

# BLOD

The Newsletter of the Oklahoma Hemophilia Foundation

July 1994

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## OHF Hosts NHF Region V Conference

Don Bell OHF Administrative Assistant

Chapter delegates and members of the hemophilia community from a nine-state region converged on Oklahoma City June 3—5 for the NHF Region V Annual Meeting. Persons with hemophilia, their family members, friends and support personnel gathered at the Oklahoma City Marriott for a full weekend of learning, sharing, and organizational development. Region V includes Arkansas, Iowa, Kansas, Louisiana, Missouri, Nebraska, New Mexico, Oklahoma and Texas. Rhonda Manion of Miami chaired the Regionals Program Committee, presenting an excellent mix of education and good discussion, renewed friendships, and reaffirmation of shared goals. Providing primary assistance was Johnnie Smith of Plasma Alliance, who coordinated the entertainment and outside activities, and Mike and Debbie Klein, who led the group-handling logistics of the program. Special assistance was provided by Don and Martha Miller, Scott and Donna Lewis, Jerry and Debbie Vaughn, as well as many other volunteers too numerous to mention.

Highlights of the meeting included an address by Dr. Glenn Pierce, President of the National Hemophilia Foundation; special presentations by Libby Fisackerly, exiting Region V Director, and OHF President Tom Duncan; and educational programs presented by Renee Paper R.N., Director of the Nevada Hemophilia Foundation, Rachel Warner, director of the ACCESS program from Quantum Health Resources, Susan Zappa R.N., of Cook-Fort Worth Children's Medical Center, Yale S. Arkel M.S., Director of the Blood Disorder Center for Hemostasis and Thrombosis, and Dr. Heather Huszti of the Oklahoma Hemophilia Treatment Center, just to name a few. Topics covered included: current and future trends in hemophilia, SSI and SSDI, utilization of a local anesthetic, incorporating HIV services into your chapter, grant writing for chapters, and an update on NHF activities.

Friday night, after a full day of educational programs and special chapter activities, guests were rounded up, put on buses and herded toward the National Cowboy Hall of Fame. Attendees had free run of this prestigious museum prior to a terrific Oklahoma roundup barbecue. Special presentations and a tribe of authentic Indian dancers rounded out the evening. Kirby Feathers, a member of the Oklahoma hemophilia community whose family are OHF members, was featured in the dance. Kirby is a member of the Ponca tribe. Saturday night, our group put together a genuine Oklahoma hoedown, complete with the Jimmie Lee Band, one of the most popular country groups in the southwest, sponsored by Hall's Pharmacy of Dallas. One of Oklahoma City's top dance instructors and a nationally recognized team of cloggers rounded out the activities and got everyone dancing!

A special Saturday event was attendance at the Hemaldo Windfree Show, an afternoon talk show with audience participation on various hemophilia-related subjects. Hosted by our own Hemaldo (Brian Wager of Armour Pharmaceuticals), guests battled it out over such topics as chapter/hemophilia treatment center



relationships, when is too much care, and how to discipline the unruly hemophiliac—husband or child! Done with much flair and highlighting humor, the actors actually presented good information on various subjects in a hilarious format. Special recognition to Brian, Heather, Libby, Renee and Debra Scott for their performances, and of course our cue card lady Debbie Klein! Commercials were presented by several of the event sponsors, who got into the swing of things by presenting humorous vignettes about their products and services (Andy, we loved your new persona!).

In addition to the regular Region V business and meeting, the OHF sponsored a regional teen conference. Topics included leadership and its responsibilities, strategies for leaders, being an effective leader, Hemophilia 101, teens and HIV, and strategies for living with HIV. Karen Hayhurst of Wyoming was flown in to present the program because of her special expertise in the area: she runs such programs in the schools in that state.

