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2001

## The Allure and Peril of Genetic Exceptionalism: Do We Need Special Genetics Legislation?

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### Recommended Citation

Sonia M. Suter, *The Allure and Peril of Genetic Exceptionalism: Do We Need Special Genetics Legislation?*, 79 Wash. U. L.Q. 669 (2001).

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**THE ALLURE AND PERIL OF GENETICS EXCEPTIONALISM:  
DO WE NEED SPECIAL GENETICS LEGISLATION?**

SONIA M. SUTER, M.S., J.D.<sup>1</sup>

**Introduction**

The Human Genome Project has been big news. After a much publicized race between the private and public sector, the human genome has been completely decoded. Much has been made of this accomplishment. Scientists promise that genetics will provide the key to understanding disease, the developmental and aging processes, and the human species. Ultimately, they hope it will prevent illness, help us tailor medicine to individual needs, and even extend human life.

But as sanguine as people are about the promise of genetics, they are even more captivated by its potential threats. Legal and bioethics scholars have written extensively about the dangers of genetics discrimination by insurers, employers, and society. The media also describe and scientists increasingly point out the perils of genetics. The public has absorbed these messages. My students, friends, family, and cocktail-party acquaintances are all versed on the possible sources of genetic discrimination. Policy makers, attuned to public sentiment, are no less aware of these fears. Responding to increased concerns about genetics discrimination and privacy, legislators have been extremely active in promoting genetics legislation. Although a few states have had narrow versions of genetics legislation in place since the 1970s, forty-four states currently have some form of legislation, most of it enacted in the last decade, that protects genetic information. In addition, numerous genetics bills have been introduced in Congress since 1995, though none has become legislation. To put it simply, public fears of genetics have

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intensified with the speed of genetic sequencing.

As we confront the newly-sequenced human genome, it is time to reassess the publicly shared discourse about the ethical, legal, and social implications of genetics. Nearly all discussions of the threats of genetics explicitly or implicitly suggest that the problems are as new and fresh as the technology underlying it. In other words, we face a brave new world not only of technology, but of social controversy. In the rush to identify and focus on the social implications, most discussions skip over the initial and essential question – is there really anything new here? Are we really in a brave new world of social and ethical issues, or does the new technology simply ask us to reexamine long-standing, persistent, and thorny social issues that we have never resolved?

The idea that genetic information is qualitatively different from other medical information and therefore raises unique social issues has recently been described as “genetics exceptionalism.” This notion is not merely abstract or theoretical but has dramatically influenced policy efforts at the state and federal levels in recent years. This article challenges this approach, arguing that concerns about genetics raise long-standing problems concerning privacy and discrimination. Policy makers, however, wrongly view these concerns as exceptional merely because the issues are cloaked in new technological guises. This article asserts that genetic information is not unique and that concerns about abuses of information should not be limited to genetic information, but should extend to other medical information.

The problem with genetics exceptionalism, however, is more serious than its underlying conceptual confusion about whether medical and genetic information are different. Not only is genetic information like other medical information, but treating the two differently under the law leads to unintended inequities between individuals and classes, raising serious questions about the propriety of public policy based on genetics exceptionalism. As we shall see, concerns about genetics discrimination and privacy are concerns primarily of the middle to upper classes. Not surprisingly, public policy that focuses solely on those concerns leaves unattended equally serious concerns about discrimination and privacy regarding medical risks that primarily affect the most disadvantaged in our society.

To understand fully the problem of genetics exceptionalism, one must consider its origins. Only a few scholars have begun to draw attention to the problem of genetics

exceptionalism and none has examined the various institutional forces that inspire and affirm this perspective. Part I therefore describes the allure of genetics exceptionalism among the media, popular culture, scientists, and policy makers. All of these groups contribute to and reinforce the mystical view of the gene as powerful and uniquely threatening. This perspective sparks the fear of genetics and has inspired a spate of genetics statutes at the state level and genetic bills at the federal level, all of which embody genetics exceptionalism.

As Part II will discuss, this genetics legislation poses drafting challenges. Defining genetic information so as to distinguish it from medical information is not easy, which squarely presents the question whether genetic information is *qualitatively* different. Part II argues that it is not. In fact, genetic information is an under- and over-inclusive category with respect to the policy concerns motivating genetics legislation. Not all genetic information requires protective legislation, making genetics legislation over-inclusive. More important, a great deal of other medical information shares many of the features of genetic information that have inspired this legislation, making it dramatically under-inclusive.

This under-inclusiveness, Part II argues, reflects the perils of genetics exceptionalism, first because it results in inequities between similarly situated individuals, and worse because it exacerbates class inequities. Until now, no one has fully fleshed out the problem of individual inequities or, more important, addressed the problem of class inequities, which is the most serious criticism of genetics legislation. Because genetics legislation only protects genetic information, those facing non-genetic risks will not be protected. While genetic risks transcend socio-economic class, non-genetic risks frequently do not. The poor and minorities face a disproportionate degree of non-genetic, environmental risks and therefore are disproportionately disadvantaged by laws that protect against discrimination based only on genetic risks.

Part II further advances the discussion of genetics exceptionalism by examining a plausible defense for this under-inclusiveness – namely, the incremental strategy of addressing one problematic issue at a time. This topic has received little scholarly attention in this context. While incrementalism can sometimes be a useful strategy, Part II offers reasons to doubt its ability to fulfill the promise of expanding the protections of genetics information to other medical information in light of the deeply entrenched perspective of genetics exceptionalism.

Given that incrementalism may not lead to the needed reform, Part III considers why we

should be particularly troubled by the under-inclusiveness of genetics legislation. This under-inclusiveness results in class and racial inequities that raise questions about important, though under-enforced, constitutional values and norms embodied in the Equal Protection Clause. Although such legislation would probably survive judicial review, equal protection *theory* nevertheless offers normative policy reasons legislators should find the inequities of genetics legislation morally problematic. Specifically, by attending to middle-class concerns, this legislation unintentionally, disproportionately disadvantages the poor and minorities with respect to fundamental interests in health care, employment, and privacy.

In order to avoid those inequities, Part III argues for more comprehensive protections that extend beyond genetic information. To achieve that goal, genetics must be demystified and the discourse about genetics among the public, media, and scientists must change. Rather than focus on genetics per se, policy makers should turn their attentions to the *features* of genetic information that make it seem uniquely threatening. As they do so, they will discover that these features apply to most other medical information. It is my hope, that this recognition will inspire efforts to address the problem of insurance/employment discrimination and privacy more broadly by focusing on medical information, rather than just genetic information. Part III suggests legislative approaches that avoid the inequities of genetics legislation by taking a broader focus of the problems of privacy and insurance/employment discrimination.

The recent privacy regulations promulgated by the Department of Health and Human Services under the authority of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) offer an ideal example. The federal privacy regulations protect *all* individually identifiable health information used or disclosed electronically or orally by health plans, health clearinghouses and health care providers. In other words, the regulations protect the most sensitive of medical information – identifiable medical information – and they include, but are not limited, to genetic information. The HIPAA privacy regulations, in short, avoid the trap of genetics exceptionalism.

In the wake of these regulations, which set a national “floor” of privacy standards, above which the states are free to set more stringent protections, states must begin to evaluate the relationship between their genetics privacy statutes and the HIPAA privacy regulations. This necessary reexamination of their privacy statutes provides an opportune moment for state

legislatures to rethink the trend of treating genetic information differently from other medical information. As a “reformed” genetics exceptionalist, I am hopeful that the federal example combined with education that changes the social norms and discourse that contribute to genetics exceptionalism will move state legislatures to reject a genetics exceptionalism approach and develop more comprehensive reform in the area of insurance/employment discrimination and privacy.

## **Part I. The Allure of Genetics Exceptionalism**

It is no accident that genetics exceptionalism is so alluring and pervasive. The gene evokes powerful images of promise and destruction, which are perpetuated in different ways by various institutions and which render the gene exceptional in the public’s eye. Because genetics exceptionalism is integral to the problems inherent in genetics legislation, Part I examines this perspective among the public, the media, scientists, and finally legislators. Each group is susceptible to and plays a special role in perpetuating this notion. Public perceptions are shaped by media messages and scientific statements; the media use images of genetics that appeal to the public; and scientists are attentive to public perceptions in trying to ensure funding for their work. Likewise, legislators respond to public concerns, media stories, and scientists’ messages, even as their legislation provides news material and shapes public views. In the end, a confluence of factors and institutional forces individually and synergistically shape and reinforce the notion that genetic information is uniquely threatening and susceptible to misuse.

### **A. Public Perceptions**

The public has a complicated, almost love-hate, relationship with genetics. It reveres and fears things genetic, as evidenced by popular culture’s portrayal of the gene as both sacred and powerful – a “cultural icon” as Dorothy Nelkin and M. Susan Lindee describe so persuasively in *The DNA Mystique*.<sup>2</sup> Underlying this view is a strong (and misguided) sense of genetic determinism, the notion that genes determine and explain everything about us. For many, genes define our essence, make us human,<sup>3</sup> and explain “our place in the world: our history, our social

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<sup>2</sup> DOROTHY NELKIN & M. SUSAN LINDEE, *THE DNA MYSTIQUE: THE GENE AS CULTURAL ICON* 2 (1995).

<sup>3</sup> *Id.* at 40 (quoting former director of the Human Genome Project and Nobelist,

relationships, our behavior, our morality and our fate.”<sup>4</sup> The popular culture is replete with evocative images of single genes with tremendous predictive and explanatory power. Headlines suggest that behavior such as infidelity might be in our genes<sup>5</sup> and the media report attempts to identify the “novelty-seeking gene,” the “homosexuality” gene, and the “aggression” gene.<sup>6</sup> Movies, cartoons, and science fiction also contribute to the notion that a tiny alteration of DNA determines behavior and traits.<sup>7</sup> These ideas have become part of our language. Not always in jest, we attribute complex traits and predilections to a single gene – the laziness gene, the obsessive gene, the gardening gene, the book gene, etc. – as if personal traits could be summed up neatly in a few thousand base pairs of DNA.<sup>8</sup>

If the public believes that genes can reveal one’s propensity to be unfaithful or a successful gardener, it should be no surprise that the public has great faith in the power of genetics to heal and cure social ills. Sixty-six percent of respondents in a 1986 Harris poll

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James Watson); *see also id.* at 44-46 (In movies such as *Blade Runner*, and comics like *DNAgents* and *the X-Men* “shared DNA is the essential characteristic defining humanness.”).

<sup>4</sup> *Id.* at 57. It promises to explain distinctions among groups and individuals, *id.* at 102-126, why some people are evil and others aren’t, *id.* at 83-101 (discussing evil and good genes); 127-48 (discussing genetics as an alternative explanation for criminal behavior, rather than poor parenting).

<sup>5</sup> *See, e.g., Infidelity: It May Be in Our Genes*, TIME MAGAZINE (Aug. 15, 1994) (cover story).

<sup>6</sup> *See* Keay Davidson, *No Easy Link Between Genes, Behavior*, SAN. FRAN. CHRON., Feb. 13, 2001, at A3. These studies and claims have been roundly criticized on methodological grounds. Behavioral genetics generally is highly controversial politically and scientifically.

<sup>7</sup> *See* NELKIN & LINDEE, *supra* note 2, at 44-46.

<sup>8</sup> *See id.* at 96-97, for wonderful examples, including the New York Times’ reference to the “poetry genes” of the Ginsberg brothers and an obituary explaining Isaac Asimov’s success as being “all in the Genes.” *See also* Philip R. Reilly, *Genetic Discrimination*, in GENETIC TESTING AND THE USE OF INFORMATION 127 (Clarisa Long, ed., 1999) (noting frequent “references to the ‘shopping’ gene, the ‘thrifty’ gene, and other biological absurdities”).

thought that “genetic engineering” would improve their lives.<sup>9</sup> Each new gene discovery offers the promise of cures, if not today, in the future. Often in the rush to promote this research, the media or scientists may leave the public with an inflated sense of genetics’ power to heal. Much of the public does not understand how far we still are from using our knowledge of genetics to cure diseases.<sup>10</sup> Moreover, the strong sense of genetic determinism reinforces the misperception that genetics alone holds the key to eradicating illness, when other important factors, such as environment and complex multigene interactions, are equally important.

The public’s perception of the power of genetics is not all positive, however. The horrific abuses of genetics in Nazi Germany and our own deeply problematic history with eugenics,<sup>11</sup> shroud genetics with a threatening aura. Less than a century ago, eugenics was viewed as a noble social engineering solution to combat social ills,<sup>12</sup> accepted within popular culture,<sup>13</sup> and legitimized by legislation in over thirty states prohibiting the “genetically inferior”

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<sup>9</sup> See Reilly, *supra* note 8, at 118.

<sup>10</sup> Gene therapy, for example was touted as being just around the corner in the mid 1980s. More than fifteen years later, scientists are struggling not only with the technical challenges of gene therapy, but recently with potential risks in the procedure. See Richard Weiss & Deborah Nelson, *Gene Therapy’s Troubling Crossroads*, WASH. POST, Dec. 31, 1999, at A3; Rick Weiss & Deborah Nelson, *Penn Settles Gene Therapy Suit*, WASH POST, Nov. 4, 2000, at A4; Rick Weiss, *FDA Seeks to Penalize Gene Scientist*, WASH. POST, Dec. 12, 2000, at A14.

<sup>11</sup> “The term ‘eugenics’ was coined by the British scientist and mathematician Sir Francis Galton in 1883. The word originates from the Greek root for ‘noble or good in birth’ and was understood as the science of improving the hereditary quality of a race or breed. Howard Markel, *The Stigma of Disease: Implications of Genetic Screening*, 93 AM. J. MED. 209, 210-11 (1992).

<sup>12</sup> See Paul Lombardo, *Medicine, Eugenics, and the Supreme Court*, 13 J. CONT. HEALTH L & POL’Y 1, 2 (1996) (noting that physicians were the strongest proponents of eugenics).

<sup>13</sup> “Eugenics was not a single idea but a thousand ideas, not a simple, coherent doctrine but a messy public discussion that served many agendas.” NELKIN & LINDEE, *supra* note 2, at 20. To understand the eugenics movement, one must consider the “broad popular interest” in the subject. *Id.* at 21. The American Eugenics Society sponsored a nationwide system of “mental and physical perfection contests,” in which babies were judged based on physical

from reproducing.<sup>14</sup> Indeed, even the Supreme Court, in the now notorious opinion, *Buck v. Bell*,<sup>15</sup> promoted the virtues of eugenics when Justice Holmes upheld such a statute on the grounds that “three generations of imbeciles are enough.”<sup>16</sup>

Even our more recent history with genetics is not untarnished. In the 1970s, state legislatures began to mandate genetic screening of African Americans for sickle cell anemia, an inherited disease that occurs most commonly in people of African descent.<sup>17</sup> Although the initial impetus for such legislation came from African American leaders and was grounded in public health concerns, the legislation proved to be poorly thought out with extreme negative implications.<sup>18</sup>

This unfortunate history contributes to the fears of genetic discrimination, which is very

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measurements and physical tests. Similar contests were held at state fairs for “fitter families,” all with the goal of encouraging the eugenic ideal. *Id.* at 27.

<sup>14</sup> Lombardo, *supra* note 12, at 5. Eugenics efforts took many forms including the Federal Immigration Restriction Act, enacted in 1924 “to combat ‘the rising tide of defective germ-plasm’ carried by suspect groups migrating from Southern and Eastern Europe.” *Id.* Eugenics was ostensibly based on legitimate scientific study. In fact, most “genetic” claims were based on unfounded extrapolations of genetics, poor scientific studies, or sometimes mere assumptions. Early geneticists grossly overstated the role of genetics with respect to such characteristics as criminality, laziness, and other moral transgressions. NELKIN & LINDEE, *supra* note 2, at 19-37.

<sup>15</sup> 274 U.S. 200 (1927).

<sup>16</sup> *Id.* at 207. This case has never been formally overturned. Moreover, “the validity of eugenically-founded, hereditary assumptions as a basis for law,” Lombardo, *supra* note 12, at 19, remains a more or less subtle strand in reproductive rights cases, even as recently as *Roe v. Wade*. *Id.* at 12-24.

<sup>17</sup> Markel, *supra* note 11, at 212.

<sup>18</sup> Several criticisms were leveled at these statutes (and even those that made genetic testing voluntary): the fact that testing was limited to only African Americans, when other ethnic groups, such as those of Mediterranean origin, can also carry the gene; the “scientific inaccuracy” of much of the legislation, which led to confusion and stigmatization of unaffected carriers of the disease gene (those who had one, as opposed to two, copies of the disease gene); and the lack of protective safeguards to ensure confidentiality of results, genetic counseling, and education. *See id.* at 213.

much on the minds of Americans.<sup>19</sup> A recent film, *GATTACA*, taps into this public unease by describing a world in which “genoism” – discrimination based on genes – is rampant, despite its illegality. Virtually all choices and options are defined largely in terms of genetic make-up, which can predict at birth one’s abilities, future diseases, and when one will die. Discrimination, the narrator tells us, had become a science, leading to a new underclass of “degenerates.” *GATTACA* describes precisely the world the public fears could become reality with genetic technologies.<sup>20</sup>

As this admittedly brief and simplified description suggests,<sup>21</sup> the public perceives genetics as uniquely powerful, both for good and bad. Its strongly deterministic view of genes intensifies the sense that genetic information is uniquely threatening and susceptible to misuse. As is developed in more detail below, the media and scientific community contribute to this

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<sup>19</sup> A 1992 Harris poll indicated that 38% of respondents thought that until privacy concerns had been resolved, genetic testing should be stopped. Another 1992 poll indicated that 99% of respondents did not believe that employers should be able to screen prospective employees for genetic conditions. The numbers reduced to 60% if the screening was for possible health risks. In 1993, a Harris/Westin poll showed that 91% of respondents did not believe genetic information should be used by employers to reduce health benefit costs, and 86% opposed genetic testing by health insurance companies for underwriting decisions. Reilly, *supra* note 8, at 118-19. Interestingly, some of these surveys also show that the majority of employers and insurers – the entities that most inspire fear of genetic discrimination – do not believe they should be allowed to discriminate on the basis of genetic information. *Id.* at 120.

<sup>20</sup> A related fear concerns reproductive uses of genetics and other advanced technologies. In my many discussions about genetics with students or lay people, very little time passes before they recast their concerns about genetic discrimination as concerns about genetic selection, genetic enhancement, or cloning. Although most find these technologies repugnant, I suspect it is not genetics per se that troubles them as much as the tinkering with human reproduction. In my view, however, it is a mistake to confuse the use of genetic information to construct a particular kind of individual with using genetic information for insurance or employment purposes. The two, I believe, raise conceptually, ethically, and scientifically different issues, which are beyond the scope of this article.

<sup>21</sup> I recognize that such a brief discussion cannot capture the complexity and breadth of views that exist in a pluralistic society such as ours. There is not a single public, nor even a single popular culture, but instead a complex and overlapping mix of groups within each. How anyone understands and conceives of genetics has a great deal to do with one’s level and degree of scientific and general education.

perspective.

## **B. The Media**

The media play a significant role in shaping public perceptions about genetics in large part because they offer one of the few sources of such information for a public remarkably uneducated about genetics. Of course, a chicken and egg problem exists. The media's decisions about which stories to publish and how to package them are influenced by public attitudes. And public attitudes are influenced by the stories and manner in which they are told. Whether the media's coverage of genetics captures the public's imagination because of DNA's sacred role in our secular society or whether such coverage makes DNA sacred is difficult to unpack.

Whichever element initiated this cycle, one thing is clear: stories about genetics sell. But more importantly, stories that emphasize the *power* of genetics sell. In the early days of the Human Genome Project (prior to 1993!), front-page headlines announced the discoveries of new genes and the promise of cures for physical and social ills.<sup>22</sup> As the identification of new genes became almost common place, stories about genetic's promise lost some of their edge. It was not long before the media discovered another angle – “how genetics can be used against you.”<sup>23</sup> After a seminal study on genetics discrimination was published in 1992,<sup>24</sup> the perils of genetics became grist for the media's mill.<sup>25</sup> Although the media still waxed poetic about genetics'

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<sup>22</sup> See *Cystic Fibrosis Gene Possibly Identified, Scientists Report*, SAN DIEGO UNION-TRIB., Apr. 30, 1987, at A3; Thomas Maugh, *Faulty Gene That Causes Gehrig's Disease is Found*, L.A. TIMES, Mar. 4, 1993, at A1; Thomas Maugh, *Genetic Marker Helps Pinpoint Causes of Huntington's*, L.A. TIMES, Nov. 16, 1987, at 5; See, e.g., Mike Toner, *Fragile X Defect Gene Discovered*, ATLANTA J & CONST., May 30, 1991, at A1.

<sup>23</sup> Mike Snider, *How Genetics Can be Used Against You*, USA TODAY, Nov. 17, 1993, at 9D.

<sup>24</sup> Paul Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENET. 476 (1992). The study defines genetic discrimination as “discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the ‘normal’ genome of that individual.” *Id.* at 477.

<sup>25</sup> My research assistant's LEXIS-NEXIS search for newspaper articles on genetics discrimination prior to 1993 was unsuccessful. A search for stories from 1993 on yielded more than 300 hundred articles. In addition, she observed a frequent pattern in which discussions of

promise, most stories concluded with strong words of caution about the threats to privacy and liberty this new technology presents.<sup>26</sup> In particular, articles focused on stories about people losing health insurance or jobs based on genetic tests or information. In short, the media began to give an “avalanche of attention [to problems like] genetic discrimination.”<sup>27</sup>

The formula for stories on genetics today is captured in the title of a few articles, “The Promise and Peril” of genetics.<sup>28</sup> This format offers a compelling image of science as deliverer of good and evil, consistent with the popular culture’s conception of genetics. The media promise that genetics will both provide ready, potent cures for disease and pose dark threats of insurance and employment discrimination. The media’s emphasis on both promise and peril, however, is often overstated and sometimes imprecise, contributing to the public’s sense that genetics is exceptionally powerful.

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the promise of genetic discoveries were followed by concerns regarding discrimination.

<sup>26</sup> See, e.g., Richard Saltus, *Dana-Farber Launches Cancer Genetics Unit*, BOST. GLOBE, Feb. 14, 1995, at 2 (noting the important role of genetics in cancer, but mentioning that research participants will have the added worry of discrimination); Rick Weiss, *Colon Cancer Gene Test Still Has a Way to Go*, WASH. POST, Dec. 7, 1993, at Z7 (describing the identification of the gene associated with inherited colon cancer and concluding with concerns about insurance discrimination based on the presence of this gene); Thomas Maugh, *Unraveling the Secrets of Genes*, L.A. TIMES, Oct. 31, 1993, at A1 (noting the numerous genes that had been discovered by that point, including cystic fibrosis and Duchenne’s muscular dystrophy, and closing with concerns about potential discriminatory uses of this information); Lisa Goldstein, *If You Knew Your Child Would be Born Deaf . . .*, SAN FRAN. CHRON., Feb. 1, 1999, at A19 (discussing the advantages of identifying a gene linked to deafness, and ending with a discussion of the possible discrimination that could result from screening for such traits).

<sup>27</sup> Reilly, *supra* note 8, at 117. So important has this angle on genetics become that journalists frequently call scholars like Reilly, hoping to identify someone who has been discriminated against. *Id.* at 118. Reilly concludes that “journalists are desperate to find . . . citizens who will make that claim.” *Id.*

<sup>28</sup> Sherman G. Finesilver, *The Promise and Perils of Genetics*, DENVER ROCKY MOUNTAIN NEWS, Sep. 6, 1996, at 49A; Susan Ferraro, *Promise and Peril in Gene Therapy*, DAILY NEWS, Jun. 4, 2000, at N24; Perry Greenbaum, *Promises and Perils: Scientists Discoveries Cause Delight, Caution as They Decode the Human Genetic Blueprint*, THE GAZETTE, Apr. 24, 1999, at S4; Robert Steinbrook, *The Promise and Peril of New Genetic Screening*, L.A. TIMES, Nov. 1, 1993, at A1.

Genetics is neither as close to curing physical and social ills as the media promises nor as close to wreaking havoc as it warns. The identification of new genes is still many long and complicated steps away from the possibility of treatment. Gene therapy, for example, touted as near success in the mid 1980s, has proven not only elusive but possibly riskier than imagined.<sup>29</sup> In fact, just understanding the role of genes in disease has proven exceedingly complex, particularly as we identify genes associated with multifactorial conditions (which most medical conditions are) in which environment and multiple other genes play important and complex roles.<sup>30</sup>

The media exaggerate not only the promise of genetics, but also the threats of genetic discrimination, which are based on only a few studies. The media and many commentators interpret these studies as strong evidence of current insurance and employment discrimination based on genetic information. Yet, inherent methodological problems make it difficult to conclude much from these studies for several reasons.<sup>31</sup> First, the studies rely only on self-reported incidents of discrimination.<sup>32</sup> The impossibility of confirming the alleged reasons for denial of insurance or employment limits the data's persuasiveness. Second, the method of

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<sup>29</sup> See *supra* note 10.

<sup>30</sup> “In the study of human diseases with a genetic component, complexity has become the rule rather than the exception.” Jon Beckwith & Joseph Alper, *Reconsidering Genetic Antidiscrimination Legislation*, 26 J.L. MED. & ETHICS 205, 208 (1998). Even some of the apparently most straight-forward genetic diseases have turned out to be far more complex than imagined. For example, after scientists discovered the gene for cystic fibrosis, a recessive, inherited condition, they learned that cystic fibrosis gene did not always (as prior understanding had held) result in cystic fibrosis, but might lead only to infertility or asthma. Gina Kolata, *Cystic Fibrosis Surprise: Genetic Screening Falter*, N.Y. TIMES, Nov. 16, 1993, at C1. Dr. Norman Fost concluded that these findings demonstrate that “there is, in fact, no such thing as a single-gene disorder.” *Id.* Instead, genes work together with environment in complex ways that vary from individual to individual.

<sup>31</sup> Overcoming these methodological problems would be next to impossible.

<sup>32</sup> Two of the most widely cited studies based their conclusions entirely on self-reporting, without any attempt to confirm claims of alleged discrimination. See Reilly, *supra* note 8, at 110, 114-115.

soliciting survey participants<sup>33</sup> biases the data, making meaningful statistical conclusions impossible.<sup>34</sup> Finally, the actual number of reported incidents of discrimination represents only a very small fraction of the surveyed group,<sup>35</sup> giving pause to claims that genetic discrimination is so widespread.

