

1997

## Changing Positions and Entrenched Polemics: A Brief History of the Association to Benefit Children's View on Pediatric HIV Testing, Counseling, and Care

Colin Crawford

*Special Counsel, Association to Benefit Children; Associate Professor, Thomas Jefferson School of Law*

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### Recommended Citation

Colin Crawford, *Changing Positions and Entrenched Polemics: A Brief History of the Association to Benefit Children's View on Pediatric HIV Testing, Counseling, and Care*, 24 Fordham Urb. L.J. 729 (1997). Available at: <https://ir.lawnet.fordham.edu/ulj/vol24/iss4/6>

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# CHANGING POSITIONS AND ENTRENCHED POLEMICS: A BRIEF HISTORY OF THE ASSOCIATION TO BENEFIT CHILDREN'S VIEWS ON PEDIATRIC HIV TESTING, COUNSELING, AND CARE

*Colin Crawford\**

## Introduction

It is not, I think, false self-regard to say that the Association to Benefit Children (“ABC”) has for the better part of this decade been one of a few parties at the center of the controversy in New York State over the difficult and complicated issue of pediatric HIV testing. To some extent, this was by design. I cannot say with certainty that ABC reintroduced the issue for public consideration; unbeknownst to us, Assemblywoman Nettie Mayersohn was gathering support for her efforts in Albany at about the same time that we first contacted the AIDS Institute of the New York State Department of Health to revisit questions of infant HIV testing, counseling and treatment. But I can say with confidence that our participation helped generate attention on the issue, and in the process contributed to the changes in the law about which many of today’s speakers commented.

What has not been widely recognized, I think, is that ABC’s position on the issue of how and when pediatric HIV testing and counseling should be administered changed over time. The furor over infant HIV testing thus helped focus and refine our thinking about crucial questions such as those surrounding confidentiality in HIV care and medical issues connected with family, maternal and infant health. A careful review of our changing position would have revealed to our opponents that we were hardly the intransigent zealots we were often depicted to be. Now that things have quieted down somewhat—or, perhaps I should say, have quieted down *for the time being*—with respect to this issue, this symposium provides a useful opportunity to examine the changes in ABC’s

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\* Special Counsel, Association to Benefit Children; Associate Professor, Thomas Jefferson School of Law. Work on this essay was made possible in part with support from the Brooklyn Law School Faculty Fund.

own position over time. For this chance, ABC and I are deeply grateful.

In my remarks today, I intend to do three things. First, I want to document the trajectory of ABC's approach to this issue, which was considerably more layered and nuanced than often characterized by the press and, certainly, by our most virulent opponents. Second, I aim to offer some reflections as to why the debate became as acrimonious as it did, and how that impeded resolution of this issue satisfactory to the widest possible number of people. Third, I hope that these reflections will provide a basis for some suggestions as to how future debate on these and related, pressing issues of family, maternal and infant health, and HIV might become more civil and, in the process, achieve consensus on compelling policy issues in a more efficient and humane fashion.

### **I. The History of ABC's Involvement**

The modifications in ABC's position are revealing not only of the need for all of us constantly to readjust our convictions when they concern the changing realities of the HIV epidemic, but also of the compromises all of us are forced to make in the course of responding to such a complicated—because still imperfectly understood—disease. In late 1991, I received a call from Gretchen Buchenholz, ABC's Executive Director. Gretchen described to me horrific situations that ABC, as a day care and foster care provider, had recently witnessed, like that of Marsha T. Marsha was born on Christmas Day, 1990 to a mother who was an intravenous drug user. She was placed in foster care at birth. Like every baby in New York State, Marsha T. was tested for HIV at birth. The results of her HIV test, however, were not shared with anyone—not her birth mother, not her foster parents, not even her doctor or other health care providers. Instead, Marsha's HIV test was "blinded." This means that the test results were separated from Marsha's medical records and used only to assist state health experts collect statistics on the spread of AIDS.

Marsha's first four months were harrowing. Less than two months old, she developed hepatitis. A month later, she was hospitalized with bronchitis. The next month—April 1991—Marsha went into respiratory arrest and was hospitalized again. Despite her mother's drug use and that each of these illnesses taken alone can be evidence of possible HIV-infection, it was only then, nearly four months old, that she received an "unblinded" test for HIV. When her positive result was confirmed, Marsha was started on

drug trials and is now reasonably healthy, although developmentally delayed as a result of the debilitating illnesses she suffered in her precious, early months.<sup>1</sup>

Gretchen explained to me that Marsha's foster parents had faced extraordinary obstacles in trying to have her tested, owing to New York State's strict HIV confidentiality law. This had serious, life-threatening implications for the life of a small child, she elaborated, because many of the gravest pediatric HIV killers typically affect children early, in their first three to six months of life.

My initial reaction to what she told me was one of shock. This reaction, I might add, is one that I have since found to be most common among people unfamiliar with the issue. The reason was that it seemed incomprehensible (and still seems so to me) that state medical authorities would test for HIV but not relay the results to the infant's parents or guardians. Gretchen further explained to me, however, that she and ABC had only in mid-1991 come to believe that it was worth challenging the strict confidentiality imposed on pediatric HIV results by New York law. This was because, she explained, new developments in pediatric HIV care meant that infants whose HIV status was known could now have a reasonable chance at a childhood—and maybe even an adolescence beyond that.

