

REVIEW & OUTLOOK

AIDS Babies

In the 15-year hunt for an AIDS cure, there has been just a single glimmer of success: We have learned how to save babies. Recent studies by the National Institutes of Health have found that giving AZT to HIV-positive mothers before and during birth can cut by two-thirds the number of babies born infected with HIV. That means that every year, up to a 1,000 babies born with a life expectancy of 24 months instead could have one of 70 years. Doctors estimate that combining AZT treatment in these cases with better infant care for other babies of HIV mothers could save yet more lives. Sounds like God's work. But we don't do it.

To save the babies we need to know their HIV status at birth, and that of their mothers during pregnancy. But mothers at risk of AIDS frequently resist testing, often because they are advised to "protect themselves against discrimination" by rights-obsessed counselors. So the mothers are not tested or treated, so more babies are born with the lethal virus. Babies *are* tested sometimes, but only in anonymous studies that protect their "privacy." These go home untreated with unknowing mothers; some of the lucky ones who were born AIDS-free occasionally then catch the disease from their mother's milk.

Today health committees from the House and Senate have a chance to right some of these wrongs—and save a few babies—when they sit down in conference on the Ryan White Care Reauthorization Act. They can keep the language of an amendment sponsored by Reps. Gary Ackerman (D., N.Y.) and Tom Coburn (R., Okla.) and passed with the bill in the House. Ackerman-Coburn would require mandatory AIDS testing of infants whose mothers were not tested. Or the conferees can opt for an inadequate amendment sponsored by Senator Nancy Kassebaum (R., Kan.) and passed in the Senate; it mandates counseling but not testing. At this writing, the conference members were split five to five on preserving Ackerman-Coburn.

How did the American system arrive at a point where it discovers it can save HIV-infected babies and then decides not to? Over the years the most hard-line AIDS activists convinced much of the American health establishment—and even the Centers for

Disease Control—that the survival of newborns is less important than a declared right to privacy. And feminist groups have supported this argument, because their logic does not allow support of anything that puts a fetus—or even an infant—before a mother. "This is just one example of the erosion of a woman's right to control her own body . . ." the NOW's Diane Welsh wrote in the New York Times last year.

The result of such attitudes has been gross inconsistency in public health policy. State or federal law already mandates testing newborns and young children for a variety of diseases, such as syphilis and tuberculosis. But when it comes to an invariably fatal plague, it suddenly becomes an abuse of the Constitution to save babies, mothers—or unwitting spouses.

Some health professionals have lost the stomach for administering such hypocrisy. Rep. Coburn says his commitment to testing derives in part from the fact that he's a doctor. In New York, an AIDS center, health commissioners have departed office over this issue; Dr. Stephen Joseph told New York Newsday, "I am haunted by the thought of all those women in northern Manhattan and the Bronx and Brooklyn whose lives could have been saved." Some argue that the no-testing policy is racist because most of the infant victims are black or Hispanic. "Charges of genocide by the African-American Community will be hard to rebut," says Shepherd Smith of Americans for a Sound AIDS-HIV Policy, an AIDS organization with a public health focus.

The anti-testing factions also argue that testing babies will cost too much, a novel public-policy concern from these precincts. But of course these are compassionate folks who will insist that all available treatment and care be given these infants *after* they're terminally ill with AIDS. If ever there was an argument for the efficacy of preventive care, Ackerman-Coburn is it.

So which is it going to be—saving babies, or another stretch for the "rights" rubber band? If Congress reauthorizes the Ryan White Act without Ackerman-Coburn, it will have reached a new level of absurdity: It will fail to include HIV-infected infants in a law whose title bears the name of a child who died of AIDS.

Coburn
file

Letters to the Editor

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HIV Surveillance Testing: Taking Advantage of the Disadvantaged

US state and federal health agencies cooperatively appropriate a portion of blood specimens as part of a national investigation to determine human immunodeficiency virus (HIV) infection rates.^{1,2} Four things about this are unique: no one receives notice and no one gives consent to the testing; the specimens are surreptitiously obtained; most doctors and test subjects know nothing about the testing; and neither the physicians nor the test subjects receive the results.

The mass HIV screening uses people seeking medical services at several facilities: public health clinics³; sexually transmitted disease clinics⁴; drug treatment centers⁵; family planning clinics^{6,7}; tuberculosis clinics⁸; runaway and homeless shelters⁹; sentinel hospitals¹⁰; and some colleges.¹¹ Additionally, reproductively

active women are tested through specimens from their newborn infants.^{12,13}

First, obtaining blood for one purpose (such as neonatal metabolic screening) and using a portion for HIV testing is deceitful, if not unlawful.¹⁴ Second, in a self-serving interpretation of laws and regulations, health agencies decided in 1986 that they could covertly test people for HIV if they removed personal identification from the specimens.^{15,16} Third, deleting names from specimens prevents linking test results to people. Those who test positive never receive notification. Health agencies are performing body counts without any intention of making early medical referrals, enrolling anyone in a treatment protocol, or even providing direct counseling to reduce the risk of disease transmission. Can three wrongs make a right?

