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# Science Fact or Science Fiction? The Implications of Court-Ordered Genetic Testing Under Rule 35

By ANTHONY S. NIEDWIECKI\*

**I**MAGINE BEING FORCED to undergo medical testing for a disease that has no cure and no treatment. This scenario may soon become a reality as litigants attempt to discover previously unknown genetic information using Rule 35 of the Federal Rules of Civil Procedure<sup>1</sup> or an equivalent state law.<sup>2</sup> Rule 35 allows a court to order physical or mental examinations of a party and is most often used by defendants to disprove plaintiffs' claims of physical or emotional injuries.<sup>3</sup> Since a Rule 35 order compels a person to undergo a medical procedure, it is one of the most intrusive forms of discovery. Without stringent safeguards, the order has the potential to cause litigants great emotional or physical harm. This is especially true when a court orders genetic testing for a disease that has no cure or treatment. In such circumstances the court has provided the examinee with nothing less than a death sentence.

## Introduction

Even before genetic testing was possible, courts have been willing to order examinations that have the potential to cause great psychological harm to the examinee. The most dramatic example of a court-ordered test occurred when a federal district court ordered a plaintiff

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1. FED. R. CIV. P. 35.

2. Rule 35 is generally duplicated under each state's discovery rules. Any mention of Rule 35 in this article also refers to each state's equivalent unless expressly stated otherwise.

3. See, e.g., *Thiessen v. General Elec. Capital Corp.*, 178 F.R.D. 568 (D. Kan. 1998) (disproving physical injuries of water in the lungs and congestive heart failure); *Neal v. Siegel-Robert, Inc.*, 171 F.R.D. 264 (E.D. Mo. 1996) (attempting to disprove a claim that plaintiff suffered psychological trauma from alleged discrimination).

to undergo Human-Immunodeficiency Virus ("HIV") antibody testing.<sup>4</sup> In an effort to reduce the amount of future damages to be awarded, the defendant asked the court to order an HIV test to prove that, if the result was positive, the plaintiff would have a shorter life expectancy.<sup>5</sup> Because of the traumatic nature of a positive HIV test result, and the court's apparent ease in mandating such a test, this case has severe implications for court-ordered genetic testing in the future.

With the advent of new scientific technology, litigants increasingly rely on the use of scientific evidence, most notably genetic information, to prove their cases or to discredit their opponents' cases.<sup>6</sup> This is especially true in criminal cases where prosecutors use Deoxyribose Nucleic Acid ("DNA") analysis to link defendants to certain crimes.<sup>7</sup> The use of genetics has now made its way into the civil courtroom as well.<sup>8</sup> When Rule 35 was first adopted in 1938, genetic science was almost nonexistent and no one could have possibly contemplated the advances that are currently being made on an almost daily basis.<sup>9</sup> Not even twenty years ago could people realistically have predicted that one day a scientist could examine a piece of hair and determine so much information about an individual, including whether he or she may be susceptible to developing a particular disease.<sup>10</sup>

Such advances are now possible because scientists from around the world are discovering the entire blueprint of the human genome

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4. See *Pettyjohn v. Goodyear Tire & Rubber Co.*, No. 91-CV-2681, 1992 WL 105162, at \*1 (E.D. Pa. 1992).

5. See *id.*

6. See, e.g., *Pennsylvania v. Koehler*, 737 A.2d 225 (Pa. 1999) (holding DNA evidence admissible to show that defendant could not be excluded as the source of the semen found on the murder victim's body).

7. See *id.*

8. See *Bennett v. Fieser*, No. 93-1004-MLB, 1994 WL 542089, at \*2 (D. Kan. 1994); *Dodd-Anderson v. Stevens*, Nos. 92-1015-MLB, 92-1016-MLB, 1993 WL 273373, at \*1 (D. Kan. 1993). These cases are discussed more thoroughly later in this article. See *infra* Part I.

9. See generally Tim Friend, *Project to Chart All Genes*, GANNETT NEWS SERV., Oct. 3, 1989, available in 1989 WL 4860540 (discussing the advances and goals of the Human Genome Project).

10. For a more complete discussion on how genetic testing has evolved, see Michael J. Malinowski, J.D. & Robin J.R. Blatt, M.P.H., R.N., *Commercialization of Genetic Testing Services: The FDA, Market Forces, and Biological Tarot Cards*, 71 TUL. L. REV. 1211, 1217 (1997); Robert Guy Matthews, *Traces of You: The Perfect Crime May be a Thing of the Past, Now That DNA Testing Can Identify a Person by Hair, a Speck of Skin or a Drop of Saliva. But is This Science to be Feared?* Baltimore Sun, Aug. 13, 1998, at 1F.

in a project called the Human Genome Project (“Project”).<sup>11</sup> The Project began in 1990 with the dual goals of identifying the estimated 100,000 genes in the human DNA by 2005 and to develop tools to analyze the three billion pairs of chemical bases of which DNA is made.<sup>12</sup> The mapping of the human genetic code is expected to be nearly complete by the spring of 2000, with a final map expected by 2002.<sup>13</sup> The ultimate goal of the Project is to find a cure for all genetic diseases.<sup>14</sup> As a result of the Project, doctors are now able to screen for serious health conditions including cancer, Alzheimer’s Disease, and heart disease.<sup>15</sup> Mapping allows scientists to identify genetic mutations responsible for causing specific diseases.<sup>16</sup> The identification of such mutations, however, does not necessarily mean that science has discovered a cure or treatment: “Progress to date indicates that the ability to diagnose a genetic abnormality precedes the development of therapeutic interventions and that this gap may be growing.”<sup>17</sup>

Each genetic test produces varying types of information depending on the characteristics of the disease being tested and the accuracy of the test.<sup>18</sup> For example, a positive result for one test may indicate an eighty percent chance of developing a debilitating and deadly disease within fifteen years, while a positive result for a different test may predict only a twenty percent chance of contracting a manageable and treatable disease.<sup>19</sup> Depending on the information produced by a genetic test, a number of potential risks may be involved. Such risks include: psychological harm to the individual tested; emotional harm to third parties;<sup>20</sup> and economic harm if the information is disclosed to persons outside of the litigation.<sup>21</sup> Since genetic tests are limited in the type of information that they produce—usually only predicting a statistical likelihood that a person may develop a medical condi-

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11. See Leroy Hood & Lee Rowen, *Genes, Genomes, and Society in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA* 3, 8 (1997).

12. See Mark A. Rothstein & Sharona Hoffman, *Genetic Testing, Genetic Medicine, and Managed Care*, 34 WAKE FOREST L. REV. 849, 853–54 (1999); Carl T. Hall, *Genome Project Within a Year of Completion, Official Says*, S.F. CHRON., June 11, 1999, at A7.

13. See Hall, *supra* note 12, at A7.

14. See Rothstein & Hoffman, *supra* note 12, at 854.

15. See *infra* Part II.B.

16. See *infra* Part II.B.

17. OFFICE OF TECHNOLOGY ASSESSMENT, CONGRESS OF THE UNITED STATES, *MAPPING OUR GENES: GENOME PROJECTS: HOW BIG, HOW FAST?* 83 (1988).

18. See *infra* Part II.B. (discussing the difference in genetic test results).

19. See *infra* Part II.B. (discussing the difference in genetic test results).

20. See *infra* Part IV.

21. See *infra* Part IV.

tion<sup>22</sup>—they have limited usefulness to the truth-seeking mission of the court. The statistical data produced by a genetic test may, therefore, only confuse the court and cause undue harm to the person tested.

This article proposes an analysis for courts to follow when faced with a Rule 35 motion to compel a party to undergo genetic testing or any other procedure that tests for a specific medical condition. Part I explains the analysis courts generally conduct for a Rule 35 motion. Generally, courts make a factual inquiry into whether there is a need for the procedure and whether the examinee has placed his or her physical or mental condition in controversy.<sup>23</sup> Rarely have courts examined the risks associated with ordering an examination.<sup>24</sup> When courts do examine the risks, they continue to show a willingness to order exams that are quite intrusive, that impact persons outside of the lawsuit, and that involve tests open to a wide range of interpretations.

