

# GENETIC HEALTH AND EUGENICS PRECEDENTS: A VOICE OF CAUTION

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## I. INTRODUCTION

Genetic health is a confusing but increasingly important cultural construct. A little over a decade ago, I delineated the difference between a social or relational definition of health, which is embedded in any given society’s basic beliefs about the nature of illness and death, and a biological conception of health and illness as the absence of disease.<sup>1</sup> The growing prevalence of genetic explanations for disease means our contemporary concept of biological health includes the idea of an individual’s *risk* of disease or even death. A genetic definition of health thus incorporates the idea of the absence of the *risk* of illness processes, not necessarily in ourselves, but in those to whom we are genetically related. The goal of “genetic medicine”—if we start to use that term—would be to reduce or eliminate the genetic risks to health.<sup>2</sup> Ironically, genetic health is the ultimate notion of a relational concept of health because the risk of disease or ill health is not individual, but social. Thus, the concept of genetic health—or in its negative form, “genetic disease or defect”—always involves a social unit: the family, a couple contemplating having children, an individual planning single parenthood, or an ethnic or geographically de-

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1. See LARRY PALMER, LAW, MEDICINE AND SOCIAL JUSTICE 10-11 (1989).

2. At present, “gene therapy” only reduces risk rather than provides a “cure” in the traditional sense of medicine’s goals. Gene therapy interventions are fairly labeled “experimental.” Cf. Daniel S. Greenberg, *Stricter Regulation Proposed for U.S. Gene-Therapy Trials*, LANCET, June 3, 2000, at 1977 (describing initial heightened regulatory response to death of 18-year-old Jesse Gelsinger during gene therapy research trial at University of Pennsylvania).

fined group. Let me illustrate this point with a bit of personal history.

### A. A Narrative

When my youngest son, Reid, was *in utero* in 1982, his mother's physician informed us that the routine blood tests he had ordered indicated an antibody reaction that was troublesome. After consulting with several specialists, we had a diagnosis—a genetic incompatibility between Reid's blood and his mother's blood that created risks of stillbirth or elevated bilirubin<sup>3</sup> at birth. After he was born he became jaundiced and blood tests indicated high levels of bilirubin with risks of mental retardation, physical impairments, or death.<sup>4</sup> After a complete blood transfusion and ten days in the special care nursery, he was able to come home.

Reid's condition at birth—"little C/big C incompatibility on the RH factor"—is extremely rare. Even twenty years ago, health care practitioners knew that the more familiar RH factor was really a matter of three different genes.<sup>5</sup> The hemoglobin shot usually given to mothers with the RH factor did not deal with the C gene problem.<sup>6</sup> Reid's pediatrician advised us that bilirubin problems tended to get worse with each subsequent pregnancy. He hypothesized that the mild jaundice we saw in our first child, Barry, might have been caused by the same incompatibility. Since Reid was our third child, he advised us to consider the consequences of having more children.

Fortunately, there were no disability issues to confront with Reid due to the genetic mismatch between his mother and myself. Reid is a healthy 20-year-old college junior. At some point I will have to talk to Reid and his two older brothers about the genetic risks that they *may* have inherited from their biological parents. At the very least, they and any prospective mates are entitled to know what I discovered in 1982, and any new knowledge that might be available in the

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3. "[A] reddish bile pigment . . . resulting from the degradation of heme . . . in the liver: a high level in the blood produces the yellow skin symptomatic of jaundice." RANDOM HOUSE WEBSTER'S UNABRIDGED DICTIONARY 207 (2d ed. 1999).

4. Kernicterus is the medical term for the condition when the breakdown of red blood cells caused by the concentration of bilirubin occurs in newborns. See "For Prevention and Promise," Parents of Infants and Children with Kernicterus, *available at* <http://www.bilirubin.net> (last visited Aug. 25, 2002) (on file with author); see also K. Carter, *Kernicterus in Full-Term Infants—United States, 1994-1998*, in 50 MORBIDITY & MORTALITY WEEKLY REPORTS 491-94 (2001), *available at* <http://www.cdc.gov/mmwr/PDF/wk/mm5023.pdf> (last visited Aug. 8, 2002) (on file with author).

5. For a description of the disease caused by blood incompatibility problems between mother and infant, see Jayashree Ramasethu & Naomi L.C. Luban, *Alloimmune Hemolytic Disease of the Newborn*, in WILLIAMS HEMATOLOGY 665-75 (Ernest Beutler et al. eds., 6th ed. 2001).

6. *Id.*

Human Genome Era<sup>7</sup> about the risks of stillbirth, disability, or death in their progeny. I live with the implications of notions of “genetic health” for me and my three sons. As genetic knowledge grows, the number of families coping with genetic risks and emerging notions of genetic health will increase.<sup>8</sup> To put the point another way, genetic health makes us think of illness, disease, and death in terms of reproductive partners, who our parents were, and our memberships in various ethnic, social, or even geographical groups.<sup>9</sup>

### B. *The Genetic Health of the Society: Eugenics*

The ethical and legal risks of using a concept of genetic health in social decisions is captured by the term “eugenics,” the idea that certain individuals are genetically too risky for the society to tolerate. Eugenics has bad—even “evil”—social connotations. No respectable scientist today would endorse eugenics. The mainstream mantra of the Human Genome Era, however, is that there is really only one “race” of any biological significance, the “human race.”<sup>10</sup> Although the study of ethical, social, and legal aspects of genetic advancement was made a part of the Human Genome Project<sup>11</sup>—scientists seem to be saying, “Let us get on with the job of helping health care professionals develop new ways of managing disease processes. Health care professionals can be trusted to implement these new genetic treatment modalities in accordance with prevailing legal doctrines and ethical standards respecting individual autonomy.” Our culture, however, has a long history of eugenic practices and genocides that were not recognized by cultural, social, and legal institutions as such until long after the practices have taken place.<sup>12</sup>

To take the most infamous of these practices, the Nazi experiments on concentration camp inmates were not the work of a few

7. Defined as “[a] period in which biomedical research will be dominated by the assumption that genetic knowledge will improve health care delivery and presumably overall health status—not only in this country, but throughout the world.” Larry I. Palmer, *Disease Management and Liability in the Human Genome Era*, 47 VILL. L. REV. 1, 2 (2002).

8. The interest in the incompatibility on the C gene in the RH factor as it relates to different groups is apparently growing. See Sabeena Setia et al., *Neonatal Jaundice in Asian, White, and Mixed-Race Infants*, 156 ARCHIVES PEDIATRICS & ADOLESCENT MED. 276, 276-79 (2002); Martine G.H.M. Tax et al., *RHC and RHc Genotyping in Different Ethnic Groups*, 42 TRANSFUSION 634, 641-43 (2002).

9. See generally Mark A. Rothstein & Phyllis Griffin Epps, *Ethical and Legal Implications of Pharmacogenomics*, 2 NATURE REV. GENETICS 228-31 (2001).

10. See Dr. Francis Collins, Remarks at the White House Press Conference upon the completion of the Human Genome Project (June 26, 2000), at [http://www.ostp.gov/html/00628\\_2.html](http://www.ostp.gov/html/00628_2.html) (last visited Jul. 24, 2002) (on file with author).

11. See National Human Genome Research Institute, Policy & Ethics: Critical Issues and Legislation Surrounding Genetic Research, <http://www.genome.gov/PolicyEthics/> (last visited Aug. 12, 2002) (on file with author).

12. See JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* 13-15, 16-29, 241 (1993).

physicians and scientists gone awry. Social, historical, and legal contexts certainly played a role in the ability of the scientists to carry out their atrocities, as recent—albeit controversial—scholarship on the Holocaust demonstrates.<sup>13</sup> But the cultural antecedents of the Nazi Doctors have their roots in our collective experience of Doctor Frankenstein as an icon of evil rather than simply a nineteenth century novel by an 18-year old woman.<sup>14</sup> But as Daniel Kevles, a historian of science, and Paul Lombardo, a bioethicist and lawyer, have pointed out to legal and non-legal audiences, respected scientists in this country, not just scientists in Nazi Germany, endorsed governmental policies to eliminate certain groups of individuals on the hypothesis that they were “genetically” and socially too risky.<sup>15</sup>

Justice Holmes—a powerful intellectual influence on legal realists<sup>16</sup>—gave constitutional blessings to some of these governmental policies in his famous, but scientifically inaccurate, retort in *Buck v. Bell*: “Three generations of imbeciles are enough.”<sup>17</sup> *Buck v. Bell* is cited primarily to question its standing as “good law” by legal scholars,<sup>18</sup> but our awareness of social misdeeds in the name of the genetic and biological social defense, or the pursuit of scientific knowledge,

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13. See DANIEL JONAH GOLDHAGEN, *HITLER'S WILLING EXECUTIONERS: ORDINARY GERMANS AND THE HOLOCAUST* (1996). Although I found Assistant Professor Goldhagen's book illuminating, his fellow historians of the Holocaust have not been as kind to him. There have been over fifty reviews of his book in scholarly and popular journals, some of them highly critical of Professor Goldhagen's thesis and his scholarship. See, e.g., Christopher Hitchens, *Minority Report: History for Fools*, NATION, June 9, 1997, at 8, 8; David Schoenbaum, *Ordinary People?*, NAT'L REV., July 1, 1996, at 54, 54; Fritz Stern, *The Goldhagen Controversy: One Nation, One People, One Theory?*, FOREIGN AFF., Nov.-Dec. 1996, at 134. There has even been a book published about the controversy over Goldhagen's book. NORMAN G. FINKELSTEIN & RUTH BETTINA BIRN, *A NATION ON TRIAL: THE GOLDHAGEN THESIS AND HISTORICAL TRUTH* (1998).

14. Note the continued interest in Frankenstein, which remains a literary classic and required reading in many college classes. MARY SHELLEY, *FRANKENSTEIN* (J. Paul Hunter ed., Norton Critical ed. 1996). The American Library Association and the National Library of Medicine will support an eighty-two library exhibition of the classic work beginning in the fall of 2002. See <http://www.ala.org/publicprograms/frankenstein> (last visited Oct. 17, 2002) (on file with author).