The food was great, the company terrific, and the education outstanding. Everyone had a good time, learned a lot, became empowered to take charge of their own health care, and left with a feeling of hope for the hemophilia community's future. Rhonda, Johnnie, Debbie, Mike and the whole crew: "you done real good"!

## *A FOND FAREWELL TO MARY BOWMAN*

Don Bell

HTC researcher/psychologist and OHF Board member Mary Bowman married Smith Cummings Jr. on Sunday, July 26th. The wedding took place on a private yacht in the Gulf of Mexico near Orange Beach, Alabama. The couple will reside in Mexico City, where Smith is a consultant with ICA-FluorDaniel, an international construction and engineering firm. Mary hopes to continue her work with the hemophilia/HIV community in Mexico City, following her research in the Hemophilia Growth and Development Study.

Mary will miss the now-teenage group of young men with whom she has worked for the past six years, and their families, with whom she has developed close ties. Leaving Oklahoma means leaving her friends at the OHF and her passion for the important role of the foundation in the hemophilia/HIV community. Mary has been a key figure in the development of the chapter and was responsible for the grants which fund our activities and many of the functions of the OHF. She will be missed by her friends and the many persons her work has aided.

Mary has admired the strength and courage of our OHF families and the special relationships between the parents and their children. She will use that knowledge in development of her own family, which she and Smith hope to start soon!

While in Mexico City recently, Mary attended the World Federation of Hemophilia conference held there. She had an opportunity to meet many persons involved in hemophilia from throughout Europe and South America, and particularly Mexico. Mary will no doubt maintain her ties to the community with whom she has worked with so diligently.

All of Mary's friends at the OHF will miss her and her efforts on behalf of our organization and persons living with hemophilia and HIV. She has been a great friend and major supporter of OHF causes, and her work on our grants particularly will be missed! We'll miss you Mary! Good luck and keep in touch!

*Check out the beautiful bride and the yacht shot on the next page!* ➡



## PRESIDENTIAL PONDERINGS

by Tom Duncan

OHF President

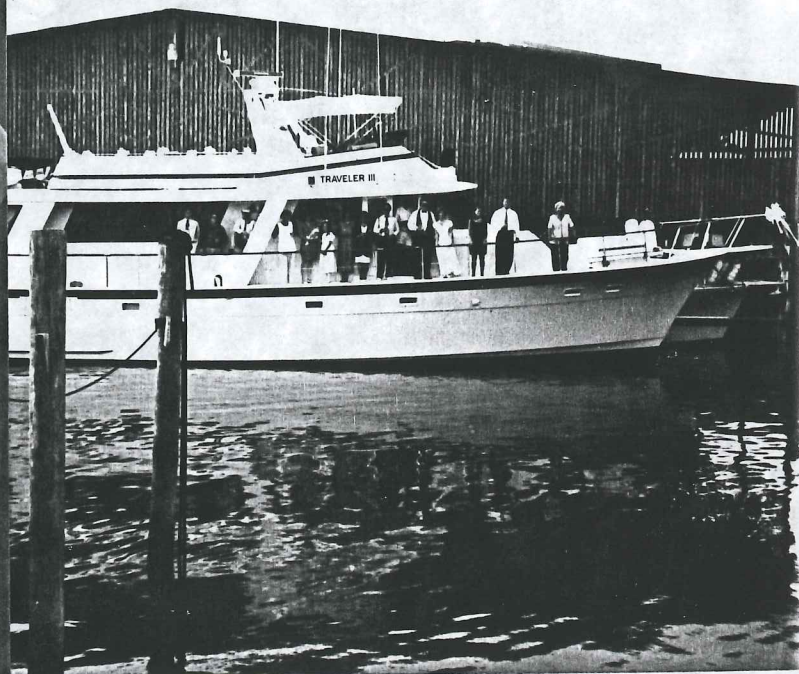
Since I took office as President of the chapter, I have been asking a lot of questions about the history and future of the OHF. I have come to one major conclusion: communication is the key to our success. I experience daily frustration trying to coordinate programs and fundraising activities from my home in Tulsa with our chapter office in Oklahoma City. As your President, I cannot be effective unless lines of communications are improved, so for this reason I will be asking you, at our Annual Meeting, to consider moving the chapter office to Tulsa. I will also ask you to vote for a change in our chapter's bylaws to allow for the election of a second Vice President. Having two Vice Presidents will allow me to have responsible OHF officers in each of Oklahoma's major cities. The ultimate goal of these changes is to encourage statewide participation by recognizing geographical barriers. If you have questions, concerns or opinions about what I have proposed, please call me at any time. My work number is (918) 591-8214, or after 5 o'clock you can reach me at home: (918) 250-8936. The Annual Meeting will be held in Tulsa on August 28th, and you will be notified when a location and time is determined. Thank you for your continued support!

