

OKLAHOMA HEMOPHILIA FOUNDATION NEWS

February 1994

3033 N Walnut #E102 ♣ Oklahoma City OK 73105 ♣ (405) 521-1171

OHF Teens See Magic Johnson

Don Bell OHF Administrative Assistant



The OHF's MANN program sponsored a group of teens' attendance at an appearance of Magic Johnson, whose All Star Team was in town February 16th to play an exhibition game with the Oklahoma City Cavalry CBA team. Teens from the eastern and western borders of the state joined the central group to witness Magic's Oklahoma stop in his cross country tour. A record (and near sellout) crowd watched the match. Our group had prime floor seats ten feet behind a goal, so we could see the "big guy" up close and personal.

Olympic gymnast Shannon Miller was also a special guest, but Magic was the star for the night. He, his All Stars, and the Cavalry put on quite a show for the crowd—they certainly know how to entertain! The Cavalry put up quite a fight, and led many times, but the All Stars prevailed in the end, 126-121. The Cavs have made many appearances at the hospital for our boys and have always been very supportive. We had hoped for a personal meeting with Magic, but his schedule wasn't able to permit it. He was, however, able to autograph a basketball for our own basketball player Philip Tepe, who was unable to attend the game.

My Adventures In China Pat Nelson Resigning President

I have accepted an offer for a position as Maintenance Coordinator over the China project that Phillips Petroleum Company has undertaken. This will be a three year assignment overseas. I am very excited about this opportunity and it is something that I have worked toward for my entire career with Phillips—not necessarily in China, but the overseas opportunity is what I wanted.


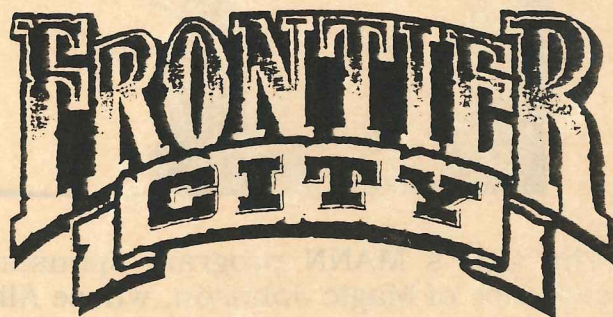
I will be living in a city called Shekou (pronounced surkoe). It has a population of about 1/2 million—not small by any means. It is located on the Nantou peninsula about 20 miles west of Shenzhen. It was once a small fishing village but is now a very large tourist and industrial city. It is about a 45 minute ferry boat ride from Hong Kong. I will be working primarily in the downtown office, but will spend some time out on both of our platforms. It's going to be a big job for me and quite a change, but I feel that I'm up to it and I am looking forward to the challenge.

The most undesirable part of this opportunity is that I have to leave a lot of very good friends. This will be hard for me because, as most of you know, the OHF means a lot to me. Three years isn't very long if you say it fast enough, but I know that I will miss everyone very much. I do want you to keep one thing in mind, and that is that I will be back. Hopefully after this assignment I will have to opportunity to come back to Oklahoma to work once again for both Phillips and the OHF. I wish everyone well and my thoughts will always be with the Oklahoma Hemophilia Foundation and my many friends.

And a short note from Tom Duncan

Dear OHF members & supporters: 1994 will indeed be a challenging year for the chapter, and I look forward to serving as the new President. If you have any special needs or questions, call me at home: (918) 250-8936 (after 5 p.m.) or at work: (918) 591-8214.

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 begins at 10 a.m. on May 1st, while we will begin at 10:30 a.m. on May 22nd at White Water Bay. Tickets must be reserved by calling Don at the OHF office (the number is on the front page). 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.



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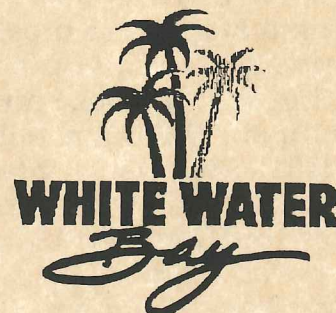
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**FRONTIER
CITY**



WHITE WATER
Bay

Young Women's Retreat Planned

Don Bell

The OHF, our WONN chapter, the HTC, and the Oklahoma State University Chapter of Farmhouse Fraternity 'Little Sisters' will offer our first 'Teen Retreat for Young Women with Bleeding Disorders' on the weekend of March 25-27, 1994. The program will take place on the OSU campus in Stillwater. There is no charge for the program. Housing and meals will be provided, and some assistance with transportation costs is available. Teens should arrive before 6 p.m. on Friday and will leave after lunch Sunday.

