



## Safety of Replacement Products

### Third-Generation Recombinant Factor VIII Product Now Available:

Baxter's Advate® Represents Advance in Safety to Protect Against viral Transmission

THE HEMOPHILIA COMMUNITY has a long-standing concern regarding the safety of replacement products due to viral diseases patients have been exposed to through concentrates. These viruses include hepatitis A (HAV), B (HBV), C (HCV), and HIV, among others. Concerns remain regarding the emergence of as yet unidentified viruses that may potentially infect our patient population whenever an infusion product has exposure to human or animal proteins in the manufacturing, processing, or final preparation. For this reason, the Medical and Scientific Council (MASAC) of the

Patients affiliated with the IHTC's program are informed of all appropriate new product licensures.

National Hemophilia Foundation (NHF) has continued to urge clotting factor manufacturers to make all efforts to remove these proteins from all parts of the processes utilized to produce these products to ensure the highest level of safety. The IHTC supports MASAC's recommendation.

To this end, Baxter BioScience has developed a new generation recombinant factor VIII concentrate to meet this need: Advate®. This new clotting factor product was licensed by the Food and Drug Administration on July 25, 2003. Advate® is ▶ 6

## Living With Hemophilia In His Own Words by Bob Edrington

EDITOR'S NOTE: Today's improved therapies for persons with hemophilia - second and third generation recombinant clotting factor products - are a far cry from the therapies that our adult population previously had available for treatment. Bob Edrington's personal story of growing up with hemophilia represents an important memory for our community. It is also a reminder of how far we've come in improving the lives of persons with hemophilia through scientific advancements.

In Bob's words...When I was born in 1941, I was found to have severe factor VIII deficient hemophilia. My brother, three years my senior, also had hemophilia.

When I was 7 years old, I had a very bad stomach ache. The doctors said it was appendicitis. They told my parents I needed surgery and that I had less than a 50 percent chance of surviving. My sister Nellie was in the fourth grade at the time. She was called to the school office and asked if she wanted to go



home because her brother was dying. While operating to remove my appendix, the surgeons found it was not my appendix causing the problem but an internal bleed dripping into the appendix. Since they already had me open, they removed the appendix. I received a lot of whole blood and the community had blood drives for me. I was in the hospital about 6 weeks.

When I was in third grade, the school told my parents that my brother and I should attend a school for disabled children. We did attend that school for a short time until my parents discovered that most of the students were mentally challenged. We then returned to Royerton Elementary.

Back then, very little was known about hemophilia. All my folks knew to do was keep my brother and me from running.

Because of their parental concern, we could not participate in physical education. The treatment when I had a bleed was bedrest, alternating cold and hot packs on the swollen area. In the sixth, seventh, and eighth grades I was on ▶ 2

crutches most of the time. In ninth grade I became very self-conscious. I would stay home rather than go to school on crutches. And, I missed a lot of school. By the ninth grade, I knew that if I were going to work, it would need to be a job which did not involve physical labor. Drafting was the one thing in high school that I could do. In 1959 I graduated from Royerton High School.

My parents had no idea what hemophilia was when my brother was born. His knees were gone at an early age, and he lived his adult life on disability. He passed away before the age of 50 from AIDS after receiving contaminated clotting factor.

When I had a bleeding problem with an arm or leg, I would make excuses like, "You should have seen the other guy." I would not tell people that I had hemophilia; I just made sure to have other plans when invited to participate in any type of activity that might cause a bleed.

At that point, getting a job and doing something with my life became my most important goal. I read an ad in the newspaper from Allied Institute of Technology in Chicago to "earn \$5,000 to \$10,000 a year." My mother and brother drove me to Chicago in a 1954 Hudson Wasp. That turned out to be the second saddest day of my life, watching the Hudson pull away. The first was when my father passed away on my 16th birthday, in 1957. Now I was on my own and didn't know anyone.

After working in a machine shop running a drill press, I got my first drafting job at Arthur A. Crafts in Schiller Park, Ill. It was 1963. I was now a tool designer at Charles Brunning company in Mt. Prospect, Ill. This was one of the best jobs in my life, and I made a whopping \$3.05 per hour. On Aug. 8, 1963, I received two diplomas: a Bachelor of Tool Engineering and a Bachelor of Industrial Engineering. I was still having problems with my joints, mainly my knees. I would keep them wrapped with elastic bandages. When I was in real pain, I would "brown-bag it" so I wouldn't have to walk to the cafeteria. I had a lot of excuses, but I never told anyone that I had hemophilia. My job was 99 percent board work. In the days before computer, all design work was done on drawing boards. When it would get close to quitting time, I would stand at my board and get my knee straightened so I could walk to the parking lot.