15. See DANIEL J. KEVLES, *IN THE NAME OF EUGENICS: GENETICS AND THE USE OF HUMAN HEREDITY* 96-112 (1985); Paul A. Lombardo, *Medicine, Eugenics, and the Supreme Court: From Coercive Sterilization to Reproductive Freedom*, 13 J. CONTEMP. HEALTH L. & POL'Y 1, 6 (1996); Paul A. Lombardo, *The American Breed: Nazi Eugenics and Origins of the Pioneer Fund*, 65 ALB. L. REV. 743, 745 (2002) (citing the recent best seller, RICHARD HERNSTEIN, *THE BELL CURVE* (1994), as an example of the continuing presence of eugenic thought in our society); Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30, 33 (1985) (investigating the background of the infamous case).

16. See William N. Eskridge, Jr., *The Decline and Fall of Formalism*, in *CASES AND MATERIALS ON LEGISLATION: STATUTES AND THE CREATION OF PUBLIC POLICY* 560, 562 (2001).

17. 274 U.S. 200, 207 (1927).

18. See, e.g., Roberta M. Berry, Note, *From Involuntary Sterilization to Genetic Enhancement: The Unsettled Legacy of Buck v. Bell*, 12 NOTRE DAME J.L. ETHICS & PUB. POL'Y 401, 423 (1998).

encourages legal actors to establish certain events as “precedents” that law should prevent from recurring. Thus, “eugenic precedents” are cases that legal decision makers should avoid. The Nazi Doctors Case and the Tuskegee Syphilis Experiment on the Negro Male are often cited in the bioethics literature as prototypical cases of eugenic precedents that should be used as the backdrop for judicial decision-making.<sup>19</sup>

### C. A Recent Case: A Voice of Caution

The highly celebrated case of *Grimes v. Kennedy Krieger Institute, Inc.*,<sup>20</sup> indicates that bioethics scholarship is starting to influence courts. The judges in this case used the Nuremberg Judgment in the Nazi Doctors Case (the origins of the Nuremberg Code) and the Tuskegee Syphilis Experiment to support their holding that a biomedical research institution, internationally known for its research and care of children with a variety of disabilities,<sup>21</sup> could be held liable for flawed informed consent processes in a lead abatement study involving children.<sup>22</sup> There is thus a growing confidence on the part of bioethicists that vigorous enforcement of informed consent by judges, supposedly established in these eugenic precedents, will help us achieve the appropriate risk-benefit ratio as genetic health<sup>23</sup> is used as a guideline for disease management and research.

Although I agree with the Court’s result in *Grimes*, I seek to provide a voice of caution against embracing the *Grimes* court’s approach during our Human Genome Era. That voice of caution comes partially from my understanding of how the institutional arrangements of a given society can influence ordinary people—those who reflect the society’s basic and almost unspoken premises about the nature of evil—to react or fail to react to the genocides of their time.<sup>24</sup> We should recall, for instance, that many “ordinary people” knew

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19. See George J. Annas, *Mengele’s Birthmark: The Nuremberg Code in the United States Courts*, 7 J. CONTEMP. HEALTH L. & POL’Y 17, 19-22 (1991).

20. 782 A.2d 807 (Md. 2001).

21. The Kennedy Krieger Institute’s (KKI) stated goal is the training of practicing professionals and the discovery of new treatments and prevention of developmental disabilities in children. It was originally founded to treat cerebral palsy as the Children’s Rehabilitation Center in 1937. KKI has expanded to assist parents and legal guardians who care for children with disabilities and to conduct research on various disabilities as well as maintaining a seventy-bed pediatric hospital. KKI enlists professors of Johns Hopkins University from a variety of fields including medicine (mainly the field of pediatric neurology), psychology, education, physical and occupational therapy, audiology, speech and language therapy, as well as social work, child development, nutrition, and nursing. See The Kennedy Krieger Institute: A Comprehensive Resource for Children with Disabilities, <http://www.kennedykrieger.org> (last visited Aug. 25, 2002) (on file with author).

22. See *Grimes*, 782 A.2d at 813.

23. See GEORGE J. ANNAS ET AL., INFORMED CONSENT TO HUMAN EXPERIMENTATION: THE SUBJECT’S DILEMMA 49 (1977); Annas, *supra* note 19, at 24-25.

24. See GOLDHAGEN, *supra* note 13, at 375-79.

about the Tuskegee Syphilis Study, but did nothing until 1972. My caution also comes from my view of the limits of law in imposing a certain ethical vision on the institutions of science and medicine.<sup>25</sup>

These so-called eugenic precedents do, however, contain important institutional lessons—but not precedents in a technical sense—or helpful guidelines for the type of decisions institutions and individuals must face in the Human Genome Era. Genetic knowledge and its use and misuse are not likely to arise as they did in the clearly horrific examples of the past. More likely, use and abuse issues will arise in the increasingly common situations in which individuals encounter scientists and healthcare professionals on the fuzzy boundary between the search for new knowledge and traditional notions of disease management as a mere *cure* for disease. I use the term disease management, however, to describe the range of activities that modern health care professionals perform: research, treatment of diseases, management of chronic illnesses or conditions, and even palliative care for terminally ill patients.<sup>26</sup>

The eugenic precedents provide guidance for ethical reasoning about the modern disease management process, but the social values underlying ethical reasoning cannot readily be translated into judicial analysis because of the institutional arrangements of law, medicine, and science. As I have stated elsewhere, a comparative institutional analysis of the “eugenics problem” requires some difficult political and social tradeoffs that neither legislatures nor courts have heretofore been able to make upon behalf of society.<sup>27</sup>

I will argue that our focus should be on how genetic knowledge shapes disease management and on how courts, using liability doctrines, should respond to the risks and benefits of emerging notions of genetic health. My approach is essentially incremental, suggesting that law may not be the primary factor in preventing the horrors of past eugenic practices from recurring. On the other hand, my approach should help illuminate some issues that a variety of social institutions, such as families, must face and resolve as notions of genetic health start to dominate public and private discourse. The ge-

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25. See LARRY I. PALMER, *ENDINGS AND BEGINNINGS: LAW, MEDICINE AND SOCIETY IN ASSISTED LIFE AND DEATH* 3-18 (2000).

26. Traditional approaches to liability have separated attempts to distinguish between liability for mishaps in attempts to cure and liability for accidents in clinical research. While there are important doctrinal distinctions having to do with differences between negligence and “strict liability,” I propose to use the more inclusive term of disease management to determine the purposes and contours of a generalized theory of liability. See Palmer, *supra* note 7, at 3-4. I am thus assuming that a major cultural event such as the incorporation of genetic explanations into everyday explanations of illness, disease, and death, will eventually force a rethinking of legal doctrine.

27. See PALMER, *supra* note 25, at 4-7; Larry I. Palmer, *Paying for Suffering: The Problem of Human Experimentation*, 56 MD. L. REV. 604, 617-19 (1997).

netic health cases—wrongful birth or wrongful life—are currently separated in literary and judicial reasoning from the “eugenic precedents” that are relevant to the underlying ethical reasoning, if not the precise legal holdings of the cases emerging in the Human Genome Era. The way to link the ethical reasoning of the eugenic precedents and the genetic health cases is through a theory of liability for modern disease management. Thus, this Article provides an outline of an ongoing project to propose a theory of liability in medical management for the Human Genome Era.<sup>28</sup>

My argument has four parts. Part I reinterprets the lead abatement study case as a social, if not strictly a biological, genetic case. A public health perspective on the liability issues involved in *Grimes*<sup>29</sup> provides a means of arriving at the court’s holding without invoking the eugenic precedents of the Nazi Doctors or Tuskegee. Part II provides an institutionalist analysis of liability cases when parents seek to impose liability on physicians for failure to warn them of the risk of disability from an inherited condition in their offspring. I will thus seek to answer the question: Is there a standard of care for genetic health? Part III suggests using the Tuskegee Study and the Nazi Doctors Case as sources of institutional lessons rather than as legal precedents. The most important lesson derived from this analysis is that political action—an apology for the Tuskegee Study by the President of the United States<sup>30</sup>—institutionalized the notion that the ethics of scientific research aimed at better disease management will be judged in hindsight.<sup>31</sup> Part IV argues that the informed consent doctrine in liability cases needs to be reformulated in terms of disclosure rather than in terms of promoting individual autonomy in the Human Genome Era. A recent case illustrates the view that judges should start using liability doctrines to provide incentives for physicians, scientists and their related organizations to share genetic knowledge with consumers, patients, and their representatives. In effect, I will propose a theory of liability for dealing with disease management not simply as physicians treating patients, but in terms of research to improve overall health of defined groups,

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28. Other aspects of this project are discussed in my recent piece, Palmer, *supra* note 7, at 13-33, and Larry I. Palmer, *Medical Liability for Pharmacogenomics*, in PHARMACOGENOMICS: SOCIAL, ETHICAL, AND CLINICAL DIMENSIONS (Mark A. Rothstein ed., forthcoming 2003).

29. See Larry I. Palmer, *Patient Safety, Risk Reduction, and the Law*, 36 HOUS. L. REV. 1609, 1635 (1999).

30. See President William J. Clinton, Remarks by the President in Apology for Study Done in Tuskegee (Mar. 16, 1997), at <http://clinton4.nara.gov.textonly/New/Remarks/Fri/19970516-898html> (last visited Jul. 26, 2002) (on file with author).

31. See Palmer, *supra* note 7, at 25; Jeffrey J. Rachlinski, *A Positive Psychological Theory of Judging in Hindsight*, 65 U. CHI. L. REV. 571, 576 (1998).

i.e., from the perspective of public health.<sup>32</sup>

Ironically, in the end, it will be genetically, socially, or ethnically identified groups of individuals who will have the greatest stake in minimizing the risks and optimizing the benefits of genetic knowledge. As notions of genetic health emerge, it is the small genetic difference among individuals that might affect health status, which is of interest to both scientists and to each of us as citizens.<sup>33</sup>

#### D. Public Health, Groups, and Genetic Health

*Grimes v. Kennedy Kreiger Institute, Inc.*,<sup>34</sup> held that public health research could lead to liability of research institutions for failure in the consent process or in its selection of research subjects. Describing the context—the surrounding “facts”—of this ruling of potential liability depends upon one’s frame of reference.<sup>35</sup> Since I will argue that *Grimes* is about genetic health in at least the popular, if not the scientific, sense I will first present the facts and the policy debate about modern research from the narrowest of legal perspectives—what the appellate court believed the “facts” were from the sparse record.

