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# Commentary: "Genetic Testing in Children and Adolescents: Parental Authority, the Rights of Children, and the Duties of Geneticists"

CAROL ISAACSON BARASH<sup>†</sup>

## I. Introduction

In taking on this challenging new area, Pelias and Blanton provide a thorough discussion of background questions and undertake the difficult task of interconnecting issues regarding parent-child relations, the interests of government and the privacy of the family, and the relationship of medical provider and health care consumer. The task is unmistakably daunting and I applaud their efforts. Moreover, as neither a trained attorney, nor geneticist, I will not comment on the legal technicalities they present. Rather, my critical remarks are made on the basis of my training and experience as both philosopher and policy analyst.

Recalling the earliest *clinical* opinion on the subject, namely that "no children should ever be tested for the gene that causes Huntington disease,"<sup>1</sup> Pelias and Blanton contend that what this opinion "fails to acknowledge, however, are the interests and obligations of parents, who are charged by society with providing for their children, and who may well justify their quest for learning their children's genotypes even if the gene . . . may not begin to work its damage until years later."<sup>2</sup> By their analysis, they suggest that properly analyzing the complex issues that surround decisions about genetic testing requires a legal framework which defines the limits of parental authori-

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1. This opinion first appeared in the 1992 Physician Guide to Rare Diseases, around the time that the causative gene was discovered.

2. Mary Z. Pelias and Susan H. Blanton, *Genetic Testing in Children and Adolescents: Parental Authority, the Rights of Children, and Duties of Geneticists*, 3 U Chi L Sch Roundtable 525, 528 (1996).

ty, the rights of children, and provides the opportunity to balance potentially competing interests on the part of family members.

Two central themes emerge from their discussion of this legal framework: 1) the rights of parents versus children and adolescents vis à vis genetic testing, and 2) the proper role of professionals who will inevitably encounter intrafamilial conflict when they provide genetic counseling. They contend this framework should be used to formulate and specify the moral/legal duties of clinical geneticists and other professionals who provide genetic counseling in the delivery of genetic services. In other words, Pelias and Blanton attempt to clarify and resolve disputes about duties to provide due care and informed consent by using case law to define the fiduciary relationship between the genetic service provider and the providee.<sup>3</sup> Once the nature of this fiduciary relationship can be generally defined with respect to the unique considerations inherent in clinical genetics,<sup>4</sup> they believe that it can be applied to specific situations and that the "gravity of the disease" tested for is likely to drive the parameters of the decision and the outcome.

The crux of my commentary will be based on the following three issues: 1) the relevance of existing legal opinion to this discussion, 2) the nature of balancing tests intended to weigh competing interests and values or balance conflicting duties and rights, and 3) the principle of autonomy.

## II. The Relevance of Legal Opinion

Pelias and Blanton look to judicial opinion to define the nature and limits of parental authority regarding decisions about their children. They thereby imply that judicial opinion serves as the proper basis for legitimating parental authority with regards to decisions about the genetic testing of their children. Moreover, they argue that the nature and extent of autonomy conferred to children in such decisions ought to be defined by legal opinion as well, though their discussion is less focused on constitutional or statutory support for children's rights and on case law regarding parent-child disputes in a medical context.<sup>5</sup>

First, what exactly is the value of framing the discussion as such? Undoubtedly, the legal system is crucial in enabling rights and protecting against abuses, and represents an authoritative mechanism for dispute resolution. However, the contribution of legal opinion is typically to define the outside limits of dispute, and not to provide a basis for resolving the nitty gritty

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3. Pelias and Blanton, 3 U Chi L Sch Roundtable at 526-27, 537 (cited in note 2).

4. This is a new relationship. The patient is no longer an individual; instead, the patient is the family unit.

5. See, generally, Comment, *Finding Their Own "Place to Be": What Gregory Kingsley and Kimberly Mays' "Divorces" From Their Parents Have Done for Children's Rights*, 39 Loyola L Rev 837 (1994); Barbara Bennett Woodhouse, *Out of Children's Needs, Children's Rights: The Child's Voice in Defining the Family*, 8 BYU J Pub L 321 (1994).

conflicts embedded in specific cases, such as familial interests regarding a particular genetic test. Moreover, as Ellen Wright Clayton argues, parents do not have a constitutionally protected right to demand that unwilling physicians perform these tests, nor is there risk of tort liability as a result of a physician's refusal to do so.<sup>6</sup> Thus, the relevance and impact of the law with respect to debate about the genetic testing of children is limited.

