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May 1, 1996

CONTACT: Roland Foster

Coburn Proposal Approved, Infants Lives to be Saved

U.S. Rep. Tom Coburn said that the lives of infants will be saved because of new HIV testing requirements approved by the House of Representatives on Wednesday.

The proposal, written by Coburn, would eventually require states to begin mandatory testing of newborns.

A compromise between House and Senate negotiators will require the mandatory testing if there is not a significant reduction in infants born with HIV.

"This is a caring approach that says public health policy should be about saving the lives of newborns. There were 7,000 infants delivered to mothers who had the AIDS virus last year."

"We now know that we can save the lives of infants whose mothers carry this deadly virus by giving the drug AZT before birth and up to 6 weeks after birth. We need to do everything possible to identify infants that have AIDS," Coburn said.

Coburn was the author of the House version that required mandatory infant testing. The Senate version had only voluntary testing of the mother.

The conference compromise will compel states to enact the Center for Disease Control guidelines regarding HIV and pregnant women. If the guidelines fail to make dramatic reductions in the number of AIDS babies within 18 months, states who receive Ryan White Care Act funds would be required to enact mandatory HIV testing of newborns.

Coburn, a physician who specializes in obstetrics, has actually delivered babies with HIV. "There is nothing more heart-breaking than to deliver a new life that you know will be short-lived. We have an obligation to try to give these infants a chance for life," Coburn said.

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May 1, 1996

Baby AIDS Compromise
As included in the Ryan White Care Reauthorization Act

This measure will save babies from AIDS by compelling states to enact the CDC guidelines regarding HIV and pregnant women. If these guidelines fail to make dramatic reductions in the number of AIDS babies, States would be required to enact mandatory HIV testing of newborns. This Act will ensure the saving of countless young lives through education and testing.

The following is a brief summary of the proposal:

Within **120 days**, States must adopt the guidelines issued by the CDC regarding HIV counseling and voluntary testing for pregnant women. States must also determine the rate of reported AIDS cases as a result of perinatal transmission (If States choose to track HIV, that standard would supersede reported cases of AIDS).

Not later than **180 days** after the expiration of an **18 month period** beginning with the implementation of the CDC guidelines, each state must demonstrate:

- (1) A 50% reduction in the rate of new AIDS cases as a result of perinatal transmission compared to the rate of such cases in 1993 (If States choose to track HIV, that standard would supersede reported cases of AIDS),
- or
- (2) That at least 95% of women who received at least two prenatal consultations have been tested for HIV.

If a State fails to reach either of these criteria, that State will be given **18 months** to meet one of these criteria or to enact mandatory testing of newborns whose mothers' status is unknown (assuming that it is deemed a routine medical practice).

States which still can not demonstrate one of these criteria will no longer be eligible for funds allocated under Title II of the Ryan White CARE Act.

\$10 million is authorized to carry out these provisions.

Chicago Tribune

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10 Section 1

Friday, May 3, 1996

Editorials

A promising HIV-test compromise

A compromise reached by congressional negotiators Tuesday on the controversial issue of mandatory HIV testing for newborns won't please everybody—compromises rarely do. But it is nonetheless a sensible plan that addresses both the practical realities of pediatric AIDS and the crying need to curb incidence of the disease.

The HIV infection that triggers AIDS is passed from mother to baby either during pregnancy, labor, delivery or breastfeeding. Between 1,000 and 2,000 babies are born each year to infected mothers, but only about one-fourth of them develop the AIDS virus.

Studies show that treating infected pregnant women and newborns with the drug AZT can substantially reduce the number of infants with AIDS. So no one denies that testing and treatment—the sooner the better—is extremely important. But battle lines have been drawn over whether testing should be mandatory and who should be tested.

The Tuesday compromise calls for states to require health-care workers to counsel pregnant women of unknown HIV status on the importance of being tested. The plan provides \$10 million to help states implement guidelines developed by the Centers for Disease Control and Prevention for voluntary testing, counseling and treatment.

Equally important, however, the compromise locks in a fallback measure if voluntary efforts don't produce results. By the year 2000, each state must show

that the number of newborns who test positive has fallen by 50 percent or that 95 percent of pregnant women have been tested for AIDS.

If neither benchmark is met, the state must begin mandatory testing of newborns or lose federal funds for treating AIDS patients.

It's a wise carrot-and-stick approach to a complicated issue. Those who favor mandatory testing overlook that there may be a more practical way to rein in a disease that strikes a narrow and identifiable segment of the population.