The purpose of the retreat is to: reduce isolation, present information about women with bleeding disorders, discuss issues common to teen women, address HIV issues in women, develop peer relationships, and introduce teens to a collegiate environment. Participants will stay at the Baptist Student Union, which sits directly across the street from the main University concourse, in the middle of Fraternity and Sorority row. OSU boasts a beautiful campus with excellent facilities and an ideal collegiate atmosphere.

The Farmhouse Fraternity Little Sisters will serve as our campus hosts, and will be involved in making local arrangements. They will lead icebreaker activities and discussions about relationships. A group of Farmhouse men will also take part in the relationships discussion. Also, Renee Paper, R.N., of Las Vegas, and Jill LaFon of Bloomington, Indiana have been secured as presenters during the weekend. Renee will focus on bleeding disorders and their effect on women, while Jill will examine HIV and special problems of women. Dr. Heather Huszti of the HTC will join in focus groups during the weekend, and Oklahoma WONN Coordinator Debbie Klein will also have a presentation.

The retreat is planning to welcome 15-20 teen women from NHF Region V, which also includes Arkansas, Iowa, Kansas, Louisiana, Missouri, Nebraska, New Mexico, and Texas. It is hoped that the young women attending this function will take an active part in their local WONN

program and will attend the National Conference on Women with Bleeding Disorders in Dallas on August 19th-23rd. For more information, contact me at the OHF office (the number is on the front page) or the HTC at 1-800-688-5288.

Young Men's Retreat Coming Too

Don Bell

The OHF, our MANN chapter, the HTC, and the Oklahoma State University Chapter of Farmhouse Fraternity will be holding our second 'Teen Retreat for Young Men with Bleeding Disorders' on the weekend of April 15-17, 1994. The program will take place on the OSU campus in Stillwater. There is no charge for the program. Housing and meals will be provided. Some assistance with transportation costs is available. Teens should arrive before 6 p.m. on Friday and will leave after lunch Sunday.

The teen retreat will allow participants to: discuss issues of hemophilia and HIV; build a network of peer support with other teens who have had similar experiences; learn and practice new ways to approach problems; increase skills needed to develop relationships; increase communication, decisions making, and safer sex skills; and participate in peer interaction. OSU will be used as the host site, with the Baptist Student Union serving as the host facility. The BSU sits directly across the street from the main University concourse, in the middle of Fraternity and Sorority row. OSU boasts a beautiful campus with excellent facilities and an ideal collegiate atmosphere.

The Farmhouse Fraternity will again serve as our campus hosts, and will be involved in making local arrangements. Last year, the retreat drew 15 teens from Oklahoma and Arkansas, and the University men interacted with them and together developed a supportive peer network. The teens participated in formal discussions, informal group projects, and social activities: Eskimo Joe's, Hideaway Pizza and the University's Olympic swimming pool were highlighted activities. Teens, keep an eye out for special mailings, and make sure you are included in this year's program.

OHF Hosts NHF Regional Meeting

Rhonda Manion Regionals Committee Chair

This year's NHF Region 5 meeting will be held on June 3rd, 4th and 5th at the Marriott in Oklahoma City. (Region 5 also includes Iowa, Kansas, Louisiana, Missouri, Nebraska, New Mexico, and Texas). The planning committee has been working diligently on organizing all the necessary details. First, we want to be sure all our Oklahoma families are aware of the upcoming events, and are making plans to attend. Second, we need (you guessed it) volunteers! Some volunteers will be needed during the planning process and others will be needed to work at the meeting itself. There will be a registration fee for anyone who plans to attend; this fee will be waived for all volunteers. Registration forms and an agenda will be mailed out in the spring. We want a good showing for Oklahoma, and feel that the information given at the meetings and the 'fun' times we have planned will benefit everyone. If we can count on your help, call me collect at (918) 540-1768 or contact Debbie Klein at (405) 670-2589.

Benefit Garage Sale Set For Oklahoma City

Mary Bowman OHF Board Member / **Michael Lee** Editor/OHF Secretary

The OHF will be participating in the eighth annual "Largest Garage Sale In Oklahoma City" on April 9th 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 start your spring cleaning now, and call Don at the OHF office for further details and drop off times, or to make pickup arrangements, if necessary. Volunteers are also needed to work shifts in our booth and to help tag merchandise the week before.

