



Update on West Nile Virus

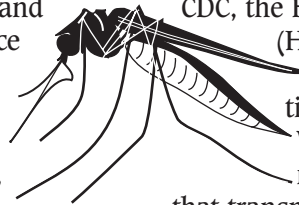
Information excerpted from material published by the National Hemophilia Foundation, American Academy of Pediatrics, and the Environmental Protection Agency

THE THREAT OF WEST NILE VIRUS has returned for the summer season. In conjunction with the National Hemophilia Foundation (NHF), we want to keep you informed of the history and recent developments of this disease and provide you precautions for avoiding it. West Nile Virus causes encephalitis and meningitis, and has been identified in the state of Indiana. Since 1999, the outbreak has reached 37 states.

The NHF has provided the following information about West Nile Virus:

NHF Medical Advisory #394 – October 10, 2002

West Nile Virus (WNV) is a new disease in the United States, but unfortunately, its incidence is growing at an alarming rate. According to the CDC (Centers for Disease Control and Prevention), nearly 3,000 individuals have been diagnosed with WNV and the death toll from the infection has risen to nearly 150 individuals. The NHF has established a web page on WNV, which includes the



latest information from the CDC and other government and private agencies. As this web page is updated frequently, you are encouraged to visit the site often at www.hemophilia.org.

In **Medical Advisory #393**, the NHF indicated that the CDC, the FDA (Food and Drug Administration), HRSA (Health Resources Services Administration), and state and local health departments were investigating seven cases of possible transmission of WNV via transfusion and transplantation. It now appears that we can say with confidence that transmission via transfusion of blood and blood components as well as organ transplantation did occur. NHF has asked the manufacturers of all clotting factor products how they plan to demonstrate that WNV is destroyed or removed from their specific products.

NHF Medical Advisory #395 – December 20, 2002
From May through October 2002, 13 cases of meningoencephalitis, an inflammation of the brain ▶ 6

Location is Everything: IHTC Pharmacy Program Now Located at the Center



ABOUT A YEAR AGO, the IHTC made an important business decision: to discontinue its contract pharmacy relationship and bring the pharmacy program in house. This move is a key part of the center's evolution, as we continue to offer the finest in healthcare services for our bleeding disorders patient population.

IHTC Pharmacy Background

The IHTC is a Public Health Services (PHS) designee. This is an important distinction in that, as Indiana's only member of the federal network of comprehensive hemophilia treatment centers, the IHTC is eligible to have a PHS pharmacy. The PHS program is overseen by several federal agencies, including the Office of Pharmacy Affairs and the Office of Maternal and Child Health. As PHS designees, the IHTC and its sister comprehensive centers are able to purchase clotting factor product at a discount from the manufacturers.

The IHTC's factor pricing philosophy is aimed at reducing the cost of care to those who must bear this burden: from patients and their families to insurance companies and government insurance programs. Our factor pricing is structured to cover the cost of doing business, which includes: product dispensation, inventory management, specialized insurance billing services, patient consultations – both pharmacological and insurance related, pharmacy staff, office space and equipment, infusion supplies, product shipping and receiving, and more. **All proceeds from the sale of clotting factor go directly to support the IHTC and its patient services and programs.** The IHTC was formed as a 501(c)(3) nonprofit organization. And so we conduct our business within the nonprofit spirit. Our sole intent in operating a PHS pharmacy is to cover the costs of the IHTC's patient care program, which provides you and your family the finest in comprehensive bleeding disorders care available. ▶ 2

IHTC Pharmacy Program from page 1

As those of you on our homecare service have come to know, we haven't skipped a beat in transitioning the former contract pharmacy service to an in-house program. Whether it's clinical or pharmaceutical services, we set the bar at the same level: peak performance.

The beauty of the IHTC Pharmacy Program is that it...

- *Minimizes the rising costs of clotting factor.* As an IHTC homecare patient, you receive clotting factor at reduced prices as guaranteed by the federal government's PHS program. Lower factor prices are important to you and your insurance provider. Lower prices result in patients reaching their lifetime limits on their health insurance coverage at a slower rate.