Testing groups of people without their knowledge of it is an issue that has yet to meet with public scrutiny. Obviously, it is important to have an understanding about HIV disease and its spread. However, vast amounts of money and manpower are devoted to testing instead of to services for those who need more than labeling and stigmatization.¹⁷ In this regard, published titles^{18,19} parallel prior unethical studies.^{20,21}

Surreptitious testing is deceitful. Testing without notice and consent affronts respect for the individual. Serosurveillance exploits vulnerable populations, affronts equity concerns,²² and fails to provide test subjects with any benefits. Those who are forced by economics to use public health clinics should not be robbed of their personal dignity, nor should they be used by scientists taking advantage of dependency on public services.²³ Child-bearing women should have a say in the study of their serostatus.²⁴ In the quest to eliminate self-selection bias, epidemiolo-

gists are ignoring the difference between human subjects and laboratory animals. □

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Editor's Note. See related annotation by Bayer (p 496) in this issue.

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Colorado's HIV Partner Notification Program

Ron Bayer and Kathleen Toomey's August Health Law and Ethics article on partner notification is terrific.¹ It provides a long overdue, thoughtful, and balanced discussion of an honored preventive pub-

lic health measure that the nation has been sadly tardy in applying to the human immunodeficiency virus (HIV) epidemic. Any doubt about the lag in applying partner notification and other constructive public health measures to the epidemic has been bluntly addressed by Dr. Steve Joseph in his recently published *Dragon Within Our Gates*,² a highly recommended account of his controversial but far-sighted leadership, as New York City health commissioner, to institute partner notification and other measures.

Bayer and Toomey write about the serious misunderstanding that partner notification is or should be mandatory and coercive. They courageously target such figures as Sen. Jesse Helms and Rep. William Dannenmeyer who, with their colleagues, would undermine the pragmatic lessons of 4 decades in sexually transmitted disease control. Bayer and Toomey also emphasize another extremely important point: the essential role of public health departments in the full partner notification process, including assistance to reluctant and untrained physicians in the task of notification. "Such an approach has the advantage of utilizing the skills of those who have been trained in partner notification and who are aware of how crucial confidentiality is in the process of informing contacts."³(p1163)

Colorado's early and ongoing successful utilization of partner notification as one component of a broad-based HIV prevention program has depended on the confidence gained from 3 decades of successful partner notification in sexually transmitted disease control. The confidentiality of HIV test results was further buttressed in 1987 by the state legislature. As noted by Bayer and Toomey and many others, partner notification is labor intensive and costly, but the intravenous-drug and unsafe-sex partners of HIV-infected persons are at the very highest risk of further HIV transmission. Rarely do disease control officials have such high-payoff opportunities to work with specifically identified and accessible persons in slowing an epidemic's spread.

From 1986 through June 1992 in Colorado, 4773 partners of 2837 index persons were identified, and 4185 notified.³ Among the 2550 persons tested, 272 have been HIV positive, all learning of the fact for the first time. All partners identified and located—whether agreeing to testing or whether found to be negative—were counseled by skilled personnel.

Colorado's partner notification program has operated exactly as prescribed

for good public policy by Bayer and Toomey: as one component of a broad HIV prevention program; fundamentally voluntary; and optimally protective of confidentiality and individual privacy. Your publication of their article advances the nation's ability to use partner notification more widely and effectively as a prevention tool to stem the tide of this epidemic. □

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Non-Hodgkin's Lymphoma and Occupational Exposure to Hair Dyes among People with AIDS

We were intrigued by the finding by Zahm et al.¹ that women who used hair coloring products are at increased risk for non-Hodgkin's lymphoma. Because the risk for non-Hodgkin's lymphoma among people with acquired immunodeficiency syndrome (AIDS) is 50 to 100 times higher than the general population,² because previous studies have shown increased risks of non-Hodgkin's lymphoma for persons occupationally exposed to hair dyes,^{3,4} and because beauticians and cosmetologists are greatly overrepresented among people with AIDS,⁵ we wondered if beauticians and cosmetologists with AIDS have increased risk for non-Hodgkin's lymphoma compared with other persons with AIDS. If documented, such a risk might be reduced by changes in safety practices. We conducted a case-control study to test this hypothesis.

