



## Countdown to a *Great Time*: Camp Brave Eagle 2001 is Just Days Away!

**THE SUMMER-LIKE SPRING WEATHER** has spirits soaring in anticipation of the third annual Camp Brave Eagle, held once again at YMCA Camp Carson in Princeton, Ind.

This year marks a new chapter in the evolution of summer camp for Indiana's children with bleeding disorders. Hemophilia of Indiana Inc. (HII), the state's only National Hemophilia Foundation (NHF) chapter, is joining the Indiana Hemophilia & Thrombosis Center Inc. (IHTC) and YMCA Camp Carson staff in planning the week-long funfest for children with bleeding disorders and their siblings, ages 7-16.

"We're absolutely delighted to have Hemophilia of Indiana on board with us for this year's camp," notes Amy Shapiro, MD, IHTC medical director. Dr. Shapiro was instrumental in establishing camp for children with

bleeding disorders 13 years ago and in creating Camp Brave Eagle. "The foundation's involvement with camp will help to further solidify the bleeding disorders community. Michelle Rice's energy and enthusiasm and Steve Bassett's organizational skills – and the fact that

he's a former Eagle Scout! – are all great assets in planning and implementing this year's camp." Rice and Bassett joined HII last year as assistant director and director, respectively.

Bassett is just as enthused about camp as Dr. Shapiro, who annually spends the entire week at camp.

"We are really looking forward to participating in this year's camp," Bassett comments. "It's been a great collaborative planning effort by the IHTC and HII. If the spirit of cooperation that exists now between both organizations is any indication of the type of experience ▶ 2



## IHTC Authors Bleeding Disorders CD-ROM for Primary Care Physicians, OB/GYNs and ER Docs

*Interactive Educational Tool to be Distributed to HTCs in U.S. and Canada*



*Bleeding Disorders: An Interactive CD-ROM Medical Resource.* The CD-ROM is intended for physicians who don't regularly treat persons with bleeding disorders, but who may well be called upon to do so.

*A Physician's Primer* is the brainchild of the Indiana Hemophilia & Thrombosis Center Inc. (IHTC). Jennifer Maahs, the IHTC's pediatric nurse practitioner and co-author, recalls, "When we originally discussed the pro-

**AN INTERACTIVE LEARNING** experience is now available for physicians to increase their knowledge on the management of bleeding disorder patients. It's called *A Physician's Primer on Hemophilia and Other*

ject, we wanted a teaching tool for physicians and nurse practitioners that was easy to use. The 17 scenarios we created are based on actual patients and situations that we – and every other hemophilia treatment center – have experienced." The scenarios cover both pediatric and adult hemophilia and von Willebrand disease treatment situations, including those of carriers.

*A Physician's Primer* is an interactive extension of the "Do you know me?" bleeding disorders educational poster developed by the IHTC and designed in 1999. The poster, originally distributed to hospital emergency rooms throughout Indiana, was sent to HTCs across the United States for distribution to local ERs. Baxter Hyland Immuno graciously sponsored both the national mailing of the poster and is underwriting the *Physician's Primer* CD-ROM.

The poster outlines at-a-glance emergency room ▶ 5

## Camp Brave Eagle from page 1

kids can expect this year, it will be one heck of a camp.”

Camp Brave Eagle 2001 will be held Sunday, June 17, to Saturday, June 23. The format is similar to last year’s successful camp. Campers will play in and on the water, swimming and boating, making use of kayaks and canoes. They’ll play near the water, fishing for bass, bluegill and catfish. They’ll play on land, hiking and engaging in endless games. And they’ll even play on friendly four-legged animals – without horsing around and under close supervision of the camp’s well-trained equestrian staff.

Once again, adolescents will be treated to a special teen program. This year, plans are in the works for an overnight canoe trip down the Blue River, one of the state’s most attractive waterways.