- *Offers uninterrupted service to every homecare patient in the state of Indiana.* We are able to provide both scheduled and emergency shipments 24 hours a day, seven days a week, and on all holidays.

- *Provides the best possible management of factor supplies during shortages.* The center is able to keep sufficient clotting factor on hand to meet all our patients' needs. As the state's only federally recognized comprehensive hemophilia treatment center, and because of our excellent relationship with clotting factor manufacturers, the IHTC is well positioned to ensure your supply of factor is not disrupted. (In fact, it was the IHTC's efforts that allowed patients in Indiana to get through the worst national shortage of recombinant factor VIII on record in 2001.)

- *Has the finest in factor insurance issues resolution expertise.* The center staff is able to respond immediately to any insurance questions or issues that might come up.

- *Integrates care programs.* IHTC pharmacy and healthcare professionals interact on a daily basis at the same business location. This allows our staff to handle all your medical and pharmaceutical needs in an immediate, well-coordinated fashion.

- *Provides support to a key community partner.* Because of our improved efficiencies resulting from moving the pharmacy in house, the IHTC is able to provide financial support to Hemophilia of Indiana, further benefiting the Indiana bleeding disorders community.

- *Gives our research coordinators the convenience of immediate access to the pharmacy* and stored research product in working with patients who are participating in clotting factor research studies.

- *Provides other medication or supplies.* The IHTC Pharmacy has all the latest in clotting factor supplies for our homecare patients. As well, the pharmacy carries other medications associated with our bleeding disorder patients' special needs.

- *Arranges compassionate care clotting factor for those in need.* Patients between insurance program coverage or having other financial difficulties can access,

through the IHTC Pharmacy, compassionate care product.

Pharmacy Program Staff

The IHTC Pharmacy Program is managed by **Jon Winay, RPh, MBA**. Jon came to the IHTC from a home healthcare infusion services company where he served as pharmacy director. He also brings experience in hospital setting pharmacy services, having formerly worked for Community Hospitals of Indianapolis. This unique

combination of professional pharmaceutical experiences makes Jon well qualified to direct our pharmacy program and provide you the finest hemophilia specialty pharmacy services available.

Janet Mulherin, RDH, whom many of you know as the IHTC's dental hygienist, is currently teaming with Jon as the pharmacy program's patient services coordinator. Janet has worked for the IHTC and Dr. Amy Shapiro for 14 years. Her experience, bleeding disorders

healthcare knowledge, and long-time relationship with the IHTC's hemophilia patients and their families made it clear to us that Janet would be an asset to the pharmacy program.

Judy Moore, LCSW, the IHTC's social worker, is also a long-time player in the Indiana hemophilia community. Judy worked as the Hemophilia of Indiana social worker for 10 years before coming on board with the IHTC in 1999. Judy's expertise in assisting patients and their families in addressing socioeconomic challenges, often involving insurance issues, makes her the perfect initial point of contact for our homecare patients' insurance questions.

A Word on Homecare Choice

Of course, the IHTC, as a comprehensive hemophilia treatment center, honors your choice in selecting a homecare agency. We make sure to provide our patients and their families the names of other reputable homecare companies serving the Indiana hemophilia community. Nonetheless, we believe the advantages of being serviced by the IHTC Pharmacy – and the fact that our nonprofit program to date has reinvested every dollar earned back into the center to support its extensive patient care services and programs delivered by a skilled multidisciplinary team – are clear. Certainly, the IHTC wouldn't exist if it weren't for our homecare program. The proceeds derived from the IHTC's Pharmacy Program and its sister programs throughout the country are crucial to the survival and growth of treatment centers as they continue to deliver the latest advancements in medicine to our special patient population and to their families – to you and yours.

