

BLOOD

The Newsletter of the Oklahoma Hemophilia Foundation

September 1994

3033 N Walnut #E102 * Oklahoma City OK 73105 * (405) 521-1171 * (800) 753-1171

Camp Independence 1994

Beverly Stevens R.N., B.S.N./Camp Director



For the third year in a row, Camp Independence took place this summer at the Central Oklahoma Christian Camp just southeast of Guthrie. Held August 1st through 5th, we had thirty campers and ten full- and four parttime counselors. We also had several special features that volunteers came to camp to conduct.

On Monday, making rockets was the order for the afternoon, with archery instruction after supper. The day ended with homemade ice cream sundaes with all the toppings. On Tuesday morning, campers were treated to a Tae Kwon Do demonstration; then that afternoon the older campers received golf instruction at Silverhorn Golf Club in Oklahoma City, while the younger ones got to enjoy "Amazing Animals" from the Oklahoma City Zoo. That evening all the boys left for an overnight campout at Lake Arcadia; back at the campsite, the girls had a Mary Kay party thrown by one of the mothers.

On Wednesday, everyone spent the day at Lake Arcadia. We had numerous

activities all going on at the same time: fishing, boating, kneeboarding, waterbiking, and swimming. That evening, returning to camp, we had a cookout at the pavilion with all the works: hot dogs, smores, etc. Next came this year's highlighted sport: soccer. We had two coaches who came out and instructed the boys. Meanwhile the girls got their chance at "roughing it" for the night at Arcadia. Thursday the campers were again divided into groups, the older teens heading to Kickingbird Golf Course in Edmond for more instruction, then hitting the links for a bona fide round of golf. The younger group went to Oklahoma City's Omniplex, a hands-on science museum. That evening we finally had what the kids had been asking for for years: a dance. One of our families brought a sound system, another couple came to teach line dancing, and the campers danced the night away, while devouring the cake and nachos we were having in celebration of one camper's birthday.

Friday morning saw one last trip to the waterfront, then gathering to launch their rockets. After lunch it was a mad dash to finish packing and cleaning, cram everything into the vehicles, pose for the group shot, and say goodbye until next year! I want to say a big **THANK YOU** to everyone who made camp possible this year:

SPONSORS

Alpha Therapeutics
 American Red Cross
 Armour Pharmaceutical
 Caremark Therapeutic Services
 Helen Enox Fine Fabrics
 Lynn Hickey Dodge
 Hyland Therapeutics
 Kickingbird Golf Course
 Miles Inc.
 Piddlin' Place
 Quantum Health Resources
 Silverhorn Golf Club

INDIVIDUALS

Lynson Autry
 Chuck Baxter
 Nancy Baxter
 Karen Duncan
 John Dunham
 Gerald Edwards
 Tim Hagan
 Paul Hardin
 Rick Jackson
 Brian Soerensen
 Gary Stevens
 Zac Stevens
 Kathy Stone
 Linda Vincent
 Ray Vincent

COUNSELORS

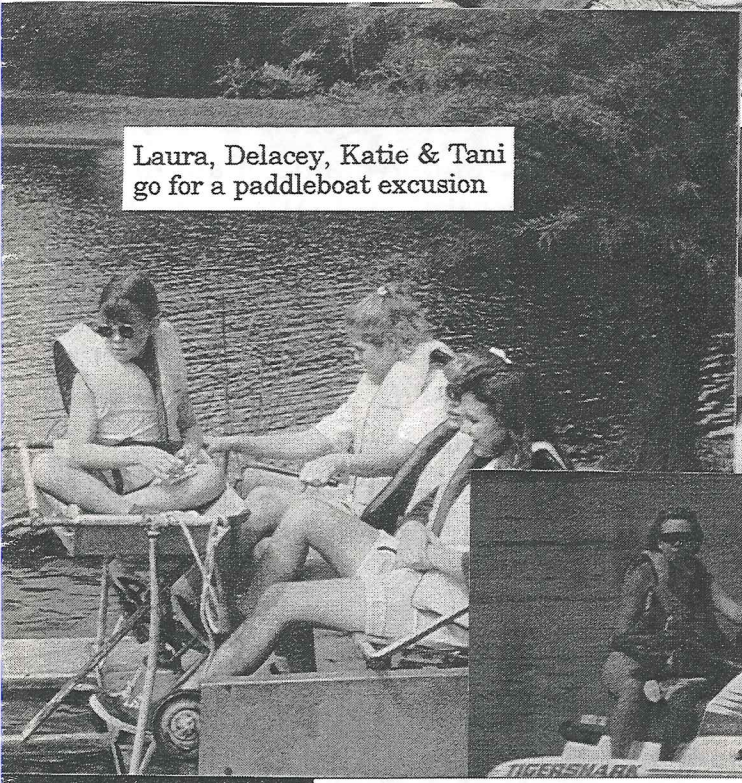
Peggy Brakefield
 James Cross
 Brooke Gage
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 Tyler Hagan
 Mike Lee
 Benny Locker
 Betty Locker
 Charles Sexauer
 Beverly Stevens
 Dennis Valentin
 Mark Vansickle
 Brian Wagner



