

OKLAHOMA HEMOPHILIA FOUNDATION NEWS

October 1993

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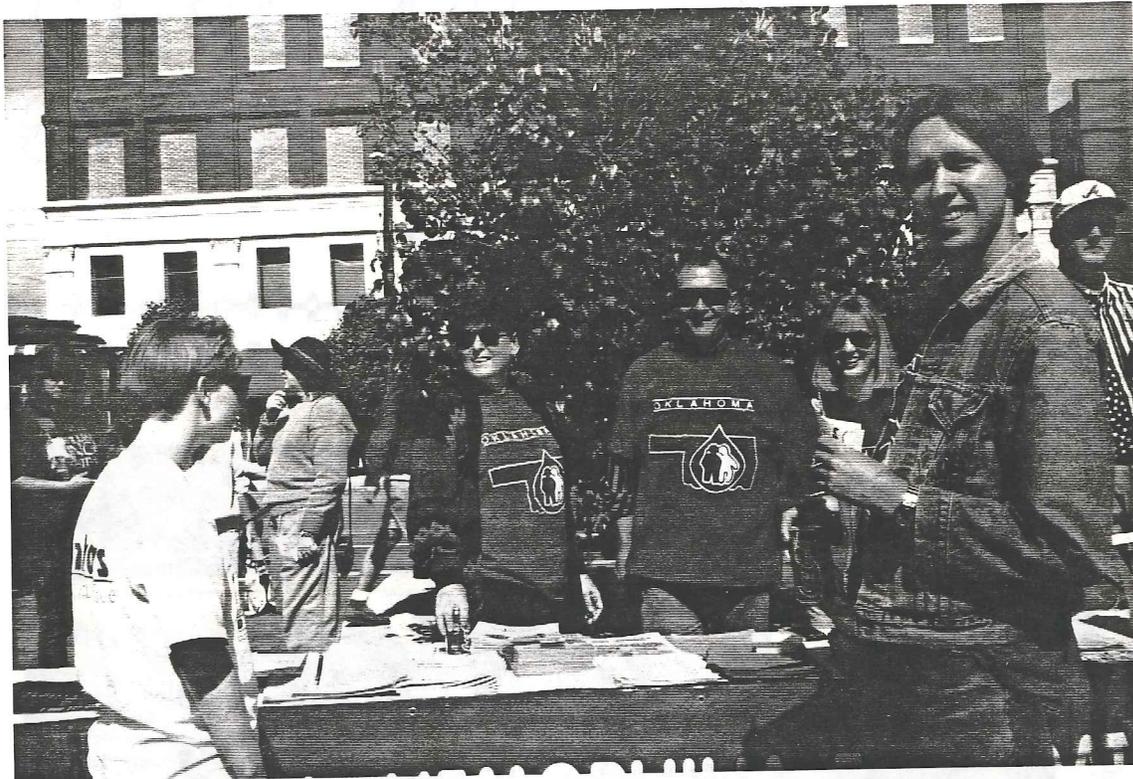
Plasma Alliance's Johnnie Smith, OHF's Don Bell, Philip and Dorecia Tepe, and OHF intern Hillary Koenig posing at the AIDS Walk

AIDS WALK OKLAHOMA Don Bell OHF Administrative Assistant

On October 10th, the Second Annual AIDS Walk Oklahoma was held in Oklahoma City's Bricktown. A major program to raise funds and awareness of HIV/AIDS, it received a big boost when the Lone Wolf 'gang' showed up to express their support for Philip Tepe in his battle against AIDS. Philip, a student at Lone Wolf High School, has faced the battle head-on after going public last year. He has received the support of many friends in the community, school, and his church. People from each group were represented at the walk.

AIDS Walk Oklahoma is designed to provide support for fourteen different organizations, including the OHF, which provide direct support for persons living with AIDS and their families. The event, which drew nearly 2000 persons from all walks of life, raised nearly \$50,000 for AIDS care. Each of the participating groups will receive a share of these funds.

The Tepe fan club numbered about forty from Lone Wolf, and they were joined by OHF members Johnnie Smith, Mary Bowman, Bill Glover, Mike Lee, Sarah and Rebecca Hawk, Linda, Jason, and Stephen Autry, Hillary and Chris Koenig, and myself. We would have liked to have more pictures to show, but unfortunately the film in Mary's camera broke, so we only managed five snapshots! Thanks anyway to Mike for *running* to the front of the walk so he could snap a picture of everybody as they strolled by; hopefully we'll have better photo luck next year!



Johnnie, Don, Hillary, and Mike Lee manning the OHF's information table at the AIDS Walk

STATE OF THE FOUNDATION Pat Nelson OHF President

Once again it is time to ask for your help. Due to unforeseen circumstances, we are in need of a Treasurer for the OHF. Nancy has asked to be allowed to resign because of her increased workload at school and upcoming job. She was willing to stay on for awhile until we could find someone else to perform her duties. If anyone is willing to take on the responsibilities of Treasurer, or if you might know of someone who would be, please contact me at home or Don at the OHF office. This is a responsibility that should not be taken lightly. It will involve the day to day bookkeeping of the OHF plus auditing. It is a thankless job that will require someone to be totally committed to the task.

On the lighter side of things, we have had a good quarter since the last newsletter came out. Our annual fishing tournament in Ada went well, raising over \$3100. Special thanks to the Carsons, Doug McClain, and the rest of the staff of Carmac Wholesale Fishing Supplies, as well as the fish-and-fries fryers, KADA radio for their live broadcast, all the companies which donated prizes, and the 91 teams of two who participated this year. And a round of applause for our OHF volunteers: Tom and Emily Duncan, Rhonda and Nathan Manion, Mike and Debbie Klein, Lynson Autry, Genny Goodley, Mike Lee, Plasma Alliance's Johnnie Smith (and son Jason), Armour's Brian Wagner, Quantum's Dalla Johnson, Dennis Valentin, and John Dunham, and Caremark's Debbie Astleford and Annie Petrikat. Pictures from the tournament are on pages 14 and 15. We also had a successful trip to the National Hemophilia Foundation Convention (see article on page 11), and a good turnout at the AIDS Walk. Our thanks to all who participated in these activities as well.

Fundraising efforts in the Tulsa area are booming! A lot of excitement seems to be building in that part of the state, and anyone who wants to get involved should get in touch with the Millers or Lewises and lend a hand. I understand that the bean project is well under way and that poinsettia sales are being planned. Once again, we can use all the help you can give in our fundraising efforts, to support the projects we now have in progress.

The information and product fairs have been planned and should have taken place while this newsletter is being published. I do hope that everyone took advantage of this opportunity to learn a little more about hemophilia and the products that are available to all of you. A special thanks goes out to all the sponsors of the fair and all those who helped make it a success. Look for a report on it in the next newsletter.

