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Sender's City	Sender's State	Sender's Zip

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF NATIONAL DRUG CONTROL POLICY
Washington, D.C. 20503

March 6, 1998

INFORMATION

MEMORANDUM FOR SANDRA THURMAN, DIRECTOR, WHITE HOUSE OFFICE OF NATIONAL AIDS POLICY

FROM: HOOVER ADGER, JR., MD, MPH
DEPUTY DIRECTOR

SUBJECT: REQUESTED INFORMATION FOR THE INTERDEPARTMENTAL TASK FORCE ON HIV/AIDS

This memo is in response to your request for information for the Interdepartmental Task Force on HIV/AIDS. The Office of National Drug Control Policy is primarily a policy office, however a number ONDCP initiatives include HIV-related efforts:

- **The *National Drug Control Strategy***. The Strategy recognizes the link between drug use (especially injecting drug use and crack cocaine use) and HIV/AIDS. Specific priorities in the *1998 Strategy* include:
    - **Drug Treatment**. The FY 1999 budget request includes an increase of $200 million in the Substance Abuse Block Grant. An increase in funding would help in closing the gap between drug treatment capacity and need. Effective drug treatment can serve as a component of comprehensive HIV prevention efforts.
    - **Regulatory Reform**. ONDCP is working with the Departments of Health and Human Services and Justice on the reform of methadone treatment regulations. These reforms can serve to improve program quality and make methadone, LAAM, and other pharmacotherapies more widely available.
    - **Performance Measures of Effectiveness.** The *National Drug Control Strategy* contains specific, quantified targets for the reduction in drug abuse-related HIV infection, Tuberculosis, and Hepatitis B.
- **The US-Mexico Demand Reduction Conference**. The conference will take place in El Paso on March 18-20, 1998. The conference will include HIV/AIDS prevention as one of the demand reduction priorities. The issue is important both to the Mexican government and to ONDCP.

- **The National Youth Anti-Drug Media Campaign**. The Campaign is a central feature of the Administration's effort to prevent illicit drug use among the nation's youth -- the number one goal of the *National Drug Control Strategy*. The campaign will focus on children between the ages of nine and seventeen and adults who influence them, including parents, teachers, coaches, and mentors. ONDCP appreciates the input provided by ONAP. The campaign will include some public service announcements that will focus on the consequences of drug use such as HIV/AIDS.

I hope you find this information useful. If you require further assistance please do not hesitate to contact myself or Jane Sanville, Office of Demand Reduction, ONDCP.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

March 11, 1998

Dear Colleague:

One of the parts of my job that I enjoy most is when there is an opportunity to share good news.

Today I am writing to call your attention to the power of good science. Recently, we shared the very positive news of a CDC/Ministry of Public Health of Thailand collaborative clinical trail. The trail demonstrate that a short, simple, and affordable regimen of AZT given late in pregnancy and during delivery reduced the rate of mother-to-infant HIV transmission by 51% and is safe for use in the developing world. Attached is an MMWR article, released today, about this important research.

These findings provide, for the first time, a feasible intervention for reducing perinatal transmission in the developing world. This is of crucial importance since it is estimated that 1600 children are born HIV-infected each day, with over 90% of them from the developing world.

Now I have the pleasure of reporting some activities set in motion, in large part, by findings from the Thailand study. Glaxo-Welcome (Glaxo) has announced plans to cut prices of AZT for pregnant women in developing nations by as much as 75%. The attached article from the Thursday, March 5th Wall Street Journal describes in greater detail Glaxo's plan. UNAIDS will soon convene an international meeting to discuss the Thailand results, Glaxo's plans, and what all of this means for HIV prevention in developing countries.

CDC will continue to participate in these discussions and will do whatever we can to facilitate implementation of the short-course AZT regimen for pregnant women in developing countries. While Glaxo's price reduction will not eliminate all barriers, it is certainly a step in the right direction.

As tempting as it is to hope for a "magic bullet", there is no single solution that will bring the HIV epidemic to an end. Still, it is very encouraging to see public health, international development, and business communities working together to create solutions. It should remind all of us that there is reason to hope, to fight the good fight, and to never, never give up.

Sincerely,

Helene Gayle

Helene D. Gayle, M.D.,M.P.H
Director, National Center for HIV, STD and TB Prevention
Centers for Disease Control and Prevention

Tetanus Among Injecting-Drug Users — Continued

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Administration of Zidovudine During Late Pregnancy and Delivery to Prevent Perinatal HIV Transmission — Thailand, 1996–1998

Worldwide, approximately 500,000 infants are perinatally infected with human immunodeficiency virus (HIV) each year, most of whom are born in developing countries (*1*). In 1994, a clinical trial in the United States and France demonstrated that zidovudine (ZDV) administered orally five times a day to HIV-infected pregnant women starting at 14–34 weeks' gestation, intravenously during labor, and orally to their newborns for 6 weeks reduced the risk for perinatal HIV transmission by two thirds (*2*). In 1994, this regimen was recommended as standard care in the United States (*3*); however, because of its complexity and cost, this regimen has not been implemented in most developing countries, and no other intervention had been efficacious in reducing perinatal HIV transmission. In 1996, the Ministry of Public Health of Thailand and Mahidol University, in collaboration with CDC, initiated a randomized, placebo-controlled trial of a simpler and less expensive regimen of ZDV to prevent perinatal HIV transmission. This report describes preliminary trial results, which indicate that a short-term antenatal regimen of ZDV reduced the risk for perinatal HIV transmission by approximately half.

HIV-infected pregnant women gave written informed consent for participation and were randomly selected at each of two study hospitals in Bangkok to receive either ZDV or a placebo. The ZDV regimen consisted of 300 mg orally twice a day from 36 weeks' gestation until onset of labor and 300 mg every 3 hours from onset of labor until delivery. All women were provided infant formula and counseled not to breastfeed, consistent with national guidelines for HIV-infected women in Thailand. The planned sample size was 392 women, selected to provide 80% power to detect a 50% lower transmission rate in the ZDV group compared with a transmission rate of 24% in the placebo group. The study endpoint was the HIV-infection status of the infant at age 6 months, determined by results of polymerase chain reaction (PCR) testing for HIV DNA performed on blood specimens obtained at birth, 2 months, and 6 months.

Zidovudine to Prevent Perinatal HIV Transmission — Continued

The proportion of children found to be infected by age 6 months in each treatment group was estimated by using the Kaplan-Meier method. The null hypothesis of no treatment effect was tested by using a normally distributed Z statistic computed from these estimates. As a result of two interim evaluations of treatment efficacy for data and safety monitoring in July 1997 and January 1998, the critical value of the Z statistic for rejecting the null hypothesis of no treatment effect at the end of the study was 2.05. The trial protocol was approved by human subjects committees in Thailand and at CDC, and the conduct of the trials was monitored by a data and safety monitoring board at the U.S. National Institutes of Health, which included a senior health official from Thailand.

From May 23, 1996, through December 31, 1997, a total of 397 women were enrolled; four women were lost to follow-up before delivery, and 393 women delivered 395 live-born infants (Table 1). At enrollment, the median age was 24 years, and the median CD4+ cell count was 424 cells/μL. Fourteen percent of women had cesarean deliveries. The median duration of antenatal treatment was 25 days, and the median number of doses during labor was three. Of these enrollees, 99% took at least 90% of the prescribed doses of ZDV during the antepartum period, and 99% took at least one dose during labor; 96% of study visits were kept. Baseline and delivery characteristics, protocol adherence, and adverse event rates were similar in the two trial groups. No women breastfed their infants.

As of February 13, 1998, PCR data were available for 391 children (Table 1). Of these, 52 children have tested PCR positive (17 in the ZDV group and 35 in the placebo group), all by their 2-month visit. Of the remaining 339 children, 310 tested PCR negative at age ≥2 months, and 29 children tested PCR negative at birth but have not yet been evaluated further. The estimated HIV transmission risk for the ZDV and placebo groups were 9.2% (95% confidence interval [CI]=5.0%–13.5%) and 18.6% (95% CI=13.0%–24.0%), respectively, representing a 51% (95% CI=15%–71%) decrease in

TABLE 1. Study outcome of perinatal zidovudine (ZDV) trial, by treatment group — Bangkok, Thailand, 1998

Category	Treatment group	
	ZDV (n=198)	Placebo (n=199)
Median CD4+ count (cells/μL) at enrollment	428	410
No. women lost to follow-up before delivery	3	1
No. women who delivered infants	195	198
No. live-born children*	196	199
No. children with at least one polymerase chain reaction (PCR) result†	193	198
No. children with positive PCR	17	35
Risk for perinatal transmission *(95% confidence interval)*§	9.2% *(5.0%–13.5%)*	18.6% *(13.0%–24.0%)*
No. children died	3	4

*Includes one set of twins in each treatment group.
†Excludes one child from each set of twins. In addition, one child died without a PCR result, and one child's first result is pending.
§Estimated using the Kaplan-Meier method.

Zidovudine to Prevent Perinatal HIV Transmission — Continued

transmission risk. On the basis of these data, the Z statistic for testing for a difference between the groups was 2.67 (p=0.008). Assuming that all infected children will be detected by their 2-month visit and that the transmission risk among the children whose infection status is pending is as high as 24%, the probability is >98% that the null hypothesis of no treatment effect will be rejected when all results are available.

Reported by: P Vuthipongse, MD, Ministry of Public Health; C Bhadrakom, MD, P Chaisilwattana, MD, A Roongpisuthipong, MD, A Chalermchokcharoenkit, MD, Dept of OB/GYN; S Chearskul, MD, N Wanprapa, MD, K Chokephaibulkit, MD, M Tuchinda, MD, Dept of Pediatrics; C Wasi, MD, R Chuachoowong, MD, Dept of Microbiology, Siriraj Hospital, Mahidol Univ; W Siriwasin, MD, P Chinayon, MD, S Asavapiriyanont, MD, Dept of OB/GYN, Rajavithi Hospital; T Chotpitayasunondh, MD, N Waranawat, MD, V Sangtaweesin, MD, S Horpaopan, MD, Queen Sirikit National Institute for Child Health, Bangkok; The HIV/AIDS Collaboration, Nonthaburi, Thailand. Div of HIV/AIDS Prevention–Surveillance and Epidemiology, National Center for HIV, STD and TB Prevention, CDC.

Editorial Note: This report is the first to describe the efficacy of a short-term regimen of an antiretroviral drug for preventing perinatal HIV transmission. The regimen studied in this trial is more feasible for implementation in Thailand and other developing countries than the regimen now used in the United States (*3*) because it is less expensive (i.e., $50 versus $800) and logistically simpler (i.e., later start in pregnancy, shorter duration, less frequent dosing, oral labor dosing, and no infant treatment). If implemented, thousands of perinatal HIV infections annually could be prevented in Thailand, where an estimated 20,000 HIV-infected women deliver infants each year.

Although this trial was not designed to compare the short-term ZDV regimen to the longer regimen (*2*), the decrease in transmission rate (51%) using the shorter regimen is less than the 66% decrease with the longer regimen. The smaller treatment effect could result from the shorter duration of treatment, oral rather than intravenous administration during labor, lack of treatment for the infant, different study populations, random variation, or a combination of these factors. However, this clinical trial demonstrates that a shorter regimen of ZDV given only during pregnancy can substantially reduce perinatal transmission.

Reasons are unknown for the lower transmission rate in the placebo group (18.6%) than in untreated women (24.2%) studied in the same hospitals during 1993–1994 (*4*). The lower than expected background transmission rate highlights the importance of having included a randomized, concurrently enrolled, untreated control group. Had the test regimen been inactive, a transmission rate of 18.6% may have suggested some efficacy when compared with historical data.

CDC has sponsored another placebo-controlled trial of the same regimen of ZDV in collaboration with the Ministry of Public Health in Côte d'Ivoire in west Africa, where most HIV-infected women breastfeed their infants. Because the trial in Thailand demonstrated that the short-term regimen is efficacious in reducing transmission around the time of birth, and because preliminary data from the trial in Côte d'Ivoire have shown the regimen to be safe in this population, enrollment in the placebo group of the Côte d'Ivoire trial has been stopped. All women enrolled in the study are being offered the short-term ZDV regimen. Because breastfeeding is associated with postnatal HIV transmission from mothers to infants (*5*), follow-up of enrolled infants will continue to determine whether the short-term ZDV regimen results in an overall lower risk for mother-infant HIV transmission in populations where HIV-infected women routinely breastfeed.

Zidovudine to Prevent Perinatal HIV Transmission — Continued

To implement these findings, ministries of health, donor agencies, and other international agencies should develop policies and practices to strengthen access to prenatal care, testing and counseling for HIV infection, and provision of ZDV for HIV-infected pregnant women. Operational research is needed to optimize provision of this intervention to HIV-infected women in resource-poor settings. Further evaluation is needed of the effect of breastfeeding on the efficacy of this regimen.

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HIV/AIDS Among American Indians and Alaskan Natives — United States, 1981–1997

A total of 641,086 cases of acquired immunodeficiency syndrome (AIDS) had been reported to CDC through December 1997. Of these, 1783 (0.3%) occurred in American Indians and Alaskan Natives (AI/ANs). AI/ANs represent <1% of the total U.S. population (272 million persons) and are characteristically diverse, comprising many tribes—of which 557 are federally recognized (*1*). Each tribe has its own traditions and culture.

This report* 1) describes characteristics of AI/ANs with AIDS reported to CDC through 1997; 2) summarizes trends in AIDS incidence among AI/ANs from 1986 to 1996; and 3) for the 25 states in which surveillance was conducted during 1994–1997 for human immunodeficiency virus (HIV) and AIDS, compares the characteristics of AI/ANs who had reported HIV infection (without AIDS) with those of AI/ANs who had AIDS. These findings, which highlight the characteristics of AI/ANs for whom HIV or AIDS had been diagnosed, can assist in the development of targeted prevention strategies.

Trends in AIDS incidence among AI/ANs aged ≥13 years were evaluated using estimated incidence of AIDS-opportunistic illness (AIDS-OI) adjusted for reporting delays, unreported risk/exposure, and changes in 1993 in the AIDS case definition for persons aged ≥13 years (*2*). Trends in estimated incidence of AIDS-OI were analyzed by 6-month interval of diagnosis for January 1986–December 1996 (i.e., the most recent date for which AIDS-OI incidence could be estimated reliably). Estimated AIDS-OI incidence rates per 100,000 population by sex, race/ethnicity, and year of diagnosis were

*Single copies of this report will be available until March 6, 1999, from the CDC National AIDS Clearinghouse, P.O. Box 6003, Rockville, MD 20849-6003; telephone (800) 458-5231 or (301) 519-0459.

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The Wall Street Journal Interactive Edition -- March 5, 1998

AZT Price Reduction Is Expected For Third-World Mothers-to-Be

By MICHAEL WALDHOLZ
Staff Reporter of THE WALL STREET JOURNAL

After two years of secret international negotiations about drug profits and public health, Glaxo Wellcome PLC is expected to unveil Thursday a surprising plan to slash the price of the AIDS drug **AZT** for pregnant women in developing nations by as much as 75%.