It is evident to me that certain people have had a definite impact on my life. Comforting words, a helping hand, encouragement, guidance, and friendship from special people have played a big part of my life. This is especially true of my family. In 1965, my heart did an extra beat when I met Judith Jansen, who became my wife in 1966. In July of 1976, Judy quit her full-time job, and that year my daughter Jessica Ann was born on August 3. That was one of the happiest days of my life! On April 11, 1978, my son Alex was born, another very happy day!

EDITOR'S NOTE: In 1964 Bob would have an accident that resulted in a hospitalization. In the emergency room, he told the doctor on duty that he had hemophilia.

While there, he received cryoprecipitate for an internal bleed. The next day, the doctor asked if Bob's employer knew that he had hemophilia. Upon his return to work, Bob had no choice but to inform his employer, as the ER doctor who cared for him happened to be the company's physician!

In 1978, Bob would undergo a total right knee replacement. He says, "It was successful in that the pain was gone. I could hardly wait to have the left knee done." This would take place later that year.

Bob, now 63, is retired. His hobbies are photography and antique cars. He owns four 1950's Cadillac automobiles, including a 1953 Eldorado and a 1976 Eldorado Bicentennial convertible. Photography has been a hobby for a number of years; however, the digital camera has added a new dimension to his hobby, especially when combined with the computer. He enjoys doctoring up his photos!

## HERE ARE SOME QUESTIONS WE ASKED BOB:

♦ *Bob, can you provide an update on your current status?*

Due to pain in my ankle, I spent a number of years getting around on an electric scooter. However, in 2001 I had my ankle fused; no more pain. I can now walk a good distance without the aid of the scooter. I had a shoulder replacement done in 2003; that took care of the pain in the joint so I can do a number of things I haven't been able to do for a good while.

♦ *Do you want to voice an opinion about what boys with hemophilia should keep in mind these days as they grow up?*

I wish I had taken better care of my body when I was younger; I was usually careful, but not always. I personally feel that the boys should not be abusing their bodies even though treatments have progressed so much since I was young. I feel the factor is a blessing to stop the deterioration of the joints due to bleeds, but I don't think it should give license to participate in contact sports. Every person has limits as to what they can do; a person with hemophilia should know what their body can take. What may be fun at the present time will have consequences in the future. They should do as well as they can in school now so they can learn a profession that uses their heads instead of just their bodies. They should be careful to keep their weight down to reduce the strain on the knees and ankles.

♦ *What do you think the future holds or is possible?*

For me, I am feeling better now than I have for a number of years. I look forward to enjoying each day I am given. For people with hemophilia, it's encouraging to see doctors like ours who care so much for their patients! Their young patients will have lives with less pain, more enjoyment and potentials fulfilled. Treatments and research have added quality to our lives. ◀

# Jennifer Maahs Named NHF's Nurse of the Year

JENNIFER MAAHS, the IHTC's pediatric nurse practitioner, received the National Hemophilia Foundation's Nurse of the Year Award of Excellence at the NHF's 55th annual meeting. The meeting took place in November 2003 in Salt Lake City.

To be eligible for the Nurse of the Year Award, candidates must have at least two years experience in nursing. Jennifer has worked in hemophilia nursing care for ten years, nine of those at the IHTC.

Nominations for the award are made by members of the hemophilia community and are selected by the NHF, based on the following criteria:

- ♦ Commitment to hemophilia nursing
- ♦ Participation in the activities of the hemophilia community
- ♦ Commitment to caring for persons with bleeding disorders

"I have witnessed Jennifer, as a hemophilia nurse, repeatedly go out of her way to help patients and provide support to IHTC staff, all the while extending herself to achieve excellence in patient care," notes Dr. Shapiro. "Jennifer is most deserving of this special national recognition for her achievements, dedication, and standard of nursing care." ◀



Jennifer Maahs, PNP

**Join us in congratulating Jennifer on this well-deserved award!**

## Patient Satisfaction Survey brings high marks while identifying several areas for improvement

LAST SEPTEMBER, the IHTC invited the people that we serve to evaluate the services we provide. The IHTC received 241 responses to our most recent Patient Satisfaction Survey. We were pleased by the high response rate. Surveys are useful tools to gauge our performance. We have used the responses to celebrate the areas in which we have done well, and examine the areas we need to improve.

