

# HEM FILE

The Newsletter of the Oklahoma Hemophilia Foundation

April 1996

525 N.W. 13th St. \* Oklahoma City OK 73103 \* (405) 235-3855 \* (800) 735-3855

## Ricky Ray Act/Class Action Suit Updates

Mike Lee OHF Secretary

"The Ricky Ray Hemophilia Relief Fund Act of 1995" continues to garner support: over 40% of the 435 members of the House of Representatives have signed on as co-sponsors of bill H.R. 1023. Once a majority is reached, Act-spearhead Porter Goss from Florida will have more leverage to get the bill moving into hearings by the Judiciary Subcommittee on Immigration and Claims. Unfortunately, *none* of the co-sponsors so far are from Oklahoma, so we are printing their addresses and phone numbers again, on page 2. If you have yet to express your support of the Act to our Congressmen, now is an imperative time. If you *have* called or written, do it again! They can't be told too often how important this restitution is. Let them know how hemophilia and HIV have affected you and/or your loved ones, where you stand on the issues, and what the passage of the Act will mean to you personally and the affected community at large. For those of you who find it hard to put your thoughts into words, a sample letter is on page 3. If you like, you can copy it verbatim, insert your name and address, your (or all) Representative's name(s), sign it, and mail it off. Our Senators' addresses are also listed on page 2, so you can also acquaint them with the Act before it is introduced to the Senate. The full text of the Act, as well as continuing updates, can be received from The Committee of Ten Thousand, 155 Longwood Ave., Brookline MA 02146, 1-800-488-2688, or from the NHF at 1-800-42-HANDI.

On Monday, March 18th, Quantum Health Resources' A.C.C.E.S.S. Program sponsored a Rally Party at the local branch to support the Ricky Ray rally that was held in Washington D.C. later that same week. While munching on cake and swilling punch, attendees collected sample letters and information, used Quantum's fax machine to send missives to the Representatives, and signed off on a giant banner next to their painted-on handprints. The banner was then sent to Representative Coburn's office.

As for the class action lawsuit against the pharmaceutical companies and the NHF, on January 17th Judge Grady decertified the class, which means that the class members may now file their own individual lawsuits, if they wish. The Young Lawyers Division of the AIDS Legal Resource Project,

sponsored by the Oklahoma Bar Association and headed by Darlene Shadid, offers free legal assistance to the HIV-positive; they can be reached at 405-524-4611. Several states have also enacted legislation to stay the statute of limitations for a year; Oklahoma is not one of them. If you would like to help in getting that done here, call the Hemophilia Federation for assistance at 1-800-230-9797. On a related note, there was a case in California where the courts ruled that the statute of limitations starts *not* at the time of diagnosis with HIV infection, but at the time of conversion to full-blown AIDS.

Representative Bill Brewster  
1727 Longworth  
Washington DC 20515  
(202) 225-4565

Representative Tom Coburn  
511 Cannon  
Washington DC 20515  
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Representative Ernest Istook  
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Washington DC 20515  
(202) 225-2132

Representative Steve Largent  
410 Cannon  
Washington DC 20515  
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Representative Frank Lucas  
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Representative J.C. Watts  
1713 Longworth  
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Senator Jim Inhofe  
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Senator Don Nickles  
133 Hart  
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(202) 224-5754

Representative

Washington DC 20515

Dear Representative

I am writing today to ask you to co-sponsor a very important bill that was presented to the House in February 1995 by Congressman Porter Goss of Florida. This Bill is H.R. 1023, *The Ricky Ray Hemophilia Relief Fund Act*. It is named for one of our fallen brothers. Ricky Ray died of AIDS after contracting the disease by using medication that was contaminated by the HIV virus.