The plan, effective immediately, marks a landmark step towards getting **AZT** to the estimated three million infected pregnant women in the impoverished parts of the world that account for 90% of the world's AIDS cases. But the move is likely to intensify the outcry for drug makers to provide drugs to others in developing nations at significantly reduced prices or even for free. And the pressure isn't over for Glaxo, which is cutting prices for a short course of **AZT** aimed at preventing the spread of AIDS to newborn children -- but not for the long-term treatment of their mothers.

Glaxo Wellcome Draft Announcement

United Nations AIDS Draft Announcement

Study Says Short Treatment Cuts Mother-Child HIV Transmission (Feb. 19)

Glaxo's announcement comes two weeks after pathbreaking research confirmed that transmission of the virus to newborns can frequently be blocked by treating infected mothers for as little as a few weeks before birth with a small dose of **AZT**. Last year alone, about 600,000 children world-wide died from AIDS contracted from their infected mothers.

The Glaxo announcement will mark the first time one of the world's giant drug makers has agreed to slash the price of an AIDS medicine to get it to the regions where the epidemic is killing tens of thousands of people a year and devastating local economies. Under pressure from activists and public-health officials, Glaxo has cut AZT's price in the U.S. several times. When the drug was first introduced in the U.S. 10 years ago, it sold for $12,000 for a year of therapy. The cost now is about $4,000. Last year, Glaxo's world-wide **AZT** revenue was $471 million.

Hard to Get

Even if **AZT** does become affordable, many health officials doubt the

drugs will reach poor women any time soon. Few places, especially in Sub-Sahara Africa where the epidemic is raging, can afford the medical facilities or staff to identify infected women and treat them daily for three to four weeks before they give birth.

"I fear even beyond the price of the drugs, there are many problems to be solved before the treatment can become widely available," says Jerry Coovadia, the head of pediatrics and child health at the University of Natal, in Durban, South Africa.

Nevertheless Glaxo's decision to cut AZT's cost to pregnant women, which it reached in the past few days, is expected to surprise many AIDS activists and health officials. They have long argued that AZT's high price has been a major barrier to delivering the drug beyond the industrialized world.

In 1994, research found that administering **AZT** to infected pregnant women for several months prior to birth and for some time afterward could reduce HIV transmission to infants by two-thirds. As a result, the so-called long course of **AZT** therapy is now common practice in U.S. hospitals, where the treatment typically costs $800 to $1,000.

The U.S. Centers for Disease Control and Prevention report that between 1992 and 1996, the regimen reduced mother-to-child transmission 43%.

The agency also reports that the number of children infected with HIV annually dropped to 500 in 1996 from a high of about 2,000 in the early 1990s.

That success encouraged researchers to study whether a much lower and cheaper regimen -- from four weeks to even a few days before delivery -- could be equally effective. But the studies generated a storm of controversy late last year when critics charged they were unethical. In several studies, doctors gave some women the short course of therapy and compared them with women who received placebos.

"It was an outrageous and unacceptable research design," says Marcia Angell, executive editor of the prestigious New England Journal of Medicine.

Essential Placebo

But Joseph Saba, a top official at UNAIDS, the United Nations agency spearheading the international battle against the disease, says the use of a placebo was essential. "We needed the most rigorous study and findings we could produce if we were going to convince the [poorer] countries and others to invest in the [medical services] needed to distribute the drugs safely and effectively," he says. "The countries told us they were interested in implementing the [**AZT**] regimen, but they all told us, "Before we go ahead, give us the proof." "

That proof arrived two weeks ago from a study in Thailand. The research, initiated in 1996 by the CDC and UNAIDS, found that just three weeks of **AZT** pills given daily reduced transmission rates by

half -- somewhat less effective than the longer course but still impressive, researchers say.

The Thai report galvanized efforts to get Glaxo to drop its price. Glaxo officials say the company had been considering a price cut ever since it began offering **AZT** free of charge for use in the dozen or so studies testing shorter regimens. Indeed, Dr. Saba of UNAIDS first broached the subject with Peter Young, a top Glaxo executive, in the summer of 1996.

Long before the company decided how to make the expensive drug available, "we were committed to working with Dr. Saba to make this happen," Dr. Young says. "But we knew, too, that it would be no good to make the drugs available if there was no way to get them to people."

Those struggling to get **AZT** to developing nations agree that progress to date is largely due to the aggressive activity of the 37-year-old Dr. Saba. The infectious-disease physician, a Lebanese native who is now a French national, has been attacking the mother-to-child transmission problem since the formation of UNAIDS in early 1996 and for two years before that at the World Health Organization.

"If not for Dr. Saba, none of this-not the studies, not the interest by Glaxo or the countries affected-would have happened," says Catherine Wilfert, science director of the Los Angeles-based Pediatric AIDS Foundation.

No Free Drugs

While awaiting results of the short-course studies, Dr. Saba and his UNAIDS colleagues developed a cost-effectiveness formula they hoped would be powerful enough to persuade the developing countries and Glaxo that the short course of therapy would be impossible to resist at a discounted rate. He says that several countries, including South Africa, Botswana, Zimbabwe and Thailand, have said they are prepared to create the services needed to deliver the drugs to some areas of their nations. He has scheduled a two-day meeting at the end of this month at which Glaxo, the developing countries and richer nations such as the U.S. will work on eliminating existing obstacles.

Dr. Saba and others say they don't favor free drug distribution because "we all understand that the drug makers need to make something on their products; that's just the way things are."

Glaxo's Dr. Young says the company will negotiate a price with each country depending on the country's economic situation. But those familiar with the plan say Glaxo will likely charge about $50 to $150 for the short course. Dr. Saba says he hopes the therapy's cost will drop even further; new studies expected to be completed by year's end are investigating whether a single dose of the drug given at the time of delivery will also block transmission. If true, that **AZT** regimen would cost less than $10, some speculate, but would still involve hefty costs for drug delivery.

People familiar with Glaxo's discounted price offer believe that only about 10% to 25% of the three million affected women will get the drug in the next few years, meaning that added revenue to Glaxo would be about $60 million or so a year. That additional revenue isn't expected to have much impact on Glaxo's earnings.

Many activists hope Glaxo's action and the willingness of countries to buy the drug will create a model for getting other AIDS drugs to people who are already infected. Many health officials expect the topic to gain wide attention at the International AIDS Conference to be held in Geneva in early July.

Still, some activists believe even a reduced price is too high. Says Larry Kramer, a longtime AIDS activist and writer: "After all the millions [Glaxo] has made on **AZT**, it should give it away."

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The George Washington University
WASHINGTON DC
MEDICAL CENTER

FORUM FOR COLLABORATIVE HIV RESEARCH

March 27, 1998

Dear Colleagues:

Attached you will find the third Quarterly Report of the Forum for Collaborative HIV Research (FCHR). The report describes both the substantive and procedural activities of the FCHR from December, 1997 through February, 1998. The report is submitted as a requirement under the FCHR's contract with the Department of Health and Human Services. However, I like to make this report available to all parties interested and involved with the FCHR to update you on our activities.

In the coming weeks, the FCHR will release the conference report from its conference on adherence to HIV therapy. We will also release our report on research in anti-retroviral treatment failure. In May, the FCHR will hold a workshop to develop a strategic plan for the dissemination of HIV clinical practice guidelines to providers and patients. We will also hold a meeting to discuss the emerging role of managed care organizations in the provision of HIV care and research.

If you have any questions or comments about anything you read in this report or any issue which you feel would be appropriate for investigation by the FCHR, please do not hesitate to call me at 202-530-2307 or e-mail: ihodxb@gwumc.edu You can also learn more about FCHR activities through our home page at: http://www.gwumc.edu/chpr/hivforum.htm FCHR reports are available through this site.

Yours truly,

David Barr
Director

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The George Washington University
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MEDICAL CENTER

FORUM FOR COLLABORATIVE HIV RESEARCH

Quarterly Report - Third Quarter

The following is the third quarterly report for the Forum for Collaborative HIV Research (FCHR), as required under Contract No. HHS-100-97-0015. This report covers the period from December 1, 1997 through February 28, 1998, and will provide information about the progress of the FCHR.

Membership/Administration

Executive Committee

During the third quarter, the FCHR Executive Committee (EC) held one meeting and five teleconferences. The EC meeting was held on Sunday, February 1st in Chicago (summary report from that meeting is attached). Agendas for that meeting and for each teleconference were sent to EC members in advance[1]. These meetings are regularly scheduled and provide the EC membership with regular reports on : (1) the administration and finances of the FCHR; (2) the development of analytic reports, and (3) communications efforts of the FCHR with the membership and the public[2]. As in the previous quarter, the EC discussed the status of current FCHR projects (described below), the growth of FCHR membership, the evaluation and continuation of the FCHR and the development of new projects.[3] At its February 1st meeting, the EC re-evaluated the scope of work for the FCHR, emphasizing the need to increase support among health care providers and payors. The topics raised at the February 1st meeting included (see below and attached meeting summary for details of these discussions):

- FCHR financial status;
- Review of planned FCHR events;
- Scope and methodology of FCHR projects;
- Participation of third-party payors;
- Funding for Fiscal Year '98-99;
- FCHR Data Base

[1] As required, HHS Delivery Order #HHS-100-97-0015 (hereinafter HHS DO), Task 4.2
[2] HHS DO, Tasks 1.4, 3.3, 4.4
[3] HHS DO, Tasks 3.4

Progress on Funding for FY '98-99

Both the public and private-sector EC representatives agreed that the FCHR should continue into FY '98-99 and are now actively seeking financial support. This would include the possible continuation of the Task Order through the Office of the Assistant Secretary of Planning and Evaluation. EC Government Representatives met to discuss this option (see below). The four pharmaceutical companies represented at the February 1st meeting each committed to renew their financial support for the FCHR and seek continued support from the industry membership. The EC also determined that it would be appropriate for the FCHR to seek out other methods of funding, including support from foundations and additional government-sponsored grants and contracts. The Forum Director will seek out funding options and present them to the EC as they arise.

FCHR Evaluation

The FCHR Director presented two proposals for the upcoming evaluation of the FCHR. The EC Evaluation Sub-Committee met to discuss these proposals. The Sub-Committee determined that both proposals were broader in scope than necessary at this time. While the proposals would be a good basis for an evaluation of FCHR activities in a year from now; at this point, the FCHR needs an evaluation of how it has met its initial objectives and the expectations of the membership. Mr. Barr was asked to speak with individuals with expertise in evaluations of new projects at the George Washington University and to meet with consultants from two private organizations. Since that discussion, Mr. Barr has met with representatives from two private consulting firms and described the scope of the proposed evaluation of the FCHR. Both firms are submitting proposals for review.

Constituency Group Meetings

During this quarter, three of the member constituency groups held teleconferences. Each group received updates on all FCHR projects from the FCHR Director and then discussed possible future projects and continued support for the FCHR during FY '98-99.

- Pharmaceutical membership - the members were pleased with the projects and work that the FCHR had undertaken to date, but expressed concern about the perceived under-representation of private-sector health care provider/payors (see below for the EC discussion on this topic.). Diane Goodwin from Glaxo Wellcome replaced Cheryl Karol from Hoffman La Roche as an EC representative.
- Patient Advocacy Group - the members requested that monthly calls be arranged to better inform them about FCHR activities. William Strain from AIDS Project Los Angeles and a member of the ACTG Community Constituency Group became an EC community representative, replacing Vanessa Johnson.
- Government membership (two meetings) - The members agreed to continued support for the FCHR and is working toward securing funding for FY '98-99. Three government agencies identified their representatives to the FCHR: HRSA - Joseph Palenicik, FDA - Terry Toigo, CDC - Jon Kaplan.

Participation of Third-party Payors

At the meeting of February 1st, the EC continued its discussion about how to increase the participation of third-payors and managed care organizations in the FCHR. The EC agreed that the participation of public- and private-third party payors is necessary in furthering the goals of the FCHR. The EC then examined the levels of participation by payors thus far and discussed how to increase that participation over the coming months. Here is a synopsis of those discussions:

- While there is a relative lack of participation among private third-party payors, the public sector is very active in the FCHR and its activities. The Health Care Financing Administration (HCFA), the Department of Veterans' Affairs and the New York State AIDS Institute are all members of the FCHR Executive Committee. In addition, the Health Resources and Services Administration (HRSA) has been an active FCHR member, contributing financially to the government funding and participating in FCHR events. These payors provide health care services to the large majority of people with HIV in the United States.
- Two private payors have contributed financially to the FCHR - Harvard Pilgrim Health Care and Kaiser Permanente. Several other private third-party payors participated in the FCHR's Conference on Adherence to HIV Therapies.
- The EC members agreed that there are two major difficulties we face in bringing private third-party payors into the FCHR: (1) for the majority of private payors, HIV care is not a priority issue because so few plan members are HIV-infected; (2) payors are not used to participating in discussions about clinical research and drug development. The EC agreed that educating payors about why these issues are relevant to them should be a high priority (see Next Steps below).

The EC decided on several steps that can be taken to address the concerns raised by the Pharmaceutical Industry members. These are:

- Efforts to involve increased payor participation will involve the all the members of the Executive Committee, rather than just FCHR staff and the EC payor representative.
- The FCHR will conduct a meeting between the FCHR Executive Committee members, public and private third-party payors, professional associations representing payors, and health-care practitioners. The meeting would: (a) provide payors with information about the work of the FCHR, (b) identify issues in HIV clinical care and health care utilization research that are of concern to payors and appropriate as FCHR projects, (c) discuss the integration of HIV clinical research in health care delivery, and (d) how payors can participate as members in the FCHR. This meeting is now being organized and is planned for late May.
- FCHR staff will develop a report on current research findings and efforts regarding HIV-related health care utilization. This report will serve to better inform FCHR members about how HIV care is accessed in the United States and will allow us to better target those payors who would be most interested in the work of the FCHR.

The report will also be an important tool for the FCHR Project to Develop a Research Agenda in HIV Patient Outcomes Research.

- Both the Clinical Practice Guidelines Dissemination Project and the Patient Outcomes Project, which have generated considerable interest among payors and health care providers are to be considered high priority projects for the FCHR;
- The Executive Committee determined that it would be more advantageous to seek FCHR financial support from third-party payors for specific projects, instead of contributions to overall FCHR funding at this time. Once we have built a more solid working relationship with private payor organizations, we will seek overall financial support.

FCHR Projects

Adherence to HIV Therapies

FCHR staff met with staff from the co-sponsoring organizations (NIH Office of AIDS Research and the National Minority AIDS Council) to draft the report from the November 20th and 21st conference entitled *Adherence to HIV Therapy - A Research Conference.* The report consists of three sections: (1) a research agenda developed from the discussions of workshop participants from the second day of the conference; (2) summaries from the presentations of the first day of the conference; and (3) a bibliography and summary of the literature on adherence to treatment. FCHR participated in the writing and editing of each section. The draft report was circulated for comment to the project Planning Committee. Final edits are now completed and the report is in production. The report will be mailed to all 500 conference participants, the individual mailing lists from the three sponsoring organizations, and placed on the FCHR web site.[4] The FCHR Director will present the findings from the report at several upcoming conferences including the XII International AIDS Conference in July, the National AIDS Update Conference in March and the 4th International Congress on HIV Drug Therapy in November.