Meanwhile, the OHF experienced great success with the garage sale at the Tulsa Fairgrounds on February 12th. Aply manned by the Duncans, Manions, and Millers, they sold nearly everything, amounting to a take of almost \$600; what was left over was taken by the Salvation Army. Coverage was provided by local TV stations as the gang wheeled and dealt and sold off the likes of sinks, washing machines, TVs, chairs, cooktops, and clothing. Tom even sold a one-eyed man some broken binoculars for 50¢! Start stockpiling your stuff for next year now!

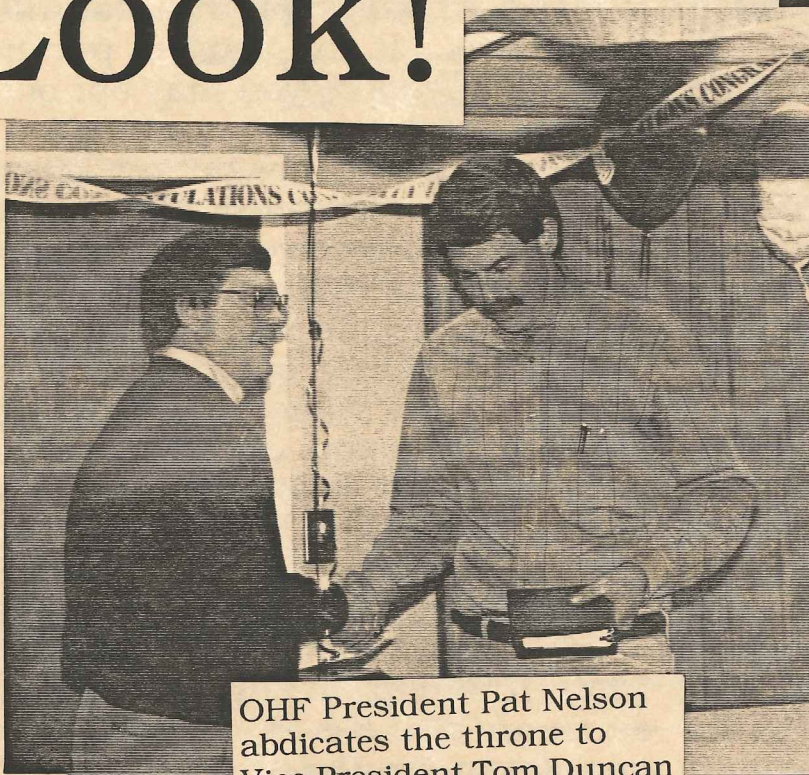
OHF Cookbook Nearing Completion

Debbie Klein WONN Coordinator

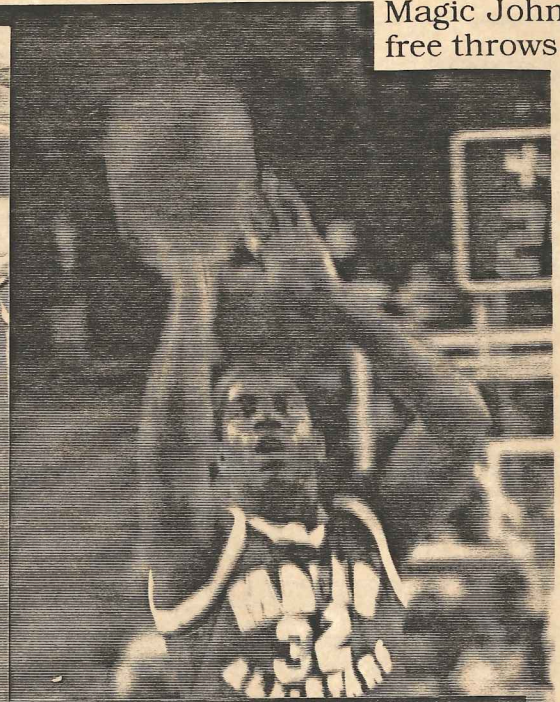
Attention all OHF members and friends—we still need your recipes for our cookbook fundraiser! We've put off publication until later this year, because we have yet to get enough participants to qualify for the publisher's guarantee to buy back our unsold cookbooks. We need to have 75 individuals involved, and currently only have 41. So if you haven't sent yours yet, head to the kitchen right now, while you're thinking about it, and find us a recipe or two. If you hadn't planned to participate, please reconsider. We need everyone to help, so this fundraiser can be a great success. Send your recipes to the OHF office.

Look!