If you are interested in learning more about our program or would like to place a factor order, please contact the IHTC Pharmacy toll free at 1-(877)-MED-INDY (633-4639) or (317) 829-7778. ◀



Transitioning to Peripheral Venipuncture from PORTs

By Amy Shapiro, M.D., IHTC Medical Director

DO YOU OR YOUR CHILD HAVE A PORT? If so, do you remember the first discussion we had with you about placing it? You were probably focused on how it would be placed and learning to use it. Although we noted the usefulness of PORTs, we also tried to convey that they are usually a temporary means to an end. The end, in this case, is performing infusion through veins, usually in your arm or hand, which is a process known as *peripheral venipuncture*. Once your PORT was placed, you became accustomed to it, and were freed from visiting the clinic and emergency rooms for infusions. The memory of that early discussion about some day moving to peripheral venipuncture began to fade. Why change what works? Why subject a child to peripheral venipuncture?

There are good reasons to revisit the subject of using peripheral venipuncture.

The use of central venous access devices (PORTs) has increased over the last 10 years. Prophylaxis has been proven to be effective in preventing joint disease in patients with severe hemophilia or those with frequent bleeding episodes. PORTs have been a tremendous asset to many of our patients and families in facilitating prophylaxis and home therapy. This is especially true for children with severe factor VIII deficiency whose infusion programs are minimally three times a week, or for those living at a distance from the IHTC. However, PORTs can be associated with medical problems. The two most common are infection and thrombosis (excessive clotting) around or in the PORT or where the line enters the blood vessel.

At the IHTC, we have tracked our PORT patients and how frequently infection occurs. Infections should be calculated based upon 1,000 catheter days, which translates to approximately 2.7 years. The infection rate at the IHTC is approximately 0.45 per 1,000 catheter days overall, but 0.66 in those with a history of an inhibitor, and 0.38 per 1,000 catheter days for those without a history of inhibitor. This translates to about 1 infection in 6 years overall, 1 infection in 4 years for those with a history of an inhibitor, and 1 in 7 years for those without a history of an inhibitor. To many families for whom a PORT represents the best way to achieve prophylaxis or early home therapy for their affected child or adult, these infection rates do not seem to outweigh the advantages. Nonetheless, fevers need to be taken seriously! Call the center whenever a temperature of 101.5 degrees Fahrenheit occurs. And remember that antibi-

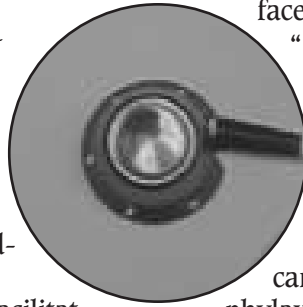
otics need to be taken before dental work is performed.

Recent reports concerning PORTs and thrombosis and our experience with them have confirmed that development of a thrombosis (abnormal blood clot) is becoming an important issue in our hemophilia population. *One study found that 66% of patients with PORTs that were in place longer than 5 years developed clots.* At first glance, it doesn't seem reasonable that people with bleeding disorders would develop excessive clotting. But indeed it is true that this can and does occur. These clots may decrease or block the blood return within the large veins of the chest and cause other smaller veins to enlarge. Blood vessels visible on the chest may become bigger. There may also be swelling of the arms and

face. In many cases, however, these clots are "silent," meaning the patient does not show any signs of a problem. To check for clots, we perform a venogram or an ultrasound. A venogram involves injecting dye in one or both hands, and the blood vessels are then viewed on an x-ray.

In order to provide you the best care we can, it is vitally important that people on prophylaxis, even those not experiencing bleeding episodes, come to clinic every six months for regular follow-up. A physical examination may reveal clues that lead us to perform specific tests to diagnose problems. These visits also allow us the opportunity to share new information with you regarding your infusion product and protocol, as well as other issues related to PORTs.

The methods we are using to teach peripheral infusion are proving to be successful, even with small children. Don't be afraid of peripheral infusion. We will help you be successful. We encourage you to discuss any concerns about the transition from PORT to peripheral infusion with us. For more information regarding PORTs, please contact the IHTC at (877) 256-8837 or (317) 871-0000 or by email at info@ihtc.org. ◀



Remember...

