

March 1995

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OHF Welcomes New Executive Director



I'd like to take a moment to introduce myself to those of you whom I have not met. My name is Dana Cooksey, and I was hired by the OHF's Board of Directors in December as your new Executive Director. I have been involved with non-profit organizations for over four years, including past positions in fundraising with the American Red Cross, in public relations with BloodCare of Dallas and the Oklahoma Blood Institute, and special events with the Leukemia Society. I graduated from the University of Central Oklahoma with a Bachelor of Arts in Public Relations, and I also attended Oklahoma State University (Big 8 Tournament Champions 1995)!

After three months of planning, cleaning, planning, moving, planning, and meeting, I'm proud to say that the OHF has started 1995 with big goals, a fresh attitude, and new ideas. I've finally gotten settled in our new office in the Support Center (note the address and new phone numbers above), where we share space as well as resources and ideas with several other non-profit groups. Our calendar is chock full of events and new fundraisers, and our Board is raring to redouble the success the OHF has seen since its reorganization in 1991. You can take a look at our new budget on page 2.

My personal goals are to make sure that the needs of the hemophilia community are met through programs and services, and that sufficient funds are raised to carry these programs out. With the help of volunteers, the OHF is going to have a very busy and very successful year. I'd like to invite each and every one of you to join in the new activities that will be taking place in the course of 1995. Look at the Calendar of Events on the back page, and start planning to attend. I look forward to meeting you; please drop by the new office or give me a call when you have a moment!

OKLAHOMA HEMOPHILIA FOUNDATION PROPOSED BUDGET AND EXPENDITURES 1995

Expenses		Projected Income	
Youth Peer Program	\$ 5000	Youth Peer Program	\$ 3333
WONN Program	3300	WONN Program	3333
MANN Program	3300	MANN Program	3333
Office	3000	AIDS Walk Grant	3800
Camp	10000	Tulsa Garage Sale	500
Visitation/Bereavement	2500	Oklahoma City Garage Sale	400
Benevolence Fund	500	Poinsettia Fundraiser	1750
Training	1000	Golf Tournament	2000
Newsletter	2250	Fishing Tournament	3100
Rent	900	Membership Campaign	1000
Travel	4500	Combined Federal Campaign	500
Financial Assistance	3000	Plasma Alliance Fundraising	7500
Hospital Bill Assistance	2000	Bean Sale	300
Awards	500	Cookbook/Calendar Sales	200
Miscellaneous Fund	2000	Major Fundraisers (Celebrity Event)	4000
Seed Money (Startup)	500	Direct Mail Campaigns	1500
Telephone	4000	Financial Audit Grant	1500
Financial Audit	1500	Staffing Grant	21000
Staff & Fringe Benefits	35000	TOTAL ESTIMATED INCOME	59099
TOTAL ESTIMATED EXPENDITURES \$85050		An additional \$27000 needs to be acquired through grant writing, major donor campaigns, memorial programs and fundraising actituies.	

HEALTH FORUM

Dana Cooksey

With the rapidly shifting climate of our healthcare system, all non-profit health care agencies such as the OHF share an obligation to ensure that patients are empowered with the knowledge of their rights, and that the healthcare system recognizes and acknowledges those rights. Changes occur every day which could affect those rights.

With this focus in mind, the OHF, in conjunction with Pfizer Pharmaceutical, hosted a Health Leaders Forum on March 1st, 1995, at the Clarion Hotel in Oklahoma City. Twenty-two persons from five area non-profit and health care agencies attended the luncheon to discuss topics such as quality safeguards, open process, disclosure and "Medicaid patients in a managed care environment".

Leigh Brown, J.D., Deputy Administrator for Health Policy and Planning for the Oklahoma Health Care Authority, spoke to the group regarding Oklahoma's health care plan, and Representative Calvin Anthony from Stillwater explained some of the bills currently in legislation that may have an effect on Oklahomans.

A second Health Leaders Forum to be held in Tulsa is being planned for early summer. If you have any questions or concerns you would like addressed at the next forum, please contact me at the OHF office (the numbers are on the front page).