Statement of Dr. Arthur Ammann
May 22, 1995

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At last, there is some good news about AIDS: With appropriate care begun early in pregnancy, an HIV-infected woman can significantly reduce the chance that her baby will be born infected. This is the first time that a drug has been shown to be effective in preventing the transmission of HIV.

It is important that people understand and appreciate this progress, because it comes in the midst of a number of confused policy debates, some of which could do significant damage to efforts to prevent and treat HIV infection. In this debate the message must not be lost that only routine, voluntary, prenatal testing with counseling provides maximum benefit to pregnant women and their infants.

A part of the debate is about the long running CDC study on the infection rate in newborns around the nation. This study gathers infants' blood samples from which all identifying information has been removed. It has provided valuable statistical information over the years and was ethically acceptable during the era in which no treatment could be offered to those infants. Once pneumonia prevention treatment was recommended for infants, however, I believe that the study should have been discontinued as ethically unsound. While it was no ones intent to do so, the removal of identification from the samples had the effect of withholding potential treatment from these babies. For that reason, I believe that either the test results should be given to the parent(s) of the child or that the seroprevalence study must be discontinued.

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My first preference is for the study to be discontinued (as the Public Health Service has done) and for the \$10 million in funding that it consumes annually to be converted to programs to provide routine, voluntary counseling and testing and AZT treatment to pregnant women. To continue the seroprevalence study in its current form will only count infections in infants. To continue the study with names attached will render the statistics questionable (since some women may decline to participate) and could at best help with temporarily postponing the illness of some infants. This misses the

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mark. The goal of HIV testing is to provide treatment for mothers and infants to prevent HIV infection. Newborn testing does not provide optimal health care for either mother or infant. Embarking on a program to routinely provide voluntary prenatal counseling and testing and treatment can actually prevent pediatric AIDS -- saving lives and saving dollars. I support the Public Health Service's suspension of the study; now it must take the next logical step and devote the freed up funds to preventing pediatric HIV infection through counseling, testing, and treatment of pregnant women.

I believe that voluntary testing programs for pregnant women will actually result in more women being tested for HIV than any mandatory program. As with any disease, the trust and cooperation between patient and physician are essential. The data are clear on voluntary programs. In Miami and San Francisco, in France and Italy, 90-96% of pregnant women agree to be tested voluntarily. The dangers of mandatory programs are equally clear. From mandatory HIV testing for marriage licenses to mandatory drug testing in drug treatment programs, people refuse to take part in programs that they are afraid of. We lose what is needed -- the long term relationship between patient and physician. If we are to succeed in reducing HIV infection among babies, we must educate women and doctors alike to believe in the efficacy of the new treatment and in each other. Without such education and trust no program can succeed.

I believe that mandatory testing for newborns is a blind alley. We lull ourselves into believing that we are doing our best to help the infant when we are not. If we are really interested in preventing HIV infection in infants, in saving their lives, we must put all our effort into routine, voluntary, prenatal testing. If we can succeed in a program to provide routine, voluntary testing to pregnant women we will not need to test their newborns.

It should be obvious also that no testing program will be effective in accomplishing any goal if treatment is not available. The treatment needed during pregnancy to prevent HIV infection is far beyond the personal means of most women with HIV. Only if the Federal government maintains its commitment to making therapies available to women of little or moderate means will our efforts be successful. And only if we provide health care and

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During the debate concerning routine prenatal testing, two states, New York and California, and the United States Congress, considered mandating newborn testing. This was the outgrowth of the controversy surrounding anonymous testing of newborn blood samples for HIV. These legislative approaches to HIV testing do not address the most important advance in HIV therapy - **HIV infection can be prevented.** Mandated testing of newborns for HIV does not provide HIV infected mothers with an opportunity to choose treatment for themselves or allow for timely intervention to prevent HIV infection of their infants. Only prenatal testing affords this dual opportunity. I would like to emphasize that point - **only prenatal testing will lead to the prevention of HIV infection and save lives.**

Mandatory testing is an easy way out. It gives the illusion that we are doing all that we need to do. Mandatory testing does not insure counseling of women regarding the prevention of transmission of HIV to their sexual partner, or transmission of HIV to their infant, or treatment of their disease, or treatment to prevent HIV infection of their infants, or education on how to avoid becoming HIV infected. Nor does it assure the availability of funds for treatment and care. And equally important, it does not gain the confidence and trust of the mother who must be counseled as she must confront difficult health care decisions.