1. All patients on prophylaxis should be seen every 6 months.
2. Learn peripheral infusion when your child is 5 years old – or sooner.
3. Have a venogram performed on any PORT that has been in place for at least 3 years.
4. Contact the IHTC to discuss your concerns.

Facts About Iron

By Marie Underwood, RD, CD

IRON IS AN IMPORTANT MINERAL AND PERFORMS MANY FUNCTIONS IN THE BODY. Iron is necessary for the production of red blood cells that deliver oxygen to all parts of the body. It's also important in helping muscles to work, and in breaking down harmful substances in the body.

Red blood cells contain hemoglobin, the protein that carries oxygen. Hemoglobin is "complexed" with iron, meaning they work together. If there is inadequate iron, the body is not able to produce the needed amount of hemoglobin and therefore red blood cells, and this situation leads to anemia. This type of anemia is called iron deficiency anemia. (There are other causes of anemia, which are not discussed here.) The most common symptoms of anemia are weakness and fatigue.

Those at the highest risk of anemia are children 6 months to 4 years of age, adolescents (especially girls), and pregnant women. Those with bleeding disorders are also at risk. If a child between the ages of 6 months to 4 years becomes iron deficient, it is important to discuss the child's diet with your physician or a nutritionist to determine why the child has become iron deficient and what dietary modifications should be performed to prevent this from recurring.

Iron-Rich Diet

Eating a diet with iron-rich foods can help prevent iron-deficiency anemia. Good sources of iron include the following:

- Meats – beef, pork, lamb, liver, and other organ meats
- Poultry – chicken, duck, turkey (especially dark meat), and liver
- Fish – shellfish, including clams, mussels, and oysters; sardines and anchovies
- Leafy greens of the cabbage family, such as broccoli, kale, turnip greens, and collards
- Legumes, such as lima beans and green peas; dry beans and peas, such as pinto beans, black-eyed peas, and canned baked beans
- Yeast-leavened whole-wheat bread and rolls
- Iron-enriched white bread, pasta, rice, and cereals

Tips For Better Iron Absorption

- Iron absorption is improved by including vitamin C (60-75 mg per meal or about 4-6 oz orange juice). An iron supplement may be added if one is prescribed, along with high iron foods.
- Iron in non-meat foods (called non-heme iron) is not as well absorbed from the gastrointestinal tract as the iron in meat. But foods rich in vitamin C (oranges, papaya, cantaloupe, broccoli, brussel sprouts, raw green peppers, grapefruit, strawberries, etc.) can be effective

in improving iron absorption from non-heme iron sources.

- Use iron-fortified grains such as bread, cereal, and pasta to supplement iron in the diet.
- Cooking in cast-iron pans will increase the iron content of the diet. However, this form of iron is not absorbed very well.
- If iron supplements are prescribed, you should take them with an acidic juice such as apple or orange juice, and not have any milk products for an hour before or after the iron. Milk products impede the absorption of iron from the gastrointestinal tract. Unfortunately, iron supplements can cause constipation. This side effect can be offset by making sure that the diet is high in fiber from whole grains, fruits, and vegetables, and by drinking plenty of water.

Iron Supplements

Iron supplements may be prescribed to improve the symptoms of iron-deficiency anemia. Ferrous sulfate is the most common form of oral iron supplement. Other available forms include ferrous fumarate, ferrous succinate, ferrous gluconate, ferrous lactate, ferrous glutamate, and ferrous glycine. Iron is best absorbed on an empty stomach with a good source of vitamin C such as orange juice. If taking iron on an empty stomach is not well tolerated, take it with a small amount of food such as iron-enriched bread, pasta, rice, or cereal. Supplemental iron should be taken only under the supervision of your healthcare provider.

Possible Interactions

The following medications will decrease the absorption of iron: cholestyramine, colestipol, tetracycline, omeprazole, lansoprazole, ranitidine, cimetidine, and antacids that are often prescribed for the treatment of ulcers and other stomach problems.

