

Dr. Tancabelic is the first in her family to become a physician, although they have quite a few pharmacists. She has a striking passion for her work, which is becoming increasingly rare in the medical field today. What she enjoys most, she says, is taking care of patients; "overcoming potential disabilities can be challenging, but also very rewarding." She enjoys the basic science aspect of hematology, the interaction of proteins, platelets, and blood vessels, as well as taking care of the clinical manifestations of different blood disorders. "Without blood, there is no life!" she argues.

Dr. Tancabelic received her medical degree from the University of Rijeka Medical School in Rijeka, Croatia. She also has a diploma in Medical Microbiology and Parasitology from the University of Zagreb Medical School in Zagreb, Croatia. Dr. Tancabelic completed a residency in Pediatrics at St. Joseph's Hospital in Marshfield, Wisconsin, followed by a fellowship in Pediatric Hematology/Oncology at Columbia University in New York, New York. In addition to her experience as a Primary Care Physician and Medical Microbiologist/Parasitologist in Croatia, she has also worked for the Department of Health Services in Berkley, California, where she served as a Public Health Microbiologist. Dr. Tancabelic is board certified in both Pediatrics and Pediatric Hematology/Oncology.

Since 1998, Dr. Tancabelic had served as an Assistant Professor of Pediatrics at the University of South Dakota School of Medicine. She had been the Director of the South Dakota Center for Bleeding Disorders since 1999, where she gained valuable exposure to hemophilia and thrombosis. She was interested in focusing more in this area, and wanted exposure to caring for the wide range of patients served by the IHTC's nationally recognized program.

When asked about her experience at IHTC so far, she responded with alacrity, "The IHTC staff is phenomenal - I was very well received and everybody has been very helpful." Please join us in welcoming "Dr. T" to Indiana and the IHTC. We are honored to have her as a member of our medical staff, and look forward to working with her for many years.

Three More Added To IHTC Staff

Karen Heiston RN • Research Coordinator

Karen brings a wealth of knowledge and 29 years of nursing experience to the Research Department at IHTC. Before coming to IHTC, Karen worked for 12 years in the gastroenterology research department of Indiana University Hospital. Her diverse experience working on a range of drug and device studies will be very beneficial in her role at the IHTC. Karen has enjoyed developing relationships with the patients currently participating in the various active studies at IHTC, and looks forward to meeting those who are interested in participating in the future.

Nina Meschino RN • Clinical Nurse

Nina comes to IHTC with a unique variety of nursing experience in surgery, home health and infectious disease. She enjoys the opportunities offered at IHTC to expand her knowledge of hematology, and feels that the Center is very well advanced in improving patient care. Nina also takes pride in the ability of the IHTC to perform clinical procedures not typically offered in a non-hospital setting.

Sarah May • Research Assistant

Sarah recently came on board with IHTC as the newest addition to our Research Department. Sarah transitioned to nursing a few years ago, and has since worked on studies involving a range of neurological disorders, as well as some pulmonary drug studies. She has found research to be a very rewarding field; she enjoys tracking the progress made by patients and the benefits they receive from their participation in studies.

The Changing Face of Health Care

Discussions about ever-rising U.S. healthcare costs have been waged for three decades and are likely to continue. Causes have been identified and solutions have been suggested and tied. Some problems have been resolved but many remain.

While the debates rage on, there is one thing on which everyone can agree. The collective effort to control healthcare costs over the last few decades has revolutionized the face of health care and will continue to do so for years to come. For members of the hemophilia community, this change is profoundly more relevant than it is for the average American because most of the problems and solutions that have been discussed significantly affect the lives of chronically ill people and their families.

According to a 2002 PricewaterhouseCoopers (PwC) white paper, general inflation ranks first among the many factors affecting healthcare cost increases. The report notes, however, that healthcare inflation has risen at a significantly higher rate than general inflation, so general inflation is just one piece of the cost increase puzzle.

The white paper ranked prescription drugs and other medical advances as the second largest contributor to rising healthcare costs. The proliferation of advertisements for new prescription drugs, especially on television, has been cited by payors as a major driver of the increased demand for prescription drugs.