Dissemination and Evaluation of HIV Clinical Practice Guidelines

The Planning Committee for this project met on December 12, 1998. The minutes from that meeting were distributed to the Committee and to the EC. A proposal for the project was developed by the FCHR Director based on the discussions of the Planning Committee. That proposal was then discussed by the Planning Committee and a final proposal was completed and distributed (attached). The original goal of the project was two-fold: (1) to develop a needs assessment and strategic plan for the dissemination of the information contained in the HIV Clinical Practice Guidelines; and (2) to develop a research agenda to examine the effects that the clinical practice guidelines have on patient outcomes and health care delivery. One outcome from the Planning Committee meeting is

[4] This report will be submitted to HHS as a deliverable to HHS DO, Task 3.3

to split there two goals into distinct and separate projects. The planning for the first project, Guidelines Dissemination Project, is now underway, with a workshop scheduled for May 11th and 12th (see attached Project Proposal for detailed description). The goal of the project is:

> *To develop a strategic plan for the dissemination of the information contained in the HIV Clinical Practice Guideline for health care providers, patients and caregivers. The Plan will include a determination of who needs the information and address the formats in which the information should be provided. The plan will provide strategies for both dissemination of information and the evaluation of the effectiveness of those dissemination efforts and whether the guidelines have been implemented in clinical practice. Finally, the plan will provide recommendations for the implementation of the proposals.*
>
> The project will consist of three components:
>
> (1) preparation for a two-day workshop to examine the needs and strategies for information dissemination, including the preparation of a bibliography and summary of current knowledge about information dissemination and evaluation techniques;
> (2) the two-day workshop, which will: (a) provide participants with information about current dissemination efforts, (b) identify gaps in those efforts, (c)determine strategies for filling those gaps and (d) develop evaluating those strategies and their impact on health care practice;
> (3) the preparation of a written strategic plan based on the outcome of discussion from the workshop, along with recommendations for implementation of the plan.

Planning for the second project, Patient Outcomes Project, will continue after the scheduled meeting of FCHR members and third-party payors. The EC believes both these projects will go far to increase payor participation in the FCHR and that this second project will benefit from greater participation from managed care organizations in the planning stages.

Research on Treatment Failure

The first draft of the report on research regarding the development of treatment strategies for patients who are failing on anti-viral therapy is now completed. The draft must now be sent to the Project Team for review and comment. Once those comments are incorporated into the draft, the report will move into production and distribution. Although the report was scheduled for a February release, the writers needed more time to include the large amount of new and relevant information from the recent Retrovirology Conference. There were also delays in obtaining responses from private-sector FCHR members about their current research efforts.

Following the release of the report, the Project Team will schedule a meeting of a Planning Committee to determine the next steps in the project. The Planning Committee will develop a workshop or series of workshops using the report as a basis for discussion to

identify the gaps and impediments in the research effort and make recommendations for filling those gaps.

FCHR Data Base

The prototype of the data base is now on-line and available for exploration by the EC members. The Data Base was described to EC members at the February 1st meeting and the members have been asked to investigate the data base and make comments on its structure and format. In the interim, a survey of pharmaceutical companies was taken by the FCHR staff regarding their current research efforts in strategies to address treatment failure. This results from this survey will be reported in the treatment failure report. However, the survey is also the prototype for information collection for the data base. Most participants responded to the survey, though only after repeated reminders. The survey utilized draft information-collection forms that will be standard for the data base. The data base will allow users to input information using printed forms or through on-line submission.

Metabolic Consequences of HIV Disease and Treatment

Since the FCHR held its meeting on this topic in September, interest in this area has risen dramatically. Several treatment journals and newsletters have printed stories about the metabolic abnormalities patients are experiencing while on anti-viral therapy. Many posters on the subject were presented at the recent Retrovirology Conference in Chicago. The FCHR meeting was the first time that there had been a coordinated discussion about these events. Initially, a second FCHR meeting was tentatively planned for March. However, the EC determined that before holding a second meeting, the Project Coordinator should present a proposed structure and agenda for the follow-up meeting. In the meantime, the Project Coordinator will compile the abstracts and articles on this subject and summarize them. The articles, abstracts and summary will then be made available to FCHR members and the public through a mailing and our website.

HIV Drug Resistance

The FCHR meeting on drug resistance provided an opportunity for researchers in academia and industry to share information and discuss the steps necessary to apply technology to measure drug resistance in the clinical setting. The EC determined that researchers have several other opportunities for discussion and interaction on this subject and, given the limited resources of the FCHR, it would be better not to have the FCHR attempt to coordinate communication efforts here. This is an area that can be re-visited based on the outcome of the Treatment Failure Project.

Heartland CARES

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March 7, 1998

Sandra L. Thurman, Director
Office of National AIDS Policy
The White House
1600 Pennsylvania Avenue
Washington, DC 20500

Heartland Cares, Inc
RICHARD FORTENBERY

Ph: 502-443-6044
Fax: 502-443-~~4009~~ 6065

P.O. Box 2875
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Dear Ms. Thurman:

You may recall we met and spoke briefly following your presentation to the *Allocating Healthcare Resources* conference sponsored by the International Association of Physicians in AIDS Care in November of 1997 in DC. I believe I mentioned I am a friend of Debbie Runion of Nashville.

I am writing to provide information on the progress of Heartland CARES as we enter our second year of community-based organization and begin final preparations to open our interstate system of rural clinical sites to provide primary care for persons living with HIV / AIDS in western Kentucky and southern Illinois. I wish to express sincere thanks to you, President Clinton, and Vice President Gore on the critical leadership and support you provide which is essential to empower those of us living with HIV to organize locally responsive systems of care. I have enclosed a letter to Dr. Joe O'Neill which further describes our program and thanks him for the wonderful progress the new HIV / AIDS Bureau is making in coordinating the titles and programs of Ryan White to increase efficiency and coordination.

As we all should realize, there are many more things we need to do in addressing the AIDS epidemic. Unfortunately, not all can be done, at least not at one time. This epidemic is not only the medical manifestation of the human immunodeficiency virus, but also the collective manifestation of a whole constellation of social and economic problems that were with us long before a particular virus emerged. While new medications and assured access to them are important, we all share responsibility for addressing all the problems in operation, not just a prescription for an infection.

We as a front-line organization and I personally recognize we must do the most possible for the most people living with HIV all across America. Unfortunately but practically, this must

be done in an environment largely hostile to even our most basic efforts to ensure access to care and services. The national legislative environment is not unlike our general cultural climate in making our work very difficult. We must "choose our fights carefully".

Our nation desperately needs a drug policy environment where treatment is preferred over jail for those who are caught in substance abuse but not engaged in drug distribution. This is not "soft", it is sensible. High-risk behavior so prevalent today in the adolescent population requires much more than a solely *Levitican* approach wherein the "wages of sin are death" by societal neglect. In a public health context, we do indeed need universal access to clean needles for IV drug users unable to access substance abuse treatment due to long waiting lists and we do indeed need universal access to comprehensive family planning services for *everyone* approaching, negotiating, or post-puberty. Children born in and never exposed to an environment other than drug-and-crime infested ghettos cannot be reasonably expected to behave as if they were raised in the suburbs. The scenarios are, of course, endless. All these problems were with us before HIV. The AIDS epidemic makes them much more evident and pressing.

I respectfully but ardently disagree with our some of our colleagues that the most important issues are those which feed the irrational distortions of the Jesse Helms' and Gary Bauers' and their followers. We must remain focused on providing care for all with HIV, *including* substance abuse treatment and family planning services. We can ill afford to jeopardize these by dividing our ranks over issues such as national needle exchange. I am certain there are a few folks who may be in need of an exchange program in our area and, when that may be appropriate and acceptable, our organization will certainly be willing to participate. But we, perhaps more than our urban colleagues, understand the necessary evil of political finesse as we tread into less-than-friendly territory with even the most basic of services where they are largely unwelcomed even today. *Many specific problems are local in magnitude and priority and are appropriately addressed at the local level.* Needle exchange is just such an issue.

In these days of sensationalism, media-fueling controversy and witch-hunting inside the Beltway, I hope to extend my encouragement and express my support and appreciation for the critically essential dedication of the Clinton Administration to our work. Please be assured I express these feelings at every opportunity in our community. Our work is too important to be distracted by tabloid "journalism" becoming the daily and hourly norm of our mainstream media. If I can ever be of assistance to you in our shared cause and work, please feel free to call anytime.

Sincerely,
Heartland CARES, Inc.

Rich Fortenbery, President

ATT: Joe O'Neill 3/7/98
Summary of Programs and Progress 3/1/98
RW3 EIS Abstract

COPY

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March 7, 1998

Dr. Joseph O'Neill
HIV/AIDS Bureau
Health Resources and Services Administration
5600 Fishers Lane
Rockville, Maryland 20857

Dear Dr. O'Neill:

I would like to take this opportunity to congratulate you on your position as administrator of the HIV/AIDS Bureau and commend you and the staff of HAB on the progress to date in integrating the various titles and programs of the Ryan White CARE Act. I have received your letter of February 18 to CARE Act grantees and look forward to contributing to the data collection and evaluation project. I felt, however, I would like to write to you directly to offer some observations and encouragement. I am particularly impressed to know you serve as the Bureau administrator and also maintain regular clinical work with Johns Hopkins. Your dedication in this regard is truly commendable.

You may recall approximately a year ago, we were experiencing considerable difficulties in our area with respect to getting services funded through Title II to clients on an equitable and fair basis. The local project sponsor, largely responsible for the myriad problems, withdrew from the Kentucky HIV Care Coordinator program last May. Since that time, we have rebuilt our basic infrastructure with client control of the consortium, a new Care Coordinator with a new sponsor agency who is doing an incredible job of reforming the program. We have developed a new and highly productive relationship with our state Title II administrator, Jamie Rittenhouse, and have enjoyed tremendous progress in our community-based grass roots organization, infrastructure development, and service capacity through Heartland CARES. Thank you for your letter of June 11 responding to my requests for assistance from HRSA. The results of everyone's efforts today model the responsiveness needed to make such critical programs as Ryan White work.

Heartland CARES is one of the fifteen Title III planning grantees in the second class of 1997. I have enclosed a fact sheet describing the progress we have made as we celebrated our first anniversary this past week. In working with the staff of the new Division of Community-

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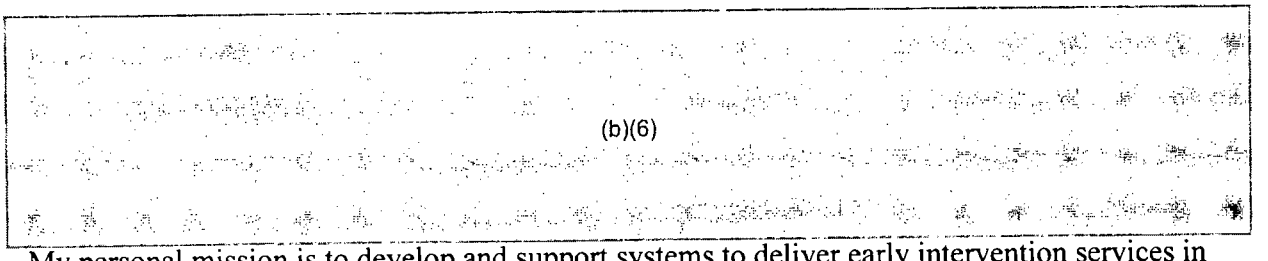
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

Based Programs, I have met some of the most wonderful colleagues in our world of work. I am working closely and on a continuing basis with Susan Thorner of Training Resources Network and we have charted some ambitious but critically needed work in linking programs and resource persons to develop a model for integrated primary care systems in the rural Southeast and Midwest. Diane Cairnes has been great as our project officer. Deborah Parham, Andy Kruzich, Barry Waterman, and Judy Humphrey have been wonderful sources of inspiration and guidance.

Twenty five years or so ago I worked with the early grass-roots implementation of the Emergency Medical Technician program in this area to replace the funeral home – hearse – ambulance system with the professional EMS system we all take for granted today. There was political resistance, controversy, and an uphill battle to provide a service relatively few believed was really needed in our area. During that experience, I met a wonderful group of people who shared an appreciation of need and a vision for meeting the need. I have lost track of most of them, but have a context of experience that I feel again today in working with the Ryan White program.



My personal mission is to develop and support systems to deliver early intervention services in the context of the model prescribed in the Title III EIS program here at home and through assistance to others in rural areas. [001]

We have applied for funding as a new EIS program this year and will begin our clinical program in July of this year when our medical director arrives. I was honored to be called for the objective review committee to evaluate the Title III competing continuation programs last November and look forward to serving on the ORC for the next class of Title III planning grants in the 1998 program year and well into the future. I am committed to supporting the work of the HIV AIDS Bureau in any way and hope you and the Bureau staff will feel free to call anytime.

Sincerely,
Heartland CARES, Inc.

Rich Fortenbery
President

ATT: Summary of Programs and Projects 3/1/98

Heartland CARES, Inc.

Summary of Programs and Projects

(Revised 3/1/98)

Heartland CARES, Inc. was established March 4, 1997 to study the needs of persons living with HIV disease in Western Kentucky and Southern Illinois and seek means of meeting those needs. The areas targeted for service development were expert primary health care, mental health and substance abuse assessment and treatment services and housing stabilization. In studying these issues, we realized the needs of those living with HIV are the same for a number of persons living with other disabilities. For many, loneliness and isolation with mental health and substance abuse complications, and inability to work consistently to earn a living are more troublesome factors in chronic homelessness than HIV infection itself. During the first year we have reached these milestones of progress:

Primary Health Care

- Secured funding for planning and development of a primary care system for persons living with HIV through Title III of the Ryan White CARE Act;
- Recruited a physician medical director whose credentials include board certifications in both internal medicine and infectious disease medicine
- Filed an application for operational funding through Ryan White Title III
- Designed a larger organization to provide health care to uninsured and underinsured persons and persons with disabilities other than HIV
- Employed two nurse practitioners to work in the clinical program, one each in Kentucky and Illinois

Mental Health and Substance Abuse Treatment Services

- Initiated a program to develop a culturally appropriate and responsive protocol for on going neuropsychological assessment, preventive and therapeutic intervention in individual and guided group settings, mental health counseling and referral and outpatient substance abuse prevention and treatment
- Developed a collaborative program to implement the integrated neuropsychological protocol through existing mental health and substance abuse provider agencies throughout the Heartland Clinic service area;
- Designed a plan to link on going mental health and substance services to housing stabilization and integrate these into primary health care and social services. The plan is being finalized and will soon be submitted for funding review.