In the end, these surveys offer only anecdotal accounts of genetic discrimination that cannot be objectively confirmed or rejected. And indeed, some data – though equally susceptible to the same methodological attacks – suggest that most insurers and employers are not *currently*

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<sup>33</sup> *Id.*

<sup>34</sup> Survey participants were solicited via advertisements in journals and newsletters for genetics professionals and genetic disease support groups, for example. Reilly, *supra* note 8, at 115 (“[N]o attempt was made at random sampling from among that larger cohort.”); Beckwith & Alper, *supra* note 30, at 205-206.

<sup>35</sup> One commentator concludes that the first and most widely cited study “is remarkable for how few incidents of genetic discrimination it was able to discover.” Reilly, *supra* note 8, at 110. Solicitations were mailed to 1,119 professionals in genetics or related areas and to genetics support groups (presumably the most likely to have contact with individuals at risk of genetic discrimination). Yet, after just over half a year, the research group received only 29 usable responses, reporting 41 incidents of insurance (32 incidents) or employment (7 incidents) discrimination. *Id.* at 109. Another study conducted four years later, sent survey instruments to 27,700 individuals who were either at risk of a genetic condition or parents of children with genetic conditions. Lisa Geller et al., *Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis*, 2 SCI. & ENGINEERING ETHICS 71 (1996). Nearly 50% (455) of the 917 respondents claimed to have suffered discrimination, which is only 1.7% of the surveyed population. Reilly, *supra* note 8, at 114.

Of course it is possible that these numbers under-represent the incidence of genetic discrimination. Under-reporting might occur, particularly among parents of children with genetic conditions, who may be so fully consumed with the day-to-day tasks of caring for their children that they simply have no time to answer surveys on discrimination. In addition, having to mail in replies and do more than just check boxes may have dissuaded some from responding to surveys. After spending hours battling insurers, one might be understandably reluctant to write about the experience. See Ellen Wright Clayton, *Comments of Philip R. Reilly’s “Genetic Discrimination,”* in GENETIC TESTING AND THE USE OF INFORMATION 134-35 (Clarisa Long, ed., 1999). In the end, it is impossible to determine exactly how to explain the currently low incidence of accounts of genetic discrimination.

using genetic testing or information.<sup>36</sup> That the media significantly overstate the incidence of genetic risks is not surprising. A nuanced discussion of the methodological limitations of these studies is far less compelling than descriptions of anecdotal accounts of genetic discrimination. Instead, the dramatic anecdotes have become rich material for news stories on genetics discrimination.<sup>37</sup> Americans love to hate their villains, especially when they include large corporate entities, such as insurance companies, which are already in public disfavor.<sup>38</sup> As a result, in spite of uncertain evidence of genetic discrimination, virtually all media reports of genetics describe the risk as currently threatening. These anecdotes touch a chord in a public already sensitized to the view that genetics concerns are uniquely problematic.

To be fair, even if genetic discrimination is not currently a significant problem, the future remains uncertain. As our understanding about the clinical significance of various disease genes increases, genetic tests will improve and become more prevalent and cost-effective. Potentially vastly increasing numbers of individuals will undergo genetic testing. Insurers and employers

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<sup>36</sup> See Beckwith & Alper, *supra* note 30, at 206. A 1983 survey showed that only 6% of 366 large industrial companies had even conducted genetic tests. 1983 OTA Report. A study conducted ten years later demonstrated that very few life insurers were conducting genetic tests. Although insurers were interested in *existing* information of applicants, the survey showed that little actuarial data existed for underwriting decisions based on genetic information. Jean McEwen et al., *A Survey of Medical Directors of Life Insurance Companies Concerning Use of Genetic Information*, 53 AM. J. HUMAN GENETICS 33 (1993). Similarly, a survey of insurance commissioners turned up “only a minuscule number” of complaints regarding genetic discrimination. Reilly, *supra* note 8, at 112. One reason for this might be the limited number of genetic tests currently available and the fairly high cost of genetic testing, which might change in the future. See *infra* TAN 38. Another explanation might be employer and insurer norms against genetic testing and discrimination either because they believe it is morally wrong or because they are concerned about negative public relations in being perceived as discriminating based genetics.

<sup>37</sup> See David A. Hyman, *Lies, Damned Lies, and Narrative*, 73 IND. L.J. 797 (1998) (discussing the power of anecdotes to influence and shape public policy).

<sup>38</sup> See David A. Hyman, *Regulating Managed Care: What’s Wrong With a Patient Bill of Rights*, 73 S. CAL. L. REV. 221, 237-244 (2000) (describing the public’s strong dislike, even hatred, of managed care organizations).

may be far more interested in using this information as it becomes more meaningful.<sup>39</sup> Although the actuarial value of this information will likely be weaker than the public imagines,<sup>40</sup> insurers or employers may still want to use some of this information.<sup>41</sup>

Whether genetic discrimination will become problematic in the future is less important for this discussion than the fact that the media overstate both the promise and current risks of genetic discrimination, reinforcing genetics exceptionalism.

### C. The Scientific Community

The media are not alone in perpetuating the image of genetics as powerful. In subtle and less subtle ways, the scientific community has also contributed to this perspective. Funding decisions, scientists' genuine interest in minimizing the threats of their technology, and scientists' understandable faith in the value of their enterprise reinforce the public's sense that genetic information is fraught with risk and full of promise.

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<sup>39</sup> See Beckwith & Alper, *supra* note 30, at 206 (noting that as a consequence of "the availability of a rapidly growing number of genetic tests for a wide variety of diseases . . . an ever increasing number of people will lose insurance or will not be able to afford the higher premiums charged because of their genetic susceptibility."). *But see* Catherine Arnold, *Britain Backs Insurers' Use of Genetic Testing*, NATIONAL UNDERWRITER, Nov. 27, 2000, at 10 (describing the decision of the Genetics and Insurance Committee of Britain's health ministry not to ask insurers to withdraw the use of test results for HD, although insurers are not permitted under their code of practice to require such genetic tests). Recently the EEOC alleged that a company was performing genetic tests, without consent, on employees who filed claims for work-related injuries based on carpal tunnel syndrome. *See* Sarah Schafer, *EEOC Sues to Halt Worker Gene Tests*, WASH. POST, Feb. 10, 2001 at A1. The case was ultimately settled. *See infra* note 353.

<sup>40</sup> Most common chronic diseases are multifactorial, which means that multiple genes and environment work together in complex ways to create disease. Even genes associated with increased risks of cancer or other conditions, may prove highly unreliable in predicting the risks for any individual person, given that so many different mutations exist, and that the same mutation may express differently from individual to individual. *See* H. Gilbert Welch & Wylie Burke, *Commentary: Uncertainties in Genetic Testing for Chronic Disease*, 280 JAMA 1525, 1526 (1998).

<sup>41</sup> Actuarial decision making, for example, is more art than science. *See* John V. Jacobi, *The Ends of Health Insurance*, 20 U.C. DAVIS L. REV. 311, 329 (1997). The few anecdotal instances of genetic discrimination appear to be based primarily on misconceptions

One of the more subtle factors influencing the genetics exceptionalism perspective is the fact that the Human Genome Project has allocated five percent of its \$3 billion budget to explore the ethical, legal and social issues associated with genetics.<sup>42</sup> The inspiration for this remarkable and novel occurrence in the history of science was undoubtedly mixed. Although legitimate concern about the social impact of scientific research largely drove this effort,<sup>43</sup> public relations must also have been a motivator. Whether intentional or not, the plan to set aside a portion of the Human Genome Project funds for ethical and legal studies was politically astute given the public's fears about genetic technologies.<sup>44</sup> Dr. Watson, the first director of the human genome project office at the National Institutes of Health ("NIH"),<sup>45</sup> was certainly aware of the success of prior "scientific self-policing" efforts in genetics, which many viewed as a model of scientific integrity.<sup>46</sup> Many regarded the decision as "a laudable willingness to look beyond the laboratory

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about the meaning of the data. *See Beckwith & Alper, supra* note 30, at 206.

<sup>42</sup> "The ELSI program budget increased from 3% in fiscal year (FY) 1990 (\$1.5 million) to 4.7% in FY 91 to an average of 5.1% in fiscal years 92-95 (\$6.3 million in FY 1995)." National Human Genome Research Institute, *Review of the Ethical, Legal and Social Implications Research Program and Related Activities (1990 -1995)* at 4 [hereinafter *NHGRI, Review*]; Nicholas Wade, *Reading the Book of Life: A Historic Quest*, N.Y TIMES, Jun. 27, 2000, at F5 [hereinafter *Wade, A Historic Quest*] (The allocation was increased from 3 to 5 percent of the genome project budget.).

<sup>43</sup> Certainly, many proponents saw value in preparing society to address the moral, legal, or social issues the technology might raise – particularly in light of a recent and problematic past with genetics research in our country and others. *See supra* TAN 10-18.

<sup>44</sup> It is difficult to attribute precise motivations to this decision since Dr. James Watson first announced the plan in response to an anonymous reporter's question at a press conference. Eric T. Juengst, *Self-Critical Federal Science? The Ethics Experiment Within the Human Genome Project*, 13 SOC. PHIL. & POL'Y 63, 63, 65 (1996). Whether the question coincided with his plans or whether it inspired the idea is not clear.

<sup>45</sup> Wade, *A Historic Quest, supra* note 42, at F5.

<sup>46</sup> A few decades ago, scientists self-imposed a voluntary moratorium on early recombinant DNA research in response to public concerns about the dangers of this new technology. *See* Juengst, *supra* note 44, at 68 & n.12. More recently, the scientific community has adopted another self-imposed moratorium with respect to human reproductive cloning.

in conducting scientific work, in order to help society craft its science policy.”<sup>47</sup> But the plan was also met with skepticism, both within and outside the NIH. Some described it as “simply enlightened scientific self-interest”<sup>48</sup> or “a clever attempt to create a screen of ethical smoke behind which the Human Genome Project’s juggernaut could build up speed.”<sup>49</sup> Either description seems simplistic. Undoubtedly both a genuine commitment to consider the social impact of genetics research and a desire to build public trust so as to maintain continued support for the Human Genome Project influenced the creation of ELSI.<sup>50</sup>

Whatever the motivations, the creation of ELSI and its *raison d’être*<sup>51</sup> have inspired a particular brand of scholarship that contributes to the genetics exceptionalism perspective. Money allocated for the ethical, legal, and social issues of genetics ultimately encourages scholarship that identifies *genetics issues*.<sup>52</sup> Such a focus emphasizes the putative *uniqueness* of genetics issues and the fact that genetics raises *problems*. Even if the scholarship does not explicitly state that genetics raises distinct issues,<sup>53</sup> the vast number of articles addressing

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<sup>47</sup> *Id.* at 68.

<sup>48</sup> *Id.*

<sup>49</sup> *Id.* at 67. One senior NIH official asked Dr. Watson why he wanted ““to spend all this *money* subsidizing the vacuous pronouncements of self styled “*ethicists*”!”” *Id.* at 66. Another response was ““What’s the big deal about all this ethical and legal stuff?”” Robert Weir, *Why Fund ELSI Projects?*, in *GENES AND HUMAN SELF-KNOWLEDGE: HISTORICAL AND PHILOSOPHICAL REFLECTIONS ON MODERN GENETICS* 189 (Robert F. Weir et al. eds., 1994).

<sup>50</sup> “To the extent that the social environment of genetic research can influence their work, it makes sense for scientists to pay attention to developing a social context in which genetic research can flourish.” Juengst, *supra* note 44, at 68.

<sup>51</sup> ELSI’s creation was based on the recognition “that mapping and sequencing the human genome would have profound implications for individuals, families, and society. . . . and concern that information would be gained that might result in anxiety, stigmatization and discrimination . . . .” *NHGRI, Review, supra* note 42, at 2.

<sup>52</sup> “Implications” is after all what the “I” in ELSI stands for.

<sup>53</sup> Watson hinted at this fact when he established ELSI, stating that “The

insurance discrimination,<sup>54</sup> employment discrimination,<sup>55</sup> and privacy<sup>56</sup> can leave that

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[ethical/social] problems are with us now, independent of the genome program, but they will be associated with it.” Leslie Roberts, *Genome Project Gets Underway at Last*, 243 SCI. 167, 167-68 (1989). Dr. Eric Juengst, the first director of the ELSI program, notes that many of the challenges raised by genetics technology have long existed in biomedical research and clinical care, though he believes that because of “the special public interest and concern . . . need to be addressed if only for prudential reasons.” Juengst, *supra* note 44, at 72.

<sup>54</sup> See, e.g., Norman Daniels, *The Genome Project, Individual Differences and Just Health Care*, in JUSTICE AND THE HUMAN GENOME PROJECT 114-115 (Timothy F. Murphy & Marc A. Lappé eds. 1994); Alexander K. Glazier, *Genetic Predispositions, Prophylactic Treatments and Private Health Insurance*, 23 AM. J. L. & MED. 45 (1997); Kathy L. Hudson et al., *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, 270 SCIENCE 391 (1995); Nancy E. Kass, *The Implications of Genetic Testing for Health and Life Insurance*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 299 (Mark A. Rothstein ed., 1997); Thomas H. Murray, *Genetics and the Moral Mission of Health Insurance*, HASTINGS CTR. REP., Nov.-Dec. 1992, at 12; Robert J. Pokorski, *Insurance Underwriting in the Genetic Era*, 60 AM. J. HUMAN GENETICS 205, 208-09 (1997); Karen H. Rothenberg, *Genetic Information and Health Insurance: State Legislative Approaches*, 23 J.L. Med. & Ethics 312 (1995).

<sup>55</sup> See, e.g., Council on Ethical and Judicial Affairs, American Medical Association, *Use of Genetic Testing by Employers*, 266 JAMA 1827 (1991); Lori B. Andrews & Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J.L. & MED. 75 (1991); Mark S. Dichter & Sarah E. Sutor, *The New Genetic Age*, 42 VILLANOVA L. REV. 613 (1997); Jill Gaubling, *Race, Sex, and Genetic Discrimination in Insurance: What’s Fair?* 80 CORNELL L. REV. 1646 (1995); Lawrence O. Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109 (1991); Paul Steven Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL’Y 225 (2000); Mark A. Rothstein, *Genetic Discrimination in Employment and the American with Disabilities Act*, 29 HOUSTON L. REV. 23 (1992).

<sup>56</sup> See, e.g., George J. Annas et al., *The Genetic Privacy Act and Commentary* (unpublished, D.O.E. No. DE-FG02-93ER6126, Feb. 28, 1995); Lawrence O. Gostin, *Genetic Privacy*, 23 J.L. MED. & ETHICS 320 (1995); Ami S. Jaeger & William F. Mulholland, II, *Impact of Genetic Privacy Legislation on Insurer Behavior*, 4 GENETIC TESTING 31 (2000); Karen Ann Jensen, *Genetic Privacy in Washington State: Policy Considerations and Model Genetic Privacy Act*, 21 SEATTLE U. L. REV. 357 (1997); Michael M.J. Lin, Note, *Conferring a Federal Property Right in Genetic Material: Stepping into the Future with the Genetic Privacy Act*, 22 AM. J.L. & MED. 109 (1996); Michael Hugh Miller, III, *DNA Blueprints, Personhood, and Genetic Privacy*, 8 HEALTH MATRIX 179 (1998); William F. Mulholland, II & Ami S. Jaeger, *Genetic Privacy and Discrimination: A Survey of State Legislation*, 39 JURIMETRICS J. 311 (1997); Patricia Roche et al., *The Genetic Privacy Act*, 37 JURIMETRICS 1 (1996); GENETIC SECRETS (Mark Rothstein ed.,

impression. This effect is magnified by the fact that ELSI funding “represents the largest expenditure of money for biomedical ethics and health law in the country.”<sup>57</sup> The prospect of an ELSI grant surely makes genetic issues more enticing to scholars who might otherwise have focused on other issues in biomedicine and health policy. The research focus is further shaped by the nature of ELSI’s high priority areas, which during its first five years were privacy and fair use of genetic information.<sup>58</sup> Not surprisingly, numerous articles soon addressed these concerns, with particular attention to insurance and employment issues. The influence of ELSI on research is so strong that some worry it could “distort research in bioethics.”<sup>59</sup>

As research focuses on genetics issues, the more trendy the topic becomes; consequently more is written about it, creating a spiraling effect. Even if all of the scholarship is not explicitly premised on notions of genetics exceptionalism,<sup>60</sup> the plethora of articles, books, and essays on

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1997).

<sup>57</sup> Weir, *supra* note 49, at 189 (noting that the ELSI funds enable “ethicists, attorneys, and social scientists to have an unprecedented opportunity to do funded research”). See also *NHGRI, Review, supra* note 42, at 4.

<sup>58</sup> *NHGRI, Review, supra* note 42, at 1-2. The other three priority areas are integration of new genetic technologies in clinical care, genetics research issues, and public and professional education. *Id.*

<sup>59</sup> See George Annas & Sherman Elias, *Social Policy Research Priorities for the Human Genome Project*, in *GENE MAPPING* 275 (George Annas & Sherman Elias eds. 1992) (quoting Eric Landers, who when asked if the Human Genome Project would distort research for molecular biology, replied that “It is much more likely to distort research in bioethics”); Juengst, *supra* note 44, at 69 (An “ELSI program could distort the research agenda of bioethics, by attracting scholarly attention to issues that, in the grand scheme of current issues in biomedicine and health policy, might not merit top priority.”).

<sup>60</sup> Indeed a small amount of the scholarship and policy work supported by ELSI is explicitly opposed to genetics exceptionalism. For example, the Joint NIH-DOE Working Group on the Ethical, Legal, and Social Implications (ELSI), Task Force on Genetic Information and Insurance noted that the concerns regarding genetics discrimination in insurance applied equally to other medical information. NIH-DOE, WORKING GROUP ON ETHICAL, LEGAL & SOCIAL IMPLICATIONS OF HUMAN GENOME RESEARCH, GENETIC INFORMATION AND HEALTH INSURANCE, REPORT OF THE TASK FORCE ON GENETIC INFORMATION INSURANCE (1993) [http://www.nhgri.nih.gov/About\\_NHGRI/Der/Elsi/itf.html](http://www.nhgri.nih.gov/About_NHGRI/Der/Elsi/itf.html) (visited 6/9/01). In addition, the

the topic intensifies the media's attention to genetics issues and public fears about genetics.<sup>61</sup> At the very least, the fact that so much has been written about genetics and the absence of similar government programs to study other issues in biomedical research might suggest that something unique is at stake.<sup>62</sup> Whether or not ELSI was premised on this notion, the effect has been to promote a discourse that addresses the issues solely in terms of genetics, reinforcing the genetics exceptionalism perspective among the public, media, and legislators.

Although ELSI may have contributed to this perspective, the genetics research community has also reinforced the public's sense of the power and possibility of genetic information. The very fact that three billion dollars were allocated to decode the human genome reveals both Congress's and many scientists' faith in the great value of genetics research.<sup>63</sup> The

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article coining the term "genetics exceptionalism" first appeared in Thomas Murray, *Genetic Exceptionalism and "Future Diaries,"* in GENETIC SECRETS 68 (Mark Rothstein ed., 1997), a book which was funded with an ELSI grant. The examples are minimal, however, when compared with the vast amount of literature that focuses specifically on genetics concerns.

<sup>61</sup> Some worry that ELSI projects can lead to "alarmist hype." Juengst, *supra* note 44, at 64. In Watson's defense of the ELSI project, he noted that the cat – the public's ethical concerns about genetics – was already out of the bag, to which one NIH official responded "'But why *inflate* the cat? Why put the cat *on TV*?" (quoted in *id.* at 66); *see also id.* at 70.

<sup>62</sup> My point is not that the creation of ELSI was inherently problematic, for I see the wisdom of proactive contemplation of the social consequences of new technologies (although I would question whether such study should be limited only to one new technology). *See id.* at 71-72 (observing that if genetic concerns mirror those in other areas, one conclusion might be to extend the ELSI approach to all institutes of NIH). One might also wonder whether such proactive study should be funded by the very entity conducting the research, which creates disincentives against critiquing the research. *See id.* at 64, 67. Those problems aside, I am sympathetic to the Catch-22 problem for scientists. To avoid addressing the social and ethical concerns would be politically unwise and might inspire public mistrust. The public wants to know that scientists are considering their interests. In trying to allay public fears by studying these issues, however, they focus attention on the negative implications of a new technology and may unintentionally validate and strengthen public fears.

<sup>63</sup> Some have criticized the big science approach to genetics as creating its own distortions of biological research. NIH funding in general has increased recently, reflecting Congress' and scientists' enthusiasm for medical research in general.

research community's deep faith in the integrity and value of genetics research and knowledge<sup>64</sup> inspires grandiose claims about genetics in the efforts to promote public support and funding.<sup>65</sup> Scientists' understandable enthusiasm is often translated by the press as grand promises that genetics will unravel the mysteries of the body to eliminate illness and even social ills, such as homelessness.<sup>66</sup> From day one, the scientific community has proselytized the public with promises of genetics, often recruiting biblical or religious images that infuse the terms "genetic" and "genes" with mystique and iconic status.<sup>67</sup> These sometimes hyperbolic statements make good press and shape the public imagery associated with the all-powerful gene.

Consider, as one small example, the way in which this scientific enthusiasm, combined with media hype, surrounded the completion of the *rough* draft of the human genome. The announcement itself was "carefully orchestrated"<sup>68</sup> by the leaders of the genome projects both to show that success had been achieved earlier than expected and to dispel concerns about growing

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<sup>64</sup> Juengst, *supra* note 44, at 68 (Whether one accepts the more laudable or more crass motivation, the rationale for "supporting social-impact studies assumes that the enterprise of genetic research itself and the knowledge to be generated by it are unalloyed prima facie goods.").

<sup>65</sup> See Jon Beckwith, *The Human Genome Initiative and the Impact of Genetic Testing and Screening Technologies*, 17 AM. J.L. & MED. 1, 5 (1991).

<sup>66</sup> Daniel Koshland, the former editor of SCIENCE, has been frequently cited for his statement that "[t]he homeless problem is tractable. One third of homeless are mentally ill – some say 50%. These are the ones who can most benefit from the human genome project." His rationale is that mental illness has a genetic basis, and therefore the Human Genome Project can help us uncover the underlying cause of homelessness. Cited in Jon Beckwith, *A Historical View of Social Responsibility in Genetics*, 43 BIOSCIENCE 327 (1993); see also Daniel Koshland, *Sequences and Consequence of the Human Genome*, 246 SCI. 189 (1989). Of course this statement grossly overstates the power of genetics and understates social and environmental factors in homelessness.

<sup>67</sup> See NELKIN & LINDEE, *supra* note 2, at 39-41.

<sup>68</sup> Paul Jacobs & Aaron Zitner, *Genome Milestone*, L.A. TIMES, Jun. 27, 2000, at A1.

tensions between the private and public research groups.<sup>69</sup> Front page articles adopted the biblical imagery used by scientists to refer to the human genome, announcing that “scientists have *finished* a genetic blueprint of the human body – one of the *holy grails* of biology – that is referred to as the *Book of Life*.”<sup>70</sup> The headlines described the work in only the grandest terms: “Genome Milestone,”<sup>71</sup> and “Reading the Book of Life: A Historic Quest.”<sup>72</sup> Announcements compared the achievement “to Lewis and Clark’s mapping of the continent” and to Thomas Jefferson’s meeting with explorer Meriwether Lewis to look at the first crude map of the North American continent.<sup>73</sup> World leaders likened the achievement to “putting a man on the moon”<sup>74</sup> and “learning the language in which God created life.”<sup>75</sup>

This hyperbole was inspired and reinforced by comments from scientists themselves, who described this as “a historic point in the 100,000-year record of humanity,”<sup>76</sup> “a milestone in biology unlike any other,”<sup>77</sup> “the first glimpse of our own instruction book, previously known

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<sup>69</sup> See Eliot Marshall, *Talks of Public-Private Deal End in Acrimony*, 287 SCI. 1723 (2000); Paul Smaglik, *Relations Thaw Between Genome Rivals as Finish Line Draws Near*, 405 NATURE 721 (2000).

<sup>70</sup> Tim Friend, *Genome Projects Complete Sequence*, USA TODAY, Jun. 23, 2000, at 1A (emphasis added).

<sup>71</sup> Jacob & Zitner, *supra* note 68, at A1.

<sup>72</sup> Wade, *A Historic Quest*, *supra* note 42, at F5,

<sup>73</sup> Jacobs & Zitner, *supra* note 68, at A1.

<sup>74</sup> Larson et al., *The Book of Life*, DALLAS MORNING NEWS, Jun. 27, 2000, at 1A.

<sup>75</sup> Nicolas Wade, *Reading the Book of Life: The Overview*, N.Y. TIMES, Jun. 27, 2000, at A1.

<sup>76</sup> Larson et al., *supra* note 74, at 1A (quoting J. Craig Venter).

<sup>77</sup> Natalie Angier, *Reading the Book of Life: The Context*, N.Y. TIMES, Jun. 27, 2000 at A1 (quoting Francis Collins)

only to God,”<sup>78</sup> and “a revolutionary step for biology . . . the equivalent of getting the structure of the atom, of getting the periodic table.”<sup>79</sup> They promised that this work will “revolutionize”<sup>80</sup> and “have an impact on all aspects of medicine.”<sup>81</sup>

Once the final draft was completed,<sup>82</sup> however, the images of the all-powerful gene were surprisingly absent. Rather than being a “seminal event in scientific reductionism,”<sup>83</sup> the general tenor of both the media and scientists was considerably more subdued.<sup>84</sup> This was not only because completion of the final draft was old news after the hoopla surrounding the rough draft, but also because some surprising discoveries suggested that genes might be less important than was originally presumed. The human genome, it turns out, comprises closer to 30,000, rather

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<sup>78</sup> Larson et al., *supra* note 74, at 1A (quoting Francis Collins)

<sup>79</sup> Jeff Ristine, *Scientists Giddy at Milestone in Genetic Mapping*, SAN DIEGO UNION-TRIBUNE, Jun. 24, 2000, at A1.

<sup>80</sup> Wade, *A Historic Quest*, *supra* note 42, at F1 (quoting Stephen T. Warren, a medical geneticist at Emory University).

<sup>81</sup> Todd Ackerman, *Racing to the Finish Line*, HOUSTON CHRON., Jun. 26, 2000, at A1 (quoting George Weinstock, of Baylor College of Medicine). Scientists declared that “[n]ow scientists everywhere can do a lot of things they couldn’t do before.” Friend, *supra* note 70, at 1A (quoting Mike Pallazzola, senior director of biosystems at Amgen, Inc.)