Overall, the IHTC received high marks. Our philosophy and goal is to provide the best care possible to our patients. The survey process identified several opportunities for improvement.

Ninety one percent (91%) of respondents reported a wait of 20-minutes or less in the exam room. This is an excellent response rate; however, our goal is to be sensitive to patients' time as being just as important as ours. When it is not possible to meet this goal, patients are informed of the delay and every effort is made to provide prompt service.

Another area that we asked about was the IHTC website. Only seven percent (7%) of respondents reported visiting the IHTC website. This response had several messages for us. We need to assess how many patients have internet access and if they were informed of the availability of the website. We encourage patients who do

have access to the internet to visit the site at [www.ihtc.org](http://www.ihtc.org). The website provides information about IHTC services and also encourages communication between patients and the center.

The IHTC newsletter was another area that was addressed. Only 51% of the survey participants who were established patients responded that they had received the newsletter. This response rate has required that we examine how we distribute the newsletter. We have in the past year implemented a database that will allow for more accurate demographic information to be collected, including addresses. If your address has changed recently, please notify the center so that we have correct information for mailing. You may call our office at (317) 871-0000 or (877) 256-8837 to update your information.

Finally, we asked respondents to rate the level of satisfaction with their visit to IHTC. Seventy four percent (74%) rated their overall experience with their IHTC visit at the highest satisfaction level. We, of course, would like this response to be in the 90<sup>th</sup> percentile. We have carefully examined all of the responses we received and are working on customer service issues so that our patients receive the best care possible. Please be sure to continue to let us know how we can improve our service to you and your family. ◀

# Manufacturers Offer Patient Assistance Programs: Bridging Gaps in Insurance Coverage

**CHOOSING AN INFUSION PRODUCT** is important for a variety of reasons, not least of which are safety and efficacy (how well it works). However, sometimes these decisions can be difficult when products are similar. Knowing the manufacturer of a particular product can be another important issue to add into the decision-making process. Many manufacturers have patient assistance programs that may be very important when insurance coverage lapses due to job changes, reaching lifetime maximums, and other changes in coverage. What would you do if your medical insurance coverage lapsed? Where would you turn to get clotting factor

We at the IHTC are committed to assisting you at all times with these issues. We need your **participation** in order for you to take advantage of these important programs.

for your hemophilia? These are questions that should be of concern to everyone in the bleeding disorder community. The following is a brief overview of some manufacturers' patient assistance programs, which has been taken from *HemAware*, January/February 2004 Issue. *HemAware* is a publication of the National Hemophilia Foundation. Many eligible patients who have been informed of these programs are not taking advantage of them. We at the IHTC are committed to assisting you at all times with these issues; we need your **cooperation and participation** in order for you to take advantage of these important programs.

## Manufacturers' Product Assistance Programs

by David Linney

Many manufacturers of factor products offer special programs to supply factor when a patient loses insurance (including reaching a lifetime cap) or has no insurance. These programs are commonly referred to as manufacturers' factor assistance or patient assistance programs. For this article, we will refer to these programs generically as *manufacturers' patient factor product assistance programs* (MPFPAP).

### Program Types

There are different types of MPFPAP. Each has its own eligibility criteria, application process and benefits. *General descriptions of programs sponsored by the major manufacturers follow. Descriptions of program types have been created for this article and may not be used in practice. Information is as of October 2003.*

**Certificate programs** are often compared to frequent flyer miles programs sponsored by airlines. Under this program, factor product credits are earned based on the number of units of a particular manufacturer's product that have been received. Quarterly certificates for unit credits earned are issued. There are limits to how many unit credits can be earned per quarter and per year. Certificates can be utilized or "cashed in" at the time of a loss of insurance, including a loss due to reaching a lifetime cap. Note that the patient must have insurance to participate in a certificate program. Certificate programs have established guidelines for application, eligibility and quantity of factor product.

**Aventis Behring/Choice Assurance (1-866-415-2164; [www.ChoiceAssurance.com](http://www.ChoiceAssurance.com))** Factor product credit certificates are issued every three months, based on utilization of Helixate-FS, Humate-P, Mononine or Monoclata-P. Patients can redeem up to one year of product. Maximum amounts redeemable vary by product. Certificates are good for five years after being issued. Patients with health insurance, but not Medicare and Medicaid, are eligible to participate. (The program is administered by a third-party administrator.)