I wish to thank everybody for their kind support and caring after the death of my husband Michael Klein. Your kind letters and support were truly appreciated by me and my family during this difficult time. You were all important and loved by Michael, and I know you will miss him as much as I will. Love and gratitude, Debbie Klein

The OHF will once again be participating in the Frontier City "89er Adventure Days" and the White Water Bay "Tropical Adventure Days" in Oklahoma City this year. The Frontier City activity will begin at 1 p.m. on April Oth while

activity will begin at 1 p.m. on April 9th, while we will begin at 10:30 a.m. on May 21st at White Water Bay. Tickets must be reserved by calling Dana at the OHF office (the numbers



are on the front page) before April 6th. The cost is \$3 each, and the

proceeds will go to help offset the cost of Camp Independence. Please bring a snack food or dessert to share in our OHF picnic

area. Drinks, paper plates, cups, etc. will be provided. Be sure to take this opportunity to bring the family to meet other OHF families, and make new friends. Financial help and transportation can be provided for all who wish to attend.

GOOD NEWS & BAD NEWS

Michael Lee OHF Secretary

The good news is that "The Ricky Ray Hemophilia Relief Fund Act of 1995" was introduced to the House of Representatives last month. It asks that, due to the federal government's failure to require the blood-products industry to take available precautions to prevent the spread of HIV, partial restitution be made to those who were infected. It calls for the establishment of a trust fund, from which the HIV-infected (or their survivors) may make claims upon, and receive \$125,000, either in a lump sum, or over a period of time. Upon acceptance, all claims against the United States due to the infection shall be considered satisfied. Monies received shall not be considered as income or resources for determining eligibilities for benefits such as Social Security, nor as income under the internal revenue laws.

Now it's your turn—you have to make sure all our Oklahoma Congressmen know about this Act, and know why they should vote in favor of it. A personal visit is best, but obviously not always possible. Phone calls and letters are the next best bet. Our Congressmen's addresses and phone numbers are listed below. 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. Don't wait—do it *now*, before it comes up for a vote. The longer it's on their minds, the better. Also, be sure to refer to the bill number: HR 1023. 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.

Then there's the bad news: the class action lawsuit against the pharmaceutical companies and the NHF has been decertified. The federal appeals court ruled in a 2-1 vote that the judge who certified the class action exceeded "the permissible bounds of discretion"—that the action would allow one jury to "hold the fate of an industry in the palm of its hand" and could "hurl the industry into bankruptcy". Lead attorney David Shrager said he would seek a rehearing before the full seven-member appeals court. Continuing updates on the lawsuit can also be obtained from the sources mentioned above.

Senator Don Nickles 133 Hart Washington DC 20510 (202) 224-5754

Senator Jim Inhofe 453 Russell Washington DC 20510 (202) 224-4721

Representative Steve Largent 410 Cannon Washington DC 20515 (202) 225-2211

Representative Tom Coburn 511 Cannon Washington DC 20515 (202) 225-2701 Representative Bill Brewster 1727 Longworth Washington DC 20515 (202) 225-4565