In 1995, Donna Shalala commissioned a board of medical and scientific experts to study the transmission of AIDS in our community. This study was performed by the Internal Office of Medicine, and the results were released in a report on July 13th, 1995: "HIV and the Blood Supply: An Analysis of Crisis Decisionmaking." The report clearly identifies the role that governmental agencies played in this tragedy. It concludes that the agencies responsible for bloody safety did not show the appropriate level of diligence in screening the blood supply, did not move as quickly as they should have to approve blood products that were potentially safer, and failed to warn the hemophilia community when the government knew, or should have known, that the blood supply might not be safe. The report further suggests that restitution is in order. Families affected by hemophilia are being devastated financially and emotionally by AIDS; the deaths are mounting at an average of two a day. This includes over 4500 hemophiliacs as well as their inadvertently-infected spouses and children.

Please contact the office of Representative Goss for the specific mechanics of the bill. I look forward to seeing your name joining the list of over 190 House co-sponsors of H.R. 1023, *The Ricky Ray Hemophilia Relief Fund Act*, so we can continue to see to the plight of HIV-infected hemophiliacs in Oklahoma and across the United States being addressed and redressed.

Sincerely,

# HEMOPHILIA TREATMENT CENTER NEWS

by Beverly Stevens R.N. B.S.N.  
and Sarah Hawk P.A.-C.

## Exciting Changes at the HTC

We've already begun our new look for comprehensive evaluations. Firstly, clinic days are now on Fridays; and we've moved them into the new Jimmy Everest Center for Cancer and Bleeding Disorders in Children. As you drive down N.E. 13th Street you will see the new white tower at the west end of Children's Hospital. The Hematology/Oncology Clinic resides in the *entire* third floor! For those of you who haven't seen the new facility, but remember growing up in the cramped quarters of our previous clinic, you will be in for quite a surprise! One thing that has not changed: we will continue to work with patients of all ages. And we want to thank all those who helped make our new facility possible!

We'd also like to note that the Hemophilia Treatment Center is now "offline"—our telephone is now off the answering service! The only exceptions will be if it rings several times, the service will answer, and after hours the service will take messages that will be addressed the next working day. The 1-800 number will ring directly in the office as before.

## Cigarette Smokers Alert

AIDS patients, who are at high risk of disseminated Mycobacterium avium infection already, should be alerted that several batches of four different brands of cigarettes were recently processed for the isolation of the organism. It was recovered from the tobacco, cigarette paper, cigarette filters, and even from filters after the cigarettes had been smoked. Yet another reason for the HIV-infected to stop smoking *now*.

## HIV & Nutrition Newsletter

A nutrition product manufacturer, Ross Products, is offering a free quarterly newsletter, InFocus News, which would be sent confidentially. Call Sarah at the HTC for a subscription form.

## TeleClinic Teaches Hemophilia Care

Supported by a grant through Bayer Pharmaceuticals, the newest in the continuing series of Family TeleClinics, designed to reach patients and their families with information and advice about hemophilia, will concentrate on day-to-day care. Two experts will share their teaching techniques and experiences with several hundred families who are expected to join the one-hour call-in audio conference on Saturday morning, May 11, 1996. They will explore ways in which parents can help their children to assume appropriate responsibility for their treatment throughout their life.

Brenda Riske, R.N., M.S.N., M.B.A., from Denver, and Heather Huszti, Ph.D., from our own Hemophilia Treatment Center, will each bring a different slant to the subject during the scheduled times of 9:30 and 11:30 A.M. Ms. Riske is an author and speaker with 12 years of experience at the University of Colorado Mountain States Regional Hemophilia Center where, as the Regional Coordinator, she has been responsible for program evaluation and training for hemophilia care. She is presently the coordinator of a 5-year national study, funded by the Centers for Disease Control and Prevention, on the use of prophylaxis in children with hemophilia.

After presenting their prepared remarks, the lines will open for questions, comments, and discussion with the speakers and with one another. Participation is free of charge from any telephone. Anyone interested in participating may register by calling 1-800-TELECLINIC (835-3254). They will receive a pre-program packet with instruction on the use of the personal 800 number required to join the conference.

## Upcoming New Coagulation Products

1. A second-generation recombinant product, rVIII SQ, will be in clinical trials for at least two more years before potential licensing. It is free of albumin, the only product derived from human blood which is presently in recombinant factors currently on the market, thus reducing the risk of introducing harmful agents. Its cleansing by solvent detergent further reduces risk of transmitting lipid-coated viruses.