Infants infected with HIV are born to mothers who have had blood transfusions, used intravenous drugs or had sexual relations with men in high-risk groups. At least in the first instance, it is more cost-effective to reach out to that relatively small group of women, educate them on the risks, test and treat them than to test 4 million pregnant women and their infants every year.

But what if, as mandatory-test proponents fear, high-risk women still choose not to be tested?

That's when mandatory testing of newborns comes in. At the least, it would allow for quick treatment of infected babies.

Some political groups have tried to make the testing of women and infants for the AIDS virus a privacy issue, but they are wrong. It is first and foremost a public-health issue—one that affects the lives and well-being of the most vulnerable among us.

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REVIEW & OUTLOOK

A 'First Sane Step'

That's how Tom Coburn (R., Okla.) characterized the decision of the House-Senate conference on the Ryan White reauthorization bill to link the bill's \$700 million in AIDS funding to testing of mothers and infants. We'd have to agree. In 10 long years of AIDS politics and AIDS funding, this is actually the first AIDS legislation to pass in this country that will rescue babies—prevent them from catching a disease that takes its victims before they make it to the third grade.

Specifically, the Baby AIDS language starts with counseling for mothers and moves to mandatory testing of newborns if it turns out that many mothers are still going untested. By pushing states to convince mothers to get tested—or lose hundreds of millions in funding—what is known as the Baby AIDS compromise will widen prenatal testing. Pregnant moms who test positive may then take AZT, which recent studies have shown reduces their babies' chances of getting the deadly infection from one in four to one in 12. The bill also contains anti-discrimination and confidentiality language that goes a good way to ensuring the news of mothers' test results won't be broadcast to landlords, insurers or employers.

The main Baby AIDS provision, testing infants after birth, will also save lives. The blood of those who do not have the infection nonetheless carries useful information: it reveals if their mothers are infected. That gives

doctors a chance to warn the mothers against infecting their babies through practices such as breast-feeding.

Such change is necessary: New York state found that long after counseling on voluntary testing for mothers was official policy, mothers often refused testing. The result was that blinded blood tests showed that 60% of HIV-positive mothers took their babies home without knowing that they carried the disease. State Assemblywoman Nettie Mayersohn estimates that in New York alone, some 1,000 to 1,600 babies a year are born infected with AIDS. One of the original Baby AIDS activists, she and a pro-family AIDS group called Americans for a Sound AIDS/HIV Policy lobbied Congress because, as she put it, "not testing babies was plain old medical abuse."

Seen in the context of 10 years during which the survival rights of uninfected families or partners have been subordinated to the privacy rights of AIDS carriers, Baby AIDS is a victory of some moment. Tom Coburn, a family practitioner who turned to politics, thinks we ought to rename AIDS yellow fever or Hantavirus II and start treating it "like any other epidemic." While we're not sure a disease adults often contract through elective behavior can be put in the same class as the plague, we can say that the Congressman is right on one count: AIDS is a fatal disease. Not testing for it when we test for diseases 10 or 20 times as rare is crazy.

Odd political bedfellows come together to help pass law mandating HIV infant testing

By A.B. Stoddard

This week's enactment of the Ryan White Care Act, including a mandate to increase HIV testing of infants, marked the end of a legislative battle that paired Reps. Pat Schroeder (D-Colo.) with Bob Dornan (R-Calif.) and caused several poster children of the American Civil Liberties Union to temporarily fall from grace.

They supported a provision written by Reps. Tom Coburn (R-Okla.) and Gary Ackerman (D-N.Y.) that originally required mandatory HIV testing of infants. When the bill became attached to the politically popular Ryan White Care Act, which provides \$350 million in grants for medical and support services for low-income persons who are HIV-positive, the measure lost support in the Senate and became more voluntary than mandatory.

The law now gives states until the year 2000 to reduce their number of pediatric AIDS cases by 50 percent or test a minimum of 95 percent of pregnant women who have been counseled about HIV testing. Those states that fail to meet the targets must then adopt mandatory testing or lose their Ryan White funding.

Dornan called opposition to mandatory testing a "straightforward case of murdering children to satisfy anonymity." Many Republicans agreed, but the legislation managed to pit civil libertarians against their traditional liberal friends.