Representative J.C. Watts 1713 Longworth Washington DC 20515 (202) 225-6165

Representative Ernest Istook 119 Cannon Washington DC 20515 (202) 225-2132

Representative Frank Lucas 107 Cannon Washington DC 20515 (202) 225-5565

Benefit Garage Sale Set For Oklahoma City

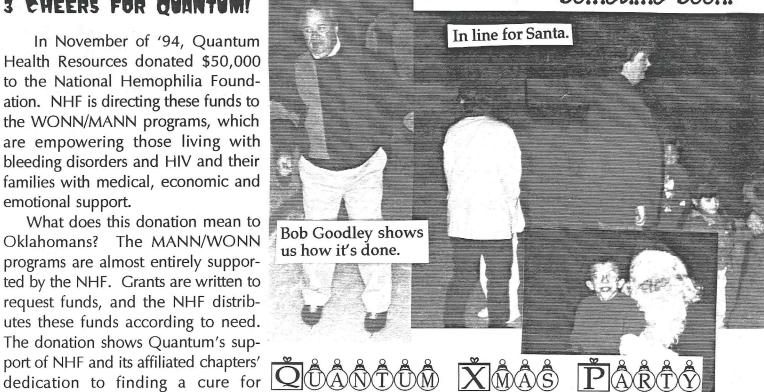
The OHF will again be participating in the annual "Largest Garage Sale In Oklahoma City", on April 1st at the State Fairgrounds' Made In Oklahoma building. Many other non-profit groups will be present, each in their own 10 x 25 foot booth, and all funds raised go to the groups, less a \$60 booth rental fee. So clean out your closets and attics quick, and call Dana at the OHF office (numbers on the front page) for further details and drop off times, or to make pickup arrangements, if necessary. Volunteers are also needed to work shifts in our booth. Meanwhile, thanks to our volunteers' and donators' efforts, we netted \$500 from the Tulsa garage sale last month! It's a Girl!

3 CHEERS FOR OWNTUM!

In November of '94, Quantum Health Resources donated \$50,000 to the National Hemophilia Foundation. NHF is directing these funds to the WONN/MANN programs, which are empowering those living with bleeding disorders and HIV and their families with medical, economic and emotional support.

What does this donation mean to Oklahomans? The MANN/WONN programs are almost entirely supported by the NHF. Grants are written to request funds, and the NHF distributes these funds according to need. The donation shows Quantum's support of NHF and its affiliated chapters' hemophilia and related disorders.

Congratulations to Armour Pharmaceutical's Brian Wagner and his wife Donna on the birth of Brianna Michelle on January 1st at 11 p.m. She weighed in at 6 pounds 10 ounces, and was 19 3/4 inches long. Everyone's happy and healthy, and Brian and Donna are looking forward to getting some sleep sometime soon!



OKLAHOWA HEWOPHILIA TREATWENT CENTER NEWS

by Sarah Hawk P.A.-C.

Liver Disease In Hemophilia The NHF sponsored this Atlanta conference March 3-5. It was attended by over 300 consumers and providers from

more than 10 countries. An overview of hepatitis:

Hepatitis A is completely unaffected by solvent—detergent: only high heat can kill it. People are most infectious for 2 weeks before they develop any symptoms or lab changes. A Hepatitis A vaccine will be available shortly and will probably become routine for persons with bleeding disorders. This is because Hepatitis A can be extremely severe in people who already have liver disease. Hepatitis B vaccine may cause one out of every eight people to develop antibodies to the core protein—this makes it seem like the person actually had hepatitis, not the vaccine. The person does not have Hepatitis B, cannot transmit Hepatitis B, and is still protected against Hepatitis B.

Hepatitis C will not have a vaccine available any time soon. There are many different strains (even in the same person) and it can mutate easily, thus avoiding detection. Interferon treatment may be less effect—ive in people with hemophilia because they usually have had the disease (and multiple virus types) for a long time. But it seems important to treat early to minimize liver damage since your liver will need to work properly for genetic treatment of hemophilia to be effective. There wasn't a clear answer on how early is early. Liver biopsy can have complications, but current blood tests don't give a good picture of liver

disease.

Hepatitis "X" (final name "E" or "F") is still being identified. It is transmitted by blood and generally does not cause jaundice. Twenty—five percent of cases will become chronic and it can cause persistent severe anemia. A panel discussed new infections to screen for, and different methods to test and treat blood products. Dr. Mannucci, of Milan, Italy, recommended that a final inactivation step occur after the factor concentrate is in the vial to treat any "human error".

Worst jokes heard at the conference — "I'm not bald. I'm a hair donor" and "Two cannibals were cooking a clown for dinner. One tested

the broth and said to the other "Something tastes funny to me."

More "How To Stay Healthy" Hints: Don't adopt pets under 6 months old. stray pets or pets from the animal shelter or crowded stores/breeding farms (cryptosporidiosis). Avoid cats under 6 months of age, and avoid rough play with cats which might encourage scratching (cat scratch fever, bartonella). Avoid moist bird/bat waste such as in chicken coops, farms, bird roosting sites, caves (histoplasmosis). Wash hands after handing animals, especially before eating. Reptiles are a particularly good source of salmonella. Wash hands after handling children: you never know where they've been or what they were doing!

