FOIA Number: 2018-0758-F

FOIA MARKER

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

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Todd Summers

Subseries:

OA/ID Number: 21080

FolderID:

Folder Title:
Issues - Prevention - Prenatal Transmission

Stack:	Row:	Section:	Shelf:	Position:
S	66	6	3	3

Department of Health and Human Services
National Institutes of Health
National Institute of Allergy and Infectious Diseases

FOR RELEASE

Wednesday, July 14, 1999
12:00 p.m. Eastern Time

CONTACT:
Office of Communications
And Public Liaison
(301) 402-1663

Researchers Identify a Simple, Affordable Drug Regimen That Is Highly

Effective In Preventing HIV Infection In Infants of Mothers with the Disease

A joint Uganda-U.S. study has found a highly effective and safe drug regimen for preventing transmission of HIV from an infected mother to her newborn that is more affordable and practical than any other examined to date. Interim results from the study, sponsored by the National Institute of Allergy and Infectious Diseases (NIAID), demonstrate that a single oral dose of the antiretroviral drug nevirapine (NVP) given to an HIV-infected woman in labor and another to her baby within three days of birth reduces the transmission rate by half compared to a similar short course of AZT. If implemented widely in developing countries, this intervention potentially could prevent some 300,000 to 400,000 newborns per year from beginning life infected with HIV.

"This extraordinary finding is the most recent in our efforts to bring an end to AIDS, not only in the United States but in countries around the world," says Health and Human Services Secretary Donna E. Shalala. "American scientists along with our international partners are committed to developing treatments that not only work, but that are also feasible in other health care settings. These results achieve both those goals."

"This study represents the most promising advance to date toward the goal of finding strategies that can be used worldwide to prevent the spread of HIV from infected mothers to their infants," says NIAID Director Anthony S. Fauci, M.D. NIAID is a component of the National Institutes of Health.

In an announcement from Kampala this morning, Ugandan officials hailed the finding. "This research provides real hope that we may be able to protect many of Africa's next generation from the ravages of AIDS," says Crispus Kiyonga, M.B.Ch.B., Uganda's Minister of Health. "We commend the collaborative effort of our country's scientists, led by Professor Francis Mmiro from Makerere University Faculty of Medicine, and their U.S. colleagues, led by Dr. Brooks Jackson from The Johns Hopkins University School of Medicine."

Finding affordable interventions for developing countries is key to curtailing the global AIDS epidemic. In parts of the hardest-hit area, sub-Saharan Africa, up to 30 percent of pregnant women are infected with HIV, and 25 to 35 percent of their infants will be born infected. The UNAIDS estimates that approximately 1,800 HIV-infected babies are born every day in developing countries.

Unfortunately, the standard AZT regimen used to prevent perinatal HIV transmission in the United States is too expensive and impractical for widespread use in developing countries where many women may not receive prenatal care.

Based on average U.S. wholesale costs, the cost of the drug used in the nevirapine regimen in the current study is approximately 200 times cheaper than the long-course AZT used in the United States, and almost 70 times cheaper than a short course of AZT given to the mother during the last month of pregnancy - a regimen tested in Thailand by the Centers

ISSUES -

for Disease Control and Prevention and reported effective in 1998.

The Uganda study investigators, part of the NIAID-supported HIV Prevention Trials Network (HIVNET), opened the trial two years ago at Mulago Hospital, affiliated with Makerere University, in Kampala, Uganda. They completed enrollment last April. All women entered into the study were in their ninth month of pregnancy. None had taken antiretroviral drugs while pregnant.

The study, known as HIVNET 012, compared the safety and efficacy of two different short-course regimens of antiviral drugs administered late in pregnancy. The women were assigned at random to receive either a 200-mg dose of oral nevirapine at the onset of labor, followed by a 2-mg/kg oral dose given to their babies within three days of birth; or a 600-mg dose of AZT at the onset of labor, and 300-mg doses every three hours thereafter during labor. The infants born to mothers in the AZT group received 4 mg/kg given twice daily for the first week of life. Both drugs appeared to be safe and well-tolerated.

Study design, data collection and analysis was provided by a team of researchers led by Dr. Thomas Fleming, a biostatistican at the Fred Hutchinson Cancer Research Center and the University of Washington School of Public Health and Community medicine in Seattle.

For the interim analysis, the study team looked at data from 618 mothers (308 receiving AZT and 310 receiving nevirapine) and their infants.

Nevirapine was markedly more effective. At 14 to 16 weeks of age, 13.1 percent of infants who received nevirapine were infected with HIV, compared with 25.1 percent of those in the AZT group.

"In this study, the short-course nevirapine regimen resulted in a 47 percent reduction in mother-to-infant HIV transmission compared with a short course of AZT. The implications of this study for developing countries, where 95 percent of the AIDS epidemic is occurring, are profound," says Brooks Jackson, M.D., the lead U.S. investigator on the trial.

Long-term follow-up of both the mothers and their babies remains a high priority to assess any late drug toxicities as well as long-term survival. The mothers and their children will continue to be actively followed until the babies are 18 months old. This period is critical to establish the efficacy of the intervention because even if a baby is born HIV-free, he or she may acquire the virus during breastfeeding. The data analyzed so far cover only the first three months of the newborn's life. Ugandan and U.S. investigators will soon launch a follow-up study to evaluate the efficacy of nevirapine administered to the mother during labor and to the newborns for a longer period of time.

Breastfeeding is practiced widely in developing countries. Most studies indicate that the rate of HIV transmission via breastfeeding is highest in the first few months of life. No intervention has yet been shown to prevent HIV transmission through breast milk other than not breastfeeding.

The single-dose nevirapine regimen to mother and infant substantially lowers the cost barrier that has kept many countries from adopting drug strategies that prevent perinatal HIV transmission. Still, access to other health care services required to implement this regimen, such as counseling and voluntary HIV testing, are beyond available resources of many developing countries. But if further research upholds nevirapine's good safety record, the investigators say that potentially all pregnant women who live in areas of high HIV prevalence could receive the drug during labor, even in the absence of an established HIV diagnosis.

In the United States and other industrialized countries, many HIV-infected pregnant women already take combination drug regimens that include AZT. A study now being conducted in the United States and Europe is evaluating if adding nevirapine to standard treatment regimens will have any extra benefit in preventing perinatal HIV transmission in these countries. For pregnant women who do not know their HIV status until they begin labor, the nevirapine regimen provides a last-minute prevention option.

Nevirapine, developed by Boehringer Ingelheim Pharmaceuticals, is a non-nucleoside reverse transcriptase inhibitor, and is in a different class of antiviral drugs than AZT but works against the same HIV target enzyme that is critical for the virus to infect new cells. It can be easily stored at room temperature. Besides being inexpensive and potent, nevirapine is rapidly absorbed and transferred across the placenta to the infant, and it breaks down slowly. For these reasons, it was thought that even a single dose to the mother and infant might provide enough protection to the baby during the time of exposure to HIV at birth. In March 1996, nevirapine was licensed in the United States for treatment of HIV infection in adults. AZT, made by Glaxo Wellcome, was first approved in the United States to treat AIDS in 1987. In August 1994, AZT received an additional indication for use in preventing perinatal HIV transmission.

NIAID is a component of the National Institutes of Health (NIH). NIAID conducts and supports research to prevent, diagnose and treat illnesses such as HIV disease and other sexually transmitted diseases, tuberculosis, malaria, asthma and allergies. NIH is an agency of the U.S. Department of Health and Human Services.

###

TV Reporters, Editors and Producers: a b-roll about the study is available via satellite.

