



IHTC Goals for 2005: Striving to Serve You Better

AS EACH year draws to a close and the New Year is upon us, we at the Indiana Hemophilia & Thrombosis Center reflect on last year's work and accomplishments, and establish goals for the coming year. This past year we have worked to improve our center patient care programs and data management. Some of these endeavors may be seen and felt by you, some remain in the background, but all contribute to improve how the IHTC functions and the care we strive to provide.

There are articles in this newsletter that describe and provide an update on some of the new initiatives and programs we put in place this year including the CEO program, STEP teleconferences, Advoy infusion reporting system, and our database efforts. We also describe some of the new staff at the center and their roles, a report from our Patient Advisory Board, and an update on insurance issues pertinent to our community. I hope that you read and enjoy this information. As always, please feel free to contact us to provide input on any of these programs and services, or to give us your ideas going forward.

We look forward to continuing the programs we began in 2004, evaluating how these programs are

working, their impact, and refining how we implement them. Setting goals for the New Year is never an easy task. There always seems to be many things to do, it is challenging to prioritize them, and difficult when we know that we cannot do everything

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we want to, given limited time and resources. Some of the projects we are considering for this year include updating our website, increasing the number of comprehensive clinics available, methods to speed the reporting process for comprehensive clinic,

improving our communication and feedback around the Advoy system, and evaluating methods to assist and increase your access to insurance coverage, to mention a few. Do you have suggestions that we should consider adding to this list of goals for 2005? Are you interested in partnering with us to increase available resources and therefore programming?

This year as we go forward together, remember that our programs and care are designed with you and your family's needs in mind. You are an important part of the team- this is your center, let's work together to make it the best we can. Happy holidays from all of us at the IHTC; we wish you and yours a happy and healthy New Year!

Insurance and reimbursement update

A RECENT nationwide study indicated that health care costs should not rise more than 6.6% in 2005, which is good news for those insured by employer groups. The study found that the annual average increase in the cost for businesses to renew group health insurance is slowing even more than anticipated. Health care costs began a sharp upward trend in 1998 when they increased by 12%. The trend reached its peak at 16% in 2003.

Two committees charged by the Indiana General Assembly with looking at ways to improve Indiana's

Medicaid program wrapped up their work in November. The Select Joint Commission on Medicaid Oversight, an interim study committee of the Indiana General Assembly, issued its final report on November 1, 2004. The Medicaid and Human Services Subcommittee of the Government Efficiency Commission submitted its findings and recommendations to the full commission on November 18.

The Select Joint Commission is made up entirely of legislators, six members each from the House and Senate. The 2004 General Assembly added to the

Insurance and Reimbursement Update

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Commission's ongoing responsibility for oversight of the Medicaid Program, by assigning the task of studying continuous eligibility as it relates to Indiana's Program.

According to the Commission's report, "Continuous eligibility is the procedure whereby, once determined to be eligible for Medicaid services, an individual is considered eligible for a predetermined amount of time, regardless of changes in the individual's financial and non-financial circumstances." The General Assembly instituted a 12-month continuous eligibility policy in 1998 for the Medicaid Program and in 1999 for the Children's Health Insurance Program (CHIP). However, the policy was repealed for both programs in 2002.

In its report, the Commission recommended that the continuous eligibility policy be reinstated "as soon as the state fiscal crisis ends and the budget situation improves." The Commission further found that "12-month continuous eligibility improved retention and continuity of care for Indiana's children."

The Commission also recommended that the Renewal Task Force, originally created by the Children's Health Policy Board be reconvened. The purpose of the Task Force is to "develop specific plans to improve the process of renewing coverage in Medicaid, CHIP and related programs."

The Subcommittee on Medicaid and Human Services was charged, as part of a broader initiative to increase

efficiency in state government, with examining Medicaid operations and making recommendations for improvement where necessary. Subcommittee members included representatives from business and organized labor as well as members of the medical and legal professions.

The Subcommittee's report included 22 recommendations organized under the following headings: Efficiency Efforts, Pharmacy Benefit, Funding Options, Organizational Structure, and General.

The annual average increase in the cost for businesses to renew group health insurance is slowing even more than anticipated.

Recommendations that have the most potential to affect members of the Hemophilia community are:

- Expansion of managed care for Medicaid clients
- More aggressive pursuit of Medicaid waivers
- More stringent participant rules for the Medicaid buy-in program (MedWorks)
- Expansion of the Preferred Drug List to reduce costs
- Enactment of a broad-based provider tax to be dedicated for the state's portion of Medicaid costs.