In the two cases involved in the *Grimes* appeal, parents of minors who had agreed to participate in a study of lead abatement in Baltimore filed an action for negligence against the research institute conducting the study.<sup>36</sup> The plaintiffs claimed the research organization breached its duty of care when it failed to promptly inform them of the elevated level of lead in the minor’s blood sample and thus of the risk of lead poisoning from the environment in which the plaintiffs lived. The plaintiffs also alleged that the defendants had a duty to warn them of the risks of lead poisoning when the defendants’ tests indicated the presence of elevated levels of lead dust in their respective residences. In both of the cases, lower courts ruled that the research organization was entitled to summary judgment.<sup>37</sup>

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32. See Ellen Wright Clayton, *The Complex Relationship of Genetics, Groups, and Health: What it Means for Public Health*, 30 J.L. MED. & ETHICS 290, 291 (2002) (advocating community consultation between researchers and defined groups in order for genetic treatment to progress while reducing risks of abuse). For variously proposed definitions of “public health,” see Mark A. Rothstein, *Rethinking the Meaning of Public Health*, 30 J.L. MED. & ETHICS 144, 147 (2002) (arguing for a narrow definition).

33. See Palmer, *Medical Liability for Pharmacogenomics*, *supra* note 28, at 199.

34. 782 A.2d 807 (2000).

35. See DONALD A. SCHÖN & MARTIN REIN, *FRAME REFLECTION: TOWARD THE RESOLUTION OF INTRACTABLE POLICY CONTROVERSIES* 30 (1994).

36. Appellant Ericka Grimes and her mother resided in a dwelling that researchers claimed had already been completely abated. See *Grimes*, 782 A.2d at 824-26. Appellant Myron Higgins and his mother resided in a dwelling deemed to require Level III (\$6000-\$7000) abatement, but received only Level II abatement (\$3500). See *id.* at 828.

37. The research organization filed a third party complaint against the owners of the property. The plaintiffs first sought to add the owners of the property as defendants in an

The nature of both the written form—used to obtain the parents’ consent—and the research were important to the court’s holding. The study was sponsored by a grant from the Environmental Protection Agency (EPA). Its purpose was to determine if measures short of full “lead abatement” were as effective in reducing the risks to children as full-fledged lead abatement. To achieve a differential level of lead abatement in various groups of dwellings, the state of Maryland provided loans to property owners.<sup>38</sup> The investigators recruited families with at least one child to live in these various dwellings and obtained the parents’ consent to participate in the study over a two-year period. Kennedy Krieger’s written consent form informed the parents of the purposes of the study, promised free blood tests for the children,<sup>39</sup> and provided periodic inspections of their premises.<sup>40</sup>

The majority of the court treated the case as one of first impression, but eventually held that summary judgment was improperly granted.<sup>41</sup> Thus, a determination of the facts necessary to support an ultimate holding that the research institution is liable would await a trial.<sup>42</sup> Furthermore, in response to a motion for reconsideration, the court clarified its holding regarding the legal inability of parents to consent to “non-therapeutic” research involving their children.<sup>43</sup>

However, it was what the court said in arriving at its holding that is important to genetic health scholarship. The court’s use of the Tuskegee Syphilis Study and the Nazi Doctors Case to bolster its wide, sweeping opinion has placed an ethical question mark on public health research involving disadvantaged or low-income urban dwellers, most of whom are members of minority groups.<sup>44</sup> So while

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amendment to their complaint, but later dismissed the actions against the owners. *Id.* at 826, 829.

38. *Id.* at 822.

39. While the consent form indicated that the blood tests were not to replace the “regular medical care your family obtains,” *id.* at 824, this fact does not affect the broad theory of liability for which I will argue (*see* discussion *infra* Part IV). Some might argue that the lack of a physician-patient relationship means there is “no duty,” but this reflects a narrow view of the duty and does not incorporate the various ways in which liability doctrine operates.

40. *Grimes*, 782 A.2d at 824.

41. *Id.* at 858.

42. The case is still awaiting trial.

43. The court claimed that its use of the words “any risk” meant “any articulable risk beyond the minimal kind of risk that is inherent in any endeavor.” *Id.* at 862. The majority’s implication that parents could not consent to putting their children at risk has caused a great deal of concern among members of the research community. I do not directly address those concerns in this Article.

44. It is worth noting that Johns Hopkins felt compelled to defend Kennedy Krieger. *See* Kennedy Krieger Institute Lead-Based Paint Study, <http://www.hopkinsmedicine.org/leadpaint.html> (last visited Aug. 5, 2002) (on file with author). It is interesting to note that in the amicus brief that Johns Hopkins signed, it highlighted its role in dealing with minority health issues. For example, in regard to sickle cell anemia it stated that: “Johns Hopkins Medical School faculty are engaged in important research to find a cure or treat-

in a technical sense minority groups—particularly those defined as such by their race—are not a genetic group, historically and currently race is constructed biologically.<sup>45</sup> Since the court’s result in *Grimes* could have been arrived at on a much narrower ground,<sup>46</sup> one might wonder if the majority’s invocation of eugenic precedents was driven by an underlying fear of racial neglect that leads to institutional neglect and eventually the notion of genocide.

Consider the various ways *Grimes* could be viewed as one considers facts not cited in the record before the appellate court. At one level, *Grimes* is about environmental health, not genetic health. But if we go back and examine the social and economic justification for the study, we can see that the research community, judging from their briefs,<sup>47</sup> saw a “public health crisis” in the city of Baltimore. They suggested that the poor and disadvantaged were faced with the dilemma of living in “unhealthy housing” or no housing, at least in the city of Baltimore.

This is not the first time that a disease metaphor was used to justify certain government housing policies such as urban renewal.<sup>48</sup> Justice Douglas’s opinion, written in 1954, illustrates how deeply science and medicine have since shaped our public discourse:

The experts concluded that if the community were to be healthy, if it were not to revert again to a blighted or slum area, as though possessed of a *congenital disease*, the area must be planned as a whole. It was not enough, they believed, to remove existing buildings that were insanitary [sic] or unsightly.<sup>49</sup>

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ment for sickle cell anemia, a chronic hereditary blood disease occurring primarily among Africans and African-Americans.” Brief of Amici Curiae Association of American Medical Colleges et al. at 6, *Grimes v. Kennedy Krieger Inst., Inc.*, 782 A.2d 807 (Md. 2001) (Nos. 128-29), available at <http://www.hopkinsmedicine.org/press/2001/SEPTEMBER/briefs.htm> (last visited October 11, 2002) (on file with author) [hereinafter Brief].

45. Rothstein & Epps, *supra* note 9, at 229.

46. The concurring opinion by Justice Raker stated that summary judgment was improperly granted because sufficient facts supported appellants’ contention that a special relationship existed between the parties. *Grimes*, 782 A.2d at 859. This special relationship gave rise to a duty of care that if breached would constitute negligence. *Id.* Thus, there was no need to broach the issue of contract. *Id.* at 859-61.

47. See Brief, *supra* note 44, at 10.

48. *Berman v. Parker*, 348 U.S. 26, 34 (1954). In upholding the constitutionality of legislation authorizing the taking of non-dilapidated housing as part of redevelopment or “renewal” of inner city “slums,” Justice Douglas also rejected a commercial owner’s claim that his otherwise safe and “healthy” property could not be publicly condemned and turned over to a private developer. For a discussion of the importance of metaphor in legal writing, see Larry I. Palmer, *Writing Law*, in *WRITING AND REVISING THE DISCIPLINES* 113, 122-124 (Jonathan Monroe ed., 2002). I am indebted to the late Donald A. Schön for bringing this issue to my attention. See Donald A. Schön, Cornell: Marrying Science, Technology, Artistry, the Humanities, and Professional Practice, Keynote Address at the Cornell Conference on Professionalism, Vocationalism & Liberal Education 4 (Apr. 9, 1988) (transcript and audio cassettes available in the Cornell University Library).

49. *Parker*, 348 U.S. at 34 (emphasis added).

There are many reasons today to question the effectiveness of urban renewal as a housing policy for inner city areas, but Justice Douglas's enthusiasm for "technical rationality"<sup>50</sup> as a guide for evaluating legislative determinations continued for many years. Twenty years later, in *Village of Belle Terre v. Booras*,<sup>51</sup> Douglas relied upon his urban renewal decision to uphold a definition of "family" in a local zoning ordinance that prevented unrelated individuals from living in a village on Long Island.<sup>52</sup> As Justice Marshall's dissenting opinion pointed out, the effect of Douglas's *Belle Terre* opinion is to allow the local government to use traditional definitions of family in zoning ordinances that have adverse effects on various individuals or groups.<sup>53</sup>

Today, equally well-meaning researchers see the risks of lead poisoning to disadvantaged children as minimal compared to what the researchers see as the children's alternatives. There is in fact no forum in which the policy framework can be challenged, particularly by these modern-day urban dwellers, since the policy framework for lead abatement has been institutionalized in law<sup>54</sup> and in real life such that lead is no longer used in new housing construction.<sup>55</sup> But when middle and upper-middle class families move into older city neighborhoods, does their "renovation" or "gentrification" of these older homes involve complete lead abatement? How can we know?

So *Grimes* is a "genetic case" in a social sense, but with a twist on what risks certain groups ought to bear. To reduce the biological risks of the environment, some individuals must be put at risk, however slight, in order to gain the knowledge necessary to make the environment "healthy." Those at risk—economically disadvantaged children in inner cities—are positioned as the beneficiaries, not necessarily as individuals but as a group, from the increase in scientific knowledge.