## MUSES FROM MANN

by LYNSON AUPRY

MANN COORDINATOR

Just a short note to report that I and Don Miller will be attending the MANN Coordinator meeting in Denver July 28—31st; we'll have an indepth report for you in the next newsletter. Don and I will be splitting our efforts and concentrations to the east and west parts of the state, respectively; and resigning MANN man Mike Klein *will* still be involved in our activities.





## Words From Wonn Debbie Klein WONN Coordinator

I just returned from the WONN national training workshop in Denver and I thought I'd take this time to share with you some of the highlights from the workshop. This is WONN's fifth year anniversary, and in those five years WONN has grown from a roomful of ladies to a nationwide program.

The Women's Outreach Network of the NHF is a chapter-based program supported and attended by the members of each chapter. WONN programs are as unique and individual as each state's chapter. Each group decides for themselves what services and activities it will have based on their needs. The purpose of the WONN program is to cultivate each woman's strengths, enhance their skills, and facilitate her access to medical information and care, in the hopes that, through our collective strength, we can address the problems faced by women and their families in the bleeding disorder community today. At the workshop I was given a lot of training on how to be a better coordinator for our group in Oklahoma. They covered everything from how to plan potential programs to how to facilitate groups once they are formed.

The WONN training was well-attended by NHF staff and CDC personnel. NHF President Glenn Pierce discussed the NHF's last few years, the lawsuit, and the special assistance bills. He explained that a working committee had been formed between the various hemophilia groups in order to consolidate the bill proposals being presented to Congress. Essentially the message was if we don't unite, nothing will likely get passed. He says the committee was working full speed and we could possibly see parts of what the hemophilia community wants introduced in Congress within a month or two. He stressed the importance of every member of our community writing or contacting their Congressman and asking support for these bills.

The training sessions were varied. Loss and grief, sex and safety, self-care, and survival skills were all covered in depth, and I will be sharing what I learned in future articles. Two interesting speakers to me were Lisa Sorrenti-Little and Clare Cecchini from the Women Helping Women Support Network of the Canadian Hemophilia Society. Their network was begun shortly after the WONN program. There are 2500 hemophiliacs in Canada, which has a national health care program that provides factor and healthcare. But the concerns of the women in Canada are similar in many ways, and many of their programs echo our own. Their latest effort is the national "It's A Boy" program that delivers baskets full of goodies, necessities and information to new parents of hemophiliacs. Their compensation settlement was also discussed. They received a \$120,000 four-part lump sum for each infected individual from the national government, and in January began receiving \$30,000 per year for life from the Provincial government. Surviving family members (spouses and parents) will receive \$30,000 a year for five years, and surviving children will receive \$4000 a year for four years. This is in addition to factor and healthcare. Of special interest to some of our Oklahoma members was the attendance of the new NHF Executive Director Dennis Hirshfelder. After spending the weekend at our workshop meeting and learning about the special problems of women with bleeding disorders, he has promised to expand the programs and services for those so afflicted.

