

College Students:

Look for the **2006 Scholarship Application** in this issue of *the BloodLine*.

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**Co-Editors: Kari Atkinson
& Nancy Patrilla**

Changes...

As you will notice in this issue of *The BloodLine*, there have been some changes at the Chapter level as well as in the newsletter. We always encourage your input and opinion. Please contact any of the current Board members with your concerns or you can contact Karl or me at hoi_bloodline.com and we will pass along any and all comments to the Board.

All articles for the next issue will be due by February 20, 2006. They can be mailed or e-mailed to Kari or me. Our mailing addresses are listed on the Board and Officers information page.

Upcoming events include the Adult Retreat overnight here in Cedar Rapids. A great deal of effort has been put into this event, and it looks like a lot of fun! I would encourage you to make the effort to attend if at all possible. Watch your mail for the specifics such as date, location, schedule and costs.

Other events to put on your calendar are: Annual Golf Tournament in June, Summer Camp also in June, and the Annual Meeting in September.

What is a Storm Log? Living in Iowa we might think it has to do with the

weather but this time it doesn't. LA Kelley Communications, Inc, and The Bruckner Group, Inc., have made the Storm Log available to consumers. Baxter has also contributed to the availability of this kit. The kit is a packet of items that contain a Guidebook that describes the current insurance situation, software for your PC that will provide daily reminders to stay on top of your insurance as well as a calendar and other information. With all the changes on the horizon for insurance, it is a great idea to stay informed about your policy and health insurance in general!

Scholarship Recipients Thank Hemophilia of Iowa

"Thank you very much for the scholarship! I really needed it. Most of my tuition was taken care but there are so many other extra expenses that go along with it. I put most of the money towards my books for the semester. ...I really appreciate this scholarship. Thank you very much."

JoDee Edmonds

"Thank you for the scholarship gift of money I received for college (\$750). I will be taking Environmental Studies Program at Iowa Lakes Community College in Esterville, Iowa. I've enjoyed being part of a great support group in Iowa. Thanks for remembering me and how important this money can be to my education."

Brad Jones

Project Red Flag

"Project Red Flag is the National Hemophilia Foundation's (NHF) public awareness campaign to reach the more than two and a half million women nationwide with undiagnosed bleeding disorders. The campaign will educate women and their healthcare providers about the symptoms of bleeding disorders, especially von Willebrand disease (VWD), and encourage proper diagnosis and treatment." If you are interested in learning more about this Project, visit NHF's website: www.hemophilia.org.

Camp News

Mark your calendars for the Hemophilia-Bleeding Disorder Summer Camp. It is a medical camp for children ages 6-17 with hemophilia, von Willebrand's, platelets disorders, or other bleeding

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disorders. Camp dates this year are: June 18-23, 2006. Information will be mailed in March or April to current patients of the Hemophilia Treatment Center in that age range. Look for more information in the March BloodLine.

Bayer Receives FDA Approval for Room Temperature Storage of Kogenate@ FS

Extended storage labeling provides greater flexibility for individuals living with hemophilia A

Berkeley, Calif. (Oct. 6, 2005)—The Biological Products Division of Bayer HealthCare, LLC (Bayer BP) announced today that Kogenate@ FS (Antihemophilic Factor [Recombinant], Formulated with Sucrose) received approval to be stored at room temperature (770 F, 250 C) for up to three months. The new storage guidelines for the treatment will provide users with greater flexibility and simplify storage options.

The United States Food and Drug Administration (FDA) approved the storage labeling change based on data from testing to assure the labeled potency (number of recombinant FVIII units contained in a vial) remains within specified limits through the expiration date of the product. The room temperature storage option is expected to be a significant convenience for Kogenate@ FS users. "As a busy mom, the new room temperature storage feature will make managing my son's treatment easier," said Chris Barnes, mother of a three-year-old boy with hemophilia A. "Storage convenience is important for us, especially when we head out on extended vacations. I feel this is a significant development for Kogenate@ FS users."

Starting in November 2005, each package of Kogenate@ FS will include a special notification with details on the new labeling. While

the new room temperature storage option may be used, Bayer recommends refrigerating (36-46 F, 20-80 C) Kogenate@ FS whenever possible. It also is important to note that product stored at room temperature should not be returned to refrigeration. Kogenate@ FS users who may have additional questions about storage requirements for their existing product inventory should call Bayer Clinical Communication at 800-288-8371 (option 3).

"We are pleased with the approval and the opportunity to provide our customers with this convenience," said Terry Tenbrunsel, Vice President, Sales and Marketing, Bayer BP. "Room temperature storage will be a fresh addition to our overall Kogenate@ FS product offering. Along with other product features such as the 2.5 ml low volume diluent and the EX=log handheld electronic patient diary, this new labeling will provide greater freedom and allow individuals with hemophilia A to lead full, active, and productive lives."

University of Iowa Hemophilia Treatment Center News

The first "Glamour Weekend" was held on October 8, 2005, for teenage girls with von Willebrand disease or platelet disorders. We had lunch, picked out "PJs" for our slumber party, and went to LaJames for hair, makeup and manicures. After the girls were "dolled up," they posed for three hours of "glamour shots." The photography was done by Ten Dovico, of Reflections. Teri is the daughter of late Dude Cremer (a former president of Hemophilia of Iowa). We can't wait to see how they turned out! Dinner, bowling and driving around listening to music followed before they called it a night.