Transitional Housing Stabilization

- Secured funding through the Housing Opportunties for Persons With AIDS (HOPWA) program to develop and implement transitional supportive housing to persons who are HIV positive and homeless or at high risk for homelessness. Heartland CARES is working with the Housing Authority of Paducah, the Madisonville Housing Authority, and the Kentucky Housing Corporation in implementing the infrastructure of this program
- Is working with the Purchase Continuum of Care Board to expand the transitional supportive housing services to include persons living with disabilities other than HIV

Current Projects

- Comprehensive development and implementation of the primary care program, as well as expansion of the basic model to incorporate the US Public Health Services Sec. 300 Community Health Centers program and related specialized targeted care programs
- Implementation of the first phase of the Community Care and Housing Program (CCHP / HOPWA component)
- The Multiple Diagnoses Initiative (MDI) Team is an on going program and protocol development group concerned with integrating primary care with other essential supportive services, especially mental health and substance abuse treatment services
- Continuing research and identification of funding opportunities with application for financial support from appropriate private and public sources
- A basic but comprehensive educational program for clients to increase understanding of living with HIV and the importance of and strategies for ensuring adherence to treatment

Future Directions

- Developing a program for clinical research on HIV and AIDS in the Heartland CARES program to access standard of care medications for clients without means of paying for treatment, maintain cutting-edge clinical knowledge, and contribute directly to the rapidly expanding base of scientific understanding of the biology and treatment of HIV disease
- Replicating the model of care and services established in Paducah in the Pennyrile Area Development District of Western Kentucky and in the Southern Illinois portion of the service area
- Pursue programs to further develop capacity to serve a broader group of persons in need of health, mental health, substance abuse, housing stabilization, and other essential services to enable self-sufficiency in living with disabilities and breaking the cycle of homelessness.

---

*For more information, contact **Vivian Pence, MSN** or **Rich Fortenbery, E.D.** at*

Heartland CARES

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PROJECT ABSTRACT
Heartland CARES, Inc.

The Heartland Clinic Project

Heartland CARES, Inc. (HCI) is a collaborative non-profit corporation whose mission is to plan, implement and operate a comprehensive continuum of care for persons living with HIV in the Heartland of America. Constituent organizations of Heartland CARES include community-based AIDS service organizations, HIV consortia and current providers of various components of care for those living with HIV and AIDS in our service area. Our guidance in this process is the system of primary care defined by the Ryan White CARE Act and supportive services specified in the Housing Opportunities for Persons With AIDS (HOPWA) program and the Multiple Diagnoses Initiative, a joint program co-sponsored by the Department of Health and Human Services and the Department of Housing and Urban Development. Our philosophy is holistically-based and strives to encourage self-sufficiency while fostering personal responsibility with adequate appropriate health and social service support. Our strategy is to reach out to enlist the support and technical assistance of our nearest current HIV care providers, some 150 to 200 miles to the Southeast and Northwest.

Targeted Population. Heartland CARES' service area consists of 32 counties, which comprise two HIV consortium regions. The Purchase Pennyrile HIV Care consortium includes 17 counties in Western Kentucky. The Southern Illinois Ryan White Title II consortium includes 15 counties. A map of the service area is found in Attachment B. Within the Heartland CARES service area, some 400 persons are known to be living with HIV. We estimate approximately one in five or six persons infected with HIV are reported. We project an actual HIV-infected population of some 2,000 to 2,500 persons, the majority of whom are unaware or unsure of their HIV serostatus and/or have not presented for care ***yet.*** Of these, we expect some five to six hundred will seek care during the next three years. The state health departments are currently experiencing an annual increase of some 35 to 40% in newly reported HIV cases.

HIV epidemiologic data from the state health departments are neither complete nor uniform in format. A client survey conducted recently by the regional state consortia and HCI indicate an increasingly youthful population presenting for care of HIV. When contrasted with age and other demographics of those reported Living With AIDS (LWA), the presumably more recently infected population Living With HIV (LWH) is *increasingly younger, increasingly female and increasingly non-white.* The conservative rural environment of the service area presents myriad practical and cultural barriers to the spectrum of care necessary to maintain health and reduce progression of persons living with HIV to persons living with AIDS. Transportation, economic and literacy barriers are common in our service area. Social institutions and charitable services still prefer to frame HIV as a problem that will go away on its own. Behaviors popularly associated with HIV infection often elicit more sanction than compassion in rural faith congregations.

Current HIV Service Activities. Limited HIV-specific services currently exist in the region. Many persons in the service area living with HIV travel to Nashville, TN or St. Louis, MO for primary care. Many are unable to manage their own transportation, so several organizations and

individuals in the Heartland CARES group assist with transportation to access care. Others who have been receiving care from family physicians locally are frequently referred to primary care providers in these cities when they progress toward AIDS. Local health departments provide HIV counseling & testing with varying consistency and quality of service. A regional mental health agency provides general mental health and substance abuse treatment in 9 of the 32 counties. Agencies in each of the two consortium regions provide case management and limited financial assistance through Ryan White Title II programs. Otherwise, no HIV-specific service resources exist in the area.

Heartland CARES is proud to be a recipient of the Ryan White Title III planning grant. This assistance greatly enhances our ability to effectively and efficiently develop our program. The planning grant has afforded us the opportunity to seek expert technical assistance and guidance, conduct site visits to successful Title III programs, and develop financial and management information systems. The planning grant funding will terminate if this application for EIS funding is approved.

Problem. Essential components of primary care providing early detection and intervention with respect to HIV are fragmented and frequently require unreasonable travel time, distance, and expense. As one's condition deteriorates, the frequency of travel increases, as does the cost and stress of travel on health. We are indeed fortunate to have the commitment of an infectious disease specialist physician to relocate in Paducah, the center of the Heartland CARES service area, in July 1998. In this context, our challenge lies in developing and organizing the infrastructure and supportive organization necessary to deliver high-quality holistic care. We have identified and enlisted key stakeholders in the design and development of a comprehensive continuum of care for HIV.

Goals and Objectives. Our goals and objectives are extensively developed in the workplan of this application document. In summary, **the Heartland Clinic project seeks to ensure:**

1. Availability of **high-quality HIV counseling and testing** service will be increased by providing at least 500 C&T encounters by July 1, 1998 through innovative approaches to implementing the CDC guidelines and applicable sections of the Ryan White CARE Act; at least 500 C&T encounters will be provided each year during 1999 and 2000;
2. **Comprehensive primary care** for 500 clients living with HIV will be ensured by June 30, 2000 through developing the necesary clinical infrastructure;
3. **Mental health and substance abuse treatment** will be accessible by 100% of HCI clients by Sept. 31, 1998 through increasing current provider capacity;
4. **Oral health care services** will be accessible for persons living with HIV in the region through developing provider networking and agreements by June 30, 1999;
5. **Case management services** of the existing Ryan White Title II programs will be coordinated with and enhanced by the Heartland Clinic project by Sept. 31, 1998 to increase quality of service for 100% of current and new clients; and
6. **Resource procurement and asset management** will ensure continually increasing high-quality, responsive primary care and supportive services for all persons living with HIV in the *Heartland of America* by June 30, 2000.

Excerpted from Ryan White Title III *Early Intervention Services* Application, 10/10/97

Heartland CARES, Inc.

Multiple Diagnoses / Integrated Primary Care Program

Goals of the Program

1.) Develop and convene a multidisciplinary working group to examine the particulars of program design and evaluation structure to integrate primary health care for HIV infection, mental health, and substance abuse assessment, early intervention and outpatient treatment;

2.) Design a team approach to facilitate "cross-training" of clinicians and counseling staff to develop and maintain a broad knowledge of both fields among all providers;

3.) Integrate primary care components so clients do not distinguish physical and mental health care services and are not intimidated by and resistant to "mental health services";

4.) Develop and design a protocol to implement this integrated care model;

5.) Identify and address sociocultural factors inherent to the rural Southeast and Midwest;

6.) Establish and maintain a network for consultation, referral, and on going education (quarterly conference proposed) to update and reinforce the knowledge base and share experiences of multidisciplinary practitioners;

7.) Develop a psychoeducational and cognitive-behavioral model for implementing preventive mental health care in group settings to encourage provider-client interaction so a therapeutic partnership is developed with each client which is already established at times of crises (e.g., deterioration of labs, viral breakthrough in treatment, HIV+ progresses to AIDS diagnosis, first and recurring opportunistic infections, etc.);

8.) Maximize client education and self-empowerment in the therapeutic alliance to provide consistent reinforcement of the care plan by all providers, which will enhance treatment and risk-reduction adherence while minimizing non-compliance;

9.) Encourage client empowerment along a continuum from adherence and self-care to training "peer counselors" who can contribute directly to the work of the CBO, particularly in mentoring new clients and bringing enlightened and motivated clients into the on going education and program development processes; and

10.) Provide a mechanism for ready replication in rural service systems by enhancing technical assistance and experience-sharing resources to mentor new CBO programs who seek to serve clients with a culturally responsive integrated system which ensures a continuum of care with minimal staffing requirements. A national resource for internships of mid-level practitioners will be developed and a tremendous resource for program development will be available.

Clinton Presidential Records
Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

Purchase-Pennyrile HIV Care Consortium

c/o P.O. Box 2875
Paducah, KY 42002-2875

First Quarter 1998 Meeting

January 19, 1998
1:00 p.m.
at Patti's 1880 Restaurant
Grand Rivers, KY

The Purchase-Pennyrile HIV Care Consortium meets at least quarterly to provide a forum for discussion and advice to the Purchase Pennyrile HIV Care Coordinator program. Other organizations providing services for persons living with HIV in the Purchase-Pennyrile area may also report activities and receive input from the Consortium, as well.

AGENDA

Welcome and Call to Order / Introductions

Reports of Organizations

- HIV Care Coordinator Program – Joe Farless
- Heartland CARES, Inc. – Rich Fortenbery
- KIPWAC – Alan Thomas
- Others

HOPWA (Housing Opportunities for Persons With AIDS) Program

- Current Status: Community Care and Housing Program (CCHP)
- Expansion to include a Pennyrile regional site
  - Call for task force committee
  - Technical support and assistance
- 1998 HOPWA program mission and goals

Heartland Clinic Program

- Ryan White Title III Program
  - Planning Grant
  - *Early Intervention Services program*
  - Technical assistance and support
- Scope of Services
  - HIV Counseling & Testing Services (CTS)
  - Primary Care
    - Infectious Disease Specialist physician
    - Nurse Practioner providers / medical case management
  - Mental Health & Substance Abuse Treatment

❑ TARZANA FACILITY
MAIN OFFFICE
18646 Oxnard Street
Tarzana, California 91356
(818) 996-1051
Fax (818) 345-3778

❑ LONG BEACH FACILITY
2101 Magnolia Avenue
Long Beach, California 90806
(562) 218-1868
Fax (562) 591-0346

❑ ANTELOPE VALLEY FACILITY
44447 No. 10th Street West
Lancaster, California 93534
(805) 726-2630
Fax (805) 726-2635

❑ RESEDA FACILITY
7101 Baird Avenue
Reseda, California 91335
(818) 342-5897
Fax (818) 345-6256

SERVICES:

- Detoxification
- Residential
- Women's Residential Including Children
- HIV Services
- Home Healthcare
- Outpatient Services Adult and Adolescent
- Drug Education
- Prevention
- After Care
- Partial Hospitalization
- Sober Living
- Transitional Housing
- Family Counseling
- Primary Medical Care
- Crisis Counseling
- Domestic Violence

TARZANA TREATMENT CENTER, INC.

Integrated Behavioral Healthcare

March 18, 1998

Ms. Sandra Thurman
Director
Office of National AIDS Policy
808 17th Street, NW 8th Floor
Washington, DC 20006

My dearest Sandy:

Just a quick note to tell you how great it was to see you and spend some time with you on Wednesday, March 11th . It's so great that you are always willing to take time out from your incredibly busy schedule to meet with representatives of the CAEAR Coalition.

I listened closely to what you said and you can be assured that, in the future, consumers of Title I and Title III services, at least in Los Angeles, will get off their behinds and let their feelings be known to you and other members of the Administration. Specifically, my folks WILL call about our requests for Budget increases in the amounts of $105 million for Title I and $36.7 million for Title III.

I don't know what else can be said regarding Needle Exchange and our hopes that Secretary will do the right thing and lift the Federal funding ban by March 31s. My constituents, many of who benefit from the services of the NEP administered by Tarzana Treatment Center, appreciate your support of their rights to decrease their risk of HIV infection. However, without adequate funding and accompanying sanctions against criminalization, these men and women continue to have to seek their services under less than optimal conditions.

Again, my friend, know that we are glad you are there. Call if there is anything, absolutely anything that we can do to help ease the burden of the heavy load you are carrying on our behalf.

Yours in the Struggle,

Suzi Rodriguez, CAEAR Coalition Vice-Chair
Public Policy Advisor, Tarzana Treatment Center, Inc.

INTERNATIONAL ASSOCIATION OF PHYSICIANS IN AIDS CARE

225 West Washington St.
Suite 2200
Chicago, IL 60606-3418

Telephone: 312.419.7295
FAX: 312.419.7160
EMail: IAPAC@iapac.org
Web site: http://www.iapac.org

FOR IMMEDIATE RELEASE
Thursday, March 19, 1998

Contact: Jose Zuniga
(312) 419-7512

IAPAC LAUNCHES EXPANDED COMPREHENSIVE HIV/AIDS WEB SITE AT www.iapac.org

CHICAGO, Illinois (USA) – The International Association of Physicians in AIDS Care (IAPAC) today announced the launch of its newly expanded comprehensive HIV/AIDS web site at www.iapac.org. The IAPAC web site, which before its expansion averaged 163,000-plus hits a month, is a reflection of the association's ongoing HIV treatment and prevention educational activities, as well as its advocacy and grassroots mobilization efforts around such issues as healthcare access and vaccine research.

"The improvements and additions to the IAPAC web site are in response to what our 5,500-membership expects from their primary source of HIV/AIDS information, as well as a reflection of IAPAC's expanding mission on behalf of people living with HIV/AIDS worldwide and the physicians and other healthcare professionals who are charged with their care," said Gordon Nary, IAPAC's executive director.

Among the expansions are medical/scientific sections focused on Clinical Management, Vaccines, and Science. These sections contain peer-reviewed patient and physician educational materials, conference reports on issue-relevant conferences, book reviews, interviews with HIV/AIDS thought leaders, and interactive question-and-answer sites.

Within the Clinical Management section are peer-reviewed educational materials covering such areas as antiviral therapies, opportunistic and coinfectious diseases, anemia and fatigue, diagnostic technologies, nutrition and wasting, women's health, mental health, and pediatrics. This section contains comprehensive reports on major international conferences and symposia, as well as articles covering antiretroviral drug resistance and the role of resistance monitoring, and antiretroviral drug interactions.

The Vaccines section includes a series of articles exploring the need for an AIDS vaccine (as seen through the eyes of a medical professional in one of the pandemic's epicenters), and the economic and scientific obstacles to the

–MORE–

development and optimal utilization of AIDS vaccines. The site also features regularly updated information about IAPAC's push to test a live-attenuated HIV vaccine in healthy volunteers by the year 2000, as well as ongoing media coverage of IAPAC's vaccine-related activities.