There were a lot of nice things said about Oklahoma at the meeting; our young women's retreat and Regional meeting were praised by all. The women who attended Regionals were spreading the word about what a nice time they had in Oklahoma. I want to thank everyone who helped with Regionals, but there are too many hard workers to list here; but Rhonda Johnnie and Don all worked their tails off! And one WONN woman went beyond the call: my special thanks goes to Donna Lewis, who did an outstanding job. Donna and her family worked really hard for our chapter and their work helped create a meeting everyone is still complimenting!



# HEPATITIS B BOOSTERS - ARE YOU DUE? SARAH HAWK P.A.-C.

Look in the laboratory section of your comprehensive clinic report for the "anti {or anti-body} Hepatitis B surface" result (antiHBs). We are now doing quantitative testing to see if you still have protection against Hepatitis B infection. People who have been exposed to Hepatitis B through blood products or personal contacts may become "chronic carriers" who have active Hepatitis B virus in their bodies and can infect others through blood or body secretions. Five to twelve percent of hemophiliacs are chronic carriers. This is generally shown by positive "Hepatitis B surface antigens" (HBsAg).

People previously exposed to live Hepatitis B virus generally become positive for antiHBs and "Hepatitis B core antibodies" (antiHBc). They have antibodies (protection) against the virus and are not infectious. People who only received the Hepatitis B vaccine will have positive HBs antibodies, but not antigens or core antibodies.

Without repeated exposures, the body eventually "forgets" and stops making anti-bodies. The Hepatitis vaccine appears to last for 5-10 years before another dose is needed. After you receive this "booster", the antiHBs levels should be checked in about four weeks. Sometimes you need the full set of three shots again. People previously exposed to the live virus can also lose their protection and may need to be vaccinated for the first time. The HTC follows the Centers for Disease Control guidelines in determining whether you have adequate protection. If you have questions regarding your lab results, please call the office.

## "BEARING" THE PAIN AT HTC

On July 21st, the Hemophilia Treatment Center received a generous donation of cuddly stuffed bears from the Teddy Bear Collectors of Norman, Inc. One of their members had a relative with hemophilia and knew how hard those many "sticks" and hospital visits could be. They are a non-profit organization that raises funds for donating teddy bears to various civic groups to promote goodwill, alleviate trauma and suffering, and spread love and compassion. Their fundraiser, the "8th Annual Teddy Bear Affair" will show and sell bears from exhibitors across the country on October 8th at the Sheraton in Norman.

Our 12" bears are dressed with bow ties and t-shirts which say "Because We Care". The back of the shirt has an original poem written by a local member:

*A smile for your eyes / A hug for your heart / I'll help you to Bear it / By doing my part*

The first recipient was Tani Sims, who has von Willebrand's and was in the hospital for surgery. The Daily Oklahoman came out for a photo session, and the presentation will be written up shortly for a Community Section feature.



## HTC WELCOMES A NEW "VOICE"

The Hemophilia Treatment Center is pleased to welcome our new secretary, Debra Henderson, who started July 18th. She had worked at the O'Donoghue Rehabilitation Institute in administration for a number of years, and is helping us get back on schedule with the paperwork. Over the next month she will update our files on current addresses, your local doctor, new spouses... Please let us know when any of your "vital statistics" change, or if there is a better way for us to reach you. Our previous secretary, Susan Robinson, retired in April after thirty years of service, seven in hemophilia. We understand she's thoroughly enjoying her garden and grandchildren!