Ackerman, who is used to receiving 100 percent ratings from the ACLU, bucked the group's stance by being co-author of the legislation. He did so because, he said, three of every four infants born with their



MAURA BORUCHOWITZ/HILL
Rep. Gary Ackerman

mother's HIV antibodies and who test positive can be treated and later become HIV negative.

The ACLU and several gay rights and women's groups objected to mandatory testing of one section of the population, saying it would not only violate the constitutional right to privacy, but could lead to the widespread mandatory testing of the population at large.

"The right of privacy is far smaller than the right to save the life of a child," said Rep. Peter King (R-N.Y.). "We're not talking about abortion. I am pro-life but can understand the argument on the pro-choice side. In this there is no argument."

Opponents also argued that the requirement would keep women from seek-

ing prenatal care and force them to deliver their children away from hospitals.

Schroeder said there is no evidence that would happen. "They say if you test the baby then you are testing the woman and these women will go underground," Schroeder said. "But I can't see why a mother wouldn't want to help her child."

Coburn said the best policy for controlling an epidemic is testing, but so far the health care system has only focused on the gay and drug-using population while ignoring most women.

"Nobody would say we wouldn't want the government to protect us from an Ebola outbreak in Washington," Coburn said, "but HIV is just as deadly."

The origin of the Coburn/Ackerman legislation — modeled after a bill still mired in the New York state legislature — was a study the Center For Disease Control conducted for several years on infants in 45 states. The CDC study tested infants anonymously for purposes of tracking the disease, which Ackerman found appalling.

Once he introduced the legislation with Coburn, Ackerman was visited by the head of the CDC and a representative from the Department of Health and Human Services. They offered to stop the study if he and Coburn would abandon their bill, Ackerman said.

"I said, 'That's not the answer to this,' Ackerman told *The Hill*. "It's absolutely horrible. That's not the help that people are looking for."

The CDC later stopped its study, and the legislation was rewritten. Despite the visit Ackerman received from the HHS of-

ficial, a spokesman for the Clinton administration said Monday that it supports the entire Ryan White Care Act, including the testing provisions. President Clinton signed the bill Monday.

Another vocal critic who later came around was Rep. Gerry Studds (D-Mass.), an openly homosexual member of Congress. According to Mark Agrast, the senior legislative assistant to Studds, the congressman strongly opposed mandatory testing but believes that targets for voluntary testing represent a reasonable plan to reduce infection.

"The states now have the opportunity to arrive at public health goals without resorting to mandatory testing," said Agrast. "Every state will have an opportunity to lower its rate by voluntary means in a time frame that is achievable and desirable."

The ACLU said the compromise for testing still goes too far.

"We are very concerned there is a mandate included in the law," said Alexander Robinson, senior legislative representative for the ACLU. "We're concerned that this goes back on what we believe to be a proven strategy of making the public health system non-coercive."

Ackerman said his opponents, including the ACLU, are simply wrong.

"As soon as there is something that medicine can do, then you have a moral obligation to do something about it," said Ackerman.

Coburn agreed. "In this country we have somehow decided it's not politically correct to do the right thing medically," said Coburn. "I'm willing to do the right thing medically, even if it's politically incorrect."

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Congress of the United States
House of Representatives
Washington, DC 20515-3602

June 23, 1995

SAVE BABIES AND STOP THE SPREAD OF AIDS

Dear Colleague,

As you know, the Commerce Committee will mark-up the Ryan White CARE Act within the next several weeks. As a physician who has had first hand experience caring for AIDS patients, I recognize the importance of this legislation which will help pay for the basic medical and social services to families and individuals affected by HIV.

However, I believe that our policy should not be solely limited to the programs funded by this Act. We have lacked a cohesive national AIDS strategy. We have handled this disease from a purely political perspective and have failed to treat it from a health perspective. This disease is not limited to any particular group or lifestyle, and the largest group now at risk for infection are women aged 16 to 25. Therefore, with the support of various AIDS organizations as well as those in the medical field, I will be offering an amendment which begins to treat AIDS as the serious health epidemic that it is.

My amendment would protect the welfare of innocent children and slow the spread of the disease. It would do this by requiring that all states, in order to be eligible for Ryan White CARE grants, enact legislation that every newborn be tested for HIV if the mother did not undergo prenatal testing.

This is a very important step in combatting AIDS. In fact, studies have shown that the rate of transmission of the virus from mothers to children can be reduced by two-thirds if the drug AZT is administered during pregnancy, labor and the first six weeks after birth. Knowing the status of a baby right away would allow treatment and counseling to begin immediately and prevent an uninformed mother from transmitting HIV to her baby through breast feeding.