Secondly, does the case law presented set out relevant boundary issues? Is the chosen law representative of commonly confronted issues? Were the decisions good ones? Indeed, constitutional authorities may well object that the case law selected for discussion here is based on decisions which are subject to substantial criticism. For example, Justice Douglas chastised the *Yoder*<sup>7</sup> majority for failing to elicit the children's preferences, arguing that even if the children now preferred an Amish education, they may later prefer to compete in the larger American society and in so doing discover themselves inadequately educated to fulfill their desire.<sup>8</sup>

Independent of these concerns, are questions raised by the legal analysis presented. Two independent types of authority disputes are presented. On the one hand, there are disputes between parental authority and the State regarding the proper education of children, and on the other are questions of parental prerogative versus the State's interest in the welfare of the child. In the first type of authority dispute, two State interests are at stake: 1) an interest in the welfare of the child, and 2) an interest in a well-educated citizenry for the purpose of serving a democracy. These interests are in dispute with the parental desire to control their children's education. The *Yoder* case is arguably not the best representative of this issue since the applicable standards were First Amendment issues regarding religious freedoms, and the court is typically reluctant to decide against First Amendment principles. The second line of reasoning discusses the point at which the State can intervene on behalf of the child and in derogation of parental authority and mandate medical care or removal from the parents.

In other words, judicial opinions lay out two different legal boundaries regarding the rights of parents. How the authors choose among these opinions and how they apply to questions of genetic testing requires additional explanation. Moreover, how the two lines of reasoning interface, or what common position they embody, requires further clarification and explanation. To what extent are these two lines of case law applicable to the question of whether the government can require genetic testing? If not to raise this question, then what is the relevance of these disparate lines of reasoning? Or, to put it

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6. Ellen Wright Clayton, *Removing the Shadow of the Law from the Debate About Genetic Testing of Children*, 57 Am J Med Gen 630, 631 (1995).

7. *Wisconsin v Yoder*, 406 US 205, 242-46 (1972) (Douglas dissenting).

8. See also Wendy Anton Fitzgerald, *Maturity, Difference, and Mystery: Children's Perspective and the Law*, 36 Ariz L Rev 11, 31-33 (1994). This article advocates the legal recognition of, and respect for, children's perspectives in those legal disputes most profoundly affecting their lives.

differently, what is the purpose of protecting the child against the State interest in genetic testing, if no threat has been identified to the child?

The case law cited suggests that the State may have a right to mandate genetic testing of children. Clearly, it may and surely has exercised that right in so far as newborn screening is mandated in every state—though the specific tests vary state by state. Moreover, in the early to mid-70's a majority of states mandated sickle cell disease and trait screening as a precondition of admission to public school. For various social policy reasons, screening for trait has been discontinued.

The speed with which tests are becoming commercially available raises further questions about the potential State interest in the genetic testing of children. As recently as 1993, for example, researchers in Colorado and Georgia conducted genetic tests on children in special education classes in selected public schools.<sup>9</sup> The genetic screening programs were designed to identify children affected by Fragile X Syndrome—an inherited form of mental retardation. In Colorado, researchers justified the screening program on economic grounds, citing recent reports that Colorado spends \$1,609,852.63 over the lifetime of a person with Fragile X Syndrome, over and above the expenses it incurs for a “normal” person.<sup>10</sup> They extrapolate these estimated costs to a “current burden” of caring for people with Fragile X Syndrome of nearly \$4 billion in expenses for Colorado, and \$280 billion for the nation.<sup>11</sup> These researchers argue that large scale screening programs, coupled with reproductive counseling, could reduce this “economic burden” by one half.<sup>12</sup> While State interference with individual rights is generally discouraged because it is inconsistent with present norms about the role of government, shameful decisions in legal history, such as forced sterilization laws, evince otherwise.

Yet, the cases cited involve parent-state disputes regarding the education of children. Are these opinions instructive to the genetic testing issues? Clearly, state and federal laws governing education exist due to the state's interest in rearing individuals who can give back to society. And clearly, those laws permit parents to decide the venue of education, providing those venues are in compliance with such laws. In other words, parents, over the objections of their children, have the liberty to send their children to private or parochial schools, or to home-school them. However, case law not discussed by the authors shows that the state intervenes on behalf of the best interests of children when the state believes parental judgment is misguided. In the early 80's, for example, under the Reagan administration, parents were afforded the

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9. Robert Cooke, *Fragile X Genetic Screenings Raise New Hopes of Treatment, and Whole New Set of Problems*, *Newsday* 7 (May 30, 1993). See also Diane Loupe, *Fragile X Testing Debated*, *Atlanta J and Const E1* (Oct 9, 1993).