## NHF National Quilt Project

Bea Pierce & Suzanne Broullon NHF

The National Hemophilia Foundation will be sponsoring, for the second time, a display of memorial quilt panels made at chapters and hemophilia centers around the country, at the NHF Annual Meeting, October 27-30th, in Dallas. If you, or individuals you know, would like to participate, please fill out a "Quilt Panel Registration Form", which can be requested through the OHF office, as can the two-page flyer "How To Create A Panel". These registration forms will enable individuals and groups to reserve a display space at the Meeting. The deadline for receipt of registration forms is August 31st; all quilt panels will be expected to arrive at National no later than September 30th. If, however, there is a late creation, special arrangements can be made by calling Sonia Dixon at the NHF office (212-219-8180 extension 3024), between August 30th and September 30th. We are sure you are aware that the creation of memorial quilt panels is a wonderful way to celebrate and honor the lives of loved ones who have been affected by hemophilia and HIV. The NHF Memorial Quilt Project is a national program of the Women's Outreach Network of the NHF (WONN). We very much hope that you are able to work with women at your chapters and treatment centers to bring the reality of the quilt to your local hemophilia community. We will be delighted to display panels from your area in Dallas. In November, we will be packaging the hemophilia quilt squares and sending them on to the National Names Quilt Project. If you have any questions, please contact Sonia, and good luck in your local efforts.

## The Bill McAdam Scholarship Fund

Pamela Ingham NHF

Applications for the Bill McAdam Scholarship Fund are now being invited. The fund is in memory of Bill, who lived with hemophilia for forty-four years and died of AIDS in October of last year. The purpose of the \$2000 scholarship is to enable a person with hemophilia, von Willebrand's, or other bleeding disorder, or his/her partner, spouse, child, sibling, or other family member, to further his/her education through college, trade, or technical school, or some type of certification program. The application deadline is September 1st; and a final decision will be announced by November 1st. The scholarship is to be used for the term beginning January 1995, and will be awarded directly to the winner's institution. If you need an application, call the OHF office.

## New Region V Directors Chosen

Raymond Stanhope & Debra Scott Region V

**From Raymond Stanhope, new Regional Director:** Unity of the community is primary. Our community is too small to continue to be subdivided into even smaller fragments. My vision is to: 1) Establish both quality and uniformity of health care within the region and nationally for both hemophilia and HIV; 2) Have input into how NHF will be restructured and how that will best serve the hemophilia community; 3) Work to see that chapters receive quantitative services for being a chapter of NHF; 4) Strengthen MANN, WONN, and CODP programs within the region; 5) Ensure that the needs of hemophilia are addressed in the national debate over health care reform.

**From Debra Scott, new Alternate Regional Director:** My first involvement with NHF was in June 1984, on the chapter level as a board member, and then as the WONN Coordinator for Louisiana. Currently, I serve as the Region V Policy Coordinator on the Women's Advisory Committee (WAC). The future of NHF is very important to me. My experience as the mother of a 7-year-old child with severe hemophilia can help NHF to meet the needs of people affected by hemophilia.



# Healthcare Bills of Rights

## PATIENT BILL OF RIGHTS American Medical Association

The AMA is concerned about patients as well as physicians. We feel a great responsibility to the people we serve. The AMA Principles of Medical Ethics for physicians is an example of this commitment. The AMA Patient Bill of Rights is another. Both help ensure your rights as a patient. Physicians who belong to the AMA support these six rights:

- ✓ The patient has the right to receive information from physicians and to discuss the benefits, risks and costs of appropriate treatment alternatives.
- ✓ The patient has the right to make decisions regarding the health care that is recommended by his or her physician.
- ✓ The patient has the right to courtesy, respect, dignity, responsiveness and timely attention to his or her needs.
- ✓ The patient has the right to confidentiality.
- ✓ The patient has the right to continuity of healthcare.
- ✓ The patient has a basic right to have available adequate healthcare.