Magic Johnson
free throws



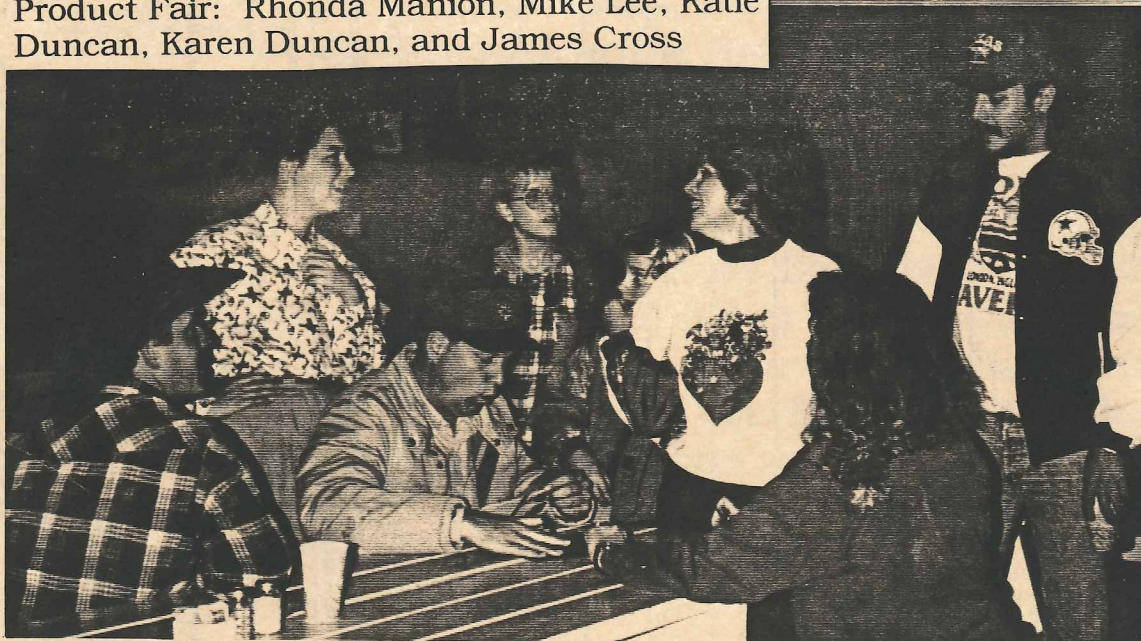
OHF President Pat Nelson
abdicates the throne to
Vice President Tom Duncan



Eating, drinking, and being merry at the Tulsa
Product Fair: Rhonda Manion, Mike Lee, Katie
Duncan, Karen Duncan, and James Cross



Iceskating at
the Quantum
Christmas
Party: Rebecca
Manion, Santa
Claus, Nathan
Manion, and
Eric Baxter



Visiting at
the OHF
Christmas Party:
Scott Lewis,
Donna Lewis,
Keith Manion,
Katie Duncan,
Emily Duncan,
Karen Duncan,
Rhonda Manion,
and Ken Cole.
You'll have to ask
Keith what he's
doing—we don't
know.

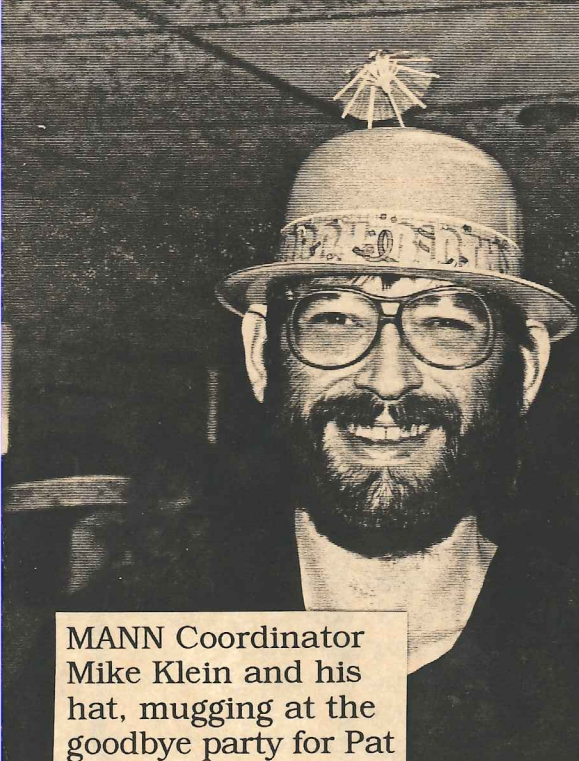
The scene at the Tulsa Product Fair



HTC's Beverly Stevens, R.N., Quantum's Tawny Hagan, and Ethan Stevens at the Quantum Christmas Party



The OHF office during our successful poinsettia fundraiser in December. Just joking—it wasn't quite that bad (but almost). This is a shot from the nursery we got them from.