It is likely that the General Assembly will consider recommendations from both the Oversight Commission and the Subcommittee when the 2005 legislative session convenes in January. We will closely monitor any developments that could impact the hemophilia community and report on those activities in future newsletters. ◀

IHTC Disease Management Program:

Serving Indiana's high risk insurance population

STARTING in October of 2004, the IHTC began a pharmaco-economic evaluation of, and disease management program for, the bleeding disorder population insured by the Indiana's high risk insurance program.

The purpose of this program is to further evaluate the overall care of hemophilia patients in conjunction with a federally recognized, comprehensive hemophilia treatment center (HTC). By utilizing a single source replacement product provider accessing Public Health Service pricing, using mobile technology (Advoy) for home infusion data collection, and utilizing a comprehensive HTC to optimize use of healthcare resources, the program will contain costs and seek to achieve an improved clinical outcome.

The Disease Management Program looks at every

aspect of patient care and will evaluate the clinical and financial outcome when patients with bleeding disorders receive their care in collaboration with the IHTC. Not only will we be analyzing the benefits of our educational sessions and our patient's compliance with treatment regimens, but with the use of electronic treatment logs and replacement product dispensation data, we will be able to evaluate the efficacy of treatment patterns and product usage.

The goal of the program is simple - to provide the best possible care in a cost efficient manner. The program is one of the first of its kind evaluating pharmaco-economics within the bleeding disorder community and will add considerable value to the increasing popular concept of disease management. ◀

Careers Education Opportunity:

The goal for all those served by the IHTC

LISA BUNCH sees her role with youth as much greater than her career counselor title. "I like to think of myself more as a life coach," she says. "I want to help empower our youth and their parents to succeed. I am their advocate and will help lift them up. But it's up to them to make good life choices."

Lisa joined the Indiana Hemophilia and Thrombosis Center this past September to head up the center's new Careers Education Opportunity (CEO) program. She says the idea for the program was born from watching some of the children and adolescents served by the center struggle to overcome challenges and become independent adults with well-paying jobs. "The reality for most people with hemophilia is that small companies cannot afford to employ them due to the high cost of insurance coverage. We want to show our patients that they still have many options," says Lisa.

How Lisa shows each child his or her options varies depending upon each person's circumstances. In some cases, it is helping high school students research possible career paths, or navigate the college placement process. Lisa may also help a middle schooler develop better study habits. Whatever the need, though, her goal is the same: "I want to help these young adults find their place in the world so they can grow up and make a contribution."

Lisa now tutors one of these young adults, a junior at Lawrence Central High School, two to three times a week in math. In addition, Lisa regularly communicates with his teachers and counselors to make sure he is on their radar screens. His mother told us that "right before Lisa started tutoring him, he had just gotten his report card and wasn't doing well in math. He had gotten D's and F's on tests. Right after she started tutoring him, he got a C on a test, and then a B+ on the next one. He says it's him, but I know she's helping him. Lisa and I have good communication, we may disagree at times but we are able to bounce ideas off of one another and figure out how to best help him. I want him to succeed but he has to try for himself."

In another situation, Lisa met an IHTC family who

had removed their son from a hostile school environment and home schooled him. This did not seem to be the best solution for him. With Lisa's help, the family found an alternative school environment that could better meet the child's needs.

"The most important part of my role is to connect with IHTC families and help them to identify and overcome barriers their child may have in the growing up process. I want to see all of the IHTC kids grow up to be healthy happy young adults with a promising vision for their future," says Lisa.

How The CEO Program Can Help Your Child:

Through the CEO program, Lisa Bunch sees children ages 8 to 20 and provides assistance in the following areas:

- Counseling on school progress/situations
- Identifying learning styles
- Coaching parents and children
- Developing conflict resolution skills (bullying, disagreements)
- Identifying personality types, interests and passions using the Meyers-Briggs and SHAPE model
- Working with teachers and school counselors
- Tutoring
- Goal-setting with rewards and consequences
- Exploring career options: research, job shadowing, interviews, volunteering
- Helping with college admissions
- Identifying aspects of personality that need to be nurtured or developed
- Visiting schools and other learning environments
- Identifying and removing barriers to education



All assistance is provided free of charge to patients with bleeding disorders. To contact Lisa Bunch, call (317) 871-0011 ext. 352 or toll-free at (877) 256-8837. You can also email her at lbunch@ihtc.org. ◀

Indiana Hemophilia Registry

A genetic database for families with hemophilia

THE IHTC has been working on a new project creating a genetic database for the families with hemophilia in Indiana, called the Indiana Hemophilia Registry. We have purchased special software to design a database to collect the family information. We have been reviewing and updating the family histories of all of the individuals with hemophilia that come to IHTC. The family trees (also called pedigrees) are entered into the database along with information such as what the alteration in the factor gene is in the family, which family members are living in Indiana, who in the family is a carrier of hemophilia, the factor levels of individuals in the family, etc.