Downlink Information:

Date: Wednesday, July 14, 1999
Time: 1:00 p.m.-1:15 p.m. EST AND 3:00 p.m. - 3:15 p.m. EST Satellite: Telstar 6 (93 degrees west longitude)
Downlink frequency: 3820
Polarization: horizontal
Audio frequency: 6.2 and 6.8
C Band
Transponder 6/Channel 6

NASTAD Issue Brief

a publication of the National Alliance of State and Territorial AIDS Directors
July 1998

An Overview of Recent State Policies, Programs, Data Collection and Evaluation Activities Related to Reducing Perinatal HIV Transmission

1998 Summary Report

The National Alliance of State and Territorial AIDS Directors conducted a brief survey of state health department HIV/AIDS programs in April 1998 to gather recent information on state level activities related to reducing perinatal HIV transmission.[1] The chief goal of the survey was to obtain current trend information on state legislative, policy and regulatory activity, and pinpoint the availability of state specific information on programs, surveillance data and evaluation studies related to perinatal HIV issues.

Many state public health programs are in the process of examining ways to improve efforts to reduce perinatal HIV transmission and demonstrate the effectiveness of HIV prevention interventions. There are also two important benchmarks expected in 1998 related to federal and state policy on perinatal HIV transmission which are requirements of the Ryan White CARE Act Amendments of 1996.

The Institute of Medicine (IOM) of the National Academy of Sciences is undertaking, during 1997-98, an evaluation of the extent to which State efforts have been effective in reducing the perinatal transmission of HIV. Specific issues that the IOM will address include: assessment of factors affecting perinatal HIV transmission (e.g., inadequate provision of prenatal counseling and testing); availability and effectiveness of interventions to prevent the transmission of HIV from mother to newborn; and the extent to which states have implemented existing U.S. Public Health Service guidelines for preventing perinatal transmission of HIV. This report is being carried out by a committee with experts in pediatrics, obstetrics and gynecology, preventive medicine, women's health, social and behavioral sciences, public health practice, epidemiology, program evaluation, health services research, and other fields. The IOM report is expected to be completed by October 1998.

The CARE Act also requires the Secretary of the U.S. Department of Health and Human Services to issue a determination by October, 1998 whether it has become routine practice in the provision of health care in the U.S. to conduct mandatory HIV newborn testing of all infants whose mothers have not undergone prenatal HIV testing. If the Secretary determines that such testing has become routine practice, after an additional 18 months (by April, 2000), a state must demonstrate one

[1] A brief questionnaire was sent to every state health department AIDS program director in March and April 1998. Completed survey responses were received from all states and Puerto Rico with the exception of the District of Columbia, Kansas, Louisiana, Maryland, and New Mexico for a response rate of 90% (47 states out of 52 surveyed).

of the following in order to receive Ryan White Title II funding: a 50 percent reduction in the rate of new perinatally transmitted AIDS cases (or, for states with fewer than 10 cases, a comparable measure) comparing the most recent data to 1993 data; or at least 95 percent of women who received at least two prenatal visits have been tested for HIV; or require HIV testing for all newborns whose mothers have not undergone HIV testing.

Given these important developments, policymakers, researchers and program planners need further information on state efforts to set policies, establish responsive programs, and measure the effectiveness of HIV prevention and care efforts related to perinatal HIV transmission.

Overview of Findings

NASTAD's survey and summary report seek to assist in identifying state activities, describe state progress in implementing the standard of care, and state responses to potential federal legislative requirements. The survey report identifies information sources for further investigation in three main areas:

Policy, legislation and regulations: New, updated information is needed given the rapidly developing nature of both scientific findings and policy change. The report provides an update on developments in several states vis a vis recent state legislation, policies and regulations regarding HIV counseling and testing of pregnant women and newborns, including general trends.

Availability of pediatric HIV/AIDS surveillance information: Information and data is needed to track state pediatric HIV/AIDS cases and perinatal HIV exposure, in order to indicate potential gaps and highlight findings of successful reductions in HIV/AIDS cases. There is significant variability, however, in the scope and types of information collected by state public health programs across the country. The survey seeks to identify and describe the kinds of information that is readily available from states. This information can be used as the basis for further exploring surveillance reports from both the federal Centers for Disease Control and Prevention (CDC) and state public health programs.

Evaluation studies: The survey report identifies research and evaluation studies that have been conducted or are in development which demonstrate progress, successes or problems in implementing the standards of HIV care for women, infants and children.

In addition, the report indicates contact names for further investigation on policy, research and evaluation related to perinatal HIV transmission in most states.

The report is not intended to be the last word on state progress in reducing perinatal HIV transmission, nor be an exhaustive description of state policy, surveillance and evaluation activities. Rather, it is meant as a starter for further investigation, data collection and information dissemination which may be useful for the Institute of Medicine, the U.S. Department of Health and Human Services, states, national organizations and other entities.

Background

In 1994, ACTG 076 Clinical Trial results clearly documented the efficacy of AZT monotherapy in reducing HIV perinatal transmission from HIV-infected mother to infant. Several sets of federal recommendations have been subsequently developed that relate to these findings.

- In 1994, *Recommendations for the Use of Zidovudine [AZT] to Reduce Perinatal Transmission of HIV* were developed outlining use of AZT for pregnant women infected with HIV. These guidelines were revised in 1998 as *Recommendations for Use of Antiretroviral Drugs During Pregnancy for Maternal Health and Reduction of Perinatal Transmission of HIV-1*. They cover use of antiretroviral therapy to reduce perinatal transmission of HIV; special considerations for use of antiretroviral drugs in pregnant women; update clinical trials on use of ZDV chemoprophylaxis to reduce HIV-1 perinatal transmission; and monitoring of pregnant women and infants. Included in these updated guidelines is information about the importance that pregnant women with HIV be treated for their own HIV disease (given data on the efficacy of combination antiretroviral therapies). This is an important consideration given that use of ZDV monotherapy, while demonstrated effective in re-

ducing HIV perinatal transmission, is not a recommended antiretroviral therapy for treatment of HIV disease.

- *Public Health Service Recommendations for HIV Counseling and Voluntary Testing for Pregnant Women* were formulated in 1995, outlining procedures to increase universal counseling and voluntary HIV testing of pregnant women so that they might benefit from these new findings. For women identified as infected with HIV, recommendations were made to provide medical and psychosocial services, offer AZT for reducing perinatal transmission, and provide counseling against breastfeeding.

The Ryan White CARE Act Amendments of 1996 contain multiple provisions related to HIV testing and health and support services for women, infants and children. They include the following:

- Proportionate Spending (Section 2611). Each state must spend a percent of Title II funding for services to women, infants, and children with HIV disease that is not less than their percent of the state's total AIDS cases. For example, in a state where women, infants, and children constitute 30% of the reported AIDS cases, at least 30% of that state's Title II award must be used to support services to women, infants, and children with HIV disease.

- Implementation of PHS Recommendations on HIV Counseling and Testing of Pregnant Women (Section 2625). All states have provided certifications to CDC, by September 1996 as required by this provision, that they have in effect regulations or have adopted measures to implement the *Public Health Service (PHS) Recommendations for HIV Counseling and Voluntary Testing for Pregnant Women*. The PHS recommendations stress that women should be routinely counseled and voluntarily tested for HIV (with informed consent) early during their pregnancy. Those identified as HIV-infected should be counseled and offered antiretroviral therapy to reduce the risk of perinatal HIV transmission, which has been documented as effective in significantly reducing the risk of transmission from mother to fetus. Grants to states are also authorized (although funds have not been appropriated) to conduct counseling on HIV disease for pregnant women; outreach for women at risk of HIV who are not currently receiving prenatal care; making voluntary HIV testing available to such women; and offsetting state costs for implementing CDC's guidelines, surveillance activities for assessing new cases of HIV perinatal transmission, and newborn testing for HIV.

- Perinatal Transmission of HIV Disease (Sections 2626 and 2627). States must annually determine the rate of reported AIDS cases resulting from perinatal transmission; CDC must implement a system for reporting on perinatal transmission AIDS cases; and the Secretary of HHS must determine (by October, 1998) whether it has become routine practice in the provision of health care in the U.S. to conduct mandatory HIV newborn testing of all infants whose mothers have not undergone prenatal HIV testing. If the Secretary determines that such testing has become routine practice, after an additional 18 months (April, 2000), a state must demonstrate one of the following in order to receive Title II funding: a 50 percent reduction in the rate of new perinatal transmission AIDS cases (or, for states with fewer than 10 cases, a comparable measure) comparing the most recent data to 1993 data; or at least 95 percent of women who received at least two prenatal visits have been tested for HIV; or require HIV testing for all newborns whose mothers have not undergone HIV testing. States that implement testing requirements must prohibit health insurance companies from canceling or altering coverage based solely upon the individual's HIV status.