Our second Amish Outreach Clinic was held on November 5, 2005. We saw nine patients in

comprehensive clinic and screened ten patients, identifying two new patients.

As a result of the annual meeting and guest, Diane Horbacz, we have been given a few innovative ideas to use in our Pediatric Hemophilia Comprehensive Clinic. It has been a FUN, informative, and helpful way to teach children about hemophilia using visual components to help the kids learn. We have been able to teach how the blood "clots" when someone does not have hemophilia and what happens when you have hemophilia. Several of our "students" have said that it was COOL and they learned more about their hemophilia. Another awesome education tool is the "Factor Fun!" booklet that was written by Diane Horbacz and created by Kelley Communications. It offers educational tips that can be used at home to begin teaching your child about their hemophilia in a casual and safe environment. Please contact the HTC or Kelley Communications if you are interested in obtaining a booklet and to find out what other children's educational material is available.

Nosebleed Woes???

Between allergies and dry weather, nosebleeds can often be a problem for many people. To help prevent nosebleeds in your home, add moisture to the air by using a humidifier or cool mist vaporizer. Saline spray or gel can be self-administered into the nose to keep the mucus membranes moist too. If nosebleeds plague you anyway, read further for some other treatment tips...

1) "Nasal Plugs", manufactured by the biopharmaceutical research and development company SEAL-ON, may be used to treat this bleeding symptom. The plug acts as a sponge by filling the nasal cavity and absorbing blood, while also releasing

a powder that expedites the clotting process. This over-the-counter product is available in the U.S. and the U.K.”

Source: *Daily Mail (London), October 11, 2005 via eNotes: NHF's website*

2) Watermelon Frost, a natural supplement, has shown some promise in stopping nosebleeds. It can be purchased through a health food store or over the Internet. It comes in a liquid preparation, and you put a few drops in the affected nostril.

3) Salt Pork, another natural supplement, has been used for years to stop nosebleeds in people with hemophilia.. It is used for an active nosebleed and placed into the affected nostril frozen. As the salt pork thaws, it expands, placing pressure in the affected area. Since it contains so much salt, it shrinks the blood vessels reducing the blood flow to the area.

After several hours, it can be removed easily due to the oily lubrication, preventing the clot from becoming dislodged. It can be purchased at a locker or in the meat department at a grocery store.

4) ActGel Hemostatic Gauze is a new product from Acmehealthcare. When used, the gauze turns into a gel, which expands and causes pressure on the blood vessels and controls bleeding. It also helps unite the platelets and clotting blood to assist with the stabilization of a blood clot.

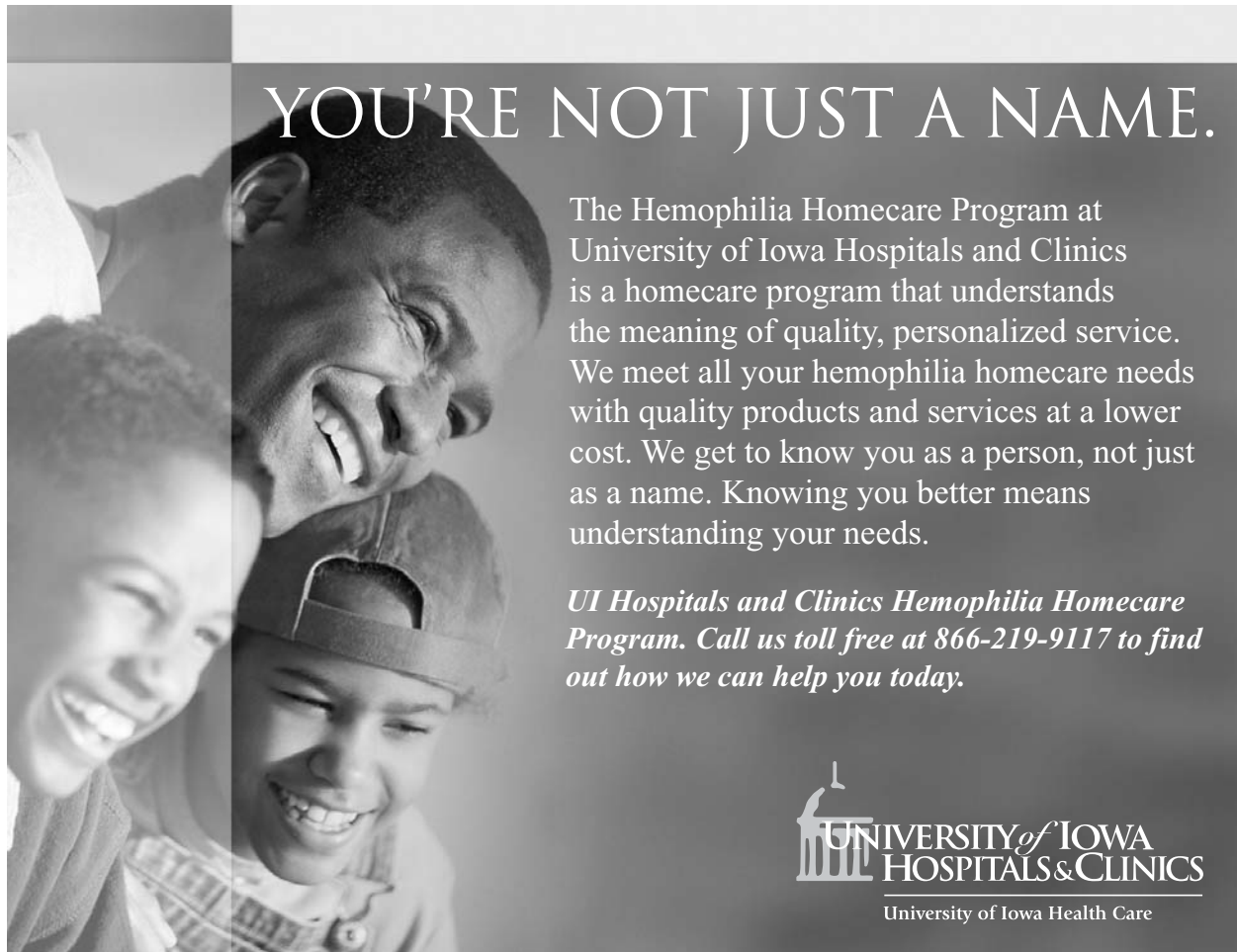
5) Nosebleeds QR is a powder. It is not a drug and does not help with the blood clotting process. The ingredients mix with the blood and secretions from the wound or injured area to form an instant, flexible scab that seals the wound. It also helps prevent infection and contamination. Nosebleed QR can be purchased at stores like Wal Mart, Walgreen's or Osco. Free