Many healthcare consumers see prescription drug advertisements and decide that the advertised drugs will help alleviate their medical problems. They then make appointments to visit their primary care physicians to obtain prescriptions. This sequence of events often results in costly and unnecessary visits and inflated demand for advertised prescription drugs. The inflated demand leads to higher prices and the result is further strain on the healthcare system.

Rising provider expenses have contributed nearly as much to health-care inflation as prescription drugs and other medical advances. The consolidation of hospital and healthcare systems has given the resulting entities more market share and, therefore, more negotiating leverage, leading to increased costs. In Indiana, many see the duplication of services and technology created by the un-checked proliferation of new hospitals as a major contributor to Indiana's perpetual ranking among the states with the highest healthcare costs.

Other contributing factors cited by PwC include government mandates and regulations, particularly the cost of complying with HIPAA privacy regulations, and litigation and risk management costs, although Indiana's cap on medical malpractice damages should diminish the effect of malpractice claims on Indiana's healthcare costs.

Commercial and government payors are responding to the factors contributing to these increases in a variety of ways. The one constant is that all payors, whether private or public, now incorporate elements of managed care into their cost control systems.

For at least two decades, payors have addressed increasing consumer demand and provider costs by employing two commonly used managed care tools: prior authorization and medical case management. Prior authorization

requirements call for a provider to contact the payor for authorization before certain services, such as hospitalizations and surgeries, will be covered. Medical case management applies specialized oversight of all services related to high cost medical conditions. A case manager, usually a nurse, is assigned to each participating enrollee who has a condition that is considered to be costly or difficult to manage.

The drug formulary is another managed care tool that has been employed by most payors for several years. A drug formulary is a list of brand-name and/or generic drugs that are covered by a plan, or covered to a greater degree by a plan. Most payors convene utilization review boards, comprised of providers, pharmacists, and health finance experts, to determine which drugs will be listed on the payor's drug formulary. Indiana's Medicaid Drug Utilization Review Board is an example of such a group.

Another response to rising drug costs that usually accompanies drug formularies is the use of tiered benefits. A tiered benefit structure uses lower co-payments to entice people to choose less expensive prescription drugs. For example, the lowest co-payment is usually charged for generic drugs, the next lowest for brand-name drugs that are on the plan's drug formulary, and the highest co-payment is charged for brand-name drugs that are not on the plan's formulary.

"Because of the effects that some of these managed care tools have on people with hemophilia... it is very important to know which plans use them and how they will affect access to replacement factor."

More recent managed care tools employed to control prescription drug costs are the use of pharmacy benefit managers (PBMs) and specialty pharmacies. The use of PBMs and specialty pharmacies have significantly affected the way that people with hemophilia obtain replacement clotting factor.

A PBM is a firm that acts as both claims administrator and pharmacy case manager for a payor. The PBM is employed to administer a payor's pharmacy benefits in a manner that will result in the most savings for the payor.

Some payors have separate coverage plans for specialty drugs and require that those drugs be obtained exclusively from the plan's contracted specialty pharmacy or pharmacies. The goal of the specialty pharmacy is to reduce the cost to the plan for certain high-priced drugs by handling the entire volume of those drugs for the plan.

Of course, the use of a specialty pharmacy significantly impacts people with hemophilia, as most plans require that replacement clotting factor be purchased from the plan's specialty pharmacy. Some state Medicaid programs are considering a sole source system, which is the use of one specialty pharmacy to supply all of the factor for the entire state. To date, there has been no indication that Indiana intends to move to a sole-source system.

Because of the effects that some of these managed care tools have on people with hemophilia and other chronic diseases, it is very important to know which plans use them and how they will affect access to providers and replacement factor when choosing among available options during employer group open enrollment periods.

Government and commercial payors have employed a number of additional measures to keep healthcare costs down. Among them are carve-out (separate) plans for specialized services, such as mental health, initiatives to reduce the use of the emergency room for non-urgent care, and reduction of administrative costs. One innovative example is the recent announcement by Indiana's Secretary of Family and Social Services that he would like to allow health care facilities to enroll people in Medicaid rather than maintaining a statewide staff to perform enrollment functions.