  Based on extensive state and federal surveillance activities, surveys and evaluations, NASTAD does not believe "that it has become routine practice in the provision of health care in the United States to conduct mandatory HIV newborn testing of all infants whose mothers have not undergone prenatal HIV testing." Currently only one state (New York) has policies in place requiring HIV screening of newborns.

- Institute of Medicine Report Evaluating State Efforts to Reduce HIV Perinatal Transmission (Section 2628). The Institute of Medicine shall complete an evaluation of the extent to which state efforts have been effective in reducing HIV

perinatal transmission and analyze barriers to further reductions in such transmission.

These scientific and policy developments represent the backdrop for specific state efforts to reduce perinatal HIV transmission through policymaking, monitoring and evaluating activities.

State Policies/Legislation/Regulations

The survey indicates that there has generally not been a substantial growth in state legislative activity on perinatal HIV issues, with several notable exceptions. Eight out of the 47 states responding (17%) reported some type recent legislative activity in this area. The bulk of state legislative and policy activity in this arena occurred between 1994 and 1996, on the heels of the ACTG-076 findings and implementation of the *PHS Guidelines*. Although there have been fewer laws and regulations enacted since that time in most states, there is a trend in the more recent laws to attempt to *assure* that universal HIV counseling occurs and that testing is offered to pregnant women – generally with the right of refusal. These newer laws and policies may reflect a concern that, although universal counseling and offering of voluntary testing to pregnant woman should be a standard, counseling and testing is not being conducted universally and is being done too selectively in some jurisdictions.

Current or pending activity related to perinatal HIV transmission, whether legislative, policy-related, regulatory in nature or guideline-related was an area of inquiry which NASTAD focused on in the survey. *The following states reported 1998 legislative and policy related activity:*

A new 1998 ***Indiana*** state law authorizes physicians to screen newborns for HIV if the mother was not tested during prenatal care. As originally proposed, the Indiana legislation would have mandated testing of all newborns for HIV, akin to New York State's "Baby AIDS Bill" requirements. The final version of the law authorizes physicians to order the newborn be tested no later than 48 hours after birth if the doctor believes that testing is medically necessary. The physician must notify the mother that the test is being done, and he or she must provide HIV counseling to the mother. The doctor must explain the purpose of the test, outline the risks and benefits of testing, describe how HIV is spread, and discuss how the woman can reduce the chance of transmitting HIV through breast feeding. The woman must be referred to other HIV prevention, health care and psychosocial services. The physician must tell the woman of the result of the newborn's test and the information is to be kept confidential. The only ones exempt from testing are children of parents who voice religious objections.

In April, the Indiana Health Department's executive board approved an emergency rule giving physicians more guidance in following a 1997 state law that requires physicians to counsel all pregnant woman about the risks of HIV and suggest that they be tested, either confidentially or anonymously. A law passed by the 1997 Indiana General Assembly (House Bill 1280) requires obstetricians, family physicians and other providers of prenatal care to conduct HIV counseling, to offer HIV testing to each pregnant woman, and to document this in the patient's chart. But testimony in the 1998 legislative session on newborn screening showed that many providers where not complying with the prenatal counseling and testing statute. According to the state health department, the failure to comply seemed to result mostly from a lack of awareness about the new law and possibly from an incomplete understanding of the importance of counseling and appropriate testing of each pregnant woman regardless of her apparent risk for contracting HIV.

The Indiana State Department of Health will employ two new health educators to work throughout Indiana to educate women and health care providers about the current law and the new rule. In addition, a number of associations and organizations have united with the State Department of Health to provide input into the development and implementation of the new rule. Under the rule, physicians are to fill out a form indicating that they provided counseling and recommended an HIV test. The form reminds physicians that they are to explain why testing is important, but that it is voluntary. It also prompts them to discuss findings of the 076 clinical trial which showed that taking AZT during pregnancy and delivery and after childbirth reduces HIV transmission by two-thirds.

In ***Tennessee***, the "Tennessee HIV Pregnancy Screening Act of 1997" became effective January 1, 1998. This bill requires "...all providers of health care services who assume responsibility for the prenatal care

of pregnant women during gestation to counsel pregnant women regarding HIV infection and, except in cases where women refuse testing, to test these women for HIV and to provide counseling for those women who test positive."

The Tennessee State Department of Health shall make all educational and counseling materials required available to providers responsible for the counseling. After she has received the counseling and information specified, a pregnant woman under the care of a health care provider shall sign a form developed by the Department of Health indicating that she has been informed and indicating her consent or refusal to the HIV testing. A health care provider shall arrange for each pregnant woman under his or her care to be tested for HIV as early as possible in the course of the pregnancy unless the woman has refused testing in writing on the form.

There is a 1998 bill in the ***Delaware*** legislature which would require prenatal HIV antibody testing as part of the routine prenatal STD work-up. The current legislation would rescind the already existing statute which mandates counseling, and requests voluntary testing, if consent is obtained.

The bill "Targeted Outreach for Pregnant Women Act of 1998" passed in the ***Florida*** legislature. The bill is intended to reduce both the number of women who give birth to HIV-infected babies and the number of newborns who have been exposed to illegal drugs. The bill requires the Department of Health to establish a two-year pilot program to provide outreach services to high-risk pregnant women in the five counties (Dade, Broward, Palm Beach, Hillsborough, and Orange) with the highest prevalence rates of HIV in pregnant women and the largest population of substance-exposed newborns.

These services will focus on encouraging high-risk pregnant women to be tested for HIV; educating women not receiving prenatal care on the benefits of such care; providing HIV-infected pregnant women with information so that they can make an informed decision about the use of AZT; linking women with substance abuse treatment when available; and acting as a liaison with Healthy Start, Children's Medical Services, providers funded under the Ryan White CARE Act, and other Department of Health services. The bill takes effect October 1, 1998.

A bill passed the ***South Carolina*** House in March 1998 (HB4387) which mandated counseling of pregnant women, testing with consent/informed refusal, documentation in mothers' record, and testing of newborns whose mother's status is unknown.

Several laws were passed in states in 1997 which relate to counseling and testing of pregnant women; these include the following:

A 1997 ***Arkansas*** law requires that pregnant women, as early as reasonably possible in their pregnancy or, if not attended prenatally, at the time of delivery, must be tested for HIV. If for any reason the pregnant woman is not tested for syphilis, HIV or Hepatitis B, that fact shall be recorded in the patient's records, which, if based upon the refusal of the patient, shall relieve the physician of any responsibility under the law. Every provider shall provide counseling and instruction for HIV in a manner prescribed by the state Department of Health.

A 1997 ***Maryland*** law requires health care providers to counsel pregnant women concerning HIV testing as part of the woman's prenatal care program. The law requires the counseling to include a prescribed set of information. The law also provides: that the pregnant woman is not required to consent to an HIV test; and the pregnant woman will not be denied prenatal care by the health care provider or health care facility because the woman refuses to have a test performed.

In 1997, two pieces of legislation were passed in ***Minnesota*** related to perinatal HIV transmission. All existing statutes were amended concerning medical assistance coverage for diagnostic, screening and preventive services to include "prenatal HIV risk assessment, education, counseling and testing." In addition, funds were appropriated for a 2-year period ($200,000 total) to the Minnesota Department of Health for "activities related to prevention of perinatal transmission of HIV, a statewide education campaign for pregnant women and their health care providers, and demonstration grants to providers to develop procedures for incorporating HIV awareness and education into perinatal care." The state recently released a Request for Proposals for pilot projects for universal counseling and voluntary HIV testing in prenatal clinics. The purpose of the pilot projects is to develop and implement strategies for incorporating counseling and voluntary HIV testing into routine prenatal care. Three projects are being funded in the Minneapolis-St. Paul

metro area and two outside of the metro area for a 12-month period starting July 1, 1998.