The NHF regional meeting is being hosted by the OHF next year in Oklahoma City, and the

help of everyone would be greatly appreciated and is dearly needed! It's going to be a lot of work, but I know the OHF is up to it. Lots of plans have been made, but there is still plenty to do. For those of you who would like to help on this project, again, contact Don.

Until next time, please feel free to give me a call if there is anything I can do for you or if there is anything you would like the OHF to do. We are here to serve you and the needs of the hemophilia community. Without you there would not be a need for the OHF, so let us hear from you!

OKLAHOMA HEMOPHILIA TREATMENT CENTER NEWS

NEW GRANT FOR OHTC Heather Huszti Ph.D.

The OHTC recently received word that they and the Oklahoma State Department of Health received a grant from the Centers of Disease Control. The grant is called, "The Surveillance of Hemophilia and its Complications in Oklahoma." The purpose of the grant is to find out exactly how many persons with hemophilia A and B there are in Oklahoma. In addition, the grant will look at the types of complications (such as joint problems) that persons with hemophilia have. The grant will help the OHTC hire an additional clinical person, most likely another physician's assistant. The OHTC received one of 6 grants awarded across the country (the others were in New York, Georgia, Massachusetts, Colorado and Louisiana).

NEW ACTIVITIES Heather Huszti

The OHTC is finally ready to start some new activities for persons with hemophilia and HIV infection. These new activities will include retreats, telephone support groups, couples counseling, and individual counseling. The participants will be able to choose what types of activities they want. We are developing the activities with input from local consumers. The first set of activities will focus on enhancing general communication skills. Communication skills can help you with your personal, work, family and medical relationships. There will also be some special interest activities on either enhancing relationships or developing relationships. The second set of activities will focus more on communicating about safer sex and safer sexual behaviors. As with all of our activities, in order to show if the program works and whether or not we should still fund it, we need to evaluate it. That means there will be more questionnaires (sorry!). All persons who are eligible to attend the activities will soon receive a brochure with more information about the activities. A couple of weeks later you will receive a questionnaire. After we get questionnaires back we will be ready to start the activities. We'll be sure to give you plenty of notice. If you have any questions, please give me a call at the OHTC: (405) 271-5311 or 1-800-688-5288.

SCIENCE CLASS: CANDIDA Sarah Hawk P.A.-C.

The Yeasty Beasties, or the Fungus that Follows Us All, Candida, is seen as little red bumps in moist places, shaggy red ulcers or little pieces of 'cotton' in the mouth. This yeast infection grows best in warm moist places, or when normal bacteria have been killed by antibiotics. Babies often develop thrush or diaper rash due to Candida. Sometimes it is enough to feed them yogurt and keep the diaper area dry; otherwise medication may be needed. Pacifiers used while a child has thrush should be sterilized or replaced.

People with dentures or orthodontic or dental appliances may complain of chronic irritation, inflammation or change of taste/smell. The problem may be a yeast infection—not a poor fit. It's hard to get rid of because the infection gets deep into the plastic and stays there—even if you don't use the appliance for several months. The usual denture cleansers and soaks don't work on Candida, and if you put a new appliance into a yeast-infected mouth, the device will be infected in less than 8 hours.

To clean dental appliances: every day, soak in equal parts of bleach, dishwashing detergent and water for at least 2 hours. Rinse and then soak in equal parts vinegar and water for one hour. Toothbrushes should be changed at least every 3 months; more often if you have frequent throat or mouth infections.

Persistent 'heat rash' that occurs in folds of skin may actually be due to yeast. Vaginitis is

often due to *Candida* and may be passed between partners. Yeast can cause painful cracking and redness at the the corners of the mouth (angular cheilitis).

Candida is usually a mild infection, except for the itching and soreness, but a painful mouth or dentures may lead to decreased appetite and weight loss. The superficial sores can allow yeast to get into the bloodstream or make internal abscesses that are life-threatening. People with immune suppression due to illness (diabetes, cancer, HIV), advanced age or medications (antibiotics, steroids) are more likely to develop serious yeast infections. Treatment ranges from creams, mouthwashes, lozenges, and pills, to IV therapy, depending on the location and severity of infection.

NUTRITION VS. AIDS *Journal of AIDS* Vol. 6 pp. 949-958

Researchers followed 296 men for 6 years to see if good nutrition would delay the onset of AIDS. Those with well-balanced diets (especially with better intake of vitamin A, riboflavin, thiamine and niacin) had a 30% lower risk of developing AIDS over the six years and their T-cells tended to stay higher. Many of these people took a multivitamin, but the vast majority of their nutrients came from their normal diet—not the vitamin.

Vitamin A (retinol): carrots, sweet potatoes, liver, greens

Riboflavin (B₂): liver, milk, yogurt, cottage cheese

Thiamine (B₁): lean pork, nuts, fortified cereal products

Niacin: meat (esp. liver), poultry, fish, peanuts, fortified cereals

TOBACCO & NICOTINE *New England Journal Of Medicine* Vol. 319 No. 20

Tolerance: For most people, their very first cigarette caused lightheadedness, rapid heart rate and nausea. As they continued to smoke, these effects went away—they became 'tolerant' and over the first several years of smoking the amount they used gradually increased.

Dependence: means a "drug has come to control behavior to an extent that it is considered detrimental to the individual or society." This is compulsive use. The drug affects a person's mood or thinking. There is often persistent use, despite awareness of harmful effects, recurrent craving and relapse after quitting, and a sense of physical need for the drug. Nicotine is the agent in tobacco that produces dependence (see Quitting below).

Dose: Cigarette smoke is acidic and mainly absorbed through the lungs. The nicotine peak occurs about 15 minutes after starting to smoke. The smoke/solution from pipes, cigars, snuff and chewing tobacco is alkaline, absorbed through the mouth membranes, and takes longer to get into the bloodstream, but stays at higher concentrations for a longer time. The actual nicotine content of the product (e.g. "low tar") doesn't really make much difference; the person just breathes deeper or chews longer to get the needed 'dose'.

Effects: For a regular smoker, the first few cigarettes of the day increase the sense of alertness; smoking may also provide relaxation during stressful situations. Nicotine causes blood vessels to contract (may put strain on heart muscle), and may relax certain other muscles. Smoking shortens platelet lifespan and affects clotting properties. It produces carbon monoxide so that red blood cells cannot carry as much oxygen. It is a major risk factor for stomach ulcers (and may greatly reduce the effect of antacids). Smoking may cause T-cells to drop faster. It also can lead to premature wrinkles. The senses of taste and smell are greatly diminished by smoking. Tobacco affects how other medications/drugs are metabolized—some medicine may need doses increased, reduced or the schedule changed.

