

OKLAHOMA HEMOPHILIA FOUNDATION NEWS

May 1994

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Young Women's and Men's Retreats Held

Don Bell OHF Administrative Assistant



The OHF, Hemophilia Treatment Center and Oklahoma State University's Farmhouse Fraternity hosted teen retreats for young women March 25-27th and for young men April 15-17th. The retreats were held just off OSU's campus at the Baptist Student Union; the programs were made possible by grants received from the National Hemophilia Foundation.

Featured speakers at the women's retreat were Renee Paper, R.N., program director of the Nevada Hemophilia Foundation and a charge nurse in the Emergency Department at St. Rose Dominican Hospital in Henderson Nevada, and Jill LaFon, Director of Project FIND (Friends IN Deed), and HIV/ AIDS Resource Specialist at South Central Community Mental Health Center in Bloomington Indiana. Renee and Jill, both women with bleeding disorders themselves, were able to share their first hand experiences and knowledge with our young women.

Debbie Klein, OHF WONN Coordinator, and Mary Bowman from the HTC served as leaders for the weekend, with a full complement of young women from Farmhouse Fraternity's Little Sisters program. Debbie was able to attend the entire weekend and spent much time answering questions or directing questions to Renee and Jill. The collegian women were able to participate on all levels with our teens and added an important component to the program. ➤

OHF teen men were privileged to participate in an AIDS Mastery program developed especially for the group and presented by Ed Kuebler and Monica Larson of the Northern Lights Program. The weekend was very pertinent to our group of young men who have been affected by the loss of so many of their friends to AIDS. Again, the collegiate component from Farmhouse Fraternity were able to share the experiences of our youth and provide a special camaraderie.

Highlights of both weekends included The Dating Game, where the collegians were asked questions about dating and relationship-building in a fun game-show format which proved to tackle very serious subjects with ease. Of course there was dinner at world famous Eskimo Joe's (this was major!) and a special pizza party at Hideaway Pizza—only the best pizza this side of Chicago! There were trips to the fraternities and sororities and visits to the dorms and other University facilities, as well as a picnic and carnival at Theta Pond. But most important: sharing sharing sharing!

Our Oklahoma women were joined by a group from Missouri, while our men welcomed back some of the Arkansan men who attended last year. The teens learned that they were not the only persons with hemophilia, von Willebrand's and/or HIV. They were presented information to assist them in dealing with their bleeding disorders and HIV/AIDS. They discussed and examined subjects common to teens such as self-esteem, relationship building and dating. A network between attendees, collegians and presenters was developed, and teens were introduced to a collegiate atmosphere. Most importantly, HIV issues including intervention techniques were examined; and, everyone had a great time!

FRONTIER CITY / WHITE WATER BAY 94

DON BELL

The OHF, HTC, and Camp Make Promises Happen again sponsored "Adventure Days" at both Frontier City and White Water Bay in Oklahoma City during the month of May. These important events brought together OHF families to spend time together talking, playing, and enjoying great entertainment and food (Nancy Baxter made those famous brownies, which alone made my day!)

This is the third year that the OHF has participated in the event, hosted by the management of Frontier City and White Water Bay as an opportunity to demonstrate their attention to special-needs groups and their willingness to provide an extra amount of care for persons who are either physically or mentally challenged. Gary Weeks, director of Camp Make Promises Happen (the Guthrie camp where our youth attend Camp Independence) put together the program and has done an excellent job of providing an important opportunity for us to get together. The OHF has used these activities to build membership from the twelve persons on our mailing list when I first came here to over 100 members now.

If you missed the events, you missed meeting some great people, networking with persons who share similar experiences, and an opportunity to develop important friendships. You also missed a great ride on the Wildcat, Lazy River, Renegade Rapids, Bermuda Triangle, Acapulco Cliff Dive, and the biggest, scariest ferris wheel you have ever seen! You also missed a savings of over \$15 per ticket to attend these attractions! It was great fun; be sure to plan to attend next year!

