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MEDICAL NEWS
March 3, 2004
Baxter Receives Approval to Market ADVATE in Europe

Baxter Healthcare S.A. announced today that the European Commission will allow ADVATE (Octocog Alfa Recombinant Coagulation Factor VIII) to be marketed in Europe. ADVATE, which is prescribed to prevent and control bleeding episodes in people with hemophilia A, is the only factor VIII made without any human or animal plasma proteins or albumin in the cell culture process, purification and final formulation, further reducing the potential for the transmission of infections, including those that could potentially be caused by viruses that have not been identified yet. ADVATE received regulatory approval in the US in July 2003 and is processed in Baxter's Switzerland facility. Of patients in Europe, 50% continue to use plasma-derived therapies. In the US, more than 75% of patients receive recombinant therapy.

Source: *Company release*

February 21, 2004
Bleeding Disorders Symposium Takes Place in Saudi Arabia

For the first time, an international symposium on bleeding disorders was held in Saudi Arabia at the King Faisal Specialist Hospital and Research Center on February 21 to 23. The event unveiled a plan for the first internationally recognized national hemophilia program in the Persian Gulf region.

Source: *Arab News*

February 17, 2004
Early Development of Biotherapeutics Event

IBC Life Sciences' first Early Development of Biotherapeutics event will be held in San Diego on April 26 to 28. The focus of the event will be on approaches for managing immunogenicity and comparability, interpreting regulations and implementing process changes. According to IBC, "Attendees will walk away with the ability to accelerate the development of their recombinant

therapeutic protein program by understanding the current industry and regulatory approaches to preclinical, clinical and product development of biotherapeutics."

IBC Life Sciences actively researches the advancements, technologies and trends impacting the development and improvement of the processes needed to produce biologics.

Source: *IBC Life Sciences*

February 16, 2004

Study Says Liver Transplant Should Be Considered for Coinfected Patients

British scientists recently published a study of treatment for patients infected with HIV and the hepatitis C virus (HCV).

The study, which appears in *Haemophilia*, states, "For coinfecting patients with end stage liver disease who are stable on [highly active antiretroviral therapy (HAART)], liver transplantation should be considered.

The study also stated that HIV has been shown to accelerate the course of HCV chronic liver disease and there is evidence that HCV infection may worsen the prognosis of HIV." The study stated that pegylated interferon (Peg-IFN)/ribavirin combination therapy

is the treatment of choice for HCV in patients with stable HIV on or off HAART with CD4 counts greater than 200x10⁶/L."

The study can be found in *Haemophilia*, 2004;10(1)1-8.

Source: *Pharma Business Week*

February 16, 2004

AIDS Vaccine Trial Begins in Germany

German scientists are beginning the country's first human trial of a vaccine designed to prevent AIDS. The vaccine attempts to elicit immune system responses to prevent people from becoming infected with HIV and developing AIDS. The trial, which received government regulatory approval, will be conducted on up to 50 volunteers in Germany and Belgium. If the vaccine, named tgAAC09, is deemed safe and elicits immune responses it may be used in larger trials.

The trial is being conducted at two universities that have partnered with the International AIDS Vaccine Initiative, Target Genetics Corporation and Columbus Children's Research Institute.

Source: International AIDS Vaccine Initiative release

February 17, 2004

Research Turns Up New Form of Mad Cow Disease

A new strain of Creutzfeldt-Jakob Disease (CJD), also known as Mad Cow Disease, has been found in Italy, according to a study released on February 16, 2004. The Italian scientists who conducted the study believe that the new form may be the cause of some cases of new variant CJD (nvCJD), the human form of the disease.

The strain was found during random testing in two Italian cows that appeared healthy. According to *The New York Times*, scientists in Europe and the United States said these findings should provide new impetus in Washington for the US Department of Agriculture to adopt the more sensitive rapid tests used in Europe, as cases like these may not show up in tests currently used.

In February 2004, the British minister of health reported a case of possible transmission of nvCJD in a transfusion recipient. This is the first

report that the disease might be transmitted to people through blood. Blood experts have speculated nvCJD might be spread through blood transfusions and in recent years have put in place precautions, such as donor deferral, should transmission ever be proven. The potential for blood transmission of nvCJD points to the continued need for vigilance by governments and blood and plasma collectors and manufacturers. In the United States, the possibility of transmission of nvCJD continues to be monitored by the US Food and Drug Administration and the Centers for Disease Control and Prevention.

Reference: McNeil, Donald. "Research in Italy Turns Up New Form of Mad Cow Disease." *The New York Times*. February 17, 2004.