Part II examines how courts have begun to order genetic tests in civil cases without any consideration of the purpose of the tests or the risks associated with ordering them. This section explores genetic testing, focusing on three specific diseases in an effort to illustrate the wide variance of information produced by different genetic tests.

Part III considers the similarities between HIV testing and genetic testing, and details the implications of court-ordered HIV testing or genetic testing under Rule 35. This section examines the cases that have considered motions for court-ordered HIV testing, and shows a division among the courts: first, those courts that recognize that Acquired Immune Deficiency Syndrome (“AIDS”) is unique, and second, those that treat HIV testing like any other type of examination. A similar division has occurred among public health officials and civil libertarians when debating policy regarding HIV. This debate has pitted traditionalists, those who believe all diseases should be treated similarly,<sup>25</sup> against “exceptionalists,” those who believe that HIV is so unique that it deserves exceptional treatment in the law.<sup>26</sup> This debate has begun to encompass policy decisions regarding genetic information.<sup>27</sup> Part III concludes by describing the current arguments in the

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22. See *infra* Part II.B.

23. See *infra* Part I.C.

24. See *infra* Part I.A.

25. See *infra* Part III.B.

26. See *infra* Part III.B.

27. See *infra* Part III.C.

“genetic exceptionalism” debate and proposes to eliminate the labeling of diseases as exceptional or non-exceptional. It is argued instead that any testing policy should be based on the characteristics that make each disease unique.

Finally, part IV proposes that courts faced with a Rule 35 motion should apply the approach developed in Part III and should thoroughly examine the unique characteristics of each genetic test. This would require the court to amend its fact-driven analysis of Rule 35 to include an “examination of the examination.” This analysis requires the court to thoroughly examine the informational risks associated with ordering a genetic test and to determine whether the test results will prove useful to the court before it orders a genetic test. This section takes a detailed look at the specific informational risks associated with genetic testing and concludes that there is a general lack of usefulness of genetic test results in litigation.

## I. Rule 35 and Its State Counterparts

Rule 35 of the Federal Rules of Civil Procedure and its state law counterparts give courts the power to compel litigants to undergo mental or physical examinations.<sup>28</sup> Courts have used this broad grant of authority to order a wide range of examinations, including psychological exams related to sexual trauma,<sup>29</sup> HIV tests,<sup>30</sup> and, most re-

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28. See *infra* Part I.A.

29. See, e.g., *Marvelle v. Nevada*, 966 P.2d 151, 154–55 (Nev. Sup. Ct. 1998) (holding that the defendant, who was convicted of the sexual assault of a child under 14 years of age, was denied a fair trial because the trial court refused to permit psychological testing of the victim); *Weiss v. Amoco Oil Co.*, 142 F.R.D. 311, 314, 316 (S.D. Iowa 1992) (holding that the plaintiff could depose a non-party witness concerning the witness’ sexual history in connection with plaintiff’s claim that he was wrongfully discharged after the witness made allegations of sexual harassment against him); *Anderson v. Alaska*, 749 P.2d 369, 371 (Alaska Ct. App. 1988) (holding that defendants, who were convicted of sexual abuse of a minor, were entitled to have the minor examined by a court-appointed mental health practitioner); *Anson v. Fickel*, 110 F.R.D. 184, 185–86 (N.D. Ind. 1986) (holding that the mental condition of a plaintiff in a traffic accident case was in controversy where plaintiff sought compensation for emotional distress, defendant had demonstrated good cause for the examination, and the federal rules authorized examination of plaintiff by a clinical psychologist).

30. See, e.g., *Sacramona v. Bridgestone/Firestone, Inc.*, 152 F.R.D. 428, 431–32 (D.C. Mass. 1993) (holding that the defendants in a personal injury action were not entitled to a compelled HIV blood test despite plaintiff’s claim for future damages and his lifestyle, which included sharing hypodermic needles); *Pettyjohn v. Goodyear Tire & Rubber Co.*, No. 91-CV2681, 1992 WL 105162, at \*1 (E.D. Pa. 1992) (holding that defendants in a personal injury suit were entitled to a compelled HIV blood test because plaintiff had placed his life expectancy in controversy by seeking future damages).

cently, genetic tests.<sup>31</sup> These tests have been ordered although the rules do not specifically refer to, nor likely contemplate, the psychologically intrusive nature of these exams. Since no discovery rules exist that specifically address (or limit) a court's authority to order genetic tests, courts have looked to Rule 35 for guidance in compelling such tests.<sup>32</sup> The members of the Ethical, Legal & Social Implications of the Human Genome Project Task Force, in fact, proposed allowing courts to use Rule 35 to compel genetic testing when they drafted the Genetic Privacy Act ("GPA").<sup>33</sup>

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31. See, e.g., *Bennett v. Fieser*, No. 93-1004-MLB, 1994 WL 542089, at \*2 (D. Kan. 1994) (ordering genetic test of a child in a medical malpractice action); *Dodd-Anderson v. Stevens*, Nos. 92-1015-MLB, 92-1016-MLB, 1993 WL 273373, at \*1 (D. Kan. 1993) (ordering genetic testing of a child in a medical malpractice action); Sally Lehrman, *Pushing Limits of DNA Testing*, S.F. EXAMINER, June 5, 1994, at A1 (discussing the unreported case of *Severson v. KTI Chems, Inc.*).

32. See, e.g., Lehrman, *supra* note 31, at A1 (discussing the unreported case of *Severson v. KTI Chems, Inc.*); *Bennett*, 1994 WL 542089, at \*2; *Dodd-Anderson*, 1993 WL 273373, at \*1-2.

33. See GEORGE J. ANNAS ET AL., *THE GENETIC PRIVACY ACT AND COMMENTARY* (1995) (available by request from the Health Law Department, Boston University School of Public Health, 80 East Concord St., Boston, MA 02118) (on file with the *University of San Francisco Law Review*) [hereinafter ANNAS ET AL., *THE GENETIC PRIVACY ACT*]. Section 123 of the Genetic Privacy Act sets forth the regulations for compelled genetic testing. See *id.* The only difference between the Federal Rule 35, FED R. CIV. P. 35, and section 123 is that the Act mandates that the genetic sample taken from the subject be destroyed at the earliest opportunity after the test has been completed. Section 123 states:

(a) IN GENERAL.—Nothing in this Act shall be construed to prohibit the collection or analysis of an individually identifiable DNA sample pursuant to Rule 35 of the Federal Rules of Civil Procedure or comparable rules of other courts or administrative agencies in connection with litigation or proceeding to which the sample source is a party and in which the genetic condition of the sample source has been placed at issue, provided that the conditions in section (b) have been met.

(b) ISSUANCE OF ORDERS.—An order under Rule 35 of the Federal Rules of Civil Procedure or comparable rules may only be made:

(1) upon motion for good cause shown and upon notice to the sample source or the sample source's representative and all parties; and

(2) the order must specify:

(A) the manner of collection of the DNA sample;

(B) the person or persons authorized to collect and analyze the sample;

(C) the purpose of the genetic analysis;

(D) that the genetic analysis is limited to that which is necessary to fulfill the purpose of the order; and

(E) that the person conducting the analysis destroy the sample at the earliest possible opportunity consistent with the purpose of that order.

*Id.* § 123.

### A. “In Controversy” and “Good Cause” Requirements Under Rule 35 and State Counterparts

Courts are likely to rely on the history and previous treatment of Rule 35 when analyzing motions for genetic testing, even though traditional Rule 35 cases have involved basic or routine psychological and physical examinations.<sup>34</sup> When analyzing a Rule 35 motion, courts must, as an initial matter, determine if the person subject to the examination has placed her mental or physical condition “in controversy” and if “good cause” exists for the examination.<sup>35</sup>

Every state except Mississippi and New Hampshire has passed Rule 35 equivalents as part of its rules of civil procedure or rules of court.<sup>36</sup> A majority of states have passed “generic” versions of the rule permitting mental or physical examinations. These provisions are either identical to the federal Rule 35, or they are constructed with substantially similar wording.<sup>37</sup> Like the federal rules, these generic

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34. See Niccol Kording & Janine P. DuMontelle, *An Overview of Admissibility of Genetic Test Results in Federal Civil Actions*, 19 WHITTIER L. REV. 681, 692 (1998).