In turn, iron decreases the absorption of the following medications: quinolones (antibiotics that include ciprofloxacin, norfloxacin, ofloxacin, and levofloxacin), tetracyclines, ACE inhibitors (a class of medications used to treat high blood pressure that includes captopril, enalapril, and lisinopril). Effective levels of carbidopa and levodopa may be reduced by iron supplements if taken at the same time as these medications.

Iron supplements should not be taken at the same time as any of the above medications. It is best to take them at least two hours before or after taking any of these medications to avoid interference with absorption.

If you have any dietary questions, please contact the IHTC nutritionist at (317) 871-0000. ◀

Special thanks to Wyeth for a nonrestricted educational grant in support of our patient newsletter.

IDEAS Software Program Improves Communication Between Hematologists and Patients

By Michelle White, IHTC Data Manager

SINCE THE LATE 1970s, patients with coagulation disorders have had the ability to infuse clotting factor at home. This has the advantage of allowing earlier treatment of bleeds and lowering the cost of treatment due to fewer episodes of hospital-based treatment. One significant difficulty associated with home infusion, however, is the lack of data available to the hemophilia treatment center and the patient's hematologist. To address this challenge, the Indiana Hemophilia & Thrombosis Center (IHTC) has partnered with Novo Nordisk Pharmaceuticals Inc. to develop the IDEAS® software program.

The IDEAS (Infusion Data Electronic Analysis System) program was designed to test a method of retrieving and analyzing more consistent and accurate data using a hand-held pocket personal computer (PPC). Data associated with each infusion recorded by the patient or family is directed through the Internet to each patient's computerized record within a database at the IHTC. The IHTC physician then checks the program, which shows if a patient's data is outside of what is expected based upon his bleeding disorder, plan of treatment, or established home infusion guidelines. The center will contact the patient to determine if follow-up or adjustment of the patient's treatment plan is necessary.

Earlier detection of problems associated with bleeding episodes and home treatment has the potential of:

- Preventing some of the medical problems associated with hemophilia, such as joint disease;
- Limiting the effect of these problems; or
- Offering an opportunity for earlier identification of inhibitors (antibodies that develop against the missing clotting factor);
- Improving the ability to maximize the use of an expensive and precious resource by helping us identify ways to tailor treatment and lower overall factor use.

Information obtained from the IDEAS program will also be provided to each participant to allow review of his treatment program, clotting factor usage, and bleeding episodes.

To test the effectiveness of IDEAS and patients' response to this new method of keeping home infusion records, 10 IHTC patients and their families agreed to participate in a pilot program. The patients were selected to vary in age, location in the state, type of treatment, and computer experience. The patients, and in some cases, their families, were trained in December 2001 to use their PPCs and the IDEAS program to record infusions and give specific bleeding event details when necessary. The primary goal of the IDEAS pilot program is to gauge participants' responses to the hardware, software and process of recording infusion information electronically. The vast majority of participants report enjoy-

ing using the system and recognize the value of it, and they have offered many valuable suggestions to the IDEAS programmers and involved IHTC staff to improve the system.

Amy Shapiro, M.D., IHTC medical director and co-creator of the program with Novo Nordisk, comments, "Feedback from the pilot program has been exciting and useful in directing our efforts to develop a state-of-the-art infusion data collection and analysis system. Overall, I'm amazed at how easy the system has been for people to use."

During the 25th International Congress of the World Federation of Hemophilia in Seville, Spain (May 19-24, 2002), Novo Nordisk rolled out the IDEAS program to attendees with the help of one of the IHTC patient participants in the pilot program. Together they presented the program and discussed the potential benefits to patients and hemophilia care providers. The program was well received by conference attendees, many of whom expressed interest in further expansion of the program and its deployment.