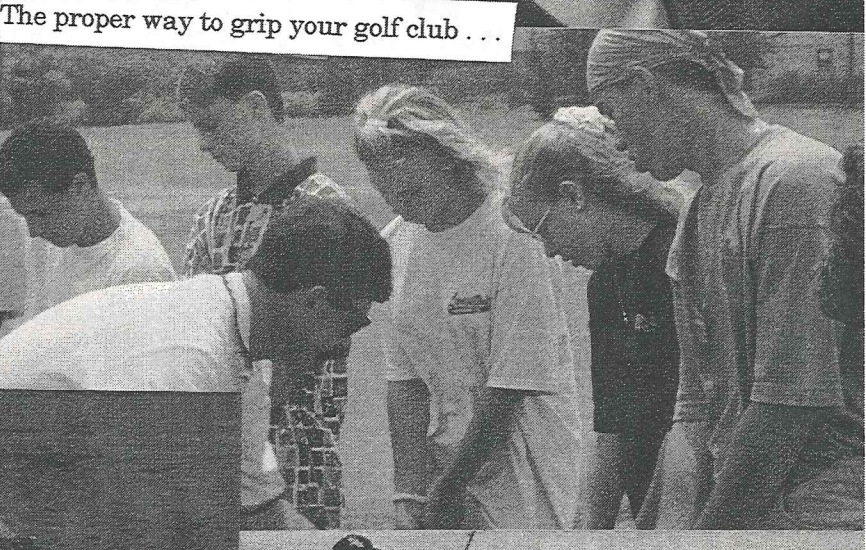
Mark, E.J., Brice, Peggy, Maurice & Sherman on the hayride



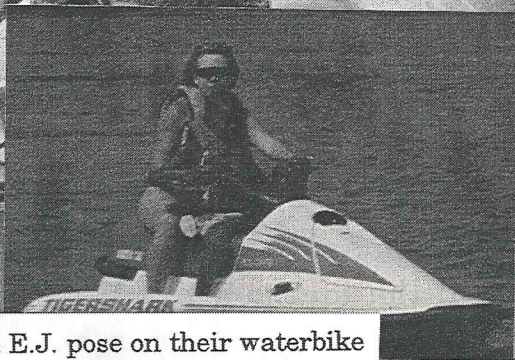
Nice glasses, Brice!



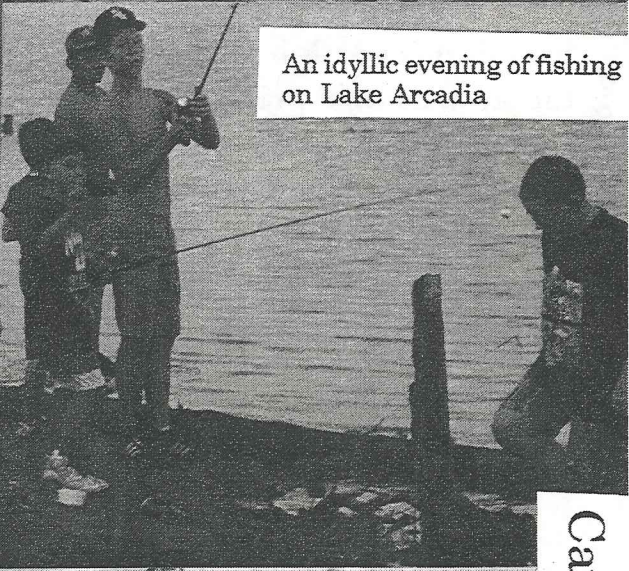
Laura, Delacey, Katie & Tani go for a paddleboat excursion



The proper way to grip your golf club . . .



Tawny and E.J. pose on their waterbike



An idyllic evening of fishing on Lake Arcadia



They can't wait to bust that piñata!



Birthday boy Eric succeeds!

Camp Independence!

ANNUAL FISHING TOURNAMENT DRAWS "SCHOOL" OF PARTICIPANTS

Michael Lee OHF Secretary

Ninety-eight teams of two fisherpersons hit the ponds and lakes of southeastern Oklahoma on Saturday, October 24th, for the 13th Annual OHF Bass Tournament, sponsored by Carmac Wholesale Fishing Supplies in Ada. Ted Carson, his partner Doug McClure, and their families and friends orchestrated the event for their third time, and a huge crowd of spectators and volunteers turned out for our summer camp fundraiser. The teams started floating into the Carmac parking lot about 2 o'clock, where they entered their weightiest stringer and their "big bass". Kathy Stone, Genny Goodley, and Rhonda Manion of Quantum Health Resources checked the teams in, while Lisa Goodley and QHR's Gaylan Williams weighed 'em in (the fish, not the teams), and outgoing OHF treasurer Nancy Nelson posted the scores. Meanwhile, behind the store, MANN Coordinator Lynson Autry filleted, Caremark Therapeutic's Annie Petrikat deribbed, and OHF Secretary Mike Lee and OHF member Scott Lewis deboned the buckets of fish ferried to them by Nathan Manion, Eric Drennon and Nicholas Hulse. Eric and Nicholas' mother Helena, MANN Representative Don Miller, OHF President Tom Duncan, and Caremark's Lora Parnell roved around, helping wherever they were needed. During the activity, entertainment was provided by a local country band and KADA radio came by for a live broadcast.

Finally getting all 400 pounds of fish fried, everyone gratefully sat down to a great bass dinner, with homemade fries, hush puppies, cole slaw, and beans. Ted then presented the awards and prizes to the winners in the various weight and team categories. Camp Independence came out a winner, too; the tournament raised over \$3500 toward next year's camp. The OHF and Carmac extend our appreciation to the following sponsors and prize donators:

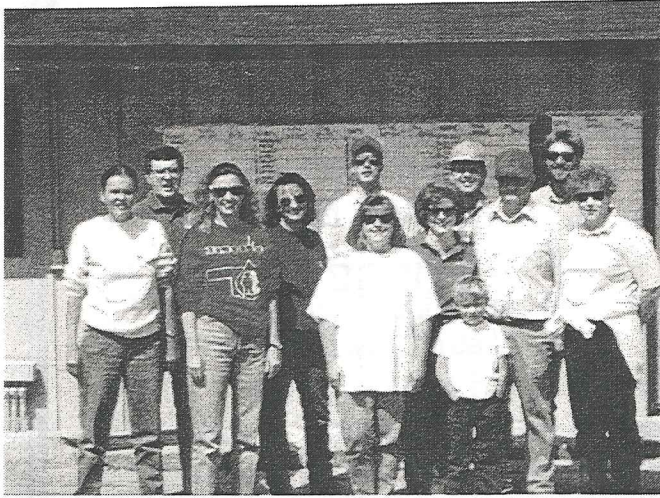
Ada Sales & Rental
Ada Veterinary Clinic
AMS Western Wear
Arlington Animal Clinic
Atwood Corp.
Baker Manufacturing Co.
Bass Assassin Inc.
Berkley
Betts Tackle Ltd.
Blakemore Sales Corp.
Bud Tucker
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Coca-Cola
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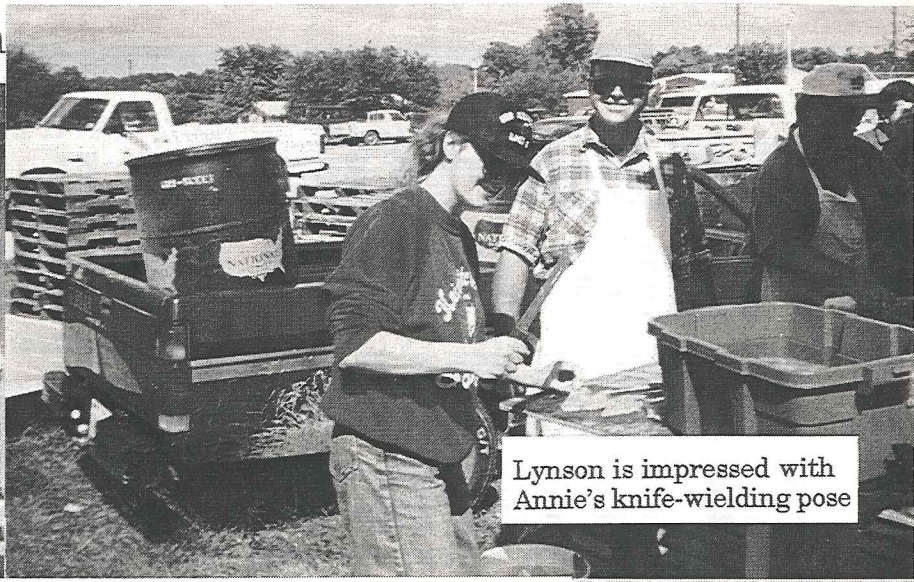
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L&S Bait Co. Inc.
Bill Lewis Lures
Little Hustler
Luck "E" Strike
McCartney's
Mel's Meat
O. Mustad & Sons
Oklahoma State Bank
Pecan Producers
Pelican Products Inc.
Professional Sporting Goods
Pruitt's
RM Engineered Products
Dutch Robinson

Rollins Sun Mart
Save-A-Lot
Shirt Nook
Smith's
Solo
Sooner Printing
Sponj-Lur Inc.
Ernie Staggs
Star Brite
Subway
Sunbeam
Tommy's Trailer
Top Brass Tackle
Tru-Turn Inc.