Regional Meeting On The Horizon

Rhonda Manion Regionals Committee Chair

It is rapidly approaching June and the NHF Region V meeting will be here soon. The planning committee has been working very hard to organize an educational and enjoyable time for everyone. We are hoping for a large turnout from Oklahoma. We have some excellent speakers lined up and we guarantee you will learn something new. Of course, we want to have fun, and the evening dinners and entertainment will be just that. Please make your reservations now. If you have any questions or would like to volunteer, call Don at the OHF office (the number is on the front page), Debbie Klein at (405) 670-2589, or myself collect: (918) 540-1768. Again, let me mention that the registration fee will be waived for all volunteers!

HBIEP Project Update

Brooke Gage M.Ed. /HBIEP Project Coordinator

The HBIEP Project (Hemophilia Behavioral Intervention Evaluation Project), or Sentinel project, is in full swing. We had our first weekend retreat in Dallas at the end of last month; participants came from Texas, Oklahoma, and Arkansas. It was a relaxing time and a great opportunity to build friendships. The focus of the weekend was on communication and its various components. Participants were taught effective skills to assist them with communicating their needs as well as getting those needs met. Our next retreat is scheduled for September 30th-October 1st. The location will be in Northeastern Oklahoma, so we can enjoy the fall foliage! We are still accepting questionnaires from individuals who have not yet enrolled in this project. You can contact me at (800) 688-5288 or (405) 271-3661.

Statewide HIV Conference in Lawton

Sarah Hawk P.A.-C

The Fifth Annual Statewide Oklahoma HIV/AIDS Conference will be held June 2nd-3rd at Cameron University, 2800 W. Gore Blvd. in Lawton. It is designed to help individuals, communities, businesses/industries and those challenged by HIV/AIDS to discover the importance of "Remembering Every Face". General registration fees are \$10 per person and \$5 per student; lodgings in the dormitory are available for \$6 per person per night. Workshop topics include "Advocacy and Policy", "Empowerment: People Living With AIDS, Family, Friends, Community", "Education and Prevention" and "Minority and Cultural Issues". Our own Dorecia Tepe will be keynote speaker; and on Wednesday June 1st, there will be a preconference play, "On Tidy Endings" at 8 p.m.—tickets are \$3. For more information call (405) 581-2284. And the program will conveniently be done in time for you to attend the Regionals in Oklahoma City Friday night!

SEPTIC JOINTS OR: THE ONLY REASON TO TAP A JOINT Sarah Hawk P.A.-C.

Infection that occurs inside a joint can cause swelling, warmth, redness, pain and bone damage. If not properly treated, an amputation or even death may result. An infection acts like a bleed, except that there will be persistent fever and pain despite proper factor replacement. An xray may not be able to distinguish between an infection and bleeding.

Joint infections generally occur in the ankle, knee or hip. It is usually spread to the joint from an infection or entry point somewhere else—dental work, infected hangnail, cut, etc. The tendon sheath over the knuckles is very easily infected by hand injuries which break the skin. IV antibiotics are required to keep the infection from spreading.

Bacteria that get into the bloodstream tend to get stuck in tiny blood vessels and on "foreign bodies" (artificial joints, central lines, pacemakers, etc.), heart valves, the ends of bones, and damaged tissue (like target joints). The way to diagnose an infection and find out which antibiotics to use requires fluid to be removed from the joint (a "tap") with a small needle. *You need factor before the tap.* Infected fluid may look like pus, filled with white blood cells trying to fight the infection.

The initial treatment is several weeks of IV antibiotics, then it may be possible to switch to oral medicines. Months of treatment may be required to clear the infection. If an artificial joint has become infected it may be necessary to remove the components.

To prevent joint infections, treat any infection in your body properly—take the *entire* course of antibiotics. If you stop taking the medicine as soon as you start feeling better, the stronger, more resistant bacteria can stay around and cause a tougher infection. People with heart problems, artificial joints, central lines and other "foreign bodies" will usually be placed on antibiotics before and after any procedures like major dental work, bronchoscopies, surgery, etc.