Michael Dwyer, senior director of sales for Novo Nordisk, says, "We are very excited to be a part of such an innovative concept to link the IHTC and its community of patients with hemophilia via the Internet. Our goal is to enable people with hemophilia to electronically complete an infusion log or 'e-diary,' thereby transmitting their data quickly and efficiently to the IHTC. With the information in this format, Dr. Shapiro and her team can quickly access, utilize, and manage this data on a routine basis. Such medically useful information may lead to changed treatment regimens, rapid treatment response, and improved overall healthcare outcomes and quality of life." Dwyer notes that plans are to make IDEAS available to hemophilia treatment centers and their communities of patients throughout the United States. ◀



Chad Stader masters navigating his hand-held pocket personal computer (PPC) as a participant in the Novo Nordisk-IHTC IDEAS project.



and its covering membrane, due to West Nile Virus, have been confirmed to be the result of infection transmitted by blood transfusion or organ transplant. During this time, surplus units of cryoprecipitate and fresh frozen plasma (FFP) were stored to be transfused at a later date. At present, there is no licensed test to detect the presence of WNV in these units.

On Dec. 12, 2002, the blood collection industry initiated a voluntary withdrawal of these frozen, untested units of cryoprecipitate and FFP. This withdrawal involves units collected and stored by the American Association of Blood Banks, America's Blood Centers, and the American Red Cross. These blood collectors supply units of blood to 90% of the nation's hospitals. This voluntary withdrawal is being done in conjunction with the FDA and the CDC in order to ensure both the safety and adequacy of the nation's blood supply.

NHF has recently reported that a rapid test kit for the diagnosis of WNV is under development by Medical Services International Inc. (MSITF) and will be available shortly, subject to regulatory approval. The same technology involved in rapid tests developed by MSITF for HIV 1, HIV 2, hepatitis B and C, and tuberculosis is being utilized in the WNV rapid test. This technology has demonstrated an accuracy of 99.8%, and it is expected that the West Nile Virus test kit will reach the same level of accuracy. The new test kit will deliver complete results in less than 20 minutes that are easy to interpret without requiring any medical or skilled personnel.

The American Academy of Pediatrics (AAP) notes

that parents are especially concerned when an outbreak occurs. According to an AAP news release, parents are advised to "rid their yards of standing water, dress their children in long sleeves and pants when outside at dawn or dusk, and to use bug spray appropriately." The AAP recommends the use of insect repellent with DEET as the most effective means of protecting people from mosquito bites when outdoors. However, DEET, the active chemical in repellent, can be harmful, and people should use caution. The Environmental Protection Agency (EPA) offers the following guidelines for using DEET-containing products:

- Read and follow all directions and precautions on this product label.
- Do not apply over cuts, wounds, or irritated skin.
- Do not apply to hands or near eyes and mouth of young children.
- Do not allow young children to apply this product.
- Use just enough repellent to cover exposed skin and/or clothing.
- Do not use under clothing.
- Avoid over-application of this product.
- After returning indoors, wash treated skin with soap and water.
- Wash treated clothing before wearing it again.
- Use of this product may cause skin reactions in rare cases.
- Do not spray in enclosed areas.
- To apply to face, spray on hands first and then rub on face. Do not spray directly onto face.

For more information about DEET, visit the EPA web page www.epa.gov/pesticides/fact_sheets/chemicals/deet.htm. ◀

HIPAA is Now a Reality

IF YOU'VE VISITED OUR OFFICE or another medical facility this year, you've probably heard about "HIPAA." HIPAA stands for the Health Insurance Portability and Accountability Act of 1996. Developed by the U.S. Department of Health and Human Services, HIPAA provides privacy protection of individual's medical health information. Patients now have more control over how their personal health information is used and disclosed, as well as guarantees for access to their medical records.

HIPAA's set of comprehensive federal regulations makes it clear that providers of healthcare must put policies and practices in place to ensure that individual health information is protected and only disclosed for specific reasons, such as treatment or billing for services, unless otherwise authorized by the patient. HIPAA regulations also provide specific language for individual rights related to protected information such as tracking and accounting of disclosures, amendment of health information, authorizations for disclosure, and HIPAA standards education of all medical facility staff. There are also provisions dictating how patient information is stored and disposed, how patient information is handled by vendors, and other information protection measures.