**Baxter/Factor Assist Program (1-800-888-4502; [www.factorassist.com](http://www.factorassist.com))** Factor product credit certificates are issued every three months based on utilization of Advate, Recombinate, Hemofil M or FEIBA VH. Patients are eligible to earn up to 25,000 units per year in credits and up to 100,000 units in credits over four years. Certificates are good for five years after being issued. Patients with all types of insurance, including Medicare and Medicaid, are eligible to participate. (The program is also administered by a third-party administrator.)

**Bayer (1-800-288-8374)** A new program is to be launched in 2004. Call the reimbursement help line number listed above for specific details.

**Specialty assistance programs** are established to provide factor product when a patient is without insurance. Programs have specific eligibility criteria, an application process and factor product benefit limits.

**Aventis Behring/Patient Assistance program (1-800-676-4266; [www.aventisbehring.com](http://www.aventisbehring.com))** For uninsured, underinsured and patients with financial

hardship, up to a three month supply of Helixate FS, Humate P, Mononine, Monoclate-P or Stimat can be provided. A form is completed by a physician and the patient/family. After three months, patient eligibility is reevaluated and benefits may be extended. A patient does not have to be a user of Aventis products to be eligible for the program, which forwards product to the physician/provider. Emergency factor product needs are considered as well under a separate process.

**Baxter/Factor Plus Program (1-800-548-4448)** For uninsured and financially needy patients, Baxter resupplies providers with Advate, Recombinate, Hemofil M or FEIBA VH after the product is dispensed. (Proram administered by a third-party administrator.)

**Bayer (1-800-288-8374)** This is a new program to be launched in 2004. Call the reimbursement help line number listed above for specific details.

**Wyeth/BeneFix Patient Assistance and ReFacto Patient Assistance Program (1-888-999-2349; [www.hemophiliavillage.com](http://www.hemophiliavillage.com))** For uninsured patients, up to a three month supply of BeneFix or ReFacto is supplied. Up to 75,000 units can be provided. A form is to be completed by a physician and the patient/family. The program has income eligibility requirements and is need-based. However, the program is flexible and extenuating circumstances are considered. A patient does not have to be a user of Wyeth products to be eligible for the program. Product is forwarded to the physician/provider. (The program is administered by a third-party administrator.)

*Special request programs are less formalized programs that provide factor product when a patient is without insurance. Manufacturers determine eligibility and quantity of factor product on a case by case basis after a request is made.*

**American Red Cross/CrossCare (1-877-235-6075; [hemaspheres@usa.redcross.org](mailto:hemaspheres@usa.redcross.org))** Benefit approval for Monarc-M is made after contact by the patient/family or healthcare provider. Product is supplied to the treater. A patient does not have to be a user of Monarc-M.

**Grifols (formerly Alpha) (1-800-421-0008)** Benefit approval for Alphanate, Alphanine and Profilnine is made after contact with a Grifols sales representative.

**Novo Nordisk (1-877-668-6777, Option 3)** Benefit approval for NovoSeven is made after contact through the reimbursement hotline number listed above. NovoSeven is supplied quarterly, on a replacement basis, to the institution that provides the product.

### COMMENTS

- For any manufacturer not listed, contact the manufacturer directly for information about their PFPAP.
- Your homecare vendor should be another resource for information about MPFPAP.
- MPFPAPs should never be considered a substitute for insurance. These programs only provide a limited amount of factor product and do not cover any other medical services.
- While certainly not all patient/family special needs requests for factor product are approved, manufacturers in general are very responsive and try hard to be supportive of special needs requests.
- For most manufacturer's programs, supply of factor product is not an issue. However, there may be circumstances (i.e. in the case of a shortage) where supply may be subject to availability.
- Aventis Choice Assurance and Baxter Factor Assist (and potentially the "new" Bayer program) offer a guarantee of factor product credit based on patient utilization.
- The Aventis Patient Assistance Program, Baxter Factor Plus and Wyeth/Patient Assistance Program and BeneFix Patient Assistance Program (and potentially the "new" Bayer program) have established eligibility criteria and product benefit limits, yet administer program benefits with some flexibility.
- The American Red Cross/CrossCare and the Novo Nordisk programs are less formalized but established programs, which administer benefits flexibly on a case-by-case basis. Grifols' program is even less formal, whereby requests are considered strictly on a case-by-case basis.