10. David P. Lauria, et al, *The Economic Impact of the Fragile X Syndrome on the State of Colorado*, 1992 International Fragile X Conference Proceedings, 393-405.

11. Paul Billings and Ruth Hubbard, *Fragile X Testing: Who Benefits?*, *Gene Watch* 1, 2 (Jan 1994).

12. *Id.*

opportunity to make decisions about terminating the life support for their children.<sup>13</sup> States have intervened on behalf of the children's best interest when they've decided that parental prerogative issuing the withdrawal of support was not in the child's best interest.<sup>14</sup> Similar State interventions have existed in emergency medical treatment cases when the state has intervened, even prosecuted, parents for negligence when refusing to give medically necessary treatment to the children.<sup>15</sup> Societal support of the parental prerogative within the privacy of the family, then, is neither universal nor absolute. Unless to show that the State may have an interest in the genetic test result of a child, the relevance of this law is unclear.

Pelias and Blanton attempt to show that the courts traditionally and consistently "vest[] decisional responsibility in the parents," as opposed to the child.<sup>16</sup> These opinions seem relevant only if we want to deny the legal personhood of children in expressing their interests in matters that profoundly affect their lives. Although the courts have issued conflicting opinions on this matter, the *Kingsley* and *Mays* cases<sup>17</sup> permitted children—as children, not as potential adults—to terminate the rights of their parents over them. These courts have accorded children the legal standing to exert their interests against those of their parents. Still, such is the exception rather than the rule. Indeed, children's interests in matters profoundly affecting their lives, as Martha Minow writes, often remain obscured behind a veil of family "privacy."<sup>18</sup>

The nature and extent of parental authority in the situation of genetic testing is apparently unambiguous. In claiming that "parents may have well-founded reasons for knowing the genotypes of their own children,"<sup>19</sup> Pelias and Blanton fail to consider the possibility of adverse consequences to the child subsequent to a genetic test result. While law and social policy, for the most part, operate from the presumption that parents act in the best interests of their children, this presumption may be profoundly challenged in the context of genetic testing. Not only may the value to the child of predictive information, especially when information gleaned from a test will not alter medical management, be negligible or even potentially contrary to the child's best interest, but more importantly, the performing of such tests on children forecloses their freedom to make such choices for themselves as adults. Thus, enforcing parental prerogative may violate a child's constitutional right.

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13. *In re L.H.R.*, 253 Ga 439, 321 SE2d 716 (1984). See also *In re Barry*, 445 So2d 365 (Fla App 1984).

14. See *In re C.A.*, 236 Ill App 3d 594, 603 NE2d 1171 (1992).

15. See *In the Matter of McCauley*, 409 Mass 134, 565 NE2d 411 (1991).

16. Pelias and Blanton, 3 U Chi L Sch Roundtable at 531 (cited in note 2) (quoting *Bowen v American Hosp Ass'n*, 476 US 610, 627 (1986)).

17. *Kingsley v Kingsley*, 623 So2d 780 (Fla App 1993); *Mays v Twigg*, 543 So2d 241 (Fla App 1989).

18. Martha Minow, *Rights for the Next Generation: A Feminist Approach to Children's Rights*, 9 Harv Women's L J 1, 7 (1986).

19. Pelias and Blanton, 3 U Chi L Sch Roundtable at 532 (cited in note 2).

Moreover, situational factors, such as consideration of adoption may impose further limitations on a child's freedom, when, for example, adoption agencies require genetic test results of "at risk children" prior to placement.<sup>20</sup>

As noted by the authors, the potential for societal and intrafamilial genetic discrimination looms as a great burden to both society at large as well as individuals within their families. Indeed, one direct result of the expanded use of genetic tests is that an increasing number of individuals who never before considered themselves disabled are discovering that their genetic endowment—both known and perceived—may serve as a basis for exclusion from societal opportunities or entitlements. The potential for discrimination on the basis of identified genetic status proved to be a primary deterrent to undergoing testing for many respondents in a recent Department of Energy Study of genetic discrimination.<sup>21</sup> This study's results indicated that individuals have experienced discrimination in a range of contexts broad enough to suggest the possibility that anyone at any point in his or her life could incur discrimination on the basis of his or her known or presumed genetic status.<sup>22</sup> While Pelias and Blanton are correct that parents generally need and want to fulfill their interests in providing "financial, medical and environmental benefits," social policy considerations, such as the societal implication of each family making decisions based solely on the family's best interest, are given only minimal weight in the decision-making process.