<sup>82</sup> For some exceptions, see Ronald Kotulak et al., *Genome Findings Open “Book of Life,”* CHI. TRIB., Feb. 12, 2001, at N1 (noting that it would reshape “our view of who we are and where we come from”); Sarah A. Webster & Darci McConnell, *Ethics May Be Research Victim*, DET. NEWS, Feb. 13, 2001, at 6 (“The ethical dilemmas spurred by the genetics revolution could be unparalleled in the history of human advances.”).

<sup>83</sup> Joel Achenbach, *Will the Real Genome Please Stand Up?*, WASH. POST., Feb. 14, 2001, at C13.

<sup>84</sup> Even the stock market’s reaction was tame in comparison to its reaction to the rough draft announcement. Victoria Griffin, *Companies and Markets: Celera Gains on Genome Release*, FIN. TIMES, Feb. 13, 2001, at 17.

than the expected 100,000 genes;<sup>85</sup> only one inch of the six-foot coil of DNA in each cell contains the genes that encode a person.<sup>86</sup> Not only is it about twice as large as the roundworm and fruit fly genomes, it is also more similar to those genomes than anyone expected.<sup>87</sup> These findings suggest that the complexity of humans must be explained by more than just our genes, challenging the notion of genetics determinism. As one of the leaders in the race to decode the genome declared, “[g]enes cannot explain all – or even most – of human biology,”<sup>88</sup> or “all of what makes us what we are.”<sup>89</sup> Of course, it must be noted that as we learn more about genetics, we are discovering not only the importance of the role of the environment, but also the role of multigene interactions. In other words, the story has become infinitely more complex than single genes being fully deterministic. Instead, we must now account for the complex interaction between environment and multiple genes.

Perhaps these more recent tempered comments and media reports mark a new

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<sup>85</sup> Kotulak et al., *supra* note 82, at N1; Nicholas Wade, *Reading the Book of Life; Genome’s Riddles*, N.Y. TIMES, Feb. 13, 2001, at F1 [hereinafter, Wade, *Genome’s Riddles*].

<sup>86</sup> Rick Weiss, *Life’s Blueprint in Less than an Inch*, WASH. POST, Feb. 11, 2001, at A1.

<sup>87</sup> Davidson, *supra* note 6, at A3; Wade, *Genome’s Riddles*, *supra* note 85, at F1. Only 300 of the 30,000 genes have no counterpart in the mouse genome. Nicholas Wade, *Genome Analysis Shows Humans Survive on Low Numbers of Genes*, N.Y. TIMES, Feb. 11, 2001, at A1, A6. Equally surprising, 223 of our genes appear to come from bacteria. Kotulak et al., *supra* note 82, at N1; Weiss, *supra* note 86, at A10. This discovery presents an enormous puzzle for researchers to explain the greater complexity in humans. Wade, *Genome’s Riddles*, *supra* note 85 at F1; Weiss, *supra* note 86, at A10.

<sup>88</sup> Tina Hesman, *Age of Discovery Lies Ahead for Researchers of Human Genome*, ST. LOUIS POST-DISPATCH, Feb. 13, 2001, at A1 (quoting Craig Venter).

<sup>89</sup> Davidson, *supra* note 6, at A3 (quoting Craig Venter). Although Francis Collins, the leader of the publicly funded Human Genome Project, disagrees that environment plays a larger role than inheritance in determining who will get a disease, Hesman, *supra* note 88, at A1, he notes that “[u]nderstanding the human genome will not take away the concept of free will . . . [or] help us very much to understand the spiritual side of human kind or to know who God is, or what love is,” Tim Radford, *Genome Project: Door Opens on Deeper Mysteries*, GUARDIAN, Feb. 12, 2001, at 6.

circumspection regarding the promise and power of the gene.<sup>90</sup> One can only hope. But it is too recent to deflect the ways in which the scientific community has contributed to the popular conception of the gene as uniquely threatening and promising and to the notion that genetics issues are exceptional.

#### **D. Legislators**

Just as the public, the media, and scientists, are informed by and help shape notions about the power and threat of genetics, so too do legislators. On the one hand, genetics legislation is undoubtedly inspired by widespread support from virtually all sectors – the public, media, researchers, clinical geneticists, and ethicists.<sup>91</sup> Much of the legislation reflects and reinforces the public’s concern about genetic discrimination, particularly with respect to insurance and employment. For example, New Jersey’s “Genetic Privacy Act” declares among other things, that the improper disclosure of genetic information “can lead to significant harm to the individual, including stigmatization and discrimination in areas such as employment, education, health care and insurance.”<sup>92</sup> On the other hand, legislators also shape the perceptions of other institutions. Genetics legislation makes legal the distinctions between genetic and other medical information that the public perceives, the media reinforce, and that scientists unwittingly emphasize.

Although genetics legislation has been in place since the 1970s in a few states, it was not

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<sup>90</sup> Many articles quoted scientists as urging the public not to expect cures too soon. *See, e.g.*, Ralph Brave, *Gene Medicine Must Be For All*, *BALT. SUN*, Feb. 13, 2001, at 15A (“We must set realistic expectations that the most important benefits will not be reaped overnight.”) (quoting researchers who led the Human Genome Project).

<sup>91</sup> One of the only detractors is the insurance industry, which has lobbied heavily to try to limit the scope of genetics-specific legislation. But even that industry seems willing to strike some sort of compromise by allowing legislation that protects genetic information, defined as narrowly as possible. Insurers are also willing to sacrifice the right to require genetic testing as long as they have the ability to use information that is known to the applicant, otherwise they fear the problem of adverse selection. *Cf.* Steven E. Zimmerman, *The Use of Genetic Tests and Genetic Information by Life Insurance Companies*, 2 *GENETIC TESTING* 3 (1998).

<sup>92</sup> N.J. STAT. ANN. § 10:5-44 (2)(c) (2000); *see also* OR. REV. STAT. § 659.705(1)(c) (1999).

until the 1990s, coincident with increasing scholarly and media attention to genetic discrimination, that genetics legislation expanded in scope and number. The initial genetics legislation was narrow, focusing primarily on genetic information associated with specific diseases.<sup>93</sup> In the 1990s, states began to impose more sweeping legislation. The protected information was no longer disease specific, but more general genetic information. The efforts have spread like wildfire, particularly at the state level, where forty-four states have enacted some form of genetics legislation. No federal genetics legislation has succeeded in spite of numerous attempts since 1995. Because genetics legislation is the most vivid embodiment of genetics exceptionalism, it is instructive to survey briefly the nature and scope of genetics legislation and bills at the state and federal levels, respectively. The overview below focuses primarily on state legislation, with a brief discussion of federal bills, since it is only at the state level where genetics legislation has actually been enacted.

Legislators use two approaches to address the threat prevent of genetic discrimination: 1) direct prohibitions of discrimination or 2) the creation of privacy protections for genetic information. The first approach – nondiscrimination legislation – is the most common. Forty-four states prohibit health insurers from discriminating based on genetic information,<sup>94</sup> and twenty-two prohibit employers.<sup>95</sup> The approaches vary considerably. Some statutes prohibit insurers or employers from *obtaining* genetic information in connection with insurance or employment decisions. For example, they might forbid insurers or employers from requiring that applicants take genetic tests or disclose the results of genetic tests or other genetic

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<sup>93</sup> For example, some states prohibited insurance decisions based on sickle cell or Tay Sachs trait. See Karen Rothenberg, *Genetic Information and Health Insurance: State Legislative Approaches*, 23 J.L. Med. & Ethics 312, 313 (1995); Kathy Hudson, *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, 270 SCI. 391 (1995). The goal of this legislation was to prohibit decisions based on genetic information that was not predictive of future illness. Jacobi, *supra* note 41, at 331. Someone with Tay Sachs or sickle cell trait carries a single recessive gene and therefore does not and will not develop the condition.

<sup>94</sup> *State Genetic Nondiscrimination in Health Insurance Laws*, <http://www.ncsl.org/programs/health/genetics/ndishlth.htm> (visited 3/13/01).

<sup>95</sup> *State Genetic Nondiscrimination in Employment Laws*,

information. Some statutes prohibit *particular uses* of genetic information in insurance or employment decisions. They might for example forbid insurers<sup>96</sup> from using genetic information to make decisions about enrollment, renewal of policies, rates, and/or coverage. They might also forbid employers from using such information to hire or promote employees, assign benefits, or determine work assignments.

States vary greatly in their approach toward nondiscrimination in insurance. Some states, like Minnesota, combine prohibitions against obtaining and using genetic information. Its “Genetic Discrimination Act” statute prohibits health insurers from 1) requiring an applicant or his/her blood relative to take a genetic test, 2) inquiring as to whether the individual or relatives took or refused a genetic test, 3) inquiring as to the results of any genetic tests, or 4) considering the fact that a genetic test was taken or refused by an individual or blood relative when “determining eligibility for coverage, establishing premiums, limiting coverage, renewing coverage, or any other underwriting decision . . . in connection with the offer, sale, or renewal of a health plan.”<sup>97</sup> In contrast, Michigan takes a narrower approach, prohibiting health insurers from requiring genetic tests or disclosure of test results or the fact that a test has been performed.<sup>98</sup> The legislation does not, however, prohibit any particular use of known genetic information. Illinois will allow insurers to consider genetic information for insurance purposes, but only if “the individual voluntarily submits the results and the results are favorable to the individual.”<sup>99</sup> Some states, such as Vermont, ban genetic discrimination by insurers unless there is an actuarial basis, i.e., “a relationship between the medical information and the cost of the

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<http://www.ncsl.org/programs/health/genetics/ndiscrim.htm> (visited 3/13/01).

<sup>96</sup> Most of the insurance legislation applies only to health insurance and some applies to disability, long-term care, and/or life insurance.

<sup>97</sup> MINN. STAT. § 72a.139 (3) (2000).

<sup>98</sup> MICH. COMP. LAWS § 3407b(1) (2000).

<sup>99</sup> ILL. REV. STAT. ch. 410, para. 513/5 (2000).

insurance risk that the insurer would assume by insuring the proposed insured.”<sup>100</sup>

Genetic nondiscrimination laws in employment also vary in their scope. All laws prohibit discrimination based on the results of genetic tests.<sup>101</sup> Some prohibit employers from both obtaining and using genetic information for employment decisions. Massachusetts’ legislation is expansive in its approach. Like some other statutes, it applies not only to employers, but also to employment agencies, labor organizations, and licensing agencies.<sup>102</sup> It also imposes broad restrictions on these entities’ ability to *obtain* genetic information. They may not request, solicit, or inquire about genetic information; require or induce the disclosure of genetic information; inquire about the genetic information of someone’s family members or previous genetic testing; or require, administer, or induce someone to undergo genetic testing. Similarly, employers are banned from *using* genetic information for a wide range of purposes, including

to refuse to hire or employ, represent, grant membership to, or license a person on the basis of that person's genetic information; . . . to affect the terms, conditions, compensation or privileges of a person's employment, representation, membership, or the ability to obtain a license; [or to] terminate or refuse to renew a person's employment, representation, membership, or license on the basis of a genetic test or other genetic information.<sup>103</sup>

Illinois, in contrast, merely requires employers to “treat genetic testing information in such a manner that is consistent with the requirements of federal law, including but not limited to the

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<sup>100</sup> VT. STAT. ANN. tit. 8 § 4724 (2000)

<sup>101</sup> *State Genetic Nondiscrimination in Employment Laws*, <http://www.ncsl.org/programs/health/genetics/ndiscrim.htm> (visited 3/13/01).

<sup>102</sup> MASS. GEN. LAWS ch. 151B (2000).

<sup>103</sup> *Id.*

Americans with Disabilities Act” (“ADA”).<sup>104</sup> Missouri does not prohibit employers from requiring genetic tests or requesting, requiring, or obtaining genetic information. Instead, it forbids particular *uses* of genetic information or genetic test results: to “distinguish between, discriminate against, or restrict any right or benefit otherwise due or available to such employee or prospective employee.” Moreover, it does not prohibit “[u]nderwriting in connection with individual or group life, disability income or long-term care insurance,” or the “use of genetic information when such information is directly related to a person's ability to perform assigned job responsibilities.”<sup>105</sup>

The second and often overlapping approach to prevent genetic discrimination is through the enactment of genetic privacy statutes, some version of which exists in twenty-one states.<sup>106</sup> Often, but not always, these privacy protections are integrated with nondiscrimination legislation.<sup>107</sup> The key to the privacy legislation is to give control to the source of genetic information by requiring consent for various uses of genetic information: to perform or require a genetic test, to obtain genetic information, to retain genetic information, and/or to disclose genetic information.<sup>108</sup> Twenty states require consent at least for disclosure of genetic

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<sup>104</sup> ILL. REV. STAT. ch. 410, para. 513/5 (2000).

<sup>105</sup> MO. REV. STAT. § 375.1306 (2000).

<sup>106</sup> *State Genetic Nondiscrimination in Health Insurance Laws*, <http://www.ncsl.org/programs/health/genetics/prt.htm> (visited 3/14/2001).

<sup>107</sup> *See, e.g.*, CAL. INS. CODE § 10149.1 (West 2000).

<sup>108</sup> Many states provide exceptions for this requirement. They often do not require consent when genetic information is obtained, retained, transmitted or used to identify someone in criminal investigations; to maintain a DNA databank for law enforcement purposes when the person has been convicted of a felony; to identify deceased people; to establish paternity; to screen newborns for genetic conditions; to determine damage awards in court proceedings; by medical repositories, for research purposes, if one’s identity is not disclosed, or for emergency medical treatment. *See, e.g.*, N.M. STAT. ANN. § 24-21-3(C)(Michie 2000).

information to third parties.<sup>109</sup> At one end of the spectrum, some states<sup>110</sup> like Colorado require written consent *only* for disclosure of genetic information to third parties.<sup>111</sup> At the other end of the spectrum, New Mexico requires consent for disclosure, as well as to obtain and retain genetic information and to do genetic analysis. Moreover, it requires *informed*, written consent.<sup>112</sup> In addition, New Mexico is one of four states that requires personal access to one's genetic information.<sup>113</sup> Five states – Colorado, Florida, Georgia, Louisiana, and Oregon – protect genetic privacy by declaring that genetic information is the “unique” or “exclusive” property of the individual to whom the information pertains.<sup>114</sup> Oregon is the only state to proclaim that one also has a property right in one's genetic *samples*.<sup>115</sup> Most of the states with privacy legislation impose specific penalties for unlawful disclosure,<sup>116</sup> including civil<sup>117</sup> and criminal penalties.<sup>118</sup>

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<sup>109</sup> *State Genetic Privacy Laws*, <http://www.ncsl.org/programs/health/genetics/prt.htm> (visited 3/14/2001).

<sup>110</sup> California, Illinois, Louisiana, Missouri, New Hampshire, and Virginia. *See id.*

<sup>111</sup> COLO. REV. STAT. § 10-3-1104.7(3)(a) (2000) (deeming genetic testing information “confidential and privileged”).

<sup>112</sup> N.M. STAT. ANN. § 24-21-3 (A), (B) (Michie 2000).

<sup>113</sup> *See also* Delaware, Nevada, New Mexico, and Oregon.

<sup>114</sup> COLO. REV. STAT. § 10-3-1104.7 (1)(a) (“unique property”); FLA. STAT. ch. 760.40 (2)(a) (2000) (“exclusive property”); GA. CODE ANN. § 33-54-1(1) (2000) (“unique property”); LA. REV. STAT. ANN. § 22:213.7(E) (West 2000) (“property”); OR. REV. STAT. §§ 659.700(1)(b) (1999) (genetic information is “uniquely private and personal” and is the property of the person to whom it belongs, except for the purposes of anonymous research).

<sup>115</sup> OR. REV. STAT. §§ 659.700(1)(b) (1999). Oregon's recently appointed task force recommended elimination of this provision. ASSURING GENETIC PRIVACY IN OREGON, Nov. 15, 2000.

<sup>116</sup> California, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Louisiana, Massachusetts, Missouri, Nevada, New Hampshire, New Jersey, New Mexico, New York, Oregon, South Carolina, Vermont. *See State Genetic Privacy Laws*, <http://www.ncsl.org/programs/health/genetics/prt.htm> (visited 3/14/2001).

Although no federal genetics legislation has been enacted to date, several federal bills concerning genetic nondiscrimination and privacy have been introduced in the House or Senate since 1995.<sup>119</sup> In the 104<sup>th</sup>, 105<sup>th</sup>, and 106<sup>th</sup> Congresses, seven,<sup>120</sup> nine,<sup>121</sup> and eight bills,<sup>122</sup>

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<sup>117</sup> See e.g., CAL. INS. CODE § 10149.1(b) (West 2000) (imposing civil penalties of no more than \$1,000 plus court costs for negligent and unauthorized disclosure of genetic information); CAL. INS. CODE § 10149.1(c) (West 2000) (imposing civil penalties between \$1,000 and \$5,000 plus court costs for willful and unauthorized disclosure).

<sup>118</sup> See, e.g., CAL. INS. CODE § 10149.1(d) (West 2000) (One who negligently or wilfully discloses identifying genetic information that “results in economic, bodily, or emotional harm to the subject of the test is guilty of a misdemeanor punishable by imprisonment in a county jail for a period not to exceed one year, by a fine not to exceed ten thousand dollars (\$10,000), or by both that fine and imprisonment.”).

<sup>119</sup> In the 101<sup>st</sup> and 102<sup>nd</sup> Congresses, Representative Conyers introduced the Human Genome Privacy Act, which would regulate the disclosure of genetic information identifiable to a specific individual. H.R. 5612, 101<sup>st</sup> Cong., 2<sup>nd</sup> Sess. (2000); H.R. 2045, 102<sup>nd</sup> Cong., 1<sup>st</sup> Sess. (1991).

<sup>120</sup> Genetic Confidentiality and Nondiscrimination Act of 1996, S. 1898, 104<sup>th</sup> Cong., 2d Sess. (1996) (Pete Domenici); The Genetic Privacy and Nondiscrimination Act of 1995, S. 1416, 104<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1995) (Mark Hatfield); The Genetic Privacy and Nondiscrimination Act of 1995, 104<sup>th</sup> Cong., H.R. 2690, 1<sup>st</sup> Sess. (1995) (Clifford Stearns); The Genetic Fairness Act of 1996, 104<sup>th</sup> Cong., S. 1600, 2d Sess. (1996) (Dianne Feinstein); The Genetic Information Nondiscrimination in Health Insurance Act of 1995, H.R. 2748, 104<sup>th</sup> Cong., 1<sup>st</sup> Sess (1995) (Louise Slaughter); The Genetic Information Nondiscrimination in Health Insurance Act of 1995, S. 1694, 104<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1995) (Olympia Snowe); H.R. 3477, 104<sup>th</sup> Cong., 2d Sess. (1996) (Joseph Kennedy).

<sup>121</sup> Genetic Confidentiality and Nondiscrimination Act of 1997, S. 422, 105<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1997) (Pete Domenici); Genetic Privacy and Nondiscrimination Act of 1997, H.R. 2198, 105<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1997) (Clifford Stearns); The Genetic Information Nondiscrimination in Health Insurance Act of 1997, H.R. 306, 105<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1997) (Louise Slaughter); The Genetic Information Nondiscrimination in Health Insurance Act of 1997, S. 89, 105<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1997) (Olympia Snowe); Genetic Information Health Insurance Discrimination Act of 1997, H.R. 328, 105<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1997) (Gerald Solomon); The Genetic Privacy and Nondiscrimination Act of 1997, H.R. 341, 105<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1997) (Clifford Stearns); Genetic Protection in Insurance Coverage Act, H.R. 2216, 105<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1997) (Joseph Kennedy); The Genetic Justice Act, S. 1045, 105<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1997) (Tom Daschle); Genetic Nondiscrimination in the Workplace Act, H.R. 2215, 105<sup>th</sup> Cong., 1<sup>st</sup>

respectively, were introduced. At this point in the 107<sup>th</sup> Congress, 3 genetics-specific bills have been introduced, two in the Senate and one in the House.<sup>123</sup>

This session, for example, Senator Thomas Daschle and Representative Louise Slaughter have introduced parallel bills in the Senate and House, entitled “Genetic Nondiscrimination in Health Insurance and Employment Act.”<sup>124</sup> These bills follow the state model in several respects. First, they prohibit insurers from using “protected genetic information concerning an individual in the group (or information about a request for or the receipt of genetic services by such individual or family member of such individual)” to make decisions about an individual’s eligibility in a group or individual health plan or to adjust premium or contribution rates on the

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Sess. (1997) (Joseph Kennedy).

<sup>122</sup> Genetic Information Health Insurance Nondiscrimination Act of 1999, H.R. 293, 106<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1999) (John Sweeney); Genetic Information Health Insurance Nondiscrimination Act of 1999, H.R. 306, 106<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1999) (Louise Slaughter); Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, H.R. 2457, 106<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1999) (Louise Slaughter); Genetic Privacy and Nondiscrimination Act of 1999, H.R. 2555, 106<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1999) (Cliff Stearns); Genetic Information Nondiscrimination in Health Insurance Act of 1999, S. 543, 106<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1999) (Olympia Snowe); Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, S. 1322, 106<sup>th</sup> Cong., 1<sup>st</sup> Sess. (1999) (Thomas A. Daschle); S. Amdt 3688 to H.R. 4577, 106<sup>th</sup> Cong., 2d Sess. (2000) (Thomas A. Daschle) (prohibiting health insurance and employment discrimination based on genetic information); S. Amdt. 3691 to H.R. 4577, 106<sup>th</sup> Cong., 2d Sess. (2000) (James M. Jeffords) (prohibiting health discrimination on the basis of genetic information or genetic services).

<sup>123</sup> Genetic and Nondiscrimination in Health Insurance and Employment Act, S. 318, 107<sup>th</sup> Cong., 1<sup>st</sup> Sess. (2001) (Tom Daschle); Genetic and Nondiscrimination in Health Insurance and Employment Act, H.R. 602, 107<sup>th</sup> Cong., 1<sup>st</sup> Sess. (2001) (Louise Slaughter); and Genetic Information Nondiscrimination in Health Insurance Act of 2001, S. 382, 107<sup>th</sup> Cong., 1<sup>st</sup> Sess. (2001) (Olympia Snowe).

<sup>124</sup> See S. 318, 107<sup>th</sup> Cong., 1<sup>st</sup> Session § 714 (2001) (amending the Employee Retirement Income Security Act of 1974, the Public Health Service Act, and the Internal Revenue Code of 1986, Title XVIII of the Social Security Act); H.R. 602, 107<sup>th</sup> Cong., 1<sup>st</sup> Session § 714 (2001) (amending the Employee Retirement Income Security Act of 1974, the Public Health Service Act, and the Internal Revenue Code of 1986, Title XVIII of the Social Security Act).

basis of such information.<sup>125</sup> In addition, the bills would limit insurer access to genetic information by prohibiting insurers from requesting, requiring, collecting, or purchasing such genetic information from an individual or a family member; from disclosing such genetic information without authorization; or from requesting or requiring individuals or family members to undergo genetic testing.<sup>126</sup>

Similarly, the bills prohibit genetic employment discrimination by making it unlawful for employers “to fail or refuse to hire or to discharge any individual or otherwise to discriminate against any individual with respect to compensation, terms, conditions or privileges of employment of the individual [or otherwise deprive an individual of employment opportunities] , because of protected genetic information with respect to the individual or information about a request for or the receipt of genetic services by such individual or family member of such individual.” Paralleling the insurance prohibitions, the bills also forbid employers from requesting, requiring, collecting, or purchasing such genetic information from an individual or family member, though several exceptions apply.<sup>127</sup> In addition, the employer may not disclose such genetic information to third parties unless the disclosure is to an occupational or other health researcher, under compulsion of a federal court order, or to officials investigating compliance with the Act.<sup>128</sup> Finally, cognizant of the numerous states genetics laws, the bills emphasize that the federal law would not supersede any provision of state law that more completely “protects the confidentiality of [such] genetic information . . . ; or prohibits

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<sup>125</sup> *Id.*

<sup>126</sup> *Id.*

<sup>127</sup> The exceptions include: 1) when the information is used for “genetic monitoring of biological effects of toxic substances in the workplace” and the employee has given voluntary, written authorization, is informed of monitoring results, and the employer receives the results in “aggregate terms that do not disclose the identity of specific employees”; 2) where the employer offers genetic services and only the employee or family member receives the results or such services; or 3) when an employer, after making a conditional offer of employment, requests, requires or collects medical information, as allowed under the Americans with Disabilities Act of 1990. *Id.*

discrimination on the basis of genetic information than [the federal legislation would.]”

Most of this enacted or proposed state and federal genetics legislation embodies the notion of genetics exceptionalism, either directly or indirectly.<sup>129</sup> Some statutes explicitly declare the uniqueness of genetic information. For example, the legislative findings of Oregon’s “Genetic Privacy” statute state that “genetic information is uniquely private and personal information.”<sup>130</sup> In addition, many statutes emphasize various features of genetic information that warrant legislative protection: DNA “contains information about an individual’s probable medical future,”<sup>131</sup> improper use of “genetic information can lead to . . . stigmatization and discrimination in areas such as employment, education, health care and insurance,”<sup>132</sup> genetic analysis may reveal information about one’s blood relatives,<sup>133</sup> and public fears of genetic

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<sup>128</sup> *Id.*

<sup>129</sup> *Id.* As will be discussed in more detail in Part III.C, Congress has enacted the Health Insurance Portability and Accountability Act (“HIPAA”), Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 262(a), 110 Stat. 1936 (1996), which eliminates the use of medical information (including genetic information) for the underwriting of group insurance plans. At this point, this statute provides the best protection against genetic nondiscrimination, but manages to do so while avoiding genetics exceptionalism, thereby killing the proverbial two birds with one stone. *See infra* TAN 340-343.

<sup>130</sup> *See, e.g.*, OR. REV. STAT. §§ 659.705(1)(b) (1999). *See also*, Beckwith & Alpert, *supra* note 30, at 208 (quoting Senator Domenici’s proposed legislation). Some of the statutes that create property rights describe genetic information as one’s *unique* property. *See* COLO. REV. STAT. § 10-3-1104.7 (1)(a) (“unique property”); FLA. STAT. ch. 760.40 (2)(a) (2000) (“exclusive property”); GA. CODE ANN. § 33-54-1(1) (2000) (“unique property”).

<sup>131</sup> OR. REV. STAT. §§ 659.705(1)(a) (1999); N.J. STAT. ANN. § 10:5-44 (2)(a) (West 2000).