For the Full Article, go to:

<http://www.nytimes.com/2004/02/17/health/17COW.html>

February 13, 2004

Mad Cow Disease Finding Reviewed by FDA Advisory Committee

The US Food and Drug Administration's (FDA) Transmissible Spongiform Encephalopathies (TSE) Advisory Committee met February 12 to 13, 2004, to review evidence and information regarding two separate incidents related to Creutzfeldt-Jakob Disease (CJD), also known as Mad Cow Disease. The advisory committee makes recommendations to the FDA commissioner regarding the regulation of products which may be at risk for transmission of spongiform encephalopathies, which includes bovine spongiform encephalopathy (BSE).

The committee first heard presentations on the presumptive transfusion-transmitted case of new variant CJD (nvCJD), the human form of Mad Cow Disease reported recently in the United Kingdom and reviewed related experimental studies in animals on the transmissibility of TSE agents by blood and the epidemiology of human TSEs.

The committee also received an update on the case of BSE, of which CJD is a type, recently recognized in the United States. The US Department of Agriculture (USDA) spoke regarding their efforts to investigate this incident and ensure the safety of US beef as well as curb the spread of the disease in the US cattle population. USDA has announced several changes in the testing and tracking of cattle since

a Washington state cow was diagnosed with BSE following slaughter in December 2003. The discovery led to the recall of more than 10,000 pounds of meat from eight Western states and has raised concerns about testing for the disease.

The advisory committee was critical of USDA's actions to date in implementing controls that could better detect and curtail the spread of the disease. The Washington cow is the only known cow in the United States to test positive for BSE, compared to more than 180,000 BSE positive cows in the United Kingdom at the height of the BSE epidemic in that country.

US blood and blood products continue to be considered safe because of the donor deferral exclusions put into place by FDA in the late 1990s and the reduction of potential agents by the manufacturing processes used to produce clotting factor products. Research and studies continue to be conducted to demonstrate the viral inactivation of these processes. The new finding about BSE does not change any of the existing treatment recommendations.

Previous alarms about the possible transmission of BSE to humans through blood products were sounded in February 2004,

when the British minister of health reported a case of possible transmission of nvCJD in a transfusion recipient. Blood experts have speculated nvCJD might be spread through blood transfusions and in recent years have put in place precautions, such as donor deferral, should transmission ever be proven.

The meeting agenda and briefing information can be found at: <http://www.fda.gov/ohrms/dockets/ac/cber04.html#TransmissibleSpongiform>. A transcript from the meeting and all presentation materials also will soon be available at this site.

Additional information on BSE, CJD and nvCJD can be found on FDA's

Web site at <http://www.fda.gov/oc/opacom/hot-topics/bse.html> or on USDA's Web site at <http://www.usda.gov/BSE/>.

LEGISLATIVE NEWS

March 1, 2004

Clotting Factor Classified As Sole Source Drugs

The Centers for Medicare and Medicaid Services (CMS) has issued a program memorandum to alter the classification of biologics, including clotting factor, to sole source for 2004 hospital outpatient payment. Reimbursement for these products will now be calculated as 88 % of AWP. This action is retroactive to January 1, 2004.

NHF recently joined with other organizations in testifying before CMS' Ambulatory Payment Classification (APC) Advisory Panel regarding the misclassification of most clotting factor products and biologicals as multiple source in the agency's January 6, 2004, interim final rule. Such classification reduced payment to 46% of AWP for many clotting factor products, a rate substantially below hospital acquisition costs. At its February 20, 2004, meeting, the APC panel unanimously adopted a recommendation encouraging CMS to consider all biologicals, including clotting factor, as sole source drugs. The attached program memorandum was released one week later on Friday, February 27.

CMS is accepting comments on the January 6, 2004, interim final rule until March 8, 2004. As a result of Friday's action, NHF will modify its comments to thank CMS for its prompt action in correcting this error.

February 27, 2004

NHF Achieves Restoration of Medicare Factor Reimbursement

NHF has played a key role in the recent restoration of Medicare reimbursement for clotting factor. The Centers for Medicare and Medicaid Services (CMS) issued a program memorandum on February 27, 2004, to reclassify clotting factor and other biologicals as sole source drugs under the Medicare hospital outpatient prospective payment system (HOPPS). The memorandum was issued in response to NHF's testimony before a CMS advisory panel and increases payment from 46% of average wholesale price (AWP) to 88% of AWP. NHF had been concerned that the reimbursement rates would result in less than optimal care for Medicare beneficiaries with hemophilia and other bleeding disorders by paying significantly below hospital acquisition costs for

clotting factor products and creating wide payment variation between the inpatient and outpatient settings.