MANN Coordinator Mike Klein and his hat, mugging at the goodbye party for Pat

Adrian Hamilton & family posing at the OHF Christmas Party



WORDS FROM WONN

Debbie Klein
WONN Coordinator

Well, it's 1994, and we're off to a fantastic start! We were approved for a new grant for this year, so now I need to hear from all you WONNderful women! You decide what WONN will be in Oklahoma, so let me hear from you—tell me what you would like to be done in 1994. Is there a special subject you would like to have addressed at a meeting? Is there something you would like our women's group to do? Do you have a special need we could meet? Is there some information we could get for you? All these things are WONN and more—you decide and let me know.

There are some exciting things on the agenda already! The Young Women's Retreat has been scheduled for March 25th-27th, and will be held in Stillwater on the Oklahoma State University campus. The Texas WONN Seminar is scheduled in Houston for April 15th-17th. The WONN/MANN annual meeting will be at our Regional meeting, mentioned in a previous article. And we have scheduled our first ever Oklahoma WONN weekend for early October!

The directory for *Women With Bleeding Disorders* will soon be sent to those women who chose to participate (be looking for it in your mail). And our first 1994 WONN meeting will be Saturday, March 12th at the OHF office at 11:00 a.m. You don't want to miss it!

Finally, I want to take this opportunity to ask all the women of the OHF for your help. We are going to need everyone's assistance to pull this Regional meeting off, and I know we can count on you. If you can serve on a committee or help in any other way, please call me at (405) 670-2589, or contact Don at the OHF number on the front page.

Growing Pains

Edited from *Physician's Assistant*
November 1992

No one knows why some children have these sensations: of leg cramps, restlessness, or 'creeping'. They generally occur deep in both legs, rarely involving the arms. Pains may be worse after long periods of running, and there may be days without any discomfort. The symptoms usually occur in the evening.

Girls seem to be affected more often than boys, and usually begin to have episodes between the ages of 3 and 12 years. The pains usually go away over 1 or 2 years. Growth pains don't actually seem to be due to growth spurts, and children with the pains grow at the same rate as unaffected children.

There may be no specific treatment, but heat, massage and vitamin C may be helpful. Muscle stretching exercises twice daily help some children. 'Growing pains' should not cause limping, reduced motion, swelling, redness or single points of pain. Unusual symptoms or persistence of pain should be mentioned to your pediatrician.

Hemalog Magazine, the magazine for persons with hemophilia and their families, will be resuming publication this spring after a year-long hiatus. To make the magazine as responsive as possible to the needs and concerns of hemophilia patients and their caregivers, they'd like *you* to tell them what you want to see in the magazine. If you have any ideas about articles you would like to see published, or concerns you would like to see addressed, contact Managing Editor J. King, c/o Materia Medica, 561 Broadway, New York NY 10012, or call (212) 219-2727. At your request, any information or suggestions you submit will remain confidential.

How to Protect Your Health Insurance Rights

In 1988, Jack McGann filed a claim for medical expenses related to his treatment for AIDS. After reviewing the claim, his employer altered its health plan, capping payments for AIDS treatment at \$5000. The company argued that this was necessary to avoid jeopardizing benefits paid to the rest of its employees. Mr. McGann sued, claiming that the company had no right to reduce his benefits retroactively. McGann lost in court. And he lost in the US Court of Appeals. So far, the Supreme Court has declined to hear the case.

The significance of this case: no one who is insured through an employer-sponsored plan is protected from having those benefits capped or reduced. That's because employer-sponsored plans are governed by a federal law, the Employee Retirement Income Security Act (ERISA) of 1974. Although the law was enacted to protect the rights of employees, a 1987 Supreme Court ruling held that ERISA is

legally
allowed
to
supersede
state
laws.

Although most states have "bad-faith" laws regulating insurance practices that would prevent an employer or insurance company from changing the terms of an insurance contract *after* a policyholder files a claim, ERISA preempts these laws. The problem is that ERISA does not contain insurance consumer protection clauses to make up for the laws it eclipses. In fact, it grants insurance companies complete immunity from punitive damage suits. Under ERISA, policyholders are allowed to sue insurers only for benefits they believe are due. They can't sue for the financial damages they suffer when they believe payment of medical bills is wrongfully withheld. And ERISA allows employers enormous leeway in how they choose to provide coverage.