Although Camp Brave Eagle’s primary concern is to provide the kids with fun, there will be opportunities for fostering a greater sense of personal responsibility and community and building lifelong relationships. Our youngest campers who need to infuse factor concentrate will be taught how to self-infuse by our team of pediatric medical specialists, which includes Dr. Shapiro, nurse practitioner Jennifer Maahs and members of our nursing staff. For those of you new to Camp Brave Eagle, please rest assured that the center’s highly trained staff is the most experienced in the state in providing a safe medical environment at camp for children with bleeding disorders. Medical staffing of Camp Brave Eagle 2001 exceeds national standards established for medical support at camps for children with bleeding disorders. Also, YMCA camp counselors are given a medical in-service each year by IHTC staff.

For the first time in three years, Camp Brave Eagle will bear a (modest) registration fee. The cost is \$300 per camper or \$500 total per family. The IHTC and HII’s joint camp planning committee have decided to implement this fee based on the philosophy of users sharing the financial responsibility for camp whenever possible, but at a very reasonable price. Please note that Camp Brave Eagle’s tradition of inclusiveness remains intact:

no eligible child will be turned away. HII will provide camperships (grants) on a first-come, first-serve basis to those families needing financial support to send their children to camp. For more information on camp costs and camperships, contact Michelle Rice at 317.543.1299 or toll free at 1.800.241.2873.

Some important dates to bear in mind concerning Camp Brave Eagle 2001:

- Buses transporting campers leave St. Vincent Hospital on Sunday, June 17, at 1 p.m.
- Camp Brave Eagle 2001 camper check-in is Sunday, June 17, at 4 p.m.
- Family Overnight cookout and awards ceremony begins Friday, June 22, at 6 p.m.
- Camp check-out is Saturday, June 23, at 9:30 a.m.

**Medical staffing of Camp Brave Eagle 2001 exceeds national standards established for medical support at camps for children with bleeding disorders.**

• Camper pick-up at St. Vincent Hospital in Indianapolis is Saturday, June 23, between 12:30 p.m. and 2 p.m. (Please be prompt in picking up your children!)

Princeton, Camp Brave Eagle’s location, is approximately 25 miles north of Evansville and 20 miles south of Vincennes, a 2.5 hour bus ride from Indianapolis.

Once again, Family Overnight participants will receive free room and board, a courtesy extended to parents and pre-campers. To learn more about this offer, contact Michelle Rice at either of the above-listed numbers.

Find out more about this year’s camp by visiting [www.campbraveeagle.org](http://www.campbraveeagle.org). Online camp registration is also available at that cyberspace location.

HII will handle any and all questions about Camp Brave Eagle programming, registration and camperships. Questions concerning camp medical issues should be directed to Jennifer Maahs at 317.871.0000 or toll free at 1.877.CLOTTER (1.877.256.8837).

The official camp registration deadline was Friday, May 25, 2001. You should have already received a copy of the camp brochure and registration form. If not, contact HII immediately to inquire about registration.

See you at camp! ◀

## A Time-out to Say *Thanks*

Donations for the IHTC 2000 Christmas Assistance Program, which served 24 families, were received from the following companies and individuals:

Aventis Behring • Genetics Institute • Novo Nordisk • Apex • HemaSource • NuFactor • Gui Squibb Memorial Fund • Hemophilia of Indiana Inc. • Franco family • Schmidt family • Spickelmier family • Indiana Hemophilia & Thrombosis Center staff

It’s the “care” in healthcare that matters most. Our deepest thanks to all who participated in the program. ◀

# Are Your Dietary Supplements Safe?

By Jennie Nicol, MS, RD

**COMPLEMENTARY AND ALTERNATIVE THERAPIES** (CAM) are used in conjunction with traditional medicine. The use of vitamin, mineral and herbal supplements (dietary supplements) has become a popular part of CAM. The Federal Drug Administration (FDA) estimates there are more than 29,000 different dietary supplements on the market, with new ones added daily. A recent article in *USA Today* (May 8, 2001) notes that sales for botanical supplements alone reached an estimated \$4.12 billion in 2000.