Cancer: Nicotine does not cause cancer. The tobacco curing process creates the compounds that cause cancer. They are largely responsible for cancer of the lungs, mouth, esophagus, pancreas, head and neck.

Women: Smoking is associated with earlier menopause, greater risk for osteoporosis and lower estrogen levels. During pregnancy, nicotine does cross over into a baby's bloodstream (these babies tend to be smaller at birth) and later into breast milk. Children of smokers have more allergies, respiratory and ear infections, and possibly more behavior problems.

Weight: Smokers tend to eat less sweets and, on average, weigh 6-10 pounds less than if they didn't smoke. Using nicotine gum or patches when quitting may prevent this small weight gain.

Quitting: Four out of five people who try to quit develop withdrawal symptoms caused by the lack of nicotine. The first 24-48 hours are the worst for feeling restless, irritable, anxious, impatient and having problems with sleep and concentration. These effects wear off over two weeks. The desire to smoke, especially during stress, can continue for months or years. Withdrawal symptoms are dramatically reduced by using nicotine gum, or patches on a tapering schedule. The gum does not cause the same fast satisfaction as smoking, but its effects last longer. Nicotine patches are worn 18-24 hours for steady coverage. These are prescription medications. Because smoking is also a personal and social habit, behavior change therapy or hypnosis may be helpful to quit permanently. Most of the effects of smoking/dipping/chewing on the body are reversible: breathing will improve within 2 weeks, and the cancer risk declines over several years. Many insurance policies and employers now offer smoking cessation programs. It is always worthwhile to quit (personal and family health, time, money . . .)

Fast facts: The average 2 pack/day smoker takes 400 puffs a day. How much time a year would this person spend smoking? Over 20 years? Nicotine is also found in some foods—especially eggplant. A 2-pack-per-day smoker will spend almost \$1500 this year for cigarettes. There may be added expenses of days lost from work for respiratory infections (the smokers', the children's), replacing clothing with cigarette burn holes, higher home owner's or health insurance rates . . .).

BOOK REVIEW Sarah Hawk

Surviving with AIDS: A Comprehensive Program of Nutritional Co-Therapy, by C. Wayne Callaway, M.D. and Catherine Whitney. This is a very readable, reasonable book about coping with the weight loss, anorexia and mouth pain that may accompany HIV infection. Much of the advice is about fighting diarrhea so that food (low fat, high carbohydrate diet) can be absorbed properly for weight gain. They include a lot of good recipes such as high calorie fruit drinks and low fat main dishes. This book is in the lending library at the OHTC.

HOME THERAPY PART II Beverly Stevens R.N., B.S.N.

The need for educating the patient/family with a chronic illness about the nature of the disorder and its treatment is the most important interchange between the family and health care provider. As the knowledge of hemophilia expanded, with better understanding of the technical resources, origination and development of the disorder, hemophilia centers adapted a comprehensive care approach.

The need for comprehensive care, together with the requirement for patient education, has been perceived and fostered by governmental grant, by state health programs, and by the National Hemophilia Foundation. This approach has been accepted by the insurance industry, and the cost of clotting factor concentrate infused by the patient/family is now covered widely.

This situation of general acceptance and cost/benefit recognition has been documented by a number of studies. Several findings are worthy to be mentioned. Hospital inpatient treatment costs and inpatient days fell dramatically after the introduction of home care management. Clotting factor replacement costs did not rise with the introduction of home care. There was a concurrent dramatic fall in absenteeism at school and work.

It is clear, therefore, that comprehensive care and the introduction of home care are cost-effective, with the additional positive financial impact on the cost to society of a potentially expensive lifelong chronic illness. However, as important as these financial benefits are, the impact of such services and the educational resources provided to those affected by the disease have immeasurable positive consequences on the quality of life for the affected patients and their families.

As hemophilia comprehensive care has evolved over the past decade, new definitions of provider roles have been created. The patient has been converted from a passive recipient to an active participant in medical care. The expanded role of nursing care has evolved to encompass expertise as a provider of primary hemophilia care and to function as a resource and patient advocate, interpreting medical information, treatments, and prognosis for the family unit. The traditional nursing skills of nurture and support have increased with new demands for the provider to act as a trusted professional and to triage the patient/family toward needed expertise in the

current AIDS era.

A major goal and focus of hemophilia comprehensive care is the education of the patient/family in the area of self- or parent-directed care, with the appropriate Center backup when the need arises. This emphasis on home health care has the objective of converting the patient or local care provider from a passive recipient of care to an active health care participant, who is fully knowledgeable about the bleeding disorder, its treatment, and especially the complications of this disease. This ideal form of patient-directed care can be maintained only by open, ongoing communication with the Center, without unnecessary controls and interference from the health care team.

HOW DO I TALK TO MY DOCTOR? HIV Frontline Jan./Feb. 1993 #11 pg. 7

This article is applicable to everyone who is seeking treatment from a health professional. Good medical treatment requires a partnership between the person receiving treatment and the person providing the treatment. Only *you* know what your symptoms are, what types of treatment you can reasonably do at home, and the side effects you may be experiencing from medication. If the health care professional doesn't know what type of information you want or need, s/he may not provide it to you. In order to give you the best medical/psychosocial treatment possible, your health care team needs *you* to be a part of that team effort. Speak up!

As a person dealing with illness, how do I talk to my doctor?

Lisa Capadini (a physician in San Francisco): The most important thing for the patient is to find a doctor with a similar communication style. Some patients like to see a doctor who deals with them in a direct way. Other patients might feel as though they are not being heard. (Note from Heather: Alternatively, if your doctor is not communicating with you in a way you like, *tell him/her* what you would like.)

To shop for a doctor is the first thing, but once in, you must prioritize your concerns and give feedback. The key is to figure out what you need and then to ask for it. A good doctor will ask, "Do you have any other questions? Does this make sense to you?" Sometimes the doctor is caught up with how hungry or tired he or she is and may neglect to ask for feedback. It is important for people to write down what they want to cover during their visit. If you get vibes from your doctor that s/he is in a rush, begin by saying, "I have a bunch of things I want to talk about, and three I want to discuss today. Should I tell you what they all are, or start with these three?"

When you think your doctor isn't giving you enough information, you can ask for a referral. It may be an issue of speciality, and a good doctor will not be threatened. However, in some HMOs (health maintenance organizations) and PPOs (preferred provider organizations), the doctors may be under the gun not to refer. The home care nurse or the social worker can become an advocate for you with the doctor. Finally, in multi-practitioner offices, if on the next visit you are not going to see your main practitioner, then you need to know who will follow up.