samples are available online at www.biolife.com. There is a \$1.99 shipping and handling charge.

If nosebleeds seem to be related to allergies, contact your local physician to discuss medication options. If they continue, despite these treatments tips and following your treatment plan, contact the HTC to obtain further recommendations.

What Exactly is ICE?


Well, it is not the frozen stuff found in your freezer or on the roads! It is actually an acronym for "In Case of Emergency." According to an article in the December 2005 Cornerstone News, there is a rapidly spreading campaign encouraging people to enter an emergency contact name & number in your cell phone under the name of: ICE1 - name/relationship & number: ICE2 - 2nd name/relationship & number.



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The Hemophilia Homecare Program at University of Iowa Hospitals and Clinics is a homecare program that understands the meaning of quality, personalized service. We meet all your hemophilia homecare needs with quality products and services at a lower cost. We get to know you as a person, not just as a name. Knowing you better means understanding your needs.

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University of Iowa Reports Gene Therapy Progress in Mice

Researchers at the University of Iowa (UI) have reported successful gene therapy delivery in mice using a new type of vector. Vectors, which are often viruses, are a key component of this process because they act as vehicles that deliver the therapy to cells. The particular vector used in this study was a combination of viruses. This hybrid vector combined a baculovirus, which infects insects such as butterflies and moths, with a modified lentivirus called feline immunodeficiency virus, which causes leukemia in cats but not in humans.

The vector delivered the gene therapy to liver cells called hepatocytes. The liver was targeted because it is able to manufacture factor VIII. Paul McCray, MD, is UI professor of pediatrics and corresponding author of the study. In explaining the logic behind targeting liver cells, McCray stated, "hepatocytes may not be the main

source of this protein, but they are relatively easy to target. So we aimed to find a way to get these cells to make more of it. In effect, we're using the hepatocytes as a factory to make this protein and secrete it into the bloodstream." Results of the study demonstrated enough of an increase in factor VIII activity to alter disease severity in mice. "In the mouse model in our study, we were able to achieve levels of gene expression that converted the hemophilia A in the mouse from a severe to a mild form. The correction lasted 30 weeks—the duration of the study," said Dr. McCray. Findings were published in the September 1, 2005 issue of the journal *Blood*.

Joining the study team, among others, was Yubin Kang, MD, a UI resident in internal medicine. Dr. Kang received a Career Development Award in bleeding disorders research from the National Hemophilia Foundation (NHF) in 2002- 2003 and 2003-2004 for a study entitled, "Non-primate Lentiviral Vector-Based

Gene Therapy for Hemophilia A." *Source: University of Iowa News Release dated August 22, 2005.*

University of Nebraska Receives NIH Grant for New Hemophilia B Treatment

The University of Nebraska-Lincoln (UNL) has received a \$9.98 million grant from the National Institutes of Health to develop a treatment for hemophilia B using factor IX (FIX) proteins from pig milk. One of the advantages of using pigs is that they have a similar biochemistry to humans. The researchers suggest that oral delivery of FIX purified from the milk of pigs, as opposed to standard intravenous infusion of factor, will bypass the inhibitor problem. Inhibitors develop when the body recognizes injected clotting factor as a foreign substance and attacks it. Although effective treatment by oral delivery requires more FIX than intravenous injection, the large amounts yielded from pig's milk could result in a more practical, viable and inexpensive therapy.