Researchers who are motivated by a sense of morality that focuses on the good of random and unidentified individuals—the future

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50. Donald Schön defined the model of technical rationality as: "[P]rofessional activity consisting of instrumental problem solving made rigorous by the application of scientific theory and technique." DONALD SCHÖN, *THE REFLECTIVE PRACTITIONER: HOW PROFESSIONALS THINK IN ACTION* 21 (1984). For how this model relates to legal positivism, see Palmer, *supra* note 29, at 1627.

51. 416 U.S. 1 (1974).

52. *Id.* at 9.

53. *Id.* at 12-20.

54. See MD. DEP'T. OF THE ENV'T, *THE ABATEMENT OF LEAD PAINT HAZARDS*, at <http://www.mde.state.md.us/health/lead> (last visited Aug. 5, 2002) (on file with author); CTR. FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T OF HEALTH & HUMAN SERVS., CDC CHILDHOOD LEAD POISONING PREVENTION PROGRAM, at <http://www.cdc.gov/nceh/lead/lead.htm> (last visited Aug. 5, 2002) (on file with author).

55. See *Chapman v. Silber*, 760 N.E.2d 329 (N.Y. 2001) (holding that landlords in New York State are required to remove lead paint if they know of its existence; thus, it is implicit that lead paint cannot be used in New York State).

good<sup>56</sup>—as opposed to traditional professional health care ethics that focus on the good of the patient, find it easy to do the cost-benefit balance for research subjects. The public good, and in this case, public health, becomes the objective. Researchers have very little incentive to consider if those outside of science and its affiliated institutions, such as modern research universities,<sup>57</sup> perceive science as aiming for the betterment of the common good. Although perhaps politically infeasible at the moment, one might wonder if a better social strategy might involve dispersing low-income residents throughout metropolitan areas.<sup>58</sup> It is also possible that the long-term consequences of the partial lead abatement program is first abandonment of older dwellings, but then rebuilding or remodeling of properties into housing that only higher income individuals can afford.<sup>59</sup> Or put another way, from the record before it, the appellate court perhaps assumed that the researchers established a framework for improving the housing conditions of those at risk for lead poisoning from their dwellings without the active participation of those groups in formulating research policy.<sup>60</sup>

Viewed thus, we can understand the moral outrage of the *Grimes* majority that led them to yield to the temptation to invoke common

56. See Robert S. Morison, *Bioethics after Two Decades*, HASTINGS CENTER REP., Apr. 1981, at 8, 9-10 (arguing that in the future ethics will face an increasing number of unforeseen possibilities due to advances in science, thereby forcing society to grapple with fundamental ethical questions in a new way).

57. For a recent attempt to place professions in the context of the growth of the modern research university, see generally WILLIAM F. MAY, *BELEAGUERED RULERS: THE PUBLIC OBLIGATION OF THE PROFESSIONAL* (2001).

58. Cf. *Spallone v. United States*, 493 U.S. 265 (1990) (involving an attempt by the U.S. Justice Department to force the City of Yonkers to change its public housing policy as a means of desegregating the public schools). Framing the “homelessness” policy might also be a similar problem of social policy in urban areas that might have a “health component.” See SCHÖN & REIN, *supra* note 35, at 141-45.

59. See NEIL K. KOMESAR, *LAW’S LIMITS* 27-32 (2001) (urging consideration of the “market” as an institutional force and warning of the effects of a “rights” perspective without considering the institutional costs of those rights).

60. There is perhaps a growing awareness of the need to “democratize” research through community participation. See DAVYDD J. GREENWOOD, *INTRODUCTION TO ACTION RESEARCH: SOCIAL RESEARCH FOR SOCIAL CHANGE* 175-78 (1998). Even the federal government is calling for “Community-based Participatory Research.” In a recent request for proposals to establish multidisciplinary centers to study health disparities, the funding agencies required that each center have at least one project that develops, evaluates, or implements one such participatory action research project. See Centers for Population Health & Health Disparities, NIH, RFA: ES-02-009 (April 1, 2002), at <http://grants2.nih.gov/grants/guide/rfa-files/RFA-ES-02-009.html> (last visited Aug. 13, 2002) (on file with author). At least one of the researchers involved with the lead paint reductions study in *Grimes v. Kennedy Krieger Institute, Inc.*, Farfel, appears to be involved as a technical consultant to a community based group. See COMMUNITY ENVIRONMENTAL HEALTH RESOURCE CENTER, *TECHNICAL CONSULTANTS AND ADVISORS*, <http://www.aeclp.org/consultants.html> (last visited Aug. 26, 2002) (on file with author). Whether his involvement constitutes the kind of “participatory action research” as defined by Greenwood, however, cannot be determined.

law reasoning to relate its cases to Tuskegee and the Nazi Doctors. The *Grimes* court, however, forgot two significant differences between the cases before it and these eugenic precedents. First, as I have noted before,<sup>61</sup> the eugenic precedents are “negative precedents” in the sense these “cases” represent policies the court, along with most members of society, are trying to avoid, not follow. Normally, when the courts claim to be using precedent, it is with the idea of furthering some fundamental policy or maintaining some appropriate balance the court has achieved. Second, whatever the holdings of these infamous cases, neither of them directly involve issues of civil liability and are not necessarily relevant to the *Grimes* court’s task of developing a theory of liability at the frontiers of science, medicine, and law.<sup>62</sup>

The *Grimes* majority should have asked the larger question regarding liability theory in relation to science and medicine: Under what circumstances should courts empower individuals to exercise social control over professionals and their organizations?<sup>63</sup> The narrower issue raised by the lower court’s granting of summary judgment is whether the plaintiffs as a group should be granted access to courts, not whether in fact the plaintiffs can convince a judge and jury of the validity of their liability theory under the facts as alleged. The former is in fact an institutional question,<sup>64</sup> of particular importance when there are few reported cases involving liability for research miscues.<sup>65</sup> Rather than write about the eugenic precedents in relation to delineating the liability risks in research, the *Grimes* court should have used the cases as an opportunity to upgrade liability theory in several important respects.<sup>66</sup>

First, the court should have been explicit about the structure of research that gives rise to liability by allowing its readers to see its underlying assumptions about how researchers, physicians, and research organizations ought to relate to each other in a normative sense. The court does not say much about the principal investigators

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61. See *supra* pp. 4-5.

62. I borrow the phrase “frontiers” from LAW, SCIENCE, AND MEDICINE 687 (Judith Areen et al. eds., 1996).

63. *Id.* at 235-312.

64. Such a question frames social issues in terms of institutions such as “family formation rather than in terms of a particular social goal, such as procreative liberty.” Larry I. Palmer, *Life, Death, and Public Policy*, 81 CORNELL L. REV. 161, 178 (1995) (book review).

65. See *Grimes v. Kennedy Kreiger Inst., Inc.*, 782 A.2d 807, 835 (Md. 2001).

66. There is no reason to believe that the *Grimes* court was liberal in its interpretation of the scope of the so-called “informed consent doctrine.” See *Wright v. Johns Hopkins Health Care Sys. Corp.*, 728 A.2d 166, 179 (Md. 1999) (discussing the Maryland Court of Appeals decision which held that physicians are not liable to the estate of an AIDS patient who was resuscitated despite a living will, which expressly stated a desire not to be resuscitated). For a discussion of the case see Palmer, *supra* note 7, at 18 n.86.

since they were apparently not named as defendants, but their backgrounds and professional affiliations are illustrative of how the modern biomedical research enterprise must operate. Both of the lead researchers held academic positions at Johns Hopkins, one in the school of medicine and the other in the school of public health.<sup>67</sup> Both also held important positions at Kennedy Krieger, but the court does not explain why this multi-layered set of relationships might be relevant to a particular theory of liability.

One possible theory of liability is that only physicians have a duty to warn individuals of the risks discovered through diagnostic interventions such as blood tests. The *Grimes* court rejects this theory and the implicit idea that lack of informed consent liability is based on contract rather than liability theories,<sup>68</sup> but fails to tell us why. I believe that the court is assuming that the researchers have an obligation to have access to physicians whenever they know there are physical risks to the subjects. The court need not assume that the researchers have an obligation, in fact, to provide subjects with access to health care professionals.<sup>69</sup> As a result, at the very least, the *Grimes* court requires researchers to inform subjects of any increased physical risks the researchers discover and advise the subjects to seek immediate professional health care.

Second, the court should have been more explicit about why it is appropriate to link public health researchers to physicians in its theory of liability. More generally, medicine and related professions such as public health, nursing, dentistry and pharmacy, are distinguished from other professions by their ethical and legal authority to routinely intrude into the human body or obtain information about the

67. Although the *Grimes* opinion cites Dr. Mark Farfel as the researcher in charge, 782 A.2d at 813, the *Baltimore Sun* op-ed piece cites the late Dr. Julian J. Chisholm and Dr. Mark Farfel as the researchers. See Don Ryan, *Researcher on Lead Hazards is Solution, Not Problem*, BALT. SUN, Aug. 28, 2001, at 19A. The late Chisholm was a founder of the Kennedy Krieger Institute's Lead Clinic and then Professor of Medicine at Johns Hopkins University School of Medicine. See Jim Haner et al., *Pioneer in Lead Study, Julian Chisholm, dies: Kennedy Krieger researcher treated poisoned children*, BALT. SUN, June 22, 2001, at 1A. Dr. Mark Farfel is Director, Lead Hazard Abatement Research Department at Kennedy Krieger, see Kennedy Krieger Institute: A Comprehensive Resource for Children with Disabilities, <http://www.kennedykrieger.org> (last visited Aug. 25, 2002) (on file with author), and Associate Professor, Department of Health Policy and Management at the School of Public Health at Johns Hopkins University, see Johns Hopkins Bloomberg School of Public Health, <http://www.jhsph.edu> (last visited Aug. 5, 2002) (on file with author).

68. See Peter H. Schuck, *Rethinking Informed Consent*, 103 YALE L.J. 899, 956-57 (1994) (discussing different manifestations of informed consent doctrine and advocating contractual view of medical liability).