### III. Pitting Parental Prerogative Against the Rights of the Child: Testing the Balancing Test

Thematic throughout Pelias and Blanton's discussion is that deciding whether children will undergo a genetic test involves at least potential for conflict between parent and child. A legally and ethically defensible decision, they argue, requires balancing parental authority against the rights of a child, as they are likely to be in conflict.<sup>23</sup> In discussing the legal history of parent-child relations, the authors are correct to point to recent expansions of children's rights. This is particularly true as in the right of children to terminate their parents' rights over them, (Kingsley, and Mays cases), the right to sue parents for wrongful life, and the consistent unwillingness on behalf of the courts to allow tort claims against parents. Pelias and Blanton state that recent court decisions affirm that children *should* participate in medical treatment decisions which involve them.<sup>24</sup> The extent to which children are able to participate in testing decisions, they claim, depends on their "level of under-

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20. Carol Isaacson Barash, *Genetic Discrimination as a Human Rights Issue*, submitted.

21. Lisa N. Geller, et al, *Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis*, 2 *Science and Engineering Ethics* 71, 79 (1996).

22. *Id.* at 75-79. See also Suzanne E. Stipe, *Genetic Testing Battle Pits Insurers Against Consumers*, *Best's Rev Life-Health Ins Ed* 38 (Aug 1996).

23. Pelias and Blanton, 3 *U Chi L Sch Roundtable* at 535 (cited in note 2).

24. *Id.*

standing and their general maturity," and implicitly all the requisite conditions of informed consent or informed refusal.<sup>25</sup> Yet, the law bestows entitlements and obligations not on the basis of level of maturity but on criteria which may be deemed more arbitrary than empirically or logically justified. The definition of "child," "minor," "emancipated youth," varies state by state, and is generally conditional on the presence of specific circumstances which are independent of age, level of maturity or ability to comprehend. In Massachusetts, for example, a child (or minor) can give consent to emergency medical treatment if that child is married, widowed, divorced, pregnant, or believed to be pregnant, a member of the military, living separately from their legal guardian, or suffering from venereal disease.<sup>26</sup> Indeed, if we are to use a legal framework for balancing/resolving disputed interests, the level of maturity and ability to comprehend are not defined nor measured by legal criteria.

Secondly, if we are to use a legal framework to balance competing interests, there is obviously no law on the subject of genetic testing and children at the state level, making it difficult to balance a known legal framework for parental prerogative against an unknown legal framework for a child's perceived best interests. Clearly, we cannot wait around for complex legal cases that force decisions upon us as to whether children are entitled to legal personhood as children, and not merely as potential adults. Nonetheless, if one agrees with the authors that the appropriate framework for raising and resolving these disputes is legal, then one needs to know what, in the absence of state law on the genetic testing of children, do we balance against what?

Furthermore, what does it mean to espouse a balancing of interests without identifying the specific interests or types of interests to be weighed, without criteria for identifying those interests to be weighed, without guidance for weighing competing interests, and without procedures for handling disfavored outcomes, such as procedures for an appeal process if the balancing test fails to resolve a disagreement? In other words, what is meant by saying that resolution is the balancing of interests?

A duty of the geneticists, Pelias and Blanton claim, is at least to attempt to facilitate familial consensus regarding genetic testing decisions.<sup>27</sup> However, this requires the geneticists to perform two potentially conflicting roles: 1) as the person who imparts information requisite to informed consent, and 2) as the person who arbitrates in the case of conflicting desires (on the part of parents versus their children). On the one hand, the family is the final authority regarding the decision, deciding whether or not the child will undergo testing, on the basis of neutral information and non-directive counseling.<sup>28</sup> On the other hand, the geneticist will advise depending on the "gravity of" the disease, and as to whether testing is indicated.<sup>29</sup> The latter implies that geneti-

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25. *Id.*

26. Mass Ann Laws ch 112, §12F (Michie 1996).

27. Pelias and Blanton, 3 U Chi L Sch Roundtable at 536 (cited in note 2).

28. *Id.* at 535.