Gretchen then went on to outline for me the opposition to her newly-changed position.<sup>2</sup> In brief, the problem is this: when a child is identified as HIV-positive, so too is her mother. Some women's rights advocates strongly oppose compulsory infant testing on the grounds that it could be used as a tool to identify women with HIV against their will. The feminist arguments against testing were compounded by the fact that the majority of women with HIV are African-American or Latina, and often quite poor. As a result, proposals about infant HIV testing raised concerns about gender and race-based discrimination, including possible constitutional

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1. ASSOCIATION TO BENEFIT CHILDREN, *A PREVENTABLE CRISIS: A SPECIAL REPORT ON THE FAILURE TO TEST AND TREAT INFANTS AND CHILDREN FOR HIV 7-9* (1993) [hereinafter *A PREVENTABLE CRISIS*] (containing other examples taken from ABC's own case files).

2. It is worth stressing that ABC had in earlier years been highly visible in its support of voluntary, as opposed to mandatory testing. See, e.g., *Stipulation and Order of Settlement, Baby Angel v. Koch*, 89 Civ. 4770 at paras. 13-15 (S.D.N.Y. 1991). *Baby Angel* was the so-called "boarder babies" litigation that led to an end of the practice of "boarding" newborns in New York City hospital. ABC was the institutional plaintiff in the case.

concerns about possible equal protection challenges and threats to protected privacy interests.

As an organization, ABC constantly advocates for the poor, and particularly poor women of color. Consequently, as Gretchen and I spoke about it, we recognized that there was a risk in public perception, if not in fact, that in taking the side of pro-testing advocates we could be seen as abandoning the people we serve.

We of course knew this was not the case. As we discussed the pros and cons of both sides, it became absolutely clear to us that, given promising developments in pediatric HIV medical care,<sup>3</sup> it was absolutely essential—in the interest of prolonging and enhancing their lives as much as possible—to come out on the side of the children and their families. Moreover, ABC's experience as a housing provider for large, homeless families suggested that when faced with a manageable problem, ABC's mothers tended to focus on their well-being and that of their children.<sup>4</sup> Thus, it was our belief that a mother who learned of her own HIV-positive status when her infant was identified would only want to concentrate with more attention and devotion than ever before to her own and her child's physical well-being. It was our view that this would include seeking medical treatment and counseling.

From the outset, ABC insisted that our advocacy of infant testing and test result disclosure was permissible only in the context of increased funding for counseling and treatment.<sup>5</sup> It seemed inescapably true to us that testing without more would be a woeful derogation of the public duty. We have never wavered from this conviction.<sup>6</sup> Nonetheless, it *was* true that at that early stage in the controversy—remember, again, that the year was 1991—that we concluded that *mandatory*, universal infant HIV testing was the only way to insure that no children's lives be needlessly lost. Things have changed so much—and, thankfully, mostly for the better—since 1991, that it is worth explaining why at that time we

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3. First Amended Complaint, *Baby Girl Doe v. Pataki*, No. 10661-95 at paras. 26-41 (N.Y. Sup. Ct. 1995) (detailing some of the most promising treatments).

4. It is important to stress this point because some critics suggested that mothers who learned that they were HIV-positive might abandon their children in despair or, at a minimum, avoid hospital care. See, e.g., Ana Dumois, *The Case Against Mandatory Newborn Screening for HIV Antibodies*, 20 J. COMMUNITY HEALTH 143, 155 (1995). I have never seen any solid proof of these inflammatory claims, however.

5. A PREVENTABLE CRISIS, *supra* note 1 at 32-35.

6. The public record amply supports this contention. See, e.g., Colin Crawford, *An Argument for Universal Pediatric HIV, Testing, Counseling and Treatment*, 3 CARDOZO WOMEN'S L.J. 31, 33-35 (1996).

came to the reluctant conclusion that a regime of mandatory testing was the only possible choice.

In the early 1990's, the acronyms "HIV" and "AIDS" were still regarded by most people as a certain sentence of quick death. Discrimination against people with HIV was more acute than is the case today. Consequently, it was our view then that anything short of mandatory testing would never be successful, and that babies' lives would be lost in the process. People were still just too fearful of being tested; the stigma was greater than it is today, just six years later. If we were to advocate for the chance to give HIV-positive infants a healthy childhood and perhaps more, it seemed that there was no alternative to mandatory testing.

Having reached this conclusion, our next step was to contact many of the entities most closely identified with HIV and family health policy. Thus, I began calling everyone from officials at the AIDS Institute to major national not-for-profits. In general, the response I received was negative: most (like the AIDS Institute) simply did not want to re-open what they considered to be the intractable and divisive issue of pediatric HIV testing. Many (Lambda Legal Defense and Education Fund, for instance) resisted the suggestion of challenging any portion of New York's strict HIV confidentiality law, appearing to me to fear that taking out one chink in that armor would cause the entire protective shield—one painstakingly codified in New York State's comprehensive AIDS confidentiality law—rapidly to disintegrate.<sup>7</sup>

However, my calls did generate interesting differences of opinion. One day in the late Fall 1991, I called both the Children's Rights Project and, in a separate call, the Gay and Lesbian Rights Project of the American Civil Liberties Union. Unofficially, the person I spoke to at the Children's Rights Project indicated an inclination to agree with ABC's emerging position favoring mandatory testing as a way of protecting the rights of infants. The representative of the Gay and Lesbian Rights Project, by contrast, strongly opposed our new stance. Eventually, the ACLU officially came out very strongly and publicly against the positions we advocated.<sup>8</sup> Nonetheless, I have never forgotten those phone calls, because they stood for me as emblematic of why this issue can

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7. N.Y. PUB. HEALTH LAW § 2782 (McKinney 1993).