If you've had an infection and aren't getting better, or if new persistent joint pain occurs—call the doctor promptly.

DDAVP NASAL SPRAY Sarah Hawk

The high-concentrate spray has recently been approved for persons with von Willebrand's disease and mild Factor VIII deficiency that have previously been tested for their response to this treatment. DDAVP (desmopressin, Stimate) is a synthetic version of a natural pituitary hormone—vasopressin (ADH). It causes the temporary release of von Willebrand factor and an increase of Factor VIII levels. This spray should be refrigerated, but may be kept at room temperature for three weeks while traveling. It can only be used if the nose is clear; it is not for use in infants, by those with severely deviated septums, or during nosebleeds. DDAVP for subcutaneous injection and intravenous use will still be available. Like the other forms, DDAVP nasal spray may occasionally cause sleepiness, dizziness, itchy eyes, sun-sensitive eyes, insomnia, chills, warm flush or other side effects. This new product delivers 150 micrograms per spray and must not be confused with the standard spray which delivers only 10 micrograms. Call the HTC or your physician to find out whether this treatment might be right for you.

Social Workers Honored During March

One would never think that social services and social work would incorporate so much hard work and effort by a dedicated group of people. But social workers provide a multitude of services to patients and staff. To celebrate their contributions, March is designated as National Social Work Month.

"Social workers are a vital part of the health care team," said Deborah Durbin, M.S.W., director of Social Work at Children's Hospital. Durbin works with 18 social workers who provide service for both Children's and the Child Study Center. Each of the nine social workers for University Hospital carries a patient load of about 100 each month, and

is assigned to work with high-risk

mothers, renal patients, HIV patients, and many others, said Ruth Tatyrek, M.S.W., the University Hospitals' Social Services director.

Regina Jones, M.S.W., director at the O'Donoghue Rehabilitation Institute, said she finds her role to be very challenging. "Generally, being a social worker at O'Donoghue has the advantage of playing an important role in the patient's rehabilitation," said Jones. She also enjoys the wide variety of the patient population as it provides the social worker with a broader scope of experience.

Social workers provide information or referral services, discharge planning, counseling with emotional support, education, psychosocial assessments, and advocacy. Sometimes these professionals deal with the physical, mental and spiritual aspects of patient care.

"Because we have an open admissions policy, we have a lot of patients who fall out and have no resources.