<sup>132</sup> OR. REV. STAT. §§ 659.705(1)(c) (1999); N.J. STAT. ANN. § 10:5-44 (2)(c) (West 2000).

<sup>133</sup> OR. REV. STAT. §§ 659.705(1)(d) (1999); N.J. STAT. ANN. § 10:5-44 (2)(d) (West 2000).

discrimination deter many from seeking genetic testing.<sup>134</sup>

Although these statements do not necessarily imply that the legislators consider genetic information exceptional, the enactment of genetics-specific legislation is consistent with a view of genetics as exceptional. It is one thing to argue in the abstract that genetic information requires protection; it is quite another to draft legislation that creates *special* protections *only* for this kind of information. Moreover, even if not all legislators are motivated by genetics exceptionalism concerns, the legislation may well be perceived by the public as evidence that genetic information is inherently and uniquely problematic.

As we have seen, the various concerns and interests of the public, the media, the scientific community, and legislators create a perpetual cycle that reinforces genetics exceptionalism. As legislatures enact more genetics statutes, the more attention the media devote to genetics issues, and the more concerned the public becomes. As a result, scientists and the public mount pressure for other legislatures to follow suit. As more such legislation is enacted, it lends authority to and reinforces the widely held view that genetics requires special protections by creating a *legal* distinction between genetic and other information, inspiring more fear and so on. In the end, genetics exceptionalism comes full circle, continuously reinforcing itself.

## **Part II. Nondiscrimination, Privacy, and the Under- and Over-Inclusiveness of Genetic Information**

Genetics legislation, intentionally or not, reinforces the idea that genetics raises unique concerns deserving of special protections. Genetic concerns regarding discrimination and privacy, however, are not exceptional. The presumption that genetic information is unique is severely tested by the fact that no sharp line divides genetic from non-genetic information. Instead, there is a great deal of overlap between these categories, making line-drawing exceedingly difficult. This problem raises the larger question of whether something morally relevant about the category of genetic information warrants attempts to distinguish it from non-genetic information. Or to put it differently, is there any difference between genetic and non-

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<sup>134</sup> ILL. REV. STAT. ch. 410, para. 513/5(2) (2000).

genetic information that makes a difference? This article argues there is not. When one examines the rationales for genetics legislation one quickly discovers that the category of genetic information is over- and under-inclusive with respect to those goals. Virtually all of the arguments for protecting genetic information apply equally to a great deal of non-genetic information. This under-inclusiveness is much more serious than the over-inclusiveness because it results in grave inequities between individuals and among classes. Although legislative under-inclusiveness is plausibly defended by the strategy of incrementalism,<sup>135</sup> that strategy is unlikely to succeed in this context, raising equal protection concerns that will be discussed in Part III.

#### A. Difficulties in Defining Genetic Information

The first chink in the armor of genetics exceptionalism appears when one tries to define the genetic information that should receive special legislative protections. This task has proven more challenging than those who presume genetic information is unique might expect. Indeed it is virtually impossible fully to distinguish genetic information from other medical information.<sup>136</sup> As one commentator notes, efforts “to separate genetic information from all other medical information” are doomed to failure<sup>137</sup> because the distinction between these two types of information is “fallacious.”<sup>138</sup> Genetic information and medical information are “so intimately intertwined that they cannot be segregated legislatively or by regulation in any way that would

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<sup>135</sup> This strategy has received little attention in the scholarship on genetics legislation, though it is a defense often uttered in backroom discussions about genetics legislation.

<sup>136</sup> See Beckwith & Alper, *supra* note 30, at 206; Mark A. Rothstein, *Why Treating Genetic Information Separately is a Bad Idea*, 44 Tex. Rev. L. & Pol. 33, 35 (1999); Michael S. Yesley, *Protecting Genetic Difference*, 13 BERK. TECH. L.J. 653, 659-62 (1998); Sonia Suter et al., *Challenges in Drafting*, in MAPPING PUBLIC POLICY FOR GENETIC TECHNOLOGIES 5-4 (1998).

<sup>137</sup> David Korn, *Genetic Privacy, Medical Information Privacy, and the Use of Human Tissue Specimens in Research*, in GENETIC TESTING AND THE USE OF INFORMATION 40-41 (Clarisa Long, ed., 1999) (noting that “it has been too readily taken as given that genetic information is unique and different in kind from all other forms of private, sensitive, and often predictive information that may exist in a medical record.”).

<sup>138</sup> *Id.* at 40.

prove operationally feasible.”<sup>139</sup> As we shall see, the various attempts to define genetic information so as to distinguish it from other medical information are inevitably unsatisfactory, suffering from under- or over-inclusiveness.

Some legislation uses very tight and narrow definitions, such as, “the results of a genetic test”<sup>140</sup> or “DNA analysis.”<sup>141</sup> But not all genetic information comes from genetic tests or DNA analysis. Indeed, of the over 10,000 catalogued genetic diseases,<sup>142</sup> genetic tests exist for only a few hundred.<sup>143</sup> Most genetic information, at this point at least, comes from clinical evaluations, non-genetic tests, and family and medical history. As a result, those narrow definitions are under-inclusive, leaving unprotected a great deal of relevant and significant genetic information. For example, a family history of Huntington’s Disease (“HD”), which indicates a 50% risk of the condition<sup>144</sup> and is precisely the kind of predictive information that people want to protect, would not fall within the legislatively protected class of information.<sup>145</sup>

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<sup>139</sup> *Id.* at 24.

<sup>140</sup> See e.g., TEX. CIV. CODE ANN. § 9031 (Vernon 2000); GA. CODE ANN. § 33-5554-3(b) (2000).

<sup>141</sup> See, e.g., FLA. STAT. ANN. ch. 760.40(2)(a) (West 2000).

<sup>142</sup> Online Mendelian Inheritance in Man, at <http://www.ncbi.nlm.gov/OMIM>.

<sup>143</sup> See Jaeger & Mulholland II, *supra* note 56, at 31 (“noting that hundreds of genetic tests are clinically available”).

<sup>144</sup> For example, if your father and sibling have Huntington’s disease, you have a 50% risk of carrying the gene and ultimately developing the condition.

<sup>145</sup> See Suter et al., *supra* note 136, at 5-4. Earlier genetics legislation tended to focus on the narrower definition, protecting information based on the results of genetic tests or the fact that a genetic test had been performed. See, e.g., WIS. STAT. ANN. § 631.89(2)(c)-(d) (West 2000) (prohibiting insurers from conditioning insurance coverage, rates, or other benefits on “whether an individual or a member of an individual’s family, has obtained a genetic test or what the results of the test, if obtained by the individual or a member of the individual’s family, were”). Over the last decade, the definition of genetic information has broadened to include other sources of genetic information such as non-genetic laboratory tests, medical examinations,

To solve this problem, some legislatures use broader definitions, such as “information about genes, gene products, or inherited traits that may derive from an individual or family member.”<sup>146</sup> These definitions would include a family history of HD, but they are over-inclusive, protecting more information than was intended, such as information about height, eye color, and sex, all of which are primarily genetic traits. Though they are genetic, they do not include the kind of information one views as particularly sensitive. Moreover they include information about conditions like heart disease, cancer, diabetes, and some mental illnesses, which have a genetic component, even though we don’t tend to think of them as genetic per se (and legislators probably did not intend to include them).<sup>147</sup>

What one discovers in trying to draw the line between genetic and non-genetic information is that the line is particularly blurry. Genes play some role in all disease, *but* environment plays a role as well, even with genetic diseases. The difference is merely the degree to which each plays a role.<sup>148</sup> AIDS and phenylketonuria (PKU) illustrate this point nicely. AIDS is a classic non-genetic condition caused by infection with HIV. Yet genetics is crucial with respect to whether the infection will cause illness,<sup>149</sup> how soon one becomes ill, and how

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and genetic histories. *See, e.g.*, ARIZ. REV. STAT. § 20-1-51 (2000).

<sup>146</sup> See, e.g., S. 318, 107<sup>th</sup> Cong., 1<sup>st</sup> Sess. §§ 714(e)(6), 2707(i)(16), 9813(c)(7), 104(C) (2001); H.R. 602, 107<sup>th</sup> Cong., 1<sup>st</sup> Sess. §§ 714(e)(6), 2707(i)(16), 9813(c)(7), 104(C) (2001); ARIZ. REV. STAT. § 20-1-51 (2000); N.J. REV. STAT. § 17B:30-12(3)(e)(2) (West 2000); Va. Code Ann. § 38.2-508.4 (Mich. 1996). The trend has been moving in the direction of these broader definitions. *See* Jacobi, *supra* note 41, at 331-33.

<sup>147</sup> See Suter et al., *supra* note 136, at 5-4.

<sup>148</sup> Of course, it is important to note that not only do single genes play a role mixed with environment, but also that there are complex gene-gene interactions at work as well. *See supra* TAN 29-30.

<sup>149</sup> Studies suggest the “risk of progressing quickly or slowly is determined largely by [one’s] genetic endowment and not the virulence of the infecting virus or the health and robustness of their immune systems.” <http://www.ama-assn.org/special/hiv/newsline/special/jamadb/hla1.htm>.

quickly the disease progresses.<sup>150</sup> Conversely, PKU, a classic genetic condition, caused by two recessive non-functional genes, is highly influenced by environmental factors. If you eliminate phenylalanine from the diet, PKU will not develop.<sup>151</sup> These points demonstrate how difficult it is to divide up the world into what is genetics and what is not.

Although no sharp line divides genetic from non-genetic information, one might argue that we can nevertheless identify distinctions at the extremes. In other words a spectrum of medical information exists: at one end lie conditions in which genetics plays a major role (Huntington's disease, for example) and at the other end, conditions in which genetics plays a minor role (AIDS and other infectious diseases, for example). We often draw lines between extremes, even if fuzziness exists at the margins. In the abortion context, for example, the law and many ethicists make a morally coherent distinction between viable and non-viable fetuses. Even though the fetus just days shy of viability is barely distinguishable from the fetus just days after viability, stark qualitative and moral differences exist between the 9-month-old fetus and the preembryo, which justify this line drawing. Similarly, one might argue, Huntington's disease looks markedly different from AIDS, even if only in the degree to which genetics plays a role. Why not then borrow from the abortion model and draw lines between what is more and less genetic?

One reason is that most medical conditions about which we are concerned do not fall at either end of the spectrum. Instead, most conditions lie awkwardly in the middle. Huntington's disease is the rarity, whereas cancer, heart disease, and numerous other conditions that affect vast numbers of individuals lie within the fuzzy margins where both genes and environment play a large, complicated, and interrelated role.<sup>152</sup>

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<sup>150</sup> Jay Ingram, *Reflections on a Bleak Anniversary*, TORONTO STAR, Jun. 3, 2001, at \_\_\_\_\_.

<sup>151</sup> Steven Zimmerman deserves credit for this apt comparison between HIV and PKU.

<sup>152</sup> Much of the debate in the genetics context has focused on presymptomatic, predictive information about conditions like Huntington's disease or inherited forms of cancer.

The fact that the bulk of information about which we are concerned lies in that murky middle range raises a second, larger concern. Is there is a principled reason for drawing such a line? The distinction between the non-viable and viable fetus is morally significant, which is why it makes sense to draw a line along the slippery slope.<sup>153</sup> Does a similarly meaningful distinction exist between the two ends of the more-or-less genetic spectrum? Without one, any line drawn between genetic and non-genetic information will be arbitrary. Section B considers that problem by assessing whether the rationales for genetics legislation provide a principled reason for distinguishing between genetic and non-genetic information. It concludes that the category of genetic information is problematic on several grounds.

### **B. Genetic v. Non-Genetic Information – Does the Difference Make a Difference?**

Various persuasive arguments can be made for protecting genetic information. But this fact alone does not offer a principled account for protecting *only* genetic information (or indeed for protecting *all* genetic information). The real issue is whether these arguments apply *only* to genetic information.<sup>154</sup> After examining the different rationales that motivate genetics

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But whether or not the focus is on the presymptomatic or symptomatic state, the conditions about which people are concerned – cancer, for example – do lie more in the middle of the genetic/non-genetic spectrum because genes and environment play a role in the development of disease.

<sup>153</sup> The viability line used in the abortion context is grounded in principles that address the conflicting interests of mother, state, and fetus. Prior to viability, the Supreme Court has held that the state’s interests are not sufficiently weighty for the state to impose an “undue burden” on the woman’s constitutional liberty interest. *See* *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833, 879 (1992). Though there may be some disagreement about whether to use the “undue burden” test or strict-scrutiny analysis, a powerful, moral argument can be made for drawing the viability line in the abortion context.

<sup>154</sup> Recently some have suggested they are not persuaded by some those arguments. *See, e.g.*, Beckwith & Alper, *supra* note 30, at 207-08; Lawrence O. Gostin & James G. Hodge, Jr., *Genetics Privacy and the Law: An End to Genetics Exceptionalism*, 40 *JURIMETRICS* 21, 31-36 (1999); Trudo Lemmens, *Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?*, 45 *MCGILL L.J.* 347 (2000); Murray, *supra* note 60, at 66; Rothstein, *supra* note 136, at 33. Although this piece builds on some of their criticisms of genetics exceptionalism, it is the only article to address all three areas of concern – insurance discrimination, employment discrimination, and privacy. It also goes further in explicitly illustrating the ways in which the arguments in favor of genetics exceptionalism are over- or under-inclusive. More important, it describes the moral and policy consequences of the problem

legislation, this section argues that they do not apply to *all* genetic information, but more important, they apply equally to other types of medical information. In short, there is a grossly imperfect fit between the justifications for carving out special protections for genetic information and the category of genetic information: genetic information is both over- and under-inclusive with respect to its legislative purposes. This imprecise fit, particularly the under-inclusiveness, suggests that the line between genetic and non-genetic information is questionable.

To some extent, any rule or law suffers from these problems. Rules and laws require classifications of the prohibited action or protected entity. Some imprecision is inevitable because laws depend on generalizations to reflect the properties or criteria to which they are intended to apply.<sup>155</sup> One might in theory want precise legislation that describes in excruciating detail the criteria and properties relevant to its purposes. But it is ultimately impractical and virtually impossible to craft rules or laws that articulate for all times and circumstances the specific criteria or properties relevant to the rule's justifications. Instead, lawmakers must rely on a generalizing factual predicate to capture the properties relevant to the law's justifications.<sup>156</sup>

Although under- and over-inclusiveness is inherent in rule or law making,<sup>157</sup> it is not necessarily a fatal flaw. Indeed, we tolerate some amount of imprecision in laws because of the compensating virtues of reliance, efficiency, predictability and determinacy.<sup>158</sup> In some instances, however, over-and under-inclusion can be problematic. For example, over-

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of under-inclusiveness. In particular, unlike other articles on genetics exceptionalism, this piece describes in detail and challenges the incrementalism argument. Moreover, it fully develops the problems of unintended inequities between individuals and introduces the problem of class inequities resulting from genetics legislation. Finally, it provides a novel, legal, moral, and policy argument based on equal protection values for broadening the protections of genetic information to include medical information.

<sup>155</sup> FREDERICK SCHAUER, *PLAYING BY THE RULES: A PHILOSOPHICAL EXAMINATION OF RULE-BASED DECISION-MAKING IN LAW AND IN LIFE* 17-34 (1991).

<sup>156</sup> *Id.* at 34-35.

<sup>157</sup> *Id.* at 31-34.

<sup>158</sup> *Id.* at 139.

inclusiveness of speech restrictions may raise First Amendment problems, and under-inclusiveness in legislation, may sometimes raise Equal Protection problems. To assess the propriety of legislation that only protects genetic information, we must consider the degree of over- and under-inclusiveness, and the interests they implicate. As this section will show, although some degree of over-inclusiveness exists with genetic information, the costs are small and legislative definitional fine-tuning can minimize the problem to some extent. The real concern, however, is the under-inclusiveness of genetic information, which applies to virtually every justification. Although Section C considers the possible defense of incrementalism, it expresses skepticism about that strategy in this context. Part III then turns to the serious normative and policy implications of this under-inclusiveness when analyzed under the lens of equal protection theory.

## 1. Rationales for Genetics Legislation

Although numerous rationales motivate genetics legislation, they can be divided into two categories: concerns related to genetic discrimination and concerns related to privacy interests. The most frequent justification for this legislation is to prevent genetic discrimination. At heart, this is a fairness argument. We cannot *control* the genes we inherit. Like race, our genetic information is an immutable trait, for which we should not be penalized.<sup>159</sup> Many believe that allowing insurers, employers, or other groups to discriminate on the basis of genetic information compounds personal misfortunes outside our control.<sup>160</sup> They contrast genetic risk factors with those we can control, such as smoking, speeding, or drinking, the burdens of which many believe we *should* bear.

Genetic discrimination is also a concern because certain characteristics of genetic information make it particularly vulnerable to insurance or employment discrimination. It is

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<sup>159</sup> See Jacobi, *supra* note 41, at 336.

<sup>160</sup> Mark Hall, *Insurers' Use of Genetic Information*, 37 JURIMETRICS 13, 16 (1996), Murray, *supra* note 60, at 66.

“like a future diary” that predicts one’s “likely health future.”<sup>161</sup> Indeed, it can be highly predictive. If you have the gene for Huntington’s disease, for example, you will almost certainly develop the disease if you live long enough. Others worry that genetic information is prone to discrimination because it can be misunderstood.<sup>162</sup> Our problematic history with genetics only intensifies these fears.<sup>163</sup>

Another justification for genetics legislation is to allay public concerns. Some have argued that public fears of genetic discrimination may prevent people from undergoing valuable genetic testing or participating in genetics research.<sup>164</sup> Thus, whether or not genetic information

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<sup>161</sup> George J. Annas et. al, *Drafting the Genetics Privacy Act: Science, Policy, and Practical Considerations*, 23 J. L. MED. & ETHICS 360, 360 (1995).

<sup>162</sup> The fact that the public and even medical professionals are poorly educated about genetics lends some credence to these concerns. Clayton, *supra* note 35, at 138. Indeed, many of the anecdotal accounts of genetic discrimination have been attributed to misinterpretation of genetic information. Beckwith & Alper, *supra* note 30, at 206.

<sup>163</sup> *See infra* TAN 11-18.

<sup>164</sup> ILL. REV. STAT. ch. 410, para. 513/5(2) (2000) (“Despite existing laws, regulations, and professional standards which require or promote voluntary and confidential use of genetic testing information, many members of the public are deterred from seeking genetic testing because of fear that test results will be disclosed without consent or be used in a discriminatory manner.”); Yesley, *supra* note 136, at 663 (noting that “[t]he laws barring genetic discrimination in health insurance do not respond to a substantial problem but to a perceived threat of loss of insurance that might hinder genetic researchers’ search for human subjects”); Beckwith & Alper, *supra* note 30, at 207 (noting that “people who would benefit from a genetic test that detects the presence of an altered gene for a disease long before symptoms associated with that disease appear may choose not to submit to a test for fear of losing their insurance.”); Testimony May 21, 1998, Francis S. Collins Director National Human Genome Research Institute Senate Labor and Human Resources Privacy of Individual Genetic Information (“[N]early one-third of the high risk people Dr. Weber invites into [her research program on breast cancer and genetics] refuse because they fear discrimination and/or a loss of privacy. So strong is the fear of misuse of genetic information obtained in research programs that many physician-researchers leave genetic test results out of the study medical record or warn participants not to give the information to their private physicians.”). This is a public-health efficiency argument, which has influenced the protection of other sensitive information. *See infra* TAN 329-331.

is in fact unique, the public perceives it as uniquely threatening. Genetics legislation therefore addresses the public health consequences potentially raised by public concerns.<sup>165</sup>

The second line of arguments describes why genetic information should be accorded privacy protections. Perhaps the most common argument, captured in part by the “future diary” metaphor, is that genetic information, like a diary, is *personal* information.<sup>166</sup> Some describe genetic information as highly *sensitive and stigmatizing*, calling it a “figurative scarlet letter.”<sup>167</sup> In addition, genetic privacy is important because, as some preambles suggest,<sup>168</sup> genetic information is unique – we each have a different genome sequence.<sup>169</sup> Indeed, because of its uniqueness, genetic analysis can be used for identification purposes.<sup>170</sup> It can also be used to

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<sup>165</sup> See Mark Hall, *When Genes are Decoded, Who Should See the Results?; Many “Greatly Overestimate the Risk*, N.Y. TIMES, Feb. 29, 2000, at F7 (noting that “the main purposes of [former President Clinton’s executive order prohibiting federal agencies from using genetic information for hiring, promotion, or dismissal decisions] is to calm public fears to spur development of genetic technologies and to help genetic researchers recruit study subjects”).

<sup>166</sup> See, e.g., Oregon § 659.705(1)(b); N.J. § 10:5-44 (2)(b).

<sup>167</sup> George P. Smith & Thaddeus J. Burns, *Genetic Determinism or Genetic Discrimination?*, 11 J. CONTEMP HEALTH L. & POL’Y 23, 45 (1994).

<sup>168</sup> See *supra* note 115.

<sup>169</sup> Identical twins, who have the same genome, are the exception.

<sup>170</sup> Ronald M. Green & A. Matthew Thomas, *DNA: Five Distinguishing Features for Policy Analysis*, 11 HARV. J. L. & TECH. 571, 579 (1998). A related issue, beyond the scope of this article, concerns the problem of confidentiality of large volumes of genetic information stored in DNA databanks as increasing numbers of states enact DNA databanking laws. See Jonathan Kimmelman, *Risking Ethical Insolvency: A Survey of Trends in Criminal DNA Databanking*, 28 J. L. Med. & Ethics 209, for a discussion of the nature and trend of such laws. A large body of literature has been written regarding possible concerns, including privacy concerns, in the creation of such databanks. See, e.g., Andrea De Gorgey, Note, *The Advent of DNA Databases: Implications for Information Privacy*, 16 AM. J. L. MED. 381 (1990); Michelle Hibbert, *DNA Databanks: Law Enforcement’s Greatest Surveillance Tool?* 34 WAKE FOREST L. REV. 767 (1999); Eric T. Juengst, *I-DNA-Fication, Personal Privacy, and Social Justice*, 75 CHI.-KENT L. REV. 61 (1999); Harold J. Krent, *Of Diaries and Data Banks: Use Restrictions Under the Fourth Amendment*, 74 TEX. L. REV. 49 (1995); Michael J. Markett, Note, *Genetic*

probe into the personal lives of historical figures, as was done to prove that Thomas Jefferson probably fathered children with Sally Heming.<sup>171</sup>

We may also have privacy interests in genetic information for a variety of more complex reasons. First, genetic information can reveal information about, and is therefore important to, family members.<sup>172</sup> Thus what we or others learn about ourselves implicates knowledge about our family, making privacy interests more complex. In addition, one may want control over one's genetic information both because it is hidden from and potentially unknown to us and others<sup>173</sup> and because it can identify health risks long before the condition manifests itself or treatment is available.<sup>174</sup> For example, although we identified the cystic fibrosis and sickle cell anemia genes long ago, we still have no cure for those diseases.<sup>175</sup>

## 2. Over-Inclusiveness

Although there are many powerful reasons for carving out special protections for genetic

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*Diaries: An Analysis of Privacy Protection in DNA Data Banks*, 30 SUFFOLK U. L. REV. 185 (1996); J. Clay Smith, *The Precarious Implications of DNA Profiling*, 55 U. PITT. L. REV. 865 (1994); Paul E. Tracy & Vincent Morgan, *Big Brother and His Science Kit: DNA Databases for 21<sup>st</sup> Century Crime Control*, 90 J. CRIM. L. & CRIMINOLOGY 635 (2000); Warren Webster, Note, *DNA Database Statutes & Privacy in the Information Age*, 10 HEALTH MATRIX 119 (2000).

<sup>171</sup> Madison J. Gray, *A Founding Father and His Family Ties*, N.Y. TIMES, Mar. 3, 2001, at B1. The longevity of DNA heightens this concern for some. See Green & Thomas, *supra* note 170, at 577.

<sup>172</sup> Green & Thomas, *supra* note 170, at 580-84. Indeed, genetic information can sometimes reveal nonpaternity. The family argument can be taken a step further to include the larger family of shared ethnicity. For example, certain ethnic groups share increased risks for particular genetic diseases. For example, those of Askenazi Jewish heritage have a higher incidence of Tay Sachs disease and sickle cell anemia is more prevalent among those of African descent. *Id.* at 585.

<sup>173</sup> Smith & Burns, *supra* note 167, at 28

<sup>174</sup> See Jacobi, *supra* note 41, at 321; Green & Thomas, *supra* note 170, at 573.

<sup>175</sup> Neil A Holtzman et al., *Predictive Genetic Testing: From Basic Research to Clinical Practice*, 278 Sci. 602, 602 (1997). This therapeutic gap has widened and will continue

information, genetic information is both over- and/or under-inclusive with respect to all of those concerns. Let us begin with the problem of over-inclusiveness, which is a lesser problem. Concerns about the lack of control over one's genes, the high level of predictiveness of genetic information, and its stigmatizing and hidden features do not apply equally to all genetic information. Though we cannot control the genes that we inherit, we can sometimes control factors that influence the degree to which genes affect our future health. For example, if one has two copies of the gene for phenylketonuria ("PKU") and phenylalanine is removed from the diet, PKU will not develop. Similarly if one has the gene for colon cancer, one may reduce the risk of developing cancer by undergoing regular endoscopies, dietary regimes, or surgery. Furthermore, although some genetic information – such as a positive genetic test for Huntington's disease – is highly predictive of disease, the Huntington's disease model proves to be the exception, not the rule. Many genes are only predisposing and do not guarantee that the condition will develop.<sup>176</sup> In fact, most genetic information does not predict future health risk. For example, information that someone carries a single copy of a recessive gene may increase the chances of having an affected child, but it does not increase the risk of future disease in the carrier.<sup>177</sup> And of course, information that a mutation is absent, as it is in most of our genes, does not predict future disease.

In addition, genetic legislation is over-inclusive to the extent that it is based on the "uniqueness" argument. Although genetic information can be identifiable, the vast majority of

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to do so as we identify more genes. Clayton, *supra* note 35, at 134.