2. The first recombinant human factor IX is in clinical trial; it is entirely free of human or animal-derived protein. Previously untreated infants with severe factor IX deficiencies are being sought for this trial. Final licensing of this product cannot be expected before 1997.

3. A recombinant factor VIIa product for persons deficient in VIII or IX and having inhibitors has been effective in achieving hemostasis in clinical trials. It is already available in Canada through Emergency Drug Release procedures.

## Parenting 101 Classes

A series of four weekly parenting classes is being offered by Children's Hospital. The focus is on children from birth to school-age with topics covering growth and development, nutrition and hygiene, discipline, when to see a doctor, and accident prevention. The \$25 cost is covered by most insurance companies or managed care plans with a primary care provider's referral. Classes start the first Tuesday of each month and are held from 7-9 p.m. If you are interested, call the Education Office at 405-271-8070.

## Bleeding Disorders Online!

Neil Staley, a Board member of the United Virginia Chapter of the NHF, has set up a bleeding disorder bulletin board—Hemophilia Bleeding Disorders Society Online. It features messages from patients and families, updates, medical research, and more. The Board goes "live" each Sunday evening. His e-mail address is: [NStaley@aol.com](mailto:NStaley@aol.com), or write to 2036 Townfield Lane, Virginia Beach, VA 23454. A separate von Willebrand's medical internet contact is through the University of Michigan at: <http://mmg2.im.med.umich.edu/vWF/>  
We also have some extensive listings for HIV information. Please call Sarah at the HTC for a copy.

## Sports After Hip or Knee Replacements

According to Mayo Clinic orthopedic surgeons, low-impact sports are fine after joint replacement. Aerobics are alright if they don't put excessive stress on the prosthesis. Specifically, 100% recommended golf, 96% swimming and cycling. Bowling, sailing, and scuba diving were also encouraged. Only 64% advised hiking. Speed walking and cross-country skiing were advised by only 60%.

Over two-thirds strongly discouraged ballet, baseball, basketball, football, hockey, karate, racquetball, downhill skiing, soccer, tennis, and volleyball after knee or hip replacement. They encouraged persons who continued to be active to have regular exams and x-rays to monitor the prosthesis.

On a related note, Rebecca King, D.D.S., head of Children's Hospital's Dental Services, says research has shown that preventative antibiotics before dental work are *not* needed for people with artificial joints. Pretreatment is still necessary for persons who have infuse-a-ports.

## Acid Reflux and Heartburn?

If food and digestive juices don't stay down in the stomach (reflux), many people notice a burning or pressure sensation. This ring of muscle (Sphincter) that closes off the esophagus is weakened by spicy food, pressure on the stomach, alcohol and smoking. A "hiatal hernia" means that part of the stomach slides up into the chest area and this also puts more pressure on the sphincter. Recurrent acid in the esophagus can cause inflammation, swallowing problems, chronic narrowing of the esophagus, dental erosion, lung irritation, and nighttime asthma.

There are some things you can do to greatly help the situation. (Be patient and consistent—it takes time to reverse tissue damage from chronic reflux): **1)** Avoid food that increase stomach acid or weaken the sphincter: coffee, tea, colas (with and without caffeine); fatty or fried food; spicy food; citrus fruits; tomatoes, onions, peppermint, or chocolate. **2)** Eat smaller meals to put less pressure on the stomach. Better to add a few snacks than to eat large meals. **3)** Reduce stomach pressure. Don't lie down or bend over right after you eat—wait a few hours to give the food time to move on down. Avoid tight belts and clothing. Watch you weight; extra pounds press on your abdomen. **4)** Avoid tobacco and alcohol. These weaken the sphincter and tobacco also increases stomach acid. **5)** Elevate you upper body (use gravity to keep acid where it belongs). Put the head of your bed on blocks (up to 10") or use a wedge under the mattress. Just stacking pillows will actually increase stomach pressure. **6)** Medications have limited use if the above measures are not continued. **Over-the-counter antacids** temporarily reduce stomach acid and coat the tissue. They can also cause constipation and diarrhea. **Prescription medications** either affect the stomach acid or muscle tone and digestive time. They are used *with* the behavior and lifestyle changes above. **Avoid aspirin and non-steroidals** (arthritis medicines). They can irritate the stomach and worsen heartburn symptoms. **7)** Surgery may be recommended for a severe hiatal hernia.