Before concluding, I would like to make a few personal remarks about anonymous HIV testing of newborns which has stirred considerable national debate this year. Anonymous testing is a sound scientific tool which has provided important epidemiologic data for the tracking of numerous epidemics including HIV. However, no scientific method is sacred, and no method can violate the traditional medical ethical injunctions of the duty to inform and the duty to provide treatment. I would argue that, once life saving therapy is available for a disease for which anonymous testing is being performed, it is no longer ethical to continue anonymous testing without simultaneously assuring that testing and treatment is available and offered to all potentially affected individuals.

5:47 PM October 24, 1995

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Ival Henoff
Wash Post
5/20/95

Another 'Tuskegee'?

After winning a Pulitzer Prize for commentary this year, Jim Dwyer of Newsday was being interviewed on the New York affiliate of National Public Radio. The host, Brian Lehrer, was puzzled—indeed disturbed—that part of Dwyer's prize was due to a series of columns exposing the fact that although New York State—like 44 others—has been testing all newborns for various conditions, it does not disclose an infant's HIV status to either the mother or her doctor. It is a "blind" test.

Dwyer considers this failure to inform—with subsequent illnesses and early death for thousands of children who could have been treated—outrageous. The interviewer, however, said to Dwyer: "You're considered a liberal columnist, but on the HIV testing of infants, you took the conservative position."

Such a seemingly liberal or pro-woman as the ACLU, the National Organization for Women and the American Red Cross do not publicly oppose the withholding of the test as an invasion of the privacy of the infant whose own interests will be respected if the child is not infected. All privacy is especially important for the child.

Dr. Gary Alvarado (D.N.Y.)—with a 100 percent ACJU rating—introduced a bill. "The New York Infant HIV Notification Act" that contains a scale requiring certain HIV tests to be done at the birth of the infant. The bill would apply to the anonymous test that there have been and conducted in 45 states by the Centers for Disease Control since 1986. The epidemiological reasons:

Infants already had 220 times more than half the blood sugar than the average range is extraordinary. Ancient liberal Pat Schroeder (D-Colo.) is allied with Robert Dornan (R-Calif.) who

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makes Pat Buchanan sound like a lyrical moderate. Also on board is Nitz Lowery (D-N.Y.), a leader of pro-choice issues in the House, and Bill McCullum (R-Fla.) whose ACLU rating has been zero.

As the bill began to gather momentum, Ackerman was visited, he told me, by Dr. David Satcher, head of the CDC, and Patricia Fleming, the White

Ackerman to abandon his bill. One of their arguments was that if mothers are told they and their children are infected, they will panic and leave the health care system. There is abundant evidence, however, that black and Latina mothers—who tend to be often, but hardly exclusively, at risk—care as much about their children as do white mothers and would not remove them from treatment.

Indeed, a recent poll by New York's Hispanic Federation—an umbrella organization of many Latino groups—revealed that two-thirds of those polled support mandatory HIV testing and disclosure for everyone, not only infants.

Gary Ackerman refused to withdraw his bill. He told me that the head of the CDC said he might then consider withdrawing the "blind" tests altogether rather than disclose the results.

Earlier, when the conversation was focusing on increasing concern—from various quarters—of the CDC's then leader Ackerman felt that it was from the CDC's perspective to be most troubled. The analysis, however, is secondary and the Tuskegee experiment's results are primary.

From 1972 to 1977, some 400 African American men with syphilis were observed—but not treated—by Public Health Service physicians. The study deteriorated and eventually died, having only 100 men left. The Tuskegee Institute entered the HIV testing debate through Dr. Arthur Ammann, a distinguished professor of Pediatrics at the University of California, in fact Dr. Arthur Ammann's research led to the CDC's anonymous testing of women for HIV. The maintenance of anonymous test results at a time when treatment and prevention are readily available will be recorded in history as analogous to the Tuskegee experiment.

Suddenly, on May 10, the CDC announced it was immediately suspending its HIV testing for newborns throughout the country, instead it would focus on encouraging women to engage in voluntary HIV testing during and before pregnancy. (CDC was silent on the fate of the sizable number of women who do not appear for any prenatal treatment or counseling.)

Key: Ackerman intends to get a majority of Congress to mandate that the CDC resume the tests—and from now on disclose the results as well as arrange for counseling. Meanwhile, the American Academy of Pediatrics is "shocked and dismayed" at CDC's total abandonment of its epidemiological tracking tests. Those were the first to show the extent of AIDS among women.

The CDC could have continued the tracking, added disclosure of results, and been free of the taint of the Tuskegee "experiment." But instead the politicized CDC has chosen to fold—extricating itself from accountability.

Pat Ammann
Remember in history
Should be mandatory

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