What this means: if you have group health insurance through your employer and must file a costly medical claim, even though you have a contract with the insurer and have paid your premiums on full and on time, the insurer is legally permitted to reduce the benefits promised in the policy *after* you become ill. The catch is that the insurer must make the same change for everyone in the group. The larger the group, the less likely this will happen, since insurers don't want to risk losing customers.

The risk is
greatest,
however,
for those

who need coverage the most. Particularly affected are the victims of catastrophic illness or accidents, who are subsequently fired from their jobs and lose their benefits because the carrier takes the position that they're no longer part of the group.

Are your benefits safe? The safest are any insurance plans that are ERISA-*exempt*, including those sponsored by public schools, churches and government agencies. Also exempt are nonemployer-sponsored group plans and coverage taken out by individuals. Relatively safe are group plans with a large number of members, union negotiated plans, and companies that have an aggressive employee-benefits negotiator. The most risky are small group plans and self-insured companies. If you fall into the risky category, look for group medical coverage through an organization or association other than your employer. Several bills now before Congress address this problem. A recent bill drafted by Rep. William Hughes (D-NJ) would bar insurers from retroactively cutting policyholders' benefits. Another bill, H.R. 1602, amends ERISA to close the loophole that causes it to override state consumer-protection laws.

**From
Personal
Advantage
July 1993**

The most common cause of nosebleeds is injury, but this does not necessarily mean a punch in the nose. Violent sneezing or overly forceful blowing, rubbing or picking a dry, itching or stuffy nose can cause bleeding. The membranes of the nose may become dry and crusty when the humidity in the house is low in winter, particularly at night and when nasal congestion leads to mouth breathing. Colds and allergies cause swelling and drying of the membranes and make them more susceptible to bleed from a slight injury.

It is always important to try to prevent problems before they occur. When the nose has a tendency to dry out, when the humidity is low, and during allergy season, it is important to keep the nasal membranes soft and moist. Humidifiers and vaporizers help. A small amount of Vaseline can be placed in each nostril at bedtime, or other times when the nose feels dry, to soften the membranes and prevent drying.

The bleeding site is usually near the front of the nose on the septum (the piece that divides the two nostrils) and can be quickly and easily controlled by proper local measures. Many 'home remedies' for stopping nosebleeds are widely used, although most of them do very little to stop the bleeding. Lying down or tilting the head back doesn't stop the bleeding, it just prevents the blood from running out where you can see it (and be alarmed by it). Instead the blood runs back into the throat & may cause vomiting. Applying a cool damp cloth to the forehead or neck makes the neck cool & damp, which can be quite pleasant on a hot day, but doesn't stop the bleeding.

The proper method for managing a nosebleed is: 1. Blow your nose gently to remove mucus and clots, which will interfere with hemostasis. The soft, stringy, jelly-like clots are not effective in stopping the bleeding. They allow blood to continue to ooze and interfere with the formation of a solid, effective clot. 2. Tilt your head forward. You want the blood to come out so you can tell when the bleeding has stopped, and so you don't get clots in the back of your throat. 3. Using a handkerchief or washcloth—dry or dampened with cold water (never hot)—apply firm pressure to the side of the nose that is bleeding for 10 to 15 minutes. 4. Release the pressure to see if the bleeding has stopped. Gently blow out any soft clots. If the bleeding continues, reapply the pressure for another five minutes. 5. When the bleeding has stopped, apply two drops of NeoSynephrine or Afrin nose drops or spray to the side that was bleeding. This will reduce the swelling and constrict the blood vessels. You will not need a prescription. 6. Gently apply a small amount of Vaseline into the nostril. This will help to keep the membranes soft and moist and prevent the formation of hard crusts which might crack and restart the bleeding. 7. However, if the bleeding continues beyond 30 to 45 minutes, a treatment may be necessary. Call the HTC for further instructions. 8. Otherwise, there is *no* need for restriction of activity.

Bleeding from injuries in the mouth is a common problem in children and may also occur in adults. This may result from cutting teeth, loosened or lost teeth, or from cuts or bites of the tongue, gums, cheeks, or lips. Bleeding in the mouth can be difficult to control. This is because the oral tissues and saliva contain substances which can break down the clots that form to control bleeding. As a result, a single transfusion may stop the bleeding temporarily, but during the next 12 to 24 hours the clot can break down. A repeated infusion and/or treatment with Amicar or Cyklokapron is generally helpful.