This issue arose on January 6, 2004, when CMS issued an interim final rule to implement hospital outpatient payment changes mandated under the new Medicare Prescription Drug, Innovation, and Modernization Act (MMA). In the rule, CMS misclassified most clotting factor products as multiple source drugs, resulting in the reduced payment. Clotting factor products are biologicals with no generic equivalents. Each product has been approved by the US Food and Drug Administration (FDA) under individual biologics licensing applications. Furthermore, these products are not rated as therapeutically equivalent by FDA in its Approved Drug Products with Therapeutic Equivalence Evaluations, or orange book.

To address this issue, NHF, along with the Plasma Protein Therapeutics Association, testified before CMS' Ambulatory Payment Classification (APC) Advisory Panel on February 20, 2004. Following this testimony, the panel unanimously adopted a recommendation encouraging CMS to consider all biologicals, including clotting factor, as sole source drugs. The program memorandum was released one week later and can be accessed at:
http://www.cms.hhs.gov/manuals/pm_trans/r113cp.pdf.

February 27, 2004

CMS Urges Programs for Disease Management in Which Costs are Lowered

The Centers for Medicare and Medicaid Services (CMS) today urged states to adopt programs to help those with chronic illnesses better manage their diseases. In a letter to state Medicaid officials, the agency announced it would match state costs of running so-called "disease management" programs aimed at improving health outcomes while lowering the medical costs associated with these diseases.

Studies have shown that persons with chronic illnesses like hemophilia, diabetes, asthma, congestive heart failure, hypertension and other long-term diseases use a disproportionate share of medical services. These patients are frequently treated by multiple providers whose care is not coordinated, potentially leading to duplicative and unnecessary

services and driving up medical expenses. Disease management is a set of interventions designed to improve the health of these individuals by working more directly with them and their physicians on treatment plans regarding diet, adherence to medicine schedules and other self-management techniques.

Today's letter to states comes on the heels of disease management initiatives being launched in the Medicare program. Currently, CMS is undertaking a series of disease management pilot projects in the traditional fee-for-service Medicare program as well as Medicare managed care programs.

The new Medicare Prescription Drug, Improvement and Modernization Act (MMA) establishes two new programs. The first, the Voluntary Chronic Care Improvement program will provide guidance to beneficiaries with chronic diseases that could be responsive to disease management interventions. The goal will be to improve beneficiary self-care and to provide physicians and other providers with technological support to manage clinical information about the patient.

The second program is the Care Management Performance Demonstration, which will establish a pay-for-performance three-

year pilot with physicians to promote the adoption and use of health information technology to improve quality and reduce avoidable hospitalizations for chronically ill patients. Doctors who meet or exceed performance standards (set by CMS) will receive a bonus payment for managing the care of eligible Medicare beneficiaries. The pilot must show that it does not cost Medicare more than the program would have spent on the beneficiary otherwise.

In its letter about the Medicaid program, CMS suggests several models that states can use that would be eligible for federal matching funds. States may contract with a disease management organization (DMO) that would manage the overall care of the beneficiary, but does not restrict access to other Medicaid services. A state may pay the DMO a capped amount per beneficiary with the organization being responsible for any expenses over the set amount. States may also establish a primary care case management program (PCCM). In these programs, the state works with PCCM providers to enhance the care it delivers to enrollees with chronic conditions. Additional support from the state could be given for especially complex cases.

Individual providers (physicians, pharmacists or dietitians) can

also contract with states to provide management services. Providers often undergo specialized training before undertaking this program. States can develop these programs under either a Medicaid waiver or state plan amendment. CMS will also provide direct technical assistance to states that request it.

Source: CMS Public Affairs

February 25, 2004

Pharmacy Benefit Manager Agrees to Disclose Rebates

Medco Health Solutions, Inc., one of the four largest pharmacy benefit managers (PBMs), and consulting firm Towers Perrin, have recently made a deal under which Medco will fully pass along pharmacy discounts and drug rebates to Towers Perrin clients and provide full disclosure regarding rebates it negotiates with manufacturers on drugs. This agreement allows Towers Perrin employer clients who use Medco as their PBM to pay Medco under a flat-rate structure, based on the number of members in a particular health plan. It also shows the client the actual prices of drugs and the rebates negotiated by the PBM for each employer health plan.

