Family Feud

Newborn-testing opponents re-enter the ring

January 1, 1999 By Liz Galst

At her desk in the cramped, fluorescent lit Manhattan offices of the HIV Law Project, attorney Kim Mutcherson reviews the details of a class-action suit her organization brought against the state of New York. Filed in July 1997, the suit challenges the state's mandatory newborn HIV testing statute, the only law of its kind in the nation.

When the bill was first proposed, attorneys at the HIV Law Project, joined by women's groups and medical associations, fought it fiercely, arguing that it discriminated by, in effect, singling out mothers for mandatory testing. (Testing a newborn measures only the mother's antibodies; if babies seroconvert, they do so months later.) Now that the bill is law, however, opponents have refocused and want its promise of getting mothers and infants into treatment fulfilled. "It's easier to ask for enforcement than it is to ask a judge to flat-out declare something unconstitutional," says Mutcherson.

Across the East River in Queens, eight-term Democratic state assemblywoman Nettie Mayersohn, the legislation's chief sponsor, touts the salutary effects of the bill she said would save innocent lives: "You're not getting babies dying of pneumocystis pneumonia anymore!" Mayersohn, also known for her tenacious advocacy for partner notification, was closely involved in the recent California debate over whether to use numerical codes or names for the state's HIV reporting (she advocated for names).

The issue of mandatory testing has been in the news of late: In October, the federal Institute of Medicine issued a report calling for routine—but not mandatory—testing of pregnant women in an effort to reduce perinatal transmission. A decision on whether to adopt the contested recommendations, which eliminate a counseling requirement as too onerous for doctors, is expected from Health and Human Services Secretary Donna Shalala by the end of 1998.

Much of this current debate over newborn testing dates back to New York's controversial law, enacted in February 1997. The bitter divisions that marked its history continue in the battle over implementation—a battle that may have bearing on federal policy and future legislation across the country. Supporters call New York's legislation a vital link to care for HIV positive babies; opponents still see it as a forced HIV test of mothers that, because it tests newborns shortly after birth, does little to stop perinatal transmission, breaching consent and occasionally confidentiality

along the way.

HIV Law Project plaintiffs and others say state lab results float back anywhere from two to four weeks after the newborn's birth, too late for a mother to choose against breastfeeding (which increases chances of HIV transmission) or to implement a potentially lifesaving therapy for the newborn. So polarized is the debate, even two years later, that it's difficult to separate rhetoric from reality.

In 1993, when Mayersohn first sponsored her legislation, New York was home to 25 percent of all pediatric AIDS cases in the nation, and the state had been blind-testing newborns—testing them anonymously—for five years in order to chart the shifting demographics of the epidemic. Mayersohn thought it unconscionable that medical providers kept the results from parents, and she wanted the tests unblinded. "We were sending babies home without this information!" Mayersohn recalls. "I thought it was the most horrendous thing I'd ever heard."

In the legislature and the press, a high-pitched debate ensued. Although the New York State Pediatrics Association, the Medical Society of New York and the American College of Obstetricians and Gynecologists all came down against the bill, Mayersohn and several newspaper editorials practically called her opponents baby-killers. Mayersohn came in for harsh criticism as well; one ACT UP flier accused her of trying to "break the law and infringe on pregnant women's rights" and of lying when she portrayed newborn testing as anything other than a test of the mother.

The bill proposed to make mothers the only group, besides federal prisoners, to face mandatory HIV testing—not only violating rights, opponents argued, but breaking down patient-doctor relationships. According to Mutcherson, "The mother has to trust what's going on in that hospital, or the child isn't going to get the care it needs."

Fordham University law professor Elizabeth Cooper, another activist in the campaign against what soon became known as the Baby AIDS Bill, recalls: "The proposal took doctors off the hook from having to talk to women about HIV, and put the burden on women, who had to deal with the results with not a lot of counseling."

Indeed, Mayersohn's initial proposal made no mention of HIV counseling for pregnant women, despite the fact that a course of AZT begun in the third trimester is the best hope for decreasing perinatal transmission (studies show a drop of more than two-thirds). Opponents noted the highly visible success of a prenatal counseling and voluntary testing program at Manhattan's Harlem Hospital, where more than 90 percent of women in prenatal care—many of them intravenous drug users or their partners—agreed to test for HIV while pregnant. The vast majority whose results came back positive began the AZT prophylaxis.

Through the efforts of activists and their allies in the legislature, says Cooper, mandatory prenatal counseling, with a recommendation for testing, was written into the bill. But that was not their only concern.