8. AMERICAN CIVIL LIBERTIES UNION, ACLU POSITION STATEMENT ON PRENATAL AND NEWBORN HIV TESTING, *reprinted in* TAKING SIDES: CLASHING VIEWS ON CONTROVERSIAL ISSUES IN HUMAN SEXUALITY 192, 201-205 (Robert T. Francoeur ed., 5th ed. 1996) [hereinafter TAKING SIDES].

become so divisive. To put it simply, the arguments in favor of both sides are compelling for different reasons, even to people working for the same general civil rights goals within the same organization. Any choice has some regrettable aspect.

### A. ABC's Changing Position

For much of the first two years of this struggle, ABC advocated universal mandatory testing. The reason was simple: we looked at the available data which recorded the failure to achieve success in getting infants tested and into treatment through maternal counseling and voluntary testing. I refer specifically to the two principal state Department of Health-funded programs, the PCAP program and the OB Initiative. I have in print and other public fora elsewhere documented ABC's view that these programs failed, and will not rehash here ABC's analysis of the tragically unsuccessful voluntary testing numbers.<sup>9</sup> Suffice it to say that our perception of this failure was the largest single influence in shaping our position. We were encouraged in this view, moreover, because as many as 87% of pediatric HIV cases were identified in the New York City metropolitan area.

In addition, I should note that our initial position was strongly influenced by the fact that New York City and State social service agencies had failed adequately to address the needs for testing and treatment of children in foster care. This moved us, as a foster care provider and an agency that worked with a large number of children in foster care, to believe that prompt, mandatory testing was the only acceptable alternative.

### B. ABC's Foster Care Challenge

Our initial conversations with the AIDS Institute made it clear that it would not review its pediatric testing policy until it was con-

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9. See, e.g., Colin Crawford, *Protecting the Weakest Link: A Proposal for Universal, Unblinded Pediatric HIV Testing, Counseling and Treatment*, 20 J. COMMUNITY HEALTH 125, 129-131 (1995), reprinted in *TAKING SIDES*, supra note 8 at 194-200. It is worth noting that this conclusion is drawn from the Department of Health's own statistics, which document the failure of its voluntary testing programs. For instance, in one state-funded survey for the period July 1-September 30, 1993, out of a documented 228 newborns born in New York State who tested positive for HIV, 27 were successfully counseled, tested and identified for treatment in state-sponsored programs. That is a success rate of 15.9%. These statistics were taken from a chart prepared by the Department of Health (on file with the author).

vinced that the medical landscape had changed significantly.<sup>10</sup> ABC strongly believed that the foster care portion of the pediatric HIV problem needed especially prompt attention because it was estimated by early 1993 that 50-60% of children in foster care were HIV-positive, a grim reality that ABC knew only too well from its experience as a foster care provider.<sup>11</sup>

The foster care crisis led us to contemplate the first of several lawsuits we considered over the course of our involvement in this controversy. We began, first, from a premise that we believed was supported by both the United States and New York State constitutions. To be specific, in consultation with *pro bono* counsel, we concluded that basic duties of care for the health and well being of New York's youngest citizens had been and continued to be breached by the executive branch agencies charged with protecting them.<sup>12</sup>

Our concerns about the inadequacy of the foster care testing procedures focused particularly on three issues. First, we were disturbed that the process of getting a child in foster care tested could take several months while the foster care provider went through the cumbersome procedures required to identify the parent or legal guardian of a child in foster care. Second, we wondered why the obligation to test children in foster care extended only to a child's second year. Presumably, to protect all children's health, it was essential to have some mechanism to test all children until they had the capacity to consent for themselves. Third, it was our view that it was crucial to screen all children in foster care for risk factors, in order to indicate when a child urgently needed an HIV test, as the first step in identifying threatened children for special care and treatment. This last view, it should be added, was directly informed by New York City Child Welfare Administration ("CWA") policies.<sup>13</sup>

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10. I refer specifically to the principles articulated by the Aids Institute at the January, 1990 Mohunk Conference. See A PREVENTABLE CRISIS, *supra* note 1, at 23-24.

11. See Crawford, *supra* note 9, at 131-134.

12. See Crawford, *supra* note 6, at 36-37.

13. This is indicated, for example, by the *Notice of Emergency Adoption and Proposed Rule Making* issued on September 2, 1994 by the New York State Department of Social Services, proposing changed procedures for identifying children with HIV in foster care. The advisory notes that affected agencies were required to include: documentation that the child in foster care has been assessed for risk factors related to HIV infection in accordance with section 441.22(b) of this Title [meaning the state Public Health Law], and, if one or more risk factors have been identified, a description of the procedures that were followed to ar-