Focus on: Warts and Moles Warts (verruca vulgaris) are caused by the human papillomavirus (HPV), of which over 40 types have been identified. Warts occur most frequently in children and young adults. They can develop on any skin surface, but are most common on the hands. Warts are spread by skin—to—skin contact and scratching. Plantar warts on the soles of your foot are flat because of the pressure of walking and standing. They bleed easily if trimmed. These are best treated by medicating the wart; surgery may hurt worse than the original problem.

In children, warts almost always disappear without any treatment. Twenty percent will go away in one month, and generally all are gone within 2-3 years. Small warts can be safely treated with over—the—counter preparations. Larger areas can be treated in a doctor's office with podophyllin, liquid nitrogen, cautery or laser treatments. These may cause very slight bleeding or a blood blister, but factor is rarely needed. Cutting on warts yourself may only spread them around or cause a local infection. Certain strains of HPV may be associated with squamous cell skin cancer. See a doctor if you have warts that are persistent, very large, or changing in color or texture. Genital warts require special treatment and screening for cervical changes.

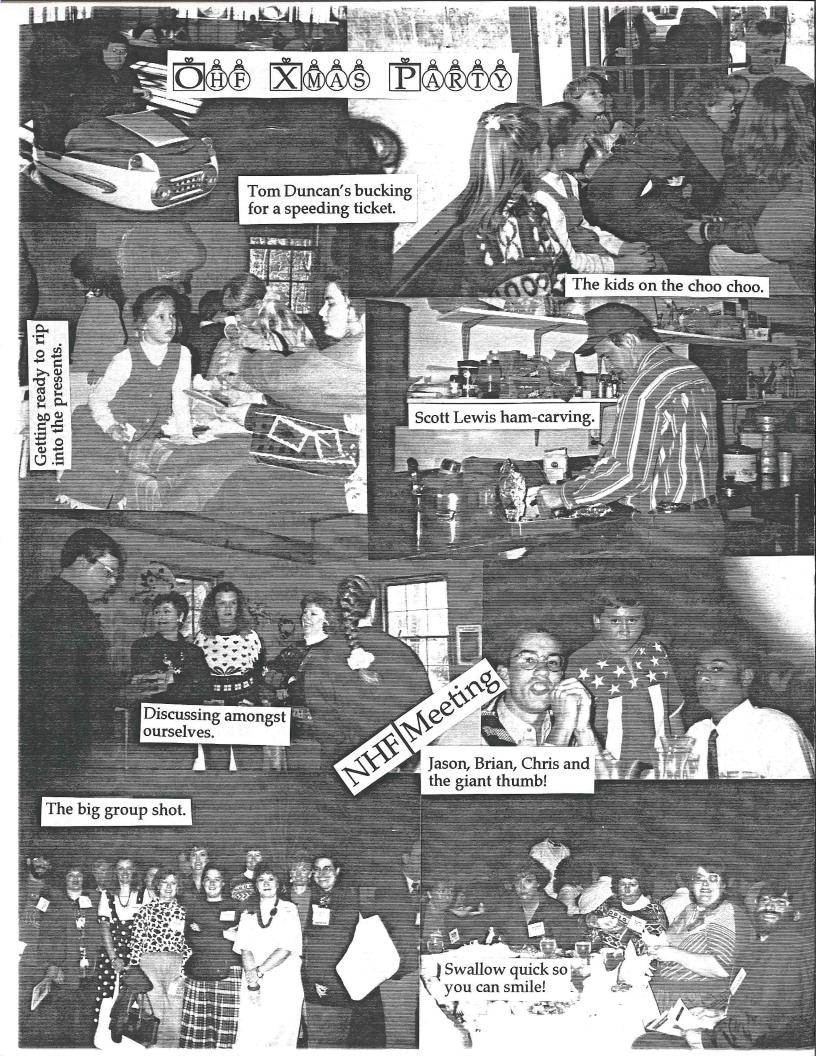
Moles (nevi) are small flat or raised areas of skin with extra brown pigment. They are usually smaller than a half inch and may be present at birth or develop later. The average adult has around 20 moles. The skin of moles is smooth and will bleed easily if scratched. Moles should not change in size or color. You should contact your doctor if you notice the skin becomes scaly, thickened or bleeds frequently. Moles are easily removed, but factor may be required, depending on the type of procedure.