State public health laws already make all sorts of tests mandatory for newborns. This amendment would merely prompt states to enact a similar law to be eligible for Ryan White CARE Act funds. It seems crazy that states have mandated testing for syphilis and hepatitis, but have failed to treat the incurable HIV in a similar fashion.

Congress of the United States
House of Representatives

Washington, DC 20515

June 26, 1995

Dear Colleague:

We thought this editorial from yesterday's New York Times would be of interest to you.

Sincerely,



Gary L. Ackerman
Member of Congress



Tom A. Coburn
Member of Congress

AIDS Babies Deserve Help, Now

Hundreds of babies infected with the AIDS virus will continue to go undetected and untreated every year unless Congress or New York State deal with this vexing public health problem. The State Legislature, immobilized by a fierce clash between those who want mandatory testing of all newborns and those who prefer a voluntary approach, has been unable to agree on a solution. Congress, knocked off course when the same fierce clash stopped a Federal survey of infected babies, has yet to take action.

Both bodies have a responsibility to get on with the job. It is simply irresponsible to let newborn babies go untreated while arguing over the mechanics of how to help them.

The need for a vigorous response is clear. Women are becoming infected with the AIDS virus in rising numbers, and about 7,000 of them give birth each year. Many pass the virus on to their babies, either in the womb or during birth. Some 1,000 to 2,000 babies are infected this way each year, with New York State alone accounting for roughly a quarter of the total. Some of the infected babies are detected through voluntary blood tests on the mothers or their newborns. The rest go undetected and untreated until they become sick, when it is too late to offer them the best shot at a longer life.

Medical science knows quite well how to alleviate this damage. The best solution by far is to identify and treat the expectant mother before her child is born. One of the few bright spots in the battle against AIDS was the discovery last year that treating a pregnant woman with the drug AZT can greatly reduce the chances that she will pass the AIDS virus on to her child, saving most of the babies from infection.

Unfortunately, large numbers of women never come near a clinic for prenatal care and many of those who do come in for such care never get tested for the AIDS virus. So a fallback solution is to identify all infected newborns as early as possible; through blood tests, so that they can be closely

monitored and treated. Doctors have no way to cure these infected babies, but they can ward off many of the infections that typically kill them, thus prolonging and improving the quality of their lives.

Although the medical solutions are in hand, they are not in fact being broadly applied. In New York State, for example, clinics try, with widely disparate vigor and success, to get women to agree to be tested during pregnancy or at birth and to allow their babies to be tested. But surveys suggest most of the infected babies are missed. A more vigorous effort is clearly needed.

Unfortunately, the State Legislature may be headed for another stalemate. The Senate has passed a bill to require mandatory testing of all newborns and mount a more aggressive voluntary testing program aimed at pregnant women. The new voluntary approach would make it harder and less likely for women to decline testing. But the Assembly has taken no action yet and has only four days before adjournment. Its leaders have traditionally opposed mandatory testing but seem inclined to accept a more vigorous voluntary effort for both pregnant women and newborns.

Either approach would be better than the status quo. This page has long endorsed mandatory tests for newborns on the ground that the health of the baby is more important than any privacy risk to the mother. But there is virtually no political appetite for imposing mandatory tests on pregnant women, so a strong voluntary approach is the only feasible alternative.

The best solution would be a national policy insuring that all infected babies are identified for monitoring and treatment. Representative Gary Ackerman, Democrat of New York, and Representative Tom Coburn, Republican of Oklahoma, will unveil an amendment this week that would require states, as a condition for receiving certain Federal AIDS funds, to test all newborns whose risk of infection has not been determined through voluntary testing of the expectant mother. That approach would provide a needed incentive for the states to identify and help these neglected babies.

The New York Times

SUNDAY, JUNE 25, 1995

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Clock ticking on AIDS babies

AS THE DAYS dwindle down in the legislative session, Assembly Speaker Sheldon Silver must stop playing politics with babies' lives. If the Legislature fails — for the second straight year — to enact *mandatory* HIV testing for newborns, hundreds more infants will suffer needlessly and die.

It's that simple. There is no room for compromise — and no more time for delay.

The state Senate has passed a bill that would require doctors to counsel all pregnant women about AIDS and test them for the virus unless they declined in writing; all newborns would be tested automatically and the results released to their parents.