35. FED. R. CIV. P. 35. Rule 35 provides:

When the mental or physical condition . . . of a party . . . is in controversy, the court in which the action is pending may order the party to submit to a physical or mental examination by a suitably licensed or certified examiner . . . . The order may be made only on motion for good cause shown . . . .

*Id.* See *Schlagenhauf v. Holder*, 379 U.S. 104, 119–20 (1964) (holding that, where defendant’s bus collided with plaintiff’s tractor-trailer, a sufficient showing was not made under Rule 35 to support any medical or psychological examinations of defendant bus driver); *Jansen v. Packaging Corp. of Am.*, 158 F.R.D. 409, 411 (N.D. Ill. 1994) (appointing independent expert to conduct medical examination of plaintiff because plaintiff had placed her mental condition in issue in her action against her employer for sexual harassment). These two requirements contrast with the very liberal discovery rules under Rule 26 of the Federal Rules of Civil Procedure, FED. R. CIV. P. 26, where the only limitations on discovery are that the information sought not be privileged, and the request for information be reasonably calculated to lead to admissible evidence. See FED. R. CIV. P. 26(b)(1).

36. Mississippi is the only state without a rule setting forth the conditions and scope of mental or physical examinations. See MISS. R. CIV. P. 35. Mississippi specifically declined to adopt a rule providing for independent medical examinations as part of the Mississippi Rules of Civil Procedure. The comment to the omitted Mississippi Rule 35 states that “Rule 35, Physical and Mental Examinations of Persons, is omitted from these rules.” *Id.*

New Hampshire’s Rule 35 equivalent is not spelled out as a specific and independent rule like the remaining states. Rather, it is incorporated in a general provision governing discovery in the New Hampshire Rules of Court. See N.H. R. SUPER. CT. 35. The provision states that parties may obtain discovery by physical or mental examinations, but makes no mention of the “in controversy” or “good cause” requirements of the federal rule. See *id.* However, discovery under this provision is limited to “any matter, not privileged, which is relevant to the subject matter involved in the pending action.” *Id.* at 35 (b)(1).

37. See FED. R. CIV. P. 35; ALA. R. CT. 35(a); ALASKA CT. R. 35(a); COLO. CT. R. 35(a); DEL. R. CIV. P. 35; D.C. CT. R. ANN. 35(a); FLA. R. CT. 1.360; GA. CODE ANN. § 9-11-35 (1993); HAW. CT. R. 35(a); IDAHO CT. R. 35(a); IND. CT. R. 35(A); IOWA R. CT. 132; KY. R.



state versions of Rule 35 require the mental or physical status of the potential examinee be "in controversy" and "good cause" be shown for the examinations.<sup>38</sup> They also require that notice be given to the potential examinee setting forth the time, place, manner, conditions, name of examiner, and scope of the examinations.<sup>39</sup> Additionally,

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CT. CR 35.01; LA. CODE CIV. PROC. ANN. art. 1464; ME. R. CT. 35(a); MD. CODE ANN., CIV. PROC. § 2-423 (1998); MASS. ANN. LAWS, CIV. R. 35(a); MICH. CT. R. ANN. § 2.311(A); MINN. STAT. ANN. § 35.01 (West 1996); MO. CT. R. 60.01(a); MONT. R. CT. 35(a); NEB. CT. R. & PROC. 35(a); NEV. REV. STAT. ANN. § 35(a) (Michie 1999); N.J. R. CT. 4:19; N.M. R. ANN. 1-035(A); N.C. R. CIV. PROC. & EVID. ANN. R. 35(a); N.D. CT. R. ANN. 35(a); R.I. CT. R. ANN. 35(a); S.D. CODIFIED LAWS § 15-6-35(a) (Michie 1984); TENN. CT. R. ANN. 35.01; VA. R. SUP. CT. 4:10; W.VA. CODE ANN. § 35(a); WYO. CT. R. ANN. 35(a).

38. See FED. R. CIV. P. 35; ALA. R. CT. 35(a); ALASKA CT. R. 35(a); COLO. CT. R. 35(a); DEL. R. CIV. P. 35; D.C. CT. R. ANN. 35(a); FLA. R. CT. 1.360; GA. CODE ANN. § 9-11-35 (1993); HAW. CT. R. 35(a); IDAHO CT. R. 35(a); IND. CT. R. 35(A); IOWA R. CT. 132; KY. R. CT. CR 35.01; LA. CODE CIV. PROC. ANN. art. 1464; ME. R. CT. 35(a); MD. CODE ANN., CIV. PROC. § 2-423 (1998); MASS. ANN. LAWS, CIV. R. 35(a); MICH. CT. R. ANN. § 2.311(A); MINN. STAT. ANN. § 35.01 (West 1996); MO. CT. R. 60.01(a); MONT. R. CT. 35(a); NEB. CT. R. & PROC. 35(a); NEV. REV. STAT. ANN. § 35(a) (Michie 1999); N.J. R. CT. 4:19; N.M. R. ANN. 1-035(A); N.C. R. CIV. PROC. & EVID. ANN. R. 35(a); N.D. CT. R. ANN. 35(a); R.I. CT. R. ANN. 35(a); S.D. CODIFIED LAWS § 15-6-35(a) (Michie 1984); TENN. CT. R. ANN. 35.01; VA. R. SUP. CT. 4:10; W.VA. CODE ANN. § 35(a); WYO. CT. R. ANN. 35(a).

Connecticut's Rule 35 equivalent does not use the specific phrase "in controversy" when setting forth the conditions under which the court can compel medical examinations. See CONN. R. CT. 13-11. However, the rule does state that the court may order a party to submit to a medical examination only when "the judicial authority finds it reasonably probable that evidence outside the record will be required, in which the mental or physical condition of a party . . . is material to the prosecution . . . of the said action." *Id.* Thus, like the "in controversy" requirement, the terminology of the Connecticut rule creates a similar burden that must be met by the moving party before the court can order examinations.

39. Several states have added additional safeguards to their Rule 35 equivalents in an effort to protect the examinee. Common among a few states are additional clauses that permit the examinee to have a representative present at the time of the examination. See ARIZ. REV. STAT. ANN. § 35(a) (West Supp. 1998); CAL. CIV. PROC. CODE § 2032(g)(1) (West 1998); OKLA. CT. R. & PROC. § 3235(D); WASH. CT. R. 35(a); PA. R. CT. 4010(a)(1)(4)(I). Some states allow (or require) that the examination be recorded stenographically or by audiotape. See ARIZ. REV. STAT. ANN. § 35(a); CAL. CIV. PROC. CODE § 2032(g)(2); PA. R. CT. 4010(a)(1)(5)(i). Arizona permits the examination to be videotaped upon a showing of good cause. See ARIZ. REV. STAT. ANN. § 35(a). South Carolina allows the examinee's physician to be present during the examination. See S.C. R. CT. 35(a) (1999).

In further attempts to protect the examinee, California limits the number of examinations to one, and imposes a monetary sanction against any party who unsuccessfully makes a motion for an examination. See CAL. CIV. PROC. CODE § 2032. Furthermore, California prohibits any examinations that are "painful, protracted, or intrusive." *Id.* California and South Carolina both limit where an examination may be conducted. See CAL. CIV. PROC. CODE § 2032; S.C. R. CT. 35(a). In California, the examination must be conducted within 75 miles of the residence of the examinee. See CAL. CIV. PROC. CODE § 2032. In South Carolina, examination must occur in the county where the examinee, or his physician reside. See S.C. R. CT. 35(a). Also, special consideration is given to the examinee in setting the time and place of the examination. See *id.* In Illinois, the examining party shall pay any lost wages and all reasonable expenses incurred by the examinee in complying with the

many states require that the party demanding the examination deliver, upon request of the examinee, a copy of a detailed, written report setting forth the examiner's findings, including the results of all tests made, diagnoses, and conclusions.<sup>40</sup> Furthermore, the same states require a party requesting the examination to produce, upon the request of the examinee, all like reports of examinations of the same condition previously or thereafter made by the examiner.<sup>41</sup>