69. The language in the consent form which states that the study is intended only "to monitor the effects of the repairs and is not intended to replace the [family's] regular medical care," *Grimes*, 782 A.2d at 824, is not problematic under my analysis. In theory, allowing for independent medical care protects the interests of subjects as well as investigators, although social, economic, and geographical factors may limit the access of the *Grimes* subjects.

functioning or malfunctioning of the human body.<sup>70</sup> Although the investigators were not named in the lawsuit,<sup>71</sup> the court assumes that health care professionals are linked in some way, probably through a variety of organizational and, ultimately, economic relationships that are so sufficiently institutionalized that they need not be discussed. For instance, Johns Hopkins' Institutional Review Board oversaw the research protocol in *Grimes*<sup>72</sup> even though the Krieger Institute is a legally distinct entity. Despite the legal form of the various not-for-profits involved in some way with the research, the *Grimes* court viewed the professionals in these various organizations as connected by their professional ethos.<sup>73</sup> Although perhaps holding different types of licenses or educational credentials, health care professionals are viewed as united through their commitment to "technical rationality"<sup>74</sup> in defining and solving problems, especially when it comes to research.

Third, and perhaps most important, the *Grimes* court shifts the focus from the liability of individual researchers to the liability of the organization. Traditionally, liability theory in health care is centered in the special standard of care established for physicians in negligence law—malpractice.<sup>75</sup> With the idea that most physicians and surgeons in this country are legally independent contractors,<sup>76</sup> liabil-

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70. There is, of course, no easy way to explain why some individuals who routinely touch and intrude upon the human body—hair stylists, for instance—are licensed, but not thought of as "health care professionals." For the purposes of my discussion in this Article, it is sufficient to point out that those whom we think of as "health care professionals" are judged by the standard of negligence, even when they use products that injure clients, whereas hair stylists are strictly liable for the products they use on their clients' bodies. *Newmark v. Gimbel's, Inc.*, 258 A.2d 697 (1969) (holding that a beauty parlor operator could be held strictly liable for injuries caused by the use of a product to give the "customer" a permanent wave, even though a dentist was only liable in negligence for using a needle with a latent defect).

71. Kennedy Krieger Institute, Inc. is the only defendant named in the opinion. *Grimes*, 782 A.2d at 813-14.

72. Kennedy Krieger Institute, Inc. is described as an "affiliate" of Johns Hopkins according to a joint press release. See Kennedy Krieger Institute, *Johns Hopkins Response to Court of Appeals Ruling in Lead Paint Case*, at <http://www.hopkinsmedicine.org/press/2001/October/courtofappeals.htm> (last visited Aug. 5, 2002) (on file with author).

73. The nature of professionalism or even health care professionalism is a matter of considerable debate. The traditional notion of professions as "self-regulating" is being challenged on a number of fronts, including health care. See, e.g., E.J. Emanuel & L.L. Emanuel, *What is Accountability in Health Care?*, 124 ANN. INTERNAL MED. 229, 229-39 (1996); L.L. Emanuel, *A Professional Response to Demands for Accountability: Practical Recommendations Regarding Ethical Aspects of Patient Care*, 124 ANN. INTERNAL MED. 240, 242-43 (1996).

74. See definition of technical rationality, *supra* note 50.

75. For the classic statement on the standard, see Allan H. McCoid, *The Care Required of Medical Practitioners*, 12 VAND. L. REV. 549, 558 (1959).

76. There are economic and social forces encouraging physicians to become "employees" or even beholden to third party networks or health plans, but the idea of physicians as independent contractors is deeply embedded in liability doctrine, at least in the United States. See, e.g., *Sword v. NKC Hospitals, Inc.*, 714 N.E.2d 142 (Ind. 1999) (struggling with

ity of hospitals for the mistakes of physicians has been rare until fairly recently.<sup>77</sup> But the *Grimes* court allows a suit against the research organization without explicitly stating that research is governed by principles of what has been referred to as “enterprise liability.”<sup>78</sup> The principal investigators in *Grimes* may turn out to be employees of the Institute as the facts are later developed, making the case for vicarious liability clear. But there are some general features about modern research that the *Grimes* court does not explain that make enterprise liability the norm for research, even if individual researchers remain liable in some situations.

Under federal regulations, the entity receiving federal research funds is responsible for the overall conduct of the research.<sup>79</sup> It is the research organization that is ultimately accountable for the research to the federal government. In the current regulatory scheme, the institution is supposed to supervise the investigator, who in reality does the actual study or experiment; the institution provides oversight for the consent process through its Institutional Review Board. More explicitly, the investigator has an ethical obligation to protect the subject in his or her study, but the organization has at least a regulatory obligation to protect human subjects generally. The *Grimes* court, with explicit support from the regulations,<sup>80</sup> simply held that the organization’s failure to provide that protection, in vio-

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theories of apparent agency to determine if a hospital might be liable for the alleged misdeeds of an anesthesiologist who is not an employee but who practices within the hospital).

77. See Clark C. Havighurst, *Vicarious Liability: Relocating Responsibility for the Quality of Medical Care*, 26 AM. J.L. & MED. 7, 22-24 (2000).

78. Enterprise liability has been defined generally as “[a] legal regime in which manufacturers are liable for the costs of all product-caused accidents.” Jon D. Hanson & Douglas A. Kysar, *Taking Behavioralism Seriously: Some Evidence of Market Manipulation*, 112 HARV. L. REV. 1420, 1423 (1999). Enterprise liability is defined in health care as “various circumstances when an organization, for instance a hospital, health maintenance organization, or even a health plan is potentially liable to injured patient.” William M. Sage et al., *Enterprise Liability for Medical Malpractice and Health Care Quality Improvement*, 20 AM. J.L. & MED. 1, 1-28 (1994) (discussing medical malpractice and reform theories of liability). For example, the hospital might be liable for failure to fulfill its obligations to patients by not providing appropriate staff in the emergency room. In another example, a hospital might be held legally responsible for the injuries caused by a non-employee, such as a surgeon, who is considered an independent contractor. See *id.* at 18-20. For the use of enterprise liability in attempts to reduce medical error and assuage provider concerns about “malpractice” see William M. Sage, *Principles, Pragmatism, and Medical Injury*, 286 JAMA 226, 227 (2001).

79. See generally 45 C.F.R. §§ 46.101-46.120 (2001).

80. Many clinical researchers and their lawyers believe that IRB approval provides immunity from lawsuits, but the federal regulations are specific:

No informed consent, whether oral or written, may include any exculpatory language through which the subject or the representative is made to waive or appear to waive any of the subject’s legal rights, or releases or appears to release the investigator, the sponsor, the institution or its agents from liability for negligence.

45 C.F.R. § 46.116 (2001) (cited in *Grimes v. Kennedy Krieger Inst., Inc.*, 782 A.2d 807, 847 (Md. 2001)). See Palmer, *supra* note 7, at 32.

lation of a court-established duty, could potentially constitute negligence. From a systems perspective on accountability for subject protection in research, allowing the liability to fall on the research organization rather than on the investigator or physician makes sense.<sup>81</sup>

More generally, “enterprise liability,” as opposed to “professional liability,” as the locus of a liability theory<sup>82</sup> makes sense in an era of genetic health for two reasons. First, enterprise liability encourages organizations to exercise some degree of control over the physicians and investigators operating within the organization. While professional liability and its accompanying professional/client dyad is the ethical foundation for liability doctrine, enterprise liability acknowledges the multidisciplinary reality of modern health care. In cases involving genetic health, as demonstrated in Part II, it is apparent that research and treatment involved in genetic health are complex and involve patient and family member interaction with a number of different professionals—for example, physicians, nurses, lab technicians and genetic counselors—who have various levels of related competencies.

Second, enterprise liability acknowledges what was only implicit in the earlier “wrongful birth” and “wrongful life” cases: genetic health requires a degree of specialization or a special branch of professional knowledge to be acquired by health care providers. In effect, liability doctrine can be used to encourage only certain providers (with the appropriate expertise)—academic medical centers—to deal with genetic health. Although not all individuals or groups have equal access to academic health centers, it is not clear that universal access to genetic health practitioners is in fact a social good, given the eugenic risks.<sup>83</sup>

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81. A reporting systems approach was first suggested as a means of reducing medical errors or achieving greater patient safety. See *TO ERR IS HUMAN: BUILDING A SAFER HEALTH CARE SYSTEM* 86 (Linda T. Kohn et al. eds., 2001); Palmer, *supra* note 29, at 1623-24. For a recent report on deaths occurring during clinical experiments at leading institutions such as Johns Hopkins and University of Pennsylvania, see John Herzfeld, *OHRP Suspension of Johns Hopkins Research Led to Improved Safety, Attitude, Deans Say*, 1 *MED. RES. L. & POL'Y* 142, 142, (2002); Joann Loviglio, *Gene Therapy Patient Dies Under HUP Care*, *DAILY PENNSYLVANIAN*, Sept. 30, 1999, at <http://www.dailypennsylvanian.com> (last visited Aug. 26, 2002) (on file with author).

82. Sage et al., *supra* note 78, at 28.

83. A “rights” approach to access to health care might lead one to argue for greater access to genetic research and interventions on the part of disadvantaged individuals. But an institutional approach poses questions of access in terms of trade-offs. Given a choice between new genetic therapies and access to primary health care, it is not clear what disadvantaged individuals might choose. It has been said that the US has the “best” medicine or health care in the Western World, but it is not clear that the overall health status of the entire population is poor when compared to other industrialized countries. In point of fact, the US ranks near the bottom in terms of health status indicators when compared to socie-

## II. IS THERE A STANDARD OF CARE FOR GENETIC DISEASE?

Although there is a great deal of scholarship and numerous judicial opinions dealing with so-called “wrongful life” or “wrongful birth”<sup>84</sup> cases, I propose to treat these as raising one larger question: Have courts established in liability law a standard of care for how health care professionals should deal with issues of genetic health? By framing the question in this manner, I seek to situate the issues of genetic health within the traditional specialized standard of care for health care professionals in liability doctrine.<sup>85</sup> Such juxtaposition immediately highlights the fact that traditional malpractice standards are built on the paradigm of physical injury and physically invasive treatment.<sup>86</sup>

Most of these genetic health cases arose after judges introduced

ties with more drinkers and smokers than ours such as France or Sweden. See Barbara Starfield, *Is US Health Really the Best in the World?*, 284 JAMA 483, 483 (2000).