Regulation Related Activities (Including Revisions)

Eleven states out of the 47 responding (23%) reported some type of regulation-related activity, including development of guidelines and/or policies, or activities relation to the distribution of information, materials and educational efforts.

The Department of Public Health has a proposed revision of the Notifiable Diseases Act of the ***Alabama*** Code which would authorize the State Board of Health to establish by rule which sexually transmitted diseases and by which procedures pregnant women and newborns will be tested. This revision will permit the State Board of Health to require testing for additional sexually transmitted diseases, notably at this time, HIV infection.

In ***New York***, regulations became effective February 1, 1998 which add HIV to the list of conditions routinely tested for under the Department's Newborn Screening Program. As a consequence, the result of HIV testing conducted on each newborn is given to his/her mother or, if she is unavailable, to the person legally responsible for consenting to health care for the newborn. Hospitals and birthing centers are required to: (a) inform each new mother in the postpartum setting that her newborn will be tested for HIV and that the result will be returned to her, (b) assess the mother's past HIV-test history, (c) provide the mother with HIV counseling tailored to her past test history and knowledge of HIV status, and (d) assess the mother's needs for special support in the event of a positive test result. Testing is conducted by the State laboratory, and the result is returned to the hospital of birth for transfer to the infant's pediatric provider. Specialized Maternal Pediatric HIV Care Centers are available to provide consultation regarding the post-test counseling and care of HIV-exposed infants and their mothers or to provide these services directly upon referral. It is the responsibility of the birth hospital to ensure that HIV positive newborns and their mothers are linked to care. If the hospital cannot locate the mother or newborn, field follow-up is available from the Department of Health.

Development of Guidelines and/or Policies

Colorado reports multiple types of perinatal HIV related policy as outlined in its Ryan White Title II and HIV prevention appropriations. The HIV prevention community planning comprehensive plan also has a chapter which is devoted to perinatal HIV transmission.

Practice guidelines for providers and insurance companies in the state of ***Maine*** are currently being developed. These guidelines will be for HIV counseling and testing of pregnant women.

In ***Utah,*** the *PHS Guidelines* are part of all counseling and testing local health department contract provisions.

The ***Vermont*** Department of Health, with counsel from an advisory panel, is developing policy that recommends universal HIV counseling and voluntary testing be the "standard of care" for health care providers serving pregnant women and women considering pregnancy. This policy is currently circulating throughout programs within the Health Department, especially within the "Healthy Babies" Program.

Activities Related to the Distribution of Information, Materials and Education

There is no formal legislation, but the ***Minnesota*** Department of Health is directing their efforts towards the early diagnosis of HIV during pregnancy. The state has issued an RFP for pilot projects to develop strategies to incorporate universal counseling and voluntary testing into routine prenatal care. The state will also be developing a statewide educational plan directed towards health professionals with a training to reinforce and support the *PHS Guidelines.*

There is no formal legislation in ***Nevada***, but Nevada Medicaid is working with the Health Care Financing Administration (HCFA) to expand outreach efforts to pregnant women in Nevada.

Ohio is in the process of distributing both the *PHS Guidelines* and a brochure summarizing the Department of Health's guidelines on perinatal transmission to practicing physicians. They are doing this in collaboration with American Academy of Pediatrics and Title IV FACES clinics.

A 20 minute pre-test counseling video and a risk behavior/patient consent form has been produced and distributed to all providers of obstetric services in ***West Virginia***. A copy of the risk assessment form is being mailed back to the state AIDS Program in a confidential envelope to monitor that this service is being provided as a standard of care to comply with the *PHS Guidelines* of mandatory counseling and voluntary testing of all pregnant women statewide. Three HIV/AIDS surveillance nurses are following up with providers of obstetric care to encourage compliance and respond to any questions. They are also presenting a segment on HIV/AIDS legal reporting requirements during a one-day provider training course. They have added a new section regarding females' pregnancy status to the HIV history form submitted with blood drawn for HIV antibody testing at public health HIV prevention centers. They have published articles about this perinatal plan in several newsletters/journals. A free, one-day HIV counseling and testing training with continuing education units (CEUs) is being offered at eighteen different locations statewide.

Utah is using additional funds obtained this year to conduct a few additional activities related to perinatal HIV transmission, such as education to providers, consultation to providers, survey of providers and a training workshop.

Previously Enacted Legislation/Regulations/Guidelines/Policies

California Senate Bill 889 became effective January 1996 and required the offering of counseling and testing to all pregnant women in California. The Perinatal Project developed, with the state Office of AIDS, a set of counseling and testing guidelines with supportive material for distribution to all perinatal providers (English and Spanish versions available).

Policy has been communicated to providers around the state of ***Connecticut*** which states that all pregnant women should be offered an HIV test. The state also has legislation on the books that says all obstetricians and gynecologists tell women about the availability of HIV testing.

Statutes in ***Kentucky*** require approximately two hours of HIV/AIDS education for initial and relicensure of 16 different health care professions. In November 1996, the Kentucky HIV/AIDS Program required providers of these courses to include information about perinatal transmission and about ACTG-076 protocols to prevent transmission (this effectively reaches over 65,000 providers each year). The Patient Services Manual issued by the Department of Public Health includes a requirement that all women seen in prenatal clinics be offered HIV counseling/testing as part of the routine diagnostic work-up. These clinics see approximately one-third of the women giving birth in Kentucky each year. This has been in place since October 1995. In addition, HIV Care Coordinators regularly include discussions of perinatal prevention with their female clients.

A law in ***New Jersey*** mandating HIV counseling of pregnant women and offering of voluntary HIV testing went into effect in August 1995. Providers are required to document the counseling and whether the woman chose to be tested.

The ***New York*** State Department of Health has developed two publications which have been disseminated to providers throughout the state: (a) "A Clinician's Guide to HIV Pre-Test and Post-test Counseling;" a tri-fold, pocket-sized card that includes sections on counseling of pregnant women and recommendations on the use of therapy to reduce perinatal transmission, and; (b) "Clinical Guidelines for the Use of ZDV to Reduce Perinatal Transmission of HIV." Regulations which became effective May 1, 1996 require that all facilities regulated by the Department of Health provide HIV counseling with testing recommended to women in prenatal care. State regulated facilities include hospitals, clinics and managed care organizations. The Department of Health does not have the authority to regulate physicians in private practice, but it has worked with the American College of Obstetrics and Gynecology and the American Academy of Pediatrics to ensure that HIV counseling with testing recommended is adopted as a standard of prenatal care in New York State. Educational sessions on the regulation have been held throughout the state. Educational materials about counseling and testing and the reduction of perinatal transmission have been developed for consumers and providers of prenatal care; special educational materials, including an audio tape, have been developed for physicians in private practice.

The ***Massachusetts*** Department of Public Health released a Clinical Advisory in November 1994 that recommended all pregnant women be counseled about HIV and offered testing. The Advisory further out-

lined protocol for administering AZT during the perinatal period. A clinicians guide to HIV pre- and post-test counseling was released by the Department in 1996 which includes a section on perinatal HIV transmission.

A regulation was enacted in ***North Carolina*** in 1995 that required that all pregnant women receive counseling about HIV infection and be offered voluntary HIV testing as part of prenatal care. All providers of prenatal care are required to comply.

During 1992, counseling and testing for HIV among pregnant women was established in ***Puerto Rico*** as an initiative of the Health Department and by 1995 treatment with ZDV for pregnant women with HIV and their newborns (for reduction of perinatal transmission of HIV) was established as public policy. A committee made up of representatives from the State Department Health and outside consultants has established an implementation process and monitoring system throughout the island. Additionally, for the privatized public health system, contract monitoring and implementation are being developed.

It is required in ***Texas*** that all health providers offering prenatal services to pregnant women provide HIV counseling and offer voluntary HIV testing.