## B. The Constitutionality of Rule 35

The Supreme Court first upheld Rule 35 in *Sibbach v. Wilson*,<sup>42</sup> where the plaintiff was ordered to undergo a medical examination in a personal injury case.<sup>43</sup> The plaintiff challenged Rule 35 on the basis that, in promulgating the rule, the Court exceeded the scope of its authority under the Rules Enabling Act.<sup>44</sup> The Court affirmed the Act's validity and concluded Rule 35 did not deal with "important and substantial rights theretofore recognized."<sup>45</sup> Rule 35 does not compromise the privacy right to freedom from invasion of the person since a party is free to refuse to comply.<sup>46</sup> The Court explained that "[t]he suggestion that the rule offends the important right to freedom from invasion of the person ignores the fact that, as we hold, no invasion of freedom from personal restraint attaches to refusal so to comply with its provisions."<sup>47</sup> Justice Frankfurter, speaking for the dissenters,

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order for examination. ILL. CT. R. & PROC. 215. Finally, Illinois can also name an impartial medical examiner to take the place of the examining party's named examiner if the court believes that an independent examiner will "materially aid in the just determination of the case." *Id.*

40. Thirty-six states specifically require in their Rule 35 equivalents that the examining party make and deliver a copy of the examination report to the examinee. This report must set out the findings of the examiner, including results of all tests made, diagnoses, and conclusions. *See* ALA. R. CT. 35(a); ALASKA CT. R. 35(a); HAW. CT. R. 35(a); IDAHO CT. R. 35(a); NEV. REV. STAT. ANN. § 35(a); N.M. R. ANN. 1-035(A); W.VA. CODE ANN. § 35(a); WYO. CT. R. ANN. 35(a).

41. After delivery of the written report to the examinee by the examiner, 34 states and the federal rules entitle the person causing the examination to a like report of any examination, previously or thereafter made, of the same condition. *See e.g.*, FED. R. CIV. P. 35; ALA. R. CT. 35(a); ALASKA CT. R. 35(a); CAL. CIV. PROC. CODE § 2032; CONN. R. CT. § 13-11; COLO. CT. R. 35(a); HAW. CT. R. 35(a); IDAHO CT. R. 35(a); N.M. R. ANN. 1-035(a); N.C. R. CIV. PROC. & EVID. ANN. R. 35(a); N.D. CT. R. ANN. 35(a); OHIO CIV. R. 35 (1999-2000); WASH. CT. R. 35(a); W.VA. CODE ANN. § 35(a); WYO. CT. R. ANN. 35(a).

42. 312 U.S. 1 (1940).

43. *See id.*, 312 U.S. at 16.

44. *See id.* at 7; *see also* Rules Enabling Act, Pub. L. No. 73-415, 48 Stat. 1064 (1934) (authorizing the Supreme Court to promulgate the Federal Rules of Civil Procedure).

45. *Sibbach*, 312 U.S. at 13-14.

46. *See id.* at 14.

47. *Id.*

viewed orders to undergo a medical examination as an “invasion of the person” and noted that, as such, the orders “stand on a very different footing from questions pertaining to the discovery of documents, pre-trial procedure and other devices for the expeditious, economic and fair conduct of litigation.”<sup>48</sup> Although *Sibbach* was decided by only a 5-4 majority, the authority of federal court-ordered medical examinations has not again been seriously challenged.<sup>49</sup>

### C. The Scope and Application of Rule 35

In *Schlagenhauf v. Holder*<sup>50</sup> the Court set forth guidelines for the “in controversy” and “good cause” requirements of Rule 35.<sup>51</sup> The Court stated that these requirements impose a greater burden than mere relevancy:

[These requirements] are not met by mere conclusory allegations of the pleadings—nor by mere relevance to the case—but require an affirmative showing by the movant that each condition as to which the examination is sought is really and genuinely in controversy and that good cause exists for ordering each particular examination. Obviously, what may be good cause for one type of examination may not be so for another. The ability of the movant to obtain the desired information by other means is also relevant.<sup>52</sup>

Rule 35 determinations, therefore, have been termed “intensively fact-specific.”<sup>53</sup> Evaluating whether a movant has satisfied the “in controversy” and “good cause” requirements of Rule 35 requires the court to scrutinize the specific facts of a lawsuit and their relation to the particular examination sought.<sup>54</sup> In particular, proving the “in controversy” requirement calls on the court to examine the particular facts of each case to determine if the mental or physical condition of the party is really at issue in the lawsuit.<sup>55</sup> Often, this analysis can be done simply by reading the complaint.<sup>56</sup> For example, when a plaintiff seeks to recover for physical injuries, his physical condition is “in contro-

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48. *Id.* at 18 (Frankfurter, J., dissenting).

49. See generally *The Supreme Court, 1964 Term*, 79 HARV. L. REV. 168, 169–70 (1965) (discussing the two Supreme Court decisions regarding Rule 35: *Sibbach v. Wilson*, 312 U.S. 1 (1940) and *Schlagenhauf v. Holder*, 379 U.S. 104 (1964)).

50. 379 U.S. 104 (1964).

51. See *id.* at 117–21.

52. *Id.* at 118.

53. See *Lahr v. Fulbright & Jaworski*, 164 F.R.D. 196, 199 (N.D. Tex. 1995) (examining the specifics of the alleged sexual harassment before ordering the test).

54. See *Schlagenhauf*, 379 U.S. at 118.

55. See *id.* at 119–21.

56. See *id.* at 119.

versy.”<sup>57</sup> A similar determination is made with respect to mental examinations. Courts generally require more than a “garden variety” claim of emotional distress before ordering a plaintiff to produce mental examination records or to undergo an independent mental examination.<sup>58</sup> However, this analysis is fact-driven, with little or no examination of the medical or psychological procedure to be used. Similarly, “good cause” requires a simple factual showing that there is either a need for the examination, or that there is no less intrusive means available for obtaining the information.<sup>59</sup>

Only after the movants have satisfied the “in controversy” and “good cause” requirements will a court examine the procedures to be used to gather the evidence. While the movant may satisfy the two factual requirements of Rule 35, the court can still limit the *scope* of requested examinations or deny them altogether.<sup>60</sup> In exercising its discretion, the court balances the rights of civil litigants to discover relevant facts against the privacy interests of persons subject to discovery.<sup>61</sup>

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57. See *Vopelak v. Williams*, 42 F.R.D. 387, 389 (N.D. Ohio 1967).

58. See *Sabree v. United Bd. of Carpenters & Joiners of Am., Local No. 33*, 126 F.R.D. 422, 426 (D. Mass. 1989); see also *Jansen v. Packaging Corp. of Am.*, 158 F.R.D. 409, 410–11 (N.D. Ill. 1994) (holding that, where plaintiff claimed she suffered “ongoing emotional distress due to alleged sexual harassment . . . by her former supervisor,” defendant corporation was entitled to an examination of the plaintiff); *Smedley v. Capps*, 820 F. Supp. 1227, 1232 (N.D. Cal. 1993) (holding that defendant employer was entitled to compel plaintiff to undergo a mental examination to refute her allegation that she suffered only “normal” emotional distress).

59. See *Marroni v. Matey*, 82 F.R.D. 371, 372 (E.D. Pa. 1979). For state-equivalent rulings, see *Cody v. Marriott Corp.*, 103 F.R.D. 421, 422 (D. Mass. 1984); *Ex parte Wal-Mart Stores, Inc.*, 729 So.2d 294, 298 (Ala. 1999); *Martin v. Tindell*, 98 So.2d 473, 475 (Fla. 1957), *cert. denied*, 355 U.S. 959 (1958); *Coates v. Whittington*, 758 S.W.2d 749, 752 (Tex. 1988); *Williams v. Sanderson*, 904 S.W.2d 212, 214 (Tex. Ct. App. 1995); *Crouch v. Gleason*, 875 S.W.2d 738, 739 (Tex. Ct. App. 1994).