HIPAA regulations state that every healthcare provider must inform each of its patients of provider practices related to protected health information and retain proof that privacy protection policies were given to the patient. Each IHTC patient is presented our Notice of Privacy Practices and required to sign a form indicating he/she has read the information. The form is then placed in the patient's record. These records must be maintained for six years from the last date that the patient was treated by the provider after April 14, 2003.

The IHTC has examined every practice of handling protected health information under the HIPAA guidelines and has set into motion policies regarding health information disclosure so that we are in full compliance with the new law. Copies of the IHTC's Privacy Practices document have been placed in the IHTC clinic patient waiting room, and we are happy to provide you a copy upon request. The IHTC website (www.ihtc.org) also contains a copy of our Privacy Practices.

If you have any questions about HIPAA and how it stands to affect you, please contact Stephanie Silver, IHTC clinic manager and HIPAA compliance officer, at 871-0011 x220. ◀

Insurance 101: Tips on How to Successfully Navigate the Medical Insurance Maze

BY ITS NATURE, INSURANCE IS A COMPLICATED PRODUCT.

And when it comes to comprehending the ins and outs of your healthcare insurance, understanding the policy's limitations and what out-of-pocket expenses you might encounter can be mind-boggling. In the interest of you better understanding the primary issues involving your healthcare plan, please take a moment to review the following list of helpful hints. Whenever you are first enrolled or considering enrollment in a medical insurance program, you should discuss these important points with your insurance agent or other customer service representative.

1. Always read everything that is mailed to you from your insurance or medical coverage program.

2. Call your insurance provider if there is anything you don't understand in the correspondence you receive from them. And be sure to keep a log of whomever you talked to, each representative's direct telephone line number, and the date of every call. Building a relationship with a customer service representative can go a long way in your receiving the maximum benefit out of your medical coverage.

3. Be sure to know what kind of plan you have: Is it an HMO, PPO, POS?

HMO – health maintenance organization. In an HMO, doctors are employees of the plan, and referral outside the HMO provider roster is often difficult to obtain.

PPO – preferred provider organization. Doctors can elect to join these organizations as plan providers. Usually, you can go outside your PPO without a referral, but keep in mind that the insurance company will only pay a certain percentage of the cost of out-of-network services rendered.

POS – point of service. In a POS insurance arrange-

ment, your physicians are the gatekeepers of the services you receive. You cannot go out of network without a physician referral. If you do, the service will not be paid for.

4. Does the plan have a list of providers, hospitals, and special clinics?

5. **For hemophilia patients specifically:** Is clotting factor considered a blood product or prescription medication?

6. Is there a yearly limit of prescription drug coverage?

7. Are there any limits on pre-existing medical conditions?

8. What are your annual deductibles?

9. What are your out-of-pocket expenses?

10. What are your co-pays? You may be responsible for co-pays when you visit the doctor or when you get prescription drugs. Please note that these co-pays are contractual obligations between the patient and his/her insurance provider. Your healthcare providers are also contractually and legally required to charge and collect co-pays.

11. Does the plan require pre-authorization for inpatient and/or outpatient surgery?

12. Are there any limits on the number of times you may receive a specific service?

13. Are there lifetime maximums or annual benefit caps, and if so, what are they?

As an insurance consumer, you deserve to get the best out of your coverage whenever a need arises. The more informed you are, the better your chances of doing just that.

The IHTC provides health insurance counseling services to all our patients. If ever a question about your coverage arises, especially concerning services rendered by the IHTC, please call Judy Moore, IHTC social worker, at (317) 871-0011 x228 or toll free at (877) 256-8837. ◀

Remember Your Travel Letters This Vacation Season

VACATION SEASON IS HERE! So the IHTC would like to remind you of the need for hemophilia patients who are traveling to be sure to have an updated travel letter in hand from the center.