Many people assume that since a dietary supplement is “natural,” it must be considered safe. However, this is not always the case. Legally, dietary supplements are considered a food. So the supplements are not required to undergo years of animal and human studies, as is the case for pharmaceutical products, before they are put on the market.

Many people also assume that the advertisements associated with dietary supplements are accurate. If a manufacturer claims certain health benefits are derived from taking their pill, then that must be the truth.

Certainly, some supplements have scientific studies supporting their claims, but most do not. Keep this in mind when considering the claims of supplement advertisers: if it sounds too good to be true, it probably is!

There are, however, several “home remedies” that can be safe and effective. For example, many doctors now recommend glucosamine and chondroitin supplements for the relief of arthritis symptoms. Taking these supplements can be effective and have fewer side effects than some prescription drugs. Furthermore, if your insurance doesn't reimburse for medications, glucosamine and chondroitin can also be cheaper than prescription drugs for arthritis. Please note that if you do have prescription drug coverage, dietary supplements are not considered prescription items and it is unlikely that you will be reimbursed for purchasing them.

## Helpful, Harmful or Snake Oil?

Have you been feeling a little blue lately? St. John's Wort has been effective in treating mild to moderate depression and has less risk of side effects than antidepressants prescribed by doctors. However, St. John's Wort has been shown to interfere with alcohol and several drugs. For example,

St. John's Wort can stimulate a liver enzyme that inactivates protease inhibitors, which are used to treat HIV infection. As a result, drug levels of protease inhibitors can be too low to fight disease.

Concerning hepatitis and the use of dietary supplements, existing hepatitis therapies often have unpleasant side effects. As a result, people may turn to herbal remedies. Milk thistle has shown benefit in some humans with alcoholic cirrhosis and hepatitis B in improving liver function and decreasing mortality. However, studies have not shown a benefit for milk thistle and hepatitis C. Regardless, taking milk thistle supplements appears to be reasonably safe.

Note that while a vitamin, mineral or herbal supplement may be considered beneficial for one ailment, it can be harmful for another. For example, several supplements recommended for the treatment and prevention of heart disease can prolong the time it takes for blood to clot. If you have a bleeding disorder, taking a supplement that may further prolong clotting time is not recommended. Supplements that may affect clotting

include ginseng, ginkgo biloba, bromelain, flaxseed, fish oil, large doses of vitamin E, garlic, ginger and bilberry fruit.

The bottom line is, dietary supplements may improve your health. However, they

also have the potential to be harmful. Avoid those supplements that have been shown to interfere with medications you are taking and those that have been proven to affect pre-existing medical conditions (e.g., bleeding disorders). Most important, report all vitamin, mineral and herbal supplements you are taking to your doctor so that he/she can determine their safety and effectiveness.

**Editor's Note:** Jennie Nicol has left the IHTC. Jennie is spending the summer at home with her two children, Mackenzie, 6, and J.J., 4. She is also considering attending nursing school in the fall. We wish her the best, and thank her for her five years of service to the IHTC.

Our new dietitian is Marie Underwood, RD. Marie comes to us after concluding 10 years as a dietitian at Methodist Hospital working in radiology with oncology patients. You'll be seeing Marie at IHTC comprehensive and outreach clinics. ◀



**If you have a bleeding disorder, taking a supplement that may further prolong clotting time is not recommended.**



# Volunteer Opportunities Available at the IHTC

## *Volunteer Committee Now Forming*

*The fragrance always remains in the hand that gives the rose. – Gandhi*

WHEN IT COMES RIGHT DOWN TO IT, human life seems to have but one reason for being: *sharing*. The real currency of philanthropy – which isn't measured in our gross national product (GNP), unlike monetary donations – is one's time. The Indiana Hemophilia & Thrombosis Center Inc. (IHTC) could benefit tremendously from volunteers' time, energy and spirit, as could the bleeding disorders community at large. So we're asking for your help in recruiting a corps of volunteers to work here at the center.