But Silver continues to sit on the Assembly version, pandering to the American Civil Liberties Union, the Gay Men's Health Crisis and other wrongheaded opponents.

Their ostensible argument — that mandatory testing will frighten women away from seeking health care — is nonsense. It implies that theoretical privacy issues are more important than the well-being of helpless children.

In truth, the real motive of opponents is crystal clear next to the fact that testing is mandatory for syphilis, sickle cell anemia and half a dozen other more benign afflictions. Only politics — radical politics — explains the separate standard for AIDS.

The federal Centers for Disease Control and Prevention carried this illogic to an absurd end by requiring testing of newborns, then keeping results secret. That let officials track the epidemic, but denied treatment. Fearful of the push to use the results for actual care, the CDC turned churlish and quit testing.

The move infuriated many in Congress, and some are pushing the states to step in. The House Commerce Committee is scheduled to vote today on a measure that would cut off federal AIDS funds to states that do not have mandatory testing. That would cost New York \$139 million. Though the bill — drafted by Reps. Gary Ackerman (D-Queens) and Tom Coburn (R-Okla.) — faces an uncertain future, the threat of a cut-off should give Silver & Co. pause. Yet they must not wait to be forced to act.

Voluntary AIDS counseling and testing simply do not work. Too few women volunteer to make a significant difference. Last year, about 1,800 newborns left New York hospitals infected with the virus — 25% of the nation's pediatric AIDS cases.

If pregnant women were routinely tested, those found to be infected could be treated with AZT, which substantially reduces babies' chances of being born with HIV. For infants who test positive, treatment with inexpensive antibiotics can quickly wipe out pneumonia and simple infections that can be fatal.

There is only one right thing to do. Silver must do it. Now.

6/27/95

A.S.A.P.

Americans for a Sound AIDS/HIV Policy

P.O. Box 17433 • Washington, D.C. 20041 • Telephone: 703/471-7350 • Fax: 703/471-8409

July 10, 1995

Dear Commerce Committee Member,

This is only the second letter in our nine year history that we've written on behalf of a proposed amendment concerning AIDS/HIV legislation before the U.S. Congress. The first was on behalf of a confidential and voluntary partner notification measure which lost on a straight party line vote, 25-19, in 1989. Because of the extensive work we do with families and children affected by AIDS/HIV, we quickly saw the adverse consequences wrought by policies bereft of partner notification.

At the time the amendment was defeated only a handful of states had enacted any partner notification legislation; today well over half have, with the trend toward all states ultimately having such a critical public health program in place. It is our strong belief that management, and ultimate curtailment, of the HIV epidemic cannot occur until knowledge of infection is gained on a greater scale by the medical/public health community.

The Ackerman/Coburn Infant Testing Amendment offers the Congress the opportunity to reverse past trends, and place emphasis on the value of knowledge over ignorance. It will also begin to balance the rights of the infected with the rights of the uninfected, acknowledging the responsibilities of those infected with HIV. Such measures are long overdue, and ultimately will limit total suffering in respect to HIV disease.

This fully funded measure is critical to pass if you believe, as we do, that the quality of life and optimal medical care is crucial for every young American. Voluntary measures of the past have failed. It is time to address AIDS/HIV as the medical problem it is. It is time to save lives.

Sincerely,

Shepherd Smith

W. Shepherd Smith, Jr.
President

Dedicated to limiting total suffering from AIDS/HIV.

American Medical Association

Physicians dedicated to the health of America

BOLD



James S. Todd, MD
Executive Vice President

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July 12, 1995

The Honorable Tom A. Coburn
U.S. House of Representatives
511 Cannon House Office Building
Washington, DC 20515-3602

Dear Representative Coburn:

The AMA is writing to express serious concerns regarding your amendment to the Ryan White CARE Reauthorization Act that would require that all newborns be tested for antibodies to HIV unless the mother was tested for HIV while she was pregnant.

Where appropriate, the AMA believes the proper place for HIV testing to occur is with the mother. This is because, as a matter of medical science, testing a newborn during the first 12 to 18 months of his or her life only indicates whether the mother is HIV positive, not necessarily whether the baby is HIV positive. While tests exist that can identify primary HIV infection in babies as young as two weeks of age, these tests are expensive, technically complex, and not widely available.

As you are aware, recent studies have indicated that women who take AZT during pregnancy and labor and whose children receive postnatal AZT for a period of time reduce the fetal transmission rate from 25% to 8%. The AMA strongly supports maternal HIV screening and recommends that all women be educated on HIV, particularly those who are or might become pregnant. The AMA believes, however, that the final decision about whether or not to be tested should be the woman's to make. In this regard, we are in full accord with recent CDC guidelines on the subject.