Travel letters are important for local medical facilities you or your family member may need to visit along your vacation or business travel route or at your destination. Your letter will indicate to medical staff your type of factor deficiency and how you or your family member should be treated for bleeding episodes. **It is vitally important that you keep this letter and a dose of factor with you at all times while traveling.** Many small community hospitals or medical centers may not carry your type of factor replacement product. It is also important for persons with hemophilia to remember to **always wear a Medic-Alert bracelet or tag.**

During these times of heightened security, travel letters also serve another important purpose. Your travel

letter demonstrates the need for you or your family member with hemophilia to have immediate access to clotting factor and the needles and syringes used to administer these medications.

One way to obtain your travel letter is during your annual comprehensive clinic visit – which we strongly recommend! Comprehensive clinic is held at the IHTC in Indianapolis every second and fourth Monday morning each month. We also provide outreach clinics throughout the state to make accessing comprehensive clinic more convenient for you. And remember, these visits are free to our patients (not including laboratory and diagnostic testing fees).

Comprehensive clinic appointments tend to fill up quickly during the summer months, so be sure to schedule your appointment as soon as possible by calling the center toll free at (877) 256-8837 (CLOTTER) or (317) 871-0000. ◀

QUESTION CORNER

Q: Is there any reliable emergency treatment information for bleeding disorders available on the Web for me to refer to emergency room medical personnel, should I or a family member require such treatment?

Yes. You can refer emergency room medical personnel to:
www.hemophiliaemergencycare.org.

This website is derived from a print booklet, *Emergency Care for Patients with Hemophilia: An Instruction Manual for Medical Professionals*, published last year especially for medical professionals who would like practical information about the treatment of bleeding disorders. Both the book and the website are sponsored by Novo Nordisk Pharmaceuticals.

As the site's homepage indicates, the content is specifically designed for medical personnel involved in initiating hemophilia treatment in the emergency room setting. A variety of emergent bleeding situations are covered, including joint hemorrhages and head injuries. The content contains treatment guidelines, recommendations, and suggestions. Of course, it's mentioned that the attending physician carries the ultimate responsibility for making the appropriate diagnosis and treatment.

Particularly worth noting about the site is the posting of custom factor dosage calculations per IHTC guidelines for factor VIII and IX deficiencies (hemophilia A and B). Both routine and major doses for these bleeding disorders are covered. The address for the IHTC dosage calculations page is:
www.hemophiliaemergencycare.com/htc/hp/IndianapolisIN.html. This page also lists contact names and numbers for IHTC medical staff.

*If you would like to have a copy of *Emergency Care for Patients with Hemophilia* sent to your primary care provider or local hospital's emergency room director, contact Jeanne Sagar, RN, IHTC treatment nurse, at (317) 871-0011 ext. 215 or nurses@ihtc.org. The IHTC also has wallet-sized cards with the website address we can make available to you. ◀*



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Thrombosis Nurse Practitioner
Janice Porter, NP
Acute Care Nurse Practitioner
Alison Stanley, MSN NP
Risk Reduction Nurse Practitioner
Allison Pfothenauer, RN, Research Coordinator
Barbara Williams, RN, Treatment Nurse
Jeanne Sagar, RN, Treatment Nurse
Laura Peddle, RN, Treatment Nurse
Beth Ansert, RN, Treatment Nurse
Molly Simmons, RN, Treatment Nurse
Mary Spath, RN, Outreach Coordinator
Patsy Yoder, RN, Outreach Nurse
Teri Waldman, Clinic Coordinator
Marie Underwood, RD CD, Nutritionist
Janet Mulherin, RDH, Dental Coordinator
Meadow Heiman, MS, Genetic Counselor
Judy Moore, MSW, Social Worker
Anita Ohmit, Physical Therapist
Michelle White, MA, Data Manager
Gina Bryant, Administrative Assistant
Sarah Albrecht, Administrative Assistant

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