According to Dr. William Velander, head researcher and professor of chemical engineering at UNL, "the oral therapy would be a Godsend, a true miracle. If you have an abundance of the protein, you can potentially overcome the inefficiencies of orally derived therapies.. Dr. Velander also noted that prior research in the area has been promising, "the animal testing results with oral delivery have been thus far pretty stunning.. The pigs used in this study are transgenic animals, meaning they carry a foreign gene that has been deliberately inserted into its genome. The foreign gene is constructed using recombinant DNA technology. In this case, the transgenic pigs have been produced to yield higher levels of FIX proteins in their milk. The transgenic FIX pigs are patented by the American Red Cross and the Commonwealth of Virginia.

The National Hemophilia Foundation's Medical and Scientific Advisory Council Document #151 stated that methods to manufacture coagulation products more inexpensively, such as the use of transgenic animals, would increase supply and availability worldwide. To read the entire recommendation go to www.hemophilia.org/research/masac/masac151.htm.

Source: University of Nebraska-Lincoln news release dated September 12, 2005

Scholarship News You Can Use

Following is a greatly abbreviated list of scholarships available to the bleeding disorder community:

Hemophilia of Iowa (look for mailing)
Arthur B Kane -888-508-6978

Bill McAdam -313-563-1412
BioRx & H of NC-cbames@biorx.net
Calvin Dawson -800-293-6527
Christopher Pitkin -626-793-6192
Eric Dostie -800-323-6832 x1300
Factor Support-www.FactorSupport.com
Hemophilia Fed -800-230-9797
Artistic Endeavors -800-230-9797
Parent Continuing Ed -800-230-9797
Sibling Continuing Ed -800-230-9797
H of Michigan -800-482-3041
HHS Memorial- 800-800-6606 x5175
Kevin Child -800-42-HANDI
Lawrence Medeiros -518-863-2668
Michael Sutton -e-mail us for address
Mike Hylton/Ron Niederman-877 -376-4968
Millie Gonzalez -877-376-4968
New Horizons -866-3HORIZON
Rachel Warner -800-488-2688
Scott Tarbell- 800-800-6606 x5175
Seven SECURE -877-NOVO-777
Soozie Courter -888-999-2349

Call the above numbers for more information on the scholarships.



January 15, 1992

Joey was born in Nashville, Tennessee and diagnosed with hemophilia. Joey's family was devastated, confused, and at a loss as to what this meant for their son.

Hemophilia Health Services was there.

HHS provided Joey's family with the education, the medication, and the support that empowered them to take charge of living with a bleeding disorder — a mark in their journey toward a fulfilling and rewarding life — one without fear.

August 12, 2003

Joey led his little league baseball team to the state championship as their star pitcher. His family could not have been more proud.

Hemophilia Health Services was there.

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Left to Right: Pete O'Malley, Tami Bullock, Lisa Wolterman & Peggy Wier

Hemophilia of Iowa, Inc., Wins Grand Prize in Camp SuperFly Competition

The results are in! Hemophilia of Iowa, Inc., is a grand prize winner in the Camp SuperFly competition! Due to an outstanding effort on behalf of chapter members and the University of Iowa HTC, the "Iowa Water Bugs" earned an impressive 5,960 points in the competition, which was sponsored by Baxter, earning a grand prize award of \$10,000.

On September 10, Pete O'Malley, Vice President of National Accounts, Baxter's BioScience business in North America, presented President Lisa Wolterman with the prize at a special awards luncheon during Hemophilia of Iowa's annual educational weekend. Tami Bullock and Karla Watkinson from the University of Iowa HTC were also on hand to accept the award. The award presentation highlighted the importance of camp as a means of instilling self confidence and a

sense of independence in young people with hemophilia.

The chapter plans to use the award to implement a camp for children under the age of six and their families. According to Wolterman, "These individuals can also benefit from the tools and knowledge camp can offer." During her speech at the luncheon she explained that this camp will provide families with children too young to attend camp with an opportunity to enjoy an educational and fun weekend with other members and help prepare them for an independent camp experience when they get older.

Camp SuperFly presented a great opportunity for the members of Hemophilia of Iowa to work together to support Camp Tanager and their campers. The chapter is looking forward to an even better turnout from the "Iowa Water Bugs" next year!

New Index Helps to Measure Fibrosis Levels in HIV/HCV Patients

A recent study by Harvard University researchers examined a way to accurately measure liver fibrosis (scarring) in patients co-infected with HIV and hepatitis C (HCV). Study participants, randomly selected from the Johns Hopkins HIV Clinic cohort, were tested using the SHASTA index. Fibrosis severity was determined by systematically scoring the results of biopsy and chemical tests.

As fibrosis advances and becomes more severe, there is an increased risk for permanent liver scarring called cirrhosis. Patients with cirrhosis are more likely to develop irreversible liver damage. This damage inhibits the organ's ability to carry out its vital functions.

"Amongst HIV/HCV co-infected patients, serum testing for hyaluronic albumin, and aspartate aminotransferase, SHASTA Index

was able to accurately stage mild and advanced fibrosis," reported Dr. Thomas Kelleher and his colleagues. The study is entitled, "Prediction of hepatic fibrosis in HIV/HCV coinfecting patients using fibrosis markers: The SHASTA Index." It was published in the July 2005 issue of the Journal of Hepatology.