The Science section features interviews with some of the chief HIV/AIDS global thought leaders about future trends in HIV research and treatment. Among the distinguished interviewees are David Ho, MD, of the Aaron Diamond AIDS Research Center; David Cooper, MD, Dsc, of Australia's National Centre in HIV Epidemiology; and Anthony Fauci, MD, of the US National Institute of Allergy and Infectious Diseases at the National Institutes of Health.

IAPAC also launches a new section at www.iapac.org under the Public Policy designation. This new section includes news about how IAPAC's members in 42 countries can engage in ongoing national and international advocacy efforts, featured IAPAC and guest viewpoints, legislative reports (both US- and international-focus), ethics/human rights reports, and reports about AIDS in different parts of the world. The section also includes book reviews, conference coverage, and an AIDS at a Glance feature that will be updated quarterly.

Upcoming additions include monographs on all principal anti-AIDS drugs, which will be updated quarterly, and an Abstracts section containing abstracts of important AIDS-specific and -related articles appearing in other peer reviewed journals.

The IAPAC web site is funded by individual member contributions and unrestricted educational grants from Abbott Laboratories, Bristol-Myers Squibb, Ortho Biotech, and Roche Diagnostics.

# # #

The International Association of Physicians in AIDS Care (IAPAC) is devoted to developing and implementing global strategies to better the quality of life of all people affected by HIV/AIDS. IAPAC has 5,500 members in 42 countries. In the United States, IAPAC's member physicians care for the majority of people living with HIV disease.

Data Entry Form

Letter ID	Writer First Name	Writer Last Name	Received Date	Subject
10584	Robert	Nickerson	2/19/98	Newsletter

☐ Response Required?

Response Type	Response Date	Responder ID	Responder Name	Action Promised
			S. Thurman	

Action Completed	Action Date	Addressed To

Notes

Sender's Organization	Sender's Street1	Sender's Street2
SS, Office of Commissioner		

Sender's City	Sender's State	Sender's Zip

SOCIAL SECURITY

Office of the Commissioner

February 18, 1998

Ms. Sandra L. Thurman
Director
Office of National AIDS Policy
Executive Office of the President
808 17th Street, NW, Suite 820
Washington, DC 20006

Dear Director Thurman,

On World AIDS Day, Commissioner of Social Security, Kenneth Apfel with the assistance of your staff and AIDS Action, sent a letter to all offices and agencies nationwide that assist persons with HIV/AIDS expressing the Social Security Administration's continued efforts on behalf of persons with HIV/AIDS. During this past week, the Association of Nurses in AIDS Care (ANAC) forwarded the Commissioner's letter to their membership in their February 1998 newsletter: *Anacdotes.* A copy of that newsletter is enclosed.

I wish to again thank your staff for their assistance with this effort. It is gratifyng to know that the word is getting out.

Sincerely,

Robert A. Nickerson
Executive Assistant to the Commissioner

Enclosure

ANAC
ASSOCIATION OF NURSES IN AIDS CARE

February 13, 1998

Kenneth S. Apfel
Commissioner of Social Security

Dear Commissioner Apfel:

On behalf of the Association of Nurses in AIDS Care (ANAC) I want to thank you for your letter of December 1, 1997. I was so impressed with the letter that I wanted to share it with my colleagues in the Association. After discussing the matter with Robert Nickerson, he agreed we might publish your letter in our newsletter ANACdotes. In this way, a larger number of health care providers can be aware of the services available through the Social Security Administration.

Once again, thank you for sharing your commitment to people living with HIV/AIDS with the Association of Nurses in AIDS Care.

Sincerely,

Inge B. Corless

Inge B. Corless RN, PhD, FAAN
President, 1997 - 1998

IBC/pmf

11250 ROGER BACON DRIVE, SUITE 8, RESTON, VA 20190-5202
(TEL) 703.925.0081
(FAX) 703.435.4390
(800) 260.6780
(E-MAIL) AIDSNURSES@aol.com
http://www.anacnet.org/aids/

ANACDOTES

NEWSLETTER OF THE ASSOCIATION OF NURSES IN AIDS CARE

VOLUME 9 NUMBER 1 FEBRUARY 1998

FROM THE PRESIDENT

HAVE A HEART

Dear Colleagues,

It is a privilege to write to you as president of the Association of Nurses in AIDS Care. It is a privilege for which I strive daily to be worthy.

Inge Corless
ANAC President

I'd like to begin this letter by thanking Barbara Russell, Sheila Davis, the members of the Conference Committee, and Amy, Rand, Lisa, and Tom for a wonderful meeting in Miami. It was a great conference. Thank you one and all.

The sad news this newsletter is the death of our friend and colleague Frank Lamendola on January 11. Our condolences to his partner, James Haines, his family, and friends. The loss of Frank's brilliant scholarship, inspiring leadership, and warm personhood leaves us all bereft (See Rick Ferri's touching memorial on page 3).

On a happier note, I am pleased to report ANAC has come to a verbal agreement with our former management company so further legal action is unnecessary. That will save us time, energy, and money. And money is the main topic of this issue's presidential letter. Now what, you may wonder, does money have to do with a heart? While we each may have our own ideas, let me share with you the ANAC connection between the heart, the head, and money.

Last year, the 1996–1997 Board of Directors concentrated on developing the infrastructure of ANAC. That work is essential as an organization moves from the idealism and charisma of the founders of an association to the more mundane but essential tasks necessary to provide member services in an organization of our size. That work will continue this year so our structure facilitates our activities rather than impedes them. With all of the changes in HIV care as well as health care, an efficient, effective organization is essential if

continued on page 8

GAINING SUPPORT OF HIV RESOLUTIONS: MISSISSIPPI CENTRAL CHAPTER'S STORY

by Janie Butts

The members of the Mississippi Central Chapter of Nurses in AIDS Care (MCC-NAC) recently presented two emergency resolutions to the House of Delegates at the Mississippi Nurses' Association's (MNA) Convention (a part of American Nurses' Association) in October 1997. Certain situations in Mississippi motivated MCC-NAC to elicit support from the Mississippi Nurses' Association on an emergency basis. MCC-NAC members believe that making problems involving HIV/AIDS known to MNA delegates and other MNA members will increase knowledge of and support from nurses in Mississippi.

The first resolution entitled, "Healthcare Workers Who Are HIV Positive in the Work Place," was adapted from ANAC's workplace resolution of 1997. In Mississippi, it is known that one health care worker who is HIV positive has been removed from a position in which the worker was qualified to function and placed in a position requiring less qualification. MCC-NAC members agreed emergency support should be elicited from MNA so MNA lobbyists will speak out in support of the resolution when attending future MS legislative activities. Ultimately, it is hoped strict compliance with the Americans with Disabilities Act will be maintained. The MCC-NAC resolution addressed health care workers' rights to confidentiality in all situations concerning a positive status, as well as rights of reasonable accommodations in the workplace for the position in which they are qualified to function, as the Americans with Disabilities Act clearly has stated. The workplace resolution passed unanimously in MNA's 1997 House of Delegates.

The second resolution did not pass so easily. This resolution entitled, "The Mississippi HIV/AIDS Assembly's Solicitation of Financial Support from MS Legislators for Treatment/Medications for Individuals Who Have HIV/AIDS," was written by MCC-NAC members in response to the crisis that exists in Mississippi. In a previous article in *ANACdotes*, Butts and Janes (1997) discussed the dilemma existing in Mississippi. A financial crisis arose when the expensive protease inhibitors were introduced as part of the new "drug cocktail." Because the state of Mississippi contributes no funding to HIV/AIDS prevention, treatment, or care, there is no funding, other than federal funding, to assist in HIV treatment. The ADAP (AIDS Drug Assistance Program) Title II Ryan White CARE Program's funding cannot be stretched far enough to cover the costs of treatment for the 880 people with HIV/AIDS currently enrolled in the program. In an effort to resolve the crisis, the MS HIV/

continued on page 4

HAVING YOUR SAY IN ANAC

by Anne Hughes and John Roberts

There are a number of ways for you as a member of ANAC to have a concern or issue addressed. We want to describe a few so you have the information you need to have your concern heard. Any ANAC member can bring (and in the past has brought) a concern to an ANAC staff member or the ANAC Board of Directors (generally through the president). ANAC staff will bring policy or procedural concerns raised by members that they are unable to resolve to the Board.

Depending on the nature of the concern or if the member believes the issue has not been resolved, the concern can be placed on the agenda of an ANAC Board meeting for discussion/decision. All ANAC Board meetings are open to members (with the exception of closed sessions, which discuss personnel and/or legally sensitive issues). In order for an issue to placed on a Board meeting agenda, the president needs to be informed about the matter at least one month prior to the scheduled Board meeting (when she/he is setting the meeting agenda).

The most effective way of influencing ANAC policy is by voting for leaders who will represent your views and speak to your concerns (see article on the call for nominations on page 11 of this issue). A third way of having your say—if you have a particular policy position that you wish ANAC to adopt—is to draft a resolution for presentation to the members for a vote at the Annual Business Meeting.

Still another approach is to raise your concern at the Annual Business Meeting, which is held at the ANAC conference (This year the conference will be held in San Antonio, November 15 to 18).

The Annual Business Meeting is a more formal setting to raise a concern because it is conducted according to Roberts Rules of Orders, Revised. Roberts Rules of Order is the most commonly used form of parliamentary procedure used by nonprofit, membership organizations in the United States to conduct Annual Business Meetings.

An Annual Business Meeting is required of all corporations (even nonprofits) to advise their stockholders (or members) of the activities of the organization in the preceding year.

Parliamentary procedure ensures that minority opinions are heard; even though a majority vote will direct policy decisions. Knowing how to work Roberts Rules is critical to ensure your voice is heard. We hope these few pointers will help you.

The Annual Business Meeting will always be organized by an agenda. The agenda for the Annual Business Meeting is developed by the president (who serves as chair of the meeting) but belongs to the group or body. The agenda generally includes: introduction of the Board and the parliamentarian (the person who serves as consultant on Roberts Rules), adoption of the standing rules, adoption of the agenda, presentation, and when indicated, adoption of standing reports, and new business.

The first order of business at the Annual Business Meeting (i.e. the first decision made by the voting members) is the adoption of the standing rules. Standing rules are the procedural rules that govern the conduct of the meeting. An example of a standing rule is, " All motions shall be in writing, signed by the maker, and presented to the secretary (of the Board). Forms for motions will be available in the meeting room."

The proposed standing rules are printed and distributed in advance of the meeting. Generally they are not read into the record unless the body asks the chair to do so. Other standing rules may be added or deleted by a majority vote of the voting members. Once the standing rules are adopted, all members are expected to know the rules and use them to conduct any business. Generally all standing rules include a rule about how to suspend the standing rules.

The next order of business is the adoption of the agenda. The agenda may be modified at this point. Since the agenda belongs to the members, if an item was not listed, a member could ask that it be added to the agenda. The group would vote to add or to not add this item to the agenda before the agenda in total is approved.

If a member wants to make a motion related to a report on the agenda, the motion should be made when the report appears on the agenda. Hypothetically, if a member wanted ANAC to commit 70 percent of its net revenues to educational activities, at the time of the treasurer's report this motion (having been received in writing by the secretary in advance) would be open for discussion.

If you aren't sure when to introduce a motion you have the right to go to the microphone and state "Chairperson, I rise to a point of order." The chair will seek the advice of the parliamentarian and will assist you in presenting your motion. This process can be quite cumbersome and is not how most of us work day-to-day. Knowing the rules in advance and enlisting others as supporters for your concern will help get your voice heard more effectively.

Most important is that you feel heard within ANAC, *your* association. As elected representatives, the Board is obligated to hear your concerns. Please help us learn what else we can do to ensure your voice is heard.

WE GRIEVE THE LOSS OF OUR FRIEND AND COLLEAGUE

FRANK LAMENDOLA

FEBRUARY 4, 1949–JANUARY 11, 1998

Frank Philip Lamendola died on January 11, 1998 at his home in Minneapolis from AIDS complications. He was surrounded by friends, family, and his partner James Haines.

Frank committed his life and career to people living with HIV. His most recent focus was on providing care to care givers. Some career milestones include his work as a nurse at Rush Presbyterian-St. Lukes Hospital in Chicago; as a hospice home care nurse at North Memorial Medical Center; as a health education director for the Aspen Medical Group in Minneapolis-St. Paul; as a grief counselor and the first nurse case manager for the Minnesota AIDS Project; and as an educator, counselor, and consultant for Journeywell, the company he confounded. Through Journeywell, Frank was able to plan and coordinate many HIV conferences and retreats. He even produced three videos on the education of care givers.

Frank had been honored in life for his work. Some of the many well deserved recognitions include: the Minnesota Nurses Association Distinguished Service Award; the ANAC Nursing Fellowship Award; the Minnesota Nurses Association C.E. Anderson Scholarship; the Sigma Theta Tau, Zeta Chapter Certificate of Achievement for Creativity, Leadership, and Contributions in Nursing; and the U.S. Public Health Services Assistant Secretary of Health Award for Outstanding Leadership in the Care of People with HIV/AIDS. At the time of his death, Frank was a PhD candidate at the University of Minnesota School of Nursing. He had passed his orals and was midway through his dissertation, "Patterns of the Caregiving Experiences of Nurses in Hospice and HIV/AIDS Care."

In addition to his stellar nursing career, Frank founded the Twin Cities Gay Men's Chorus and sang in the chorus for a decade.

The world has become somewhat less interesting with Frank's passing. We will miss him greatly.

Richard Ferri

FROM THE GOVERNMENT RELATIONS COMMITTEE

by Martha Jones

Greetings for a healthy and productive New Year from the Government Relations Committee. It was really great to talk to so many of you in Miami. It also very much fits into our mission over the next 12 months and that is to become more alerted to the issues that affect you and your clients.

One of the things we are trying to do within the committee is to begin to address and support state efforts. We are very aware of the continuing issues of funding for the Ryan White Drug Programs and the lack of funding for the community programs such as family services, prevention, and reentry into the work force. We would very much like to hear the types of problems you are facing within your state. We are committed to giving the same energy to the state issues as we are to the NORA issues and national problems. We also feel building coalitions from the grassroots is very important to the mission of the committee as well as ANAC.

The Government Relations Committee's focus is to be a conduit for members to gain that all important introduction into that all important dive into the health and public policy arena. Being aware of where your legislators stand on these issues is important so you can help educate your elected officials.

ANAC has an ethical and moral obligation to go on record when injustices are being done to those people we have pledged to support. We support people living with HIV in our research, our clinical practice, and our educational and policy efforts. Please help us to do the best job we can. Feel free to contact me with issues your state may be facing. My e-mail address is Moze1J@aol.com, or please call me at home, 602-978-6226. Your voice is important.

Mississippi Central, *from page 1*

AIDS Assembly was formed by concerned citizens and providers of Mississippi.