## BEDDING PLANT FUNDRAISER

BETTY LOCKLER OHF WESTERN VICE PRESIDENT/FUNDRAISER CHAIRPERSON

The First Annual OHF Spring Bedding Plant Fundraiser is in full swing and we need your help! We would really appreciate your assistance in one or more of the following ways:

**Place your order:** Make the most of Spring by sprucing up your home's flower beds and pots!

**Organize a group order:** Collect orders from your neighbors, co-workers, and friends. We'll provide you with order forms and pictures.

**Provide us with new contacts:** Let us know the name of your church or business. They may be interested in purchasing bedding plants for their own landscaping needs. We'll be happy to contact them.

**Volunteer your time:** We need help with follow-up phone calls and distributing plants.

**ALL ORDERS ARE DUE NO LATER THAN NOON ON APRIL 12TH. IN OKLAHOMA CITY, PLACE YOUR ORDERS AT THE OHF OFFICE (405-235-3855); IN TULSA, CALL DONNA LEWIS (918-486-3695).** The plants come from Guthrie Greenhouses, and range from Pansies and Geraniums to Impatiens and Moneywarts! The prices are inexpensive and the plants are beautiful! Delivery will be between April 17th-19th.

And coming this September, get your and your friends' taste buds ready—our fall fundraiser will be the famous Blue & Gold Sausage, the most successful fundraising product in Oklahoma (one bite will tell you why)!

## **OHF Executive Director Dana Cooksey Attends "Portfolio of State Issues" Conference**

On March 7th, 8th, and 9th I was honored to be invited to attend the Institute for State Policy Studies program regarding State Health Care Reform in the 90's in Naples, Florida. The Institute was established in June 1996, and it is legally incorporated as a not-for-profit corporation. The goal and purpose of the Institute is to organize and conduct forums that bring together state policy and legislative leaders with private-sector executives to discuss and examine major state issues of mutual interest.

The Institute's educational meeting examined major state policy issues on State Health Care Reform with an emphasis on how various policy options might impact the private sector. Legislative leaders from states that are active on the particular conference policy topics were invited to participate in the Institute meetings, and the program design emphasized interaction among legislative leaders and myself.

I was briefed on Legislative Demographic Services, which is a computer program that matches constituents to legislative districts. This program is offered to the OHF free of charge and can be used as a direct lobbying tool, a quick reference guide to find our legislators, and as a grassroots mobilization/activation tool.

The second day consisted of sessions including "The New Era of Medicaid", which discussed pending Medicaid restructuring proposals and the implications for state programs and policies. There was a panel of representatives of major provider and patient groups which defined state policy issues under reduced funding, and we got to hear the assessment of the Tennessee reform act called TennCare.

The most valuable part of the conference for the OHF was the chance to sit at roundtable discussions with Senators and Legislators from across the country and let them know our concerns about health care reform.

### **WONN Needs Recipes!**

The Oklahoma Chapter of the Women's Outreach Network of the NHF needs your favorite recipes to include in their upcoming fundraiser cookbook. Mail them to Betty Lockler at 202 N. Donald, El Reno OK 73036, before April 17th!

### **Start Gearing Up for Camp!**

The OHF and the Hemophilia Treatment Center are pleased to present a new, exciting change in the camping experience for attendees of Camp Independence: **CAMP BARNABAS!** Camp Barnabas is an exciting camping adventure existing to provide an unmatched camping experience for children and teens living with hemophilia and other bleeding disorders . . .

and their *siblings!* The camp is set on the edge of the Ozark Mountains southeast of Joplin, Missouri. Activities include rappelling, canoeing, innertubing, swimming, high and low ropes courses, horse-riding (every *day* if you chose!) and jumping on the Blob . . . you'll have to come to find out what the Blob is!