Janet Mitchell, MD, then chief of Harlem Hospital's perinatology program, believed that the mothers' health care would be ignored. "The law mandated things that institutions had to do to assure that the baby got into quality care, and it did not mandate those same things for the mother." Her prediction was borne out: The law now requires that a doctor who will supervise the child's treatment be named on a release slip, while there's no such incentive for the mom.

Mayersohn has never addressed specific criticisms of the bill; to this day she calls all arguments against it "nonsense." The state had already mandated testing newborns for seven other diseases, she argued at the time, including sickle-cell anemia and hypothyroidism (none of which carry the same social stigma as HIV). "I was debating mostly people who had no children," she says now. "You would have to search far and wide to find a mother who wouldn't want to protect her baby."

For more than three years, a tense, public standoff continued. But in the summer of 1996, Congress passed provisions of the Ryan White CARE Act that required, by the year 2000, mandatory newborn testing (with disclosure of results to the infant's parents) or proof of either reduced perinatal transmission or near-universal voluntary HIV testing. Pressured to bring the state into compliance with the Ryan White regulations—and facing an upcoming election—powerful Democratic state assembly speaker Sheldon Silver switched his position against mandatory testing, thus allowing the measure to come to a vote. The bill became law.

Newborn screening hasn't quite been the nightmare some advocates imagined. The state Department of Health's AIDS Institute claims extraordinary results. Of 957 HIV positive infants born between February 1 and December 31, 1997 (the most recent statistics available), 99.1 percent, the institute says, were linked to care.

New York City AIDS surveillance data show a decline in pneumonia among young HIV-infected children, from 24 cases in 1996 to five in 1997. And the screening program has indeed identified women who seroconverted after testing negative early in their pregnancies. "We've been able to handle the situation well enough so that rather than the mother feeling as though something has happened to her that she had no control over," says pediatrician Shaffiq Essajee, MD, of New York City's Bellevue Hospital Center, "she can use the experience in a positive way."

But advocates question each of these apparent successes:

Being "linked to care," under the state's definition, simply means a child has received a positive PCR test, confirming the child has seroconverted. Since the test is always performed by a medical professional, says the State Department of Health's Frances Tarlton, "We take that as evidence that the child is in care. We don't have doctors reporting otherwise." (All HIV positive women in New York have access to care through Medicaid or the AIDS Drug Assistance Program.) "They've simply created this definition that lets them not have to follow up," counters Mutcherson, who proposes that the state call providers and mothers to insure ongoing care.

The law alone can't account for the declines in PCP. According to Keith Krasinski, MD, an assistant epidemiologist at Bellevue who initially fought for unblinding the HIV tests, "Some of the decrease

is the result of PCP prophylaxis, which doesn't have to do with the law, and another big drop is from the decrease in total perinatal transmission."

Most important, the two-to-four-week turnaround at the state lab doesn't get results to mothers in time. The delay precludes a mother from knowing whether to choose early AZT prophylaxis for her newborn, a treatment that, when administered in the first few days of life, can decrease the likelihood an infant will seroconvert by up to 66 percent. "I know of cases where the women were not counseled to be tested, and they find out a month after the baby is born that it's positive," says Susan Rodriguez, who coordinates the Pediatric Working Group at the PWA Health Group in New York City. Rodriguez is HIV positive herself, and has a child with HIV. "I don't know who the law is supposed to protect, but it's not protecting newborns."

Doctors and advocates report an additional set of problems. One client at Iris House, an HIV service center in East Harlem, was counseled in English at a nearby hospital, even though she speaks only Haitian Creole. "She was completely unprepared for the results, and her husband bugged out," says Marie St. Cyr, Iris House's director. A doctor at Montefiore Medical Center in the Bronx says that, on occasion, the HIV status of an adolescent's newborn, and thus the status of the teen herself, has been disclosed to her parents.

And women who receive prenatal care at private clinics or don't fall into "high-risk categories" may slip through the law's mandates. One of the HIV Law Project's plaintiffs, an HMO patient, never received HIV counseling while pregnant, nor was she encouraged to seek prenatal testing. "Her doctor actually said to her, 'I just never thought I'd have to worry about this with you,'" Mutcherson reports. (The plaintiffs in the Project's suit chose not to speak with POZ.)

Mayersohn, though, has shifted her concern to other issues. She ignores the law's critics and has neglected to push for better implementation. "To this day," she says, "I still listen to the arguments to see if there's a rational one anywhere, and I haven't found it."

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