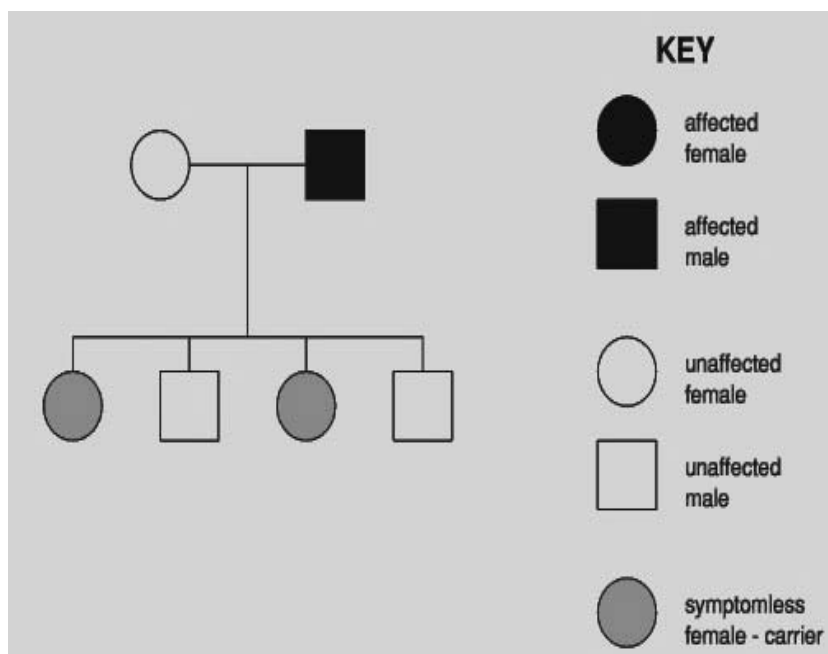
The database will serve many functions when it is completed. First it will keep us organized by holding all of the current family trees in one location. The database will also store a large amount of data about our families. We will be able to determine how many carriers we have in the state of Indiana, and how many women who may be carriers but haven't been tested. We would like to

find out how many women there are with low factor levels who may need treatment. It will also help us know when an individual may benefit from a family member's information. For example only one individual with hemophilia in each family needs to have genetic testing for the factor gene alteration, then the whole family can benefit from this information.

Don't worry, your private health information will

not be shared with your family members without your consent. However, we would like to obtain consent from individuals who have had genetic testing completed, to share these genetic test results with their family members if needed. If the genetic change in your factor gene has been identified in the past, you should have received a consent form in the mail asking for your permission to release this result to your family members in the future. We would want to share your result with your family in situations where family members would benefit from this information. For example, if your nephew or cousin with hemophilia wanted to have genetic testing completed to identify the change in his factor gene, we would like to be able to tell him

that someone else in his family has already had the testing completed and he does not need to be tested. If your sister, niece, or granddaughter called us and wanted to have carrier testing, we would need to be able to share with her whether the change in the factor gene has been identified in her family. Additional



information about your health and your care at IHTC is not necessary and would not be shared with others.

If you have questions about the Indiana Hemophilia Registry, would like to update your family history, or have questions about the consent to release your genetic testing result, you are encouraged to contact Meadow Heiman at IHTC. ◀

Please Join us in welcoming the following new clinical staff at IHTC



Lisa Johnson, Clinical RN, comes to us with twenty years of experience in the medical field. She has spent the past five years as a registered nurse working in hematology and oncology at Community East Hospital. She is incredibly compassionate, competent and caring, fitting right in at IHTC. She has found the center to be very welcoming and especially enjoys working with the IHTC physicians.



Terri Barclay, Research RN, has been in nursing since 1985. She moved to Indianapolis from Houston, TX and began working in General Pediatrics at Wishard in 1990. A couple of years later she began working in the ICU at Riley and then graduated from Indiana University School of Nursing in 1999. She has also worked in research in the endocrinology department at IU. She enjoys her role at IHTC because she is able to combine her passion for both pediatrics and research.