84. See *Turpin v. Sortini*, 643 P.2d 954, 957 (Cal. 1982) (noting that lower California courts recognized wrongful birth actions); *Quinn v. Blau*, 1997 W.L. 781874 at \*2 (Conn. Super. Ct. 1997) (unpublished opinion stating that “Connecticut courts have recognized a cause of action for wrongful birth brought by parents”); *Procanik v. Cillo*, 478 A.2d 755, 758 (N.J. 1984) (noting that in *Berman*, New Jersey recognized that parents may recover for emotional distress for wrongful birth of child born with birth defects); *Berman v. Allan*, 404 A.2d 8 (N.J. 1979) (sustaining cause of action for wrongful birth of child with Down’s Syndrome); *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483, 492 (Wash. 1983) (taking “major step” recognizing wrongful birth action); Lori B. Andrews, *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 HOUS. L. REV. 149, 150-61 (1992) (analyzing history and future of “wrongful birth” and “wrongful life” cases where liability hinged on failure to test or warn about genetic risk). See generally Carolyn Lee Brown, *Genetic Malpractice: Avoiding Liability*, 54 U. CIN. L. REV. 857 (1986) (discussing perils of genetic counseling); Janet L. Tucker, *Wrongful Life: A New Generation*, 27 J. FAM. L. 673 (1989) (discussing “wrongful life” cases, which she defines as an “action brought by or on behalf of an infant born with genetic defects”).

85. See Daniel W. Shuman, *The Standard of Care in Medical Malpractice Claims, Clinical Practice Guidelines, and Managed Care: Towards a Therapeutic Harmony?*, 34 CAL. W. L. REV. 99, 100 (1997) (noting that common set of instructions provides that “the duty of the professional [is] to use such skill, prudence and diligence as other members of his profession commonly possess and exercise”) (quoting *Bily v. Arthur Young & Co.*, 834 P.2d 745, 772 n.21 (Cal. 1992)). For a discussion of the history of standard of care, see James A. Henderson, Jr., & John A. Siliciano, *Universal Health Care and the Continued Reliance on Custom in Determining Medical Malpractice*, 79 CORNELL L. REV. 1382, 1383-1400 (1994) (discussing how tort law seeks to police delivery of health care); Michelle M. Mello, *Of Swords and Shields: The Role of Clinical Practice Guidelines in Medical Malpractice Litigation*, 149 U. PA. L. REV. 645, 654-62 (2001) (discussing evolution and development of standard of care physicians are held to in medical malpractice cases); Philip G. Peters, Jr., *The Quiet Demise of Deference to Custom: Malpractice Law at the Millennium*, 57 WASH. & LEE L. REV. 163, 201-05 (2000) (discussing history of standard of care for physicians in medical malpractice cases in relation to broader fabric of general negligence law).

86. See Suzanne K. Ketler, Note, *The Rebirth of Informed Consent: A Cultural Analysis of the Informed Consent Doctrine After Schreiber v. Physicians Insurance Co. of Wisconsin*, 95 NW. U. L. REV. 1029, 1034-39 (2001) (providing explanation of this older line of battery-based cases concerning informed consent as well as shift to using negligence-based liability).

another theory of medical liability, the doctrine of lack of informed consent.<sup>87</sup> Thus the prototype case relating to genetic health arose in the 1970s and later involved not the issue of whether the health care provider performed a procedure or intervention in accordance with “prevailing medical standards,” but whether the parent should have been informed of certain genetic risks. The emerging standard of care for genetic health issues in law is thus a *post hoc* determination by judges and juries that a physician should have told the parents of the risk of some inherited disorder in their child.<sup>88</sup>

The underlying assumption of these genetic health cases is that the prospective parents have been deprived of the opportunity to decide not to have a child with the disease or disability, or the opportunity to prepare themselves for a child with such a disability. Of course, without a woman’s legal right to have an abortion, as the New Jersey courts have pointed out, these genetic liability claims would not be theoretically possible.<sup>89</sup> But I believe the better articulation of the assumption is in terms of the lack of opportunity to choose whether to risk having a child with a disability. Recall the story of my son’s birth. The knowledge that he *might* need a complete blood transfusion when born helped at least this parent endure the four hours that the blood transfusion took and the subsequent days and nights in the special care nursery.<sup>90</sup>

The latest permutations of this line of cases involves whether the duty to disclose imposes an obligation on the health professional to inform a patient’s child or relative of the risk of inheritable disease.<sup>91</sup>

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87. See *Canterbury v. Spence*, 464 F.2d 772, 787 (D.C. Cir. 1972) (holding that test for determining whether potential peril must be divulged is its materiality to patient’s decision); *Cobbs v. Grant*, 502 P.2d 1, 11 (Cal. 1972) (analyzing physician’s duty to patient and determining that there is a duty of reasonable disclosure concerning available choices with respect to proposed therapy and dangers inherently and potentially involved).

88. See *Pate v. Threlkel*, 661 So. 2d 278, 280 (Fla. 1995) (holding that a physician has a duty to warn a parent of the genetically inheritable nature of his or her disease); *Schroeder v. Perkel*, 432 A.2d 834, 842 (N.J. 1981) (holding that doctor was liable for failing to recognize cystic fibrosis in the first child and inform the parents that they were carriers of disease, which deprived them of informed choice to assume risk of second child). For a discussion of *Threlkel* see Palmer, *supra* note 7, at 15-16.

89. See, e.g., *Hummel v. Reiss*, 608 A.2d 1341, 1343 (N.J. 1992). Indeed most courts acknowledge that the right to procreative choice stems from a woman’s right to an abortion established in *Roe v. Wade*, 410 U.S. 113 (1973).

90. Without that knowledge, I suspect there is a greater risk on the part of at least some parents in the shock of discovery of “problems” to stigmatize the child as “sick,” “disabled,” and perhaps “unlovable,” at least until the child is restored as “healthy.”

91. See *Threlkel*, 661 So. 2d at 282 (holding that patient’s children were within foreseeable zone of risk and patient can ordinarily be expected to pass on warning). See L.J. Deftos, *Genomic Torts: The Law of the Future—The Duty of Physicians to Disclose the Presence of a Genetic Disease to the Relatives of Their Patients with the Disease*, 32 U.S.F. L. REV. 105, 106 (1997) (describing cases and statutory law regarding genetic information as developing into area of law dubbed “genomic torts” and proposing that genomic concepts of

These cases are an indication that the very notion of genetic health and disease pushes the parameters of the assumption of the traditional standard of care. Or put another way, if the justification of a special standard of care for health care professionals was based in part on preserving the special social function of the professional/client relationship, issues of genetic health question that basic assumption. Another way of stating this point is to suggest that knowledge-flow in the traditional understanding of standard of care is from the professional to the client.<sup>92</sup>

But once the notion of genetic health is institutionalized in health care practices through genetic screening of prospective parents, fetuses, and embryos,<sup>93</sup> the flow of knowledge must be from professional to some type of genetically defined group. While there is a risk to traditional notions of client/professional confidentiality in this suggestion,<sup>94</sup> recall that I am only making an argument for cases involving aspects of genetic health.

In making this argument, I should also note that there is no uniformity among courts about the theoretical basis of liability for failure to disclose information to patients.<sup>95</sup> Furthermore, legislatures have reacted to the so-called "first revolution" of informed consent<sup>96</sup> and limited the circumstances under which individuals can recover.<sup>97</sup>

privity and privilege will dissolve third-party shield that often protects defendants from remote plaintiffs).

92. See JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 48-59 (1984) (arguing that the doctrine of informed consent cannot protect patient autonomy).

93. Some of the papers in the symposium issue will make this point.

94. See Janet L. Dolgin, *Choice, Tradition, and the New Genetics: The Fragmentation of the Ideology of Family*, 32 CONN. L. REV. 523, 551 (2000) (noting that the doctrine of informed consent is "[a]ttractive . . . in part because it placates concerns about variations of privacy while interfering less with the goals of industry and science than rules defining genetic information as property").

95. See *Duttry v. Patterson*, 771 A.2d 1255, 1257 (Pa. 2001) (holding that a surgeon's personal characteristics were irrelevant to a patient giving informed consent).

96. The decision in *Johnson v. Kokemoor*, 545 N.W.2d 495 (Wis. 1996), has been called the second revolution in informed consent doctrine. See generally Aaron D. Twerski & Neil B. Cohen, *The Second Revolution in Informed Consent: Comparing Physicians to Each Other*, 94 NW. U. L. REV. 1 (1999) (discussing changes that might occur due to *Kokemoor*); Ketler, *supra* note 86, at 1052 (discussing *Kokemoor* and new cases which further expand informed consent in Wisconsin in therapeutic settings). For a more moderate perspective on the expected effect of *Kokemoor*, see Lynn M. LoPucki, *Twerski and Cohen's Second Revolution: A Systems/Strategic Perspective*, 94 NW. U. L. REV. 55 (1999) (arguing that effect of change will be moderate rather than revolutionary, and that Twerski and Cohen focus on legal issues that the *Kokemoor* court left undecided).

97. See *Hecht v. Kaplan*, 645 N.Y.S.2d 51, 52 (N.Y. App. Div. 1996) (holding that under New York statutes on informed consent, plaintiff must prove that there was some "unconsented-to affirmative violation" of her physical integrity in order to sustain cause of action). In *Hecht*, the physician drew an extra vial of blood and performed a blood test for Human T-Cell Leukemia Virus (HTLV), a contagious disease, while his patient only consented to have her blood tested for cytomegalovirus (CMV). See *id.* at 52 (discussing plaintiff's claim that testing of blood for HTLV amounted to "human research without her consent"). Although the HTLV test result was positive, the physician failed to inform the pa-

As a consequence, some courts, relying upon statutory definitions regarding lack of informed consent<sup>98</sup> and legislation protecting genetic privacy,<sup>99</sup> might well hold that physicians have no duty to inform relatives of the risks of genetic disease. This lack of uniformity in approaches to disclosure liability cases generally should remind us, first, that court-developed liability doctrine is always subject to political reaction or even reformulation.<sup>100</sup> Second, and perhaps just as important, liability doctrine remains primarily local in the sense that it is a function of state law in our system, but the ethical and social impact of notions of genetic health will be global.