In terms of phone conversations, if I get a message that says, "This is John Smith and I have had a fever for two days," I don't know what to do with it. It helps me a lot more to get the message, "This is John Smith, I have had a fever for two days; I feel fine otherwise. Should I do anything or, if not, how long should I go with it until you want to see me or send me for some tests?" If a simple informational answer is adequate, if one asks the question very specifically of the staff and the staff gets the question to the doctor, the answer comes back faster and clearer.

It is helpful to write down the names of your medications and keep the list in your wallet. No one can remember all of these unfamiliar names and our charts may not be up-to-date. If you are really concerned that something is urgent, you have to make your sense of urgency clear to the staff. You could say, "Could you let me know within an hour whether I should go to the ER or just relax?"

Sometimes you don't need to involve the physician. For example, you could call the office and say, "I was too sick to make my trip. Could you write me a letter to the airline that says "X" and send it to "Y"?" With disability forms I appreciate it if people fill out everything they can, even medications, before they hand it to me. When you minimize the work of the doctor or the doctor's staff, things happen faster. For some doctors or their offices this would be seen as arrogance. One strategy is to say, "I need to have this filled out by tomorrow. I can do it or you can do it, your choice. What can we do?"

RADIOACTIVE SYNOVECTOMY Curtis Gruel M.D.

I attended a conference on radioactive synovectomy for the treatment of hemophilic arthropathy (joint problems) at Orthopædic Hospital in Los Angeles on August 21st of this year, and would like to summarize for you some of the information I was able to glean from this meeting. I will also give you my impressions on the potential role for this therapeutic treatment in our hands.

The technique of radionuclide synovectomy involves the injection of radioactive material into the joint to dissolve or shrink its lining (the synovium). It has been used for about twenty years in France, largely for the treatment of rheumatoid synovitis (joint inflammation), but also for hemophilia. There are centers in Buenos Aires, Argentina and in Caracas, Venezuela who have been using this for hemophilia for about ten years. Most of the North American experience comes from James Luck in Los Angeles and Georges Rivard in Montréal. Federico Fernandez Palazzi from Caracas, and Drs. Luck and Rivard all attended this conference and reviewed their experience to date.

There seemed to be universal agreement on several points. First, the therapy is indicated for target joints, repeated bleeders. Also, it was generally agreed that it is very desirable to treat the joint relatively early in the disease process, before loss of motion and joint-destructive changes occurred. Most people agreed that failure of medical treatment, such as prophylactic factor administration, would be an indication. However, there is certainly no consensus regarding who should have the treatment. On one extreme was Dr. Rivard, who believed that it should not be used in anyone under the age of twelve, because of the unknown risk of oncogenesis (cancer development). The other extreme was Dr. Palazzi, who felt that three bleeds in a six month period was a sufficient indication, and that there should be no lower age limit. He felt that the development of a chronic synovitis should "compel" one to do it, and that the procedure was most useful when used in this "preventive" fashion. He stated that he would not use it in late joints, and thought that they were best treated with intermittent steroid injections. Dr. Jerome Weidel from Denver said that they often will place patients on prophylactic factor replacement therapy for years at a time if they are felt to be poor surgical candidates for one reason or another. Dr. Luck said that he used the procedure for recurrent or chronic hemarthrosis (joint bleeding) with no specific frequency, failure of medical treatment, and early to moderate arthropathy. Most people seemed to agree with this last point, in that the results from all types of treatment are better if rendered prior to the development of significant joint changes. He also said to try to get to them before they start to lose motion and develop muscle atrophy. The surgeons in attendance all agreed that this is true for surgical therapies, also.

This is one thing that I think we need to change in our approach. I am now convinced from what I have heard and from my own experience, that if we want to have a high degree of success in addressing the bleeding itself, we need to be getting to the joints earlier than has been my practice in recent years. I also thought it was interesting that they found that even years of treatment with prophylactic factor did not succeed in resolving significant synovial hypertrophy (enlargement). They concluded that longterm prophylaxis in this circumstance was only useful as a delaying measure.

Drs. Luck, Palazzi, and Rivard presented their experience with radioactive synovectomies in 170 patients, totaling over 230 joints treated. The vast majority of people thought the procedure had been helpful—reducing the frequency of bleeding, and improving range of motion, endurance and quality of life. Sometimes a second treatment was needed, particularly if the synovium was very thick. Inhibitor patients appeared to have a slightly lower success rate.

One of the chief concerns about radionuclide synovectomy is the risk of cancer development. Although the true risks are unknown, there has been some work and experience in this area. Radionuclide synovectomies have been done in Europe for about two decades, largely for rheumatoid arthritis, comprising approximately 4000 cases. To the knowledge of the participants of this course, there have been only two tumors which might be related to the treatment in these patients.

Dr. Palazzi reported doing followup chromosome studies in his patients after radionuclide synovectomy. After Au(198) treatments, he found a 13-17% incidence of chromosome breakage, and some premalignant lesions in the early years following treatment. These changes were no

longer present a few years after treatment. He stated that these changes are similar to those seen with viruses and after non-steroidal anti-inflammatory drugs. He later switched to renium. With it he found a lower incidence of chromosome breakage and no premalignant changes. Dr. Rivard reported his experience using ³²P chromic phosphate. He found chromosome breakage in 7-18% (mean 12.5 %). Ten of the eleven were associated with HIV positivity.

Radionuclide synovectomy is a new treatment for hemophilic arthropathy with basically the same indications as surgical synovectomy. It has a much lower cost and morbidity than surgery. However, its effectiveness is still in question and is probably not as good as surgery. It has very little attendant risk, except for the imputed risk of carcinogenesis. The true magnitude of this risk is unknown, but it is probably quite small. This is potentially a very valuable adjunct in the treatment of this condition, but its role is still undecided. It is obviously of great interest in the treatment of patients with inhibitors, because of the tremendous risk of bleeding with surgical treatment. It is also of interest in the treatment of patients who are HIV positive, because the exposure risk to health care workers is lessened, and the oncogenic risk to this group of patients is less disturbing, because of their uncertain prognosis for longterm survival in any case. It is most successful if done early, before loss of motion, muscle atrophy, and joint destructive changes ensue. It is worth considering in a joint in which loss of motion would be very detrimental, because the risk of lost motion may be less than with open surgery.

LEGAL SERVICES OFFERED TO PERSONS LIVING WITH HIV Don Bell

At last, free legal assistance is available to the HIV positive thanks to the Young Lawyers Division of the AIDS Legal Resource Project, headed by Darlene Shadid. This group, sponsored by the Oklahoma Bar Association, will handle creditor problems, bankruptcy, estate planning, family issues, state and federal entitlement law, insurance, and discrimination issues in employment, housing, education, transportation, and medical care. Lawyers will not be paid in this program, even if they gain a monetary settlement. Shadid expects few cases to actually end up in court, as "people aren't going to be helped by litigation that will take five years."