As has been the case throughout the pediatric HIV controversy, our initial approach was to work for change by trying to convince the state Commissioners of Social Services and Health to initiate public review of the issue. When that approach failed, we resorted to the blunt tool of litigation, going so far as to prepare a complaint naming then-Governor Cuomo and his Commissioners in a suit alleging their nonfeasance of constitutionally-directed and other responsibilities. Fortunately, days before we filed suit, the Commissioner of Social Services recognized the strength of our case and, on June 6, 1994, issued on an emergency basis, new regulations for children in foster care. The regulations addressed each of our concerns: (1) streamlined procedures so that, especially in emergency situations, a child could be tested after good faith efforts were made to identify the parent or legal guardian; (2) the extension of the testing period beyond age two to "capacity to consent";<sup>14</sup> and (3) adoption by regulation of substantially the same list of risk factors that would direct medical professionals to conduct an HIV test as that used by the New York City CWA.<sup>15</sup> Within less than three months, Department of Social Services ("DSS") Commissioner Michael Dowling issued emergency regulations formalizing these requirements.<sup>16</sup> To our delight, not only

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range for appropriate HIV-related testing including obtaining the necessary written informed consent for such testing . . . .

NEW YORK STATE DEPT OF SOCIAL SERVICES, NOTICE OF EMERGENCY ADOPTION AND PROPOSED RULE MAKING (Sept. 2, 1994) (copy on file with author).

14. In preparing this lawsuit, ABC arrived at the conclusion that the phrase "capacity to consent" was open to interpretation as a matter of law, and could mean anyone from a pre-adolescent able to understand his/her rights to a young adult as old as 17 or 18. However, because our focus was on infants and very young children, we did not object to the phrase.

15. See, e.g., Memorandum from Kathryn Croft, Executive Deputy Commissioner, Child Welfare Administration of the Human Resources Administration, City of New York, to heads of foster care and related agencies (Sept. 13, 1994) (on file with the author). The memorandum states:

This LCM is to inform you that [DSS] will now build on the CWA experience and develop statewide requirements to ensure that all New York foster children who may be HIV-infected are provided with the advantage of early diagnosis and treatment. [DSS] will develop regulations and guidelines requiring that all foster children, without regard to age, be screened on the basis of a specified list of risk factors within five working days of entry into foster care. . . . If the assessment identified one or more risk factors, designated social service staff are to be informed immediately so that steps necessary to secure an HIV test may be completed no later than 30 days after the child's entry into foster care.

*Id.*

16. See *supra* note 13 and accompanying text.

were the regulations issued with relative speed, but the relevant agencies acted quickly to implement them.<sup>17</sup>

From ABC's point of view, these changed regulations constituted an important but partial victory. We remained convinced that the foster care part of the pediatric HIV testing problem was only the most glaring example of how earlier policy had failed. We continued to believe that all children, including those not in foster care, needed to be served. Consequently, we considered next how to translate the foster care victory into a larger one benefitting all of the state's children.

Then a crucial, unanticipated event occurred that, inadvertently, moved the struggle in an entirely new direction. In November 1994, George Pataki was elected Governor. Quickly after taking office, on January 6, 1995, in keeping a campaign promise to cut down on the size and reach of government, Governor Pataki issued an Executive Order<sup>18</sup> that placed a moratorium on the promulgation of any new regulations. Because DSS issued the pediatric HIV foster care regulations on an emergency basis, thus requiring further notice and comment, they were covered by the moratorium order. Our achievements with respect to the new foster care pediatric HIV testing regulations had suddenly and unexpectedly been put on hold, imperiling the efforts of the previous four years.

The Governor's regulatory moratorium forced us to undergo a thorough reconsideration of our position—and our options. In fact, with one fell swoop, the Governor's act forced us to reevaluate our entire position. Also, because all that we worked for had so suddenly been threatened, we also became convinced that we were compelled to act quickly.

### **C. ABC's Lawsuit on Behalf of All Children with HIV in New York**

On March 15, 1995, a group of plaintiffs consisting of numerous children and their mothers or natural guardians, ABC's Executive Director, Gretchen Buchenholz, as guardian *ad litem*, and ABC filed suit against Governor Pataki, Mary Glass, his Commissioner of Social Services, and Barbara DeBuono, his Commissioner of Health, for violations of the New York Social Services and Public Health Laws, the New York State Constitution, and the Due Pro-

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17. See *supra* note 15 and accompanying text.

18. Kevin Sack, *New York's New Governor: The Overview; Pataki Promises a Reduced Budget and Lower Taxes*, N.Y. TIMES, Jan. 5, 1995, at A1.

cess and Equal Protection clauses of the United States Constitution.

This lawsuit set in motion what in retrospect appeared, from ABC's perspective, to be the most crucial seven months of our organization's entire effort on this issue. ABC was convinced that it was necessary to take some action that would compel the Governor to lift his moratorium, and also to address the problem of all children at risk of HIV. The relief sought in the lawsuit was simple: (1) a declaration that defendants violated the laws mentioned above, and (2) preliminary and permanent injunctions compelling defendants to provide for routine HIV testing for all newborns in New York and, where appropriate, treatment and counseling for HIV positive infants, their mothers and other family members and caregivers.<sup>19</sup> It is worth adding that our conviction in the appropriateness of bringing this lawsuit was supported by increasing medical evidence on the value of early testing.<sup>20</sup> Throughout the ensuing, turbulent months, further information demonstrated the wisdom of our choice, including news from the state's own Department of Health that the exceptionally precise polymerase chain reaction ("PCR") HIV test (which tests DNA) would be available at no cost for pediatric HIV tests.<sup>21</sup> Because of its low false positive rate, the PCR was an especially reliable test in that it allowed medical professionals to determine with much greater accuracy than ever before those children with actual HIV, rather than those who carried maternal HIV antibodies that they would later shed.<sup>22</sup>

### 1. *Defendants-Intervenors*

Perhaps the oddest development of these months was the opposition to ABC's efforts by people who most benefitted from our approach. I refer specifically to the intervention on the side of the state defendants of the HIV Law Project, with support from other AIDS advocacy organizations.<sup>23</sup> Despite the fact that ABC staff

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19. *Baby Girl v. Pataki*, No. 106691-95 at pp. 28-29 (N.Y. Sup. Ct. 1995).