Resource development is a

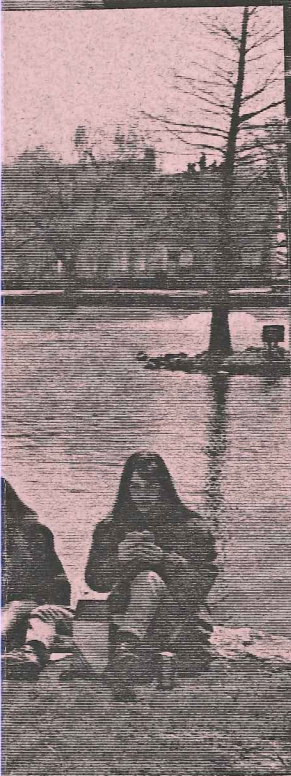
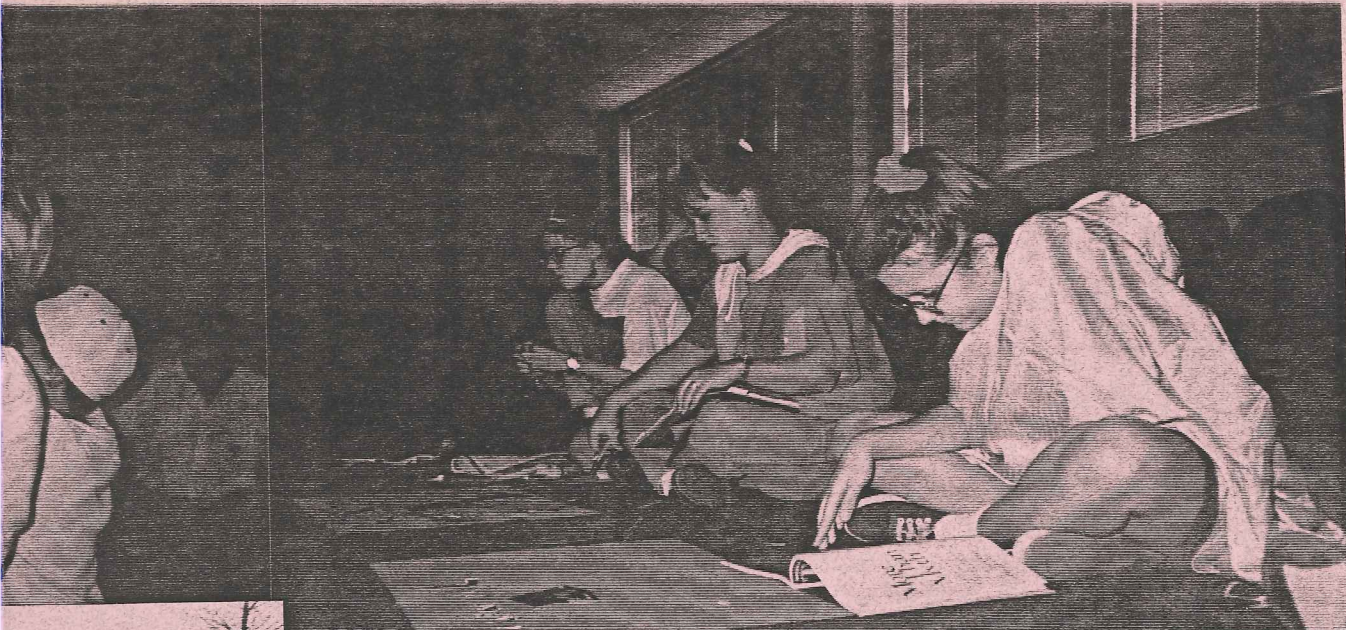
big issue with us," Tatyrek said. The patients "fall out" by suddenly finding themselves ill or without an income; lonely or depressed; dealing with a sick child; or caring for an elderly parent.

A focus on the special needs of the physically challenged, and ways of meeting the needs of the patients and family is the social work goal at O'Donoghue. Whereas, at Children's, Durbin said focusing on the whole family and assisting them with their social needs is vital to the recovery of the child. To meet the many needs of the hospitals' patients and to deal with the many ambiguous and seemingly unsolvable situations, social workers often find themselves frustrated and stressed. "However," Durbin explained, "good working relationships with staff, supportive colleagues, and a sense of humor helps social workers keep things in perspective."

Kris Williams - University Hospitals



Look!



WORDS FROM WONN

Debbie Klein Wonn Coordinator

WONN has been very busy since I last talked to you, and there is a lot to report. The Young Women with Bleeding Disorders Retreat was held at OSU and I feel it was a great success. The girls had an educational and fun time learning about their bleeding disorders and meeting other girls like themselves. We had a wonderful group of college sorority girls who hosted and ran a lot of the programs. As one of the chaperones, I can't begin to tell you how great these ladies were. From the first night when we gorged ourselves on pizza to the sad goodbyes, these ladies did all they could to make it a wonderful time for our girls.