Source: *Biotech Week, August 31, 2005*

FDA Approves Generic AIDS Drugs

The U.S. Food and Drug Administration (FDA) approved generic versions of the antiretroviral drug zidovudine (AZT), used to inhibit the spread of the AIDS virus in HIV patients. This approval became possible upon the recent expiration of a longstanding patent. The pharmaceutical company GlaxoSmithKline had been the exclusive commercial manufacturer of AZT.

The recent FDA licensing of generic AZT drugs made by Ranbaxy Laboratories of Gurugram, India, Aurobindo Pharma of

Hyderabad, India and Roxane Laboratories of Columbus, OH allows less expensive HIV treatment alternatives to be released into the market. "These approvals will now allow those infected with HIV more access to these life-saving drugs within our country," said Mike Leavitt, secretary of the Department of Health and Human Services.

Source: *The New York Times, September 20, 2005*

New Clinical Trial to Test Tarvacin

Peregrine Pharmaceuticals, Inc., a biotechnology company based in Tustin, CA, has received U.S. Food and Drug Administration (FDA) approval to begin a clinical trial using its product Tarvacin to treat patients infected with chronic hepatitis C (HCV). Under an investigational new drug (IND) authorization, the study will assess the effect of a single intravenous infusion of Tarvacin in as many as 32 HCV patients. The trial subjects will be patients who were either unresponsive to standard

pegylated interferon plus repairing treatment or who relapsed after being treated with the combination therapy.

Peregrine hopes that Tarvacin, an antiphospholipid therapy that targets exposed cellular components of cancer and viral cells, will become a treatment alternative for the approximately 50% of HCV patients who do not achieve therapeutic response to pegylated interferon plus repairing. "We are excited to begin exploring another clinical indication for Tarvacin. We anticipate this study will accrue patients rapidly due to the prevalence of chronic hepatitis C infections in the U.S. and the need for new therapies to treat this disease," said Joseph Shan, senior director of clinical and regulatory affairs for Peregrine.

The World Health Organization estimates that 2.7 million people in the U.S. and 170 million people worldwide are currently living with chronic HCV.

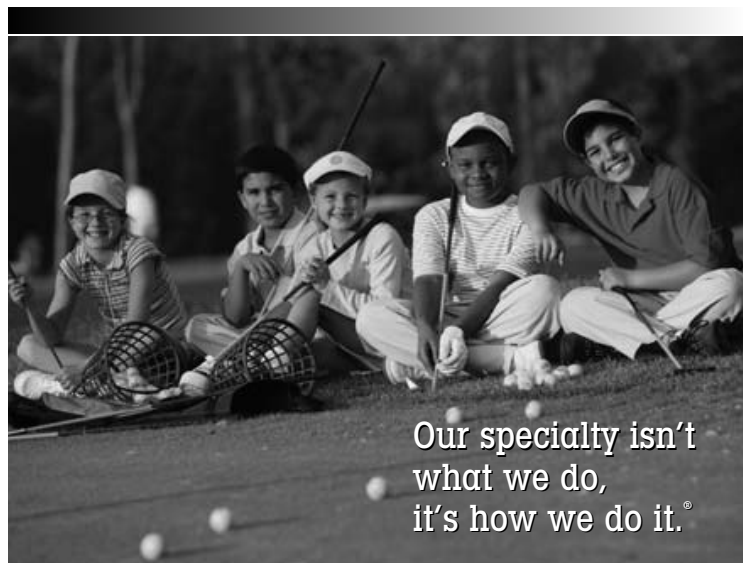
Source: *Immunotherapy Weekly, June 29, 2005 via NHF eNotes, July 2005*

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PSI Offers Assistance to Those with Chronic Illnesses

Patients Services, Inc. (PSI), a nonprofit charitable organization based in Virginia, has been expanding its effort to help patients with chronic illnesses pay for rising drug costs. PSI, which was founded in 1989, solicits monetary donations from pharmaceutical companies and then uses the funds raised to pay the high health insurance premiums and drug co-payments of eligible individuals. The charity raised \$22 million last year and was able to pay the premiums and co-payments of almost 20,000 patients across the country with chronic and costly illnesses such as hemophilia.

The co-founder and president of PSI is Dana Kuhn, a 52-year-old with hemophilia. "It's a win-win situation. Patients are helped and companies are helped," said Kuhn. An increasing number of drug companies are making contributions to charitable programs such as PSI. The National Organization for Rare Disorders has also instituted a similar program.

Some in the field counter that the broader and most pervasive issue of increasingly exorbitant drug costs is not being addressed. "I don't want to discount the legitimate help they provide to people in need. But it's really a clumsy way for manufacturers to game the system so they can continue their high pricing," said internist Scott Howell, vice president of pharmacy affairs with the health insurance company Highmark Inc., part of Blue Cross and Blue Shield.

Companies assert that research, development and more sophisticated manufacturing processes albeit expensive, are necessary to be able to produce products used to treat chronic and often life-threatening conditions. Critics argue that by paying

premiums and co-payments pharmaceutical companies transfer much of the price of these drugs to insurers, who then cover the cost by raising the premiums of their other enrollees.