Studies have shown that most women who receive HIV education choose to be tested. In one urban hospital in Atlanta, 96% of pregnant women who received HIV education asked to be tested.

Appropriate counseling and voluntary testing for the 4 million women who become pregnant each year should become a routine part of prenatal care. In those instances in which women do not receive prenatal care, they should be offered HIV testing for themselves or their babies after birth but this should not be mandatory for all.

In addition, the AMA is concerned that such mandatory testing may constitute an unfunded mandate, since states would be required to pay for the testing of newborns on Medicaid.

Thank you for considering these concerns.

Sincerely,

James S. Todd MD

James S. Todd, MD

cc: Members of the House Commerce Committee



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July 20, 1995

The Honorable Tom Coburn
United States House of Representatives
Washington, D.C. 20515

Dear Representative Coburn:

I want to take this opportunity to clarify New York State's position on mandatory testing and disclosure for HIV in newborns.

On July 11, I wrote to you and other members of the Commerce Committee expressing New York State's concern with your amendment that would tie Ryan White AIDS funding to mandatory testing and disclosure for HIV. This letter stated that while the State supported the goals of your amendment, we had reservations with a federal mandate.

Subsequent to my July 11 letter, however, Governor Pataki and other state proponents of a testing and disclosure policy for newborns determined that a federal mandate requiring testing and disclosure as a condition for receiving Ryan White funding would be the most effective way to overcome state legislative opposition to such a policy. Consequently, New York State supports your efforts to mandate state testing and disclosure to protect newborns as a condition of receiving Ryan White AIDS funding.

If you have any questions, please feel free to call me.

Sincerely,

A handwritten signature in cursive script that reads "Wayne Cimons".

Wayne A. Cimons

cc: The Honorable Thomas J. Bliley, Jr.

Babies and AIDS: Require tests of newborns?

Bipartisan legislation

Legislation presently in Congress would save and prolong the lives of newborn infants.

This bipartisan measure would require newborns in all 50 states to be tested for the AIDS virus if the infant's mother was not voluntarily tested during her pregnancy. It also would forbid insurance companies from terminating the insurance of anybody who undergoes an AIDS test, regardless of the test results.

Thousands of American babies have suffered and continue to die from HIV. Those woe-filled lives and early deaths can largely be prevented, but only if those babies with HIV are identified. The question is simple. What fit mother would not want to know if her baby is HIV positive?

First, this legislation strongly advocates that all pregnant women be counseled and voluntarily tested for HIV. The medical profession has indicated that this will be the standard of care. If HIV-positive mothers-to-be are treated with AZT, we can prevent in utero transmission of the virus in more than 50 percent of

As much as we encourage the voluntary approach, it will never be 100 percent effective.

their newborns.

Certainly, in an ideal world, convincing all pregnant women to undergo testing is the best approach. But as much as we encourage the voluntary approach, it will never be 100 percent effective. To convince every single pregnant woman to voluntarily get tested will realistically be impossible. So what then do we tell their babies? Do we merely allow them to fall through the cracks?

And what about the women out of the health-care system, those who show up at the hospital for the first time when the baby is born?

Aren't their babies entitled to be tested? What about women who refuse to be tested? They certainly have a right to refuse treatment. But the real question is the rights of the baby, once born. It is simply immoral and unconscionable if we as a civilized society allow any newborn to go undiagnosed and untreated. A child who tests positive for HIV at birth has as much right to health care as anybody else in America.

Effective treatment is presently available for infants who test positive at birth. Their lives can be extended and improved through therapies such as prophylaxis care for various infections; anti-retroviral drugs; and intravenous immunoglobulin, which boosts the immune system and delays the onset of PCP pneumonia, tuberculosis and other diseases that usually mark the beginning of the end. This treatment also improves the baby's mental and cognitive development.

If children are identified and treated for the virus, they can be kept alive long enough to give science the chance to find a cure. In addition, approximately 75 percent of babies who are initially positive at birth eventually shed the antibody and ultimately test negative. But if the mother does not know she is HIV-positive, she will almost certainly reinfect the infant through breast feeding.