Be sure to remember: 1. Diet should be restricted to soft, cool, or lukewarm foods until the area is fully healed. Suggested foods: jello, soda, sherbet, lukewarm soups (not cream soups), spaghetti, baby foods, and blenderized or puréed foods. 2. Avoid milk products—they will break down a clot that has formed. 3. Avoid using a straw—the sucking action can aggravate the bleeding site. 4. Take medications as prescribed. Do not omit a dose. 5. Do not allow bleeding to continue without treatment. Often large amounts of blood can be swallowed without the patient realizing it. It may be necessary to check your blood count. 6. Other than dietary restrictions, *no* activity restrictions are necessary.

Pneumocystis Carinii Sarah Hawk P.A.-C.

Pneumocystis was first recognized in 1909, and for the initial sixty years or so it was an uncommon cause of pneumonia in people with damaged immune systems (people with cancer, children with severe malnutrition, people receiving steroids, transplant patients). Now we most often hear about it occurring in people with HIV infection, who already have symptoms related to the HIV or less than 200 CD4 cells.

It is unclear whether Pneumocystis is a fungus or a protozoan. It is found in the lungs of many animals and most of us were exposed at a young age—we have the organism in our lungs now. The cysts go into hibernation and do not become active unless the immune system is suppressed. It can be passed from person-to-person, presumably from air-borne droplets (sneezing, coughing).

When the cysts become activated, they injure the lung lining, and the small air sacs cannot expand properly, so the person becomes short of breath. The body starts an inflammatory response, which makes the lungs even less efficient, and the pneumonia worsens.

Preventive therapy (prophylaxis) is effective. It is started when people have CD4 counts fall below a certain level. Traditionally the treatment of choice is trimethoprim/sulfamethoxazole (Bactrim, Septra, Cotrim). For people who are allergic to sulfa drugs, other oral regimens include Dapsone, Fansidor (pyrimethamine+sulfadoxine) or monthly pentamidine by IV or breathing treatment.

Symptoms of Pneumocystis carinii pneumonia (PCP) develop gradually and usually include persistent fever. There's usually a dry cough but sputum can be produced in people with chronic lung disease or an additional bacterial pneumonia (10-30% of cases). People notice increasing shortness of breath and fatigue with normal activities. Although it most commonly causes pneumonia, Pneumocystis can also invade the liver, spleen, lymph nodes, gastrointestinal tract, bone marrow or eye. Symptoms include fever, fatigue, and specific complaints related to the area infected. These infections outside of the lungs are more likely to occur when prophylaxis is given as a breathing treatment. The medications used to treat acute pneumonia also work for the other sites of disease.

Diagnosing Pneumocystis involves several steps. The chest Xray may initially be normal, but later shows changes from the pneumonia. A gallium scan (IV dose of tracing agent, then a series of Xrays over time) may show changes even when the chest Xray is normal, but cannot *prove* pneumocystis infection.

A good sputum specimen (breathing treatment may be necessary to get a really good cough) is checked for cysts by using special stains. If that is unsuccessful a bronchoscopy will be needed. This involves a flexible fiberoptic tube which allows the surgeon to look directly at the lungs and take samples of the secretions. Sedation is given prior to the procedure, and for people with bleeding disorders, pre- and post-treatment with factor is very important. Arterial blood gases (drawn from the wrist) are important for determining the severity of pneumonia and need for oxygen. Factor should be given prior to this procedure as well.

Treatment involves at least 3 weeks of antibiotics. Mild PCP can be treated with oral medication and close out-patient follow-up. More severe cases will require hospitalization with intravenous antibiotics, possibly oxygen or even temporary use of a ventilator until the medicine starts to work.

As the antibiotics kill the Pneumocystis, the dying cells may actually make breathing worse for the first 3 to 5 days. If there is no improvement by the end of a week, different medications may be needed.

In moderate to severe pneumonia, a short treatment of steroids is given with the antibiotics to reduce the lung inflammation. This significantly improves the chance for survival.

CALENDAR OF EVENTS

MARCH

12 WONN Meeting - OHF Office
and Red Tie Night - Oklahoma
AIDS Care Fund
25 — 27 Young Women With
Bleeding Distorders Retreat
Oklahoma State University

APRIL

9 Garage Sale - Fairgrounds - OKC
15 — 17 Young Men With
Bleeding Distorders Retreat
Oklahoma State University
16 — 17 WONN Seminar -
Houston
29 Adult/Couples HIV Retreat -
Dallas

MAY

1 @ 10 a.m. — 8 p.m.
Frontier City
89er Adventure Days Family Outing
Oklahoma City
22 @ 10:30 a.m. — 6:00 p.m.
White Water Bay
Tropical Adventure Family Outing
Oklahoma City

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
25 — 30
NHF Annual Meeting
Dallas

NOVEMBER

DECEMBER

TBA
OHF Christmas Party

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 April 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.