60. See *Stinchcomb v. United States*, 132 F.R.D. 29, 30 (E.D. Pa. 1990); *Hardy v. Riser*, 309 F. Supp. 1234, 1241 (N.D. Miss. 1970). If, for example, the examining expert seeks to use unreliable evaluative techniques, the court may deny the motion. See Edward D. Cavanagh, *Decision Extends Daubert Approach to All Expert Testimony*, N.Y. St. B. J., Aug. 1971, at 9 (discussing the factors determining admissibility of scientific evidence). In *Usher v. Lakewood Engineering & Manufacturing Co.*, the District Court for the Northern District of Illinois ordered a psychiatric evaluation of a plaintiff alleging sex discrimination, but refused to allow the defendant to conduct a battery of psychological tests. See *Usher v. Lakewood Engineering & Manufacturing Co.*, 158 F.R.D. 411, 413–14 (N.D. Ill. 1994). The court accepted the plaintiff’s demonstration of “the inadequacy of the correlation factors and the validity factors of all” the tests at issue. *Id.*, at 413. Thus, according to the court, while the tests might uncover relevant evidence, the probative value of such evidence “is substantially outweighed by the danger of unfair prejudice, confusion of the issues, or misleading the jury.” *Id.* (citation omitted).

61. See *Crowe v. Nivison*, 145 F.R.D. 657, 658 (D.C. Md. 1993).

Even with these seemingly stringent requirements and the courts' broad discretion to limit examinations, courts have ordered examinations in some controversial circumstances, sometimes delving into very personal and private affairs.<sup>62</sup> Courts commonly justify their rulings by stating that the ordered testing is necessary to promote a fair and judicious conclusion to the dispute, even though they recognize the potentially painful or invasive effects of the testing.<sup>63</sup> As illustrated by the following cases, courts are willing to order examinations that are overly intrusive, not useful, and involve third parties. These cases should give genetic ethicists great cause for concern, because allowing courts to mandate certain genetic tests will intrude into parties' very personal affairs and invade the autonomy of third parties. Further, juries tend to give undue weight to genetic evidence.

In *Lowe v. Philadelphia Newspapers, Inc.*,<sup>64</sup> the court did recognize the intrusive nature of a psychological exam.<sup>65</sup> There, the plaintiff filed an action against her employer for racial discrimination in failing to promote her and for retaliating after she complained about the discrimination.<sup>66</sup> She asserted that the employer's actions caused her severe emotional and physical harm and distress for which she sought both compensatory and punitive damages.<sup>67</sup> The defendant requested a psychological exam of the plaintiff to defend against the emotional distress claim.<sup>68</sup> The plaintiff argued that any inquiry into her past physical and emotional problems, as well as her past social and private activities should be precluded unless it directly related to her job performance.<sup>69</sup> The plaintiff further argued that allowing broad discovery of a claimant's personal history would discourage claimants from filing meritorious actions for discrimination.<sup>70</sup> The defendant contended that, because plaintiff alleged defendant's conduct caused her severe emotional and physical damage for which she sought punitive

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62. See, e.g., *Pettyjohn v. Goodyear Tire & Rubber Co.*, No. 91-CV2681, 1992 WL 105162 (E.D. Pa. 1992) (holding that defendants in a personal injury suit were entitled to a compelled HIV blood test of plaintiff because plaintiff had placed his life expectancy in controversy by seeking future damages).

63. See generally Kording & DuMontelle, *supra* note 34, at 692-94 (discussing the discovery of genetic testing and the courts' willingness to order these tests without explaining the reasons for their rulings).

64. 101 F.R.D. 296 (E.D. Pa. 1983).

65. *Id.* at 298.

66. See *id.*

67. See *id.* at 298.

68. See *id.* at 298-99.

69. See *id.* at 298.

70. See *id.*

and compensatory damages, her life history should be subject to inquiry through a mental and physical examination.<sup>71</sup> The defendant maintained that the claimed physical and mental suffering were the result of a culmination of the plaintiff's history of medical and psychological problems, and were not the result of any activities by defendant.<sup>72</sup>

The court granted defendant's request to have a psychiatrist explore the plaintiff's "entire life history," including her marital life and private activities.<sup>73</sup> The court reasoned that, as long as plaintiff sought compensatory and punitive damages for her alleged physical, mental or emotional harm, the defendant was entitled to inquire about her entire life history, even through a mental or physical examination.<sup>74</sup>

Courts have even ordered examinations of non-party witnesses for issues unrelated to the facts of the lawsuit. In *Lewin v. Jackson*,<sup>75</sup> the court did not apply Rule 35, but used the spirit of the rule to order a mental and physical examination of a non-party elderly man in order to determine whether he was competent to testify at a deposition.<sup>76</sup> The lawsuit concerned a slander claim in which the plaintiff argued that the defendants, by defaming her, had induced her wealthy father to disinherit her.<sup>77</sup> The defendants wanted to depose the plaintiff's father and plaintiff claimed that he was not fit to testify.<sup>78</sup> The plaintiff alleged "that a deposition would subject the elderly man, in his feeble state, to an undue burden so severe it could threaten his life."<sup>79</sup> The Arizona Supreme Court noted that the examination was not for dis-

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71. *See id.*

72. *See id.*

73. *See id.* at 299.

74. *See id.* at 298-99. *But see* *Vinson v. Superior Court*, 239 Cal. Rptr. 292 (1987). In *Vinson*, the plaintiff alleged that harassment by an interviewer for whom she eventually worked caused continuing emotional distress, loss of sleep, anxiety, mental anguish, humiliation, and reduced self-esteem, for which she sought compensation under state tort law. *See id.* at 296. Interpreting a California procedural rule similar to Rule 35, the court held that plaintiff's claims of "various mental and emotional ailments" placed her mental state in controversy, but the court restricted the order granting a medical examination in two respects. *See id.* at 297. First, it restricted the scope of the examination, holding that the plaintiff's right to privacy precluded the defendant from exploring her sexual history and practices. *See id.* at 298. Second, the court stated in dicta that it would not order an examination in a "simple sexual harassment claim asking compensation for having to endure an oppressive work environment" where the complainant did not seek monetary damages for ongoing psychological injuries. *Id.* at 297.

75. 492 P.2d 406 (Ariz. 1972).

76. *See Lewin*, 492 P.2d at 408-10.

77. *See id.* at 407.

78. *See id.*

79. *Id.*

covery purposes and thus Rule 35 did not apply.<sup>80</sup> However, the court had inherent power to “take all steps necessary to assure itself not only that a witness’s testimony will be accurate . . . but also that the act of testifying will not endanger the health of the proposed witness.”<sup>81</sup> The court held that, under the circumstances, because the court’s purpose was to make sure the father was competent to be deposed, the examination was acceptable.<sup>82</sup>

Courts have used Rule 35 to order tests that are inexact in their results and are open to several interpretations. In several cases courts have granted defendants’ Rule 35 motions to conduct intelligence quotient (“IQ”) testing of plaintiffs’ mothers and siblings in lead exposure tort litigation.<sup>83</sup> In one lead exposure case, the court granted defendant’s motion to compel IQ testing of the plaintiff’s mother, and ordered the release of academic records of the plaintiff’s family.<sup>84</sup>

As is typical of Rule 35 cases, in each of these lawsuits the court focused on the particular facts of the case and the need for the examination while avoiding any discussion of the particular examination to be used. The courts’ failure to discuss the procedures to be used in these cases is logical given the general acceptance of psychological, competency, and IQ tests. Genetic tests, however, are not as widely accepted or understood. Because courts and juries may not fully understand that genetic test results have a number of possible interpretations, they may incorrectly perceive the tests to be accurate and

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80. *See id.* at 409.

81. *Id.*

82. *See id.* at 408–09.

83. *See Salkey v. Mott*, 656 N.Y.S.2d 886, 887 (N.Y. App. Div. 1997); *see also* Jennifer Wriggins, *Genetics, IQ, Determinism, and Torts: The Example of Discovery in Lead Exposure Litigation*, 77 B.U. L. REV. 1025, 1042 (1997) (discussing *Campbell v. Bonner*, No. 92-7771, at 3–4 (D.C. Super. Ct. Jan. 7, 1994)).