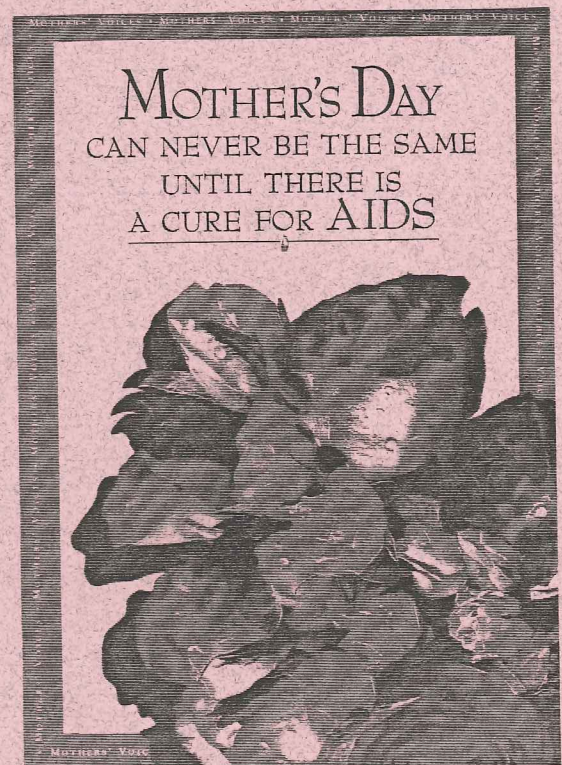
Renee Paper, R.N., herself a woman with von Willebrand's, gave a very informative talk on bleeding disorders as they apply to females. Jill LaFon, our other guest speaker, and also a woman with a bleeding disorder, gave an interesting talk on attitudes, HIV, sex and dating. I gave a short talk about WONN and answered the girls' questions about living with someone who is HIV-infected.

There was a full schedule of activities: games, a tour of a sorority dorm room, a picnic, breakout talks, dinner at Eskimo Joe's. Probably the favorite was The Dating Game, where the girls got to ask college fraternity guys some pretty good questions. All in all, I think everyone had a really good time, and only missed out on some sleep (boy can those girls talk!). Special thanks and acknowledgement needs to be given to Don Bell for all his work on this retreat; without him it would not have taken place. Good job Don!

Some of we WONN women and MANN men were very busy before Mother's Day collecting signatures on special Mother's Day cards. We asked for the cards from Mother's Voices, a non-profit organization working to raise public awareness of the AIDS epidemic and to change public attitudes and policies. You can see the front of the card below; inside it reads "Congress must act now. We demand more money, more research, a cure." Our group was able to gather over 1000 signatures. The cards were hand delivered by a delegation of mothers from Mother's Voices, who traveled to Washington and gave the cards to every member of the House and Senate. I want to take this opportunity to again thank everyone who helped collect signatures and gave their signatures in this effort to keep our government focused on AIDS and the search for a cure.

WONN has been working very hard on the joint WONN/MANN Annual Meeting that will be held at the NHF Regional Meeting in Oklahoma City June 3-5. We have a really good program planned for our WONN women. On Sunday we have three excellent speakers lined up. First, Heather Huszti, Ph.D. will be speaking to mothers about "Talking with your Child about Sensuality".

I was fortunate to hear Heather speak on this subject in Houston last month and it was well worth attending. Marty Barnes was scheduled to speak to the wives and significant others on "Safer Sex and Other Adventures", but due to health problems, Marty will be unable to attend. In her stead will be Nancy Haller, R.P.H., whom I understand is very knowledgeable in this field and is an enjoyable speaker. We also have Joan Foreman from RAIN (Regional AIDS Interfaith Network) who will be speaking to the whole group on "Caregiving for the Caregiver". Joan is really excited about the opportunity to do this for us. She has done this presentation statewide and hopes we will be uplifted by the experience. Many of you have never attended a WONN meeting, and may have some misinformation or apprehension about attending. I want to assure you there is nothing to worry about. The only thing that happens at WONN meetings is meeting other women just like yourself who come together to talk, listen and learn. Mostly we just make new friends. Hope to see you there! If you need additional information or assistance you can call me at (405) 670-2589.