Many MCC-NAC members were instrumental in the formation of the MS HIV/AIDS Assembly and currently participate in the meetings. The participation in the assembly has illuminated MCC-NAC's sense of responsibility and, thus, has stimulated interest in striving to resolve the crisis in Mississippi. As a result, members of MCC-NAC elicited support from the MNA 1997 House of Delegates. It is hoped, in the future, MNA lobbyists will speak out in favor of state funding for HIV treatment when the occasion arises with the Mississippi legislators.

Though adopted by MNA's House of Delegates, this resolution passed only by a slight margin. Several questions were asked by the delegates during the deliberation of this resolution, which involved a lengthy discussion. One question was, "If MNA supports this resolution and state funds are awarded to assist with the costs of treatment for the 880 people, will state assistance be withdrawn from another vital health program of equal value and transferred to an HIV treatment program?" Since the state of Mississippi's money allocation could not be forecasted at MNA's 1997 House of Delegates, the answer to this question remained unanswered. The other question that was asked was, "Why should MNA support state funding to a greater degree for HIV treatment over another health program in the state?" The MCC-NAC supporter explained if MNA lobbyists spoke out in favor of an HIV treatment program, this support would in no way downplay or minimize the importance of another health program in the state. Some Delegates still remained undecided or against this resolution even after it was adopted by the House of Delegates.

Since then, both resolutions have been published in *The Mississippi RN* (1997). The adoption of these resolutions by MNA moved MCC-NAC, other nurses, and persons with HIV/AIDS one step closer to maintaining preservation of human rights. If you would like more information or a copy of these resolutions, please contact Janie Butts at e-mail: janie.butts@usm.edu or phone: 601-266-5320, or write to Janie Butts, The University of Southern Mississippi, College of Nursing, Southern Station, Box 5095, Hattiesburg, Mississippi, 39406-5095.

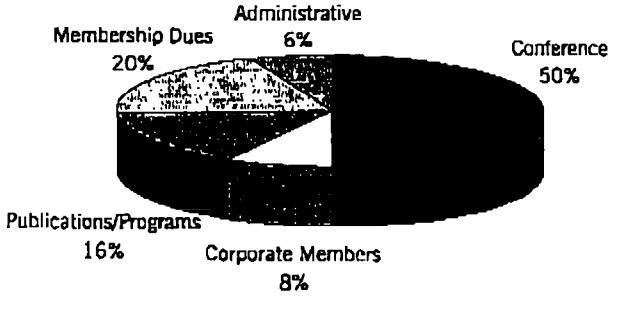
Janie Butts, MSN, RN, is instructor at the University of Southern Mississippi in Hattiesburg, MS; a doctoral candidate at the University of Alabama at Birmingham; and currently a member of ANAC's Governmental Relations Committee.

FROM THE TREASURER

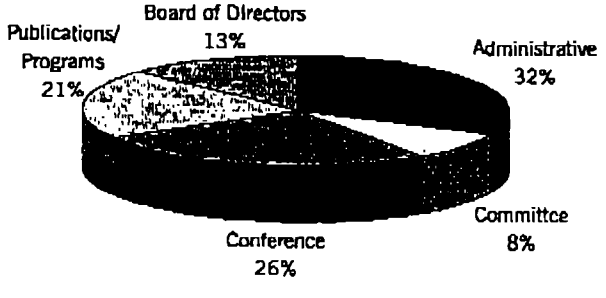
by Patrick Robinson

January has never been my favorite month. One Chicago January will leave you with no question as to why this is so. It also seems nothing good really happens in January—Christmas is over, school starts, summer is 6 months away, etc., etc. I am always prepared for the worst in January. It was in this frame of mind that I awaited the year-end ANAC financials. As you know from my previous communications, it has been a financially challenging year for us. The good news is our Miami conference made a healthy profit of $120,000. I extend hardy gratitude to all conference organizers, but especially to you the attendees. The bad news is, as expected, we ended the year with a deficit of $47,270. Please refer to the accompanying year-end financial statements and pie charts for specific information on revenue and expenditures. The resultant deficit has produced a current first quarter cash flow problem (see accompanying balance sheet). We have begun our 1998 corporate partner campaign and anticipate this revenue will alleviate our immediate problems. In addition, in 1998 we will move to a biannual membership dues invoicing (in continued preparation for annual dues invoicing in 1999), so we anticipate significant second quarter revenue. As always, cost containment strategies remain a top priority for your Board of Directors. For example, we have significantly cut the cost of Board meetings and continue to be creative in ways to "tighten our belt." Please contact me in Chicago at 773-665-3713 with any questions or concerns.

REVENUE



EXPENSES



ASSOCIATION OF NURSES IN AIDS CARE BALANCE SHEET

December 31, 1997

Assets	
Checking—George Mason Bank	3,978
Nations Bank	30,195
Accounts Receivable	0
Deposits	5,139
Prepaid Expenses	13,423
Total Assets	**52,735**
Liabilities and Fund Balance	
Accounts Payable	3,745
Deferred Dues for Year Subsequent	4,900
Deferred Evidence-based Conference	500
Total Liabilities	9,145
Beginning Fund Balance	90,859
Current Earnings	(47,269)
Total Fund Balance	43,590
Total Liabilities and Fund Balance	**52,735**

ASSOCIATION OF NURSES IN AIDS CARE 1997 STATEMENT OF REVENUE & EXPENSES

Revenue	
Membership Dues	125,209
Corporate Members	49,764
Administrative	39,601
Conference	309,685
Publications/Programs	100,049
Total Revenue	**624,308**
Expenses	
Board of Directors	87,188
Committee expenses	55,057
Administrative	213,099
Conference	176,726
Publications/Programs	139,508
Total Expenses	**671,578**
Excess Revenue over Expenses	**(47,270)**

LETTER TO THE EDITOR

I wish to connect with nurses working in long-term AIDS care facilities. My unit has been an AIDS terminal care unit for 6 years, but now we need to redefine our role in the community. We are getting more HIV dementia patients and many more, demented or cogent, who are drug abusers. Instead of a short stay, many of these patients are not terminal but unable to care for themselves in an assisted living facility. Additionally, the facility management is more interested in the bottom line than need in the community.

I am looking for help in:

- defining realistic admission criteria that will help us to admit all the patients, terminal or demented, who need care, but still avoid excessive dollar losses for the unit.
- workable plans from units that have dealt with drug and psychiatric problems. All of the nurses in my unit are burned out from the stress.
- ideas and sources for research on long-term institutional care of AIDS patients.
- any ideas for cutting costs, or getting grants that will allow us to continue with the high quality personalized care we have been giving.

I look forward to any communication that can help. Please contact me at happynurse@juno.com. Thanks.

ANAC SPONSORSHIP OPPORTUNITIES FOR 1998

1998 Annual Conference	
Opening night party	$20,000
Lunch	$10,000
Coffee breaks	$ 5,000
Plenary sessions	$ 3,000
Educational sessions	$ 2,000
Discounts for ANAC chapter president registration	$6,250
Evidence-based Nursing Practice Preconference	$50,000
Nurse executive director	$95,000
Post-exposure Prohpylaxis Project	$ 5,000
Grief and Loss Program collaboration with the National Hospice Organization	$10,000
Assisted suicide monograph	$1,000
Chapter Award	$12,000
Leadership Training Workshop	$30,000
International AIDS Conference satellite meeting in Geneva	$10,000
HIV Nursing Research Grant	$5,600

For information concerning these and other projects contact: Patrick Robinson, MSN, RN, ACRN, 773-665-3713, e-mail: probinson@cath-health.org

NEW MASTER'S PROGRAM: ALTERED IMMUNOCOMPETENCE NURSING

Janice M. Zeller, PhD, RN, FAAN; Barbara Swanson, DNSc, RN, ACRN; and Joyce Keithley, DNSc, RN, FAAN, members of the Chicago chapter of ANAC, were recently awarded a $500,000 grant from the Division of Nursing, Department of Health and Human Services. The grant, "Altered Immunocompetence Nursing Specialization," supports a new master's level clinical nurse specialist program at Rush University College of Nursing, Chicago, IL.

The new program prepares advanced practice nurses who will provide specialized, research-based care to HIV/AIDS and/or oncology patients in a variety of inpatient and outpatient settings. Students may specialize in either HIV/AIDS or oncology, or they may choose a dual focus. To meet the challenges of caring for these patient populations, the following concepts are woven throughout the curriculum: critical thinking, basic and applied immunology, advanced assessment and therapeutic skills, primary and secondary prevention, care of underserved populations, community aspects of care, and case management.

While students can select as MSN degree, they may also choose to continue their education in one of Rush's nurse practitioner programs, or pursue the ND or DNSc degrees. The program of study for the MSN degree is designed for either part-time or full-time study and can be completed in approximately 2–3 years. Individual programs of study to meet the student's unique career goals (e.g., HIV and women's health) can be designed in collaboration with the academic advisor. Further information may be obtained by contacting Dr. Zeller at 312-942-3517, Dr. Swanson at 312-942-5174, or Dr. Keithley at 312-942-5820.

SOCIAL SECURITY
Office of the Commissioner
December 1, 1997

Mr. Randall C. Price
Executive Director
Association of Nurses in AIDS Care
11250 Roger Bacon Drive, Suite 8
Reston, Virginia 20190

Dr. Mr. Price:

Today, on World AIDS Day, as we remember the nearly 400,000 Americans we have lost to AIDS, I want to reiterate the Social Security Administration's commitment to providing compassionate and efficient service to people living with HIV/AIDS. Although we are encouraged by the development of new drug therapies to treat HIV disease, we know that this epidemic is not over.

We recognize that for many of the thousands of men, women, and children living with HIV/AIDS, your organization plays an invaluable role in helping them access care and services. Through our regional and field offices around the country, the Social Security Administration has worked closely with many of you as you assist your clients in applying for Social Security and Supplemental Security Income benefits. We will continue this partnership as we strive to ensure that all people living with HIV/AIDS know about the Social Security programs for which they may be eligible.

We are aware that many people living with HIV/AIDS who have benefited from recent treatment advances may want to return to work. There are important provisions in the disability programs called "work incentives" that enable a beneficiary to return to work for a period of time without losing the "safety net" of monthly case benefits and Medicare or Medicaid. If you need more information about this, or have other questions about Social Security, please call our toll-free number, 1-800-772-1213 or contact your local Social Security office. Information is also available through our Web site at *http://www.ssa.gov*.

Thank you for your very important work in serving men, women, and children living with HIV/AIDS.

Sincerely,

Kenneth S. Apfel
Commissioner of Social Security

SOCIAL SECURITY ADMINISTRATION BALTIMORE MD 21235-0001

WANTED

LPNs/LVNs to participate in networking group. Plan to meet during the San Antonio conference. First person to contact Michele Crespo-Fierro at the ANAC office will spearhead the group. Your presence and participation are invited.

ANAC NURSE MAKING A DIFFERENCE

by Dirk B. Le Flore

Ginny Lipke is the current president of our local chapter in the metro Atlanta area. Since we had no response to our "call for nominations" both Ginny and I agreed to continue to carry out our current positions. Ginny took the ACRN certification exam last year and passed. There are also many members in our chapter who are interested in taking the exam in April of 1998, but are leery and a little nervous. Hearing this, I suggested to Ginny that she give a review course and charge members about $50. I think, if an individual is going to put in this much effort, they should be reimbursed for their time and energy. We tossed the idea back and forth about giving $25 back to the local chapter and Ginny keeping $25 for her time, but she would hear nothing of it. Therefore, the course is free of charge. The review course started in January and will convene every two weeks until the exam date. The last I heard, about 15 people had signed up to take the study course. All of these people may not take the exam, but we are educating them. Through her selfless dedication, Ginny is providing nurses an opportunity to become more knowledgable about this disease. At the same time, she will be giving us the tools to be better health care providers. Hopefully, this will enable us to provide better care for those infected or affected by the Human Immunodeficiency Virus. If you would like more information regarding the review course sponsored by the Metro Atlanta Chapter, please call Ginny at 404-616-9738.

Dirk B. Le Flore, BSN/RN, is the treasurer of the Metro Atlanta Chapter.

From the President, *from page 1*

we are to achieve collectively what may elude us individually.

One of the areas that will receive continuing attention is that of revenue enhancement. (I am beginning to talk like a politician!) Worthwhile investments include such projects as obtaining continuing education provider and approver status, and securing a nurse executive director whose priority is education, policy, writing grants, and working with staff and volunteers on member services and public relations. Another project, the post-exposure prophylaxis survey, was designed to assess the rapidity with which our members have access to highly active antiretroviral therapy should an occupational exposure occur. If we discover such access is not prompt, we will convene ANAC leaders and members to develop approaches to remedy this situation. Analysis of the data will determine the appropriate next steps.

These projects and others about which you will hear in the coming months require financial support. We have compiled a wish list of the current projects and activities that require funding. This list is printed on page 6 of this issue of *ANACdotes*.

I am happy to announce a new project funded by one of our members. The Association of Nurses in AIDS Care Pediatric Nursing Research Award in Memory of Diana, Princess of Wales, an award of $500 a year, is funded for five years by ANAC member Charles Curti, LPN. It will be awarded as a seed grant for a pediatric nursing research project. Charles invites other members to contribute to this fund. Another of our members who is a friend of the Spensers will bring this grant to their attention.

This initiative by one of our members symbolizes what we as members can do to forward the agenda of the ANAC. Twenty-two other members have made contributions at the time of membership renewal. We are very grateful to each of them for their dedication to ANAC.

On an organizational level, we are planning a fund-raising event at our annual conference in San Antonio, which will likely include a silent (or not so silent) auction, as well as entertainment (You can judge how entertaining!) by individuals or groups, members, exhibitors, and other talented persons. It should be fun and raise some money for ANAC projects. You'll hear more about this in April.

Motivation for funding awards and activities include gifts in honor of family, partners, friends, and colleagues—whatever the occasion. Another important impetus for funding includes gifts in honor of dedicated nurses; both those who are HIV infected and those who are HIV negative. For the person who has everything, an award in his or her honor may be an exceptional gift. And the good news is ANAC is a 501(c)3 tax-exempt organization, so your donation may be deducted as a charitable contribution.

Why am I mentioning gift giving just when Christmas, Hanukkah, Kwanza, and other holiday bills are in the process of being paid? With a little bit of luck and a lot of hard work, you should receive *ANACdotes* prior to Valentine's Day. We'd like you to have a heart and think about how you can help ANAC to be all you would like. An important way you can help is by participating in chapters, committees, advisory councils, or the national Board of Directors. You can also help your association by making a general donation to help us with our day-to-day activities or by contributing to the funding of a project. Either contribution will facilitate ANAC's achieving its mission of "fostering the individual and collective professional development of nurses involved in the delivery of health care to persons infected or affected by the Human Immunodeficiency Virus (HIV) and promoting the health, welfare, and rights of all HIV-infected persons." (ANAC Mission Statement).

Happy Valentine's Day. When you're thinking of valentines—"Have a heart"—think of ANAC.