It's vital to Indiana's hemophilia community to have "outsiders" involved in the healthcare mission of the IHTC. By doing so, we expand our profile in the general community, the benefits of which include: greater understanding of hemophilia as a disease and its related healthcare challenges; increased support of hemophilia program funding; and wider advocacy of hemophilia issues in proposed state and federal legislation. With this in mind, do you know of a friend or acquaintance who would be interested in joining our cause? We can use help in the following areas:

- Copying and faxing
- Mailings
- Filing
- Data entry

- Proofreading
  - Escorting patients to St. Vincent Hospital
  - Running errands
  - Event planning and hosting (e.g., the annual "Links for Hemophilia" golf outing)
  - Holiday decorating
  - Babysitting during comprehensive clinic (occurring on the second and fourth Monday mornings each month)
  - And serving on the IHTC Volunteer Committee
- The purpose of the IHTC Volunteer Committee is threefold:
- to provide a sense of organization, continuity and energy to our volunteer effort
  - to continually assess volunteer opportunities and needs
  - to grow our volunteer program

Former committee or board of directors experience is not required.

If you know someone interested in becoming a volunteer for a worthy cause – serving in the interest of the patients and programs at the IHTC, the largest hemophilia treatment center in the United States! – contact Judy Moore, IHTC social worker, at 317.871.0011, x 228 or [jmoore@ihtc.org](mailto:jmoore@ihtc.org). ◀

## Volunteer *Profile*

### **Barb Williams, RN**

You may have spoken – perhaps frequently – with Barb Williams, an IHTC phone and clinic nurse. Obviously someone who just can't get enough of the healthcare profession, Barb has served as a volunteer for St. Vincent Hospital for nearly four years. She is a volunteer for The Journey, a support group for oncology patients and their families. Prior to coming to the IHTC, Barb worked as a nurse on the St. Vincent Hospital oncology floor.

Her explanation for being a volunteer is as simple as it is profound: "It gives me an opportunity to help other people." Volunteering is especially rewarding to her because "the effort is small on my part in offering my services to these special people, but it makes all the difference to them." She feels that she gives some families and patients hope and helps them through especially difficult times.

As a volunteer for The Journey, Barb networks families with one another. She also checks on the well-being of the families in her support group and offers them advice spoken from her experience as a former oncology nurse.

Barb encourages people to get involved in volunteering because "you often get a lot back for such little effort." ◀



Jacob Rich of Carmel, Indiana, is ranked 16th in the nation for his age group (12) in cross-country competition. Jacob is shown here running in the Reno, Nevada, Junior Olympic Nationals held Dec. 7-8, 2000. Of note, Jacob has severe factor VIII deficiency.

# IHTC's Second Annual Golf Outing to be Held at Stony Creek



**ATTENTION GOLFERS!** The Indiana Hemophilia & Thrombosis Center Inc. is hosting its second annual fundraising golf outing, "Links for Hemophilia," on Thursday, Aug. 16, 2001, at Stony Creek Golf Course in Noblesville, Ind. Proceeds will support the IHTC's service to individuals throughout the state with bleeding and clotting disorders.

Tee time is 1 p.m. A box lunch will be provided beforehand. And linksters take note: the Stony Creek driving range is available for you to get in some practice swings before the shotgun start.

Anyone can participate in the outing. The entry fee for a foursome is \$500; individual players can enter for

\$125 and will be placed in foursomes.

After 18 holes of golf, all participants are invited to a dinner and awards ceremony (included in the entry cost). Prizes will be awarded to the first-, second-, third- and last-place finishers (we're good sports!). And, there will be plenty of other opportunities throughout the event to win great prizes.

If you're interested in participating in Links for Hemophilia, know avid golfers who would love to play or would like to volunteer – **HELP WANTED!** – please contact Sara Forbes at 317.871.0011, ext. 224 or at [sforbes@ihtc.org](mailto:sforbes@ihtc.org).