MUSES FROM MANN

Mike Klein MANN Coordinator

I was able to join in at the Retreat for Young Men with Bleeding Disorders at Oklahoma State University this year, and thoroughly enjoyed the entire experience, especially the park across the street from the fraternity we stayed at. Watching the wrestlers in the sumo suits at the park was a lot of fun! I hear that a group of the guys from the fraternity will be coming down to Oklahoma City to help with the Teen Leadership Conference at the Regional meeting next month, so that ought to be a lot of fun. Unfortunately, Ed Kuebler and Monica Larson from Northern Lights, who presented our weekend's program, won't be able to attend, as

they both have to be somewhere else that weekend. But you'll be able to see *me* running around the hotel, so maybe I'll see you then. MANN will be selling beef jerky at the Regional meeting, and we hope to raise some money so we can have some activities this summer. So while you're at Regionals come by the OHF booth and buy some jerky and support the cause! If you think you'd be interested in a fishing trip to one of the local lakes, call me up and I'll see what we can put together. If we do go on one, let's do it before school starts. Whatever may be on your mind, let's keep in touch: (405) 670-2589.

MY BLOOD DOESN'T HAVE MUSCLES

All the mothers who attended last year's WONN retreat in Dallas were treated to a preview lecture from Lauren Kelly's next book. That book is now finally in print! It is called *My Blood Doesn't Have Muscles—How Children Understand Hemophilia, From Preschool to Adolescence*. This book should be of particular assistance to those parents with young hemophilic children. The book focuses on a developmental approach to teaching your child about hemophilia and its effects during the various stages of his or her childhood. If you would like a free copy of the book, contact Don at the OHF office (the number is on the front page). We also want to remind you that the resource center at the chapter office is full of information on all sorts of topics, and is available to OHF members at no charge. Don has a complete list of the literature available at the resource center and will be happy to help.

Walk With Us At

AIDS WALK

O K L A H O M A

Myriad Gardens

October 16, 1994

PLASMA ALLIANCE FUNDRAISING ACTIVITIES

Plasma Alliance Centers in Oklahoma City and Tulsa are running their annual fundraising events to support the educational activities of the OHF. The volunteers at the Oklahoma City branch on NW 23rd have held a pie-throwing contest, where supervisors were the targets, provided lunch for employees, and developed a special privileges program for donors called Donor VIP. They will hold a car wash on June 11th at Northwest Expressway and Rockwell, and have a bake sale, in addition to their annual basketball game with Channel 5 television. The game is Saturday, May 28th at 7:30 p.m. at NW Classen High School

The Tulsa Plasma Alliance on East Admiral has prepared pot luck dinners, held nearly daily bake sales, and have hosted a ham and bean dinner, a spaghetti dinner, and a breakfast. The group has had a drawing for a VCR, sold sandwiches, hosted pop and popcorn days, and has had a prize wheel for donations. The volunteers sold tshirts emphasizing the Walk for Hemophilia as both fundraiser and education.

These two active volunteer groups donate annually a substantial part of the OHF budget for educational activities; and we are deeply grateful for their efforts!



It is with great sadness that since our last newsletter, we have a number of deaths to report in our Oklahoma Hemophilia family. Due to newsletter deadlines and the hectic activity preparing for Regionals, look for articles on Brad Hatfield from Guthrie, Bill Soard from Tulsa, Philip Tepe from Lone Wolf, and Jeff Powell from Dewey in our next edition. Our thoughts and prayers are with their families.



FRONTIER CITY / WHITE WATER PIX!



Hemophilia Is Falling Apart

Carol Kasper MD
Orthopaedic Hospital
Los Angeles

So said a saddened physician whose career has been dedicated to the treatment of persons with hemophilia. What did he mean? Hemophilia is falling apart financially. Payment for medical services from both private insurance and public programs is lower, and an increasing percentage of persons with hemophilia are supported on the lowest-paying public programs. Some have no payor.