Antifibrinolytics History: When your blood clots, fibrin is the last ingredient. It forms a mesh to hold the clot solidly together. Several days later, when the body "thinks" the injury should be healed, it sends out anti-fibrin enzymes to break down (lyse) the clot. If the injury is not completely healed, bleeding may occur.

Antifibrinolytics slow the breakdown of clots. There are two drugs available: Amicar (aminocaproic acid), which comes as an IV solution, syrup and tablets. It must be taken every 6 hours, with or without food. The most common side effect is nausea, but may also cause dizziness, headaches, or weakness. Cyklokapron (tranexamic acid) comes as an IV solution and tablets. It is taken every 6—8 hours. It uncommonly causes tiredness, dizziness, or temporary vision changes.

Antifibrinolytics are most commonly used for dental work and mouth bleeds. For dental work, the first dose is usually taken before the procedure and continued for up to 10 days afterwards. For mouth bleeds, the medicine must be taken for up to 10 days after the last episode of bleeding. Caution: Antifibrinolytics are never used for kidney bleeds or blood in the urine. Clots in the bladder or kidneys act like stones: they plug up the "plumbing" and can hurt "real bad".

Antifibrinolytics are not used at the same time with Factor IX Complex due to the risk of extra clotting throughout the body. If you have a Factor VIII inhibitor or Factor IX Deficiency, always talk to the Hemophilia Center about how and when to properly use these products.



As you might have noticed, the Women's Outreach Network of the NHF column was missing from the last newsletter. Due to my husband's illness and death, I have been unable to fulfill my WONN duties, and for this I truly apologize. Had I written a column, you would have heard all about the fun fall WONN workshop we had at the Embassy Suites in Oklahoma City. You would have read about the interesting stress-reduction lecture given by Dr. Vernon Enflow we enjoyed, as well as the good food, and fun we had watching Becky Lockler get a beauty makeover. I want to thank everyone who helped put on the workshop; especially Genny Goodley and Kathy Stone from Quantum Health Resources, whose help was priceless. One of the best things that happened there was the addition of Jenny Drubert to the WONN leadership. Jenny is the new Area Leader for the eastern part of the state. We want to welcome her to the position, and I know she will do a great job! She can be contacted at (918) 542-9855 after 6 p.m.

At the workshop we decided to have a slumber party in February. I didn't get it arranged in time, but I haven't forgotten; as soon as I get it all together, the details will be in a forthcoming flyer—so watch your mailbox!

On a more serious note, because of the changes in my life due to my husband's death, I regretfully have found that I cannot continue as your WONN Coordinator. So the OHF is looking for a woman to replace me. It is a volunteer position, requiring a minimum of 2-3 hours per week. position is open to any woman residing in Oklahoma who is a relative or significant other of a person with a bleeding disorder, or has a bleeding disorder herself. Duties will include assisting OHF staff with planning and implementing peer activities for OHF consumers, participating in OHF phone peer support, representing the OHF WONN group at regional and national meetings, and coordination of joint events with the OHF MANN group (Men's Advocacy Network of the NHF). Staff will always be available to assist you, and you will be provided with free training by me and through the NHF. If you think you may be interested in the position, or just want more information, please call Dana at the OHF (the numbers are on the front page). Until we find a new WONN Coordinator, I will continue to serve to the best of my abilities. ▞▞▞▞▞▞▞▞

Well, it's been quiet since our last MANN meeting in December, but we're now planning our next gathering for sometime in April. We'll be having dinner and are working on getting a speaker as well. Keep an eye on your mail for specific details coming soon. And let me mention yet again: 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. We can only help if you contact us—we need your input as to what your needs are, and what our future goals should be. Please feel free to contact me at (918) 486-3916.