20. *Id.* at paras. 35-36 (citing studies from the American Academy of Pediatrics and the Federal Centers for Disease Control).

21. Letter from Barbara A. DeBuono, M.D., M.P.H., State Commissioner of Health and Louis Cooper, M.D., Chairperson, District II American Academy of Pediatrics to Medical Health Professionals (Apr., 1995) (detailing availability of PCR tests as a diagnostic tool) (copy on file with the author).

22. *Id.* (reporting that "[d]espite past concerns about the specificity of PCR tests, the Laboratory's rate for false positives was very low (three out of 1,500 specimens or 0.2 percent)").

23. See Reply Affirmation of Theresa M. McGovern, *Baby Girl v. Pataki*, No. 10661-95 (N.Y. Sup. Ct. 1995).

worked before with some of the HIV Law Project's colleagues and supporters on this issue, our organization was never contacted before the HIV Law Project commenced a vitriolic campaign against ABC, both in court and in the popular press.

On behalf of some of its clients who, it contended, would be adversely affected by the result we sought in our lawsuit, the HIV Law Project intervened.<sup>24</sup> As Defendants-Intervenors, the HIV Law Project thus entered the lawsuit on the side of New York State, opposing any suggested change of the HIV testing law. In addition, during this period ABC became the target of other, less appropriate criticism, much of it levied against us from anonymous sources who made unsubstantiated attacks on our motives. My point in mentioning these unpleasant antics is more, however, than a footnote for the historical record. On the contrary, the response of the Defendants-Intervenors and our other, unidentified critics, was notable because it underscored a central theme of this essay, namely the unwillingness of people in the HIV/AIDS activist community to depart—however briefly—from their entrenched positions to study our proposal. Specifically, I refer to the fact that our complaint sought testing only if paired with counseling and treatment.<sup>25</sup> In retrospect, it is difficult not to speculate that in their heart of hearts some of our fiercest opponents now wish that they sided with our intermediate position, since the compromise position we reached surely now must seem to them preferable to the mandatory testing plan that subsequently became law. At a minimum, it is true that the multi-faceted approach we sought to implement provided a common ground for discussion, unlike the protesting bill then making the rounds in Albany, which did not make increased counseling a precondition for mandatory testing, and only directed additional care appropriations of five million dollars.<sup>26</sup>

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24. See, e.g., Defendants-Intervenors' Memorandum of Law in Further Support of Vacatur of the Stipulation or, in the Alternative, Leave to Assert Additional Claims, *Baby Girl Doe v. Pataki* No. 106661-95 (N.Y. Sup. Ct. 1995).

25. *Baby Girl v. Pataki*, No. 10661-95 at pp. 28-29 (N.Y. Sup. Ct. 1995).

26. The draft of Assembly Bill 6747B, for the 1994 New York legislative session, proposed, in relevant part, the following amendment to Subdivision (f), of section 56 of chapter 731 of the laws of 1993: "five million dollars [for a special program for HIV services for infants and pregnant women] to establish special programs for the assistance of any child testing positive at birth for HIV and the members of such child's family . . . ." [emphasis in original] (on file with the author).

## 2. *The Lawsuit is Settled*

In early September 1995, shortly after Labor Day, ABC's superb *pro bono* counsel for this dispute<sup>27</sup> received a call from the state Attorney General's office. The caller informed us that after a serious review of the matter, the Attorney General wished to seek a settlement of this matter. The settlement, while forcing each side to cede ground, was unarguably the most significant event in ABC's five-year battle on this issue.

The settlement also represented the most drastic revision of our position. As provided in the Stipulation of Settlement,<sup>28</sup> the state Defendants provided that they would issue a Notice of Proposed Rulemaking "concerning the testing of newborns pursuant to Public Health Law Sec. 2500-a [which details the duties of the Department of Health] and not inconsistent with Public Health Law Art. 27-F [the HIV/AIDS confidentiality provisions] . . . ."<sup>29</sup> Importantly, too, the state Defendants agreed to issue such Notice of Proposed Rulemaking "providing that hospitals and other health care institutions covered by Public Health Law Art. 28 shall counsel all pregnant women seeking prenatal care about the health benefits of an HIV test, consistent with the requirements of Public Health Law Section 2781(2)."<sup>30</sup> This last provision was of crucial importance to ABC and the population it served. As our Executive Director is fond of saying, it represented a "beautiful compromise" because it protected confidentiality while also recognizing the imperative of insuring prompt access for infants and children with HIV and AIDS to life-saving medical care.