The recent news about healthcare costs is not all necessarily gloomy. A recent BusinessWeek article presented evidence that efforts to reduce costs have met with some success. Although health insurance c osts for private employers increased 7.5% in 2005, that number is down from 9.5% the previous year, and well below the peak of 11.4% in 2002. Those indicators suggest that many of the current efforts have been successful, so we can expect them to continue, and we are very likely to see additional cost saving initiatives in the future.

Each year, at its annual meeting, the National Hemophilia Foundation (NHF) brings together patients and families affected by bleeding disorders, along with concerned medical professionals and other advocates, to discuss the many issues that affect and unite the bleeding disorder community. In October, the NHF held its 2005 annual meeting in San Diego, California. Ten IHTC staff members and eight members of the Center's patient advisory board proudly represented the Indiana bleeding disorder community at the meeting.

The annual meeting offered something for everyone but much of the schedule was devoted to sessions designed to help families affected by bleeding disorders. Many of those sessions dealt specifically with issues related to children. The popular "NHF Youth and Adolescent Program" provided activities for children and teenagers between the ages of 4 and 17. "We enjoyed having some time to think about the information we were learning without having our small children around to keep us busy," said parents Cortland and Deanne Jackson. "There was just so much information to absorb. Our heads were spinning."

Several program sessions were devoted to issues that are particularly important to women. They included "Physicians Address Reproductive Challenges Faced by Women" and a symposium entitled "Raising Awareness of von Willebrand Disease." Other sessions addressed the needs of families who are new to the bleeding disorder community, and offered advice to those who want to advocate for the bleeding disorder community in their hometowns and states.

The IHTC's Dr. Amy Shapiro attended meetings that were part of the physician and researcher track, allowing her to interact with other bleeding disorder specialists about current issues and treatments. Nurse practitioner Jennifer Maahs conducted educational sessions about home infusion and thrombosis.

This was the first NHF Annual Meeting for many of the IHTC attendees. The lessons drawn from the meeting were as varied as the people who attended but they all agreed that the experience was extremely valuable for them and for their families. The Jacksons said they learned a lot by interacting with other families who are living with the same challenges. "Sometimes we feel like we are the only family dealing with hemophilia," they said. "It was comforting to know that the recommendations and treatment we receive from our treatment center are state of the art."

Mary DeArmond, who has a bleeding disorder, said the best part of the meeting for her was the symposium on Hepatitis C. "I know several persons affected by Hep C, with bleeding disorders and without," she said. "The information was very informative and was presented in an easily understandable format."

DeArmond found a one-on-one meeting with a genetic counselor and a hematologist who specializes in von Willebrand disease [vWD] to be particularly helpful. "I was also able to talk freely with other women with bleeding disorders about my concerns and personal issues," she said.

"This was my second meeting," said DeArmond. "During the meeting last year, I was busy gathering information. This year I spent more time sharing my story with other persons with vWd and offering encouragement. I would encourage NHF to continue to address the needs of the vWD community."

Nurse Patsy Yoder though that there was a good variety of consumer sessions and medical provider sessions. "I enjoyed learning on all levels," she said. "There was so much information on vonWillebrand disease. I feel like I am much more knowledgeable about this disease and its treatment," she added. Yoder was particularly impressed with the commitment of the members of the medical community who attended the meeting.

Many of the IHTC attendees found that the most difficult thing about the annual meeting was choosing which sessions to attend, because so many of the sessions addressed topics of interest to them and it was impossible to attend them all. All of the attendees said they would recommend the meeting to other patients and families. "I think anyone whose life is touched by complications from a bleeding disorder should plan on attending this meeting," said Yoder.

The 2006 NHF Annual Meeting will be held in Philadelphia, Pennsylvania, from October 12th through the 14th.

New Year's Resolution #1: I will exercise...

As the holiday season comes to a close, we finally have a chance to rethink, or perhaps evaluate, our goals for the New Year. We have spent time with family and friends and survived the overpowering temptation of holiday treats. To compensate for our potential overindulgence, many of us have resolved to improve our health through diet and exercise, only to become frustrated when we don't see immediate improvement or don't follow our health and fitness programs perfectly.