NATIONAL HEMOPHILIA FOUNDATION

CONSUMER BILL OF RIGHTS AND RESPONSIBILITIES FOR HEALTHCARE SERVICES APPROVED BY THE NHF BOARD OF DIRECTORS JULY 6, 1994



Good healthcare involves teamwork between the health care provider and the consumer. This two-part bill should serve as a set of goals for both the provider and consumer in seeking, providing and receiving high quality health care within a setting of honesty and respect. This bill takes into account the importance of both consumer rights and responsibilities.

PART I: CONSUMER BILL OF RIGHTS

- I. THE RIGHT TO BE TREATED AT ALL TIMES WITH RESPECT AND COURTESY within a setting which provides the highest degree of privacy possible.
- II. THE RIGHT TO FREEDOM FROM DISCRIMINATION because of age, ethnicity, gender, disability, religion, sexual orientation, values and beliefs, marital status, medical condition or any other arbitrary criteria.
- III. THE RIGHT TO FULL ACCESS TO INFORMATION from the health-care provider about current FDA-approved or other proven treatments. Also, any biases or conflicts of interest that the health care provider may have should be disclosed. Consumers must be advised of the risks and benefits of any proposed treatment considered to be of an experimental nature. If needed, the health care provider should discuss alternative or complementary treatments and should be allowed to make recommendations.
- IV. THE RIGHT TO KNOW the identities, titles, specialties, and affiliations of the care coordinator and all health care providers. Also, consumers have the right to know about the health care center's and health care provider's rules and regulations.
- V. THE RIGHT TO HAVE INFORMATION SHARED IN A WAY WHICH IS EASY TO UNDERSTAND, taking into account differences in each consumer's background, culture, and preferences.
- VI. THE RIGHT TO BE INVOLVED IN AND MAKE DECISIONS ABOUT THE PLAN OF CARE prior to the start of and during the course of treatment. Consumers must have the right to rethink, question and change the treatment care plan at any time. Also, when possible, requests for transfer to another facility or health care provider or for a second opinion should be promptly honored and carried out.
- VII. THE RIGHT OF CHOICE AND ACCESS TO ALL NEEDED SERVICES including, but not confined to, referral for proper care, second opinions, physical therapy, drug trials, brand choices, home care services, counseling and peer support. Also, the consumer should not be denied, pressured, punished, or left unaware of services because they are not available or adequate from the consumer's usual health care provider or center. Third party payors should not be allowed to make treatment decisions on behalf of their consumers. These decisions must rest with the consumer and health care provider.
- VIII. THE RIGHT TO DECLINE TO FOLLOW treatment plans, trials, counseling or any other service, as allowed by law, based upon the consumer's judgment of risks and benefits and without pressure or unwanted influence from the health care provider.
- IX. THE RIGHT TO NAME AN ADVOCATE such as a family member or other person to support the consumer.
- X. THE RIGHT TO HAVE AN ADVANCE DIRECTIVE such as a living will, health care proxy or durable power of attorney for health care, and to have that directive followed within the context of existing law. Also, the consumer has a right to know, in a timely manner, any care center or health care provider rules or preferences which may stop consumer's directives.

- XI. THE RIGHT TO INSPECT AND RECEIVE AN EXPLANATION OF HEALTH CARE BILLS OR PROPOSED CHARGES, regardless of payment source, and to receive needed referrals and/or help with reimbursement problems.
- XII. THE RIGHT TO VOICE COMPLAINTS AND SUGGEST CHANGES and to be informed of the process to do that within the center's/health care provider's chain of command for problem resolution, without interference, pressure, or reprisal. Also, the consumer has a right to receive a response in a timely manner.
- XIII. THE RIGHT TO CONFIDENTIALITY AND ACCESS to all treatment records and communications to the consumer's case. Information on getting copies of records should be readily available. Copies of requested records must be furnished and at a fair cost, as allowed by law.
- XIV. THE RIGHT TO BE FREE FROM ALL TYPES OF CONSTRAINTS in all dealings with health care providers and treatment plans.
- XV. THE RIGHT TO ADEQUATE PAIN MANAGEMENT through the application of approved and alternative treatments.