A revision of the state's "Informed Consent" form used for HIV testing addressed the counseling provided for in the stipulation.<sup>31</sup> The revised informed consent testing form applied only to mothers of newborns, and was to work as follows. Mothers of newborns would, soon after birth, be informed that their children were tested at birth for HIV, just as newborns are routinely tested for a number of common neonatal diseases. They would also be informed, in accordance with the confidentiality law and standard

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27. ABC's counsel were Margaret Keane and John Kinzey of the Manhattan law firm of LeBoeuf, Lamb, Greene & MacRae. See Vera Titunik, *Forcing a "Beautiful Compromise" on Infant HIV Testing*, *The Am. Law.*, Dec. 1995, at 34 (describing ABC's work with LeBoeuf, Lamb et al. as *pro bono* counsel).

28. Stipulation, *Baby Girl Doe v. Pataki*, No. 10661-95 (N.Y. Sup. Ct. 1995).

29. *Id.*

30. *Id.*

31. The existing form appears in N.Y. COMP. CODES R. & REGS. tit. 10, § 63.10 (1995).

medical procedures designed to protect patient privacy, that parental consent was required to disclose test results. The form's design advised the new parents of the possible benefits and risks of knowing the child's HIV status. Following these disclosures, the neonatal informed consent form then required a mother to choose whether she agreed to have the results of an HIV test on her child disclosed to her or not.

Although this proposal meant that ABC would no longer adhere to a program of mandatory testing, counseling, and treatment, it did serve, in our view, an important goal. Specifically, the revised consent form would do what had not been done previously, namely, inform mothers that their children would be tested, and compel them to examine the consequences of choosing not to learn their children's test results. As an organization, it has long been ABC's experience that a mother, even one in extremely distressed conditions, will almost invariably take the necessary steps to focus on the health and well being of her child and thus also herself. The revised informed consent form for use in the neonatal context would, we therefore hoped, lead to such a result. That is, we believed that most mothers would opt to learn the test results, and take advantage of the best available treatment for themselves and their children if they learned they were HIV-positive.

### *3. Results of Settlement Prove to be Effective*

In fact, our speculations proved true. During the presentation for this panel of Dr. Wendy Chavkin, of the Columbia University School of Public Health, Dr. Chavkin quoted statistics of a successful informed consent testing rate of 96% following implementation of the post-settlement, voluntary testing with a mandatory informed consent form.<sup>32</sup> The revised, post-settlement consent form asked a mother (or legal guardian) to choose whether she wanted to learn the result of her child's HIV test or not. That is, a mother was asked simply to say "YES" or "NO", after receiving the required information about informed consent principles and a brief indication of the merits of and potential problems posed by an HIV-positive test result.

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32. Telephone interview with Deborah Ellman, Research Assistant to Dr. Wendy Chavkin (Apr. 8, 1997). Deborah Ellman heard Dr. Kenneth Pass, head of the Wadsworth Laboratories (which performs all of the state's HIV testing and data collection) quote this statistic at a public presentation on HIV screening at the annual meeting of the American Public Health Association, in New York, in November 1996.

In addition, the plan envisaged by the settlement looked forward to what would happen in the event that a mother declined to sign the revised informed consent form at all. If a medical care provider had cause to believe in a strong likelihood that the child and his or her mother were infected with HIV, and the mother had not signed the informed consent one way or the other, the doctor could declare a medical emergency and direct that a test be done so that care could promptly be delivered to the child. It was this suggestion—that certain situations required declaration of a medical emergency sufficient to conduct a non-consensual test—that proved the most troublesome for ABC as we went through the notice and comment period on the proposed regulations.<sup>33</sup> Again, we endured attacks in this connection suggesting that this would lead to wide-scale, unrestrained witch hunts of potentially HIV-positive mothers.

#### 4. *Opposition to the Settlement*

The opposition to the settlement on the part of the Defendants-Intervenors was fast and furious. On October 10, 1995, a press conference was held at one of ABC's facilities. Governor Pataki, flanked by Attorney General Dennis Vacco and state Health Commission Barbara DeBuono, announced the terms of the settlement. Outside, protestors from the HIV Law Project marched in opposition, carrying placards that not only opposed the terms of the settlement, but also (and again) questioned our motives.

The Stipulation of Settlement was filed with the court that day. Over the next two months, the Defendants-Intervenors filed numerous briefs and affidavits with the court, seeking judicial disapproval of the Stipulation of Settlement. Although their claims need not be rehashed here, it is fair to say that the principal complaint was that Defendants-Intervenors should have been brought into the settlement process.<sup>34</sup> It was ABC's position, however, that this was not required since the settlement provided only that a No-

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33. See, e.g., Letter from Theresa M. McGovern, HIV Law Project and Virginia Shubert, Housing Works, Inc. to Judge William Davis (Oct. 9, 1995) (stating that "[t]he judgment as to which women fit these criteria appears to be completely subjective, thereby ensuring that low income women will be the ones denied the right to control this information"). Similar comments followed throughout the notice and comment period.

34. See, e.g., Defendants-Intervenors' Memorandum of Law in Further Support of Vacatur of the Stipulation or, in the Alternative, Leave to Assert Additional Claims at 20, *Baby Girl Doe v. Pataki*, No. 10661-95 (N.Y. Sup. Ct. 1995) (arguing that because the public interest was directly involved, the Defendant-Intervenors were entitled to an opportunity to be heard prior to the approval of the Stipulation of Settlement).

tice of Proposed Rulemaking would be issued. This Notice provides for extensive public notice and comment on the new regulations, so that no party's special interest will be compromised by virtue of settling the lawsuit.