84. *See* Wriggins, *supra* note 83, at 1059 n.159 (discussing *Atkins v. New York City Hous. Auth.*, No. 12460195 (N.Y. Sup. Ct., Oct. 1996)). For a discussion of the reliability and validity of IQ tests, *see* David Bellinger & Herbert L. Needleman, *Neurodevelopmental Effects of Low-Level Lead Exposure in Children*, in HUMAN LEAD EXPOSURE 191, 195 (1992) (“A global measure, such as an intelligence test, may not be the most valid or sensitive measure of the quality, efficiency, or flexibility of a child’s cognition or of any effects lead may have on it.”); *see also* Larry P. v. Riles, 495 F. Supp. 926, 935–59 (N.D. Cal. 1979) (recounting the discriminatory history of the development and use of IQ tests in California); Wriggins, *supra* note 83, at 1044–55 (discussing the accuracy and implications of IQ testing generally). *See generally* RICHARD J. HERRNSTEIN & CHARLES MURRAY, *THE BELL CURVE: INTELLIGENCE AND CLASS STRUCTURE IN AMERICAN LIFE* (1994) (analyzing intelligence testing data and discussing the correlation between scores on the Armed Forces Qualifying Test and educational level, income, anti-social behavior, and ethnic background); THOMAS SOWELL, *RACE AND CULTURE* 157–58 (1994) (describing international differences in intelligence test performance).

determinative scientific tools. Of the few opinions that have addressed court-ordered genetic testing under Rule 35, none have discussed the specifics of the tests, which makes it difficult to determine whether courts truly appreciate the numerous issues associated with such tests.

## II. Understanding Genetic Testing and Its Use in Rule 35 Examinations

A Kansas state court was one of the first to order a genetic test in a civil lawsuit. In *Bennett v. Fieser*,<sup>85</sup> the court ordered genetic testing of a minor child in a medical malpractice action.<sup>86</sup> Although the court focused on the physical intrusiveness of the procedure,<sup>87</sup> the court failed to reference the purpose of the test or the possible mental intrusiveness of the examination. The court seemed more interested in the minor physical intrusion caused by a blood test, and did not discuss the social or psychological implications of the test. It ordered the test because the amount of blood sought was relatively small, the pain from the test was minimal, and the apparent relevance was significant.<sup>88</sup>

Likewise, in *Dodd-Anderson v. Stevens*,<sup>89</sup> the same Kansas state court ordered genetic testing of a child in a medical malpractice action in which the plaintiffs alleged that the minor child suffered a brain injury during delivery.<sup>90</sup> The defendants sought a sample of the child's blood for genetic testing.<sup>91</sup> They also asked to have the child examined by a pediatric neurologist, a pediatric psychiatrist, and a geneticist.<sup>92</sup> In granting the orders for genetic testing and independent medical exams, the court reasoned that the relevance of testing outweighed the pain and invasive nature of the exams, even for a child.<sup>93</sup>

Both of these decisions failed to account for any possible privacy issues or psychological risks associated with the blood tests. The cursory treatment of the genetic testing issue in both cases makes it diffi-

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85. No. 93-1004-MLB, 1994 WL 542089, at \*1 (D. Kan. 1994).

86. See *Bennett*, 1994 WL 542089, at \*2.

87. See *id.* at \*2.

88. See *id.* (focusing on the "potential relevance of such testing and the nature and amount of damages sought by plaintiff").

89. Nos. 92-1015-MLB, 92-1016-MLB, 1993 WL 273373, at \*1 (D. Kan. 1993).

90. See *Dodd-Anderson*, 1993 WL 273373, at \*1-3.

91. See *id.* at \*1.

92. See *id.*

93. See *id.*



cult to determine if any privacy issues or risks were factored into the decisions to order the tests.

In a more recent unreported decision, a California court applied its Rule 35 equivalent when ordering genetic testing.<sup>94</sup> The plaintiff sued the manufacturer of chemicals to which her son was exposed during her pregnancy, claiming that the exposure caused her child's mental retardation.<sup>95</sup> The defendant sought a genetic test of the boy, claiming that the birth defects were not caused by the chemicals, but by a genetic condition called Fragile X Syndrome.<sup>96</sup> The court granted the order based on the fact that the child exhibited some similar traits to children with Fragile X Syndrome, though he lacked some other common characteristics.<sup>97</sup>

These three decisions illustrate how courts can and will order genetic testing under Rule 35. The orders in these cases focus on the facts of the lawsuit. They provide no discussion of the specifics of the medical procedures, the usefulness of the tests to the litigation, or the possible ramifications of ordering these tests. The cases highlight how courts are likely to confine themselves to a simple analysis of the "good cause" and "in controversy" requirements.<sup>98</sup> Before a court orders a genetic test it must understand the types of genetic testing available, the actual mechanics of the tests, and what type of information is produced by the test.

#### A. Testing for Genetically-Based Diseases

Genetic testing became possible when, in 1990, scientists began deciphering the human genome as part of a colossal project named the Human Genome Project ("Project").<sup>99</sup> When completed, the Pro-

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94. See Lehrman, *supra* note 31, at A1 (describing *Severson v. KTI Chemicals, Inc.*).

95. See *id.*

96. See *id.* For a discussion of Fragile X, see Tanya Gregory, *Meeting the Challenge of Fragile X Syndrome*, PATIENT CARE, Sept. 15, 1997, available in 1997 WL 25779124. Fragile X Syndrome is the most common cause of inherited mental retardation. See *id.* It is caused by a mutation on the FMR-1 gene. See *id.* Since this is an abnormality of a sex chromosome, which can be transmitted from parent to child, the term "sex-linked" or "X-linked" inheritance is used in the medical literature. See Bill McMenemy, *Facing Huntington's Disease: A Handbook for Families and Friends*, at ch. 2 (visited Jan. 21, 2000) <<http://neuro-chief-e.mgh.harvard.edu/mcmenemy/facinghd.html#contents>>. Current estimates of its prevalence vary, but some experts believe that Fragile X affects at least one in 1000 males and females. See Raymond Kammer, *Implications of Genetic Testing*, CONG. TESTIMONY BY FED. DOCUMENT CLEARING HOUSE, Apr. 21, 1999, available in 1999 WL 16946490. More conservative estimates put its frequency at one in 1500 males and one in 2500 females. See Gregory, *supra*.

97. See Lehrman, *supra* note 31, at A1 (describing *Severson v. KTI Chemicals, Inc.*).

98. See *infra* Part I.C.

99. See Hood & Rowen, *supra* note 11, at 3.

ject will change the way science and medicine deal with health care. A map of the human genome will eventually allow accurate diagnostic tools and potential cures and treatments to be developed for many inherited diseases.<sup>100</sup> A number of diagnostic tests already exist for certain genetically-related diseases.<sup>101</sup> The task force that drafted the Genetic Privacy Act<sup>102</sup> likened genetic testing to a “future diary.”<sup>103</sup> They consider the human genome a coded future diary, and a genetic test as a way of decoding that diary.<sup>104</sup>

### 1. What Does a Positive Test Result Mean? A Wide Variance of Information

The decoding of this genetic diary is not yet an exact science. The deciphering of a person’s genome will have a significant impact on the person’s life, both mentally and physically; however, the information gained may not always be definitive or accurate. A positive test result will most often predict only a *susceptibility* to the particular disease or condition.<sup>105</sup> Further, different genetic tests can produce a wide variance of information and there may be no clear explanation of what the results really mean.<sup>106</sup> For example, some positive results mean that a person has anywhere from a twenty to an eighty percent chance of getting a particular disease, and some negative results do not guarantee that the person is free from developing symptoms of a disease.<sup>107</sup>

The statistical probability of developing a disease is not the only variance associated with genetic testing. The information produced by a genetic test varies according to the accuracy of the test, the reliability of the test, the severity of the disease, and the impact of environmental factors.<sup>108</sup> Also, many genetic disorders—those referred to as poly-genetic disorders—are caused by more than a single gene.<sup>109</sup> Even as

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100. See Rothstein & Hoffman, *supra* note 12, at 854.

101. See *id.*

102. See ANNAS ET AL., THE GENETIC PRIVACY ACT, *supra* note 33.

103. George J. Annas et al., *Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations*, 23 J. LAW, MED. & ETHICS 360, 360 (1995) [hereinafter Annas et al., *Drafting the Genetic Privacy Act*].

104. See Patricia Roche et al., *The Genetic Privacy Act: A Proposal for National Legislation*, 37 JURIMETRICS J. 1, 3 (1996).

105. See *infra* Part II.B.

106. See *infra* Part II.B.

107. See *infra* Part II.B.

108. See Rothstein & Hoffman, *supra* note 12, at 856.

109. See ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 95 (1994).

the Project continues, genetic mutations are being discovered and linked to existing diseases.<sup>110</sup> Until all mutations are discovered, it will be difficult to assess the reliability of any given test<sup>111</sup> because testing for one genetic mutation provides less accurate predictions of diseases that will later be deemed polygenetic.