### III. ARE THE TUSKEGEE SYPHILIS EXPERIMENT AND THE NAZI DOCTORS CASE PRECEDENTS FOR THE DUTY TO DISCLOSE IN GENETIC DISEASE CASES?

The *Grimes* court was undoubtedly aware that neither the Nuremberg Judgment in the Nazi Doctors' trial nor the Tuskegee Syphilis Study involved issues of civil liability. When litigation was commenced on behalf of the Tuskegee survivors, the theory of the lawsuit was based on a violation of the survivors' constitutional rights, and the suit was brought against governmental entities, not research organizations such as the Tuskegee Institute.<sup>101</sup> The Nazi Doctors Case involved criminal adjudications under international law,<sup>102</sup> a long way from the kinds of cost-benefit analyses we associate with modern liability theory. It might be appropriate to extract some broader principles from these cases<sup>103</sup> were one convinced there were no other way

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tient of the results of the test for several months. *See id.* (stating that failure to inform endangered the health of the plaintiff's husband); *see also* N.Y. PUB. HEALTH LAW § 2805-d(2) (McKinney 2001) (stating that "right of action to recover for medical . . . malpractice based on a lack of informed consent is limited to those cases involving either (a) non-emergency treatment, procedure or surgery, or (b) a diagnostic procedure requiring invasion or disruption of the integrity of the body").

98. *See Hecht*, 645 N.Y.S.2d at 52 (challenging the notion that informed consent is rooted in the right to bodily autonomy).

99. *See, e.g.*, N.Y. CIV. RIGHTS LAW § 79-l(2)(a) (McKinney 2002) (banning genetic testing on "sample[s] taken from an individual without prior written informed consent").

100. One might consider if the *Grimes* court wrote such a broad opinion in order to shape the legislative debate. Notice that the legislature, with appropriate lobbying by a variety of interest groups, enacted a statute requiring the disclosure of the minutes of all IRBs in Maryland. H. Res. 917, 416th Sess. (Md. 2002).

101. *See Palmer, supra* note 27, at 609.

102. The recent use of military tribunals against some individuals following the destruction of the World Trade Center and portions of the Pentagon has made the public and legal scholars aware that military tribunals do not operate like our domestic criminal courts. *See* Neal K. Katyal & Laurence H. Tribe, *Waging War, Deciding Guilt: Trying the Military Tribunals*, 111 YALE L.J. 1259, 1260-63 (2002); Elisabeth Bumiller, *Bush Sets Option of Military Trials in Terrorist Cases*, N.Y. TIMES, Nov. 14, 2001, at A1; William Glaberson, *Closer Look at New Plan for Trying Terrorists*, N.Y. TIMES, Nov. 15, 2001, at B6.

103. *See* RONALD DWORKIN, *TAKING RIGHTS SERIOUSLY* 232 (1977) (attempting to justify extraction of non-utilitarian principles from the Constitution for judges to apply).

to arrive at the court's result,<sup>104</sup> or if there were no negative consequences to attempted extraction. The Nazi Doctors Case and the Tuskegee Syphilis Study provide two different kinds of perspectives on issues related to genetic health and liability. Before outlining the doctrinal innovations we need for genetic health and disease, let me begin with the institutional lessons Tuskegee imparts.

#### A. *Institutional Lessons from the Tuskegee Study*

It is tempting to dismiss the Tuskegee Study in legal discourse because there was no binding legal precedent from the litigation following discovery of the study in 1972. It is equally tempting to place too much emphasis on the Tuskegee Study because it has become part of our ethical discourse in popular and political culture because of the prize winning play and made-for-television movie, *Miss Evers' Boys*.<sup>105</sup> I want to draw some enduring lessons from each perspective.

Technically, the theory of the lawsuit filed on behalf of the Tuskegee "subjects/patients" was that they were chosen by state and federal agencies because of their "race." Since the federal government paid a settlement to the survivors and their representatives, one might argue that the claim had some plausibility. But what if one asks: Were the African-American professionals and health care institutions involved with the study somehow exempt from any form of legal liability? Are they to be excused ethically for their participation because of their race?<sup>106</sup>

Rather than engaging in a kind of comparative "badness" analysis, I have suggested in previous publications that all of the participants in the Tuskegee Study should be viewed as "good" individuals unable to see that they practiced medicine . . . under what were bad institutional arrangements."<sup>107</sup> So viewed, Tuskegee vividly illustrates how the professional ethos of science may be more powerful than any socially imposed notions of race or ethnicity. In the contemporary context, just because members of so-called minority or stigma-

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104. As I have noted elsewhere, there is a straightforward analysis of liability doctrine for arriving at the *Grimes* court's result, as demonstrated by the concurrence. *Grimes v. Kennedy Krieger Inst., Inc.*, 782 A.2d 807, 859-61 & n.45 (Justice Raker found that facts existed supporting appellant's contention that a special relationship existed that created a duty on behalf of appellee—thus, there was no need to broach any other issue).

105. *MISS EVERS' BOYS* (Warner Home Video 1997); it is important to remember that the Tuskegee Study is itself an enduring legacy. See Palmer, *supra* note 29, at 1655; TUSKEGEE LESSONS: SYPHILIS STUDY LEAVES BEHIND LEGACY OF MISTRUST (NPR radio broadcast, July 25, 2002) available at <http://www.npr.org/programs/morning/features/2002/jul/tuskegee/index.html> (providing audio and textual version of Dr. Vanessa Northington Gamble's commentary on the legacy of Tuskegee) (last visited Oct. 11, 2002) (on file with author).

106. See Palmer, *supra* note 27, at 608-10.

107. PALMER, *supra* note 25, at 7.

tized groups are involved in pushing the medical frontiers does not prevent eugenic abuses from occurring.<sup>108</sup>

More pertinent for this symposium, the underlying scientific and public health problem that led to the Tuskegee Study—syphilis—was at the time a “chronic disease” or at least an “incurable” disease. Medical progress as defined a half-century ago, primarily the intervention of powerful pharmaceuticals, led to an effective treatment. With the growth in knowledge about the genetic nature of disease and proposed treatment modalities, the current thrust of public policy is to ensure participation by minorities so as to avoid some of the “bad institutional arrangements,” such as treatments with adverse and less effective results in specific minority groups.

The second important lesson of Tuskegee comes from political institutions. When President Clinton apologized for the Tuskegee Study, he established that medical and scientific interventions are to be judged by current ethical understandings rather than those operative when physicians and scientists undertook the interventions—or in the case of Tuskegee, failed to intervene.<sup>109</sup> On the other hand, Clinton also helped to institutionalize the bioethics profession when he authorized funding for a National Bioethics Institute at Tuskegee. This act was in keeping with a long tradition in this country of labeling minority-focused professional activities “National” and majoritarian professional groups “American,” for example the National Bar Association as distinct from the American Bar Association. The work of legal institutions will in some respect have an overseer body—the bioethics profession and its institutional form will be the multidisciplinary bioethics commissions.

### B. *Issues of Jurisprudence from the Nazi Doctors Cases*

I will not describe the Nazi Doctors Case except to say several Nazi physicians were executed and others imprisoned by a United States-sponsored international tribunal for their participation in experiments using concentration camp inmates.<sup>110</sup> Since a court had judged their conduct as “bad” even for the conditions of war, the *Grimes* court, like many of the commentators it cites, starts with the proposition that the Nuremberg case is the “most complete and au-

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108. See PALMER, *supra* note 25, at 4-7; Palmer, *supra* note 27, at 611-13.

109. Failure to intervene in genetic health cases has come up before in the DES litigation. See *Mink v. Univ. of Chi.*, 460 F. Supp. 713 (N.D. Ill. 1978).

110. For a more complete description of the trial, see excerpts available at The U.S. Holocaust Memorial Museum, *The Doctors Trial: The Medical Case of the Subsequent Nuremberg Proceedings*, at <http://www.ushmm.org/research/doctors/> (last visited Oct. 11, 2002) (on file with author); see also the forthcoming collection on the Doctor's Case to be posted online by the Harvard Law School Library, at [http://www.law.harvard.edu/library/digital/war\\_crime\\_trials\\_nuremberg.htm](http://www.law.harvard.edu/library/digital/war_crime_trials_nuremberg.htm) (last visited Aug. 7, 2002) (on file with author).

thoritative statement of the law of informed consent to human experimentation.”<sup>111</sup> Such statements lull legal actors into believing that *courts* might be able to halt “eugenic” uses of the growing body of genetic knowledge without examining all of the problems that surround treating those ethical guidelines as “law.” Thus the first problem: What were the Nazi Doctors’ crimes in a legal sense?

The repulsion that we feel in even hearing about the atrocities committed makes us very comfortable lumping all these actions under the rubric of “war crimes.” In point of fact, the Nazi Doctors were convicted of both “war crimes” and “crimes against humanity,” which raises the question: What is the distinction between the two types of crimes under international law? In experiments aimed at aiding the war efforts, such as finding better treatment for malaria, I have argued the defendants were guilty of “war crimes.”<sup>112</sup> Asking for the inmate’s informed consent would not have made the experiments legal, in my view, since the essence of the complaint and the evidence against the doctors was that they caused “excessive deaths” by the manner in which the doctors carried out their studies.<sup>113</sup> Furthermore, the Nazi Doctors’ malaria experiments were similar in some respects to American wartime malaria experiments on incarcerated prisoners, according to the prosecutors who attempted to distinguish the two through an American “ethics expert.”<sup>114</sup> These “war crimes” charges are not sources of principles for the emerging issues of genetic health.