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

Pneumocystis Carinii Sarah Hawk P.A.-C.

Pneumocystis was first recognized in 1909, and for the initial sixty years or so it was an uncommon cause of pneumonia in people with damaged immune systems (people with cancer, children with severe malnutrition, people receiving steroids, transplant patients). Now we most often hear about it occurring in people with HIV infection, who already have symptoms related to the HIV or less than 200 CD4 cells.

It is unclear whether Pneumocystis is a fungus or a protozoan. It is found in the lungs of many animals and most of us were exposed at a young age—we have the organism in our lungs now. The cysts go into hibernation and do not become active unless the immune system is suppressed. It can be passed from person-to-person, presumably from air-borne droplets (sneezing, coughing).

When the cysts become activated, they injure the lung lining, and the small air sacs cannot expand properly, so the person becomes short of breath. The body starts an inflammatory response, which makes the lungs even less efficient, and the pneumonia worsens.

Preventive therapy (prophylaxis) is effective. It is started when people have CD4 counts fall below a certain level. Traditionally the treatment of choice is trimethoprim/sulfamethoxazole (Bactrim, Septra, Cotrim). For people who are allergic to sulfa drugs, other oral regimens include Dapsone, Fansidor (pyrimethamine+sulfadoxine) or monthly pentamidine by IV or breathing treatment.

Symptoms of Pneumocystis carinii pneumonia (PCP) develop gradually and usually include persistent fever. There's usually a dry cough but sputum can be produced in people with chronic lung disease or an additional bacterial pneumonia (10-30% of cases). People notice increasing shortness of breath and fatigue with normal activities. Although it most commonly causes pneumonia, Pneumocystis can also invade the liver, spleen, lymph nodes, gastrointestinal tract, bone marrow or eye. Symptoms include fever, fatigue, and specific complaints related to the area infected. These infections outside of the lungs are more likely to occur when prophylaxis is given as a breathing treatment. The medications used to treat acute pneumonia also work for the other sites of disease.

Diagnosing Pneumocystis involves several steps. The chest Xray may initially be normal, but later shows changes from the pneumonia. A gallium scan (IV dose of tracing agent, then a series of Xrays over time) may show changes even when the chest Xray is normal, but cannot *prove* pneumocystis infection.

A good sputum specimen (breathing treatment may be necessary to get a really good cough) is checked for cysts by using special stains. If that is unsuccessful a bronchoscopy will be needed. This involves a flexible fiberoptic tube which allows the surgeon to look directly at the lungs and take samples of the secretions. Sedation is given prior to the procedure, and for people with bleeding disorders, pre- and post-treatment with factor is very important. Arterial blood gases (drawn from the wrist) are important for determining the severity of pneumonia and need for oxygen. Factor should be given prior to this procedure as well.

Treatment involves at least 3 weeks of antibiotics. Mild PCP can be treated with oral medication and close out-patient follow-up. More severe cases will require hospitalization with intravenous antibiotics, possibly oxygen or even temporary use of a ventilator until the medicine starts to work.

As the antibiotics kill the Pneumocystis, the dying cells may actually make breathing worse for the first 3 to 5 days. If there is no improvement by the end of a week, different medications may be needed.

In moderate to severe pneumonia, a short treatment of steroids is given with the antibiotics to reduce the lung inflammation. This significantly improves the chance for survival.

CALENDAR OF EVENTS

MARCH

12 WONN Meeting - OHF Office
and Red Tie Night - Oklahoma
AIDS Care Fund
25 — 27 Young Women With
Bleeding Distorders Retreat
Oklahoma State University

APRIL

9 Garage Sale - Fairgrounds - OKC
15 — 17 Young Men With
Bleeding Distorders Retreat
Oklahoma State University
16 — 17 WONN Seminar -
Houston
29 Adult/Couples HIV Retreat -
Dallas

MAY

1 @ 10 a.m. — 8 p.m.
Frontier City
89er Adventure Days Family Outing
Oklahoma City
22 @ 10:30 a.m. — 6:00 p.m.
White Water Bay
Tropical Adventure Family Outing
Oklahoma City

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
25 — 30
NHF Annual Meeting
Dallas

NOVEMBER

DECEMBER

TBA
OHF Christmas Party

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 April 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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