When a patient/family loses insurance or has no insurance, it is important to consider other health insurance options, as well as state, federal and private benefit assistance programs. For help, follow up with any of the following resources (not necessarily all-inclusive): your hemophilia treatment center; your local/state chapter of NHF; NHFs information and resource center, HANDI at 800-42-HANDI; other hemophilia/bleeding disorder organizations; the reimbursement department of your homecare vendor; and the reimbursement departments of manufacturers. ◀

*Previous article taken from HemAware, January/February 2004 Issue. HemAware is a publication of the National Hemophilia Foundation.*

*To receive a subscription to HemAware, or for more information about the National Hemophilia Foundation, please call 1-800-42-HANDI (1-800-424-2634), or log on to [www.hemophilia.org](http://www.hemophilia.org).*



licensed to treat or prevent bleeding episodes in patients with factor VIII deficiency. Currently, there are three genetically engineered products on the market aside from Advate®. These products are often referred to as first- and second-generation products, as there are human/and or animal proteins involved in the product's manufacturing process or final preparation. Advate® is a third-generation product because there is no added human or animal protein in the manufacturing process or as a stabilizer in the final preparation.

Studies have been performed prior to licensure and are ongoing. These studies have included 154 unique patients in

four controlled clinical studies. More than 20,000 infusions were administered without any evidence of viral transmission or other issues regarding safety or efficacy. Studies have been performed and continue in pediatric and adult previously treated patients for the prevention and treatment of bleeding and in the surgical setting. The product has an added viral safety measure, solvent-detergent, to ensure the best possible protection to our patient population.

For these reasons, the Indiana Hemophilia & Thrombosis Center has recommended that FVIII-deficient patients consider Advate® as the product that ensures the highest level of viral safety. ◀

## General Information:

### ♦ "How is Advate® manufactured?"

The same cell line used for Recombinate® is also used for Advate®.

### ♦ "What is the dose, and how is Advate® supplied?"

The amount given and the time between doses for Advate® is the same as used for other factor VIII products. The number of units per vial is similar to other currently licensed products. However, there is also a super-high potency ranging from 1500-1800 IU (units) per vial for the patient's convenience. The total volume for each vial is about 5 cc.

### ♦ "What is the potential advantage of Advate®?"

1. Decreased exposure to human/animal proteins. The manufacturing process and final formulation for Advate® are completely free of added human and animal proteins.
2. Small infusion volume.

### ♦ "What are the potential disadvantages of Advate®?"

1. Increased cost. Advate® is more expensive than other current recombinant products.

If you have any questions about Advate® as a clotting factor infusion therapy, or any other clotting factor products, please contact Jennifer Maahs, PNP; Anne Greist, MD; or Amy Shapiro, MD, at 877-256-8837.

## References:

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2. Tarantino MD, Navale LM, Bray GL, Ewenstein BM. Clinical evaluation of a new generation recombinant FVIII, plasma/albumin-free method (rAHF-PFM). *Blood* 2002;100(suppl):493.
3. Shapiro A, Collins P, Tarantino M, Gruppo R, Hay C, Berntorp e, Retzios A, Sensel M, Tonetta S, Ewenstein B. Continuing clinical evaluation of an advanced category recombinant FVIII, antihemophilic factor (recombinant) plasma/albumin-free method (rAHF-PFM) in previously treated patients (PTPs). *J Thromb Haemost* 2003;1(suppl):P1643C.
4. Astermark J, Negrier C, Schroth P, Yi E, Tonetta S, Ewenstein B. Clinical evaluation of an advanced category recombinant FVIII, antihemophilic factor (recombinant) plasma/albumin-free method (rAHF-PFM) in surgical settings. *J Thromb Haemost* 2003;1(suppl):P1642.
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6. ADVATE® rAHF-PFM Product Monograph. Issue Date: September 2003. Baxter Healthcare Corporation. ◀

## Important Dates

1. The Hemophilia of Indiana annual meeting will be on August 28, 2004 from 9:00am - 6:00pm. Please call the Foundation at 317-396-0065 for further details.

# Dr. Rekha Parameswaran Joins the IHTC



**Rekha Parameswaran, M.D.**

**DR. REKHA PARAMESWARAN** joined the IHTC in August 2003, becoming the center's fifth physician. Following is a get-acquainted interview with Dr. Parameswaran.

♦*When and why did you decide to make a career of medicine?*

I decided to become a physician when I was in high school. I enjoy working with and helping people. As a physician, I think I can truly make a difference in peoples' lives every day.