ANAC

ANAC "HAVE A HEART" CAMPAIGN

Name: _____ Phone: _____

Address: _____

City: _____ State: _____ Zip: _____

Amount (circle amount): $15 $35 $50 $100 Other $ _____

Charge to my (circle one): VISA Mastercard

Account number: _____ Expiration date: _____

Card member name: _____

Issuing bank: _____

Signature: _____

Your donation to ANAC as a charity, beyond your membership dues, is tax deductible in accordance with the I.R.S. rules and regulations.

FROM HIV/AIDS NURSING CERTIFICATION BOARD (HANCB)

by Barbara Rickert

There are 110 new AIDS Certified Registered Nurses (ACRNs), this brings the total number of ACRNs to more than 800. The ACRNs took the certification examination at the annual ANAC conference in Miami. The nurses are from Alabama, Arizona, Arkansas, California, Colorado, Delaware, District of Columbia, Florida, Illinois, Iowa, Louisiana, Maine, Maryland, Massachusetts, Michigan, Missouri, New Jersey, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, Puerto Rico, Rhode Island, Texas, Virginia, Wisconsin, Ontario, Canada, and five persons from other countries.

ACRNs may purchase an ACRN pin for $10 or a pin with a diamond chip for $12, plus $3 shipping and handling charge by contacting the HANCB office.

The next certification examination will be held on April 4 at 42 sites across the country. The deadline date for registration for the examination was February 1. Nurses who applied to take the examination by the deadline are guaranteed admission at the testing site. Those who register after the deadline are guaranteed admission until seating capacity is reached. Nurses interested in taking the examination must preregister with the Professional Testing Corporation, 1211 Avenue of the Americas, 15th Floor, New York, NY 10036, phone 212-852-0400. A *Handbook for Applicants* and an application for the examination will be provided. The handbook provides the location of the testing centers, references, a content outline, and the percent of questions in each of the content areas. Additional information about certification may be obtained from HANCB, 11250 Roger Bacon Drive, Suite 8, Reston, Virginia 20190-5202, phone 703-437-4377, fax 703-435-4390.

THE ANTIRETROVIRAL PREGNANCY REGISTRY

The Antiretroviral Pregnancy Registry for: didanosine (Videx, ddI), stavudine (Zerit, d4T), lamivudine (Epivir, 3TC), zalcitabine (Hivid, ddC), saquinavir (Invirase, SQV), zidovudine (Retrovir, ZDV), lamivudine/zidovudine (Combivir), is a voluntary prospective study designed to collect observational, nonexperimental data on pregnancy outcomes following prenatal exposure to these antiretrovirals.

This registry is the only project expressly established to evaluate first trimester as well as later prenatal exposures to these antiretroviral medications. Registry data supplement other sources of data and assist clinicians and patients in weighing potential risks and benefits of treatment.

Limited data reported from clinical trials of several antiretrovirals in pregnant women do not suggest any increased risk of birth defects associated with antiretroviral use. The manufacturers of these antiretrovirals recognize, however, the need to monitor continuously the safety of their products, particularly for rare events that are difficult to identify in small populations.

Health care providers prospectively register women who have been exposed to the medications during pregnancy. The initial information collected for each patient is minimal, and includes dosage and timing of exposure. At the time of delivery, the health care provider is prompted to provide follow-up data on the pregnancy outcome. Patient confidentiality is strictly guarded in this anonymous registry, and all identifying information reported to the registry is deleted from the database when the case is closed. The registry also gathers "retrospective" information on cases that are reported only after the outcome of the pregnancy is known.

An important aspect of the registry is the Advisory Committee, which is composed of individuals from sponsoring manufacturers, the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), as well as specialists in obstetrics and gynecology, infectious disease, and epidemiology.

The Advisory Committee evaluates the registry data and assists in disseminating information. A registry interim report is prepared semiannually summarizing these aggregate data and is available to all interested health care providers.

Your contribution to this collaborative monitoring of exposures to antiretrovirals during pregnancy enables you and your colleagues to obtain up-to-date information on available data, in addition to a copy of the latest published Antiretroviral Pregnancy Interim report twice a year. For more information, contact the Antiretroviral Pregnancy Registry, P.O. Box 13398, Research Triangle Park, NC 27709; or call toll-free 800-722-9292 ext. 38465 or 919-438-8465; fax 919-315-8747.

1998 SAN ANTONIO CONFERENCE UPDATE

by Barbara Aranda-Naranjo and Michele Crespo-Fierro

Our committee has been quite busy planning this year's conference "Diversity: Walking Through the Rivers of Change/La Diversidad: Caminando Juntos Entre Los Rios de Cambios" in San Antonio at the Hilton Palacio del Rio, November 15–18, 1998. We have been studying the evaluations from Miami's conference, and we thank everyone for their insightful comments. We have been working hard to incorporate those comments and those made directly to the committee members and the Board of Directors. Enclosed in this issue of *ANACdotes* is the Call for Abstracts/Posters/Roundtable Discussions. Please submit your ideas as they will help us in planning the conference sessions. We have some exciting events planned, which we will tell you more about in the next issue. Until then...Hasta la vista, Baby!

ERROL CHIN-LOY APPOINTED AIDS COORDINATOR

Errol Chin-Loy, RN, MSN, the founding president of the Association of Nurses in AIDS Care, was recently appointed New York City's new coordinator for AIDS policy by Mayor Rudolph Guiliani. As the AIDS coordinator, Mr. Chin-Loy will advise the mayor on policy and help to coordinate the city's AIDS services. He will also chair the HIV Health and Human Services Planning Council, which recommends funding priorities for the Ryan White Care Act funds. Mr. Chin-Loy has worked in the field of HIV/AIDS for over a decade.

FROM THE SECRETARY

KEY POINTS FROM JANUARY 23–25, 1998 ANAC BOARD OF DIRECTORS MEETING

by Lucy Bradley-Springer

- The Board of Directors (BOD) discussed the problems related to ANAC's current financial deficit and made the decision to increase annual membership dues by $5 to $65. (The bylaws allow the BOD to increase dues by ten percent. A larger increase requires a vote.)
- The BOD is taking on the task of developing a "Burn the Deficit" fundraiser for the San Antonio conference.
- The BOD voted to become a "100% Giving Board"—all current BOD members will make financial contributions to ANAC.
- President Inge Corless discussed a verbal agreement with ANAC's previous management company: ANAC has no further financial obligations and there will be no further legal action.
- The ANAC trademark has been copyrighted to ANAC, and the BOD is in the process of obtaining the copyright for the JANAC trademark.
- The dates of the 1999 ANAC conference in Portland, Oregon were changed to October 14–17 to accommodate members who prefer not to meet over Halloween.
- The BOD directed Drohan Management Group (DMG) to start working on conference sites for 2000, 2001, and 2002.
- Patrick Robinson will work on developing a distinguished lecturer program for ANAC.
- The BOD set up a task force to explore the possibility of a nurse executive director position.
- ANAC is working with the Virginia Nurses' Association to become a CEU provider.
- The BOD accepted the recommendation of the *JANAC* Editorial Board that Demetrius Porche be named associate editor.

EMPLOYMENT OPPORTUNITY

AIDS Service Foundation (ASF) Orange County Full-time Position Available, RN Case Manager. ASF is seeking an RN to join our case management team. Applicant should be skilled in the following: home health care, HIV clinical issues, case management, client assessment, bilingual (Spanish) bicultural a plus. ASF is an equal opportunity employer and offers a competitive salary. Please send or fax your resume and salary history to Molly Ballinger, RN, BS, Director of Nurses Case Management, AIDS Services Foundation, 17982 Sky Park Cir., Ste. J, Irvine, CA 92614; phone: 714-253-1536; fax: 714-852-1185.

DATES TO REMEMBER

University of Minnesota Complimentary Care: from Principles to Practice including demonstrations, roundtable and experiential opportunities

Dates: March 5–7, 1998

Location: The Marsh Center, Minnetonka, Minnesota

Contact: Kay Syme, University of Minnesota, 612-625-3451; email: ksyme@mail.cee.umn.edu, or visit our Web site at: www.cee.umn.edu/pdcs/CompCare.html.

ANAC MEMBERSHIP BENEFITS UPDATE

by Connie Highsmith

Often in our lives we cannot immediately connect with a result of our actions. We complete tasks but do not see the benefit from them. This, however, is not true of our ANAC membership. ANAC memberships reap immediate rewards! For example, if taking the ACRN exam, there is an immediate savings of $150. ANAC members pay only $200 versus the nonmember rate of $350. Through our bimonthly subscription to *JANAC*, we receive the latest clinical research information important to our practice, and through *ANACdotes*, an employment column, news, and information regarding ANAC and the world of HIV/AIDS. There are also conference discounts, eligibility for awards and scholarships, access to the office through both e-mail and Web site connections, and, most important, we are connected to the largest HIV/AIDS nursing organization in the United States. In addition, ANAC is working to become a CEU provider. We are also expanding our Web site information.

ANAC is an exciting organization. We are growing and evolving everyday to meet the changing needs of our members. Our future holds many possibilities for expansion of our already rich package of membership benefits. Stay connected, if you are, and if you're not, join today! Be a part of this vital organization as we reach forward toward the year 2000.

1998–1999 CALL FOR NOMINATIONS

by Deborah Wafer

The Nominations Committee is pleased to announce the Call for Nominations. In May, the membership will have the opportunity to select a president-elect, treasurer, three directors at large, and two Nominating Committee members:

- president-elect: three-year term, one as president-elect, one as president, and one as immediate past president;
- treasurer: two-year term;
- three directors at large: two-year term;
- two members for the Nominating Committee: two-year term.

All will take office at the conclusion of the business meeting at the annual conference in San Antonio in November 1998. All eligible nominees need to have been voting members of ANAC for two continuous years prior to assuming office.

There will be a separate mailing to members from the ANAC office in Reston on how to nominate yourself or another member of ANAC to an office of the association. There will also be an article on the nominations process in the April issue of *ANACdotes*.

As ANAC members, we urge you to contribute to ANAC's future, our leadership, and your professional organization. We will work closely with local chapters and individual members to maximize the diversity of the slate of nominees. We look forward to hearing from you.

MEMBERSHIP DUES INCREASE IN 1998

Upon the recommendation of the Finance Committee, and in compliance with the association's bylaws, the ANAC Board of Directors has approved a membership dues increase of $5. The new dues, effective for 1998, are $65 per year for active and affiliate members ($120 for a two-year renewal), and $48 for associate and disabled members. This represents the first dues increase in several years. The increase is needed to keep pace with operational expenses and to allow us to accomplish our strategic initiatives. The dues increase is only part of an overall revenue enhancement strategy.

Where Your Dues Go

- *JANAC* $20
- Membership services/ administrative $45

Amounts shown are based on active or affiliate membership; allocations are proportional for other membership categories.

ANAC FRANK LAMENDOLA MEMORIAL FUND

Throughout his life, Frank Lamendola was devoted to the Association of Nurses in AIDS Care. At his request, a memorial fund to benefit ANAC has been established in his honor. Donations, made payable to ANAC, may be sent to the Association of Nurses in AIDS Care, Frank Lamendola Memorial Fund, Department 203, Washington, DC 20055-0203. Our heartfelt thanks to all who have contributed.

CONFLICT OF INTEREST POLICY

by Michele Crespo-Fierro

Since so many of us wear so many hats in our professional lives, it is important to remember that ANAC has a "Conflict of Interest Policy." Even though this policy was developed to address issues that have arisen for individuals in the ANAC leadership, it is important that all ANAC members be aware of and honor this policy. In particular, we need to be aware that in our activities we do not want to imply ANAC endorses those actions, comments, or written work. Although ANAC in its mission statement supports members in their efforts to disseminate information on HIV disease, the specific use of any ANAC title or affiliation in any business-related or other activity in which there is monetary compensation that is not directly related to ANAC must be approved by the Board. Below, please find the policy as it appears in the ANAC Organizational Manual:

Conflict of Interest Policy

Purpose: To establish guidelines for conduct of association business, to avoid any assumption or appearance of conflict of interest or unauthorized representation of the association. Conflict of interest is defined to be, but is not limited to, activities which are in opposition to, detract from, or in some manner could become detrimental to the association as described in the bylaws, policies and procedures.

1. No individual has the authority to act on behalf of the association except as such authority is outlined in the bylaws or approved by the Board of Directors or Executive Board.
2. No individual is authorized to use the association's name or logo or any terminology implying association sponsorship or endorsement without prior approval of the Board or executive Board.
3. Elected officials or committee members acting in behalf of the association shall not take part in any decision or action of the association in which they have a financial interest unless such participation is authorized by the Board after full disclosure of the facts.
4. Duality of interest or possible conflict of interest on the part of any elected official or committee member shall be fully disclosed to the association prior to entering into any formal relationship with any said person, group or organization.

If there is any question, please do not hesitate to contact Inge Corless at the national office.

RESOLUTIONS

The following resolutions were passed at the ANAC tenth anniversary annual conference in Miami.

The Association of Nurses in AIDS Care Chapters Task Force supports the formation of a task force to develop a proposal for dues restructuring

WHEREAS, the major work of achieving ANAC's goals occurs in local chapters; and,

WHEREAS, ANAC's Chapters Committee survey shows a majority of chapters that responded favor dues restructuring; and,

WHEREAS, ANAC's Chapters Committee has proposed dues restructuring; and,

WHEREAS, a single, combined local and national dues payment simplifies local chapter membership and serves as a marketing tool; and,

WHEREAS, it is difficult for some chapters to organize a system for collecting dues, and thus do not always collect what they should; and,

WHEREAS, many national members are unaware of, or do not join existing local chapters; or do not have an existing local chapter; and,

WHEREAS, these local members could have their local dues pooled and used to support local interest groups or chapters in formation; and,

WHEREAS, the ANAC staff has the resources to collect dues and disperse to local chapters; therefore be it

RESOLVED, that ANAC's Chapters Task Force supports the appointment of a task force to develop a

detailed proposal for dues restructuring to include the combined national and local collection of dues at the national level with disbursal by ANAC staff to the chapter level; and be it further

RESOLVED, that the proposal be in the form of a bylaws change subject to review and voting as required by the Bylaws Committee on, or before 11/98.

Sponsored by:

Chapters Task Force: John Roberts, Chair; Joanne Despotes; Kathy Foley; Paul Franquist; Cheryl Hamill; Connie Highsmith; Gail Kropf; George Sharpe; and Lisa Fox, ANAC staff.

Implementation Plan:

Task force to be appointed by the ANAC National Board and the Chapters Committee.

Financial Impact:

Cost of clerical support, postage, conference calls, and possible travel for members of the task force.