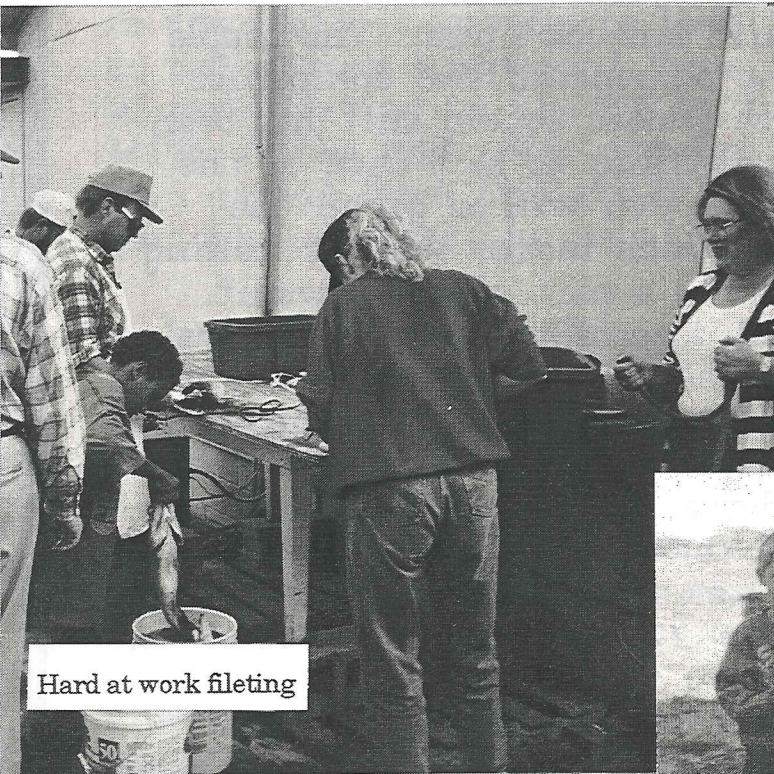
The 13th Annual Bass Tour



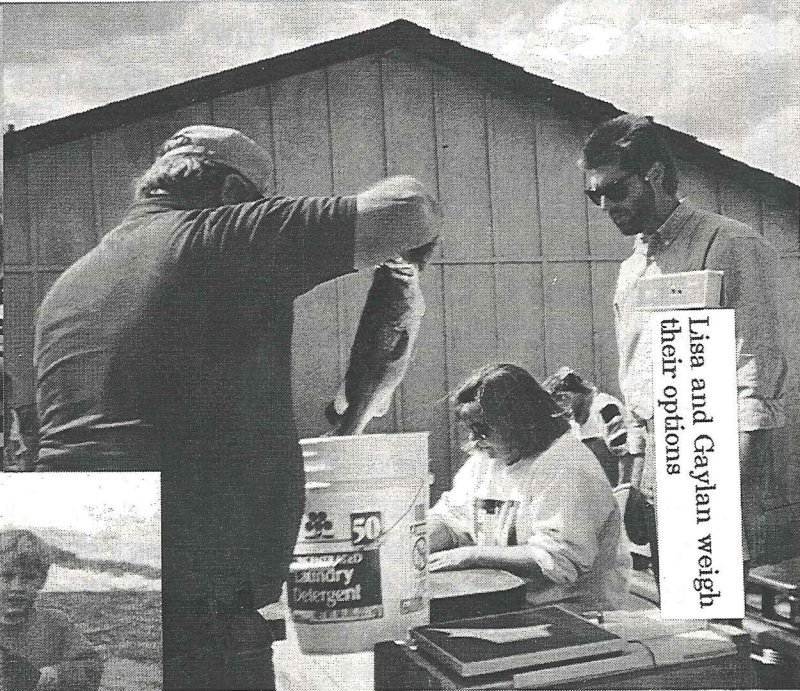
The big group shot: Helena Drennon-Hulsey, Tom Duncan, Rhonda Manion, Nancy Nelson, Lisa & Genny Goodley, Nicholas Hulsey, Lynson Autry, Don Miller, Gaylan Williams, Kathy Stone



Lynson is impressed with Annie's knife-wielding pose



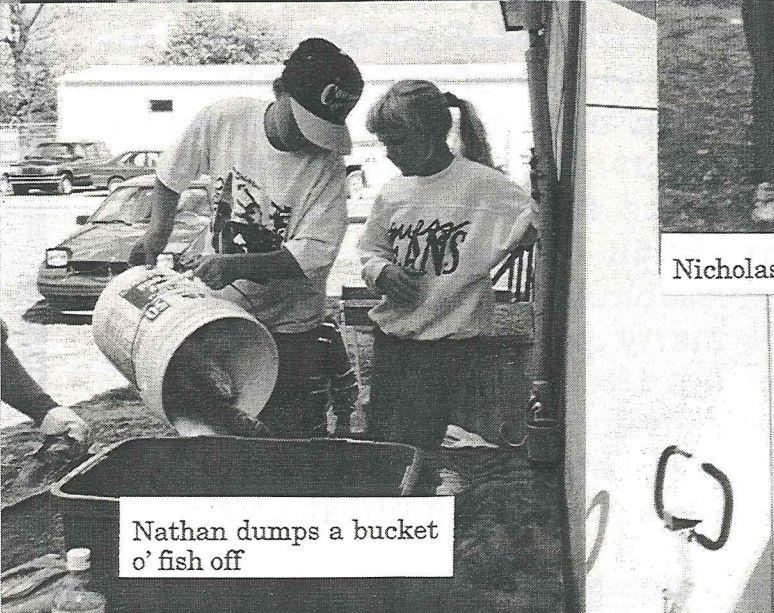
Hard at work filleting



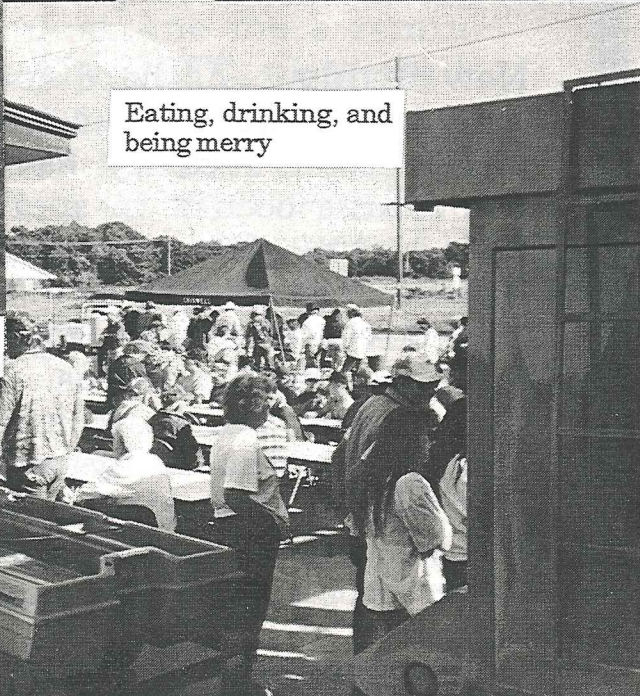
Lisa and Gaylan weigh their options



Nicholas hauls bass



Nathan dumps a bucket o' fish off



Eating, drinking, and being merry

OKLAHOMA HEMOPHILIA TREATMENT CENTER NEWS

by
Heather
Huszi
Ph.D.

Lawsuit Update If you have not yet heard, the class action lawsuit that was filed in Chicago last year was certified by the judge. This means that the lawsuit can continue. The people bringing the lawsuit are suing the pharmaceutical companies and the NHF for negligence. Once a class action suit has been certified, you do not have to do anything to be a part of the lawsuit. At some time in the future you will be given the option to "opt out" of the lawsuit, which means you are telling the court that you do not want to be a part of the lawsuit. Prior to the lawsuit being certified, two of the pharmaceutical companies offered a settlement to the hemophilia community. This settlement was equivalent to the one offered to the Special Assistance Committee last year. The people bringing the class action suit turned down the settlement offer. We will keep you updated about the progress of the suit. If you would like to know more about your rights, you may contact your personal attorney, the OHTC at (405) 271-3661 or (800) 688-5288, or the OHF at the phone numbers on the front page.