♦*Are there other people in your family who work in medicine?*

No, I am the first physician in my immediate family. I have a younger cousin who is doing her internal medicine residency in India. I grew up in India and went to medical school in Poona, a city near Bombay. I then moved to the United States in 1997 to complete a three-year residency program in internal medicine at Rush-Presbyterian/St. Luke's Medical Center in Chicago. Immediately following, I accepted and completed a three-year fellowship in hematology/oncology at the Indiana University School of Medicine.

♦*Why did you choose the specialty field of hematology?*

I chose the field of hematology because I think that hematology is a fascinating and challenging field.

♦*What are your specific areas of expertise and interest in hematology?*

My specific area of interest is hemostasis (bleeding) and thrombosis (excessive clotting). I have actually been involved with the IHTC for almost two and a half years now.

♦*What are your early impressions of the IHTC staff?*

I came here as a hematology fellow to learn more about taking care of patients with hemophilia. I was impressed with the level of care and the dedication of the IHTC staff to their patients. Importantly, I observed that the staff worked very well together, and everyone here is a team player. This is what motivated me to become part of the IHTC team. I have now been on the staff full time for about nine months and it has been a great experience working with Drs. Shapiro, Greist, Hedderman, Miller-Rice and the entire IHTC staff.

The most interesting part of being a hematologist at the IHTC is experiencing the long-term relationships we develop with patients and their families as we take care of people right from birth into adulthood.

♦*What research studies are you involved in at the IHTC?*

By working at the IHTC, I have had the opportunity to be involved in various types of research. At the annual meeting of the American Society of Hematology in 2002, I had the opportunity to present data on the use of NovoSeven® in patients with inhibitors, collected from hemophilia treatment centers across the country by the Hemophilia and Thrombosis Research Society. I have two other research papers on the use of NovoSeven® awaiting publication. Also, I will be part of a project looking more closely at von Willebrand disease, types 1, 2M, and 3. And, I am in the process of working on grants to fund the study of other aspects of hemophilia more closely.

♦*Any closing comments?*

I value the trust placed in me by our patients, and I believe that my decision to become a hematologist has been one of the best decisions I have ever made. I look forward to being a very active member of and contributor to the IHTC team in years to come! ◀

Join us in welcoming Dr. Parameswaran.

# PATIENT | ADVISORY BOARD

## IHTC Forms Patient Advisory Board

THE IHTC'S FIRST Patient Advisory Board meeting took place on March 10, 2004, at the IHTC office in Indianapolis.

"For years we have wanted to put together a board of patients/parents to provide input on the quality of our service, as well as to collaborate with us on developing programs for patients and families," explains Dr. Amy Shapiro, the IHTC Medical Director. "We are delighted by the community interest in participating on the board and look forward to what we'll learn from board members." The board is composed of a variety of consumers and/or family members representing different parts of the state and various bleeding disorders.

The board's inaugural meeting began with a slide show on the center's history, organizational structure, staff, mission, programs, services, grants and collaborative partnerships. Next, the board discussed how to improve attendance at the biweekly comprehensive clinic held at the center. Comprehensive clinic visits are provided free of provider charge to all persons in Indiana with hemophilia. Failure to attend scheduled comprehensive clinic appointments negatively impacts the center's schedule. Clinic time is reserved that might benefit other patients, and there is cost to the center if staff time is not well utilized. In answer to this issue, the board suggested consideration of alternate scheduling for greater convenience for these clinics, such as on a Friday and/or Saturday.

Another agenda item was the exploration of establishing a "welcome wagon" for newly diagnosed patients and their families. This would serve to introduce new members of the community to families of and/or patients with the same diagnoses. This idea was well received and planning will begin for this project this summer.

Other issues addressed included identification of unmet needs and expansion of camp summer programs for our older teens. The IHTC Patient Advisory Board will meet three times this year. If you would like to suggest a topic for discussion, or a concern to be addressed, please contact Judy Moore, IHTC social worker, at 317-871-0011 x228 or [jmoore@ihtc.org](mailto:jmoore@ihtc.org) ◀

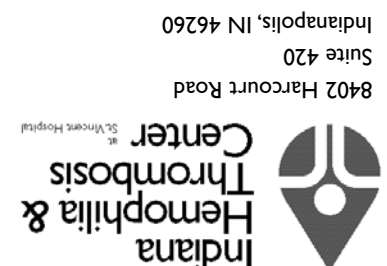
Special thanks to Wyeth for a nonrestricted educational grant in support of our patient newsletter.



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