Daphne Johnson, RN, has been in nursing for over 15 years. She has worked mostly in hematology and oncology, but also has valuable experience working with bone marrow transplant patients at IU. Prior to working for IHTC, Daphne was responsible for wound care and other skilled nursing tasks for acute homecare patients. We're excited to have Daphne as part of our nursing staff. She enjoys working with our patients and is happy to be working as part of our IHTC team.



JoAnn Weaver, Registered Dietician is quickly being recognized as "the incredibly friendly dietician" at IHTC. She comes to us with over 25 years of experience in dietetics. She has worked as a dietician in a variety of specialties, including acute care, diabetes, chronic care, and group homes. JoAnn believes in "good, basic nutrition," not trendy, and often unhealthy diets. She takes great pride in focusing on how small changes in nutrition can have a significant effect on overall health.



Kimber Hummel, PA-C, has recently come on board to assist with inpatient consultations in the hospital. She has been a physicians' assistant for two and a half years and worked in the St. Francis emergency department before coming to IHTC. We are thrilled to have Kimber as a part of our team, especially to assist with this crucial component of the services we provide.



Pat Singer, Medical Assistant, also comes to IHTC with a wealth of experience in the medical profession. Before coming to IHTC she worked as a lab assistant, processing labs for Mid America Clinical Laboratory. Pat has enjoyed working with everyone at IHTC and has proved to be a great addition to our clinical staff. ◀

Patient Advisory Board members go to National Hemophilia Foundation meeting in Dallas, Texas

THE National Hemophilia Foundation's 56th Annual Meeting took place on November 4th-6th, in Dallas, Texas. Along with several of the IHTC staff, several members of the IHTC Patient Advisory Board were able to make the trip.

Here are some of the board members' comments on the meeting:

"I attended the National Hemophilia Foundation meeting this year for the first time. It really helped me take my disorder seriously. It made me realize the value and need for educating myself about my disorder and for taking care of my health. It was extremely eye opening and moving. I wonder how I survived as a child without my parents having this knowledge and support. I met so many people who shared similar stories and experiences. It is only the first step for me in my journey to take care of myself, my family, and my son and his bleeding disorder. It made me want to spread the word and reach out to others who may think they are suffering alone."



- Mary D.

"The interaction we experienced with other parents and

patients with hemophilia was invaluable!"

- Deanne J.

"I have attended several National Hemophilia Foundation meetings over the past several years and I must commend NHF and the hemophilia community for its outreach to women with bleeding disorders. There were so many interesting topics about

women's issues discussed at the meeting. The push to promote community awareness of the needs of this population was very impressive. I was thankful to have the opportunity to attend."

- Judy R.

For a complete list and description of the activities and meetings that took place at this years NHF Annual Meeting, please visit the National Hemophilia Foundation website at:

http://www.hemophilia.org/events/dallas_04/home.htm.

Next years meeting is scheduled for October 27th - 29th, 2005 in San Diego, California. ◀

IHTC Treatment Center and Pharmacy To Move

BECAUSE of the growth in the IHTC patient base, we will be moving within the next few months. Not to worry though, as we are just moving up to the 5th floor! Negotiations are being completed with the professional building's leasing company and then the renovations to the area can begin. In addition to more space, the new office 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. The exact date of the move is not yet known, but will take at least 3 months to complete. Stay tuned for more details... ◀

Important Dates

1. February 5, Hearts for Hemophilia at the Oak Hill Mansion in Carmel, Indiana.
2. March is National Hemophilia month.
3. March 10-12, Washington Days in Washington, DC.
4. April 1- 3, Hemophilia Foundation of America's annual meeting
5. April 29 - 30, National Hemophilia Foundation's "On the road"

LabTracker: Keeping patient information up to date

ONE of our most ambitious projects at the center this year has been the implementation and maintenance of a hemophilia based computer system for keeping track of our patient's information. Our computer system has the ability to import lab results from our clinical laboratory, download treatment records from the Advoy website, as well as generating Comprehensive Clinic reports.

Not only have we been reviewing charts to update medical information, but as many of you know, we have made great efforts to contact every one of our patients. We have dedicated countless hours to ensure that we have updated demographic and clinical information on our patients, and to verify that we are doing everything possible to provide the highest level of patient care. This new system has allowed our magnificent nursing staff to contact 96 percent of the patients on our active registry - a 15% increase from last year! We kindly ask for your assistance with this project. If you have not been in contact with IHTC please give us a call to update your records.