29. *Id.* at 535-36.



cists will make claims that are not neutral. For example, they may advise against testing for sex selection. Yet, in every state but Pennsylvania, sex selection is permitted (Pennsylvania prohibited it in 1993).

While it is legal, moral, and even desirable for physicians to make decisions for their patients, as in deciding which antibiotic to prescribe, it is less ethically defensible or desirable for them to decide among various alternative treatment regimens for their patients. Instead, present norms define the proper role of the physician as to inform patients about their treatment options and the relative risks and benefits associated with each in order to enable autonomous patient decision-making. In the context of genetic testing, the role of the health care provider is complicated by the fact that the patient is a multi-party entity, not just a single individual, as Pelias and Blanton state.<sup>30</sup> Because families seeking consultation about the possibility of undergoing genetic testing will seek advice from genetics professionals (clinical geneticists and genetics counselors), Pelias and Blanton imply that these professionals ought to be the arbiters of conflict. In other words, they claim that the physician's duty is not merely to the child, though in pediatric cases he or she is legally bound to care for the child, because the entire family is the patient. Clearly, physicians who care for children know that, on occasion, parents will seek a physician to perform intervention which that physician deems clinically or therapeutically contraindicated. A physician's broad duty to care, then, does not entail a requirement that the physician perform a service upon patient demand.

Yet, how the Hippocratic oath or provider obligations apply to multiple parties is arguably more complicated than as Pelias and Blanton suggest. In real world conflicts, how does the provider do x for the patient (family and child) which is right for one but wrong for the other? In the absence of criteria and guidelines, how are these obligations fulfilled in ethically responsible and defensible ways? For example, how can the geneticists fulfill his duty to the "patient" in a situation involving testing for Huntington disease and identical twins, one of whom wants to be tested while the other does not?

Pelias and Blanton go on to add that the content and process of counseling ought to be aware of "the possible legal consequences associated with the birth of children who have predictable inherited disorders."<sup>31</sup> Again, what are the "legal consequences" and why ought we presume that geneticists not trained in the law are able to provide such counseling? Moreover, a whole host of other potential, non-legal adversities goes unmentioned. While some savvy clinicians are beginning to inform their patients about the possibility of insurance cancellation, exclusion, or higher rates as a result of insurer access to the result of a genetic test, and in rare cases even willingly to store genetic test information separately in a medical chart, the vast majority are largely uninformed about or unwilling to discuss the range of possible resulting social adversity.<sup>32</sup> In so doing they restrict decision factors to potential *medical*

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30. *Id.* at 536.

31. *Id.* at 537.

32. Providers are not mandated to do so by statute, regulation or even professional

benefits and harms.

The article presumes that if geneticists impart what they know, responsible and ethically satisfying decision-making will follow. However, in the real clinical world, it is not clear or certain that providers of genetic services have all the relevant knowledge and information, that they are able to impart it fully and effectively, and that, even if they are skilled in doing so, consumers will make decisions based on satisfying the requirements of informed consent and ones that are ethically (and legally) sound. In addition, the claim that geneticists are competent decision-makers implies that they can mediate conflicts within a family and resolve medical ethical disputes. Yet, they are typically not trained to do so, and in the absence of outside oversight, unskilled professionals may not be able to mediate such conflicts despite their good intentions.

Pelias and Blanton sketch ideal parameters for ethically and legally defensible decision-making, but, unfortunately, the real world criterion needs a fuller discussion. In reality, balancing conflicting stakes requires not only identifying conflicting interests, but deciding which interests to balance against which others, and most importantly how the relative interests ought to be weighed against each other—namely, what weight will each interest be given in the balancing, and what justifies the chosen method.

In this regard, the following may well factor into the decision-making process. For example, issues such as whether failure to provide the test constitutes neglect (or even child abuse), or whether the parent is neglecting to provide critical care if she opts against testing, and the implications of “yes” answers to these questions. For example, under mandatory reporting law, geneticists might be required to report such an instance to the proper social service agencies. Interested parties may want to know what the threshold of physician negligence is for not pursuing the parent’s wishes? Is the physician threshold of risk of negligence the same as the threshold of parental obligation?