In most states every newborn is already tested for a host of diseases from syphilis to PKU to hepatitis B. Mothers are told the results and the infants are treated. So why not add HIV to the list? Isn't HIV more serious and deadly? Why should hospitals send home sick babies who are destined to return when their tiny bodies are racked by the ravages of full-blown AIDS? Why wait until there is little doctors can do?

The Baby AIDS legislation remains one of the few bills in the 104th Congress to have a majority of the House as co-sponsors, members of all political stripes: Republicans and Democrats, liberals and conservatives.

It will pass with strong bipartisan support and soon become law. Then, we will finally begin treating AIDS as the public-health issue it is, rather than a huge political disease. We will finally stop playing politics with our babies.

Gary Ackerman, New York Democrat, is a member of the U.S. House of Representatives. This article was written for Scripps Howard News Service.

Sacrificing Babies on the Altar of Privacy

By BARBARA J. LEDEN

Some 7,000 babies are born each year in America to HIV-infected women, and about 2,000 of the infants test positive for HIV, the virus that causes AIDS. Fortunately, nearly three-quarters of these are phony positives, because the babies have their mother's antibodies, but not HIV itself. Yet these babies are at terrible risk because they are very likely to get the virus through breast feeding—mother's milk is a prime carrier of HIV.

Even those babies who have the virus, however, can receive an extended lease on life if treatment begins immediately. Without treatment, they will live an average of only a few years, but with current treatment they can expect to live into their teens. Incredibly, federal policies now ensure that, even if the babies are diagnosed in time, their parents will not be informed about the babies' disease (and hence their own). In other words, federal policies annually condemn to death as many as 1,500 babies who could be saved at virtually no cost. What's worse, the number is rising, as more and more women contract AIDS.

Arthur J. Armann, professor of pediatrics at the University of California Medical Center in San Francisco, and the man who discovered both pediatric AIDS and blood-transfusion AIDS, considers these policies a violation of the international Nuremberg Code: "The failure to inform the guardians of known HIV-infected infants when treatment is available violates both interna-

tional and national codes of ethics."

This Kafkaesque turn of events came about because of demands by AIDS activists and establishment feminists that the "privacy" of AIDS victims be preserved at all costs—even if others have to die for it. Only the patient is informed, and only if he or she asks to be told. In another grim triumph of abstract principle over common sense, not even spouses or "partners" are told in most states. The information is withheld from the parents and guardians of HIV-positive babies on the grounds that the baby's mother would then know that she had the disease, even though she had not asked to be tested for it. In the wonderland of AIDS politics, the carriers of the disease are given every "right," but their potential victims are simply part of a vast viral crapshoot.

The best solution to the problem—indeed, the only truly effective policy—is to test pregnant women directly and routinely, tell them the results and teach them how to behave in the future. If this were done, babies' chances would improve dramatically: Two-thirds of HIV infections can be prevented if the drug AZT is administered during pregnancy and if the HIV-positive mother doesn't breast feed her children. But this only works in theory; in practice, a high percentage of HIV-positive women have no prenatal care, let alone HIV testing and counseling. So though has been the triumph of activists—including the National Organization for Women—that there is no mandatory HIV

testing, either for pregnant women or for their newborns.

HIV is an exception to the rule. Some 45 states, plus the District of Columbia and the Virgin Islands, require tests for as many as nine diseases, including syphilis and sickle-cell anemia. The economics of testing and early treatment are overwhelmingly in favor of such a policy. Testing a newborn baby for HIV costs a mere \$10, and AZT treatments, while currently quite expensive (\$2,000 per year), are a bargain compared with the cost of treating AIDS victims. But the power of the AIDS activists and their feminist allies has overwhelmed those advocating greater concern for the victims.

The federal government does recommend HIV tests. The Centers for Disease Control (CDC) conducts "anonymous" testing of newborns and purely voluntary testing for pregnant women. The research on newborns was intended to provide data for evaluating the spread of the disease, and, in observing the "privacy" principle, the CDC did not inform parents and guardians. Last spring, some members of Congress started raising questions about the CDC's testing program—seeking to require that the parents be informed about their babies' plight (and their own)—whereupon the CDC bureaucrats, keen to avoid a public spat, dropped the testing program altogether.

This led to another uproar on Capitol Hill, and the CDC has reinstated its earlier anonymous testing policy. You can now

get the raw data on AIDS babies, but you still can't save the babies. As for the voluntary testing of pregnant women, Sanford F. Kuvin, the vice chairman of the National Foundation for Infectious Diseases, has pronounced volunteerism a failure and has implored Congress to take action: "[T]he mandatory reporting, testing, tracing and treating of serious diseases are what our system of public health is based upon," he says.