Since 1980, obesity rates have doubled among U.S. children and tripled in adolescents. Weight related health problems, such as Type 2 diabetes (formerly called adult-onset diabetes), joint problems, high cholesterol, and depression are beginning to be seen in children and are increasing in prevalence among adolescents.

Two out of three adults are overweight, and one of those is considered obese. Seventy percent of adults in the U.S. do not participate in the recommended thirty minutes of moderate intensity physical activity at least three days per week, and one quarter of that seventy percent get NO exercise at all. If inactivity has so many detrimental health implications, then why aren't more Americans willing to exercise?

For many of us, the word "exercise" implies workouts that are no fun, make us sweat too much, and take up too much of our time, which complicates an already busy lifestyle. Yet, we owe it to ourselves and our families to be as healthy as we can be. The good news is that day-to-day activities, like playing with the kids, housework, or gardening, are exercise too, and can help to boost fitness and shed pounds.

It takes about six months to develop a new behavior, so, to get results, you should make a commitment to engage in exercise on a daily basis for a minimum of six months. If it's necessary to skip a few days due to illness, work, or other obligations, get back to your exercise routine as soon as possible. Schedule time for exercise on your daily calendar and, even on your busy days, consider it a mandatory appointment. The more days you skip, the more likely you will be to abandon your program. Keep an exercise log to monitor your progress. Vary your activities if you are becoming bored with your routine. Don't do exercises you find unpleasant or uncomfortable, as this sets you up for injury or failure.

If you decide to purchase a piece of exercise equipment, place it in a convenient location at home so you can get on it and exercise whenever you have a few minutes to spare. Consider exercising with a buddy, either on a regular basis or occasionally. Your daily exercise routine will be more enjoyable and more difficult to abandon if you are part of a team.

It's helpful to set both short-term and long-term goals. An example of a short-term goal would be to maintain your current weight and not gain additional pounds. A long-term goal might be a five to ten pound weight loss. Set goals that are realistic and achievable. You should be willing to modify your goals upwards or downwards as needed. It is better to modify your goals than to abandon your exercise program altogether.

Here are examples of how you can incorporate exercise into your activities of daily living:

- Walk up several flights of steps rather than taking the elevator.
- Park an extra block away or at the far end of the parking lot and walk briskly to your destination. Look for the longest rather than the shortest route.
- Walk during lunch breaks.
- If your workplace has a fitness center, consider getting a membership and work out before or after work.
- Turn off the TV and play with your children.
- When you shop for groceries, move quickly down the aisles. When unloading the groceries from your car, carry one bag at a time into the house.
- View activities such as gardening, mowing, vacuuming, and dusting as opportunities to exercise.
- Learn a new sport or take dance lessons.
- Allow children to watch TV or use the computer only after they have been physically active for 30-60 minutes daily.
- Join groups that are physically active such as mall walking, hiking or biking clubs.
- Buy a pedometer and strive for 10,000 steps per day.

Three 10-minute sessions of moderate intensity exercise per day at 60% of your target heart rate (.6 x 220 [-] age) for beginners, and 70-75% of target heart rate for those in better shape, can produce many health benefits. The key to success is consistency. Occasionally, you won't have time to exercise as much as you should. On those days, just DO SOMETHING, no matter how small, to keep you in "the groove." A little exercise performed daily will produce much better results than sporadic, lengthy workouts, or no exercise at all.

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IHTC Treatment Center & Pharmacy have moved!

Due to the growth in the number of patients seen at the IHTC, the Treatment Center and Pharmacy have moved from the fourth to the fifth floor of the St. Vincent Professional Office Building. After a flurry of moving activity during the last weekend in January, including a brief but heartwarming ribbon cutting ceremony, the Center was open for business on Monday, January 30. The new area has a check-in desk with a separate nursing area, more exam rooms, and a larger reception area - with a play/educational area for kids.

Please pardon our dust as we put the final touches on our new space and remember, we're just one floor above our old space!

Caption