New Study As hard as it might be to believe, there have not been any large studies in the United States to find out how many people actually have hemophilia. People often say that hemophilia occurs in approximately 1 in 5000 to 1 in 10000 live male births; however, no one knows for sure. The Centers for Disease Control and Prevention (CDC) has funded six states to find out how many people there are with hemophilia: Oklahoma, Colorado, Louisiana, Georgia, Massachusetts, and New York.

In addition to looking at how many people there are with hemophilia, the study will also look at the complications of hemophilia. These complications will include: joint disease, liver disease, and HIV complications. By finding out exactly how many people with hemophilia experience these complications and

the severity of the complications, new treatments may be developed and more money might be put into hemophilia care.

The Oklahoma Hemophilia Treatment Center is cooperating with the Oklahoma State Department of Health (OSDH) and the Department of Biostatistics and Epidemiology (BSE) in the College of Public Health to complete this study. The OHTC will provide expertise in the treatment of hemophilia and its associated complications. The OSDH and the BSE will actually be collecting all of the information. All of the data is confidential. The OHTC will not have access to any data or names of people with hemophilia who do not receive care from the OHTC.

Because it is important to find everybody with hemophilia in the state, it is vital to identify people with hemophilia who do not receive treatment from the OHTC. If you are interested in participating in the study, please contact Barbara Erikson, MPH, at the BSE. Her number is (405) 271-3970. The information gained from this study will be of great help to people with hemophilia across the country.

Annual Meeting Update Just a reminder that the annual NHF meeting will be in Dallas from Thursday October 27th through Saturday October 29th. This meeting is pretty close to us, and if you have ever wondered about what a national hemophilia meeting was all about, this would be the perfect time to attend. If you have not received registration information, again please feel free to contact the OHTC or the OHF.

Complaints Comments Compliments Just one more reminder. If you have any of the above about the OHTC, please tell us! If we don't hear what you don't like or do like, we will not be able to do our best to bring you the best medical care possible. Please feel free to contact me at (405) 271-5311 or (800) 688-5288. Or send me a letter at CHO, Division of Hematology Oncology, 940 N.E. 13th St., Oklahoma City OK 73104. All of your comments will be confidential. I would love to hear from you!

It's A Boy! Congratulations to proud parents Sarah and Victor Hawk and big sister Rebecca, on the birth of 7 pound 2 ounce Brett Garrison Hawk, born September 3rd!

RECOMMENDATIONS FOR THE HANDLING AND DISPOSAL OF HAZARDOUS WASTE
From the NHF

Purpose: ✓ To prevent the risk of transmission of HIV and Hepatitis infection. ✓ To ensure principles of Universal Precautions are applied. ✓ To ensure safe disposal methods of all medical infectious waste for the health, safety and welfare of the public, and to prevent contamination of the environment.

Definition: As pertains to the treatment and management of hemophilia, Von Willebrand Disease or other coagulopathies, the definition of actual or potential medical infectious waste includes: ✓ Used needles, syringes, or I.V. tubing; ✓ Factor concentrate bottles, cryoprecipitate and plasma bags; ✓ Test tubes containing blood; ✓ Blood, blood products and body fluids; ✓ Any material contaminated with blood or body fluids, i.e. gauze, gloves, linen, chux, razors, tampons, etc.

Recommended Precautions: *Universal Precautions.* ✓ Protective gloves should be worn by all persons, including family members, who have direct contact with open skin, mucous membranes, blood and body fluids during infusion and with infusion clean-up. ✓ Persons who have indirect contact with the above and have dermatitis or lesions on the hands, should also wear gloves. ✓ Needles should never be recapped, bent, clipped, or removed from the syringes, or in any way manipulated by hand. Needles should never be reused. Needles should be disposed into a rigid-wall puncture-resistant container that is labeled and has a lid. ✓ Hand washing with soap and water should be done immediately after handling infectious materials, even when gloves have been worn. ✓ Work surfaces and any surface where blood or body fluid has been spilled should be decontaminated with a chemical germicide or a fresh solution of bleach and water after all procedures. ✓ Linen contaminated with blood or body fluids should be washed in hot water with an effective detergent or germicide. ✓ Eating, drinking, smoking, or applying of cosmetics should not be conducted during the preparation of factor, medications or when infusions occur. ✓ These same precautions are recommended for the handling of *all* blood and body specimens.

Hazardous waste. ✓ All needles, syringes, butterflies, cryoprecipitate or plasma bags, and factor concentrate bottles should be discarded into a clearly-labeled puncture-resistant container with a lid. The container should be kept out of the reach of children. When the container is 3/4 full, or to the indicated "full" line, it should be closed, locked and disposed of by a facility with state-approved infectious waste disposal plan. ✓ Test tubes and other materials contaminated with blood should be discarded in a clearly-labeled puncture-resistant container with a lid (sharp safe container). ✓ All other body fluids, i.e. vomit, urine, stool, etc., should be discarded directly into the sewer system. ✓ All personal products, such as sanitary pads, tampons, condoms, razors, etc. which may contain blood or semen should be disposed of properly.

Accountability: Return of containers from home infusions participants needs to be determined by state law, but in general terms, biohazardous waste should be returned to a facility that has a state-approved program for the collection and/or disposal of such waste.

MUSES FROM MANN Don Miller MANN Representative

On July 28th, Lynson Autry and I went to Denver to attend the MANN National Training Workshop. We found the experience quite interesting; learning about what those with hemophilia and/or HIV have to deal with and how they can be helped, and how to organize chapters and support groups. The training has prepared us to be of assistance to the people so affected. The future growth of this program depends upon each affected person in Oklahoma, including even those who simply know someone affected by a bleeding disorder or HIV. Lynson and I can only help if you contact us. We need your input as to what your needs are and what our future goals should be. Feel free to call either of us; my number is (918) 486-3916, and Lynson's is (405) 495-4180. Stay tuned for more information about the meeting in the Tulsa area we're planning for October, and other upcoming outings, including a fishing trip, and an OSU football game trip.