Kuhn summed up his approach towards soliciting companies. He explained, "our argument was, 'if you donate \$50,000, we can keep these people insured and provide revenue for you.'" In addition, companies often take a tax deduction for their donations. Patients eligible for the PSI program are guaranteed two years of assistance and then encouraged to find a new insurance plan. Others look at the high gross profit margins for some these drugs and offer another viewpoint. "The idea of making drugs available to people who can't afford it is very appealing, but the net effect is for the drug company to appropriate most of the gain," said Alan Garber, chairman of the Medicare Coverage Advisory Committee and director of the Center for Health Policy at Stanford University.

Source: The Ledger, December 2, 2005 via NHF website

What is First Step???



First Step is a program for parents and families of children with newly diagnosed bleeding disorders. It is an important element of the NHF National Prevention Program. Early education about bleeding disorders and preventing complications of bleeding disorders, starting as soon

as a diagnosis is made, is a highly effective prevention program.

The NHF First Step program is one model of new parent/family education. It is a collaborative model in which chapters, associations, hemophilia treatment centers (HTCs), parents and guardians work together to provide education and support for families.

Local **First Step** Update: Mary McCarthy, Kari Atkinson, and Jill Nolte are working together to get things going in Iowa. They are planning a Kickoff event in February 2006. Invitations will be sent but if you are interested, you can also contact Mary, Kari or Jill (see contact information on Board page).

They now have four mentor families trained and are very excited to get the mentoring program up and running. Anyone needing a mentor family can contact us, and we will make the necessary arrangements for you to meet your mentoring family.

We are working on different fund-raising projects. September was the Second Annual Quilt sale held by the McCarthy family at the local Pancake Day (Centerville, Iowa), and they raised \$900 for the First Step program! January is the month that Kari does her annual fund-raiser at Aegon. They will be holding some wonderful raffles. Last year this fund-raiser raised \$2400!

We offered four different corporate sponsorship levels this year. We want to thank the following sponsors.

Platinum Sponsorship - \$1000 -
BioRx
Silver Sponsorship - \$500 -
ARJ Infusions

The **Gold** Sponsorship (\$750) and the **Bronze** Sponsorship (\$100) are still available.

We very much appreciate the support as we strive to get **First Steps** going.

We are looking forward to working with you in 2006!!!

Mary McCarthy
johnclaudesmom@yahoo.com
Kari Atkinson caklatkinson@aol.com
Jill Nolte jnolte@gmail.com

Bleeding Disorders, Sports and Exercise

The National Hemophilia Foundation (NHF) recently created a new educational booklet entitled, "Playing It Safe: Bleeding Disorders, Sports and Exercise." This resource is a valuable tool for people with bleeding disorders, family members and caregivers. The conveniently sized booklet contains a comprehensive catalog of physical activities. Topics include conditioning, stretching and flexibility, weight training, many recreational activities and exercise regimens for people with bleeding

disorders, cardiovascular exercise and sports. Also included is a safety chart rating

DVD Promotes Healthy Choices for People with Hemophilia

"Living Healthy with Hemophilia," is a new educational DVD developed by Hemophilia of Indiana, Inc. in collaboration with the Indiana Hemophilia & Thrombosis Center. The DVD was funded through a National Prevention Program (NPP) grant from the National Hemophilia Foundation (NHF). The program focuses on key NPP strategies, with particular emphasis on exercise and responsible eating as way to maintain healthy joints. The program features interviews with hemophilia treatment center professionals, as well as people with hemophilia and their families.

To request a complimentary copy of any of the aforementioned resources, contact HANDI at 800-424-2634 (option two) or handi@hemophilia.org

Ribasphere Receives FDA Approval for Use in HCV Patients

Three Rivers Pharmaceuticals recently announced U.S. Food and Drug Administration (FDA) approval for its Ribasphere (ribavirin, USP) Tablets 600 mg, 400 mg, and 200 mg in combination with interferon alfa-2a for the treatment of hepatitis C (HCV).

While interferon plus ribavirin combination therapy is commonly used in HCV patients, this new FDA approval offers potential benefits such as improved efficacy and better patient adherence to treatment. "Ribasphere Tablets 600 mg, 400mg, and 200 mg provide the patient and physician an opportunity to significantly reduce the number of tablets a patient has to take each day," said Three Rivers President and CEO Donald J. Kerrish, R.Ph. "Three Rivers believes that this has the potential to lead to better patient compliance and improved patient outcomes."

Aventis Behring



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treat each child. Results indicated and that 93% of children in the prophylaxis group showed normal joints in contrast to 58% in the ondemand group. Overall, there was an 84% reduction in the risk for joint damage in patients receiving prophylaxis from an early age. All outcomes were evaluated independently by two research radiologists without their prior knowledge of the subjects' bleeding history or treatment.