<sup>176</sup> Estimates for a cumulative risk of breast cancer by age 70 with in BRCA1 carriers have ranged from 35% to 87%. See Robert J. Pokorski & Ulrike Ohlmer, *Use of Markov Model to Estimate Long-Term Insured Lives' Mortality Risk Associated With BRCA1 and BRCA2 Mutations*, 4 N. AM. ACTUARIAL J. 130, 131 (2001). Estimates for ovarian cancer risks by age 70 in BRCA1 and/or BRCA2 carriers range from 16% to 44%. Initial estimates for cancer risks associated with these disease genes were higher because studies had focused primarily on high risk families, who may face other shared genetic or environmental risks. *Id.*

<sup>177</sup> As more predictive genetic tests become available and are used, however, genetic will increasingly be predictive. The point is that not all genetic mutations are necessarily predictive of future disease. To be predictive of one's future health risk, they must affect gene expression in a non-recessive gene, such as BRCA1 or the Huntington's gene.

genetic information is not unique. We share more than 99.9% of our genetic information with others, and even 99 % with chimpanzees.<sup>178</sup> Only a very small fraction of genetic information is actually unique to us.<sup>179</sup> Similarly, not *all* genetic information is highly sensitive and stigmatizing. Blood type is neither sensitive nor stigmatizing. As far as I know, no one has lost a job opportunity because of blood type, alone. Moreover, a great deal of information is not hidden from us and others. Whether we have two X chromosomes or an X and Y is readily apparent,<sup>180</sup> as is eye color. Finally, although treatment is limited for many genetic conditions, some genetic conditions, such as hemochromatosis and PKU, are preventable.

These problems of over-inclusiveness suggest that it is not genetic information per se that is necessarily susceptible to misuse. Rather *certain kinds* of genetic information – particularly predictive or predisposing genetic information, or information that increases genetic risks in family members – raise concerns of discrimination. Over-inclusiveness is not a serious problem, however, and can easily be ameliorated with some definitional fine-tuning.<sup>181</sup> The primary concern with over-inclusiveness is that it may be unnecessarily costly to restrict uses of genetic information that do not seem particularly susceptible to discriminatory uses. For example, genetic information like eye color and sex does not seem likely to lead to insurance or

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<sup>178</sup> See Todd Ackerman, *Road Map to the Core of Mankind*, HOUSTON CHRON., Feb. 13, 2001, at A1.

<sup>179</sup> Moreover, only 1-1.5% of our DNA comprises functioning genes. Hesman, *supra* note 88, at A1. The remainder of the genome comprises non-functioning genes (24%) and “junk DNA.” Weiss, *supra* note 86, at A10; Wade, *Genome’s Riddles*, *supra* note 85, at F1.

<sup>180</sup> This is true in virtually all cases. A rare condition, such as testicular feminization syndrome, proves the exception because it results in female phenotypes in those with an XY karyotype. Joe L. Simpson, *Disorders of Gonads and Internal Reproductive Ducts*, in 2 PRINCIPLES AND PRACTICE OF MEDICAL GENETICS at 1593, 1601 (Alan E.H. Emery & David L. Rimoin eds., 2d ed. 1990).

<sup>181</sup> Indeed some of the proposed federal genetics legislation attempts to address the problem of over-inclusiveness by excluding from statutory protection “information about the sex or age of the individual.” H.R. 602, 107<sup>th</sup> Cong., 1<sup>st</sup> Sess. §§ 714(j)(1); 2707(j)(1); 9813(k)(1); 104 (11) (2001); S. 318, 107<sup>th</sup> Cong., 1<sup>st</sup> Sess. §§ 714(j)(1); 2707(j)(1); 9813(k)(1); 104 (11) (2001).

employment discrimination and we might therefore find penalties for unauthorized disclosure of such information unnecessary and problematic.

One solution, which some state legislators have employed is to limit protections to the categories of genetic information that seem particularly susceptible to misuse, such as *asymptomatic, predictive, or predisposing* genetic information or *carrier* status.<sup>182</sup> These solutions will not be perfect and will result in some lesser degree of over-inclusiveness with respect to some concerns – not all asymptomatic information is predictive, for example, and not all predisposing information is equally predictive or stigmatizing. But the cost of the over-inclusiveness may be a price well worth paying in order to protect the most stigmatizing genetic information.

### 3. Under-Inclusiveness

The much more problematic aspect of the imprecise fit of genetics legislation to its underlying concerns is its under-inclusiveness. This problem infects virtually every justification in favor of protecting genetic information, raising serious questions about the validity of limiting these protections to *just* genetic information, particularly in light of the definitional difficulties addressed in Section A. For example, consider the argument that genes are not in our control. Genetics, it turns out, proves an inadequate proxy for what is not in our control.<sup>183</sup> Although we cannot control the genes we inherit, we cannot control a great many other risk factors, such as in utero exposures, environmental conditions, or drunk drivers, which may have profound effects on our future health.<sup>184</sup> Moreover, many risk factors, which seem very much in one's control,

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<sup>182</sup> See, e.g., TEX. CIV. CODE ANN. § 9031 (Vernon 2000) (defining genetic information as the result of a genetic test, which is defined as “analysis of an individual’s DNA, RNA, proteins, or chromosomes . . . that are associated with a predisposition for a clinically recognized disorder”); MO. REV. STAT. § 375.1300 (2000) (same); MONT. CODE ANN. § 33-18-901 (2000) (defining genetic information as the result of a genetic test or evaluation that determines the presence or absence of mutations “associated with a statistically increased risk of developing a disease, disorder, or syndrome that is asymptomatic at the time of testing”).

<sup>183</sup> See Murray, *supra* note 60, at 66.

<sup>184</sup> See *id.*

may be less so than we imagine. Addictive behavior is influenced by genetic elements, as well as many social elements outside of our control, such as family, socio-economic status, and culture.<sup>185</sup> Controlling one's weight, for example, is not solely a matter of willpower.<sup>186</sup> Even addiction to smoking has genetic elements.<sup>187</sup> Thus, genetics does not function satisfactorily as an exclusive category for risks outside our control.

Genetic information is also an under-inclusive category with respect to other concerns that inspire genetic nondiscrimination laws. For example, genetic information is not alone in its predictive capacity. Before the advent of protease inhibitors, HIV infection virtually ensured the future development of AIDS. Similarly, significant asbestos exposure leads to a high risk of lung cancer. Worries that insurers or employers will discriminate based on genetic information apply equally to other medical information. Indeed, we know with certainty that insurers use medical information to discriminate (i.e., in making risk-based distinctions).<sup>188</sup> In addition,

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<sup>185</sup> See, e.g., Ronald Kotulak, *Rethinking Addiction; New Gene Research Suggests That Most People Are Vulnerable to Abuse, But It May Also Hold the Key to Antidotes*, CHI. TRIB., Mar. 15, 1999 at N1. To the extent that statutes use narrow definitions of genetic information, these risk factors would seem to be non-genetic, unless a specific disease gene was associated with these risks.

<sup>186</sup> “[T]he simple decisions of what, when and how much to eat may not be completely under people’s conscious control.” Gina Kolata, *How the Body Knows When to Gain or Lose*, N.Y. TIMES, Oct. 17, 2000, at D1, D8. Scientists have identified regions of the brain and hormones that influence or control eating. In one dramatic example, a brain injury of the “eating center” of a boy’s hypothalamus resulted in his gaining “400 pounds literally in weeks.” *Id.* (quoting Dr. Steven B. Heymsfield). The data suggest that each individual has a particular weight range that may vary about 10 percent from the midpoint. “But there is little anyone can do to change their range itself,” according to researchers. *Id.* Of course, this is not to suggest that social factors play no role in weight. Surely cultural influences, such as dietary habits also influence weight.

<sup>187</sup> Our ability to minimize genetic risk may be also influenced by various external factors, some more or less in our control – environment, income, education, access to health care, culture, etc. For example, the ability to adjust one’s diet to reduce certain health risks may require a fairly high level of income. Fresh vegetables and produce – associated with good health – are not cheap.

<sup>188</sup> Murray, *supra* note 60, at 65; See Donald W. Light, *The Practice and Ethics of*

employers use medical information in the workplace to test fitness for duty and susceptibility to workplace hazards.<sup>189</sup> And although we may worry about misinterpretations of genetic information, sadly, evidence shows that insurers and employers are careless and imprecise in their use of other actuarial data and risk information.<sup>190</sup> While that may only inspire greater fear with regard to genetic information, it emphasizes problems with the underwriting system and employer use of medical information generally; not specifically with respect to genetics. Finally, concerns that fears of discrimination will prevent individuals from participating in medical research or diagnosis for such conditions as mental illness or cancer have been used to justify the protection of other medical information.<sup>191</sup>

The privacy concerns that spark particular attention with respect to genetics also extend well beyond genetics. Genetic information is not uniquely personal or revealing. Our life histories are as personal and revealing as our genetic code. One's culture, family, friends, education, career, beliefs, and dreams all reveal as much if not more about who we are and will become than our genes. Nor is genetic information uniquely unique. Other information is personally identifying. Old fashioned fingerprints, dental analysis, iris scans, voice prints, handwritten signature measurements, and "esoteric biometrics"<sup>192</sup> can identify individuals,<sup>193</sup> as

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*Risk-Rated Health Insurance*, 267 JAMA 2503, 2504 (1992) (describing the kind of risk information that insurers use); Gauding, *supra* note 55, at 1667 (same).

<sup>189</sup> Sharona Hoffman, *Preplacement Examinations and Job-Relatedness: How to Enhance Privacy and Diminish Discrimination in the Workplace*, \_\_ KAN. L. REV. \_\_ (2001) (forthcoming).

<sup>190</sup> See Light, *supra* note 188, at 2504-05 (observing that many ways in which risk rating is inaccurate); Jacobi, *supra* note 41, at 329 (noting that actuarial rating is more of an art than a science.).

<sup>191</sup> The article addresses this argument in more detail below. See *infra* TAN and notes 330-31.

<sup>192</sup> Esoteric biometrics include vein measurement, skin-pore measurement, and body odor. See SEARCH, LEGAL AND POLICY ISSUES RELATING TO BIOMETRIC IDENTIFICATION TECHNOLOGIES 39-41 (1989)

can other less high-tech information, such as social security number, address, phone number, and credit card number. Even more general information, such as neighborhood, age, occupation, marital status, and number and ages of children, can be identifying in the aggregate.<sup>194</sup> In addition, genetics is not the only mechanism to probe into past lives. Other techniques have been used to explore the personal histories of the deceased. Bone analysis was used to determine whether Meriwether Lewis had syphilis and whether he was murdered or committed suicide.<sup>195</sup> Infrared light and computer imaging software uncovered the original image of letters thought to hold secrets of illicit love affairs or sexual relationships, such as those between Emily Dickinson and Susan Austin (the wife of Dickinson's brother) and Matthew Arnold and his older sister, Jane.<sup>196</sup> Surely, those techniques uncover facts no less private or illuminating than those revealed through genetic analysis.<sup>197</sup>

Similarly, non-genetic information may be highly sensitive or stigmatizing, perhaps even *more* so than most genetic information. Information regarding sexually transmitted diseases, mental illness, reproductive history, addiction, marital status, or a history of abuse might influence how potential partners, insurers, employers, and society view and treat us. Indeed, because people view genes as outside our control, genetic information might be *less* stigmatizing than other information associated with behavior – such as a history of sexually transmitted diseases – and therefore less susceptible to moral judgment.

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<sup>193</sup> *Id.*; Gostin & Hodges, *supra* note 154, at 34-35;

<sup>194</sup> Murray, *supra* note 60, at 63.

<sup>195</sup> Defensive wounds to the hand bones would have suggested murder, ruling out suicide. Philip Weiss, *Beethoven's Hair Tells All*, N.Y. TIMES, Nov. 29, 1998, at *Magazine Desk*.

<sup>196</sup> *Id.*

<sup>197</sup> Of course this suggests that privacy protections should be even broader than just medical information since sensitive information extends beyond the medical arena. Whether protecting the privacy of just medical information is an example of medical exceptionalism is a worthwhile issue, which goes beyond the scope of this article.

Nor is genetic information unique in its capacity to be hidden from or potentially unknown to us and others. One may be unaware of numerous hidden risks such as viral infections, prenatal exposures, abnormal biochemical levels, and even environmental risks. Cancers may grow within our bodies long before we exhibit symptoms. Although the related problem of the therapeutic gap is serious in genetics, diagnostics are also more advanced than available treatments outside of genetics.<sup>198</sup> We can diagnose many cancers that we cannot treat, and we still have no cure for AIDS, the leading cause of death among 25-44 year olds.<sup>199</sup>

Finally, genetic information is not the only information that is relevant to family members. Whether someone in the family has tuberculosis, scarlet fever, or a sexually transmitted disease may tell us something about certain family members' risks. So relevant is this information to family members that courts have imposed duties on physicians to warn families of the infectious nature of the patient's disease.<sup>200</sup> Recently, two courts have held that physicians also have a duty to their patient's family to warn of genetic risks.<sup>201</sup> Indeed, one court saw "no essential difference between [a] genetic threat . . . and the menace of infection contagion or a threat of physical harm,"<sup>202</sup> rejecting the defendant's implicit genetics exceptionalism

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<sup>198</sup> Robert Wachbroit, *Biotechnology and the Law: Making the Grade: Testing for Human Genetic Disorders*, 16 HOFSTRA L. REV. 583, 590 (1988).

<sup>199</sup> Bob Herbert, *In America: A Black AIDS Epidemic*, N.Y. TIMES, Jun. 4, 2001, at A17.

<sup>200</sup> See, e.g., *Skillings v. Allen*, 173 N.W. 663 (Minn. 1919) (duty to warn scarlet fever patient's parents of the risks of caring for her).

<sup>201</sup> *Pate v. Threlkel*, 661 So.2d 278, 281 (Fla. 1995) (Physician's duty to family member to warn of genetic risks is fulfilled by informing the *patient* of risks to that family member); *Safer v. Pack*, 667 A.2d 1188, 1192 (N.J. Super. 1996) (Physician's duty to family member to warn of genetic risks is fulfilled by taking "reasonable steps to . . . assure that the information reaches those likely to be affected or is made available for their benefit"). See also Sonia Suter, *Whose Genes Are These Anyway?*, 91 MICH. L. REV. 1854 (1993) for an overview of whether health care professionals should have a duty or privilege to warn relatives about genetic risks.

<sup>202</sup> *Safer*, 667 A.2d at 1192.

argument.

For all of these reasons, genetic information is a seriously under-inclusive category with respect to virtually all of the concerns motivating genetics legislation. Although the over-inclusiveness proves a small problem, subject to some remedy, under-inclusiveness is a more comprehensive problem, with more far reaching ramifications. In particular, as Section C shows, it results in unintended inequities in insurance underwriting, employment, and with respect to privacy interests both among individuals and among classes of individuals.

### C. Inequities

Consider first the prohibitions of health-insurers' use of genetic information for underwriting or rate-making. Imagine that two women face an increased risk for breast cancer. The first woman, Jeannie, has a positive test for BRCA1, a gene associated with an increased risk of breast and other cancers. This test result puts her at anywhere from a 35% to 87% lifetime risk of breast cancer.<sup>203</sup> The second woman, Eve, faces a significant risk of cancer, not based on a genetic test or family history,<sup>204</sup> but on other factors or tests that suggest she has a high predisposition.<sup>205</sup> For example, she may have faced significant exposure to asbestos<sup>206</sup> or

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<sup>203</sup> See Pokorski & Ohlmer, *supra* note 176, at 130.

<sup>204</sup> 90-95% of cancers are not inherited. Jane Brody, *Cancer Gene Tests Turn Out To Be Far From Simple*, N.Y. TIMES, Aug. 17, 1999, at F1.

<sup>205</sup> Whether her increased risk is as high as Jeannie's is not as relevant as the fact that she is deemed to be at increased risk, which would be factored in the underwriting process.

<sup>206</sup> Asbestos has been shown to pose significant risks of various cancers and diseases, including lung cancer, mesothelioma (a rare tumor "in the thin membranes that line the body cavity and surround the internal organs"), and asbestosis. Gerald W. Boston, *A Mass-Exposure Model of Toxic Causation: The Content of Scientific Proof and The Regulatory Experience*, 18 COLUM. J. ENVT'L. L. 181, 291-92, 294 (1993). Exposure to asbestos for ten years has been linked to an increased risk of lung cancer of 10%. *Id.* at 293. The relative risk for lung cancer after significant exposure of asbestos is five, meaning that eighty percent of lung cancers among those exposed to asbestos were caused by asbestos. *Id.* at 299-300. Asbestos also poses an "extremely high" relative risk of developing mesothelioma. *Id.* at 294. Smoking can increase one's risk of cancer from asbestos exposure, though it does not appear to increase the risk of mesothelioma. *Id.* at 300. Finally, asbestosis, "a pulmonary insufficiency caused by a destruction

she may have a precancerous condition that resulted from environmental exposures, which puts her at risk of cancer. Both women face a notable cancer risk, but one risk is perceived as genetic and the other as non-genetic. In fact, whether or not either woman ultimately develops cancer will depend on the interaction of her particular genes and environment. Various environmental factors (which we do not fully understand yet) will influence whether Jeannie develops breast cancer, and Eve's genotype will influence whether she develops cancer, demonstrating again how problematic it is to describe one risk as genetic and the other as environmental.

Assume that Eve and Jeannie live in a state with genetics legislation that prohibits insurance and employment discrimination and that protects the privacy of genetic information. Assume further that they are seeking coverage through individual insurance plans.<sup>207</sup> Although their risks depend on both genetic and environmental factors,<sup>208</sup> Eve and Jeannie will be treated very differently by genetics legislation. Legislation prohibiting insurance discrimination based on genetic information would cover Jeannie's risk,<sup>209</sup> even under the narrowest definition of

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of air sacs in healthy lung tissue," which can dramatically reduce life expectancy and impair lung capacity, *In re Joint Eastern and Southern District Asbestos Litigation*, 129 B.R. 710, 740 (E.D.N.Y., S.D.N.Y., Bankr. S.D.N.Y. 1991), has been found in 90% of people who have been exposed to asbestos for 40 years, Boston, *supra*, at 292. "Some evidence suggests that persons with asbestosis may have an increased risk of contracting lung cancer and other malignancies." *In re Joint*, at 740. Epidemiological studies have also suggested excess risks of cancer of the kidney, larynx, pharynx and mouth among asbestos insulation workers. *Id.* at 740. It is not only those exposed occupationally to asbestos that face these increased risks. Data suggest that people exposed to asbestos casually through household contact with asbestos works face increased risks of lung cancer, colon cancer and mesothelioma. *Id.* at 742.

<sup>207</sup> This assumption is necessary because the genetics insurance laws "protect significantly fewer than 10 percent of Americans" for a few reasons. Reilly, *supra* note 8, at 123. First, under ERISA preemption, state insurance legislation does not apply to self-funded employer health plans, under which one third of the non-elderly insured are covered. *Id.* Second, many of the statutes apply to individuals in the market for *individually* underwritten health insurance, a category of individuals that "is steadily declining, largely because of the high cost of purchasing such policies." *Id.* at 122.

<sup>208</sup> Of course some risk is background risk, which are those risks apart from specific environmental or genetic hazards or risks we have not yet attributed to a particular cause.

<sup>209</sup> In many states, this would only be true if she were asymptomatic. Since much of

genetic information;<sup>210</sup> but it would not cover Eve's. Eve might be denied insurance,<sup>211</sup> but more likely, she would pay higher premiums to reflect her increased risk. But Jeannie's premiums would not be raised to reflect her risk because, like others with genetic risks, everyone in the insurance pool would subsidize the genetic risks.<sup>212</sup> In other words, Eve would "cover" her known increased risk, even as she helps subsidize Jeannie's. This result is unjust because some known risks are subsidized and others aren't. Moreover, there is no coherent reason for that difference, except that one risk is "genetic" and the other is not.<sup>213</sup>

Similar inequities play out in the employment context when employers are prohibited from making employment decisions on the basis of genetic information.<sup>214</sup> Jeannie's job and

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the genetics legislation only addresses discriminatory use of presymptomatic or asymptomatic genetic information, symptomatic individuals would not be protected. That fact, alone raises serious inequities since it is troubling to imagine that one who is currently sick might be denied health insurance or required to pay extremely high rates at the very moment she most needs health care and support.

<sup>210</sup> If Jeannie's mother had the BRCA1 gene, this would also constitute genetic information under the broader definitions. Based on that family history alone, without knowing whether Jeannie had the BRCA1 gene, her risk of cancer would be in the range of 18-44%.

<sup>211</sup> "A detailed study prepared for Senator Kassebaum by the General Accounting Office found that 18 percent of people seeking new individual policies were flatly turned down because of their health status." Robert Kuttner, *The Kassenbaum-Kennedy Bill – The Limits of Incrementalism*, 337 NEJM 64, 64 (1997).

<sup>212</sup> Of course, everyone already subsidizes *unidentified* genetic and non-genetic risks, because insurers have no way of figuring out who should pay higher rates. The problem is that the *identified* risks are treated differently depending on whether they are genetic or non-genetic.

<sup>213</sup> As we've seen *supra* in Part.II.B.3, the justifications for distinguishing genetic from non-genetic information are not persuasive. One might imagine an opposite and equally troubling inequity. A person who diets to stay thin or avoids smoking may obtain lower insurance rates, whereas a person who tests negative for a genetic susceptibility would not since such genetic information would be off-limits from consideration. I thank Max Mehlman for this particular example.

<sup>214</sup> Employers might want medical information for decisions about a employee's fitness for the job, Hoffman, *supra* note 189, at \_\_\_\_\_, or susceptibility to workplace hazards, or perhaps because of concerns about insurance costs, Miller, *supra* note 55, at 261.

promotions would be protected, but Eve's might be at risk, particularly if the employer has access to all other health information.<sup>215</sup> Whether the ADA would protect both woman from employment decisions based on concerns about future productivity and health insurance costs is an open question.<sup>216</sup> Such a claim would require them to establish that any adverse employment decision was based on this risk information, a difficult task indeed.<sup>217</sup> The best protection against employment discrimination is therefore to limit employer *access* to risk information. Some forms of genetics legislation prohibit employers from obtaining genetic information,<sup>218</sup>

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<sup>215</sup> Under the Americans with Disabilities Act, employers may requires employees to undergo a medical examination once a conditional offer has been made. 41 U.S.C.A. § 12112(d)(3). The employer must not, however, limit such examination to those with disabilities; it must be required of all entering employees. *Id.* at § 12112(d)(3)(A). There appears to be no requirement that these pre-employment examinations are job-related. Rothstein, *supra* note 55, at 55-56.

<sup>216</sup> Some courts and the EEOC reason that when employers have concerns about an employee's future productivity and insurance costs, the employee is protected under the "regarded as" prong of the ADA. Miller, *supra* note 55, at 240. *But see* Mark S. Dichter & Sara E. Sutor, *The New Genetic Age: Do Our Genes Make Us Disabled Individuals Under the Americans with Disabilities Act?*, 42 VILL. L. REV. 613, 631 (1997). Moreover, even if the ADA did cover such individuals, the fact that employers can still obtain broad access to medical information through the pre-employment medical examination raises real concerns because "it facilitates surreptitious testing and discriminatory reliance upon non-job-related criteria in decisionmaking," Rothstein, *supra* note 55, at 58, which can be difficult, if not impossible, to prove.

<sup>217</sup> Moreover, even if one could prove that adverse employment decisions were based on this risk information, the recent Supreme Court trilogy of ADA cases suggests that recovery might nevertheless be difficult. *Sutton v. United Air Lines, Inc.* 119 S. Ct. 2139 (1999); *Alberstons, Inc. v. Kirkingburg*, 119 S. Ct. 2162 (1999); *Murphy v. United Parcel Serv., Inc.*, 119 S. Ct. 2133 (1999). In *Sutton*, applicants for airline pilot positions were not regarded as disabled by their employer, even though they were denied employment based on their myopia. Instead, the Court reasoned that their poor vision only precluded them from performing the single job of airline pilot and therefore did not substantially limit the major life activity of work. *See Sutton*, 119 S. Ct. at 2151. One could imagine this argument playing out in many different contexts, where employers insist that denying employment opportunities based on a medical condition or genetic trait was not a substantial limitation of a major life activity. *See Miller*, *supra* note 55, at 245-46.

<sup>218</sup> *See supra* TAN 102-106.

which would only protect Jeannie, but not Eve.<sup>219</sup> Once again no coherent reason justifies this disparity. Instead, the disparity is the result of conceptually flawed distinctions and the under-inclusiveness of the category of “genetic information.”

Finally, genetics privacy legislation may also lead to inequities, at least until April 14<sup>th</sup>, 2003, the rule compliance date for the HIPAA privacy regulations.<sup>220</sup> To the extent that privacy laws are intended to prevent discrimination by employers, insurers or others, the inequities in this context present the problems described above. But genetics privacy legislation also results in disparities with respect to self-determination, autonomy, and dignity interests. Both Jeannie and Eve have an interest in deciding for themselves whether to disclose their increased risk of cancer to others. In a state with only genetic privacy legislation, Jeannie would have greater, though not full, control over such disclosure than Eve.<sup>221</sup> The fact that Jeannie’s risk is “genetic” does not

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<sup>219</sup> Indeed, it is a common practice among employers not to hire people with asbestos exposure because they want employees with “virgin lungs,” to reduce the risk of being held accountable for future lung disease that may develop. (Personal communication with Mark Rothstein).

<sup>220</sup> See <http://www.hhs.gov/ocr/hipaa/> (visited 6/9/01). When the HIPAA privacy regulations go into effect “all medical records and other individually identifiable health information use or disclosed by a covered entity in any form, whether electronically, on paper, or orally will be covered by the final rule. <http://www.hhs.gov/news/press/2001pres/01fsprivacy.html> (visited 6/9/01). To the extent that the federal privacy rules provide less privacy coverage than some genetics statutes, some inequities may remain in those states, since the more stringent genetics privacy protections (which would not be preempted by the federal rules, which set only a “floor” of privacy protections), would cover only genetic information. As a result, the privacy of genetic information would be protected more aggressively than other medical information. However, to the extent that the federal rules provide equal to or greater privacy protections than other genetics privacy statutes, the privacy inequities would no longer exist in those states since the HIPAA rules apply to all medical, not just genetic, information. *See id.*

<sup>221</sup> In the employment context, their control might be limited if an employer were to require a pre-employment examination upon a conditional offer of employment, as it would be allowed to do under the ADA, *see supra*, note 215. More specifically, they would not have control over disclosure of medical information obtained from such an examination. Instead, they would face a difficult Hobson’s choice of refusing the job or undergoing the medical examination. If insurers are prohibited from requesting genetic information for coverage decisions, then Eve would have less control than Jeannie, since Eve would face the same

necessarily increase her interest in preventing disclosure. Indeed, Eve may feel more sensitive about her increased cancer risk, given that she has no protection against discrimination based on this information. Again, no principled reason exists for this disparity. Jeannie's and Eve's interest in controlling disclosure of personal health information is equally powerful and therefore deserving of equal forms of protection.