A booklet has been prepared by the group, entitled *AIDS and the Law: Knowing Your Legal Rights In Oklahoma*. "If you are HIV positive or have AIDS, you are likely to be facing a wide range of concerns involving legal issues", according to Shadid. "This brochure is intended to provide you with information regarding a number of those issues. It is not designed to provide legal advice about your particular case."

The booklet includes chapters on estate planning, public assistance benefits, medical assistance benefits, insurance, debt management, discrimination, anonymity and confidentiality of HIV test results, and a directory of services and organizations. If you have need for the services of this organization, or would like to obtain a copy of the booklet, please contact me at the OHF office, or Darlene Shadid at (405) 524-4611. Please, if you *are* living with HIV/AIDS, at least avail yourself of these services to prepare a will or other estate plans, and an advance directive or 'living will'. The group does operate on low income eligibility.

SPECIAL ASSISTANCE CAMPAIGN Heather Huszti

Negotiations with Pharmaceutical Companies: At the annual National Hemophilia Foundation (NHF) meeting in October, the Special Assistance Campaign (SAC) negotiating team reported to the community on their progress to date. As you may remember, SAC's purpose is to obtain a settlement, or special assistance, from pharmaceutical companies that manufactured factor concentrate in the early 1980's, for persons who have been affected by hemophilia and HIV and their family members. NHF appointed a negotiating team, mostly consisting of persons who have been affected by hemophilia and HIV, which began the process about a year ago. Prior to the annual meeting, three companies, Baxter International, Armour Pharmaceutical Company, and Alpha Therapeutic Corp., made an initial offer which amounted to about \$21,000 to \$40,000 per individual or family member and a pool of free factor. Several conditions were attached to this offer, including getting 95% of all affected persons to agree to the settlement by June 1994. Miles, Inc. declined to be a part of this offer, stating that the conditions were too stringent. The SAC team

recommended that the NHF Board decline this offer, but continue to negotiate. The SAC negotiating team felt that the companies would make a higher offer and lessen some of the conditions attached to the offer. The SAC team asked that the companies respond with another offer in 3 days. The companies did respond, but stated that due to the lawsuit that was filed one day after the initial offer (see below), they could not make a quick response. At the NHF Board meeting on Wednesday, October 6, the board voted to continue the SAC negotiating process for now.

Class Action Lawsuit: The day after the first offer was made, a group of individuals, some of whom had participated in the negotiating process, filed a class action lawsuit against four pharmaceutical companies (Baxter, Armour, Miles, and Alpha) and NHF. The lawsuit alleges all of the parties knew the factor spread HIV and gave inaccurate information about the safety of factor in the early 1980's. One of the lawyers who filed this lawsuit spoke at a special session sponsored by the Committee of Ten Thousand (COTT) at the annual meeting. She stated that a class action lawsuit means that the individuals named in the suit have filed this lawsuit on behalf of all persons affected by hemophilia and HIV. At some point you may receive a letter or see a notice in the paper asking persons affected by hemophilia and HIV if you want to be a part of this class action suit. If you do *not* want to be a part of the lawsuit, you must write to the team of lawyers and tell them so, otherwise you will automatically be included. The lawsuit asks for compensatory (money to compensate you for damages done to you) and punitive damages (money that a company or individual pays as a punishment for wrongdoing). The filing of this lawsuit has some implications for the hemophilia community. Because the NHF was named in the lawsuit, the SAC process may not be able to continue (because both parties are involved in a lawsuit). Additionally, because of the lawsuit NHF may not be able to freely release information about its activities or provide past records to the community.

Lawsuits—Pros and Cons: You may have received information in the past about filing lawsuits against pharmaceutical companies. Certainly lawsuits have advantages and disadvantages. Settlements in lawsuits may be larger than settlements gained in negotiations. Courts can demand that documents (such as memos, etc.) be given to the court. Sometimes courts can find out who, if anyone, was at fault in a given situation. Lawsuits also have disadvantages. They can take a long time to settle and even if the pharmaceutical companies lost, they can file appeals and drag the process out for some time. In addition, lawyers, who file the lawsuits and try the case in court, typically take 30% to 50% plus expenses off of the top of any award made (so the court has to make an award that is twice whatever the SAC negotiating team can get from the companies for you to come out even). No one can decide what is the best option for you, except you. Some people think a lawsuit is the best way to receive compensation, others think the negotiating process will work best.

If you have questions about your legal rights, please contact your personal attorney. If you do not have an attorney, please contact the OHF at the number on the front page, the OHTC at (405) 271-3661 or 1-800-688-5288, or the AIDS Legal Resource Project mentioned in the previous article. If you have questions about the lawsuit or SAC, please feel free to contact Heather at the OHTC or the OHF.

SPECIAL ASSISTANCE LEGISLATION Heather Huszti

At the annual NHF meeting a new national campaign was presented in a special town meeting. The new campaign was called "Special Assistance Legislation." The national campaign is to develop a comprehensive health insurance and financial assistance package for individuals affected by hemophilia or hemophilia and HIV. This goal would be accomplished by passing a law that would establish four new programs.

1. Establish a program that would provide benefits for persons with hemophilia and HIV and survivors of those who have died of AIDS. Benefits would include: coverage under Medicare for factor without a waiting period, direct monthly cash payments with unrestricted use, and long-term care benefits not covered by Medicare.

2. Establish a trust fund. This would be funded through a per liter tax on all human/ animal blood collected for use on humans. The funds would be used to provide eligible individuals with a lump sum cash payment to cover certain expenses.

3. Make sure that any cash payments from the two funds above would not jeopardize an

individual's eligibility to receive other needs-based federal programs (food stamps, etc.).

4. Entitle all individuals with hemophilia, regardless of HIV status, to Medicare benefits, including payment for clotting factor, until health care reform entitles all persons to health insurance benefits.

Many people at the meeting expressed a great deal of support for the above program. The NHF emphasized that the above program could only be passed if everyone with hemophilia, hemophilia treatment centers, and chapters support the plan. However, supporting the plan means more than just saying you like it. It means writing letters or making phone calls to your U.S. Senators and Representatives. It may mean meeting in person with your Congressmen when they come to Oklahoma, to tell them about your experiences with hemophilia and/or HIV. Persons with hemophilia and their family members are the most important part of this process. Congressmen and Senators are most affected by your personal experiences. Chapter or treatment center personnel don't have the same impact as you do. In addition, people or organizations receiving federal funds (like your treatment center staff) cannot lobby for any particular legislation.