The principal investigator for the study is Marilyn J. Manco-Johnson, MD, Director of the Mountain States Regional Hemophilia & Thrombosis Center at the University of Colorado. She has expertise in several areas such as pediatric hemophilia and joint disease prevention. Dr. Manco-Johnson, who is also a former member of the National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC), stressed the importance of the study. "This is the first prospective study that provides convincing evidence in support of prophylaxis in the treatment of hemophilia." She added, "The information we are obtaining is extremely comprehensive and will help treaters and parents make informed decisions about how best to manage hemophilia in these young boys."

Chronic and often spontaneous bleeding into joints is a common symptom for patients with severe bleeding disorders. If left untreated, bleeding into joints such as the elbow, knee or ankle, can cause orthopedic damage resulting in increased pain and diminished mobility. Prophylaxis has been recommended by MASAC (Recommendation #117) as an optimal therapy for young children with severe hemophilia A & B. Even though there are many proponents of this approach in the treatment community, there exist commonly cited drawbacks such as high cost,

lack of necessity medical complications.

The study was funded by the Centers for Disease Control and Prevention and the National Institutes of Health. All the study patients were treated with Kogenate® FS, a recombinant factor VIII product manufactured by Bayer Biological Products. A study abstract, entitled "Initial Results of a Randomized, Prospective Trial of Prophylaxis to Prevent Joint Disease in Young Children with Factor VIII Deficiency," appeared in the November 16, 2005 issue of the journal Blood.

Source: Business Wire, December 12, 2005 via NHF website

Commonly Used Pain Reliever May be Responsible for Increased Poisonings

Researchers from medical centers across the U.S. collaborated to study the detrimental effects of increased usage of the drug acetaminophen, also known by its brand name Tylenol. Acetaminophen is an ingredient of several over-the-counter products used to relieve cold symptoms and pain such as Excedrin®, Midol Teen Formula®, Theraflu®, Alka-Seltzer Plus Cold Medicine® and NyQuil Cold and Flu. Acetaminophen is also found in prescription narcotics such as Vicodin and Percocet, often used to alleviate pain following surgery or injury. Although these products are helpful to many patients, many in the medical community are concerned that the profusion of the drug is resulting in inadvertently high dosing and subsequent poisoning.

Exacerbating the problem is the fact that amounts of the drug used in over-the-counter products vary greatly, that some of the prescription products are potentially

addictive and that they are often used in combination.

Study findings have shown that these poisonings often damage the liver. Researchers monitored 662 consecutive patients with acute liver failure at 23 transplant centers from 1998-2003. The number of cases linked to acetaminophen poisoning rose from 28% in 1998, to 51% in 2003. Tim Davern, MD is one of the authors of the study and a gastroenterologist with the liver transplant program at the University of California at San Francisco. "It's extremely frustrating to see people come into the hospital who felt fine several days ago but now need a new liver. Most had no idea that what they were taking could have that sort of effect," said Dr. Davern. Clear and prominent labeling of products containing acetaminophen has been advocated by professionals such as William Lee, MD, a liver specialist at the University of Texas Southwestern Medical Center.

Although some companies have already added warning labels to their products, Dr. Lee has been lobbying the U.S. Food and Drug Administration to require acetaminophen labels to help reduce the number of overdoses.

The study results appear in the December issue of the journal Hepatology.

Source: The New York Times, November 29, 2005 via NHF website

A Look Back...

Did you know that 2006 marks the 20th Anniversary for Hemophilia of Iowa and the BloodLine?

It all started when the hemophilia nurse (Jenny Johnson) asked if people would be interested in starting a local chapter for support. We had our first meeting at the University of Iowa. There were eight people present: Jenny Johnson, John Heisner, Vance & Nancy Patrilla, Gene Blanc, Mike & Verlene Cannon, and J.J. Goedken.

It was decided at that meeting that we would like to see if a chapter would work. Gene Blanc, who owns Midland Press, has donated the printing of our newsletter for the entire time. What a great gift he has given us! J.J. Goedken printed our original letterhead, envelopes and, I believe, the first brochure.

Nancy Patrilla was the original editor and the first newsletter was called the "No Name Newsletter" for the simple fact that we had no name for it. We ran a contest and the *BloodLine* was born. Doug Knutson designed the masthead for us, and we have been using it ever since.

Terry and John Morrow were instrumental in obtaining our 501 (c)(3) status (*non-profit*). We had been told that it would take several months to get the approval but the Morrows managed to get it much quicker than that. Persistence does pay off!

Some of our first fundraisers involved raffle tickets for hand-made quilts and a limited edition fishing rod set, and gift wrapping for donations at the Sycamore mall in Iowa City for the entire month of December! The annual golf tournament in the summer was added as well as Byron's wonderful fundraiser...

Vance Patrilla, John Heisner & Mike Cannon each served as President of the chapter at some point. Nancy Patrilla was the original Treasurer (while being the Editor) until Dawn Humburg stepped in and offered her expertise. Vance and Dawn are two major reasons the chapter finally started running smoothly. Robert's Rules of Order were implemented and followed; IRS rules and regulations were followed; and we all learned how to be accountable for what was spent.

Soon the Hemophilia Treatment Center made a concentrated effort to get involved in the chapter. That marked a turning point in our working relationship with the HTC, and it has been a great experience!