A brochure with registration information will be sent out shortly. So if you would like to be on the mailing list or know of people who would like to receive an invitation, please contact Sara. Be watching for updates posted in the IHTC patient waiting room and on the new IHTC web site, [www.ihtc.org](http://www.ihtc.org). ◀

## CD-ROM from page 1

procedures for medical personnel faced with emergent treatment of a person with a bleeding disorder. Because of its imagery, sound, interactivity, realistic patient care scenarios and nonlinear yet straightforward navigation, "the CD-ROM gives the poster life," says Vince Freeman, owner of Sonar Studios and the project's lead designer. The CD-ROM teaches and entertains. A friendly question and answer format guides the viewer through each patient situation. Get an answer wrong, and helpful hints are provided. Get it right, and additional information about diagnosis and treatment is displayed.

### Cast of Characters

Seven IHTC patients with hemophilia or von Willebrand disease participated in the photo shoot for the poster, and hence, the CD-ROM. This gave the project authenticity. "Every patient we contacted immediately agreed to be a part of this," says Dr. Shapiro. "We have a great spirit of community among our patients and their families here in Indiana."

Jill Moberly, an IHTC patient with von Willebrand disease, played one of the starring roles as a poster/CD-ROM model. Says Moberly, "The CD-ROM project is exciting in that it offers healthcare professionals an innovative way to learn about treating patients with bleeding disorders. The CD-ROM allows users to 'see' actual patients and perhaps better understand our diversity and needs."

An editorial committee of distinguished hematologists from throughout North America also contributed to the project. Eight physician editors – all hematologists specializing in bleeding disorders – were assigned multiple tasks: to review the scenarios, create a patient chart to match each scenario and recommend accompanying reference material.

### Results

As Dr. Shapiro confirms, the IHTC is pleased with the CD-ROM's outcome. "It's a useful educational tool because it will help demonstrate to healthcare providers the scope of problems that individuals with bleeding disorders may develop, the kinds of patients who are affected with bleeding disorders, and some of the subtleties required for optimal patient management." The digital educational product also provides CME (continuing medical education) credits for physicians.

Dr. Shapiro emphasizes, "We want physicians to appreciate what their local federally recognized comprehensive center can do for them in assisting with patient care and what resources are available to them at the treatment centers."

The CD-ROM will be available in June 2001. If you are interested in receiving a copy of *A Physician's Primer* to provide your primary care physician, please contact Tim Mulherin at the IHTC at 317.871.0011, ext. 207 or by email at [tmulherin@ihtc.org](mailto:tmulherin@ihtc.org). ◀

# Mark Your Calendars!

## *Hemophilia of Indiana's Annual Meeting Weekend to be held Aug. 25-26, 2001 at the Brickyard Inn*

HEMOPHILIA OF INDIANA INC. (HII) is dedicated to providing all bleeding disorder community members in the state access to information to facilitate care and keep you updated on the status of research for a cure, educational opportunities and other important issues affecting our special community. This is often accomplished through mailings from the National Hemophilia Foundation (NHF) or from one of the many companies offering services to the hemophilia community. Another effective communication vehicle made use of in the past by HII is the annual meeting, where consumers gather in person to hear presentations on important issues, interact with other affected individuals and visit with various homecare and pharmaceutical company representatives.

As you know, last year HII went through a transitional period and did not hold an annual meeting. However, the chapter's new management and revitalized board of directors strongly believe in the importance of education and networking, opportunities offered by the annual meeting format. As a result, HII's annual meeting will convene once again. This year's event will be held the weekend of Aug. 25-26 in Indianapolis at the Brickyard Crossing Golf Resort & Inn, 4400 West 16th Street (adjacent to the Indianapolis Motor Speedway).

The chapter recognizes that while many of you would like to attend the annual meeting, this has proven difficult for one reason or another, such as dealing with travel challenges and finding daycare coverage. In planning this year's annual meeting, we have taken these issues into account. And so the central venue in Indianapolis and the provision of daycare service, available during the educational sessions on Saturday.

During the next month you may be receiving a telephone call from one of HII's volunteers to ask what topics you would like to learn more about at the meeting's educational sessions. The sessions will be planned exclusively based on your feedback, so don't be shy with your input!