Debate in the US Congress on the Medicare Drug, Improvement and Modernization Act passed in December 2003 included similar considerations, but the final bill did not include provisions requiring disclosure of negotiated prices and rebates. There has also been activity at the state level on PBM disclosure issues. According to a July 2003 report by the Health Insurance Association of America, 22 states introduced legislation in the first six months of 2003 to regulate PBMs or require the disclosure of financial agreements with drug manufacturers.

February 20, 2004

New Leadership to Oversee Latest Medicare and Medicaid Expansion

President Bush has named US Food and Drug Administration (FDA) Commissioner Mark McClellan to serve as the new administrator for the Centers for Medicare and Medicaid Services (CMS). The announcement was made on February 20, 2004. McClellan will succeed Thomas Scully, who left the CMS position in December 2003.

McClellan's nomination is subject to approval by the Senate Finance Committee, which oversees Medicare and Medicaid. McClellan will oversee implementing the new Medicare Drug, Improvement and Modernization Act, which expands prescription drug benefits for seniors, as well as the entire Medicare, Medicaid and State Children's Insurance Health programs.

Prior to serving as FDA Commissioner, McClellan was a member of the White House Council of Economic Advisers. Prior to that position, he worked at Stanford University as an associate professor and director of the Program on Health Outcomes Research. He also was an attending physician for internal medicine at Stanford Health Services. McClellan's brother, Scott, serves as White House press secretary for President Bush.

Lester Crawford, currently deputy FDA commissioner, will become acting FDA chief, a position he held before McClellan's FDA appointment, until a new commissioner can be named.

February 19, 2004

NHF Lends Support at Hepatitis C Advocacy Briefings

On February 18 and 19, 2004, the National Hepatitis C Advocacy Council (NHCAC) held Congressional briefings on the Hepatitis C Epidemic Control and Prevention Act. NHF attended the briefings and provided a statement in support of the legislation. The informational briefings were conducted in both the US House of Representatives and the Senate to educate Congressional members and staff about the prevention and treatment of hepatitis C. Presentations were made by the National Institutes of Health; the Centers for Disease Control and Prevention; the National Alliance of State and Territorial AIDS Directors; physicians; and Robinson Secondary School DECA Club members.

Members of the bleeding disorders community may remember working with the Robinson Secondary School DECA Club during the campaign to seek passage and funding for the Ricky Ray Hemophilia Relief Fund Act. Robinson Secondary School is a public high school located in Burke, Virginia. Each year the club selects a legislative bill and directs their marketing activities toward advocating its enactment.

NHF and the bleeding disorders community will seek support for the Hepatitis C Epidemic Control and Prevention Act during the 2004 Washington Days program. A factsheet and information on the bill is available at: http://www.hemophilia.org/events/washingtonday_positionpapers_hhec.htm.

NHCAC is a collective body of hepatitis C patient advocacy organizations. More information is available on NHCAC at <http://www.hepcnetwork.org/index.htm>.

On March 8, NHF distributed a letter to the community from President Jordan Lurie, MD, along with a paper outlining in greater detail NHF's position on issues related to people affected by HCV, including efforts to seek government compensation.

February 6, 2003

American Red Cross Issued Second Adverse Determination

The US Food and Drug Administration (FDA), on February 6, 2004, issued its second adverse determination letter in seven months to the American Red Cross after determining that problem management procedures have not been corrected as mandated under an April 2003 revised consent decree. The American Red Cross is responsible for nearly 50% of all blood collection

in the United States. NHF has been briefed by the Red Cross regarding their corrective action plans and continues to monitor Red Cross compliance with the consent decree.

FDA and the Red Cross entered into the revised consent decree last year following FDA legal action against the organization. The Red Cross' blood collection operations have been under consent decree with FDA since 1993. Consent decree is a regulatory mechanism for allowing an entity to continue operations while carrying out corrective actions. The decree represents a series of steps agreed upon by both parties to address violations to FDA regulation.

In this case, FDA has determined that the amended problem management procedures submitted by the American Red Cross do not meet the requirements of the revised consent decree. These procedures govern reporting and tracking of problems related to donor and blood safety, risk assessment and corrective action plans.

The Red Cross received its first adverse determination letter on July 22, 2003. A subsequent letter on September 2, 2003, indicated FDA intended to assess fines of \$8,500 per day for the period of June 6, 2003, through August 5, 2003, for a total fine of \$518,500.