## 2. Environmental Factors

The most critical factor in these informational variances is the impact of the environment. Often, an individual's habits, how well she takes care of her health, her exposure to workplace toxins, or other environmental factors will determine the severity of a particular genetic disorder.<sup>112</sup> As the Project has progressed, it has become increasingly clear that many genetic disorders have an environmental component.<sup>113</sup> This means that a test may only uncover a susceptibility to a particular disease without indicating when symptoms may begin, what the severity of those symptoms may be, or how long a person is likely to live.

Great strides are being made in testing for a person's pre-disposition to a genetic disease, but this information is often not useful to the patient and can, in fact, be harmful. Although the first diseases linked to gene mutations, Huntington's Disease ("HD") and Cystic Fibrosis ("CF"), are accurate predictors,<sup>114</sup> they do not provide the patient with helpful information because there are no significant cures or treatments available for the diseases.<sup>115</sup> While scientists have been

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110. *See id.*

111. *See id.* at 94-99.

112. Some diseases are influenced jointly by both a genetic defect and environmental factors. Heart disease is one example. *See id.* at 95. Scientists have discovered a gene that predisposes individuals to arteriosclerosis, the leading cause of heart disease in this country. *See Coronary Heart Disease: Important Cardiovascular Disease Gene Discovered*, GENE THERAPY WKLY, Mar. 23, 1998, at 30. The disease is linked to a single gene called ATHS. *See id.* Scientists call ATHS a classical susceptibility gene in that it does not cause arteriosclerosis by itself, but works with other factors, such as diet and possibly other genes, to put those individuals who carry it at greater risk. *See id.*

113. *See* ASSESSING GENETIC RISKS, *supra* note 109, at 62.

114. *See* Gregory J. Meissen, Ph.D. et al., *Predictive Testing for Huntington's Disease with Use of a Linked DNA Marker*, 318 NEW ENG. J. MED. 535, 535 (1988); Bat-sheva Kerem et al., *Identification of the Cystic Fibrosis Gene: Genetic Analysis*, 245 SCI. 1073, 1079. Genes are inherited in pairs, with one gene coming from each parent to make the pair. *See* Kerem et al., *supra*, at 1073. Cystic Fibrosis occurs when both genes in the pair have a mutation. *See id.* A person with Cystic Fibrosis receives one CF gene from each parent. *See id.* at 1075. The parents of a child with CF each "carry" one non-working copy of the gene and one working copy of the gene. *See id.* The parents are called CF carriers, and because they have one working gene but they have no symptoms. *See id.* at 1079.

115. *See* Meissen et al., *supra* note 114, at 541.

able to locate genes that cause or influence different diseases, and they can often manufacture a test for the disease quickly after locating its genetic basis,<sup>116</sup> treatments or cures for these diseases are not developed as quickly. There is often a large gap between the time a test is developed and when treatments are discovered.<sup>117</sup> Scientifically, these genetic pre-disposition tests represent a clear medical breakthrough, but to the many individuals with these genetic defects, these extraordinary findings are meaningless and often psychologically harmful.<sup>118</sup> The results only give a person some insight into his or her future doom, while offering no hope for possible treatments or cures. For such diseases, the test results can simply be a death sentence, of which many individuals would prefer not to be made aware.<sup>119</sup>

## B. Examples of Genetically-Based Diseases

Three genetically-related diseases that illustrate the wide variance in genetic test results are Huntington's Disease, Alzheimer's Disease, and breast cancer associated with the gene mutation BRCA1. These three diseases best illustrate the breadth of the technology available, its limitations, and the lack of cures or treatments available.

A positive test result in each of these three illnesses means drastically different things, allowing for a wide range of interpretations. A positive result for one disease may only mean that the individual has a fifty percent chance of developing the disease, while another test will show a ninety percent susceptibility. The tests that check for the probability of developing the disease, however, fail to account for when or to what degree of severity the symptoms will occur. Each test differs as to predictability and reliability. The diseases themselves differ in severity and in the availability of treatments for the disease. Without knowing these variables, courts cannot make proper assessments as to the value of the tests and the informational risks that may be associated with the results.

### 1. Huntington's Disease

HD is neurodegenerative; it is a progressive condition that results from increasing damage to the nervous system.<sup>120</sup> HD generally devel-

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116. See Rothstein & Hoffman, *supra* note 12, at 856.

117. See *id.*

118. See *infra* Part IV.A.

119. See *infra* Part IV.A.

120. See Gayle P. Andresen, *Dx Dementia: But What Kind?* RN, June 1, 1998, at 27.

ops subtly during a person's thirties or forties with the following symptoms: movement disorders, dementia, and psychiatric disturbances.<sup>121</sup>

The course of the disease may last anywhere from ten to thirty years (onset to death),<sup>122</sup> and can be divided into three stages. In the early period, patients can still perform most of their usual activities.<sup>123</sup> They may still be able to work and drive.<sup>124</sup> Involuntary movements are mild and infrequent, speech is still clear, and dementia, if present at all, is mild.<sup>125</sup> In the middle stage, affected patients become more disabled and need assistance with some of their daily activities.<sup>126</sup> Falling, weight loss, and swallowing difficulties may become problematic.<sup>127</sup> Dementia becomes more obvious to the casual observer<sup>128</sup> and involuntary movements are more pronounced.<sup>129</sup> In the late stage, patients require almost full-time care and may need to reside in hospitals or nursing homes.<sup>130</sup> When death comes it is usually caused by pneumonia.<sup>131</sup>

HD is caused by a mutation in a gene located on chromosome 4.<sup>132</sup> This gene is found in every human being and contains a section where the same three molecules repeat several times (a "triplet repeat sequence").<sup>133</sup> In the case of HD, the gene contains an abnormally large number of triplet repeats.<sup>134</sup>

Genes for diseases can be either dominant, meaning that one need only inherit the gene from one parent to get the disease, or recessive, meaning that one must get the gene from both sides of the family to have the disease.<sup>135</sup> The gene for HD is dominant.<sup>136</sup> Therefore, most HD sufferers have one expanded gene and one normal gene.<sup>137</sup> Because a parent can pass either the expanded gene or the

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121. *See id.*

122. *See* McMenemy, *supra* note 96, at ch. 1.

123. *See id.*

124. *See id.*

125. *See id.*

126. *See id.*

127. *See id.*

128. *See id.*

129. *See id.*

130. *See id.*

131. *See id.* at ch. 2.

132. *See id.*

133. *See* Ewout Brunt, *In Dominant Ataxias*, GENERATIONS, Mar. 22, 1999, available in 1999 WL 22869252.

134. *See id.*

135. *See* McMenemy, *supra* note 96, at ch. 2.

136. *See id.*

137. *See id.*

normal gene, each child has a fifty percent chance of getting the expanded copy and of inheriting the disease.<sup>138</sup> It is important to understand that people born with the mutated gene for HD will not develop the symptoms until later in life.<sup>139</sup> Therefore, someone can carry the expanded gene but not yet exhibit symptoms.<sup>140</sup> Such a person is said to be presymptomatic.<sup>141</sup>

Since the discovery of the HD gene in 1993, a predictive test has been developed.<sup>142</sup> This test can identify the carriers of the faulty gene before they develop the illness.<sup>143</sup> "Occasionally, the result falls in a 'grey area' where it is still uncertain whether the person will develop HD or not."<sup>144</sup> Even when the test does show that someone carries the faulty gene, it does not show when the disease will start to develop.<sup>145</sup>

There is presently no cure for HD nor are there any direct treatments, although researchers are working on a number of treatments that may slow down the progression of the disease.<sup>146</sup> However, there are a great many interventions available today which can make life better for HD sufferers.<sup>147</sup> In the early and middle stages of the disease, medications called neuroleptics, given in larger doses for psychiatric complaints, can be given in small doses to HD patients to suppress involuntary movements.<sup>148</sup> Depression and other psychiatric conditions in people with HD, the result of damage to the brain, can be debilitating but can be effectively treated.<sup>149</sup> Proper nutrition, exercise, and precautions in the home can prevent weight loss, falls, and

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138. *See id.*

139. *See* Wendy C. McKinnon et al., *Predisposition Genetic Testing for Late-Onset Disorders in Adults, A Position Paper of the National Society of Genetic Counselors*, 278 JAMA 1217, 1217 (1997).