Usual levels of payments do not cover the actual costs of basic services for clinics, hospitals, physicians and so on. Some hemophilia centers receive monies from a federal agency, but these are small grants. Even with such monies, nearly all hemophilia "centers" run at a loss. Physicians treating hemophilia must defend their centers against nervous hospital administrators

watching the negative bottom line. At the same time, patients and health care personnel know that the level of health care service right now, even at "centers", is not enough for the needs of this complex disorder. Is anyone doing well financially? In a May 1993 issue of *Business Week*, featuring "Hot Stocks", the success of Quantum Health Resources was lauded. Companies that deliver concentrate directly to patients ("home care" or "drop shipment" companies) have proliferated and prospered. They have taken over a segment of hemo-

philia care that can be reimbursed at a decent rate, and they are *not* subject to as much regulation as hospitals and clinics.

Patients love the service provided by these companies. At the same time, patients expect that hemophilia centers with all their expertise will be there when needed for medical catastrophes. If centers don't survive financially, they won't be there.

Hemophilia is falling apart because patients are scattering. During the 1970's,

many new hemophilia centers were founded thanks to small grants provided by the Bureau of Maternal and Child Health. Hemophilia care was centralized for most patients. Hemophilia "experts" directed treatment. It was more effective. The frequency and severity of joint problems decreased. Some of us remember that the great improvement in the physical condition of patients in the 1970s was not solely due to concentrate but also to expert advice, physical therapy, and other help. Now patient care is being decentralized by two trends: 1) the emergence of preferred provider organizations that dictate the physicians and hospitals a patient

may use without regard to the rarity or special needs of their disorder, and 2) the trend of patients to reject centers and to rely on self-care with the encouragement of home care companies. We are beginning to see the consequences: bad outcomes. Hemophilia is falling apart as a community of patients, families, doctors, nurses, other professionals and volunteers working together to improve the lives of affected persons. Patient and family militancy has increased; hostility over suspected culpability in the HIV epidemic is expressed toward centers, doctors, governments, pharmaceutical companies—but not home care companies, which have the advantage of not having been around in 1982-3. The kindest and

most devoted doctors have been attacked. Some of them react by withdrawing. At the same time, HIV-infected patients crave their concern and care, their medical and moral support. Persons with HIV infection are afraid for their lives; they want all possible attention directed to avenues of treatment and cure of HIV. Patients who are not infected have been quiet in the past, perhaps feeling "survivor's guilt". They are now beginning to feel resent-

ment. The uninfected also have needs. They want attention given to the best possible management of bleeding disorders.

Can we put Humpty Dumpty together again? Will the new national health care system help or hurt? Can trust be rebuilt?

We must try. Pray—not only for answers and cures, but for peace and love.

CALENDAR OF EVENTS

JUNE

3 - 5

NHF Regional Meeting
Marriott, Oklahoma City
Teen Conference
MANN/WONN Conference
OHF Annual Meeting

JULY

9 or 16

OHF Family Outing
Lake Thunderbird - Norman

21 - 24

WONN Training
Denver

AUGUST

1 - 5 Camp Independence
Central Oklahoma Christian Camp
Guthrie

5 - 7 Father/Son Camping Trip

19 - 23

National Women With Bleeding
Disorders Meeting - Dallas

SEPTEMBER

24

Annual Fishing Tournament
Ada

TBA

Adult/Couples HIV Retreat
Eastern OK location TBA

OCTOBER

TBA

Women's Retreat

16

AIDS Walk

Myriad Gardens-Oklahoma City

25 - 30

NHF Annual Meeting - Dallas

NOVEMBER

DECEMBER

TBA

OHF Christmas Party

JANUARY

FEBRUARY

MARCH

TBA

Garage Sale - Fairgrounds
Tulsa

TBA

Young Women With
Bleeding Disorders Retreat
Oklahoma State University

Oklahoma Hemophilia Foundation News is published bimonthly for members of the OHF, patients with hemophilia 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 deadline for submissions for the next issue is July 15th; they can be sent through the OHF office, the Treatment Center, MANN/WONN Coordinators, or directly to the editor: Michael Lee, 5757 W. Hefner Rd. #824, Oklahoma City OK 73162.

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