So if you're interested, what can you do? Send your name and address to the National Hemophilia Foundation, Congressional Outreach Program, 110 Greene St., Suite 303, New York NY 10012. The NHF will contact you directly and let you know what you can do to help. In addition, let them know if you know or have met with any of your representatives, senators, or their staff members.

WORDS FROM WONN Debbie Klein WONN Coordinator

Often, it's hard to share with other people the hopes, dreams, secrets, and fears we carry inside us. We're afraid of what people may think, do, or say. We don't want to be hurt, criticized, pitied, or laughed at. We guard our secrets carefully for fear they may be used against us.

Within the hemophilia community, we have a 'loaded' secret—loaded in that it could be used against us in many ways, from social ostracism to denial of insurance coverage, etc. It's also loaded for us individually. It can be emotionally overwhelming to carry the pain of that secret alone. Some of us have a small number of family or friends we can share with to a point. For many, that part of our lives is hidden, covered up, not spoken about, or glossed over. Few of us speak freely about the real world we live in, our feelings, fears, or hopes.

We are lucky within our hemophilia community, that our hemophilia chapter and treatment center offer so many programs that allow us the chance to meet others who are in the same situation we are. ~~What a relief it has been for me to talk with another hemophilia family member and discover my problems are not so unique. Someone else really does understand, because she is going through it too. Sharing our secrets relieves some of the pressure and sometimes I've found renewed hope along the way.~~

It's hard to always be on your guard, watching what you do, what you say, and to whom. It's comforting to know I don't have to do that with my hemophilia friends. My phone number is (405) 670-2589.

THE ART OF CAREGIVING Mel Pohl

from *The Caregiver's Journey: When You Love Someone With AIDS*—reprint from WONN Word

The art of caregiving is the art of interdependence. It's a delicate, often precarious balance: being involved and keeping perspectives; caring and yet being objective; spending time together and taking time to be alone; giving of ourselves and setting limits. One one hand, caregiving means being open, positive, and available. It means increasing our confidence by learning about the disease and acting on that knowledge. On the other hand, caregiving means admitting we don't always have the answers or know what to do. It means admitting our fears, taking time for ourselves, and getting help when we need it.

In doing these things, we give ourselves an empowering gift: freedom from perfection. As caregivers, we will take many actions to help the people we love. At times, what we do may hurt others and ourselves—even if we act with good intentions. And some of our actions truly *will* help. They will soften us, heal us, and help us forgive. This is all part of our journey. Some of our words

and deeds will hit the mark; others will fall short. That's okay. Caregiving means balancing opposites, and the line between them is never sharp and straight. Our path through the stages of caregiving will be full of curves. We may collide with obstacles and wonder how to proceed. We'll come to full stops, try detours, and even retrace our steps. No one can be a perfect caregiver every hour, every day. We need not ask this of ourselves.

From Debbie: Who is this caregiver? You are. It's important to understand that the OHTC staff, home care providers, mothers, fathers, wives, other family members, and the hemophiliac themselves are all caregivers. We all are doing our best in a common cause and if we try to remember the other caregivers on our team are trying their best too, maybe we will achieve the best possible balance.

OKLAHOMA REPRESENTED AT NHF MEET IN INDIANAPOLIS Don Bell

With the sponsorship of Quantum, Armour, and Caremark, the OHF was able to send a contingent of consumers and Board members to the National NHF Convention held the first week of October. Kathy Wray, Lynson Autry, Tom Duncan, Mike Klein, and Pat Nelson attended the event, representing the OHF (the Oklahoma Chapter of the NHF).

Participants attended scientific, medical and educational programs, as well as chapter development programs. The MANN and WONN programs held special sessions, and there were NHF business meetings which were attended. Much discussion at this year's meeting developed around the report of the Special Assistance Committee activities and the class action lawsuit against the four manufacturers of blood products and the NHF (see page 9 for more information.). Further developments on these activities will be sent as they develop. If you need a packet of information, contact the OHF office.

PHOTOGRAPHY PROJECT FOR HIV+ TEENS From The NHF

Positive Light is a photography project for teenagers living with HIV/AIDS. It has been organized by Cathy Cornell, a social worker formerly at the Boston Hemophilia Center, and Barbara O'Brien, an arts administrator with an MFA in photography. The goals of the project are to give HIV+ teenagers a way to express something about what it's like to be growing up with HIV, and to humanize this epidemic, which continues to be surrounded by so much misunderstanding and prejudice. An exhibit of some of the photos from the project has already been held at Boston City Hall, Milton Academy (a school in Milton, Massachusetts), and at Children's Hospital in Boston. Beginning in September, the exhibit will travel to various health care settings, conferences and schools where it will be a part of AIDS education and prevention programs.

Any HIV+ teenager (ages 12-20) who is interested can receive a ready-to-use camera and take photographs that express something about his or her life and living with HIV. You can participate anonymously, and your confidentiality will be protected. *Positive Light* will develop the film and return the prints to you. You then choose several photographs to be enlarged and framed to become part of the exhibit entitled *Positive Light*. With each photograph, you may also write a title or a paragraph that further explains the picture.

We know that there is still a lot of misunderstanding about HIV/AIDS and unfair discrimination against people who are infected. Many people do not want to disclose their diagnosis. For this reason, the photographs for *Positive Light* are exhibited anonymously, unless a participant wants to use his or her name. Pseudonyms can be used. We want to make it possible for kids to participate without worrying about being identified. If you decide to participate, you will also need to consider the content of your photographs and be sure that they do not reveal more than you want.

Some teenagers have done this project with their families and decided together what to photograph. Other kids have participated through their support groups, where they exchanged ideas. Others have worked on it alone. We encourage you to approach it in your own way, and to have fun thinking about what you might photograph, and what you might want to say through the photographs. If you are interested in knowing more about *Positive Light*, please call Cathy Cornell at (617) 239-3368 or Barbara O'Brien at (617) 738-5227.

OHF COOKBOOK FUNDRAISER Debbie Klein

I want to thank all the OHF members who have contributed recipes for this fundraiser. We are well on our way to having a first-rate cookbook! But we still need *your* help. If you have not contributed a recipe yet, now is the time to do it! The company that will print our cookbooks offer a guarantee on the second half of the cost of the books. This guarantee is based on how many people contribute recipes. The more members we have contributing, the more cookbooks we can order that will be covered by the guarantee. Every person counts this time. Even if you just send one recipe—it's important!