In its February 6, 2004, letter, FDA notifies the Red Cross of its intent to assess fines of \$7,500 per day for violations between October 28, 2004, and February 6, 2004, for a total of \$450,000. Fines of up to \$10,000 per day of violation are allowed under the revised decree.

A copy of the FDA's February 6, 2004 adverse determination letter can be found at: http://www.fda.gov/ora/frequent/letters/ARC_ADLetter_2604.html

A copy of the American Red Cross' press release is available at: http://www.redcross.org/pressrelease/0,1077,0_314_2271,00.html

February 4, 2004

Hemophilia Community Represented on New HHS Advisory Committee

A newly created Department of Health and Human Services (HHS) advisory committee will address needs and concerns related to heritable disorders and genetic diseases in children. HHS Secretary Tommy Thompson announced appointments to the new committee on February 4, 2004. Bleeding disorders community member Derek Robertson, a parent and healthcare consultant for the Hemophilia Alliance, Inc., will serve as one of the voting members of the committee.

The advisory committee was established in 2003 under the Children's Health Act of 2000. The act directs the department to award grants to "enhance, improve or expand the ability of state and local public health agencies to provide screening, counseling or healthcare services to newborns and children having or at risk for heritable disorders" and authorizes appropriations for such activities.

The committee will provide advice, recommendations and technical information to the secretary concerning grants and projects awarded under Title XXVI of the Children's Health Act. Committee members will advise the secretary on policies and priorities to help agencies provide the appropriate services. The advisory committee plans to hold its first meeting later this year.

Other voting members of the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children are:

- ▶ R. Rodney Howell, MD, PhD, chairman, Department of Pediatrics, University of Miami School of Medicine and chief of pedi-

atrics, Jackson Children's Hospital, Miami, Florida (chair);

- ▶ William Becker, DO, MPH, medical director, Ohio Department of Health, Southeast Ohio Regional Medical Center/University Hospital East, Columbus, Ohio;
- ▶ Amy Brower, PhD, director, Medical Informatics and Genetics, Third Wave Technologies, Madison, Wisconsin;
- ▶ Peter Coggins, PhD, senior vice-president, Perkin Elmer, Inc., president, PerkinElmer Life and Analytical Sciences, Boston;
- ▶ Gregory Hawkins, PhD, assistant professor of internal medicine and director, DNA Sequencing Laboratory, Center for Human Genomics, Wake Forest University Baptist Medical Center, Winston-Salem, North Carolina; and
- ▶ Piero Rinaldo, MD, PhD, director, Biochemical Genetics Laboratory, Mayo Clinic, Rochester, Minnesota.

NHF NEWS

March 9, 2004

Bruce Evatt Receives Hilfenhaus Award

Bruce Evatt, chief of the Hematologic Diseases Branch at the Centers for Disease Control and Prevention, received the Hilfenhaus Award on March 9, 2004, at the International Plasma Protein Conference in Brussels. The Hilfenhaus Award honors individuals who have contributed significantly to the world of plasma products during the course of their career.

In June 2003, Evatt was honored at NHF's Third Annual Gala for his ground breaking research identifying the specific dangers of HIV to the hemophilia community and his lifelong commitment to improving the lives of those with bleeding disorders worldwide.

March 9, 2004

NHF Goes "On the Road" to Tampa and Seattle

NHF will host two "On the Road" programs this year. The first will be held in Tampa, Florida on Saturday, May 1, and will be co-hosted by

the Florida Chapter of NHF and the Hemophilia Foundation of Greater Florida. The second event will take place in Seattle on Saturday, May 15, and will be co-hosted by the Bleeding Disorders Foundation of Washington.

Each event will feature National Prevention Program (NPP) education sessions, with subjects to include "Do the 5!," prevention of blood borne infections, and new hepatitis C treatments. NHF will also have programming related to insurance reimbursement issues specific to different areas of the country and discussions on family issues for all generations.

Each of the one-day events will also be preceded the Friday before by a national conference targeting a specific audience. On Friday, April 30, in Tampa, there will be a National Caucus for chapter, association and NHF leadership. This event will be a precursor to the NHF Leadership Weekend in New York in June, and will feature a presentation by NHF board member Rita Gonzales on research she spearheaded on chapter/association capacity, infrastructure and programming across the country. On Friday, May 14, in Seattle, NHF will host a national meeting focusing on women with bleeding disorders, which will include peer education for trainers and much more.

Those interested in attending On the Road may now register online at www.hemophilia.org/events/ontheroad/home.htm.

For more information on any of these events, please contact Rebecca Brodsky at 212-328-3738 or (rbrodsky@hemophilia.org), or contact Sonia Roger at 212-328-3724 or (sroger@hemophilia.org).