Many exhibitors from the pharmaceutical and home healthcare industries will be on hand at this year's annual meeting. We encourage you to visit each booth and explore the many resources available to you through these vendors. Please feel free to ask any questions of company representatives.

We know that you know that all work and no play makes for a boring meeting. That's why we're holding the annual meeting on a summer weekend at an exciting venue. Attendees are invited to spend Saturday

evening, Aug. 25, at the Brickyard Crossing Inn courtesy of Baxter Hyland Immuno and Genetics Institute, event co-sponsors. Please note that Saturday's lunch and dinner will be provided free of charge. And speaking of fun, attendees are encouraged to participate in the second annual "Wheels for Winning" bike-a-thon on Sunday, Aug. 26. Participants obtaining a minimum of \$25 in pledges will have the opportunity to walk, run or bike ride around the most famous automotive racetrack in the world, the Indianapolis Motor Speedway! Prizes will be based on the amount of pledges received by each participant. There will be carnival games and prizes for the children, and lunch will be served in the grandstands. Proceeds from the bike-a-thon will support programs and services for Indiana's bleeding disorders community.

The annual meeting weekend is a wonderful opportunity to mingle with your fellow community members and to learn about progress in the treatment of bleeding disorders. We hope to see you at this year's event.

For more information about Hemophilia of Indiana's annual meeting and/or Wheels for Winning, call HII at 317.543.1299 or toll free at 1.800.241.2873.

Best regards,



HII Assistant Director

## HII 2001 Calendar

**Parents Meeting – Southern Indiana:** June (date TBA)

**Camp Brave Eagle** (annual children's summer camp): June 17-23

**Course for a Cure Golf Outing:** June 21

**Family Focus – Indiana Beach:** July 14

**Parents Meeting – Indianapolis area:** August 8

**Parents Meeting – Northern Indiana:** August (date TBA)

**Mystery Bus Trip:** Aug. 11

**Mentoring Retreat:** Aug. 17-19

**Annual Meeting:** Aug. 25

**Wheels for Winning Bike-a-thon:** Aug. 26

**Family Retreat:** Oct. 26-28

# IHTC Web Site to Launch This Summer

AFTER MORE THAN A YEAR OF PLANNING, the IHTC will have its Web site online early this summer. The site, [www.ihtc.org](http://www.ihtc.org), will address two distinct audiences: 1) patients and families, and 2) healthcare professionals.

The first stage of the site will provide specially designed content for IHTC patients and families. Content in this stage will feature:

- *About the Center*: identification of patient populations served; comprehensive clinic information, including outreach clinics and schedules; comprehensive center staff roles; center background and philosophy
- *Visiting the Center*: pre-registration tips, the payment process, patient rights and responsibilities, maps of how to get to the center from I-465 and of the St. Vincent Hospital campus, parking information, office hours and instruction on how to contact IHTC physicians after hours
- *Blood Disorders*: brief overviews on hemophilia and von Willebrand disease, thrombosis, sickle cell disease, other bleeding disorders, women with bleeding disorders, carriers and a section covering frequently asked questions
- *Clinics*: information on the variety of clinics the IHTC offers and is planning, including the anticoagulation, sickle cell, hepatitis C, prophylaxis and immune tolerance clinics
- *Camp*: general information about Camp Brave Eagle including support opportunities and contacts; essentially, this section will point the visitor toward the official camp Web site, [www.campbraveeagle.org](http://www.campbraveeagle.org)
- *Media Center*: here information will be stored for

easy retrieval, such as previous editions of the *IHTC News* newsletters, news releases, fact sheets on bleeding and clotting disorders and sickle cell disease, and information on how to obtain copies of the emergency room patient care poster series and *A Physician's Primer on Hemophilia and Other Bleeding Disorders* CD-ROM (both created by center staff)

- *Friends of the Center*: this section serves as an information resource for those interested in making financial donations to the center
  - *Links*: links to our partners in healthcare are found here
- As is the nature of Web sites, [ihtc.org](http://ihtc.org) will be a dynamic information center in that content will be upgraded on a regular basis. So we encourage our visitors to check back often.