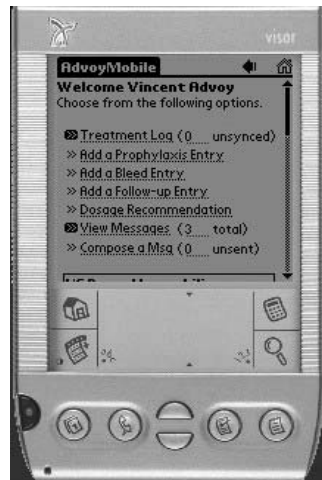
Advoy: Electronic treatment logs - improving patient care

TIRED of paper infusion logs? Advoy is an innovative healthcare website that makes it easier for hemophilia patients, caregivers and Hemophilia Treatment Centers to share and access important treatment data.

The Indiana Hemophilia and Thrombosis Center has begun utilizing Advoy with patients participating in Indiana's high risk insurance Disease Management Program.

Approximately half of these patients have completed an Advoy orientation and are currently using Advoy to record treatment and bleeding information. We hope to give all of our hemophilia patients the option of accessing this software by the end of 2005.

If you're a patient or caregiver, you will be able to use Advoy to keep accurate, up-to-date bleeding and treatment logs. The health care providers at your HTC will then have access to this information to assist them in managing your care, whether through adjusting your treatment regimen or through the early detection of target joints. Both patients and healthcare providers can produce graphs and reports with the data on the Advoy website as a way of visualizing treatment and recognizing important trends. This has proved to be much more beneficial than paper treatment logs that are often incomplete and difficult to analyze.



Don't have a computer or internet access? No problem. The Advoy software is available on a hand-held palm pilot and can transmit your logs through a phone line. The pocket-size, hand-held device is also a convenient way to store and access your treatment records. It can be used anywhere, anytime for easy, fast input of important data.

Every aspect of the Advoy website and hand-held device is HIPAA compliant and information entered and stored within the software is only available through patients or caregivers and the health care providers at your HTC. This innovative service is provided by Baxter Bioscience, which is part of The Baxter Healthcare Corporation, one of the leading names in the treatment of hemophilia, primary immune deficiency and other chronic diseases.



PATIENT LOG RECORD FOR _____

Patient: _____

View entries from: November 9, 2004 to December 9, 2004

Include Deleted Entries

6 treatment log entries found.

Date of Treatment	Date of Bleed	Entry Type	Amount	Location		
11/15/2004 3:20 PM		Prophylaxis	4,160.00			View
11/15/2004 10:05 AM	11/15/2004 10:05 AM	Bleed	2,096.00	Hip - Right	!	View
11/13/2004 10:10 AM	11/13/2004 10:10 AM	Bleed	4,160.00	Elbow - Right		View
11/11/2004 4:10 PM	11/11/2004 4:10 PM	Bleed	5,832.00	Elbow - Right		View
11/10/2004 10:30 AM	11/10/2004 10:25 AM	Bleed	2,080.00	Elbow - Right	!	View
11/9/2004 3:30 PM	11/9/2004 3:30 PM	Bleed	1.00	Elbow - Right		View

QUESTION | CORNER



8402 Harcourt Road, Suite 420
Indianapolis, IN 46260
317-871-0000
Toll Free: 877-CLOTTER (256-8837)

“My child has mild hemophilia and has not been infused for several years. We will be traveling out of state soon. Do I need to take factor with me?”

Our best advice is to always take your factor when traveling far from home. If you go to any hospital, you can never be sure that they have your infusion product. Many hospitals do not have factor at all. You should also be sure to take your travel letter with you! It includes your diagnosis and treatment recommendation.

“I have von Willebrand disease and have many relatives with bleeding problems that live out of state. What should I tell them about getting checked for vWd?”

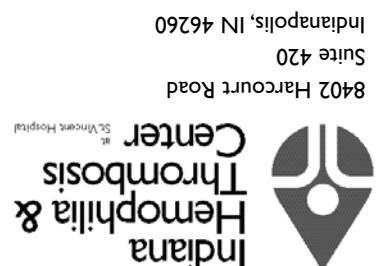
It is always better to know you have von Willebrand disease before any major bleeding events happen. The first step is to contact our genetics counselor to discuss who is at risk and who is not. Once you know who is at risk, we can provide the phone number of hemophilia centers in their area.

visit our website at: www.ihtc.org

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