March 8, 2004

NIAID to Study Transplants in People with HIV; MASAC Member Among Principal Investigators

The National Institute of Allergy and Infectious Diseases (NIAID) will sponsor an important study entitled "Kidney and Liver Transplantation in People with HIV" to evaluate the safety and effectiveness of organ transplants in this population. Kenneth Sherman, MD, of the University of Cincinnati and member of NHF's Medical and Scientific Advisory Council (MASAC), will be a principal investigator in the study. Approximately 150 kidney and 125 liver transplant patients will be enrolled over a three-year period at medical research centers throughout the United States. Further information, including eligibility criteria, is available at <http://www.clinicaltrials.gov/ct/show/NCT00074386?order=3>.

February 29, 2004

Factor Foundation of America Founder David Madeiros Dies of Hepatitis C Complications

David Madeiros, founder and executive director of Factor Foundation of America (FFA) and a well-known figure with a long history of service to the bleeding disorders community, died on Sunday, February 29, 2004, of complications of hepatitis C. Madeiros was responsible for overseeing the daily operations of FFA, including patient care and services, government relations and patient advocacy. Born with hemophilia, he stood firm in his convictions that "the disease does not rule the person." In this manner, he overcame many of the ailments and illnesses associated with bleeding disorders and enjoyed "a very happy and fulfilled life" with his wife Kim and son Jason. David is predeceased by his father Phillip and brother Larry. His family requests that donations be made to Factor Foundation of America, 7700 Congress Avenue, Suite 3109, Boca Raton, FL, 33487, or to the Jason Madeiros Fund care of Factor Foundation of America.

February 26, 2004

New Advocacy Section Debuts on NHF Web Site

NHF has updated its Web site to include a new advocacy resource section. The latest news, factsheets on key issues at the federal and state levels, blood safety information and key contact information are now available to the bleeding disorders community in a "one-stop shopping" format. To access this enhanced Web feature, please go to <http://www.hemophilia.org/resources/advocacy/>. News articles and fact sheets will be updated regularly. Additional enhancements will be added to this section and throughout the NHF Web site during the course of the year.

February 13, 2004**Dr. Johann Heinrich Joist Loses Battle with Mesothelioma**

Dr. Johann Heinrich Joist, hematologist and professor of medicine at the St. Louis University School of Medicine, died February 13 at his home in Clayton, Missouri, after a yearlong battle with mesothelioma. He was 69.

Joist served as an assistant professor of medicine at the Washington University School of Medicine in St. Louis and later became director of the Hemostasis and Thrombosis Laboratory. He also served for many years as the director of the hematology and oncology division at the St. Louis University School of Medicine, where he was also a professor from 1982 until his death.

In addition to his teaching, Joist held 17 annual conferences in St. Louis about bleeding disorders, which drew doctors from around the world. He established the St. Louis Coagulations Consultants' reference laboratory and worked to protect the blood supply. Joist was also director of the Adult Hemophilia Treatment Center in St. Louis where he received an award from the World Federation of Hemophilia in 2001 for a program he initiated with a hemophilia center in India.

Joist is survived by his wife, Nancy, three daughters and three grandsons. Memorial contributions can be made to the St. Louis University Hemophilia Twinning Program, in care of Dr. Ganesh Kudva, St. Louis University Division of Hematology and Oncology, 3655 Vista Ave., St. Louis, MO, 63110.

Source: *St. Louis Post Dispatch*

February 1, 2004**NACCHO Event Features Leadership Training, Camp Songs and Stock Car Racing**

The second annual North American Camping Conference of Hemophilia Organizations (NACCHO) was held in Tempe, Arizona, on January 30 and 31. The conference, which is funded by a grant from Wyeth, featured Michael Brandwein, a national educator who spoke about leadership training for staff and campers, as well as activities to

develop life skills, responsibility and self-esteem in campers.

On the last evening, it was time to have fun. Camp leaders each had an opportunity to be a passenger in a stock car with a professional driver. Once everyone who wanted to try it had a turn, dinner was served followed by dancing into the night. In spite of the late night, there was a full house on Sunday morning when Brandwein gave an inspirational talk on inspiring meaning and value in every person.

Other highlights included a presentation by Tom McDermott, a camp singer and guitar player, who regaled the audience with new camp songs for leaders to teach their campers. Bill Kubicek, executive director of The Next Step Fund, led a discussion in the area of transitioning teens to become responsible adults.