The most disturbing aspect of the under-inclusiveness of genetics legislation, however, is not the disparities that arise between similarly situated individuals like Jeannie and Eve. More troubling, and less immediately obvious, is that the unintended inequities of genetics legislation exacerbate social inequities. Although genetic risks transcend socio-economic class, non-genetic risks frequently do not.<sup>222</sup> Many non-genetic risks have sociological components related to poverty and environmental hazards, some of which are not in one's control. For example, numerous studies demonstrate that people of color and low income communities face disproportionate environmental impacts in the United States.<sup>223</sup> One source of such environmental risk is "hazardous waste sites, incinerators, chemical factories and sewage treatment plants," which are placed disproportionately in these lower-income communities.<sup>224</sup>

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Hobson's choice as in the employment context.

<sup>222</sup> Of course this claim is more or less true depending on the disease or health risk in question.

<sup>223</sup> See Benjamin A. Goldman, *Not Just Prosperity: Achieving Sustainability with Environmental Justice*, NAT'L WILDLIFE CONSERVATION COUNCIL 9 (1993).

<sup>224</sup> Clarice E. Gaylord & Geraldine W. Twitty, *Protecting Endangered Communities*, 21 FORDHAM URB. L. J. 771, 771-772 (1994); Peter Reich, *Greening the Ghetto: A Theory of Environmental Race Discrimination*, 41 KAN. L. REV. 272, 273 (1992); UNITED CHURCH OF CHRIST COMMISSION FOR RACIAL JUSTICE, TOXIC WASTES AND RACE IN THE UNITED STATES 13-14 (1987). *But see* Vicki Been & Francis Gupta, *Coming to Nuisance or Going to Barrios? A Longitudinal Analysis of Environmental Justice Claims*, 24 ECOLOGY L. Q. 1, 8, 34 (1997) (noting that some studies based on 1990 census data have found no significant difference in the percentage of African Americans or Hispanics in areas with or without hazardous sites, but pointing out that such studies failed to control for differences in density). A longitudinal study of the siting of undesirable land uses, such as waste facilities, between 1970 and 1990, found that "Hispanics, rather than African Americans, . . . are most at risk from" decisions about where to place treatment storage and disposal facilities sites. *Id.* at 34. One method of statistical

Minorities and the poor also face high levels of lead exposure.<sup>225</sup> Continuous exposure to such environmental hazards poses increased risks of “cancer, asthma, chronic bronchitis, emphysema and other respiratory diseases, reproductive and birth defects, immunological problems, and neurological defects.”<sup>226</sup> In addition, low socio-economic status is disproportionately associated with “virtually all of the chronic disease that are the leading causes of mortality”; infectious diseases, such as HIV or tuberculosis; traumatic injuries and death; and developmental delay and other disabilities.<sup>227</sup>

As a result, the poor, which includes many minorities, are more likely to face non-genetic risks than the middle or upper classes. Many of these risks can be measured through high cholesterol, high blood pressure, high blood levels of lead or other toxins, etc. If insurers, for example, can make actuarial decisions on the basis of evidence of non-genetic risks, but not genetic risks, we allow discrimination that will disproportionately disadvantage these vulnerable populations. Or to put it differently, we ask the least advantaged to bear their own non-genetic risks alone, even as we ask everyone, including them, to subsidize genetic risks.<sup>228</sup> Given that

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analysis, however, revealed that African Americans are over-represented in neighborhoods housing waste facilities, while other statistical analyses reached different conclusions. *Id.* In addition, the study showed that the working or lower middle classes, as opposed to the very poor, host a disproportionate share of these facilities. *Id.* This study provides some nuance to the issue of environmental justice, though it should be noted that it focuses primarily on treatment storage and disposal facilities, rather than all the possible environmental hazards that one might expect to be associated with poverty, and by inference, minority groups, given the higher incidence of poverty among minorities.

<sup>225</sup> “African-American children from poor families are subjected to dangerous levels of lead at a rate nine times that of children from more affluent families . . . . Fifty -five percent of [such children] have an increased blood level,” subjecting them to mental disability and learning impairment. Gaylord & Twitty, *supra* note 224, at 776-77. Migrant farm-workers also face a heightened risk of exposure to environmental hazards such as pesticides and other toxic substances, both through working conditions and “deplorable housing conditions.” *Id.* at 777.

<sup>226</sup> *Id.* at 771-772.

<sup>227</sup> Lawrence O. Gostin, *Securing Health or Just Health Care? The Effect of the Health Care System on the Health of America*, 39 ST. LOUIS L. J. 7, 31 (1994).

<sup>228</sup> This presumes that these individuals are part of a pool of individually underwritten insurance. Of course, to the extent that insurance is prohibitively expensive

many environmental hazards as well as other health risks are linked to poverty and low socio-economic status,<sup>229</sup> there is reason to be concerned about the social impact of a policy that only protects genetic risks, but does not protect the risks that most profoundly affect the poor and minorities.

Finally, although genetic risk factors transcend socio-economic status, the individuals currently most concerned about genetic discrimination may not represent the full socio-economic spectrum. Genetic discrimination is primarily on the minds of those interested in genetic testing for research or clinical purposes, who tend to be people whose basic health care needs have been met.<sup>230</sup> As a result, genetics discrimination is principally a concern of the middle to upper classes, who have financial resources for testing, and jobs and insurance they fear losing. This group of well-educated, well-off individuals has lobbied heavily for genetics legislation. In contrast, the groups most vulnerable to health risks related to poverty and environmental hazards do not have the same political voice or cohesiveness. There is a danger that the strong political voice of the first group outshadows the interests of equally or more vulnerable, but less politically powerful groups. In short, genetics-specific legislation becomes another “middle

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because of their high risks, they may simply opt out of insurance coverage altogether, in which case they would not subsidize anyone else’s risk. But nor would they have insurance coverage. The sort of individuals I imagine are those who do not have insurance through employers (perhaps they are only part-time workers), but who make too much money to be eligible for Medicaid. Even if they obtain insurance through their employers, however, they may face discrimination based on these health risks.

<sup>229</sup> “For virtually all of the chronic disease that are the leading causes of mortality, low income is a special risk factor. . . . The poor also suffer disproportionately from infectious disease such as HIV and respiratory diseases such as tuberculosis. Similar vulnerability is found among the poor for traumatic injuries and death. Finally, the rate of developmental and other disabilities, especially among children, is associated with poverty.” Gostin, *supra* note 227, at 31.

<sup>230</sup> Mark A. Hall & Stephen S. Rich, *Genetic Privacy Laws and Patients’ Fear of Discrimination by Health Insurers: The View from Genetic Counselors*, 28 J. L. MED & ETHICS 245, 251(2000) (“Medicaid patients are understandably much less concerned about [genetic discrimination] because their focus is on more immediately pressing needs.”); Lemmens, *supra* note 154, at 364-65 (noting the power of lobbying among groups who have insurance to lose).

class entitlement.”<sup>231</sup>

#### **D. The Defense of Incrementalism**

While these inequities are troubling, and while the motivations for genetic information apply equally to other medical information, a plausible defense for the under-inclusiveness of genetics legislation is the strategy of incrementalism. This is a common constitutional and pragmatic defense when legislation is under-inclusive with respect to its larger purposes. In a perfect world, Eve and Jeannie would be treated similarly, but under this view, we can only solve one problem at a time. The “political realists” would argue that incremental reform is far more realistic than full-scale reform. By urging reform with respect to genetics, one can move toward the ultimate goal of protecting all medical information, without directly placing on the table the fact that similar concerns apply to other medical information. Extending genetics protections to other medical information too soon, for example, might be at best, very difficult, and at worst, politically unwise.<sup>232</sup> The better approach, the pragmatist would argue, is to open the door to reform with genetics legislation, for which there is widespread political and public support. Once the door is ajar, we can incrementally open it wider over time. For these pragmatists, incrementalism is the only politically viable approach, particularly with politically charged subjects. One need only recall the debacle of the former Clinton administration’s efforts to achieve health care reform to envision the mine-fields of attempts at broad scale reform.<sup>233</sup> If we

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<sup>231</sup> In reality, it is more of a middle, to upper-middle, class entitlement.

<sup>232</sup> For example, eliminating underwriting based on all medical information would essentially create community rating in health insurance, which although employed by most Western nations, faces some political obstacles in this country.

<sup>233</sup> The Clinton administration was appropriately faulted for the *process* by which it attempted reform. See M. Susan Ridgely & Howard Goldman, *Putting the “Failure” of National Health Care Reform in Perspective*, 40 ST. LOUIS UNIV. L.J. 407, 418-19 (1996); Michele L. Procino, *Note, The Death of Health Care Reform in 1994*, 1 WIDNER L. SYMPOSIUM J., 547 578-79 (1996). Nevertheless, Americans’ discomfort with big government, see Jacobi, *supra*, at 314, 339, 370, the strengths of interests groups, see Ridgely & Goldman, *supra*, at 418, and America’s fragmented political structure, see Kuttner, *supra* note 211, at 64, undoubtedly played a large role in its downfall, despite considerable public support for the notion of health care reform. See Theodore R. Marmor, *The National Agenda for Health Care Reform*, 60

view genetics legislation as one step toward larger reform,<sup>234</sup> these inequities seem less problematic.

Such a strategy might potentially work in one of two ways. One theory is that the protections created by genetics legislation will eventually apply to *all* medical information because genetic analysis will be so integral to every aspect of future medical records.<sup>235</sup> For example, DNA chips, which will allow for the testing of multiple genetic mutations could create a medical record replete with genetic information, under even the most narrow definitions.<sup>236</sup> Under this theory, genetic tests could be performed easily and efficiently for multiple purposes: for preventive care (to determine the genetic risks a person faces so that they can reduce these risks through diet, medicine, exercise, and other measures); to personalize the prescription of medical drugs based on one's genotype (i.e., pharmacogenetics); for reproductive decision making; etc. If everyone's medical information is inextricably connected with the results of genetic tests, it will be literally impossible, under this theory, to separate out genetic and medical information. Moreover, if one takes the view, as some such incrementalists might, that genetic influences are virtually inseparable from and integral to all phenotypic phenomena, including physical appearance, non-genetic test results, and life style, than any piece of information on the medical record is essentially genetic information.<sup>237</sup> Under either view, genetics legislation is

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BROOKLYN L. REV. 83, 84-85 (1994); Ridgely & Goldman, *supra*, at 418, 420-21. Nor was this the first failed health care reform effort. "On about a twenty year cycle during this century, we have considered and rejected joining our industrialized neighbors in treating health care as a public good through national statutory health insurance." Jacobi, *supra* note 41, at 314. See Procino, *supra*, at 547-48, 575-76, for a summary of prior failed attempts at health care reform.

<sup>234</sup> Rarely is such a defense explicitly offered for genetics legislation. For one of the few statements related to this argument, *see* Beckwith & Alper, *supra* note 30, at 208-09. Their argument is slightly different, however. Rather than defending genetics legislation as an incremental first step, they argue, as I do, that genetics legislation is flawed and needs to be rewritten to protect other medical information.

<sup>235</sup> I thank Bob Cook-Deegan for his observations on this point.

<sup>236</sup> Of course the broader the definition, the more information that could be included.

the “Trojan Horse” of health care reform, because in protecting the privacy of genetic information or prohibiting genetics discrimination, legislators will have unwittingly protected *all* medical information.<sup>238</sup>

The likelihood of this strategy’s success is uncertain. Not everyone believes that genetics will revolutionize medicine so profoundly. The complexity in understanding the role of single and multiple genes and environmental factors with respect to the most common diseases, may limit the ways in which genetics can be used to identify or prevent diseases.<sup>239</sup> If genetics’ role in prevention and treatment is limited, genetics legislation may not achieve the goal of broad-scale protection of medical information.<sup>240</sup> Moreover, legislators may believe they have solved the issues of nondiscrimination and privacy and fail to broaden reform beyond genetics issues.

Another more typical incrementalist strategy would begin by taking the first incremental step – genetics legislation – as if based on principled distinctions between genetic and non-genetic information.<sup>241</sup> This draws on public support. Once genetics legislation is well

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<sup>237</sup> This view might be considered a genetics determinism perspective. It need not be a fully deterministic perspective, however, since the claim that genes play a role in all phenotype does not necessarily mean that they play the only role. In other words, one might take such a view, even while accounting for the influence of environment and complex gene-gene interactions. Of course, one might also take such a view based on a pure (and naive) genetics deterministic perspective.

<sup>238</sup> Max Mehlman deserves credit for this apt metaphor.

<sup>239</sup> See Neil A. Holtzman & Theresa M. Marteau, *Will Genetics Revolutionize Medicine?*, 353 NEJM 141 (2000).

<sup>240</sup> Of course, as we will see *infra* in Part III.C, ideally, the HIPAA privacy regulations will achieve this goal of broad scale protection of the privacy of medical information once covered entities begin to comply with the regulations. Similarly, the Health Insurance Portability and Accountability Act of 1996, moves in the right direction with respect to insurance nondiscrimination, by prohibiting group plans from making underwriting decisions on the basis of medical, not just genetic, information. See *infra* TAN 348-351.

<sup>241</sup> The extent to which this motivates genetics legislation today is uncertain. This

established, one can begin to challenge these distinctions. The goal would then be to convince legislators that the initially apparent principled distinctions are in fact not principled. Therefore, for equity reasons, the protections for genetic information should extend to other medical information. Indeed, the focus of this article is to urge policy makers to move in precisely that direction by pointing out that the concerns motivating genetics legislation extend well beyond genetic information.

There is much to be said for incrementalism. It has become the strategy of choice in other policy areas,<sup>242</sup> including health care reform. Although “there seems to be an emerging consensus that universal coverage should be the goal,”<sup>243</sup> the political fallout of the failed attempts at national health care reform in 1993-94 has been “pushing politicians to seek smaller, incremental solutions.”<sup>244</sup> Rather than attempting full-scale health reform in one fell swoop, the strategy has been “smaller, incremental solutions.”<sup>245</sup> For example, in the aftermath of the failure of the Clinton administration’s efforts to achieve health care reform, Congress enacted the

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strategy requires disguising the strategy. That the “Real Politik” argument does not appear in scholarly articles or testimony before legislators does not mean that it is not motivating this legislation, at least in part. It may not be the primary motivation for many proponents of genetics legislation who still adhere to notions of genetics exceptionalism. However, my suspicion is that this is coalescing into a conscious strategy on the part of some individuals, and perhaps even interest groups. I have heard allusions to these arguments in backroom discussions of genetics legislation. Most frequently, however, this justification is offered as speculation by those opposed to genetics-specific legislation as a plausible argument one might make in favor of such legislation.

<sup>242</sup> See James L. True, *Avalanches and Incrementalism: Making Policy and Budgets in the United States*, 30 AM. REV. PUB. ADM’N 3, 3 (2000) (noting that incrementalism is an important aspect of government decision making, though emphasizing that it is balanced by a period of “avalanche[s] of change”).

<sup>243</sup> Julie Rovner, *Embracing Incrementalism*, BUS. & HEALTH, Mar. 2000, at 12 .

<sup>244</sup> Robin Toner, *Gore and Bush Health Proposals Fall Short of Counterparts’ Plans 8 Years Ago*, N.Y. TIMES, Oct. 15, 2000, at A22.

<sup>245</sup> *Id.* See Jeffrey Plaut, *Age of Incrementalism*, CAMPAIGNS & ELECTIONS, Feb. 1998, at 63 (noting that “[i]ncrementalism is back . . . with a vengeance” as voters become distrustful of “bold pronouncements from either side of the aisle.”)

Health Insurance Portability and Accountability Act in 1996, which helps those with insurance maintain coverage. And in 1997, Congress enacted the Children’s Health Insurance Program (“CHIP”), which covers children from low-income families with incomes too high for Medicaid.<sup>246</sup> Similarly, both parties advocate expansion of Medicare coverage to include prescription drugs.<sup>247</sup> In sum, “the step-by-step approach to expanding health coverage has many defenders, who note that it has the great advantage of being politically realistic.” In addition, incrementalism offers the possibility of creating a laboratory of approaches with respect to new issues, so that policy makers can “learn by doing.”<sup>248</sup>

The success of incrementalism depends on numerous factors: political concerns, leadership, state of the economy, public attitudes and attention toward the issue. As some have observed, incrementalism and large-scale reform are cyclical.<sup>249</sup> In the area of health care, we have seen a combination of both.<sup>250</sup> Given the strong institutional forces that inspire the genetics

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<sup>246</sup> As of March 2000, two million children were enrolled in the program. Rovner, *supra* note 243, at 12.

<sup>247</sup> They differ as to precisely how to achieve this goal. Medicare has become a hot political issue because “not only do seniors vote more, but their ability to organize, to hold forums, has garnered their cause a great deal more attention than the uninsured.” *Id.* In addition, prescription drug coverage is both easier and cheaper to accomplish than other kinds of reform. *Id.*

<sup>248</sup> I credit Peter Swire with this observation.

<sup>249</sup> True, *supra* note 242, at 3 (asserting that policy making alternates between incremental change and “virtual avalanche[s] of change.”).

<sup>250</sup> The last 15 years have been characterized by incremental reform with respect of health care coverage. John V. Jacobi, *Medicaid Expansion, Crowd-Out and the Limits of Incremental Reform*, 45 ST. LOUIS UNIV. L.J. 79, 79 (2001). However, in 1965, with the Lyndon Johnson’s landslide presidential victory, a strongly Democratic Congress enacted Medicare and Medicaid, which entailed a major restructuring of financing of health insurance for large segments of society – the aged and the poor. See RAND E ROSENBLATT ET AL., LAW AND THE AMERICAN HEALTH CARE SYSTEM 369, 410-11 (1997); PAUL STARR, THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE 368-370(1982). Though neither constituted full-scale health care reform (indeed not all of those under the poverty line were protected by Medicaid), see ROSENBLATT ET AL., *supra*, at 413, the reform was far more than incremental, see

exceptionalism perspective, however, I am skeptical as to whether incrementalism can succeed via genetics legislation given prevailing views of genetics. I fear that rather than being the first step toward broader reform with respect to insurance discrimination, employment discrimination, or privacy protections, genetics legislation might be the last step.

Much of the impetus and political support for such legislation derives from and builds on deeply entrenched public sentiments that genetic information is uniquely susceptible to misuse. Even if not all proponents of genetics legislation intentionally recruit genetics exceptionalism arguments, the nature of discourse and legislation is inherently genetics-centric, which institutionalizes the genetics exceptionalism perspective and stigmatizes genetic information by suggesting it requires special protections. As long as the genetics legislation is largely understood as grounded in genetics exceptionalism, legislatures will think they have addressed the real problems and they won't want to go further. Similarly, the public, media, and even many scientists will likely feel satisfied that genetics legislation has resolved the important issues. Wrongs have been righted, justice has been promoted and everyone can rest soundly.<sup>251</sup> As a consequence, once genetics legislation is in place, public support is likely to be anemic with respect to further reform, and politicians may be reluctant to invest the political capital in extending these protections beyond genetics. More importantly, they may find it difficult to conceive of those issues as equally important, especially while genetics exceptionalism is the prevailing mindset.

This is a general problem with incrementalism, which requires “creative and specific demonstrations of why each claim to social resources is legitimate.”<sup>252</sup> Advocates must demonstrate a near crisis for their group as well as the group's moral claim to such assistance.

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True, *supra* note 242, at 6 (noting that from its inception, Medicare budgeting has featured large, as opposed to incremental increases).

<sup>251</sup> Whether the partial fix of genetics legislation changes much in reality, it has great symbolic meaning. See Hall, *supra* note 165, at F7; Reilly, *supra* note 8, at 124-26.

<sup>252</sup> Marmor, *supra* note 233, at 99.

The discussion stays narrow and reform is limited to “tinkering at the edges of current policy,”<sup>253</sup> rather than confronting larger principles. “Appeals for special help to the disadvantaged chart the details of some of our victims, but not the shape of politically viable and institutionally secure remedies.”<sup>254</sup> As each incremental step is enacted, society is lulled into a false sense of having solved the pressing crisis.

We are left with the question whether incrementalism via genetics legislation will succeed by addressing the various concerns of privacy and discrimination in employment and insurance step by step, or whether it will remain unfulfilled, leaving us with a false sense of having achieved meaningful reform and, worse, serious inequities among groups. In other words, does incrementalism have enough momentum to finish its work or must we let things get so bad that reform is inevitable?<sup>255</sup> In the end, it is impossible to predict whether genetics legislation will promote larger reform via incrementalism. In my view, its chance of success is limited because it fails to address the larger underlying concerns and it offers a false sense of having addressed social issues. Certainly we should be pessimistic about incrementalism’s potential here unless and until we change the nature of the debate and eliminate the notion of genetics exceptionalism.

### **Part III. Genetics Exceptionalism and the Threat to Equal Protection Values**

Given these reasons to be skeptical about the success of incrementalism in genetics, where are we left? The under-inclusiveness and resulting inequities are troubling, but without more, they offer insufficient reasons to condemn genetics legislation. While we might prefer all

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<sup>253</sup> *Id.* at 100.

<sup>254</sup> *Id.* at 101. Moreover, these efforts at expanding assistance to disadvantaged groups can backfire, demonstrating that “programs concentrated on the disadvantaged become disadvantaged programs.” *Id.* at 99-101 (describing the repeal of the “so-called catastrophic Medicare Act in the 1990s” by arousing the elderly’s fear of ill treatment).

<sup>255</sup> Iris Geva-May & Allan Maslove, *What Prompts Health Care Policy Changes? On Political Power Contests and Reform of Health Care Systems (The Case of Canada and Israel)*, 25 J. HEALTH POL., POL’Y & L. 717, 727 (2000) (noting that some reform occurs in response to crisis, others through “slowly emerging, incremental policy shifts.”).

statutes to be conceptually sound and precise so as to avoid such problems, they often suffer from these flaws. To criticize genetics legislation on these grounds alone,<sup>256</sup> would expose a great deal of other legislative initiatives to similar criticisms.<sup>257</sup> Because all statutes create classifications, they inevitably exclude some arguably deserving individuals from legal protections. Some level of inequity is frequently a fair price for the societal advantages of laws.<sup>258</sup>

Indeed, although the Equal Protection Clause guarantees that the government will treat similar individuals similarly, the vast majority of equal protection claims are “dismissed out of hand.”<sup>259</sup> In most cases, the courts are highly deferential to a legislature’s chosen classification. Only if the classification is deemed irrational – if there is no objective difference between the advantaged and disadvantaged or if the difference is not one to which the government can legitimately attach significance – is the classification constitutionally troublesome.<sup>260</sup> This

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<sup>256</sup> Indeed, one might wonder whether framing the problem of genetics exceptionalism as an exceptional problem raises its own set of problems.

<sup>257</sup> In the face of public fears or concerns about a particular issue, legislators often enact legislation that is over- and under-inclusive with respect to the fundamental concerns. For example, as AIDS became a public issue, many legislators responded to public concerns by enacting legislation that dealt specifically with HIV infection. For criticisms of this approach see Sheryl Gay Stolberg, *New Challenge to Idea that ‘AIDS is Special,’* N.Y. Times, Nov. 12, 1997, at A1 (questioning “AIDS exceptionalism”).

<sup>258</sup> Michael J. Perry, *The Disproportionate Impact Theory of Racial Discrimination*, 125 U. PENN. L. REV. 540, 556 (1977) (“Incidental burdens have been thought the fair price everyone . . . must pay, at some time or other for the societal advantages of law. After all, virtually every piece of legislation is burdensome to somebody.”).

<sup>259</sup> Lawrence Gene Sager, *Fair Measure: The Legal Status of Underenforced Constitutional Norms*, 91 HARV. L. REV. 1212, 216 (1978).

<sup>260</sup> Michael J. Perry, *Modern Equal Protection: A Conceptualization and Appraisal*, 79 COLUM. L. REV. 1068-69 (1979); Perry, *supra* note 258, at 557 (“[A]s long as a law does not rest on an invidious classification and has a rational basis, the consequent disadvantage is ethically inoffensive.”).

lenient standard of review reflects “sympathy for difficulties of the legislative process”<sup>261</sup> and a tolerance for the inevitable over- and under-inclusiveness of legislation.

But of course some legislative classifications are, if not constitutionally infirm, at least constitutionally suspect. When a legislative classification burdens a fundamental right<sup>262</sup> or targets a suspect class,<sup>263</sup> courts subject the statute to the virtually fatal heightened scrutiny standard of review, which requires that the legislation fit very important goals more closely than any alternative classification would.<sup>264</sup> In effect, equal protection law reflects a compromise between ideals and reality. It expresses the ideal of treating similarly situated individuals similarly, but it is also sympathetic to the challenges in achieving that ideal. This compromise means that the law often tolerates legislative imperfections, unless certain important interests or values are infringed.

Although this article does not suggest that courts would find that genetics legislation violates the Equal Protection Clause, it argues that legislators should be guided by equal protection values and under-enforced constitutional norms. More specifically, policy makers should not tolerate the under-inclusiveness and resulting inequities of genetics legislation. As legislators reexamine their genetics legislation in light of the new HIPAA privacy rules, this is an ideal time for them to consider the ways in which the flaws of genetics legislation challenge important constitutional values. Equal protection theory offers a valuable legal, moral, and policy framework for analyzing which inequities are particularly troubling. Analysis of several strands of equal protection theory suggests that, even if courts would not hold genetics legislation unconstitutional, it results in inequities that legislators should find morally disturbing

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<sup>261</sup> LAURENCE H. TRIBE, *AMERICAN CONSTITUTIONAL LAW* 995 (1<sup>st</sup> ed. 1978). Not only do legislatures face difficulties in deciding the optimal classification, but they must also consider the social, political, economic costs of more precise legislation, and the competing interests be at stake.

<sup>262</sup> *See, e.g., Harper v. Virginia State Bd. of Elections*, 383 U.S. 663 (1966)

<sup>263</sup> *See, e.g., Korematsu v. United States*, 323 U.S. 214 (1944).

<sup>264</sup> JOHN H. ELY, *DEMOCRACY AND DISTRUST* 146 (1980).

and which violate the spirit of the Constitution. Given the responsibility of legislators to respect constitutional values that courts may not always enforce, legislators should be troubled by these inequities even if judicial deference to their judgment would let these statutes stand. Although public health rationales for genetics legislation provide a justification for genetics legislation, the uncertainty as to whether genetics legislation would exacerbate the problem and whether the problem is especially great in the genetics context weakens this justification. Part III therefore concludes with final thoughts as to approaches legislators might take to eliminate the under-inclusiveness of genetics legislation, using some federal approaches as guidelines.