The 1995 ***Virginia*** legislature passed a law (Section 54.1-2403.01, Code of Virginia), which became effective in July of 1995 which required that health care providers counsel women seeking prenatal care about HIV and to offer voluntary testing. The law requires physicians to counsel pregnant women about the value of HIV testing as "...a routine component of prenatal care..." and to "...request of each such pregnant woman consent to such testing." If the woman is HIV-infected, the law directs physicians to inform her "...about the dangers to the fetus and the advisability of receiving treatment in accordance with the then current CDC recommendations for HIV-positive pregnant women."

Pediatric HIV/AIDS Surveillance: Tracking the Progress Made

While all fifty states are required to report pediatric AIDS cases, additional surveillance activities related to perinatal HIV transmission varies widely from state to state. Thirty-nine out of the 47 states responding (83%) reported additional types of pediatric or perinatal HIV/AIDS surveillance activities. The following selected examples describe the types of pediatric and perinatal HIV/AIDS surveillance activities reported by states. Additional information may be available on a state-by-state basis by contacting the designated contact person listed at the end of this document.

HIV/AIDS Surveillance Data Related To Perinatal HIV Transmission

HIV infection became reportable with patient and provider name and identifiers in ***Alabama*** in November 1987. The health department works with The Children's Hospital in Birmingham to collect additional surveillance information.

The Office of AIDS in ***California*** contracts with the University of California, San Diego and Stanford University to conduct pediatric AIDS surveillance. A study, began in 1989, covers children under 13 years of age who are HIV infected or have known perinatal exposure to HIV. Both universities conduct active surveillance of records from hospital-based clinics and from HIV-positive pediatric patients cared for through the California Children's Services Program to identify HIV-exposed and HIV-infected children. During 1998 and 1999, the Office of AIDS, in collaboration with Stanford University, will conduct the following activities: 1) identify infants born to HIV-infected women from 1990-1998 at all state surveillance sites; 2) monitor the number of HIV-exposed and HIV-infected infants and children under 13 years of age projected to live in target areas using state maternal HIV seroprevalence rates from 1990 through 1998; and 3) use the Maternal Infant Care Evaluation study to identify all HIV-infected pregnant women delivering between 1990 and 1998 at all statewide surveillance sites.

The state of ***Colorado*** has surveillance information on pediatric AIDS cases and pediatric HIV exposures (whether mother knew HIV status prenatally or whether mother received AZT prenatally or at delivery).

CDC's Surveillance and Evaluation Activities

According to presentations made by CDC to NASTAD and the Institute of Medicine, an effective strategy for preventing perinatal HIV transmission includes a "cascade of steps." This cascade first involves a commitment to preventing HIV infection among men and women, with an emphasis on women of childbearing age. Simultaneously, it involves ensuring access to early prenatal care, universal offering of counseling and testing, acceptance of HIV testing, acceptance and adherence to ZDV and finally, follow-up care for both mother and baby. With this comprehensive strategy and only with this type of strategy will the goal of reducing perinatal HIV transmission be accomplished.

CDC funds a number of current and on-going surveillance and evaluation activities that attempt to address the wide spectrum of surveillance issues related to reducing perinatal HIV transmission. These include:

- *Surveillance to Evaluate Prevention (STEP).* This is an enhanced pediatric surveillance system conducted in four project sites (New Jersey, South Carolina, Michigan, and Louisiana). This system also includes data on HIV-exposed and HIV-infected children.
- *Pregnancy Risk Assessment Monitoring System (PRAMS).* This is a population-based surveillance system based on a sample of women who recently gave birth. The information for this system was gathered through a mailed questionnaire and a telephone follow-up. In 1996, eleven states participated in this study.
- *Prenatal Evaluation Project (P-EVAL).* This project is an in-depth, ongoing four-site project using medical chart reviews and patient interview data.
- *Perinatal Guidelines Evaluation Project (PGEP).* This project includes several discrete studies in four sites (Connecticut, North Carolina, Brooklyn, and Miami) and is based on interviews with pregnant and post-partum women. The prenatal study population is restricted to women whose healthcare providers had discussed HIV with them within the previous two months. The post-partum study population was a cross-section of women delivering at the study's site hospital.
- *Pediatric Spectrum of Disease (PSD).* This study is an 8-site medical record review of HIV-exposed and infected children since 1989.

The *Survey of Childbearing Women (SCBW)* was a population-based survey (discontinued in May 1995) conducted on anonymous newborn heelstick blood samples. It was conducted in 44 states and in the District of Columbia from 1989 through mid-1995. While federal funding for this survey is no longer available, some states have continued to conduct the SCBW with their own state funds.

Trend Data Related to Perinatal HIV Transmission

The following *preliminary* trend information presented to NASTAD and the Institute of Medicine is gathered from CDC's surveillance activities. The information sheds important light on progress made in the U.S. to reduce perinatal HIV transmission.

HIV/AIDS Trends in Women

- It is estimated that between 6,000 and 7,000 HIV-infected women delivered infants each year from 1989-1995. Trend data from the SCBW show a relatively steady national rate of HIV seroprevalence for childbearing women between 1989-1994.
- Significant regional variations do exist. The Northeast (44%) and the South (36%) account for most (80%) of the HIV/AIDS cases in women. The highest rates are found in New York, New Jersey, Florida, Maryland, Connecticut and Puerto Rico. However, while the highest rates were first observed in the Northeast, in the past five years, the greatest increase in rates has occurred in the South.
- African-American and Hispanic women are disproportionately affected by HIV/AIDS.

HIV/AIDS Trends in Infants and Children

- It is estimated that more than 15,000 HIV-infected children have been born to HIV-infected mothers in the U.S.

continued on page 10

since the epidemic began. By the end of 1997, over 7,000 perinatally acquired AIDS cases had been reported to CDC by states with the majority occurring among African-American and Hispanic children.

- Five states and/or territories account for 64% of all perinatally acquired AIDS cases (New York, Florida, New Jersey, California and Puerto Rico).
- From 1984 through 1992, the estimated number of children with perinatally acquired AIDS diagnosed each year increased, then declined 43% from 1992 through 1996. From 1992 to 1996 declines were similar by race/ethnicity, regions of the country and in urban and rural areas.
- Distribution of perinatally-acquired AIDS is highly concentrated, with three-quarters of the cases diagnosed in just eight states/jurisdictions (New York, Florida, New Jersey, California, Puerto Rico, Texas, Maryland and Pennsylvania).
- According to CDC, these trend data point to the conclusion that declines in pediatric AIDS, particularly among infants and particularly since 1994, are principally related to declines in perinatal transmission rates with increasing use of maternal and newborn zidovudine (ZDV).

Prenatal Care

- As compared to the general population, HIV-infected women are much more likely to receive late or no prenatal care.
- Early provisional STEP data indicate that only 63% of HIV-infected women giving birth received prenatal care prior to the third trimester. This compares to 95-97% of women in the general population.
- Additional preliminary STEP data show that the proportion of HIV-infected pregnant women who receive no prenatal care is 35% for illicit drug users but only 6% for non-drug users.

Testing Offered

- Overall, among childbearing women responding to the PRAMS survey, approximately 75% of childbearing women said their health care worker talked to them about HIV testing during pregnancy.
- P-EVAL data indicate that pregnant women were offered counseling and testing at an even higher rate than the PRAMS survey findings.
- Preliminary analysis of STEP data indicates that certain groups are more likely to be offered testing than others. These groups include African-Americans and Hispanics, young women aged 15-19, women with less than a high school education, and women cared for in public care settings and Medicaid-eligible.

Testing Accepted

- Data from the STEP project show that between 60-80% of the study population who were offered HIV testing actually received the test.
- PRAMS data indicate a high test-acceptance rate among childbearing women with 83% of women offered testing actually receiving the test.

Acceptance and Receipt of ZDV by HIV-infected Women

- Pediatric HIV surveillance data from 29 reporting states show that between 1994 and 1996 the proportion of prenatally diagnosed mother-infant pairs receiving some part of the 076 regimen increased from 36% to 80%.
- Preliminary STEP project data based on 1995-1996 chart abstractions for approximately 500 HIV-infected women indicate that only 5% of women offered ZDV refused treatment.