The “crimes against humanity” portion of the Nuremberg Judgment, however, does provide some principles that could inform judicial attempts to develop doctrines relevant to genetic health. The prototypical crimes against humanity used by the Nazi Doctors involved the use of powerful drugs and x-rays on Russians, Poles, Jews and other groups. The object of these experiments was elimination of groups of civilians. The crimes against humanity doctrine might provide a principle for the civil lawsuits or legislation, whereas I doubt the relevance of the war crimes to civil lawsuits. But the principle one might derive from the crimes against humanity might be only a weak one: there should be some institutional checks on science and medicine, and in some circumstances liability rules provide the appropriate check.<sup>115</sup>

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111. *Grimes v. Kennedy Krieger Inst., Inc.*, 782 A.2d 807, 835 (Md. 2001).

112. See Palmer, *supra* note 7, at 28-31.

113. See JUDITH AREEN ET AL., *LAW, SCIENCE, AND MEDICINE* 993-1001 (2d ed. 1996).

114. Whether or not the so-called expert, Dr. Ivy from the American Medical Association, succeeded in distinguishing the two types of studies in his testimony is subject to some debate. See Jon M. Harkness, *Nuremberg and the Issue of Wartime Experiments on U.S. Experiments*, 276 JAMA 1672, 1673 (1996); Jon M. Harkness, *The Significance of the Nuremberg Code*, 338 NEW ENG. J. MED. 995, 996 (1998).

115. See Palmer, *supra* note 7, at 28-31.

My concern with the use of the eugenic precedents by the *Grimes*' court is twofold. First, I worry that the legal actors, including many scholars, will assume that the Nazi Doctors Case and the Tuskegee Study are clearly the eugenic type of precedents legal actors could use to prevent misuse of the growing body of genetic knowledge about the nature of disease. Second, I am concerned that a failure to understand the true legal response to these socially and ethically horrific events blurs the need for true legal innovation. There are institutional lessons to be learned and a weak principle to be derived from these events, but these lessons are mere frameworks for decision makers, many of whom may not be courts or bodies that rely upon "precedents" in the way common law judges do.

#### IV. HOW DO SOCIAL GROUPS PARTICIPATE IN ELIMINATING GENETIC DISABILITIES?

The laboratory, or more specifically the gene sequencing facility, is crucial to the development of genetically-informed treatments or even "cures," but eventually the physicians and scientists need human subjects. The combination of the legally imposed duty to inform prospective parents of genetic risks, along with the scientific imperative of alleviating disease and disability, creates a new set of tools in health care delivery: genetic screening and what some have called "eugenic abortions"<sup>116</sup> to avoid disability. As this new type of disease management takes hold, the distinctions between liability for experimentation and liability for breach of duties in treatment will break down. At some point, otherwise "healthy"—in the sense that they do not (yet) have any manifestations of the disease—individuals who may have a certain "gene" must become a part of the search for a cure.

Since some of the early genetic health cases involved Tay-Sachs,<sup>117</sup> I will use a pending case involving a similar disease, Canavan Disease, to illustrate what is on the frontier of legal liability and disease management in relation to genetic health.

Canavan Disease is a genetic disorder that affects the growth of brain fibers leading to death in its patients, mostly children before the age of ten. Through the efforts of some individuals, organizations,

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116. See *Gleitman v. Cosgrove*, 227 A.2d 689, 694 (N.J. 1967) (Francis, J., concurring) (originating the term "eugenic abortion"). "Eugenic abortion" refers to abortion intended solely to eliminate a potentially defective fetus and is used to differentiate that form of abortion from "therapeutic abortion" which is an abortion performed to protect a woman's health. See *Hummel v. Reiss*, 608 A.2d 1341, 1343 (N.J. 1992) (citing lower court opinion defining "eugenic abortion" versus "therapeutic abortion").

117. See *Howard v. Lecher*, 366 N.E.2d 64, 65 (1977) (holding parents were not entitled to recovery against doctor for his failure to warn them of the high risk that their child would suffer from Tay-Sachs disease).

and researchers and their related organizations, a genetic test has been developed allowing for the screening of prospective parents, embryos, and fetuses. The lawsuit, *Greenberg v. Miami Children's Research Institute, Inc.*,<sup>118</sup> involves a dispute between the parents of children who either died from or have Canavan Disease and their organizational supporters, and the researcher who discovered the "Canavan gene" and the holder of the patent for the gene and the related genetic tests.<sup>119</sup> The underlying issue is that the holder of the patent, the research organization, threatened the organizational plaintiff's goal of virtually free screening for one of the groups most severely affected by the disease—Ashkenazim or persons of East European Jewish descent—when it insisted upon licensing fees to use its tests.

The essence of the plaintiffs' complaint in *Greenberg* is that the researcher should have informed them of his intention to patent that gene, if discovered, when he took autopsy tissues of their dead children, and blood and other sources of DNA from them and their relatives. The plaintiffs further allege that they provided the seed money for the researcher's foray into genetic medicine and access to potential donors of tissues. The defendants have argued that the complaint should be dismissed on a number of grounds.

Since the question still remains whether the plaintiffs have stated a cause of action, I have argued that a proper reading of *Moore v. Regents of the University of California*,<sup>120</sup> where the California Supreme Court held there was a fiduciary duty on the part of a physician to disclose both his research and pecuniary interests in a patient's DNA, should lead to the plaintiffs' surviving the motion to dismiss or a motion for summary judgment.<sup>121</sup> The result of such a ruling is that the lack of informed consent doctrine in genetic health cases protects the rights of groups of individuals to participate in the dissemination of genetic knowledge.

Essentially, I am arguing that individuals, with the obvious support of organizations, have the legal right to prevent the birth of a child with what they consider a disability. The issue then is: Does supporting this right to eliminate disability through genetic testing and selective abortion or destruction of embryos increase the likelihood of stigmatization of the disabled? The answer is "yes," but it needs to be qualified by the following observations.

First, the individuals who might be afflicted with Canavan Disease are now socially linked either through genetic knowledge or

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118. 208 F. Supp. 2d 918 (N.D. Ill. 2002). The United States District Court for the Northern District of Illinois, Eastern Division, has recently transferred the case to the United States District Court for the Southern District of Florida. *Id.* at 928-29.

119. The Canavan Disease case is described in detail in Palmer, *supra* note 7, at 8-13.

120. 793 P.2d 479 (Cal. 1990).

121. *Id.* at 498.

their own ethnic and religious self-definition. The social definition might lead to less drastic means of avoiding the risk of disability by advising against having children between two prospective parents with a high risk of creating a child with Canavan. Thus, a bit of counseling and discussion could decrease the incidents of “eugenic abortion.”

Second, in an ethical sense, abortion is preferable in my view to even voluntary sterilization to avoid disability. I make this point of a continuum from contraception, to abortion, to sterilization because the most important eugenic precedent in this country is *Buck v. Bell*,<sup>122</sup> which has never been overruled.<sup>123</sup> Political institutions in this country still have the theoretical right to use scientific knowledge to eliminate the disabled. But we should not confuse the authority of political institutions with the legal and ethical rights of individuals to form families in accordance with their own values, including their views of genetic risks.<sup>124</sup>

## V. CONCLUSION

Given this lack of constitutional prohibition against sterilization of the supposedly genetically unfit, I suggest that the legal efforts to prevent the abuse of genetic knowledge in pursuit of genetic health must take place in other forums: legislatures and liability doctrine development. We can use the Tuskegee Syphilis Study and the “crimes against humanity” portion of the Nazi Doctors Case as guidelines for legal developments. At the moment, courts could use these guidelines in disease management cases to allow private individuals to exercise some control over genetics-oriented physicians/scientists. These processes of liability can be used to optimize the risks and benefits of the use of genetic knowledge.

On the legislative front, the tortured history of sickle cell anemia<sup>125</sup> should remind us that legislatures may not be good social optimizers of the risks and benefits of genetic knowledge. We should

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122. 247 U.S. 200 (1927); *see also supra* note 17 and accompanying text.

123. However, it has been almost entirely repudiated. *See, e.g., Fieger v. Thompson*, 74 F.2d 740, 750 (6th Cir. 1996).

124. This explains why I believe it is better to view the woman’s constitutional right to abortion as part of family formation instead of a “right” of privacy or autonomy. *See PALMER, supra* note 25, at 19-37; Palmer, *supra* note 64, at 167-73.

125. Screening for carriers of the disease began in the United States in the 1970s. The majority of programs were voluntary; however, a few states enacted legislation requiring screening for those with sickle cell anemia and the sickle cell trait. Congress passed the National Sickle Cell Anemia Control Act of 1972, Pub. L. No. 92-294, 86 Stat. 136, which provided funding for research and education. The act prompted many states to reverse their earlier call for mandatory screening. This act was then revised, updated, and renamed the National Sickle Cell Anemia, Cooley’s Anemia, Tay-Sachs, and Genetic Diseases Act of 1976, Pub. L. 94-278, 90 Stat. 407; *see James E. Bowman, Genetics and African Americans*, 27 SETON HALL L. REV. 919 (1997).

try to encourage a political agenda based on voluntary rather than mandatory participation in screening programs and resist attempts to immunize physicians/scientists from liability for failure to share genetic knowledge in hindsight adjudication.<sup>126</sup> There is some risk that the private market could exploit consumers/patients, but we should not allow our fears to prevent us from seeing that there is a separate but linked issue, that of equal access to health care. No matter how “good” our motives or intentions, we could adversely affect equal access to health care by trying to stop the attempt to eliminate genetic disability. To do so would be yet another example of “good” people creating “bad” systematic responses.

I hope that we will strengthen other social institutions, such as the family, to cope with the prospect of genetic disease management as we attempt to understand what is meant by “genetic health” for ourselves and for future generations.

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126. The current “malpractice crisis” in some states has caused organized medicine to put “tort liability” back on its political agenda. See Peggy Peck, *AMA Declares War on Malpractice Crisis* (June 26, 2002), at <http://my.webmd.com/content/article/1691.51255> (last visited Aug. 7, 2002) (on file with author). Whether there is in fact a liability crisis is, of course, subject to debate as it has been in previous so-called malpractice crises in the 1970s and 1980s.