Legislation introduced by Reps. Tom Coburn (R., Okla.) and Gary Ackerman (D., N.Y.) would require testing all newborns whose mothers were not tested for HIV, informing the parents or guardians and counseling them about the steps necessary to save the lives of their children. The Coburn-Ackerman measure, however, does not go far enough. If we can insist upon testing for hepatitis and syphilis, why not for AIDS? Privacy is an important principle of American society, but when its blind application threatens the health and survival of women and babies, other principles must supercede it.

With all the talk from this administration—notably from the first lady—about protecting children, this dreadful policy should have been changed long ago. Further delay will only sentence additional thousands of infants to a terrible death and deprive their mothers of a chance for a longer and healthier life.

Ms. Ledeen is executive director of the Independent Women's Forum in Washington, D.C.

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Thanks to your support
Barbara Ledeen M.D.

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Congress of the United States
House of Representatives
Washington, DC 20515-3602

September 12, 1995

AIDS BABIES NEED YOUR HELP

Dear Colleague,

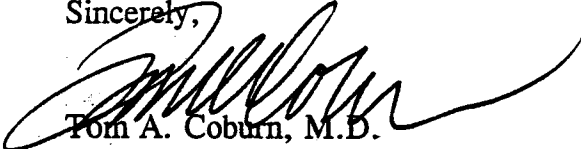
Within the next couple of weeks, we will be considering the reauthorization of the Ryan White CARE Act which provides funding for basic medical and social services to families and individuals affected by HIV. As you may know, I will be offering an amendment which mandates HIV testing for infants born to mothers whose HIV status is unknown. As a physician who has delivered over 3,000 babies, I believe that this amendment is extremely important if we are to save innocent babies and to stop the spread of this deadly virus and the incurable disease which it causes, AIDS.

Studies have shown that the rate of transmission of HIV from mothers to infants can be reduced by **two-thirds** if the drug AZT is administered during pregnancy, labor and the first six weeks after birth. Knowing the status of a baby right away would allow treatment and counseling to begin immediately and prevent an uninformed mother from transmitting HIV to her baby through breast feeding.

Therefore, passage of this measure is critical if you believe as most Americans do that the quality of life and optimal medical care is crucial for every infant. Voluntary measures of the past have failed and now is the time to address this disease as the medical problem it is if we are to save lives.

This amendment has wide bi-partisan support and has been endorsed by medical organizations, practicing physicians, family groups, national editorial boards and numerous others concerned about the welfare of children. We would appreciate your support as well. If you have any questions, please feel free to contact Roland Foster of my staff at 5-2701.

Sincerely,



Tom A. Coburn, M.D.
Member of Congress

TOM A. COBURN, M.D.

2^D DISTRICT, OKLAHOMA

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Congress of the United States
House of Representatives
Washington, DC 20515-3602

September 19, 1995

Honorable Newt Gingrich
Speaker of the House
H232 Capitol
Washington, DC 20515-6501

Dear Speaker Gingrich,

Earlier this week, the House reauthorized the Ryan White CARE Act. As you know, this bill will provide vital medical and social services to families and individuals affected by HIV. It also contains a provision offered by Rep. Gary Ackerman and myself which would mandate HIV testing for newborns whose mothers did not undergo prenatal testing.

Although this measure was approved by voice vote, I am very concerned that the testing provisions will not survive the conference committee with the Senate. Both Senators Kassebaum and Kennedy of the Labor and Human Resources Committee favor voluntary testing and would be very unlikely to support our mandatory approach.

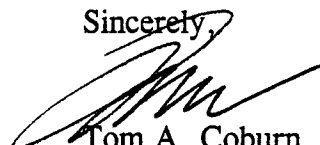
As you may know, voluntary measures have failed. And unless we insist upon mandatory testing, hundreds of babies which could be saved will die painful deaths. It is imperative that this message be made forcefully at the conference.

Therefore, I would request to be named as a conferee to the Ryan White CARE Act conference committee. As a practicing physician, I can provide first hand experience of the benefits of mandatory testing for disease, particularly for the deadly and incurable HIV virus.

I have sent a similar request to Chairman Bliley of the Commerce Committee.

Thank you again for your assistance and consideration. I look forward to hearing from you soon.

Sincerely,



Tom A. Coburn, M.D.
Member of Congress