Of the invective hurled during this period, from ABC's perspective none was stranger than the suggestion of a conspiracy to freeze the Defendants-Intervenors out of negotiations. Indeed, it was their view that "New York State Assemblywoman Nettie Mayer-sonh was an active participant in settlement negotiations."<sup>35</sup> This allegation was, to the best of ABC's knowledge, completely baseless. Once again, however, it is highly suggestive of the extremely regrettable climate of distrust and hostility that developed around this issue. What is most unfortunate about this environment of suspicion is that it prevented people who shared the same general goal—the best provision of HIV/AIDS medical care available while also protecting individual liberties to the greatest possible extent—from working together to find a consensus.

##### 5. *The Stipulation of Settlement is Approved*

Happily for ABC, Justice William J. Davis of the Supreme Court of New York agreed with our position. In an opinion rendered December 29, 1995, Justice Davis concluded that while AIDS:

is the plague of this century, . . . [t]his court . . . is not the proper venue to determine the issue at hand, which has now become: (1) a political question that has and is being presently being debated and scrutinized by both the executive and legislative branches of government . . . , and; (2) the subject matter of proposed administrative rulings under the State Administrative Procedures Act (SAPA).<sup>36</sup>

Justice Davis pointedly added that the Defendants-Intervenors contentions were:

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Defendants-Intervenors subsequently filed a Notice of Appeal in this case, dated December 15, 1995.

35. Reply Affirmation of Theresa M. McGovern, *Baby Girl Doe v. Pataki*, No. 10661-95 at para. 7 (N.Y. Sup. Ct. 1995). In fact, ABC, although broadly sympathetic with Assemblywoman Nerrie Mayersohn's goals and admiring of her energy on behalf of infants with HIV and AIDS, disagreed with her approach to the extent that it did not provide sufficient guarantees of money for counseling and treatment. This criticism of her bill was widespread. See, e.g., Kevin J. Curran, Note, *Newborn HIV Screening and New York Assembly Bill No. 6747-B: Privacy and Equal Protection of Pregnant Women*, 21 *FORDHAM URB. L.J.* 857, 883-886 (1994).

36. Reply Affirmation of Theresa M. McGovern, *Baby Girl Doe v. Pataki*, No. 10661-95 at para. 2 (N.Y. Sup. Ct. 1995).



of no moment. The defendants-intervenors have no legal basis for objecting to plaintiffs' voluntary discontinuance of this action. . . . The stipulation for voluntary discontinuance was 'so ordered' in view of the little litigation among the parties, coupled with the fact that no substantial rights of the defendants-intervenors accrued at the time of the stipulation, and the absence of any prejudice to the defendants-intervenors.<sup>37</sup>

## II. The Fruit of ABC's Efforts

Following the stipulation, the Department of Health promptly issued the Notice of Proposed Rulemaking.<sup>38</sup> The proposed rule change was simple in language but powerful in potential impact. It proposed an amendment of Section 98.2 of Title 10 of the New York State rules and regulations, to read as follows (the proposed changes are italicized):

(c) Comprehensive health service means all those health services which an enrolled population might require to be maintained in good health, and shall include, but shall not be limited to, physician services . . . inpatient and outpatient hospital services, diagnostic laboratory and therapeutic and diagnostic radiologic services, and emergency preventive health services, *including providing HIV counseling and recommending voluntary HIV testing to pregnant women, which counseling and testing shall be conducted pursuant to Public Health Law Article 27-F, referring HIV positive persons for necessary, clinically appropriate services, and including service required under Article 43 of the Insurance Law. . . .*<sup>39</sup>

The new regulations went into effect, in final form, in April, 1996. Even before then, however, the expected change in the law led to adoption of related rules, all designed both to ensure confidentiality and seek testing so that, where appropriate, prompt, effective treatment for HIV/AIDS could be made available to mothers and their children.<sup>40</sup> As indicated above, the regulations, with their system of voluntary testing following a compelled choice either to

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37. *Id.* at paras. 4-5.

38. Letter from Lucia M. Valente, Chief Special Counsel to the Attorney General, to Margaret Keane, Esq. (Dec. 11, 1995) (informing ABC that the Notice of Proposed Rulemaking had been sent for publication in the State Register).

39. *Id.* (copy of proposed draft regulation on file with the author).

40. *See, e.g.*, Memorandum from Claudette LaMelle, Director, Pediatric AIDS Unit & Hospital Baby Project, Administration for Children's Services, City of New York, to Voluntary Child Care Agencies, Field Office Directors and PAU Liaisons (Apr. 11, 1996) (describing new regulations for treating children in foster care) (on file with the author).

learn the results or not, appears to have been a tremendous success, a fact now celebrated by many of those who long opposed every step we took on this issue.<sup>41</sup> As subsequent events demonstrated, it is, to say the least, regrettable that the HIV Law Project and others refused at an earlier stage seriously to consider the revised informed consent proposals. From every point of view, ABC's proposals represented a compromise that balanced the concerns of all parties to the debate more fairly than did the procedures that replaced them.