#### **A. Equal Protection – The Peril of Genetics Exceptionalism**

Although this Section explores equal protection theory to evaluate the under-inclusiveness of genetics legislation, I must emphasize that my arguments are largely moral and policy arguments, based on the spirit of the constitution, rather than arguments based on technical constitutional infirmities. In other words, I am not claiming that genetics legislation would fail under an equal protection attack. Genetics legislation does not *directly* target any constitutionally recognized suspect classes. Moreover, the statutes do not implicate any of the fundamental interests – such as voting, the right to travel, or access to the criminal process – to which the Court has accorded special protection under the Equal Protection Clause. Genetics legislation would therefore surely be subject to the rational-basis test, which it would likely survive. The various rationales for genetics legislation discussed in Part II.A.1 as well as the incrementalism would more than suffice. Indeed, a frequent defense to assertions of under-inclusiveness is that “piecemeal legislation is a pragmatic means of effecting needed reforms, where a demand for completeness may lead to total paralysis.”<sup>265</sup>

That the courts would uphold genetics legislation on equal protection grounds is not in and of itself reason to celebrate, or indeed support, the under-inclusiveness of the legislation. In fact, to say that legislation would survive judicial review is not necessarily to say that the legislation is constitutional. Courts may sometimes uphold statutes for institutional reasons,

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<sup>265</sup> TRIBE, *supra* note 261, at 997. The potential success of that strategy need not be established as long as the statute is subjected to a rational basis test.

even when legislation is constitutionally problematic. For example, concerns about federalism, judicial competence, or judicial restraint may motivate under-enforcement of constitutional norms.<sup>266</sup> Therefore, it may sometimes be “incongruous to treat the products of such restraint as authoritative determinations of constitutional substance.”<sup>267</sup> The fact that courts sometimes show restraint and deference toward legislative classifications or that courts don’t implement certain constitutional values means that legislators have an added responsibility to ensure that their legislation is consistent with constitutional norms. In other words, legislators must take responsibility for “fashion[ing] their own conceptions of these norms and to measure their conduct by reference to these conceptions.”<sup>268</sup> Therefore they should be concerned not only with genetic legislation’s ability to survive judicial review, but also with its under-enforced constitutional and normative value.<sup>269</sup>

Even if genetics legislation would survive equal protection challenges in court, it may nevertheless be inconsistent with the goals of equal protection, namely to ensure that the state treats people equally, unless it is fair not to.<sup>270</sup> Equal protection theory offers a moral, legal, and policy framework for establishing when it is “unfair” to treat similarly situated people differently.<sup>271</sup> To demonstrate that the inequities of genetics legislation are unfair and bad

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<sup>266</sup> Sager, *supra* note 259, at 1218, 1224.

<sup>267</sup> *Id.* at 1226.

<sup>268</sup> *Id.* at 1227.

<sup>269</sup> My analysis relies on the “social good” model of legislation, which suggests that legislation is a means of “achieving what a majority of the legislature has identified as desirable ‘social objectives,’” as opposed to a “public choice” model, which views legislation as the result of “bargains struck between those helped by legislation and those who are harmed.” Scott Bice, *Rationality Analysis in Constitutional Law*, 65 MINN. L. REV. 1, 1 (1980).

<sup>270</sup> Sager, *supra* note 259, at 1215.

<sup>271</sup> See Joseph Tussman & Jacobus tenBroek, *The Equal Protection of the Laws*, 3 CAL. L. REV. 341, 344 (1949); Matthew D. Adler, *Rights Against Rules: The Moral Structure of American Constitutional Law*, 97 MICH. L. REV. 1, 67 (1998) (discussing Tussman and

policy, I turn to three equal protection theories – process theory, disparate impact theory, and fundamental rights theory. Although, I am skeptical that any of these theories alone makes genetics legislation constitutionally suspect, in conjunction, they raise significant moral, political, and legal concerns about the under-inclusiveness of genetics legislation.

## 1. Process Theory

I begin with process theory, the germ of which arose in Justice Stone’s famous footnote in *United States v. Carolene Products Co.*<sup>272</sup> In trying to clarify the role of judicial review following the wild judicial activism of the *Lochner* era,<sup>273</sup> Justice Stone suggested that the Court’s ordinary deference to legislators would be inappropriate with respect to statutes involving “prejudice against discrete and insular minorities . . . which tends seriously to curtail the operation of those political processes ordinarily to be relied upon to protect minorities.”<sup>274</sup>

Forty years later, John Hart Ely developed this embryonic idea into a more complex theory in his seminal book, *Democracy and Distrust*.<sup>275</sup> From the perspective of process theory, equal protection “principally concerns judicial solicitude for groups unable to fend for themselves in the political trenches because of disenfranchisement, blatant prejudice, negative stereotyping, or some combination thereof.”<sup>276</sup> In other words, process theory aims to protect groups “in society to whose needs and wishes elected officials have no apparent interest in attending,”<sup>277</sup> groups “who can’t protect themselves politically.”<sup>278</sup> Although a group’s lack of

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tenBroek’s article).

<sup>272</sup> 304 U.S. 144 (1938).

<sup>273</sup> Michael Klarman, *An Interpretive History of Modern Equal Protection*, 90 MICH. L. REV. 213, 221-225 (1991).

<sup>274</sup> 304 U.S. at 152 n.4.

<sup>275</sup> ELY, *supra* note 264.

<sup>276</sup> Klarman, *supra* note 273, at 310.

<sup>277</sup> ELY, *supra* note 264, at 151.

vote may raise particular process concerns, the inability to participate fully in the “pluralist’s bazaar,” may be impeded by prejudice or legislative indifference to the interests of excluded groups because the typical American legislature does not reflect the group’s demography.<sup>279</sup>

Ely relied on this theory to explain why race, poverty, alienage, and homosexuality should be treated as suspect classes.<sup>280</sup> Minority race is a suspect class in his view, not only because race-based classifications stigmatize, but also because prejudice causes the popular majorities to overlook or ignore the interests of minorities.<sup>281</sup> Though minorities have a vote and political access – indeed blacks are majorities in many cities – political access alone cannot ensure a meaningful voice in the political process.<sup>282</sup> Aliens are subject, at best, to similar neglect, and, at worst, to hostility because legislatures are entirely made up of citizens.<sup>283</sup> Ely

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<sup>278</sup> *Id.* at 152.

<sup>279</sup> *Id.* at 159. “Political access is surely important, but (so long as it falls short of majority control) it cannot alone protect a group against . . . prejudice . . . [and] out and out hostility.” *Id.* at 161.

<sup>280</sup> The Supreme Court defines suspect classes more narrowly than Ely. It has not treated homosexuality or poverty as a suspect class. *See infra* notes 284 and 285.

<sup>281</sup> The Supreme Court, however, treats race per se, not just minority race, as a suspect class. *See, e.g.,* *Korematsu v. United States*, 323 U.S. 214 (1944) (treating race as a suspect class, but upholding a military order excluding Americans of Japanese origin from designated West Coast areas following Pearl Harbor on the theory that the government interest was compelling); *Richmond v. J.A. Croson, Co.*, 488 U.S. 469 (1989) (invalidating a city plan to increase the number of minority owned businesses who were awarded city construction contracts).

<sup>282</sup> ELY, *supra* note 264, at 150-53. “If voices and votes are all we’re talking about, prejudices can easily survive (and on occasion be exacerbated): other groups may just continue to refuse to deal, and the minority in question may just continue to be outvoted.” *Id.* at 161. Racial prejudice, Ely points out, may keep blacks on “the wrong end of the legislature’s classifications.” *Id.* at 152.

<sup>283</sup> *Id.* at 161-62. *See, e.g.,* *Graham v. Richardson*, 403 U.S. 365 (1971) (invalidating a statute that conditioned welfare benefits upon either the possession of United States citizenship or minimum residence in the United States); *Application of Griffiths*, 413 U.S. 717 (1973)

applies similar analysis to the poor, who although they can vote, are not well represented within legislatures.<sup>284</sup> Finally, he argues homosexuality is a suspect class because prejudice and stereotyping can result in hostile or neglectful legislation and because the cost of revealing one's sexuality in the face of such hostility makes it difficult to advocate for one's interest.<sup>285</sup> Thus, according to process theory, laws based on such classifications should receive strict scrutiny.<sup>286</sup>

Process theory, therefore, is concerned about the very people who are disadvantaged by genetics legislation, the poor and ethnic or racial minorities.<sup>287</sup> Ely's process theory, however, focuses on legislative classifications per se as opposed to the *impact* that such legislation may have on suspect classes. He argues that, even if a statute's impact is greater on one group than another, the statute is not unconstitutional, unless the benefit concerns one to which we have substantive constitutional entitlements.<sup>288</sup> Instead he focuses on suspicious classifications to "flush[] out' unconstitutional motivations."<sup>289</sup> Although many laws may disproportionately

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(invalidating a state court requirement of citizenship for admission to the bar); *Sugarman v. Dougall*, 413 U.S. 634 (1973) (invalidating a statute requiring citizenship for any position in the state civil service system).

<sup>284</sup> ELY, *supra* note 264, at 162. The Supreme Court has not treated the poor as a suspect class. *See, e.g.*, *Dandridge v. Williams*, 397 U.S. 471 (1970) (upholding a statute whose formula for aid to families with dependent children resulted in denial of benefits to children born to families over a certain size); *San Antonio Independent School District v. Rodriguez*, 411 U.S. 1 (1973) (upholding a property tax system for financing primary and secondary education that resulted in disparities in the amount of money spent on the education of individual children).

<sup>285</sup> ELY, *supra* note 264, at 162-63. The court did not reach the question of whether homosexuality is a suspect class in *Romer v. Evans*, 517 U.S. 620 (1995).

<sup>286</sup> ELY, *supra* note 264, at 162.

<sup>287</sup> *See supra* TAN 222-231.

<sup>288</sup> *Id.* at 143, 145.

<sup>289</sup> *Id.* at 146. *See also*, Paul Brest, *Foreword: In Defense of the Antidiscrimination Principle*, 90 HARV. L. REV. 1, 44-53 (1976) (arguing that discrimination, not disparate impact, is the touchstone of the Equal Protection clause).

impact the poor, legislative classifications based on wealth are extremely rare.<sup>290</sup> As a result, although Ely's process theory of suspect classification would include the group that genetics legislation disadvantages, it cannot alone explain why this legislation is problematic since the legislation does not use race or wealth-based classifications.

## 2. Disparate Impact Theory

If we are truly concerned about protecting groups “who can't protect themselves politically,” or who are “perennial losers in the political struggle,”<sup>291</sup> it is insufficient to focus only on legislative classifications. Although legislation founded on illicit motivation with respect to suspect classes is especially troubling, legislation that is selectively indifferent to those classes is also problematic. Indeed concerns about a law's disproportionate impact on suspect classes is consistent with process theory.<sup>292</sup> For a period, the Warren Court seemed motivated by precisely those concerns, suggesting that legislation could be invalidated solely for its discriminatory *effects*, even without any evidence of overt discriminatory intent.<sup>293</sup> The Supreme Court's decision in *Washington v. Davis*,<sup>294</sup> however, ultimately rejected this non-motivational theory of equal protection, holding that there could be no unconstitutional discrimination without “discriminatory purpose” or illicit motivation.<sup>295</sup>

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<sup>290</sup> “A theory of suspicious classification will thus be of only occasional assistance to the poor, since their problems are not often problems of classification to begin with,” but problems of general societal disadvantages and governmental failures to alleviate poverty. ELY, *supra* note 264, at 162.

<sup>291</sup> TRIBE, *supra* note 261, at 1002.

<sup>292</sup> Klarman, *supra* note 273, at 263-64 (“Though [political process theory] plainly condemns legislation motivated by hostility towards disenfranchised or discrete and insular minorities, it plausibly extends as well to laws enacted out of selective indifference towards the interests of such groups.”).

<sup>293</sup> Perry, *supra* note 258, at 544-48; Klarman, *supra* note 273, at 295-97.

<sup>294</sup> 426 US 229 (1976).

<sup>295</sup> *Id.* at 246-48.

Though the Court drew a sharp demarcation between bad purpose and bad effect, it need not have. A “plausible alternative approach would treat legislatures’ selective indifference to a protected group’s interests as sufficient grounds for condemning legislative decision making.”<sup>296</sup> And, in fact, some scholars have developed such an approach in their equal protection analysis. For instance, some have argued that disparate impact theory is justified when the disadvantage faced by the group is not only the consequence of the law, but “also and more fundamentally as a consequence of prior governmental action that was constitutionally (and ethically) offensive.”<sup>297</sup> Because, for example, laws that disproportionately disadvantage blacks may reinforce racial isolation and governmental wrongs of the past, they are potentially problematic.<sup>298</sup> Disparate impact theory rests on the idea that the government has an affirmative obligation not to “exacerbate the effects of prior discrimination.”<sup>299</sup> This affirmative obligation “serves principally as a brake on the lamentable tendency of the majority race wilfully to oppress or exploit racial minorities.”<sup>300</sup>

The concern that selective indifference may “thoughtlessly and needlessly [infringe] on the interests of racial minorities”<sup>301</sup> ties in well with process theory. Part of what

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<sup>296</sup> Klarman, *supra* note 273, at 298.

<sup>297</sup> Perry, *supra* note 258, at 557.

<sup>298</sup> Perry argues that laws that disproportionately disadvantage a racial minority should be subjected to more rigorous review than the rational relationship test but less rigorous than the strict scrutiny test. *Id.* at 559.

<sup>299</sup> *Id.* at 561. Perry is careful to distinguish disparate impact theory from affirmative action. The former is “premised on the notion that government should not exacerbate the effects of prior discrimination any more than is reasonably necessary to achieve the governmental objective,” whereas “affirmative action theory calls for government to undo the effects of prior discrimination.” *Id.*

<sup>300</sup> *Id.* at 556.

<sup>301</sup> *Id.* at 587 (“Legislatures and other government agencies are not as sensitive to the interests of racial minorities as to majoritarian interests. Occasionally, a legislature will overlook less intrusive ways of advancing its objectives and, instead, will infringe thoughtlessly and

makes the poor and minorities suspect classes under political process theory is the fact that they are limited in their ability not only to counter illicitly motivated legislation, but also to persuade the legislature to overcome its indifference to their concerns. If legislative indifference leaves the politically disempowered at a disadvantage, even if only through disparate impact, political processes are unlikely to overcome this problem.

These are precisely the problems that exist with genetics legislation. Genetics legislation excludes protections with respect to the non-genetic risks that disproportionately affect the politically disempowered, i.e., the poor and minorities. Such legislation is not the result of hostility, but of insensitivity. State legislators tend to be middle or upper class individuals. Genetic testing and therefore genetic discrimination are very much on their minds. For them the threat of discrimination based on genetic risks looms larger than the threat of discrimination based on non-genetic risks. Not surprisingly, therefore, they are eager to enact genetics legislation. But because non-genetic risks do not occupy their concerns, legislators are inattentive or selectively indifferent to the equally serious threats of discrimination based on non-genetic risks.<sup>302</sup> Given the powerful and institutionalized focus on genetic discrimination,<sup>303</sup> the widespread failure to see how those concerns extend beyond genetics, and the lack of power among the groups most disadvantaged by this legislation, it would seem that disparate impact and process theory give legislators reason to be troubled by genetics-specific legislation.

### **3. Fundamental Rights Theory**

Although process and disparate impact theory bring us a long way toward explaining some of the perils of genetics legislation, fundamental rights theory takes us a step further. Because disproportionate impact theory imposes an *affirmative* obligation on states to avoid unnecessary aggravation of the disadvantaged position of suspect classes, the case will be stronger the more important or fundamental the burdened interest. Thus, the evaluation of genetics legislation should consider not only the fact that a suspect class is disproportionately

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needlessly on the interests of racial minorities.”).

<sup>302</sup> See *supra* TAN 230-231.

<sup>303</sup> See *supra* Part I.

disadvantaged, but also that it is disadvantaged with respect to a serious interest.<sup>304</sup> In other words, the inquiry brings together all three strands of equal protection theory.

The Supreme Court has invalidated statutes that disadvantage indigents with respect to the criminal process,<sup>305</sup> family law matters,<sup>306</sup> voting rights,<sup>307</sup> and the ability to engage in interstate travel.<sup>308</sup> Those decisions reflect the concerns described above and indeed could be explained in light of the three equal protection theories.<sup>309</sup> First, even though the Court has not

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<sup>304</sup> Once a disparate impact is shown, “factors other than disproportionate impact become crucial, principally the private interest, in relation to which there is a disproportionate impact, and the public interest, the pursuit of which by means of the challenged law or practice has a disproportionate impact.” Perry, *supra* note 258, at 563. “The public fisc is not exhaustible,” he notes, thus one needs to consider the importance of the private interest when balancing them against the public interests. When they are deemed “indispensable to the preservation of fundamental values,” we can justify dipping into the public fisc. *Id.* at 564.

<sup>305</sup> Griffin v. Illinois, 351 U.S. 12 (1956) (requiring the state to provide indigent criminal appellants with a free transcript of the trial when necessary for full appellate review); Douglas v. California, 372 U.S. 353 (1963) (requiring the state to provide indigent appellants with counsel for their first appeal of right); Gideon v. Wainwright, 372 U.S. 335 (1963) (requiring indigent criminal defendants accused of a felony to have court appointed counsel); Argersinger v. Hamlin, 407 U.S. 25 (1972) (requiring appointed counsel for all prosecutions that result in imprisonment).

<sup>306</sup> Boddie v. Connecticut, 401 U.S. 371 (1971) (invalidating a statute requiring payment of court costs when filing for a divorce); Zablocki v. Redhail, 434 U.S. 374 (1978) (striking a law that restricted the ability of economically poor persons to marry).

<sup>307</sup> Harper v. Virginia State Bd. of Elections, 383 U.S. 663 (1966) (finding unconstitutional Virginia’s poll tax for state elections).

<sup>308</sup> Shapiro v. Thompson, 393 U.S. 618 (1969) (invalidating statutes that denied welfare benefits to people who had not resided within the jurisdiction for at least one year); Memorial Hospital v. Maricopa County, 415 U.S. 250 (1974) (invalidating a statute requiring a minimum residency in order to receive non-emergency medical care at public expense); Saenz v. Roe, 526 U.S. 489 (1999) (invalidating a statute requiring a minimal residency requirement to become entitled to receive welfare benefits).

<sup>309</sup> In Harper v. Virginia State Board of Elections, the Court invalidated a state poll tax on equal protection grounds, noting that “[w]ealth, like race, creed, or color, is not germane

treated the poor as a suspect class, these cases reflect concern for the special needs of the poor.<sup>310</sup> Second, the invalidated statutes were not based on wealth classifications, but instead had a disparate impact on the poor by requiring, for example, criminal defendants to pay for transcripts required for appeal,<sup>311</sup> the payment of court costs in order to seek a divorce,<sup>312</sup> the submission of proof of compliance with child support obligations in order to marry,<sup>313</sup> the payment of a poll tax to vote,<sup>314</sup> or a minimum duration of residency to obtain welfare benefits or medical care.<sup>315</sup> But most important, the Court was motivated by the principle that certain interests – access to the criminal process, voting, marriage, and the right to travel – are so constitutionally significant as to invalidate statutes that impose disparate impacts based on wealth.

Although for institutional reasons the Supreme Court has not carried forward with full force the promise of these decisions,<sup>316</sup> their normative content still has weight and is highly applicable to genetics legislation. If wealth inequities with respect to voting rights and access to the criminal process raise red flags, then so should inequities with respect to even more

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to one's ability to participate intelligently in the electoral process." 383 U.S. at 668.

<sup>310</sup> See Frank Michelman, *The Supreme Court, 1968 Term – Foreword: On Protecting the Poor Through the Fourteenth Amendment*, 83 Harv. L. Rev. 7 (1960) (developing a Rawlsian “justice as fairness” theory of the Fourteenth Amendment, which imposes on the government an affirmative duty of minimal protection to fulfill “just wants.”)

<sup>311</sup> Douglas, 372 U.S. at 353.

<sup>312</sup> Boddie, 401 U.S. at 371.

<sup>313</sup> Zablocki, 434 U.S. at 374.

<sup>314</sup> Harper, 383 U.S. at 663.

<sup>315</sup> Shapiro, 393 U.S. at 618; Maricopa County, 415 U.S. at 250; Saenz, 526 U.S. at 489.

<sup>316</sup> See, e.g., Klarman, *supra* note 273, at 285-91 (explaining the Burger Court's retrenchment of the fundamental rights strand of equal protection largely because of institutional concerns such as wealth distribution).

compelling and basic needs such as food, health care, and shelter.<sup>317</sup> Indeed, the Court’s decision to invalidate a statute requiring at least a year of residency to receive publicly funded non-emergency health care was influenced by the necessity of health care.<sup>318</sup> Genetics legislation concerns interests, which even if not yet fundamental under the Constitution in the Court’s view, would be deeply important, even fundamental, to many. One’s interest in preventing health insurance discrimination is of course tied to one’s interest in health care. For many, the function of health insurance is to ensure access to the social good of health care.<sup>319</sup> Indeed, many have argued that health care is a fundamental moral right.<sup>320</sup> Similarly, protections

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<sup>317</sup> Shapiro, 394 US at 618, emphasized that a statute that denied welfare assistance to those who had been residents for less than a year resulted in the new residents’ being “denied welfare aid upon which may depend the ability of families to obtain the very means to subsist – food, shelter, and other necessities of life.” The concern that this group was disadvantaged with respect to the “necessities of life” merely on the basis of length of residence in the state, subjected the statute to strict scrutiny.

<sup>318</sup> “[D]iseases if untreated for a year, may become all but irreversible paths to pain, disability, and even loss of life.” Maricopa County, 415 U.S. at 261.

<sup>319</sup> See Daniels, *supra* note 54, at 119; Hall & Rich, *supra* note 230, at 250-51. The Michigan Commissioner of Insurance, for example, decided that certain types of insurance are essential and then created a guaranteed right to essential insurance. Gauling, *supra* note 55, at 1690; Jacobi, *supra* note 41, at 372-73. Norman Daniels argues that health care is necessary for equal opportunity and the ability to achieve normal species functioning. Daniels, *supra*, at 118. Since health care is important to restore or maintain normal species functioning, which is a crucial determinant of the opportunities available to us, Daniels concludes that justice requires access to health care. Since actuarial rating in health insurance makes access to health care benefits depend on the ability to pay and on individual risk, it does not protect equal opportunity. *Id.* Some are skeptical, however, about whether American society really treats much beyond education as a social good. Marmor, *supra* note 233, at 97.

<sup>320</sup> See, e.g., NORMAN DANIELS, JUST HEALTH CARE 39-48 (1985) (arguing that society has a moral to insure the provision of health care services based on a Rawlsian theory of justice); Peter B. Edelman, *The Next Century of Our Constitution: Rethinking Our Duty to the Poor*, 39 HASTING L.J. 1, 4 (1987); Wendy Mariner, *Access to Health Care and Equal Protection of the Law: The Need for a New Heightened Scrutiny*, 12 AM. J. L. & MED. 345, 371-77 (1986) (arguing that health care deserves special protection under the Constitution); Russell Korobkin, *Determining Health Care Rights From Behind a Veil of Ignorance*, 1998 U. Ill. L. Rev. 801 (1998) (suggesting that under the Rawlsian veil of ignorance, people would choose a society that

against employment discrimination address the importance of employment to one's well-being.<sup>321</sup> Finally, the Supreme Court has recognized a constitutional "interest in avoiding disclosure of personal matters."<sup>322</sup> As one of my colleagues notes, "[p]rivacy protects us from being misdefined and judged out of context in a world of short attention spans, a world in which information can easily be confused with knowledge."<sup>323</sup> It is, in short, a serious and deep, fundamental interest.

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guarantees some positive rights to health care); Frank I. Michelman, *Welfare Rights in a Constitutional Democracy*, 1979 WASH. U. L.Q. 659. *But see*, RICHARD A. EPSTEIN, *MORTAL PERIL: OUR INALIENABLE RIGHT TO HEALTH CARE?* (1997); Robert Bork, *The Impossibility of Finding Welfare Rights in the Constitution*, 1979 WASH. U. L.Q. 695. For critical and thoughtful discussions of these issues see Einer Elhauge, *Allocating Health Care Morally*, 82 CAL. L. REV. 1451 (1994); Mark Kelman, *Health Care Rights: Distinct Claims, Distinct Justifications*, 3 STAN. L. & POL'Y REV. 90 (1991). Much of the criticism of our approach to health care in this country has been premised on the notion that health care is a fundamental or important moral right. Justice Ginsburg has described our Constitution as "very skimpy" because, unlike many other constitutions in the world, it does not guarantee such fundamental rights as health care. *See* W. Kent Davis, *Answering Justice Ginsburg's Charge That the Constitution is "Skimpy" in Comparison to Our International Neighbors*, 39 S. TEX. L. REV. 951, 952 (1998).

<sup>321</sup> Perry, *supra* note 258, at 572 ("Employment is essential to material well-being and basic emotional satisfaction.")

<sup>322</sup> Whalen v. Roe, 429 U.S. 589, 598-600 (1977). The Court noted that this was one of two privacy interests, the other being the "interest in independence in making certain kinds of important decisions." *Id.* The under-inclusiveness of genetics privacy legislation does not implicate the privacy interests in avoiding *governmental interference* that are the basis for the constitutional right to abortion recognized in *Roe v. Wade*, 410 U.S. 113 (1973) and *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833 (1992). Rather the under-inclusiveness of genetics legislation is more analogous to the problematic, selective funding for abortions. *See* *Beal v. Doe*, 432 U.S. 438 (1977) (holding that states have no obligation to fund nontherapeutic abortions as a condition for receiving funding in a joint federal-state medical assistance program); *Maher v. Roe*, 432 U.S. 464 (1977) (holding that Connecticut's refusal to pay for nontherapeutic abortions does not violate the equal protection clause); *Poelker v. Doe*, 432 U.S. 519 (1977) (finding constitutional the decision of municipal hospitals to finance childbirth services while failing to pay for nontherapeutic abortion services).

<sup>323</sup> JEFFREY ROSEN, *THE UNWANTED GAZE: THE DESTRUCTION OF PRIVACY IN AMERICA* 8 (2000).