IMPORTANT OHF EVENTS COMING SOON!

DON BELL

OHF Administrative Assistant

Score For Hemophilia Mark Vansickle with Miles, Inc. has put together our *first* golf tournament at the incredible Karsten Creek Golf Course in Stillwater! This is a must-play course for golfers—the newest and certainly the finest course in the state! The event is our most important fundraiser this year—and essential for OHF programs. Put together at least one team per OHF family! Your employer may be interested in sponsoring a team; be sure to call the local bank and insurance company, or try to find a local golf association. The cost to enter is less than nearly any such tournament! *Get those teams entered now!* And come to the tournament to help!

NHF Annual Meeting Held in Dallas this year, it is as close as it can get. This is your chance to get all the latest information on the HIV Class Action Lawsuit, Employment of Persons with a Disability, National Health Care Reform, the Latest In Prophylaxis, Pain Management, and Issues In Bleeding Disorders. There may be a ride available from both Tulsa and Oklahoma City, and a very *few* sponsorships are available. *Plan now to attend!* Call me at the OHF office if you need help or more information. *This is your life: know about it!*

AIDS Walk Oklahoma

This *fun* event is expected to draw a crowd of thousands in downtown Oklahoma City! If you are affected with hemophilia, AIDS is a part of your life! Eighty percent of us have or will die from AIDS! Only through statewide community action can we make a difference in our own and our family's lives. The Walk is also an important fundraiser for the OHF, necessary to our programs—this stuff ain't free! Call me at the office for more information and pledge sheets. Be sure to attend and support these three events in the month of October!

OHF TULSA ZOO DAY

For just the \$1 cost of parking, come out to Shelter 4 at the Tulsa Zoo October 8th and join in the fun and friendship. Fried chicken and drinks will be provided by Armour and Quantum; but please bring a side dish to share. R.S.V.P. to Donna Lewis at (918) 486-3695 or call Rhonda Manion collect at (918) 540-1768.

FRONTIER CITY!

We'll also be participating in the Oktoberfest celebration at Frontier City in Oklahoma City, in a coordinated project with **Make Promises Happen**. Each ticket purchase helps defray the cost of Camp Independence. This day highlights the park's commitment to accessibility for persons who are physically and mentally challenged. The activity begins at noon on October 9th; tickets are \$3 each and must be reserved with Don Bell at the OHF office (numbers on the front page). Please bring a snack food or dessert to share in the OHF picnic area. Drinks, paper plates, cups, etc. will be provided. Be sure to take these opportunities to bring the family, meet other OHF families, and make new friends!

STATE OF THE FOUNDATION Tom Duncan OHF President

The Annual Meeting in Tulsa was a great success! Thank you for such good attendance and show of continued support for your chapter. Over forty attendees came to indulge in great ice cream and fellowship, and complete important business. We voted to change our Bylaws to allow for four regional Vice Presidents, and while two more candidates are sought, Betty Locker was elected to cover the entire western part of the state, and Don Miller the eastern half. Donna Lewis was elected as Treasurer, and Hector Medina was appointed to fill a Board vacancy.

Between now and the end of 1994, our chapter faces three major challenges. **Reporting:** we must bring all of our grant activity reports up to date. This means not only reporting what we have accomplished through our grants, but also how we spend the grant money. Nancy Nelson, Don Bell, and I have been working on this project and should have it completed by October 1st. Next, the **A133 audit report:** this audit must be performed by a Certified Public Accountant. Funding for this audit is provided for by the NHF and is required before any new grants can be considered by the NHF. I have engaged the services of Dick Doerr, CPA, in Tulsa to assist us in this important matter. Last but not least, we must submit a **list of fundraising events** that generate enough money to make up the difference between what our chapter development grant pays (75%) and the total staffing salary of \$35000. In other words, our chapter needs to generate \$8750 to pay our portion.

These are serious issues; issues that you need to be aware of if our chapter is to move forward. In the near future, I will be calling on many of you to assist our chapter meet its goals. Together we can accomplish great things for the OHF!

P.S. The next Board meeting will be held October 15th at 10 a.m. in the Chapter office—you don't have to be on the Board to attend!

REGIONAL MEETING KUDOS

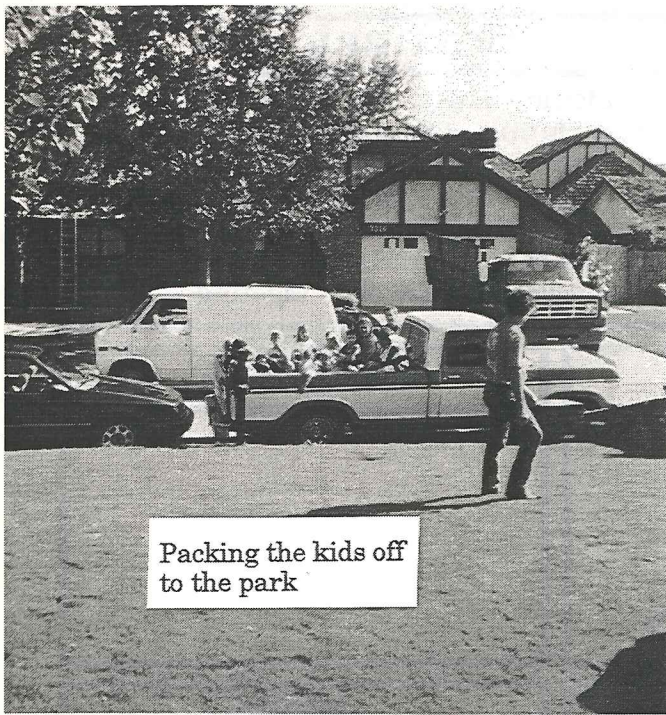
Rhonda Manion OHF Member/Quantum Representative

I would like to take this opportunity to say "thank you" to all those who made our Region V Annual Meeting a great success (except Editor Mike Lee, who left this out last time—just kidding, Mike!). Your time and dedication was greatly needed and appreciated!