To be precise, the regulations failed to last long. In the 1996 legislative session, Assemblywoman Nettie Mayersohn again introduced her so-called "Baby AIDS" bill, and by June 26, 1996, the state legislature passed it and Governor Pataki signed it.<sup>42</sup> Assemblywoman Mayersohn's bill implemented a mandatory testing scheme.<sup>43</sup> By October 16, 1996, the New York State Register published proposed regulations designed to implement the terms of Assemblywoman Mayersohn's bill.<sup>44</sup> It is sadly ironic that many advocacy organizations that once opposed ABC's efforts suddenly found themselves pleading with state health regulators not to implement the mandatory testing regime because "[t]he voluntary testing program has only been in place for six months, and has not been evaluated for its efficiency."<sup>45</sup> The regulations implementing Assemblywoman Mayersohn's bill did, however, go into effect, on

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41. Stipulation, *Baby Girl Doe v. Pataki*, No. 10661-95 (N.Y. Sup. Ct. 1995).

42. Letter from Nettie Mayersohn, Member of Assembly, State of New York to Gretchen Buchenholz, Executive Director, Association to Benefit Children (July 26, 1996) (on file with the author). See also Governor George Pataki, Executive Memorandum relating to Ch. 220, *HIV testing of Newborns—Testing for Antibodies to HIV in Newborns*, 1996 N.Y. Laws 220 (McKinney 1996).

43. N.Y. PUB. HEALTH LAW § 2500-f (McKinney 1997).

44. N.Y. St. Reg., October 16, 1996, at 33.

45. Letter from Cynthia Schneider, HIV Unit Director, & Kristin Bebelaar, Law Graduate, Brooklyn Legal Services Corp. B, to William R. Johnson, Department of Health, Bureau of Management Analysis 3-4 (Nov. 27, 1996) (on file with the author). See also THE STEERING COMMITTEE ON LEGAL ASSISTANCE, *Comment on Maternal Pediatric HIV Prevention and Care Program*, 51 THE RECORD OF THE ASSOCIATION OF THE BAR OF THE CITY OF NEW YORK 826, 828 (Dec. 1996). The comment states:

The Department of Health implemented regulations in May 1996 to encourage women to learn the results of the newborn HIV screening conducted by the State. This program has been in place for only six months and, to our knowledge, the State has not undertaken a comprehensive study to determine the success of this program both in identifying HIV-infected newborns and ensuring that they and their mothers receive appropriate HIV-related medical care.

*Id.*

February 1, 1997.<sup>46</sup> Although legal challenges to this rule are quite possible, it is true—and regrettable—that the “beautiful compromise” of an option that successfully balanced confidentiality rights against public health and HIV/AIDS pediatric treatment needs was not given a chance to succeed, this time because Assemblywoman Mayersohn remained wedded to her insistence on mandatory testing.<sup>47</sup>

### III. Conclusions: What Lessons Does This Controversy Teach?

Even allowing that hindsight provides clarity often unavailable in the heat of a protracted battle over an important social policy issue, it is possible to draw some general conclusions about what this experience teaches. First and foremost, the debate over infant HIV testing indicates the need for advocacy organizations always to seek common ground. As the above history suggests, too much time and effort was expended—not to mention the bad will that was created—either fighting for turf or, even worse, failing to listen to what the different parties were saying. I do not here, I should stress, mean to put ABC up on a pedestal. It certainly might be suggested, for example, that we could have considered the possibility of voluntary testing following a compelled choice either to learn the results or not, far earlier than we did. We could have come to this realization, moreover, from working even harder than we did to try and accommodate the confidentiality and civil liberties concerns of our opponents. At the same time, however, the pediatric HIV testing debate revealed to my mind the intransigence of many not-for-profits in the face of changing information and new treatment methods for the HIV/AIDS epidemic.<sup>48</sup>

To put it simply, the debate starkly revealed how much many HIV/AIDS service organizations continue to live in a culture of

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46. See, e.g., Deborah Sontag, *H.I.V. Testing for Newborns Debated Anew*, N.Y. TIMES, Feb.10, 1997, at A1.

47. It should be added, however, that changes in federal HIV/AIDS law perhaps rendered Assemblywoman Mayersohn's efforts redundant to the extent that they tied federal grant monies to prenatal counseling and testing. See 42 U.S.C.A. § 300ff-34 (West 1996). See also 42 U.S.C.A. §§ 300ff-21, 300ff-35, 300ff-71, and 300ff-73 (West 1996).

48. One important treatment development not addressed in this essay, but one that may in the long term have a significant effect on the proper policy approach to and regulation of this issue, is the administration of zidovudine (AZT) to pregnant mothers as a method of reducing the risk of maternal to infant HIV transmission. See, e.g., Rhoda S. Sperling et al., *Maternal Viral Load, Zidovudine Treatment, and the Risk of Transmission of Human Immunodeficiency Virus Type 1 From Mother to Infant*, 335 NEW ENG. J. MED. 1621 (1996).

fear and suspicion more appropriate in the early years of the epidemic than today. Regrettably, it is my further view that by failing to move beyond the past when such suspicion was more warranted than is now the case, these advocates may, inadvertently, end up encouraging yet further secretiveness and suspicion, indirectly helping to keep public discussion of the realities of HIV and AIDS underground. This is not to minimize valuable and sometimes heroic work by HIV/AIDS advocates. It is merely to suggest that policymaking requires flexibility, and that as treatment changes, so do the social risks for people with HIV and AIDS. This directs, in turn, the need to reconsider views—such as opposition to any form of mandatory testing—that may once have been absolutely appropriate.