PART II: CONSUMER BILL OF RESPONSIBILITIES

- I. HEALTH CARE PROVIDERS HAVE THE RIGHT TO BE TREATED AT ALL TIMES WITH RESPECT AND COURTESY.
- II. THE CONSUMER IS RESPONSIBLE FOR GIVING CORRECT AND COMPLETE INFORMATION TO THE CURRENT HEALTH CARE PROVIDER about his or her health status, and the use of other treatments, medications and health care providers. If on home care (infusion of concentrate, use of other products, etc.) patient should periodically submit a record of product use and bleeding episodes. Consumers should come prepared to appointments with a list of any questions and concerns, so that the health care providers can have the chance to address them.
- III. THE CONSUMER IS RESPONSIBLE FOR SEEKING THE FACTS AND ASKING QUESTIONS ABOUT THE RISKS, BENEFITS, AND FINANCIAL ASPECTS of a recommended procedure or course of treatment if he or she does not fully understand.
- IV. THE CONSUMER IS RESPONSIBLE FOR FOLLOWING THE AGREED-UPON TREATMENT PLAN. If the consumer is not following the agreed-upon treatment plan at any time, including when involved in a clinical trial, he or she needs to inform the health care provider of this.
- V. THE CONSUMER IS RESPONSIBLE FOR THE RESULTS IF HE OR SHE CHOOSES TO ACT AGAINST MEDICAL ADVICE or does not follow instructions of an agreed-upon treatment plan. The consumer should feel free to discuss his or her reasons for this choice.
- VI. THE CONSUMER IS RESPONSIBLE FOR KEEPING SCHEDULED APPOINTMENTS or canceling them in a reasonable time frame.
- VII. THE CONSUMER IS RESPONSIBLE FOR MAKING SURE THAT THE FINANCIAL BURDENS OF HIS OR HER CARE ARE ADEQUATELY ADDRESSED by giving correct information about payor sources, promptly submitting reimbursement forms or asking for help prior to receiving health care services.
- VIII. THE CONSUMER IS RESPONSIBLE FOR FOLLOWING RULES AND REGULATIONS of the health care providers and centers involved in their care.
- IX. THE CONSUMER IS RESPONSIBLE FOR BEING THOUGHTFUL OF THE RIGHTS, PROPERTY AND CONFIDENTIALITY OF OTHERS.
- X. THE CONSUMER IS RESPONSIBLE FOR VOICING COMPLAINTS AND ASKING FOR CHANGE in an appropriate and timely way, through the health care provider's/facility's chain of command.

OHF CALENDAR OF EVENTS

APRIL

Garage Sale - Fairgrounds Oklahoma City

Frontier City 89er Adventure Days Family Outing Oklahoma City

MAY

Second Annual "Score For Hemophilia" Golf Tournament Karsten Creek - Stillwater

White Water Bay **Tropical Adventure Family Outing** Oklahoma City

JUNE

17

OHF Annual Meeting/ Family Retreat Location TBA

24 Quantum Health Resources Picnic Oklahoma City Zoo

JULY

"Brown Bags/Casual Rags"

AUGUST

6 - 10

Camp Independence Guthrie

SEPTEMBER

23

Annual Fishing Tournament Ada

TBA

Young Women With Bleeding Disorders Retreat Oklahoma State University

OCTOBER

15

AIDS Walk Oklahoma City

TBA

Young Men With Bleeding Disorders Retreat Oklahoma State University

NOVEMBER

DECEMBER

Quantum Health Resources Christmas Party Iceland - Oklahoma City 16

> **OHF Christmas Party** Tulsa

JANUARY

Blood, 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, MANN/WONN Coordinators, the Hemophilia Treatment Center, or directly to the editor, Michael Lee, at 5757 W. Hefner Rd. #824. Oklahoma City OK 73162.

Special thanks to Quantum Neolth Resource for their sponsorship of this month's newsletter.