Recommendations

Based on the activities conducted and their findings, CDC's researchers make the following recommendations for achieving greater success in preventing perinatal HIV transmission:

(1) improve prenatal care access and utilization, especially for substance using women;
(2) improve provider knowledge, attitudes, practices especially in private care and managed care settings;
(3) improve client perception of risk and need for testing, and address fears about testing; and
(4) develop interventions to improve adherence to medications.

Surveillance data is available on AIDS trends and on pediatric AIDS cases and on children age 13 and under, reported with HIV infection, in ***Connecticut***.

AIDS surveillance and trend data is available from ***Florida*** for women and children with a confirmed AIDS diagnosis. HIV reporting was implemented in Florida in July 1997. Additional limited HIV surveillance data can be provided on women, pregnant women and HIV-infected children.

Available from ***Hawaii***: pediatric AIDS data, the number of pregnant women tested for HIV, the number of positive pregnant women of those tested, the number of live births and the number and percentage of hospitals with AZT delivery protocol.

Illinois can provide information on pediatric AIDS cases and 1995 seroprevalence data in childbearing women.

Basic information is collected from ***Kentucky***, such as gender, county of residence, etc. (with some potential exceptions due to confidentiality concerns due to a small cell size). The amount of information which is available beyond that would be variable. Since information must be coordinated with obstetricians, gynecologists and pediatricians, they rely on providers to voluntarily supply much of this information.

Pediatric AIDS cases are collected by ***Massachusetts***. In addition, they are involved in the Pediatric Spectrum of Disease Project which evaluates and provides follow-up to children who are identified as being exposed to HIV infection at birth or who are diagnosed with HIV. In Massachusetts, these projects are at all major pediatric programs. Data is also available on women presenting at counseling and testing sites with "prenatal/ ob/gyn" factor as reason for visit, on the number of pregnant women referred to Mass CAP (Massachusetts Women HIV Care and Advocacy Project) and on the use of AZT during pregnancy of women known to be HIV infected (1993-95).

The ***Michigan*** HIV/AIDS Surveillance Section, in conjunction with the CDC, has collected data on the number of children exposed to HIV, the number of children with a confirmed diagnosis of HIV/AIDS, and the number of children that seroreverted (lost maternal antibody) since 1992. In 1995, Michigan received supplemental funding from the CDC to collect more comprehensive data on perinatally exposed children, including information on maternal and neonatal ZDV use.

HIV reporting has been required in ***Minnesota*** since 1985 allowing the state to provide data on HIV/AIDS trends and perinatal transmission.

Data could be provided from ***Nebraska*** on pediatric AIDS (numbers reported by year for the last 10 years), numbers of children reported with HIV infection only, numbers of children reported as perinatally exposed and the number of live births occurring in Nebraska for any specific year

The state of ***New Jersey*** is able to provide information on the changing patterns in ZDV use during pregnancy, delivery and to newborns. In addition, they are part of the STEP projects, which provide for enhanced pediatric surveillance.

Tables are available from ***North Carolina*** listing mode of exposure by year of report for pediatric HIV infections, exposures and AIDS cases.

North Dakota reports that they could provide data concerning HIV in women, whether or not women are childbearing age.

Information from ***Oregon*** from the serosurvey of childbearing women through 1996 and pediatric AIDS cases can be provided.

Pennsylvania can provide information on pediatric AIDS (standard epidemiological data is available i.e., age, sex, race, residents, etc.) in which trends can be demonstrated. In addition, the Survey of Childbearing Women was conducted among childbearing women in Pennsylvania from January 1, 1997 - June 30, 1997 (the 5th year the survey was conducted).

Data on AIDS cases (pediatric and adult) is provided through the surveillance system of the ***Puerto Rico*** Department of Health. A surveillance system for childbearing women identified with HIV infection monitors implementation of the *PHS Guidelines* and access to care for pregnant women and their newborns. An island wide tracking system that captures information in the public health sector has been established to track pregnant women identified as HIV infected. Tracking of implementation of PHS guidelines as well as outcomes for newborn status of infection is monitored

through a centralized level within the Pediatric AIDS program.

South Carolina has continued the childbearing survey ('95 and '96 data). They also have HIV exposure and pediatric AIDS surveillance data. In addition, they are part of the CDC-funded STEP projects, which provide for enhanced pediatric surveillance.

The following data is collected from ***Texas***: 1) Pediatric AIDS since early 80's; 2) Pediatric HIV since 1994; 3) Survey of Childbearing Women: 1988-1995; 1997; 4) Pediatric HIV exposure (1989-1997) from Dallas, San Antonio, Houston, and Baylor; 5) Extended sites added: Lubbock, Ft. Worth, Galveston, Houston (UT), El Paso; 6) SCBW: 1997 Positives sent to CDC for AZT testing (not analyzed yet); and 7) Birth certificate data (Questions asked include the following: Was an HIV test done prenatally? Was HIV test done at delivery? Was AZT given prenatally?)

No HIV surveillance is conducted in ***Vermont*** and they did not participate in the SCBW. Data cells for AIDS case surveillance are small; to date, only 3 AIDS cases have been reported among children.

Surveillance data from ***Virginia*** is available on: 1) pediatric HIV from 1989 to September 1997; 2) SCBW data from 1989-1995; 3) HARS; 4) Mothers who received AZT; 5) HIV test history; 6) Enhanced Pediatric Surveillance (EPS); 7) Medical Record Abstraction.

When an HIV positive woman is reported in ***West Virginia***, obstetric care is indicated on the report form as being received, follow-up with the provider occurs to identify the expected date of delivery, whether AZT is available to the patient or a referral to ADAP is necessary. Finally, the newborn is followed to document seroreversion or HIV infection.

Evaluation Studies

Thirty-six out of the 47 states responding (77%) reported conducting a range of evaluations, activities and surveys related to HIV perinatal transmission. Many of these states have had to use state and local funds to collect this information. The following are some of the activities states have recently conducted or are planning to conduct in the near future.

Pregnant/Post-Partum Women Surveys

From October 1997 to January 1998, the ***California*** Office on AIDS, in collaboration with CDC and four local health departments, conducted a survey among pregnant women seeking prenatal care and women who had delivered within the previous six months. The objectives of this study were to: 1) investigate women's experiences with HIV counseling and testing during prenatal care, and 2) assess knowledge of AZT treatment and related attitudes towards HIV testing. They also surveyed 400 health care providers to determine whether they were complying with state law and Federal recommendations regarding HIV counseling and testing among pregnant women.

A study is currently being completed in ***Connecticut*** focusing on the treatment provided to pregnant women with HIV and their infants. In addition, Connecticut is part of the CDC-funded study in four sites on HIV testing practices of pregnant women, and provider and patient attitudes to HIV testing of pregnant women.

Two surveys in different parts of the state of ***Idaho*** are currently underway, with a third planned for later this year or next. The surveys have been administered to pregnant women admitted to the hospital for delivery. The intent of the survey was to determine the educational needs, who should be targeted (health care providers or the women) and if the needs varied throughout the state.

A post-partum survey of women giving birth in ***Illinois*** (in the city of Chicago) regarding knowledge of HIV status and HIV counseling and testing as part of their prenatal care was conducted.

Data on HIV-test history of each women giving birth in ***New York*** is collected in the postpartum setting. The categories are: (a) tested this pregnancy, (b) tested prior

to this pregnancy, (c) not previously tested, (d) test history unknown. Data analysis involves distribution by HIV-status, region, hospital, race and age. Aggregate data will be distributed annually to county health departments and other entities created by the Department to coordinate local/regional efforts to improve birth outcomes.

The HIV/STD Prevention and Care Section in ***North Carolina*** has conducted a survey of post-partum mothers to determine the proportion of mothers who recently gave birth that recall being counseled for HIV infection during their prenatal visits. That document has been submitted to the office of the State Health Department at this time. Two additional surveys (North Carolina is one of the four CDC study sites where in-depth clinical studies with women and providers is being taking place) have been conducted by researchers at the UNC-Chapel Hill and at Duke University Medical Center.