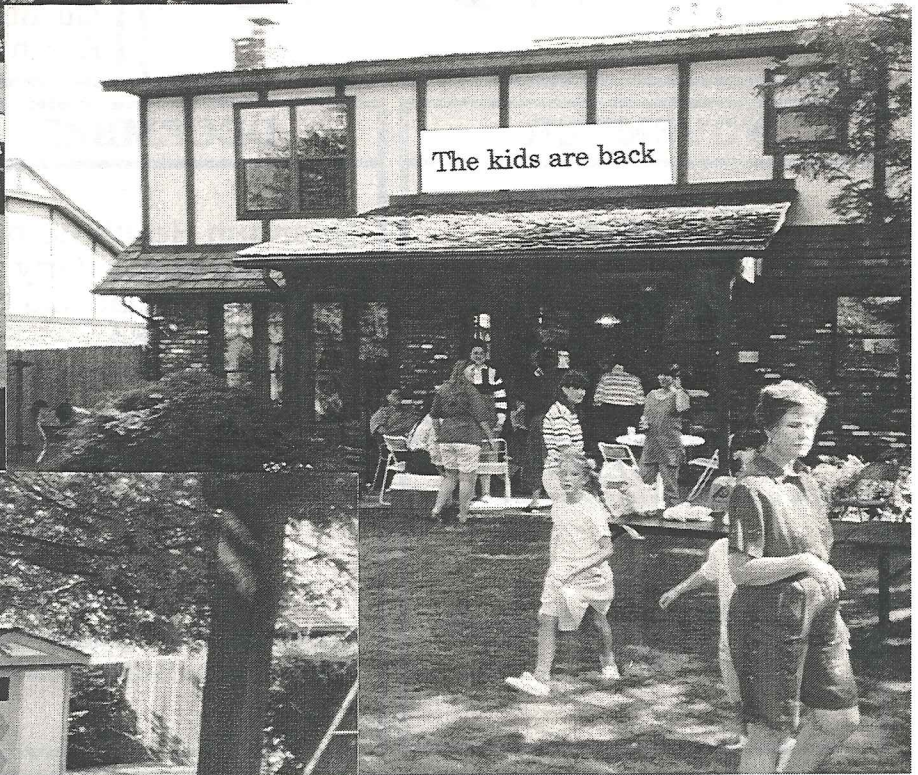
Planning Committee Members: Don Bell, Tawny Hagan, Debbie Klein, Mike Klein, Rhonda Manion, and Johnnie Smith. Also a big round of applause for all our volunteers: Ken Cole, Darrell Dionne, MaryJane Dionne, Karen Duncan, Tom Duncan, Tillie Ellyson, Mike Lee, Donna Lewis, Scott Lewis, Becky Locker, Betty Lockler, Rachel Manion, Don Miller, Martha Miller, Jerry Vaughn, Debbie Vaughn, Brian Wagner and the staff of the Oklahoma Hemophilia Treatment Center. And of course I don't want to forget all those wonderful sponsors; without their financial support, none of it would have been possible: Alpha Therapeutics, American Red Cross, Armour Pharmaceutical, Caremark Therapeutics, Guardian Health Systems, Hall's Pharmacy, Hemophilia Health Services, Hyland Therapeutics, Immuno-U.S. Inc., Miles Inc., Nova Factor, Quantum Health Resources, and Total Pharmaceutical Care Inc. The meeting was a big success. As we planned, everyone had a good time and learned some things in the process. If you missed it, *you missed it!*

Also, Quantum will be having our Fall Festival at the Reed Ranch 5 miles east of Chandler. We've chartered a bus, which will leave the Quantum branch in Oklahoma City at 11:30 on October 22nd. The cookout starts at 1:30; there will be horseback riding for those 7 and older, and a petting zoo and games for the younger kids. There's a hayride at 4:00 and the bus leaves at 5:00. Feel free to call me collect at (918) 540-1768 with any questions.