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I appreciate the effort that the staff at the HTC puts into attending our meetings. I know that it is a sacrifice for them to come because it takes away from their family time since our meetings are on weekends.

One of the reasons I am happy to see First Steps as a national support network for newly diagnosed parents (yes, parents—they are the ones who need the support in the beginning not the kids) is that I still remember what it was like to not even know how to spell hemophilia let alone know what it meant or how to deal with it. We tried several times to get support groups going but were never successful. First Steps is something that was in our hearts in the beginning so it is good to see it finally become a reality.

Did we have growing pains? You bet we did. But it has been very, very exciting and gratifying to see where the chapter is today after so much hard work on everyone's part.

Thank you to everyone who has worked, past and present, on keeping the chapter running smoothly. I think I speak for all of us when I say that we appreciate the sacrifices you have all made, the time you have spent, and the effort you have expended for us.

This & That...


Lisa Wolterman purchased some audio CDs at this years NHF meeting for Hemophilia of Iowa. They will be available to borrow as soon as we can get you a list of the titles. Lisa also wanted to express her thanks for the Board sending her and Michael to the NHF meeting. She especially felt the meeting on dealing with the ER was beneficial.

Cindy Ferrel was another attendee at the NHF meeting. She really enjoyed getting to meet the other people at the meeting and wanted to thank the Board for sponsoring her trip as well.

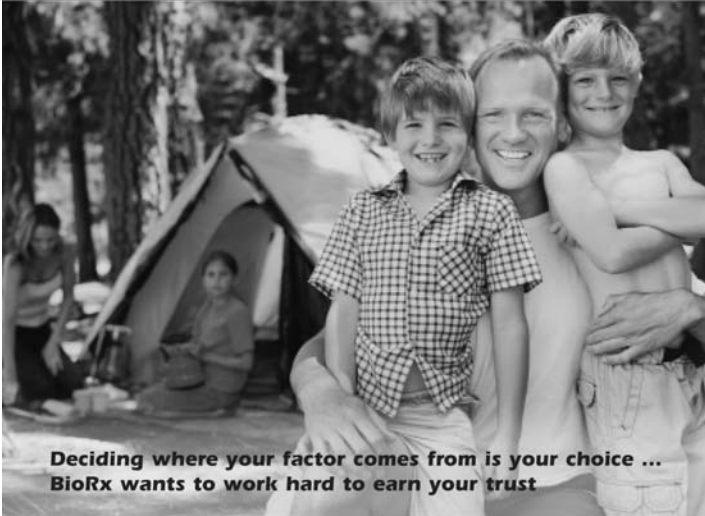
Have a great winter and remember to send us any suggestions or articles that you would like to see in the BloodLine!

**Deadline for
Submission of Ads
and Articles**

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May 20
August 20
November 20**



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HEMOPHILIA OF IOWA, INC

<h2 style="margin: 0;">Scholarship Application 2006-2007</h2>	January 1 March 31 May 1 August 1	Apply Applications Received Decision Made Money Dispersed
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No Late Applications Accepted!

Date: _____ Email: _____

Student's Last Name: _____ First Name: _____

Institution/College you plan to attend or are attending: _____

Enrollment Date: _____

College Address: _____

City: _____

State: _____ Zip: _____ Phone: _____

Parent's Address: _____

City: _____ State: _____ Zip: _____ Phone: _____

Date of Birth: _____ Bleeding Disorder _____

High School you Attended: _____ Graduation Date: _____

I hereby give the Scholarship Committee permission to access confidential information in my files to determine my scholarship need. Signed: _____ Date: _____

Scholarships Currently Available

Bleeding Disorders-Up to \$1,000.00

Family Members of a Person with a Bleeding Disorder-Up to \$750.00

Non-Bleeding Disorder Members-Up to \$500.00

John Heisner-\$1,000.00

Dude Cremer-\$1,000.00

The John Heisner Scholarship and Dude Cremer Scholarship are given to those people with a bleeding disorder that have done something special for the Hemophilia of Iowa community.

Attach a brief (one page or less) summary explaining your interest in the program you have chosen and why you believe you are deserving of a scholarship. Outline your short-range and long-range career plans and include a brief personal outline of your background.

Mail completed application to:	President, Hemophilia of Iowa, Inc. 27987 200th Ave. Cincinnati, Iowa 52549
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HEMOPHILIA OF IOWA INC.

Mary McCarthy
27987 200th Ave.
Cincinnati, IA 52549

Membership Application - Hemophilia of Iowa, Inc.

Name: _____

Address _____ City _____

State _____ Zip _____ Phone # _____

E-mail _____

Membership Dues: Single (Anyone over 21 year of age) - \$20 per year.

Family: \$35 per year

Friends of Hemophilia of Iowa \$100 per year

(Anyone who does not have a bleeding disorder in their family)

I would like to make an additional donation of \$ _____ (Tax deductible)

Would you be willing to serve on a committee: Yes ___ No ___

Would you like to be informed of workshops involving bleeding disorders provided by our various vendors?

Yes ___ No ___

Please mail the membership form and annual dues (payable to "Hemophilia of Iowa, Inc.") to:

Dawn Humburg
1002 6th Ave. SW
Humboldt, IA 50548