Analyzing genetics legislation under the three lenses of process, disparate impact, and fundamental rights theories, suggests that the under-inclusiveness of genetics legislation may not promote the social goods that underlie these theories, even if it would survive judicial scrutiny. Indeed, it conflicts with the spirit of the Constitution and may even violate under-enforced constitutional norms. Moreover, it challenges important moral and policy concerns. Legislators should therefore be wary of legislation that disproportionately impacts a vulnerable class with respect to very important interests and which exacerbates disadvantages among groups who have limited political influence to overcome these disadvantages.

### **B. The Public Health Defense – Responding to Public Fears**

Although the normative concerns about the under-inclusiveness of genetics legislation are problematic, the evaluation of the legislation is incomplete without some consideration of competing public interests. As noted earlier, equal protection strikes a compromise between ideals and political realities. It recognizes that legislators often balance a number of different objectives. Attending to inequities, even serious ones, may sometimes create more severe problems in other areas. Thus, to evaluate fully the consequence of the disparate impact of genetics, this section turns to the competing public interests. Because the inequities raise serious concerns, only strong public interests should suffice to overcome these concerns.<sup>324</sup>

We considered the incrementalism argument earlier, which might justify genetics legislation under a rational basis test.<sup>325</sup> But it is insufficient to overcome the serious inequities described above. Moreover, precisely because of the nature of the interests of the political majority and the strongly entrenched genetics exceptionalism perspective, one should be gravely skeptical about the success of such a strategy, which relies on genetics exceptionalism arguments. A more persuasive governmental interest is necessary to justify exacerbating the disadvantages of vulnerable groups.

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<sup>324</sup> Perry suggests a balancing of private and public interests that approaches an intermediate standard or review. *See Perry, supra* note 258, at 559-60; *see also* TRIBE, *supra* note 261, at 1089.

<sup>325</sup> *See supra* Part II.C.

The strongest justification for creating special protections for genetic information has to do with public perceptions, in particular the perception that genetics discrimination is a problem.<sup>326</sup> While it is difficult to establish whether that perception is well founded, the perception itself may be real. Increasingly, commentators and legislators worry that public fears may prevent society from reaping the full benefits of genetics. One worry is that the fear will dissuade people from obtaining genetic testing that might be beneficial to their health or from participating in genetics research.<sup>327</sup> The National Human Genome Research Institute has taken these concerns to heart and fought aggressively to promote genetics legislation on these grounds.<sup>328</sup>

To many, this justification for genetics legislation carries special force because it appears to be the only one that seems truly unique to genetic information. Indeed this has been the primary justification for genetics-specific legislation.<sup>329</sup> Although a great deal of attention has

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<sup>326</sup> See *supra* note 165.

<sup>327</sup> See *supra* note 164. "In genetic testing studies at the National Institutes of Health, thirty-two percent of eligible people who were offered a test for breast cancer risk declined to take it, citing concerns about loss of privacy and the potential for discrimination in health insurance." Sen. Leahy's comments for March 10, 1999 Introduction of the Medical Information Privacy and Security Act (quoted in *Standards for Privacy for Individually Identifiable Health Information, Regulation Preamble*, 45 C.F.R. § 160.101 (2001)).

<sup>328</sup> See Prepared Statement of Francis Collins, M.D., Ph.D., Director, National Human Genome Research Institute, House Science Committee Technology Subcommittee, Subject – Genetic Testing in the New Millennium: Advances, Standards, Implications, April 21, 1999 (suggesting these fears of discrimination require federal “genetic discrimination” legislation); Prepared Statement of Francis Collins, M.D., Ph.D., Director, National Human Genome Research Institute, National Institutes of Health Before the House Science Committee Subcommittee on Technology on Technological Advances in Genetics Testing: Implications for the Future, Sept. 17, 1996 (“In order to assure that the Nation benefits from the fruits of genetic research, safeguards must be in place to protect individual privacy and prevent insurance and employment discrimination.”).

<sup>329</sup> See floor statements for S. 318, 107<sup>th</sup> Cong., 1<sup>st</sup> Sess. (2001); H.R. 602, 107<sup>th</sup> Cong., 1<sup>st</sup> Sess. (2001); and S. 382, 107<sup>th</sup> Cong., 1<sup>st</sup> Sess. (2001) (all arguing that to reap the benefits of the human genome project and encourage beneficial genetic testings, genetics legislation is necessary).

been directed to this issue recently, the concern is not actually unique to genetics. Indeed, one of the arguments in favor of federal privacy protections was that some people avoid medical care because of fears of discrimination.<sup>330</sup> Similar concerns that worries about discrimination based on sensitive medical information might prevent people from participating in sensitive clinical research inspired Congress to enact legislation to protect the privacy of medical research. Specifically, the statute allows the Department of Health and Human Services, through the issuance of certificates of confidentiality, to “authorize persons engaged in biomedical, behavioral, clinical, or other research . . . to protect the privacy of individuals who are the subject of such research by withholding from all persons not connected with the conduct of such research the names or other identifying characteristics of such individuals.”<sup>331</sup>

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<sup>330</sup> The preamble of the final HIPAA privacy rules notes the importance of privacy protections so that patients will openly discuss their concerns and medical conditions with their physicians. Some evidence suggests that to “protect their privacy and avoid embarrassment, stigma, and discrimination, some people withhold information from their health care providers, provide inaccurate information, doctor-hop to avoid a consolidated medical record, pay out-of-pocket for care that is covered by insurance, and - in some cases - avoid care altogether,” thereby hindering optimal medical care. *Standards for Privacy for Individually Identifiable Health Information*, Regulation Preamble, 45 C.F.R. § 160.101 (2001). “Recent studies show that a person who does not believe his privacy will be protected is much less likely to participate fully in the diagnosis and treatment of his medical condition. . . . [and that] one in six Americans reported that they have taken some sort of evasive action to avoid the inappropriate use of their information by providing inaccurate information to a health care provider, changing physicians, or avoiding care altogether.” Similarly, nearly half of Americans with mental disorders never seek treatment because, among other things, they fear discrimination and stigmatization. Robert Pear, *Mental Disorders Common, U.S. Says: Many Not Treated*, N.Y. TIMES, Dec. 13, 1999, at A1.

<sup>331</sup> 42 U.S.C.A § 241(d). Researchers who receive the certificate of confidentiality “may not be compelled in any Federal, State, or local, civil, criminal, administrative, legislative, or other proceedings to identify” their research subjects. 42 U.S.C.A § 241(d). The original version of the statute applied only to alcohol- and drug-abuse research. Charles L. Earley & Louise C. Strong, *Certificates of Confidentiality: A Valuable Tool for Protecting Genetic Data*, 57 AM. J. HUM. GENETICS 727, 727 (1995). The initial concern was that it was difficult to find research subjects willing to admit they had engaged in illegal conduct. Mark Rothstein, *Preventing the Discovery of Plaintiff Genetic Profiles by Defendants Seeking to Limit Damages in Personal Injury Litigation*, 71 IND. L.J. 877, 905 n.200 (1996). A 1988 amendment expanded the scope of protected research to include “biomedical, behavioral clinical, or other research,” 42

Although these concerns transcend the genetics context, some might argue that the risks are greater in the genetics context, simply because so much has been made of the threat of genetic discrimination in the popular culture and media. And indeed, recently, much more seems to be written about public health threats in this area than other areas.<sup>332</sup> However, just as it is unclear how serious genetics discrimination currently is or will be, so too is it unclear how much fears of genetics discrimination actually inhibit the public from participating in genetic testing or research. Even fewer studies have examined the effects of public fears than have studied genetics discrimination.<sup>333</sup> One might therefore argue that these concerns are far too speculative to justify the costs of genetics legislation's under-inclusiveness. But that response is too glib. Given the strong intensity of public fears of genetics, it stands to reason that this might well affect public receptiveness to genetic testing and research, now or in the future. Clearly we need better data. At this point, we have too little to dismiss it as a non-problem.

Presuming for the moment that this is a significant public health concern and that it is a greater problem than the public health risk in other areas (a debatable point indeed), one might nevertheless worry that the remedy would exacerbate the very harm it intends to cure. By responding to public's fears with special protections for genetic information, genetics legislation may validate and fuel the flames of these fears as well as the underlying perspective which generates those fears.<sup>334</sup> Moreover, it tends to stigmatize genetic information by suggesting that

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U.S.C.A § 241(d), "thereby recognizing that negative consequences could attach to research subjects' lawful activities as well," Rothstein, *supra*, at 905 n.200.

<sup>332</sup> In searching for documentation of concerns that fears of discrimination with respect to other medical information prevent people from participating in health care or biomedical research, my research assistant came across articles that almost exclusively focused on this issue in the genetics context.

<sup>333</sup> One recent study found that only thirty-eight percent (8 out of 21) of genetic counselors thought that such concerns were a "major barrier" to adult patients. Hall & Rich, *supra* note 230, at 249. Only two counselors suggested as many as 80-90% of adult patients refuse genetic testing based on those fears. Two counselors estimated that two more that 50% of adult patients refuse on those grounds. Virtually all counselors indicated that pediatric or prenatal patients were not deterred by concerns of discrimination. *Id.*

<sup>334</sup> Hall, *supra* note 165, at F7; Reilly, *supra* note 8, at 126-27.

it warrants special protections. The mere presence of such legislation can perpetuate the view that genetics discrimination is a serious problem requiring the law's intervention and that genetic information is uniquely susceptible to abuse. Indeed, as the media draw attention to this legislation, the public reads more about genetics discrimination, and legislators enact more laws, the spiral of fear and genetics exceptionalism is intensified.<sup>335</sup>

How much genetics legislation will remedy or exacerbate public fears and whether this is a greater concern with respect to genetic or other medical information are empirical questions. Some might find these laws reassuring even if they intensify concerns about genetics discrimination. Others may be unpersuaded that the protections are sufficient. It is difficult to determine whether the benefit of encouraging *some* people to engage in genetic testing and research outweighs the harms of intensifying public fears and reinforcing genetics exceptionalism in others. The uncertainty as to whether genetics-*specific* legislation will remedy or exacerbate the public health concerns and whether this is a more significant issue in the genetics context than other medical areas places legislators in a quandary in light of the inequities raised by genetics legislation. They have a legitimate interest in promoting both public health and equality. Is there a solution that allows legislators to have it both ways?

### C. Moving Away From Genetics Exceptionalism

A clear – though perhaps politically challenging – solution to the quandary facing legislators does exist. Legislative protections should focus on the broader issues of

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<sup>335</sup> Similar objections have been raised against affirmative action, i.e., that the remedy exacerbates the discrimination it tries to eliminate. One fear is that it reinforces negative perceptions by stigmatizing minorities, perpetuating a dependency stereotype, Croson, 488 U.S. at 493-494; Bakke, 438 U.S. 265, 298 (1978) (Powell, J.); United Jewish Organization v. Carey, 430 U.S. 144, 173-74 (1977) (Brennan, J., concurring), and creating the misperception that minorities require special assistance because they are inferior. Brest, *supra* note 289, at 18. Some worry that because it disadvantages whites, affirmative action will create new levels of animus against minorities and enhance racial divisiveness. Randall Kennedy, *Commentary: Persuasion and Distrust: A Comment on the Affirmative Action Debate*, 99 HARV. L. REV. 1327, 1330 (1986). Finally, some fear affirmative action may affect the morale and self-image of minorities. Will they worry, for example, that their admission to college or new employment was the result of preferential treatment as opposed to “truly earned?” Kennedy, *supra*, at 1331-32.

discrimination and privacy rather than whether information is genetic or not. If legislators extended the protections of genetics information to other medical information – i.e., if they eliminated the under-inclusiveness of genetics legislation – then they could have their cake and eat it. Protections would be in place to protect the public against discrimination not only with respect to genetic information, but also with respect to other medical information. Informing the public of these protections would reduce public fears about genetics discrimination. But by avoiding genetics-specific protections, it would be less likely to exacerbate fears of genetics discrimination. Indeed, the broader scope of protection might go a long way toward eliminating genetics exceptionalism. Moreover, these broader protections would dissolve the equal protection concerns raised by genetics legislation.

Whether legislators will take that course depends on numerous factors. As noted in Part I, several institutional forces contribute to the widespread support for genetics-legislation. As long as genetics exceptionalism is the prevailing viewpoint among the public, media, scientists, and legislators, comprehensive protections of medical information will receive less support.<sup>336</sup> The goal then must be to move the debate away from genetics exceptionalism and to demystify genetics. The media must become attentive to the problem of genetics exceptionalism,<sup>337</sup> which will reshape public attitudes. And they should take care to emphasize the more nuanced messages that some scientists present about the complex role of genes and environment.<sup>338</sup> Most important, legislators must understand that genetic information is merely one point along the spectrum of important medical information. Their motivations to prevent discrimination and privacy invasions are commendable but too limited and inequitable as long as they focus on genetics alone. The more legislators understand that the same concerns exist with respect to a

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<sup>336</sup> One might think that the same arguments could be made for incrementalism. But, because the strategy of incrementalism requires masking the ultimate goal, it initially depends on claims of principled distinctions between genetic and non-genetic information that do not exist. *See supra* note 241.

<sup>337</sup> Media attitudes can change, as they did with respect to “AIDS exceptionalism.” *See Stolberg, supra* note 257, at A1 (questioning “AIDS exceptionalism”).

<sup>338</sup> *See supra* TAN 88-89.

great deal of medical information, the greater the chances for expanding the protections of genetics legislation to other areas. How the issues are framed shapes the institutional perspectives and ultimately the policies legislators promote.<sup>339</sup>

Rather than making the discussion genetics-centric, policy makers should focus on the *features* of genetic information that inspire political and public support for genetic legislation, and use those concerns to craft more far reaching legislation. In the privacy context, the HIPAA privacy rules, which went into effect on April 14, 2001, offer an ideal policy approach that both satisfies the public health concerns regarding the public's fear of genetic discrimination and avoids genetics exceptionalism. Responding to the fact that "many believe that individuals should have some right to control personal and sensitive information about themselves [and that among] different sorts of personal information, health information is among the most sensitive," the final rules protect health information generally.<sup>340</sup> Specifically, the rules protect all individually identifiable health information in any form, electronic or non-electronic, that is held or transmitted by a covered entity."<sup>341</sup> "Individually identifiable health information" is defined as:

information that is a subset of health information, including demographic information collected from an individual, and: (1) Is created or received by a health care provider, health plan, employer, or health care clearinghouse; and (2) Relates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present, or future payment for the provision of health care to an individual; and (i) That identifies the individual; or (ii) With respect to which there is a reasonable basis to believe the information can be used to identify the

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<sup>339</sup> "The factual and emotional aspects of policy images are believed to be the keys to attracting political attention, redefining issues, and mobilizing previously apathetic bystanders into political participation." True, *supra* note 242, at 8.

<sup>340</sup> *Standards for Privacy for Individually Identifiable Health Information*, Regulation Preamble, 45 C.F.R. § 160.101 (2001).

<sup>341</sup> *Id.* at §164.500.

individual.<sup>342</sup>

Because the final rules are intended to preserve existing, strong state confidentiality laws, the rules will provide a national “floor” of privacy protections for all Americans.<sup>343</sup> This approach will require state legislatures to determine whether their privacy statutes are more stringent than the federal rules. Reflecting on that question provides legislatures with an ideal opportunity to reconsider their genetics exceptionalist approaches. To stay true to the spirit of equal protection principles, and in light of the unintended inequities surrounding genetics-specific legislation, they would do well to follow the federal lead in expanding the protections of those statutes to include all medical information. Federal legislators who are considering enacting genetics privacy statutes, even in light of the HIPAA privacy rules, would also be well-advised to broaden their approach to privacy concerns.

To the extent that state nondiscrimination genetics statutes are linked to genetic privacy concerns, legislatures will also have to reexamine their approach to nondiscrimination in the insurance and employment contexts. Again, they would be advised to focus on the *features* of genetic information that inspire political and public support for genetic legislation and use those concerns to craft more far reaching legislation. For example, if what troubles the public about insurance underwriting based on genetic information is the fact that it involves risks outside our control, policy makers should focus on “control,” not genetics. Many environmental and sociological risks and pre-existing conditions include, to a large extent, elements outside of our control.<sup>344</sup> If it is the predictive or hidden nature of the information that troubles the public,

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<sup>342</sup> 45 C.F.R. §164.501 (2001).

<sup>343</sup> Specifically, a “standard, requirement, or implementation specification adopted under [the rules] that is contrary to a provision of State law preempts the provision of State law . . . [unless] the provision of State law relates to the privacy of health information and is more stringent than” the federal rules.” 45 C.F.R. § 160.203(b) (2001).

<sup>344</sup> See Theresa Williams, *Note and Comment, “Going Bare”: Insurance and the Pre-Existing Condition Problem*, 15 J. L. & COM. 375, 380-82 (1995). Many of those conditions will be the manifestation of genetic conditions or exposures to environmental risks. Shouldn’t we be as troubled by the woman with the BRCA1 gene whose insurance coverage is denied or compromised because she has actually developed breast cancer as the woman who is merely at

policy makers should examine other predictive or hidden factors beyond genetics. By parsing out the concerns in terms of *features* of genetic information that trouble the public, rather than focusing on genetic information per se, the under-inclusiveness of genetics legislation becomes strikingly apparent and increases the chance policy makers might extend those protections more broadly.

For example, the public is troubled by health insurers setting premiums on genetic information because genetic information can be predictive and outside our control. But because these features apply to other medical information, perhaps legislators should consider community rating in health insurance generally.<sup>345</sup> Currently our system has a default rule that allows insurers to access and use most medical information for underwriting purposes, with a few exceptions for race, genetics, and in some instances gender.<sup>346</sup> If policy makers understand that many risk factors are significantly outside of our control and predictive, the opposite default rule might be more appropriate. In other words, perhaps insurers should not be able to obtain or use *most* medical information for underwriting purposes, with some exceptions for certain kinds of risky *behavior*, which seem more in our control and for which we might want to create disincentives.<sup>347</sup> There have been some movements in that direction at both the state<sup>348</sup> and

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an increased risk. For the woman with cancer, access to insurance becomes a matter of life and death.

<sup>345</sup> See Jacobi, *supra* note 41, at 374-75, for arguments that various legislative actions reflect an increased acceptance of community rating or social pooling. The libertarian notion of distributive justice, however, would argue against such an approach. This view holds that it is unjust to ask people who face lower risks to bear the burdens of other people's higher risks, as community rating would do, whether or not the higher risks are beyond one's control. In short, they would view it as an unconsented taking of property without consent. See Daniels, *supra* note 118, at 112-15.

<sup>346</sup> Gaulding, *supra* note 55, at 1659-74.

<sup>347</sup> Of course, trying to carve out exceptions for either default rule is exceedingly complicated and presents perennial line-drawing problems. Given the administrative costs and complexity of analyzing and applying actuarial data, policy makers might instead employ other, likely more effective disincentives, such as taxing risky behavior.

federal level. The Health Insurance Portability and Accountability Act of 1996, for example, eliminated the use of medical information (including genetic information) for the underwriting of group insurance plans.<sup>349</sup> In addition, the interim final rules, allow group health plans to “exclude coverage for injuries that do not result from a medical condition or domestic violence, such as injuries, sustained in high-risk activities like bungee jumping.”<sup>350</sup> Group plans, however, cannot exclude people from enrollment for coverage or charge higher premiums based on risky behavior.<sup>351</sup>

Similar policy alternatives exist with respect to genetic discrimination in employment and genetic privacy. Here again, we have a federal model. The Americans with Disabilities Act (“ADA”) protects against employment and other forms of discrimination against the disabled. The protected class is defined broadly, not just with respect to certain classes of disability or perceived disability.<sup>352</sup> Such an approach is more coherent and equitable than a disease-specific approach. Ideally genetic information and other predictive information are protected by the

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<sup>348</sup> See Jacobi, *supra* note 41, at 373-78, 383-84 (noting that most states adopt some form of restriction on the setting of premium rates, though only a few are scheduled to implement pure community rating).

<sup>349</sup> The statute states that neither a group health plan or health carrier insuring the group may “establish rules for eligibility (including continued eligibility) of any individual to enroll under the terms of the plan based on any of the following health status-related factors . . . (a) health status, (B) Medical Condition (including both physical and mental illnesses), (c) Claims experience, (d) Receipt of health care (F) Genetic information, (G) Evidence of insurability (including conditions arising out of acts of domestic violence), (H) Disability.” Health Insurance Portability and Accountability Act § 102(a). Note, however, that the statute does not prohibit rate setting with respect to individual policies.

<sup>350</sup> *New Rules Prohibit Discrimination by Group Plans Based on Health Factors*, 69 U.S.L.W. 2409 (2001).

<sup>351</sup> *Id.*

<sup>352</sup> See 42 § U.S.C.A. 12102(2).

ADA, although it is unclear whether the Supreme Court would read the ADA so expansively.<sup>353</sup> Nevertheless, the ADA offers one model for addressing the concerns underlying genetic discrimination in employment.<sup>354</sup> It is far preferable to treat genetic discrimination as part of a larger category of information vulnerable to employment discrimination than as a category unto itself.<sup>355</sup>

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<sup>353</sup> In 1995, the U.S. Equal Employment Opportunity Commission interpreted the ADA as prohibiting employment discrimination based on genetic makeup. 2 U.S. EEOC COMPLIANCE MANUAL, Order 915.002, at 902-45 (1995). Though this interpretation is not binding on courts, it offers some persuasive authority. *Bragdon v. Abbott* 524 U.S. 624, 661 (1998), which recognized asymptomatic HIV as a disability that substantially limited a major life activity, has been read by some to suggest that a genetic predisposition might similarly be viewed as a disability. See *Miller*, *supra* note 55, at 242-45. But Chief Justice Rehnquist's dissent in *Bragdon* expresses concern that the majority's approach, "taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease 'disabled' here and now because of some future effects." 524 U.S. at 661 (Rehnquist, C.J., dissenting). Some argue that *Bragdon* and more recent Supreme Court cases, *Sutton v. United Air Lines, Inc.*, 119 S. Ct. 2139 (1999); *Albertsons, Inc. v. Kirkingburg*, 119 S. Ct. 2162 (1999); *Murphy v. United Parcel Serv., Inc.*, 119 S. Ct. 2133 (1999), raise serious doubts as to whether the Court would include presymptomatic or asymptomatic genetic information under the ADA. See Laura E. Rothstein, *Genetic Discrimination: Why Bragdon Does Not Ensure Protection*, 3 J. HEALTH CARE L. & POL'Y 330, 347-50 (2000).

Recently, the EEOC settled the first challenge brought under the ADA regarding genetic testing in the workplace. Under the terms of the settlement, the defendant, Burlington Northern was prohibited from requiring employees to submit to genetic tests, analyzing any blood or genetic tests previously obtained, or retaliating against any employees who refused genetic tests. *EEOC Settles ADA Suit Against BNSF for Genetic Bias*, <http://www.eeoc.gov/press/4-18-01.html> (visited 5/15/2001).

<sup>354</sup> Of course, there are tensions between broad nondiscrimination efforts and efforts to make the workplace safe. Some have argued that there may be appropriate times to discriminate in the workplace "to protect the safety of workers or the public" Yesley, *supra* note 136, at 663. On the other hand, one worries about reliance on genetic testing as the sole means of making workplaces safer. In other words, employers should be making efforts to clean up the workplace, whether or not susceptibility testing is available.

<sup>355</sup> The problem with using the ADA model in this way, however, is that it "labels" genetic and other predictive information as a disability. But given that the ADA is concerned with perceptions of as well as real disabilities, it does seem to fall within the purview of the

In short, the new HIPAA rules provide not only an ideal model of a non-genetics exceptionalist approach for state and federal legislators, but also an ideal opportunity for them to reexamine the trend toward genetics exceptionalism with respect to insurance nondiscrimination, employment nondiscrimination, and privacy protections. Legislators should be commended for the good intentions that led to genetics-specific legislation; but after nearly a decade of legislative experimentation, it is time for them to learn from the unintended negative effects of their efforts. Specifically, they should be attentive to the serious inequities of genetics-specific legislation and, in the spirit of the legal, moral and policy values surrounding the Equal Protection Clause, should broaden the nondiscrimination and privacy protections to include all medical information.

### **CONCLUSION**

Although public support for genetics legislation makes it politically low-cost, such legislation is seriously under-inclusive, resulting in troubling inequities. Genetics legislation – through legislative oversight, rather than hostility – is selectively indifferent to the fact that poor minorities face a disproportionate degree of non-genetic risks, which share many of the features of genetic information. As a result, genetics legislation exacerbates class inequities in a group that, under a process theory of equal protection, has the features of a suspect class. Because this disproportionate impact concerns serious private interests related to access to health care, employment, and privacy, the under-inclusiveness of genetics legislation raises serious normative and policy concerns and implicates under-enforced constitutional values.

Legislators have legitimate interests in allaying fears about genetics so that we can reap its full benefits. Genetics legislation, however, provides a questionable remedy because it may unintentionally exacerbate the very fears it tries to eliminate. Moreover, it retains troubling inequities. The better strategy is therefore to enact more comprehensive legislation, which eliminates the under-inclusiveness of genetic legislation and avoids the spiral of genetics exceptionalism.

I recognize that my mandate for legislators is challenging. And if given a choice between

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ADA's goals.

genetics legislation or nothing, sadly and reluctantly, I would settle for the former, all the while urging legislators to go further. But I believe that we can and should demand more from legislators. The key to the success of my strategy is to reconceptualize the problems and to shift the focus on genetics to a focus on the features of medical information that make it susceptible to discrimination and invasions of privacy. Legislation based on those concerns will be more equitable, coherent, and just.

The time is ripe for this new perspective and approach, especially in the wake of the new HIPAA privacy regulations. Moreover, the recent discoveries from the final draft of the human genome require us to reevaluate our relationship to genetics. The gene is important, but not all important. Proteins and the environment will gain prominence in our understanding of disease and behavior as we seek explanations for the diversity and complexity of humans, whose genome is only twice as large as that of a roundworm. These new puzzles offer us the chance, indeed compel us, to reframe our conception of the gene. As we enter the second phase of genetics research with a fully sequenced human genome, let us take the surprising revelations from the genome sequencing as an invitation to reject genetics exceptionalism.

But let us also take away from our experience with the legislative experimentation in genetics the larger lesson of the problem of middle-class entitlements. This problem is not unique or exceptional to genetics exceptionalism. The equal protection values described in this article transcend the problems of discrimination and privacy. They raise deep concerns about society's obligation toward the disadvantaged, not only with respect to health care, but also with respect to other deeply important interests fundamental to living a good life, such as education and housing. This piece offers a starting point with respect to the narrower problem of discrimination based on and privacy of medical information, but invites a broader application of the methodology to other areas of serious inequity.