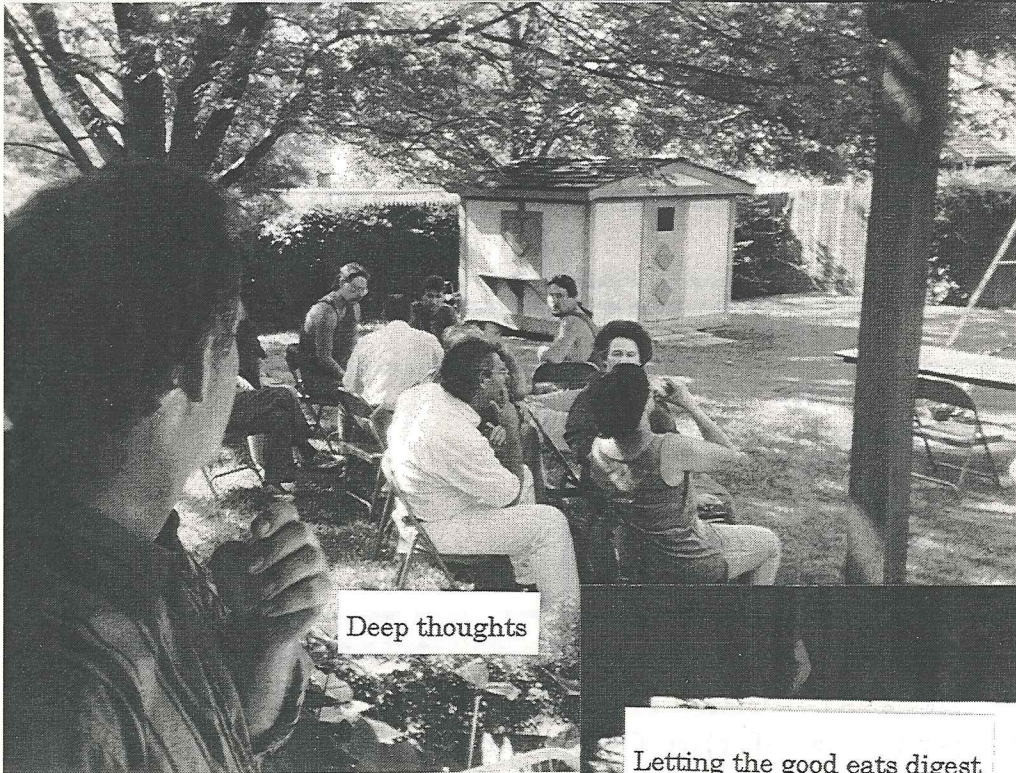
The scene at the Annual Meeting



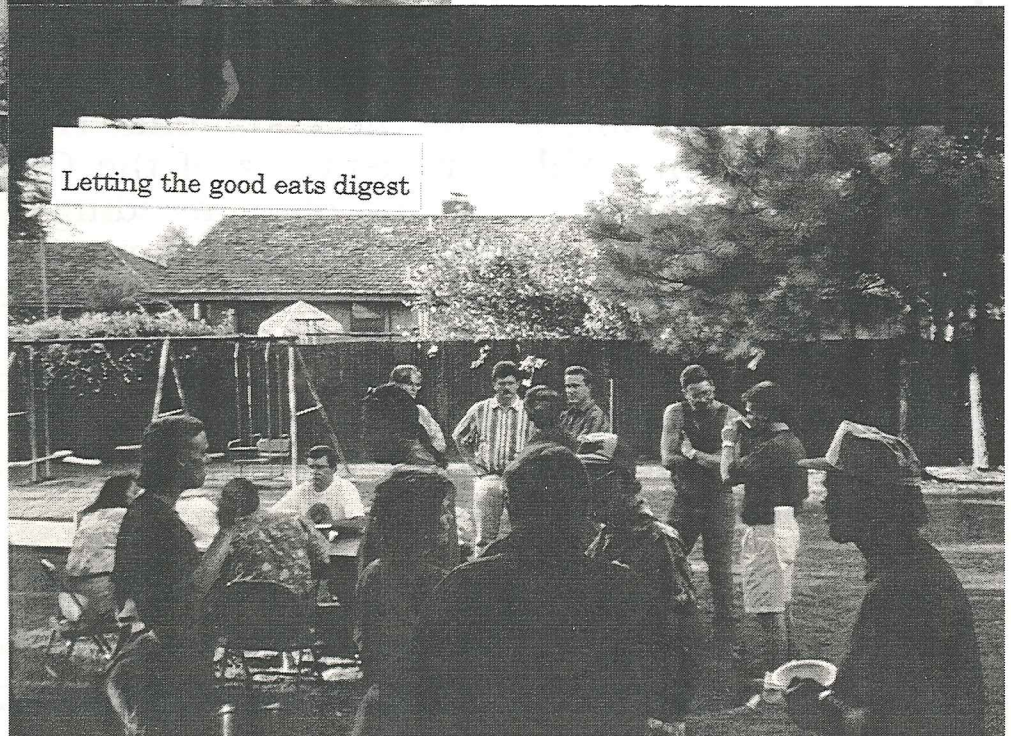
Packing the kids off to the park



The kids are back



Deep thoughts



Letting the good eats digest

CALENDAR OF EVENTS

OCTOBER

8 OHF Picnic - Tulsa Zoo 9 Frontier City
Oktoberfest Outing - Oklahoma City 15 Board
Meeting - OHF Office 16 AIDS Walk - Myriad
Gardens - Oklahoma City 17 Inaugural Golf
Tournament - Karsten Creek - Stillwater 22
Quantum Health Resources Fall Festival - Reed
Ranch - Chandler 27 - 29 NHF Meeting - Dallas

NOVEMBER

1 Poinsettia Fundraising
Project Begins
12 Product Fair/Workshop
Tulsa
TBA
Adult/Couples HIV Retreat
Eastern OK location TBA

DECEMBER

10
Quantum Health Resources
Christmas Party
Iceland - Oklahoma City
TBA
OHF Christmas Party

JANUARY

FEBRUARY

TBA
Garage Sale - Fairgrounds
Tulsa

MARCH

TBA
Young Women With
Bleeding Distorders Retreat
Oklahoma State University

APRIL

TBA
Garage Sale - Fairgrounds
Oklahoma City
TBA
Young Men With
Bleeding Distorders Retreat
Oklahoma State University

MAY

TBA
Frontier City and
White Water Bay Outings
Oklahoma City

JUNE

TBA
OHF Annual Meeting
TBA
Quantum Picnic
Lake Thunderbird
Norman

JULY

Blood, the newsletter of the Oklahoma Hemophilia Foundation, is published bimonthly 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 November 15th; they can be sent through the OHF office, MANN/WONN Coordinators, the Hemophilia Treatment Center, or directly to editor Michael Lee at 5757 W. Hefner Rd. #824, Oklahoma City OK 73162.

Special thanks to **Quantum Health Resources**
for their sponsorship of this newsletter in 1994.