The recipes do not have to be original creations. If Aunt Martha's fried chicken is one of your favorites, ask her for her recipe. We need our young people to contribute too. If you make a wicked peanut-butter-and-jelly sandwich, an awesome afternoon snack, or a gourmet masterpiece—send us your recipe! We need to hear from you men also. So what if you're not the frugal gourmet; most of you guys probably have barbecue recipes, secret chili recipes, or maybe just a few survival recipes for when the wife's away. Maybe *you're* the cook of the family—so take a few minutes and jot down your favorite dish and mail it in!

This is a fundraiser you don't even have to leave your house to participate in. You can help the OHF by simply sending in your recipes. The address is on the front page.

ONE WHO CARED Don Bell

During the past year and a half since I became involved with the OHF, I have heard persons living with hemophilia/HIV/AIDS, Board members, and even health care providers say that the public will not understand about an individual's HIV status and so should not disclose their condition. One family member told me "I do not want my son's hemophilia known because people will assume he also has AIDS." Another couple told me they do not even want her parents to know.

I have often thought how sad it is that, whether one has a particular viral infection or not, it should limit their contact with others who might support them. The saddest moment I recall since being here was when Dorecia Tepe told me that, after their very public disclosure of Philip's condition, several of her friends came to her and said they had stayed away from the Tepe family simply because they knew about his condition, but knew that the family was not comfortable discussing it. They wanted to support them, but were afraid they might be interfering. Equally sad was the lack of support our teens report receiving because they could not share their condition due to fear of discrimination.

I do not intend to support disclosure here; it is something that must be done on a very individual basis. However, when we as a family are not open in discussing this viral condition, we foster fear within the population. Most importantly, we underestimate the power of education in removing prejudice, and the ability to care that exists in so much of the public.

I want to share the following example of one who cared deeply, because of a simple class assignment. Last spring the OHF received a call from a young high school student, Jennifer Ott, about a paper she was going to write about AIDS. Jennifer wanted "all the information" available on the subject, so we sent her the usual packet (many such requests came in after our display at the teacher's convention last year). Jennifer read every piece of information available to her and called for more. She received more materials from the OHF, HANDI and other local sources.

Jennifer put together an A+ paper entitled "Hemophiliacs with AIDS" (a copy is available from the OHF office upon request) and became an advocate for care of persons with hemophilia/AIDS. She was an outstanding student and cheerleader, and maintained a 3.92 grade point average which included six honor classes. She was a member of the International Club, French Club, Fellowship of Christian Athletes, Students Against Drunk Drivers, the United States Achievement Academy, and was the Secretary of the National Honor Society. In the past, she was the Vice President of the Sophomore Class, played clarinet for the Bixby band, and was active in gymnastics. She worked with children and participated in the youth ministry at her church.

Jennifer died recently of complications of a childhood heart condition after being involved in an auto accident. Because of her involvement and dedication to improving the lives of persons with hemophilia/AIDS, her family requested memorials be made to the OHF in her name. We lost an

advocate, we lost a friend that worked on our behalf, and we hardly knew that such love and care existed. The following is an adaptation of a poem that Jennifer noticed, and saved, from a newspaper several months ago. The only changes the family made were the substitution of her name and the insertion of the word 'sister' in place of the word 'son'.

Until you've lost a loved one
 Words cannot explain
 The grief, the hurt, the heartache
 The total ache of pain
 No one heard the footsteps of
 Angels growing near
 That took from earth to heaven
 The daughter and sister we loved so dear
 An eighteenth birthday
 A graduation day
 Were days never meant to be
 Only treasured memories of the
 Years you shared with us
 The tears in our eyes
 We can wipe away
 The aches in our hearts will always stay
 Not just today but every day
 We remember our Jennifer with love

ACCESS PROGRAM Genny Goodley OHF Member/Quantum Representative

For any OHF members who may be experiencing problems regarding reimbursement issues, Quantum Health Resources has a program available that may help. Advocating for Chronic Conditions, Entitlements and Social Services (ACCESS) was developed by Rachel Warner, whose husband is a severe hemophiliac, whose daughter is a carrier, and whose family is in their sixth generation of hemophilia experience. She has been president of the Florida Hemophilia Foundation and is an active lobbyist for health care issues, devoting the last four years to finding resolutions for social and economic issues surrounding chronic, genetic disorders. The ACCESS program was created to help families cope, and receive the assistance to which they are entitled. An ACCESS booklet collects several pamphlets on subjects such as: insurance, high risk pools, and COBRA benefits; tips on applying for, and understanding the issues involved with, Supplemental Security Income and Social Security Disability; work incentives for the disabled; and general information on the ACCESS program itself. It is available through the local Quantum branch; if you would like to receive a copy, call me at 942-3961, or you can call the ACCESS program directly at 1-800-999-5433.

THE BODY Bill Glover OHF Board Member

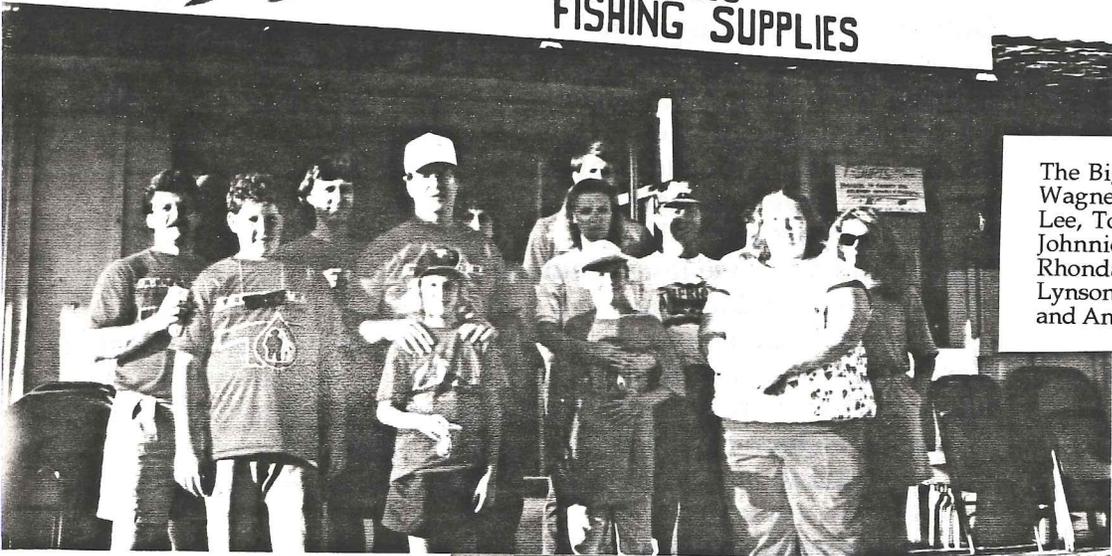
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L O N N X Y U E L P M E T G	Coccyx	Planta	Vein
E T A N I G Y N E L R S B N	Colon	Pupils	Vertebrae
H A T R P P O E U T I Z H O	Esophagus	Ribs	Vomer
R L N U H L S C N L B X C T	Fontanel	Scapula	Xiphoid
R L O T O L I K E D S F A R	Hallux	Spine	
E U F C I T R T T I I Z M A	Heart	Stomach	
M S Y P D L I S N O T K O E	Helix	Tallus	
O X U V E R T E B R A E T H	Intestine	Teeth	
V P V S M C O C C Y X L S T	Iris	Temple	
E E U S A E S O P H A G U S	Kidney	Thyroid	
I Q L U I N T E S T I N E J	Lunula	Tongue	
N O A N A T I S C A P U L A	Nasus	Tonsil	