More medically involved content – the focus of the second stage development – will be online later this year. This section will provide more in-depth information about bleeding and clotting disorders and sickle cell disease from a healthcare provider perspective and provide insight on the many programs and services we offer our patients. It will serve as an additional IHTC referral tool, so that patients with these unique disorders can be diagnosed and treated by IHTC healthcare professionals.

Be sure to bookmark [ihtc.org](http://ihtc.org) for easy reference. Because the IHTC Web site is designed specifically with you in mind, we want your input. Comments, questions or suggestions concerning [ihtc.org](http://ihtc.org) should be emailed to [tmulherin@ihtc.org](mailto:tmulherin@ihtc.org). ◀

## Public Affairs Highlights

### Ricky Ray Fully Funded

After years of hard work by devoted advocates throughout the country, the Ricky Ray Relief Trust Fund has been fully appropriated. This major victory occurred during the 106th Congress earlier this year. Many people from the Indiana hemophilia community worked tirelessly to get the original bill passed, the Ricky Ray Hemophilia Relief Fund Act, authorized in 1999. They did so by making countless phone calls to congressional offices and even traveling to the nation's capital to lobby for the bill's full funding, an appropriation of \$580 million. To all those unsung heroes from Indiana – and you know who you are – a special thank you from the entire U.S. hemophilia community.

### Washington Day 2001 Highlights

On March 2, 2001, over 130 volunteers from 26 states representing 25 local hemophilia organizations participated in the National Hemophilia Foundation's (NHF) annual legislative lobbying event, Washington Day. This year's focus was on new insurance reform leg-

islation, which includes proposed bills addressing direct access to specialized care and elimination of lifetime caps. As a voice of reason and influence in Washington, D.C., for its constituents, the NHF considers insurance reform a major priority.

On Washington Day 2001, Amy Shapiro, M.D., IHTC medical director, visited the offices of Indiana Sens. Richard Lugar and Evan Bayh and Rep. Mark Pence to inform them how insurance issues affect persons with bleeding disorders in our state.

### Indiana Legislative Update

HB 1950 establishes a Medicaid buy-in program to provide Medicaid coverage to certain working individuals with disabilities as authorized by federal law.

Status: Passed by the state legislature and is waiting to go to Gov. Frank O'Bannon for signing into law.

If you would like to access more information about HB 1950, contact Judy Moore, the IHTC social worker, at 317.871.0011, ext. 228 or [jmoore@ihtc.org](mailto:jmoore@ihtc.org). ◀

## QUESTION CORNER

*Q: Our family is planning on traveling out West this summer. Our son has hemophilia. Should we do anything special before we begin our trip?*

The most important thing you can do is to make sure you have an updated travel letter to bring along with you on the trip. This letter, prepared by IHTC nursing staff, will identify your son and his disease as well as give recommendations for treatment and factor dosing in case of a bleeding or other medical problem. The letter will also provide the name and phone number of your son's physician at the IHTC (an IHTC doctor is available 24 hours a day, seven days a week to respond to patient emergencies). The travel letter should be kept with you throughout your trip, and be readily available. It is also a good idea to make sure your son wears his Medic-Alert tag at all times in case he is ever separated from you and becomes injured (whether traveling or not). We also recommend that you call the IHTC prior to your vacation. We can provide the names of hemophilia treatment centers in the area(s) you will be traveling to and through during your trip. And, we will be happy to draft your travel letter.

Of course, be sure to take your infusion products with you when you travel. ***Never assume the local emergency room will have the product you need.*** The amount of factor you should take with you can be determined in discussion with IHTC nursing staff. The amount will be based on your son's level of deficiency, on his infusion regimen and on the amount of time you will be traveling.

For more information concerning travel and travel letters, contact Jeanne Sagar, RN, at 317.871.0011, ext. 215. ◀



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