Unfortunately, the cases chosen to illustrate conflict resolution reasoning involve the simpler, and rarer, genetic conditions. Yet even these are more complicated than presented. The reality of late onset Tay Sachs and its frequency among French Canadians make such a decision less straightforward than presumed in the illustration. Given the claim that the “gravity of the disease” factors into the resolution process, one wonders whether the more frequent polygenetic and multifactorial conditions are amenable to the same simplified decision-making process, as where the “gravity of disease” is both relatively easily determined by some (though not without a set of objections from the disability rights community)? Or are these more frequent and difficult to predict conditions far more contentious to the point of requiring considerations beyond the physician-patient relationship? I suspect so.

In addition, as alluded to previously, a panoply of other issues factor into the testing decision process, such as the reliability, sensitivity and specificity of a particular test. The speed with which tests are becoming commercially available raises for many troubling questions about whether these products are entering the marketplace before being thoroughly field tested, thus implying, at a minimum, that adequate assurances of safety, efficacy and reliability are seriously lacking. In addition, both consumer and professional ignorance about the limited predictability of particular tests emphasize the need for real world considerations.

For example, if the chances for a false positive test result were high, would the provider of the test and disseminator of the test result be liable for false diagnosis due to negligence? And would plaintiffs reasonably expect to be compensated for emotional suffering in addition to entitlement losses, and other types of exclusions? Considerations, such as these, may be significant factors in a decision.

#### IV. The Weightiness of the Principle of Autonomy

Ethical principle and legal doctrine upholding respect for the autonomy of an individual person is well-established in this country, though not without occasions of conflict. Two points are worth considering: 1) the meaning and value of the autonomy of the geneticist-expert in such matters, and 2) whether family law, which tends to assure that children's interests do not fetter parental prerogative nor burden the public's fiscal interest, requires amendment to afford children the legal personhood requisite to enabling them to participate fully in genetic testing decisions which are likely to have profound implications for their lives.

In regard to the first point, it is arguably a mistake to believe that, in real world decisions, the only constraint on a geneticist's duty is that of professional standards of care. Given the rapid and expected continued growth of managed care institutions, for example, a duty to the patient may not be the only significant driving force in the decision. With salary bonuses contingent upon overall cost saving utilization patterns, or other incentives provided by the marketers of tests, the potential for conflict of interest would seem great. So, in the absence of enforceable guidelines or regulation governing the appropriate introduction of testing, is the autonomy of the geneticist the best venue for resolving intrafamilial conflict?

Moreover, identifying an individual's wishes has been difficult in cases of "incompetency" (such as newborns, third-trimester prenatal "babies," or incompetence due to mental or physical illness). In cases where formerly competent individuals are no longer competent, the identification and implementation of wishes has been difficult despite the existence of advanced directives or living wills. Given this history, expert ability to identify independently and resolve competing interests would seem less than fail safe. In the absence of state law or policy is "unbridled authority of geneticists" in matters of dispute desirable?

Secondly, the expansion of children's rights which began in the early 70s arguably arose directly out of social circumstances deemed likely to result in adversity to a child, and the fact that alternative mechanisms for protecting children had failed or proven likely to fail. The ever expanding availability of new genetic tests creates a new venue for child welfare and social justice issues. In so doing, the adequacy of existing law to provide a satisfactory forum for structuring moral and legal conflicts regarding the genetic testing of children may not protect the interests of children from abuses instigated by parents or the State. Affording parents an interim ownership of their child's genetic information (until the child reaches adulthood), in the name of the child's best interest, may well provide the basis for a legal dispute for which children have no means of recourse.

### V. Conclusion

In light of: 1) the numerous social policy considerations which reasonably factor into such decisions to the exclusion of legal precedence, 2) well-established difficulties of parents, physicians, guardians, and the courts of ascertaining the wishes of persons deemed not fully competent (including minors depending on circumstances), and 3) the inherent difficulty in identifying and balancing competing interests, the preference for physician-patient relationship as the best mechanism for promoting ethical decision making seems to me a bit overstated and under-justified. The potential for calamity would seem great. Hospital ethics committees originated out of the inherent difficulties in such arrangements.

As an alternative, I suggest the consideration of a genetics-ethics committee—not unlike hospital ethics committees—as possibly the best forum in which to hold such real discussions and under which to achieve resolution. Difficult cases could be brought to the committee for resolution or consensus, as well as to establish national standards for future cases. We may then be far more likely to achieve a reasonable and healthy consensus through such an objective, well-balanced, and organized reasoning process, than through either a rigid lawmaking process, or the guidance of individual experts who may be knowledgeable about the underlying technical issue, but not specifically trained in either intrafamilial dispute resolution or medical ethics, and who may also be bound by other political or outside interests.