The OHF and the HTC are very excited about the fact that siblings are invited and encouraged to attend this camp. Watch your mail for the Camp Barnabas application and brochure. It's an experience you will not want to miss!

### **Committee Members Needed**

The OHF is forming a committee of volunteers to help plan the 1996 Annual Meeting. If you would like to have a say in the programs and entertainment offered during *your* Annual Meeting please volunteer your time and become a part of this committee. The Third Annual Score for Hemophilia Golf Tournament, scheduled for September, is also beginning committee recruitment. We need your help to make this important fundraiser a success! Our Teen Retreats are coming in September as well. The OHF would like to have your input on planning and executing the retreats. If you're an attendee of the retreats, your input is even more important. Contact the OHF office at 405-235-3855 to volunteer for any of these committees.

### **OHF Clowns Around**

If you missed the Shriners Circus on March 16th, you missed a great time! Over 50 OHF members came from across the state to the Oklahoma City Fairgrounds that Saturday morning to enjoy the clowns, gymnasts, bears, elephants, and the rest of the circus fun! Next year we'll plan on meeting beforehand so we can sit together! If there are any particular activities your family would like to participate in across the state, please let us know, and we'll see if we can't do something there in the future!

### **OHF Members on the Move**

OHF Board member Randy Vicknair will be participating in the 1996 Hemophilia Walk-A-Thon, held at the Kankakee River State Park in Illinois on Saturday, June 8th. Sponsored by Centeon, the annual national campaign helps raise communities' awareness of bleeding disorders. The OHF has been involved for the prior two years, and our participants have raised a combined total of over \$3500. The 8K walk raises money by pledges based on how many miles were walked,

Brian Lockler has been chosen by the NHF Youth Leaders to attend the Hemophilia World Federation meeting June 17-21 in Ireland. He will participate in training sessions and focus groups on living with a bleeding disorder with youth from around the world.

# CALENDAR OF EVENTS

## APRIL

1  
Bedding Plant Fundraiser  
kickoff

## MAY

8  
Memorial Campaign kickoff  
11  
Mom's Day Out  
Holcomb's - Sand Springs

## JUNE

TBA  
Quantum Health Resources  
Summer Outing  
22 - 30  
Camp Barnabas  
Monett, Missouri

## JULY

18 - 20  
NHF Leadership Training  
Chicago  
26-27  
OHF Annual Meeting/Retreat  
MANN/WONN Meeting  
location TBD

## AUGUST

16 - 17  
MANN Fishing Retreat  
location TBD

## SEPTEMBER

21  
Annual Fishing Tournament - Ada  
27 - 29 Young Men and Women  
With Bleeding Disorders Retreat  
University of Oklahoma - Norman  
30  
Annual Golf Tournament  
Karsten Creek - Stillwater

## OCTOBER

16 - 19  
NHF National Meeting  
San Diego  
26  
OHF Fall Gettogether  
Oklahoma City

## NOVEMBER

1  
Poinsettia Fundraiser kickoff

## DECEMBER

9  
Quantum Christmas Party  
Iceland - Bethany  
16  
OHF Christmas Party  
Tulsa

## JANUARY

## Hemofile

the newsletter of the Oklahoma Hemophilia Foundation, is published five times per year for members of the OHF, patients with hemophilia, von Willebrand's, and other bleeding disorders, providers, and friends. Letters, comments, suggestions, articles, and pictures are welcome; however, the newsletter committee reserves the right to edit, delete, publish, and censor as necessary. The submission deadline for the next issue is May 15th; they can be sent through the OHF office, 525 N.W. 13th St., Oklahoma City OK 73103; the Hemophilia Treatment Center, P.O. Box 26307, Oklahoma City OK 73126, MANN/WONN Co-ordinators, or directly to editor Michael Lee at 5757 W. Hefner Rd. #824, Oklahoma City OK 73162.