Role of the HIV/AIDS Nurse in Assisted Suicide

WHEREAS, ANAC adopted a resolution at its 1994 Annual Business Meeting to explore the role of the HIV/AIDS nurse in assisted suicide and has since appointed a task force to work on position paper/guidelines; and,

WHEREAS, the U.S. Supreme Court issued its decision in 1997 that physician-assisted suicide was not protected under the U.S. constitution, but that individual states may develop their own laws; and,

WHEREAS, the ANAC member survey on HIV/AIDS Nurses and Assisted Suicide received a large response that reflected many diverse opinions; and,

WHEREAS, the population of men, women, and children who are affected by HIV/AIDS and who are cared for by our nurse members will be directly affected by state, local, and agency actions in relation to physician-assisted suicide; therefore be it

RESOLVED, that the Association of Nurses in AIDS Care encourage members to act within the laws that govern nursing actions in a professional and an informed manner; and be it further

RESOLVED, that the Association of Nurses in AIDS Care urge its members to thoughtfully explore personal values and beliefs about physician-assisted suicide and carefully weigh one's right to conscientious objection with the professional obligations to patient advocacy, respect, and nonabandonment; and be it further

RESOLVED, that the Association of Nurses in AIDS Care encourage its members to become active participants in decision-making and policy-development activities to advocate for their personal and professional perspectives on the nurse's role in physician-assisted suicide; and be it further

RESOLVED, that the Association of Nurses in AIDS Care develop and provide its members with information that will assist them to take informed stances and advocate for their positions, regardless of whether that stance is for or against physician-assisted suicide, to use with patients, their families, and in community action.

Sponsored by:

Task Force on the Role of the HIV/AIDS Nurse in Assisted Suicide: Mary Dunlap; Emma Garza; Debbie Gleason-Morgan; Kevin Mallinson, Liaison to Board; Judith Saunders, Chair

ANAC POSITION STATEMENTS

- Funding for Advanced Practice Nursing Education
- Endorsement of the AIDS Nursing Registered Nurse (ACRN) Credential
- The Nurse as HIV/AIDS Case Manager
- Palliative Care for All Persons Living with HIV/AIDS, Including Substance Users
- Medicaid and HIV Infected Persons
- HIV Serosurveillance and Reporting
- Duty to Care
- HIV Reproductive Counseling and Care
- The Nursing Specialty of HIV/AIDS Care
- HIV Disease and Tuberculosis
- Adolescents and HIV Infection
- Harm Reduction and HIV Care

ANAC
ASSOCIATION OF NURSES IN AIDS CARE

11250 Roger Bacon Drive, Suite 8
Reston, VA 20190-5202

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ANACdotes is the official newsletter of the Association of Nurses in AIDS Care. It is published six times a year. Please direct comments and correspondence to ANAC at the address below. *ANACdotes'* purpose is to share current information pertaining to ANAC, HIV/AIDS, and AIDS care. Any discussion of treatment regimens or products does not represent an endorsement or recommendation by the association.

Editor: Clarissa Ramstead, RN, MSN(c)

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

February 9, 1998

Ms. Sandra Thurman
Director
Office of National AIDS Policy
808 17th St., NW, Ste. 820
Washington, DC 20006

Dear Ms. Thurman:

The San Francisco AIDS Foundation is pleased to provide you with the enclosed copy of our new report, "Renewing the Commitment: An HIV/AIDS Policy Agenda for the Nation."

As you know, continued federal support for HIV/AIDS programs is critical to improving the quality of life for tens of thousands of people living with HIV disease nationwide. The rapid and hopeful improvements in HIV treatments, combined with the overwhelming uncertainty about access to these treatments and their long-term efficacy, will require continued vigilance on the part of policymakers and advocates alike. It is therefore with great urgency that the San Francisco AIDS Foundation urges a renewed commitment to ending the HIV epidemic and the human suffering caused by AIDS.

"Renewing the Commitment" describes the Foundation's major federal policy and budget priorities for the coming year. We hope that it will serve as a useful reference tool for you. It provides a quick epidemiological overview of the HIV epidemic nationally, as well as recommendations on a range of important issues affecting people living with HIV/AIDS and those at risk for infection.

We look forward to working with you in the coming year on federal efforts to expand funding and promote sound policies in the areas of HIV/AIDS care, housing, prevention and research. If we can be of further assistance, please feel free to contact the Foundation's Public Policy Department at (415) 487-3080 or Ernest Hopkins directly at (415) 487-3096.

Sincerely,

Ernest C. Hopkins
Director of Federal Affairs

Regina Aragón
Deputy Director for Public Policy

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901
(415) 487-3000

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Renewing the Commitment

AN HIV/AIDS POLICY AGENDA FOR THE NATION

San Francisco AIDS Foundation

Public Policy Department

February 1998

Hospice of South Georgia

PO Box 1727
Valdosta, Georgia 31603
912-249-4100
Fax: 912-249-4102

FAX TRANSMISSION COVER SHEET

Date: 8-20-97
To: Sandra Thurman
Fax: 202-632-1096
Re: Rural Physician Program
Sender: Laurel Tepper, MSW

YOU SHOULD RECEIVE (2) PAGE(S), INCLUDING THIS COVER SHEET. IF YOU DO NOT RECEIVE ALL THE PAGES, PLEASE CALL 912-249-4100.

Call

HOSPICE of South Georgia

Post Office Box 1727 • Valdosta, Georgia 31603-1727
Telephone (912) 249-4100 • Fax (912) 249-4102

August 20, 1997

TO: Sandra Thurman, Director
Office of National HIV/AIDS Policy
FAX: 202-632-1096

FROM: Laurel Tepper, MSW
Hospice of South Georgia, Valdosta, GA
FAX: 912-249-4102

It was such a pleasure to meet you, albeit briefly, after the Town Hall Meeting last Friday in Atlanta. Your Aunt Joye had told me so much about you and I was so pleased to be able to finally meet the person Joye is so proud of.

You mentioned briefly during the Town Hall Meeting about a program (or programs) that places physicians recently out of medical school in rural areas for a period of time. I have heard mention of this before, but have never been able to find out where I can get more information. We have only one physician in this area who will serve as primary care physician for HIV+ patients. He is not an infectious disease specialist (we do not have one in Valdosta), but a GP who works two afternoons a month seeing patients in a "clinic" funded by Ryan White.

Would you be able to fax me some information about this program so I can begin to investigate the possibility of getting a physician in this community who specializes in HIV/AIDS? Thank you so much.

Data Entry Form

Letter ID	Writer First Name	Writer Last Name	Received Date	Subject
10624	Christofer	Wolf	3/20/98	Bike ride

√ Response Required?

Response Type	Response Date	Responder ID	Responder Name	Action Promised
			SThurman	

Action Completed	Action Date	Addressed To

Notes

Sender's Organization	Sender's Street1	Sender's Street2
Food and Friends		

Sender's City	Sender's State	Sender's Zip
Washington		

FOOD & FRIENDS

Christopher Wolf
President

March 18, 1998

Ms. Sandra L. Thurman
Director
White House Office of National AIDS Policy
808 - 17th Street, N.W., Suite 820
Washington, D.C. 20006

Dear Sandra:

For the third year in a row, I will join thousands of bike riders committed to fighting AIDS and helping those affected by the disease. In June, we will participate in the Washington, D.C. AIDSRide and will pedal the 350 miles from Raleigh, North Carolina to Washington, over four days, to display our commitment and solidarity. I am writing to invite you to join me — not literally, although there is room for more riders if you are so inclined! I want you to join me in spirit, and with your sponsorship.

The Washington, D.C. AIDSRide is the single most important fundraiser for Food & Friends, the agency for which I have the privilege of serving as Board President. Food & Friends prepares and delivers 10,000 meals and groceries *each* week to men, women and children with AIDS in the Washington area. Without our help, these people would not receive the nutrition so important to their fight against the disease, and to their basic comfort. The AIDSRide provides fully one-quarter of our budget. Without the income from the Ride, we simply could not meet the needs of the community.

Please do join me in the mission of Food & Friends, and sponsor me in the AIDSRide. A sponsorship form is enclosed. Please fill it out today and return it to me. I can't wait to be your riding partner!

Thanks so much.

Sincerely yours,

Thanks, Sandy!

Christopher Wolf

Enclosure

58 L STREET, S.E. • WASHINGTON, D.C. 20003-3353 • (202) 488-8278 • FAX (202) 863-1284 • TDD (202) 554-2944

Pledge Form

Rider Number	231 W
Rider Name	CHRIS WOLF

Thank You

Thank you for sponsoring the rider (named above) in the AIDS Ride. Please read over this pledge form carefully, and fill it out completely and legibly in order to prevent processing delays. We are sorry, but we cannot accept cash pledges. If you have any questions on filling out this form, please contact the pledge office at the number below. Pledges are tax deductible to the fullest extent allowed by law.

Matching Gift Programs

Many companies provide their employees with matching gift/pledges. Please check with your employer on its specific matching gift guidelines.

Washington, D.C. AIDS Ride 3
Presented by Tanqueray

Whitman-Walker Clinic Inc

Send all pledges and pledge forms directly to:

CHRISTOPHER WOLF
1233 TWENTIETH STREET NW
SUITE 800
WASHINGTON DC 20036-2396

A I'M BEHIND YOU EVERY MILE !

Please print clearly in the spaces provided below

Last Name _____ First Name _____

Last Name _____ First Name _____

Mailing Address _____ Suite/Apt. _____

City _____ State _____ Zip _____

( ) _____ Phone

○ Do not place me on any further mailings

B I'M SUPPORTING YOU IN THIS HEROIC COMMITMENT

Please mark the circle corresponding to your pledge commitment

○ **Honorary Rider**	**$1000**	○ **Commitment**	**$250**
○ **Heroism**	**$750**	○ **Spirit**	**$125**
○ **Inspiration**	**$500**	○ **Other Amount**	**$_____**

C TWO EASY PAYMENT OPTIONS

Based on my selection in section B, I would like to pay my pledge via:
(Please choose one form of payment)

➲ Single Payment Option

➲ **Personal Check or Money Order**
Please make checks payable to **Washington, DC AIDS Ride**

➲ Credit Card Payment
Choose One: ☐ Visa ☐ Mastercard ☐ Discover ☐ American Express

Account Number _____ Exp. Date _____

IMPORTANT: Your monthly statement will read **Food & Friends OR DC AIDS Ride.** Payments commence immediately upon processing of this form by the Pledge Office. Pledges are tax deductible to the fullest extent of the law.
I have read and understand the above.

Signature _____ Date _____

➲ Multiple Monthly Payments

If you wish to have your pledge debited automatically each month from your account, please read the following carefully, complete, and sign.
Monthly Debits can be payed by credit card (complete and sign above) or through your checking account (attach **VOIDED** check). Monthly payments may extend up to 10 months and have a minimum of $50.00 per month.

I would like to pay my pledge in _____ monthly payments of $_____ per month.

Important: Please read and complete the following. I (we) hereby authorize Food & Friends to initiate debit entries and to initiate, if necessary, credit entries and adjustments for any debit entries in error to my (our) account, on the 3rd Monday of each month. This authority is to remain in full force and effect until my pledge is fulfilled or until revoked by me (us) in writing. **Your monthly statements will read Food & Friends.** Payments commence immediately upon processing of this form by the Pledge Office. Pledges are tax deductible to the fullest extent of the law.

Signature _____ Date _____

THANK YOU! PLEASE MAIL THIS FORM DIRECTLY TO ADDRESS AT LEFT.

An Important Note to Donors:

The AIDS Rides® make no guarantee about what percentage of donations will go back to AIDS services. This depends entirely on how many individuals ride, and on how much money they raise. The more raised, the greater the percentage returned to services.

What percentage of dollars have gone back to AIDS services in the past?

Nearly $40 million from all Rides — a record. The American AIDS Rides® have delivered more money more quickly back to AIDS charities than any AIDS fundraising operation in history. And this is what AIDS charities need. Money. As quickly as they can get it. Since the first AIDS Ride® in California in 1994, twenty-two AIDS Ride fundraising campaigns have been completed. Approximately $70 million has been raised, and approximately 57% of every donor dollar, or a total of nearly $40 million, has gone back to AIDS services. Please note that the specific percentage for your city may be different — please call your local Ride office to find out.

Where does the rest of the money go?

About 25% of every dollar goes into administrative expenses (a good portion of which help promote AIDS awareness) and approximately another 18% goes toward rider safety and support — meals, showers, safety signage, tents, and everything it takes to move your friends and loved ones, and thousands of other people, safely from town to town each day. Safety is priority one with the AIDS Ride®.

What is the standard for return on donations?

Different organizations say different things, and it always depends on the nature of the fundraising appeal. Standards are different for a special event like the AIDS Ride® than they are for a solicitation you might get in the mail. As a person who gives to charity, you should do all you can to understand the complexities of charitable fundraising. Don't accept any one number as a norm. The amount is as important as the percentage. For instance, an event that returns 70% of your dollar back to charity may look better than one that sends 60% back. But what if the event that returns 70% raised $100,000, while the event that returns 60% raised $5 million? The 60% event returned a lot more money to the cause. One of the leading professional fundraising trade organizations, the National Society of Fundraising Executives, states that 50% of every dollar from events should go back to charity. The AIDS Ride's® historic average of 57% falls well above that guideline.

The AIDS Ride® is extremely different from most fundraising events. In addition to fundraising, it is an awareness and empowerment event. For many people, the Ride is a life-changing experience. Providing the setting for that kind of experience requires very complicated logistics and mobilization operations. The AIDS Ride® is truly a new model in a class by itself, and one for which no real standards exist. This makes it even more remarkable that the Rides DO fall within the accepted cost standards for other, less complicated events.

Have any AIDS Rides® ever performed below standards?

Out of 22 campaigns, 3 have performed below the 50% standard — 2 in Florida and 1 in Philadelphia. Too few riders participated. We have discontinued those events. The other 19 have been great successes, and performed within the 50% standard. Some, like the California Ride and the Boston⇔New York Ride, have returned as much as 62% - 65% of every dollar to charitable services. No AIDS Ride has ever lost money for a charity. Even the three that performed below standards together returned over $1 million back to AIDS services. Overall, the AIDS Rides® are one of the greatest success stories in 20th century fundraising.

Do the organizers try to get things donated?

Constantly. We have full-time staff working on nothing but bringing in corporate donations to help defray costs. Companies like Tanqueray, who donate nearly $1 million annually in cash to defray costs, continue to come on board to help us send even more dollars back to AIDS services.

An important note...

The AIDS Ride® has many intangible benefits you can be proud of — like the advertising that helps increase awareness about AIDS, like the way the Ride gives hope to HIV positive riders, like the way the AIDS riders get people talking about AIDS as they go out and seek donations, like the children that line the streets to cheer on the riders and get a first-hand experience of heroism, or like the way the Ride teaches people that we can work together to solve our problems. These are the things that make the Ride so unexplainably magical. These are important reasons to give as well. And these are things you can count on the AIDS Ride® delivering.

As presenting sponsor since the first California AIDS Ride in 1994, Tanqueray has been a proud partner in the largest AIDS fundraising effort in history. We wish to acknowledge you for joining us in the battle against HIV and AIDS. Your generous contribution will provide vital services to people living with HIV and AIDS throughout the country. Your commitment to the Ride is a special source of inspiration. From all of us at Tanqueray, on behalf of all of those benefiting from your donation—Thank you!

FOOD & FRIENDS

58 L STREET, S.E. • WASHINGTON, D.C. 20003-3353

Christopher Wolf, Esq.
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