Focus groups of women in three cities were conducted in ***Pennsylvania*** in 1997 to gauge their experience with physician visits and to gather information about their needs. One of these sessions was videotaped and sent to 500 sites, including obstetrical /gynecological clinics, family planning clinics and drug and alcohol clinics.

A study was conducted in ***Tennessee*** (Evaluation of Implementation of Guidelines to Prevent Perinatal Transmission of HIV Research Study") to learn more about how pregnant women who are infected with HIV use health care and social services.

Prenatal Care Providers

A provider practices survey was done by physicians at the Children's Hospital in ***Colorado***.

There is a Department-wide study in ***Connecticut*** of provider practices concerning testing pregnant women for bloodborne pathogens and other infections.

A statewide provider survey in ***Florida*** is being planned for late 1998, as is a comprehensive study involving two hospitals which will focus on barriers to testing and the use of zidovudine among women in a high and a medium prevalence area. Data to evaluate HIV transmission rates, as well as counseling and testing practices among pregnant women are currently being collected through a network of pediatric AIDS centers throughout the state. Data on prenatal testing for all women who give birth will be available in 1999.

A survey study which will be completed in late spring 1998 will examine the knowledge, attitudes and practices of ***Kentucky*** prenatal care providers with respect to HIV counseling/testing of pregnant women. The final outcome of this study will be the development of recommendations on specific actions that the Kentucky HIV/AIDS Program could take to increase the proportion of prenatal care providers who follow the *PHS Guidelines* on counseling and testing and also increase the proportion of pregnant women who agree to be tested.

Results of a survey conducted in 1995 in ***Massachusetts*** of provider practices concerning counseling and testing are available. Materials from an April 1997 media campaign targeting pregnant women and women of childbearing age encouraging HIV counseling and testing, and materials from New England AIDS Education and Training Center for providers on perinatal HIV transmission (focus is primary care providers) are also available.

A recent study of ***Minnesota*** physicians found that although most support universal counseling and voluntary testing, only 10% are screening patients. Anecdotally, several clinics in the metro area are routinely screening all prenatal patients for HIV. However, the state knows of only one clinic where they have done a chart audit and have confirmed they are testing 95% of prenatal patients. Another OB/GYN clinic at a large hospital had tested 74% of patients who delivered through the third quarter of 1997.

The STD/HIV section in ***Montana*** administered a survey to selected physicians after the *PHS Guidelines* were released. The survey was designed to assess current practices with regards to HIV screening as well as to implement the *PHS Guidelines*. Among other findings, the survey reflected that 90% of the respondents were aware of the PHS guidelines.

New Jersey has conducted a survey of provider practices. In addition, they also have some data from a CDC funded STEP project which evaluated medical records of HIV infected women delivering babies to determine testing and counseling, history, ZDV use, birth outcome, etc.

A survey of all prenatal care providers was conducted June 1997 in ***South Carolina*** to determine the proportion providing routine HIV screening of pregnant women, counseling and documentation. The state also has data from a CDC-funded STEP project which evaluated medical records of HIV-infected women delivering babies to determine testing and counseling, history, ZDV use, birth outcome, etc. They also have data available from patient interviews.

A telephone survey was done in September 1997 of private OB-GYN providers in ***Texas*** which asked about policies and procedures around HIV counseling and testing, and treatment and referral patterns for pregnant women. In addition, a qualitative study was conducted with public providers of obstetrical care to determine provider practices around HIV counseling and testing, treatment and referral of HIV+ pregnant women.

The HIV/AIDS Division in ***Virginia*** surveyed physicians in 1996 about their HIV counseling and testing practices. The survey collected information in several categories, including: 1) physician's response to the July 1995 law on HIV counseling and voluntary testing; 2) HIV counseling and testing practices; 3) acceptance of HIV testing among pregnant women; and 4) AZT treatment of pregnant women.

In ***Washington*** a provider practice survey was done shortly after *PHS Guidelines* were issued. In addition, a telephone survey of the general public seeking information on testing of pregnant women was conducted.

A survey of all providers of obstetric care in late 1995 was conducted and the results were published in ***West Virginia's*** quarterly newsletter, Epi-Log. The state is currently reviewing a form made available for patient self risk assessment and are following up with providers.

Prenatal provider surveys were conducted in ***Wisconsin*** in 1993 and 1996 to determine the level of provider compliance with the PHS guidelines. Reports on these surveys are available.

Medical Record/Chart Review/Monitoring Systems

From August 15, 1997 to December 31, 1997, the ***California*** Office on AIDS, in collaboration with Stanford University, conducted a Linked Maternal-Infant medical record surveillance at two pediatric surveillance sites in the San Francisco Bay Area. This study attempted to define prenatal and delivery history, HIV testing and therapy information, and vital laboratory data. This survey assisted in: 1) identifying maternal risk factors for HIV infection; 2) defining whether recommendations regarding HIV testing and ZDV use during pregnancy and during labor/delivery have been implemented in California communities; 3) determining the rate and timing of prenatal care among HIV-infected pregnant women; 4) identifying risk factors for no or poor prenatal care; and 5) determining the extent of maternal compliance to national recommendations for the medical care of HIV-exposed and HIV-infected infants.

A program in ***Maine***, entitled Pregnancy Risk Assessment Monitoring System (PRAMS), tracks the number of pregnant women who were offered HIV counseling/testing as part of prenatal care. There is also narrative information about provider practices available which was obtained from interviews with providers.

To the extent possible, universal quality of care reviews are conducted on the charts of all HIV-exposed infants and their HIV-infected mothers, including prenatal care charts in ***New York***. Measurement includes: 1) implementation of HIV counseling and testing of pregnant women; 2) quality of care, including the provision of counseling regarding therapy to reduce perinatal transmission and implementation of therapy; 3) identification of demographic and other factors related to access to HIV testing and care, including therapies to reduce perinatal transmission; and 4) identification of demographic and clinical factors related to perinatal HIV transmission.

Newborn surveys

Special studies are conducted through a Department of Health program which provides PCR testing free of charge for HIV-exposed infants born or residing in ***New York***. These studies focus on clinical factors related to HIV transmission.

Hospital surveys

In ***Hawaii***, a follow-up survey with hospitals was con-

ducted regarding AZT delivery protocol.

A comprehensive study involving two hospitals in ***Florida*** will focus on barriers to testing and the use of zidovudine among women in a high and a medium prevalence area is planned for late 1998. Data to evaluate HIV transmission rates, as well as counseling and testing practices among pregnant women are currently being collected through a network of pediatric AIDS centers throughout the state. Data on prenatal testing for all women who give birth will be available in 1999.

NEED FOR FURTHER INVESTIGATION

It may be fruitful to gather and analyze many of these studies to add to the growing body of literature that is being collected by CDC, HRSA and the IOM as evidence of the way in which progress is being documented and where there may be deficiencies in efforts to implement the PHS guidelines.

This report was produced with the support of a grant from the George Gund Foundation, and with additional support from the AIDS Policy Center for Children, Youth and Families, under a grant from the Ford Foundation

The National Alliance of State and Territorial AIDS Directors
444 North Capitol Street, NW #339
Washington, DC 20001
(202) 434-8090
(202) 434-8092 FAX
Julie M. Scofield, Executive Director
Casey Blass, Chair

This report was prepared by Joseph Kelly and Jennifer Marin.