BARMAC

Wholesale
FISHING SUPPLIES

The Fishing Tournament

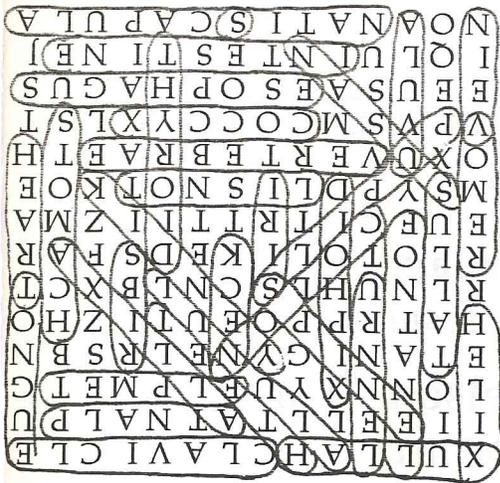


The Big Group Shot: Brian Wagner, Jason Smith, Mike Lee, Tom & Emily Duncan, Johnnie Smith, Pat Nelson, Rhonda & Nathan Manion, Lynson Autry, Debbie Klein, and Annie Petrikat

Brian, Lynson, Pat, & Doug McClain filet the catches of the day, while Jason dumps off a bucketfull of fish



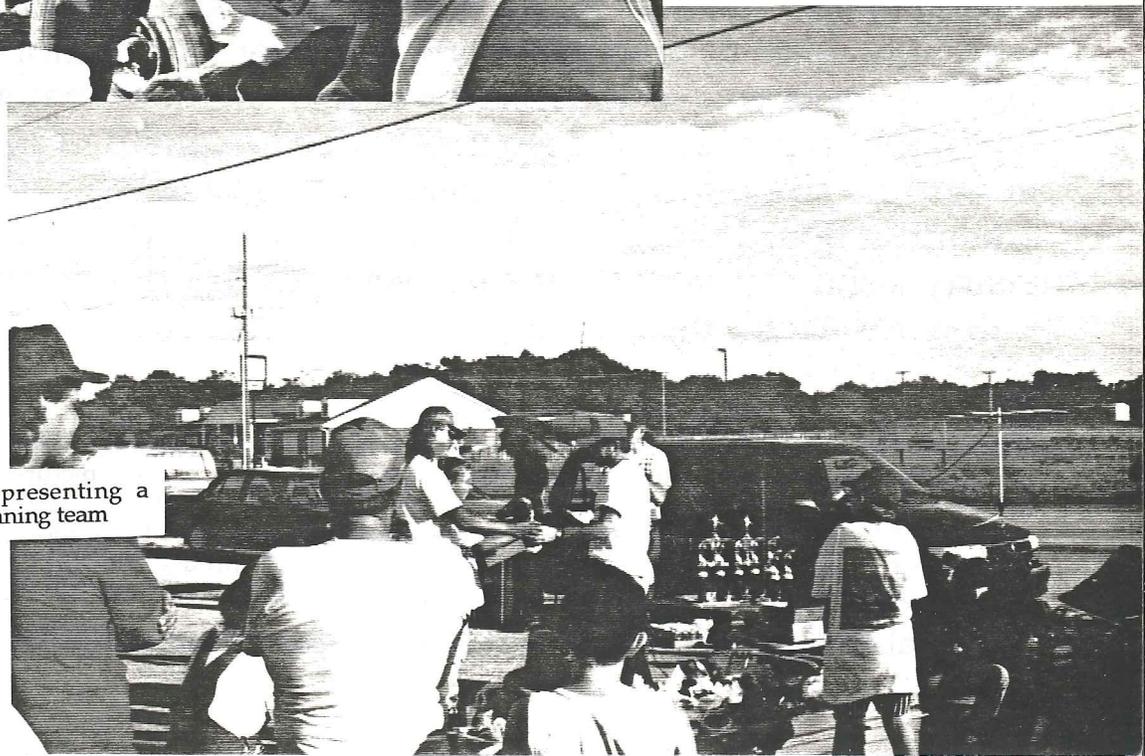
Emily watches while Dalla and Genny weigh in, and Tom directs traffic



Nathan and Emily valiantly try to sell OHF tshirts



Johnnie, Debbie Astleford, and Annie deboning away



Ted (center) presenting a trophy to a winning team

YOUR OKLAHOMA HEMOPHILIA FOUNDATION BOARD OF DIRECTORS

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HELP! From the Board

1. Can you help with poinsettia sales in your community? We will be talking orders for our poinsettia fundraiser as soon as possible, then delivering them before Christmas. We can all sell some to friends, coworkers, churches, businesses, etc.—or at least buy some ourselves to give as Christmas presents. Call Don at the OHF office number on the front page for order sheets and further information. 2. Do you have other fundraising ideas? Bake sales, auctions, local business, church or school groups who may want to help sponsor fundraisers for hemophilia services? Call Don. 3. Are you or a friend or family member experienced in accounting/bookkeeping? We desperately need a qualified person who is willing to lend us some time in reorganizing and keeping our books, as well as attending Board meetings. In addition, we need a CPA to audit our books yearly, who can volunteer their services or offer them at a reduced cost. Call who? That's right, Don!

Oklahoma Hemophilia Foundation News is published bimonthly for members of the OHF, patients with hemophilia or other bleeding disorders, providers, & friends. Letters, comments, articles, pictures, and suggestions are welcome; however, the OHF newsletter committee reserves the right to edit, delete, publish, and censor as necessary. Views expressed by individual authors should not necessarily be considered to be those of the OHF. The deadline for submissions is the last day of every odd month, & can be sent through the OHF, the Treatment Center, MANN/WONN Coordinators, or mailed directly to editor Mike Lee at 5757 W. Hefner Rd. #824, Oklahoma City OK 73162.

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