## EXPERIMENTAL SUBJECT'S BILL OF RIGHTS University of California

The rights below are the rights of every person who is asked to be in a research study at the University of California. As an experimental subject I have the following rights:

- ✓ To be told what the study is trying to find out
- ✓ To be told what will happen to me and whether any of the procedures, drugs, or devices is different from what would be used in standard practice
- ✓ To be told about the frequent and/or important risks, side effects, or discomforts of the things that will happen to me for research purposes
- ✓ To be told if I can expect any benefit from participating, and if so, what the benefit might be
- ✓ To be told of the other choices I have and how they may be better or worse than being in the study
- ✓ To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study
- ✓ To be told what sort of medical treatment is available if any complications arise
- ✓ To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study
- ✓ To receive a copy of the signed and dated consent form
- ✓ To be free of pressure when considering whether I wish to agree to be in the study

## A PATIENT'S BILL OF RIGHTS American Hospital Association

- ✓ The patient has the right to considerate and respectful care.
- ✓ The patient has the right to obtain from his or her physician complete current information concerning diagnosis, treatment, and prognosis, in terms the patient can be reasonably expected to understand.
- ✓ The patient has the right to receive from his or her physician information necessary to give informed consent prior to the start of any procedure and/or treatment. Except in emergencies, such information for informed consent should include but not necessarily be limited to the specific procedure and/or treatment, the medically significant risks involved, and the probable duration of incapacitation.
- ✓ The patient has the right to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of his or her action.
- ✓ The patient has the right to every consideration of his or her privacy concerning his or her own medical care program. Case discussion, consultation, examination, and treatment are confidential and should be conducted discreetly. Those not directly involved in his or her care must have the permission of the patient to be present.
- ✓ The patient has the right to expect that all communications and records pertaining to his or her care should be treated as confidential.
- ✓ The patient has the right to expect that within its capacity, a hospital must make reasonable response to the requests of a patient for service. When medically permissible, a patient may be transferred to another facility only after he or she has received complete information and explanation concerning the needs for and alternatives to such a transfer.
- ✓ The patient has the right to obtain information as to any relationship of the hospital to other healthcare and educational institutions insofar as the patient's care is concerned.
- ✓ The patient has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his or her care or treatment. The patient has the right to refuse to participate in such research projects.
- ✓ The patient has the right to expect reasonable continuity of care. He has the right to know in advance what appointment times and physicians are available and when. The patient has the right to expect that the hospital will provide a mechanism whereby the patient is informed of the patient's continuing health.



# OHF CALENDAR OF EVENTS

## AUGUST

1 - 5 Camp Independence  
Guthrie  
19 - 23  
National Women With Bleeding  
Disorders Conference - Dallas  
28  
OHF Annual Meeting - Tulsa

## SEPTEMBER

24  
Annual Fishing Tournament  
Ada  
TBA  
Adult/Couples HIV Retreat  
Eastern OK location TBA

## OCTOBER

3 Inaugural Golf Tournament  
Karsten Creek - Stillwater  
TBA Women's Retreat  
16 AIDS Walk  
Myriad Gardens-Oklahoma City  
27 - 30  
NHF Annual Meeting - Dallas

## NOVEMBER

1  
Poinsettia Fundraising  
Project Begins  
12  
Product Fair/Workshop  
Tulsa

## DECEMBER

TBA  
OHF Christmas Party

## JANUARY

## FEBRUARY

TBA  
Garage Sale - Fairgrounds  
Tulsa

## MARCH

TBA  
Young Women With  
Bleeding Distorders Retreat  
Oklahoma State University

## APRIL

TBA  
Young Men With  
Bleeding Distorders Retreat  
Oklahoma State University

## MAY

TBA  
Frontier City and  
White Water Bay Outings  
Oklahoma City

**Blood**, the newsletter of the Oklahoma Hemophilia Foundation, is published bimonthly for members of the OHF, patients with hemophilia, von Willebrand's, and other bleeding disorders, providers, and friends. Letters, comments, suggestions, articles, and pictures are welcome; however, the newsletter committee reserves the right to edit, delete, publish, and censor as necessary. The deadline for submissions for the next issue is September 15th; they can be sent through the OHF office, MANN/WONN Coordinators, the Hemophilia Treatment Center, or directly to editor Michael Lee at 5757 W. Hefner Rd. #824, Oklahoma City OK 73162.

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