Contacts For Additional Information

Alabama:
Dr. Marilyn Crain
Director, Family Clinic
phone: (205) 939-6703

Arkansas:
Gary Horton
Director, AIDS/STD Division
phone: (501) 661-2503; fax: (501) 661-2082
email: hort101w@cdc.gov

Alaska:
Noel Rea
Public Health Specialist
phone: (907) 269-8057
email: nrea@epi.hss.state.ak.us

California:
James D. Ruiz, M.D., Dr. P.H.
Epidemiologist
California Department of Health Services
Office of AIDS, 830 S Street, Sacramento, CA 95814
phone: (916) 445-0700; fax: (916) 327-3252
email: Jruiz@hwl.cahwnet.gov

Yvonne Maldonado, M.D.
Assistant Professor
Stanford University School of Medicine, Stanford, CA
phone: (650) 727-6565; fax: (650) 725-8040

James N. Creeger
Chief, AIDS Case Registry Section
830 S Street, Sacramento, CA 95814
phone: (916) 322-1065; fax: (916) 322-0580
email: Jcreeger@hwl.cahwnet.gov

Steve Truax
Acting Chief, HIV Testing—Data Analysis
830 S Street, Sacramento, CA 95814
phone: (916) 323-4317

Mori Taheripour
Innovative Health Solutions
(Technical assistance and educational materials development)
phone: (510) 450-0190
email: mori@innovativehealth.com

Colorado:
Ken Gershman, MD
Manager HIV/STD Surveillance
phone: (303) 692-2657
email: ken.gershman@state.co.us

Mary Kay Myers
Manager HIV/STD Operations
phone: (303) 692-2703
email: mary.myers@state.co.us

Connecticut:
Beth Weinstein
Director, AIDS Program
phone: (860) 509-7832
email: beth.weinstein@po.state.ct.us

Dr. Richard Melchreit
Medical Associate, AIDS Programs
phone: (860)-509-7833
email: melc100w@cdc.gov

Delaware:
James C. Welch, R.N.
HIV/STD/AIDS Director
phone: (302) 739-3032

Florida:
Marlene LaLota, MPH
Program Administrator, Early Intervention Section
Bureau of HIV/AIDS
phone: (850) 921-4446
email: Marlene_LaLota@doh.state.fl.us

Hawaii:
Peter Whiticar
State AIDS Director
phone: (808) 733-9010
email: Whiticar@lava.net

Nancy Partika
Staff AIDS Education Project
phone: (808) 941-6322
email: Partikan@jobsom.biomed.hawaii.edu

Idaho:
Jean Stark
HIV/AIDS Surveillance
phone: (208) 334-6657; fax: (208) 332-7346
email:
starkj{dhwtowers/towers2/starkj}@dhw.state.id.us

Illinois:
Esther Joo
Surveillance Administrator
phone: (312) 814-4846; fax: (312) 814-4844

Indiana:
Laurie Phillips
Indiana Department of Health
phone: (317) 233-7867

Iowa:
John Katz
STD/HIV Program Manager
phone: (515) 281-4936

Kentucky:
Patty Sewell
HIV/AIDS Program Director
phone: (502) 564-2154
email: psewell@mail.state.ky.us

Mollie Adkins
HIV/AIDS Surveillance Coordinator (Pediatric AIDS)
phone: (502) 564-6539; fax: (502) 564-9865
email: madkins@mail.state.ky.us

Sara Dawson
HIV/AIDS Surveillance Coordinator
(HIV/AIDS epidemiology)
phone: (502) 564-6539; fax: (502) 564-9865
email: sdawson@mail.state.ky.us

Jamie Rittenhouse
HIV Services Program Administrator
phone: (502) 564-6539; fax: (502) 564-9865
(Prenatal testing survey project)
email: jritten@mail.state.ky.us

Martha McKinney
Principal Investigator
phone: (606) 625-9614; fax: (606) 625-9001
email: mmckin@iclub.org;

Maine:
Sam Sherman
Program Coordinator, Prenatal HIV Testing Program
phone: (207) 287-3817
email: samantha.sherman@state.me.us

Massachusetts:
Alfred Demaria, M.D.
Director, Bureau of Communicable Diseases
phone: (617) 983-6550
email: alfred.demaria@state.ma.us

Michigan:
Randall S. Pope
Chief, HIV/AIDS Prevention and Intervention Section
phone: (517) 335-8468
email: PopeR@state.mi.us

Minnesota:
Richard Danila
HIV Epidemiologist, Acute Disease Epidemiology,
Minnesota Department of Health
phone: (612) 623-5415

Maria Rubin
Perinatal HIV Prevention Coordinator
AIDS/STD Prevention Services Section
Minnesota Department of Health
phone: (612) 623-5342

Linda Thompson, MD
Hennepin County Medical Center (HCMC)
Department of Pediatrics
MC-867B, 701 Park Avenue South
Minneapolis, MN 55415
phone: (612) 347-2671

Elaine Collison
Assistant Section Manager
AIDS/STD Prevention Services
Division of Disease Prevention and Control
Minnesota Department of Health
phone: (612) 623-5204
email: elaine.collison@health.state.mn.us

Mississippi:
Elisa Houston, RN
Pediatric Surveillance Nurse
phone: (601) 960-7723

Missouri:
Kurt Kleier
Linda Bell
Dr. Robert Hamm
phone: 1(800) 359-6259

Montana:
Jim Murphy
Surveillance Coordinator
phone: (406) 444-0274
email: jmurphy@mt.gov

Nebraska:
Tina Brubaker
HIV/AIDS Surveillance Coordinator
phone: (402) 471-0360; fax: (402) 471-6426
email: tbrubaker@hhs.state.ne.us

Nevada:
Cynthia Huth, MCH
Perinatal Nurse Consultant
phone: (702) 687-4885

Patty Charles
Nevada Area AIDS Education and Training Center
phone: (702) 784-1373

Dale Capurro
Medicaid
phone: (702) 687-4588

Vicki Hamilton
Washoe County District Health Department
phone: (702) 328-3742

Rick Reich
Clark County Health District
phone:(702) 383-1394

New Jersey:
Sindy Paul
Medical Director/Epi. Services Director
phone: (609) 984-6191
email: smp@doh.state.nj.us

New York:
Gloria Maki
Executive Deputy Director
AIDS Institute, New York State Department of Health
phone: (518) 473-7542; fax: (518) 486-1315
email: GJC01@health.state.ny.us

North Carolina:
Delbert E. Williams
Head, Epidemiology/Spec. Studies
phone: (919) 733-9696
email: del_williams@mail.ehm.state.nc.us

North Dakota:
Pam Vukelic
HIV/AIDS Program Manager
phone: (701) 328-3324; fax: (701) 328-1412

Ohio:
Elizabeth Cross
Epi. Supervisor, AIDS Surveillance
35 E. Chestnut, Columbus, OH, 43215
phone: (614) 466-1370
email: ecross@gw.odh.state.oh.us

Oklahoma:
Mark Turner
Director
phone: (405) 271-4636
email: markt@health.state.ok.us

Oregon:
Steve Modesitt
Chief, HIV/STD Surveillance
phone: (503) 731-4029

Puerto Rico:
Rolando Jimenez Mercado
Program Director
phone: (707) 274-5591

Rhode Island:
Lucille Minuto
Assistant Administrator
phone: (401) 222-2320

South Carolina:
Joanne Lafontaine
STD/HIV Surveillance Director
phone: (803) 737-4110

Tennessee:
Herb Stone
HIV/AIDS Surveillance Director
phone: (615) 532-8495
email: HVS2@aol.com

Texas:
Sharon Melville, M.D.
Director, HIV/STD Epidemiology Division
phone: (512) 490-2515
email: sharon.melville@tdh.state.tx.us

Utah:
George Usher
Surveillance Manager
phone: (801) 538-6096
email: gusher@doh.state.ut.us

Vermont:
Paige Lucas
AIDS Surveillance Coordinator
phone: (802) 863-7286; fax: (802) 863-7314
email: @vdhvax.vdh.state.vt.us

Virginia:
Jim Martin
Perinatal HIV Evaluation
phone: (804) 786-6267

Dena McWilliams
HIV/AIDS Surveillance
phone: (804) 786-6267

Washington:
Maria Courogen
Epidemiologist
phone: (360) 236-3458;
email: mtc0303@hub.doh.wa.gov

West Virginia:
Loretta E. Haddy
State Epidemiologist/AIDS Program Director
phone: (304) 558-5358
email: loretta@wvdhhr.org

Wisconsin:
Neil J. Hoxie, MS
Staff Epidemiologist, Wisconsin AIDS/HIV Program
phone: (608) 266-0998
email: hoxienj@dhfs.state.wi.us

Wyoming:
Terrance L. Foley
Program Manager
phone: (307) 777-5800