140. *See id.* at 1218.

141. *See id.*

142. *See* Sandi Wiggins, M.Sc. et al., *The Psychological Consequences of Predictive Testing for Huntington's Disease*, 327 NEW ENG. J. MED. 1401, 1401-05 (1992).

143. *See id.* at 1401.

144. McMenemy, *supra* note 96, at ch. 2.

145. *See* Wiggins et al., *supra* note 142, at 1401.

146. *See Facts and Myths Regarding Huntington's Disease*, BROWN U. LONG-TERM CARE QUALITY ADVISOR, available in 1999 WL 11762817.

147. *See id.*

148. *See id.*

149. *See id.*

choking on food.<sup>150</sup> Recently, scientists have concluded research, which may lead to additional treatment for sufferers of HD.<sup>151</sup>

## 2. Alzheimer's Disease

Of the diseases that produce dementia, Alzheimer's is the most common.<sup>152</sup> More than four million older Americans have Alzheimer's, and that number is expected to triple in the next twenty years as more people live into their eighties and nineties.<sup>153</sup> In 1906, Dr. Alois Alzheimer noticed changes in the brain tissue of a woman who had died of an unusual mental illness.<sup>154</sup> He found abnormal clumps and tangled bundles of fibers in her brain tissue.<sup>155</sup> The disease, which came to be known as Alzheimer's, progresses to affect language, reasoning, understanding, reading, and writing.<sup>156</sup> Eventually, people with Alzheimer's Disease may become anxious or aggressive and may even wander from home.<sup>157</sup>

The predictive value of the test for Alzheimer's disease is quite low.<sup>158</sup> Considerable evidence suggests that the presence of the gene for "apolipoprotein E-e4" increases a person's risk for Alzheimer's.<sup>159</sup> The gene for apolipoprotein E ("APOE") is located on chromosome

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150. *See id.*

151. *See* John Travis, *Thwarting Killer Enzymes of the Brain (Research of Caspases in the Brain)*, 155 *SCI. NEWS* 351 (1999) (discussing new studies in mice which indicate that blocking an enzyme involved in cell death pathways delays the onset of symptoms and death in a mouse model of HD, offering a rare ray of hope for sufferers of this uniformly fatal neurological disease). Caspase-1, an enzyme involved in controlling cell death, was activated in the brains of mice and humans with HD. *See id.* The researchers crossed mice having a portion of the human HD gene with mice deficient in normal Caspase-1 to see whether they could affect the course of a HD-like disease. *See id.* Disease onset and mortality were significantly delayed in the resulting mice, the investigators reported. *See id.* These mice also lived longer than the mice carrying only the HD gene fragment. *See id.* To further test their theory, the scientists injected an inhibitor of Caspase-1 into the brains of HD gene mice. *See id.* When this drug was infused, the mice suffered less disability and lived longer than untreated mice. *See id.*

152. *See* Kara Albusu, *As a Millennium Ends, Alzheimer Care Begins*, *NURSING HOMES*, Dec. 1, 1999, at 98, available in 1999 WL 12019512.

153. *See id.*

154. *See* *Key to Alzheimer's Located in Brain*, *CURRENT SCI.*, Jan. 7, 2000, at 14.

155. *See id.*

156. *See* Myron F. Weiner, *Alzheimer's Disease Update: Using What We Now Know to Help Patients*, *CONSULTANT*, Mar. 1, 1999, available in 1999 WL 13774866.

157. *See id.*

158. *See* Jim Edwardson & Chris Morris, *The Genetics of Alzheimer's Disease: The Number of Genetic Risk Factors Associated with This Disorder is Increasing Steadily*, *BRIT. MED. J.*, Aug. 8, 1998, at 361, available in 1998 WL 13306263.

159. *See* Weiner, *supra* note 156.

19.<sup>160</sup> Several recent studies show that its natural variations correlate well with the risk of Alzheimer's disease.<sup>161</sup>

The APOE gene comes in three varieties of alleles: e2, e3, and e4.<sup>162</sup> Everyone's APOE gene has two of these three alleles, so there are six possible combinations in any individual's DNA.<sup>163</sup> The e2 allele is associated with decreased risk of Alzheimer's disease.<sup>164</sup> The e3 allele is associated with average risk.<sup>165</sup> One e4 allele approximately doubles the risk of suffering from Alzheimer's, while two e4 alleles boosts the risk eight-to-ten-fold.<sup>166</sup>

Genetic testing for APOE alleles is currently possible, but it is not widely used because it has little predictive value.<sup>167</sup> Despite the increased risk with the existence of two e4 APOE alleles, many people with these two alleles live into old age with no sign of Alzheimer's.<sup>168</sup> Currently, genetic testing for APOE alleles only suggests an *increased risk*; it does not predict development of Alzheimer's.<sup>169</sup>

There are, as yet, no cures, but researchers studying Alzheimer's have made progress, especially in the last five years.<sup>170</sup> New drugs that can temporarily improve mental abilities in some people with mild Alzheimer's are now available, and more drugs are being studied.<sup>171</sup> These therapies appear to slow the progression of the disease somewhat.<sup>172</sup> In addition, there is a growing number of medications reaching the clinical trial phase.<sup>173</sup> Although by definition these are not yet proven to be effective, they offer added possibilities for treatment.<sup>174</sup>

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160. *See id.*

161. *See* National Institute on Aging/Alzheimer's Association Working Group, *Apolipoprotein E Genotyping in Alzheimer's Disease*, 347 LANCET 1091, 1091 (1996).

162. *See id.*

163. *See id.*

164. *See id.* at 1092.

165. *See id.*

166. *See id.*

167. *See Special Report: Genomics and Diagnostics: A Little Now, More Later*, GENESIS REPORT, Nov. 1, 1997, available in 1997 WL11413177.

168. *See* National Institute on Aging/Alzheimer's Association Working Group, *supra* note 161, at 1092.

169. *See id.*

170. *See* Albusu, *supra* note 152.

171. *See* Weiner, *supra* note 156.

172. *See id.*

173. *See id.*

174. *See id.*



### 3. Breast Cancer

The American Cancer Society has estimated that in the United States in 1999 over 176,300 women would be diagnosed with breast cancer and nearly 44,000 would die from this disease.<sup>175</sup> Breast cancer accounts for thirty-two percent of all cancers in American women; eight percent of all women will develop breast cancer sometime during her life.<sup>176</sup> Although earlier detection results in higher cure rates, breast cancer remains the leading cause of cancer death of adult women under fifty-four years of age and the second most common cause after age fifty-four.<sup>177</sup> Among women of all ages, breast cancer is second only to lung cancer as the leading cause of cancer deaths in women.<sup>178</sup> Hereditary breast cancer makes up approximately ten to fifteen percent of all breast cancer cases.<sup>179</sup>

In recent years, gene alterations have been found in some families with a history of breast cancer.<sup>180</sup> Many women in these families also have had ovarian cancer.<sup>181</sup> These alterations are most often found in genes named BRCA1 and BRCA2.<sup>182</sup> Both men and women have BRCA1 and BRCA2 genes, so alterations in these genes can be passed down from either the mother or the father.<sup>183</sup>

Genetic testing for breast and ovarian cancer risk involves looking for altered genes such as BRCA1 and BRCA2.<sup>184</sup> Testing for breast cancer risk, however, will not give you a simple "yes" or "no" answer.<sup>185</sup> Finding a gene alteration in BRCA1 or BRCA2 indicates an increased risk of developing cancer, but it will not indicate if or when cancer will develop.<sup>186</sup> There are several factors involved in calculating the chance of finding a BRCA1 or BRCA2 alteration, also called

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175. See S. Vincent Rajkumar & Lynn C. Hartmann, *Screening Mammography in Women Aged 40-49 Years (for Breast Cancer)*, 78 MED. 410 (1999), available in 1999 WL 13259068.

176. See Thomas C. Rosenthal, M.D. & Stirling M. Puck, M.D. *Screening for Genetic Risk of Breast Cancer*, 59 AM. FAM. PHYSICIAN 99, 99 (1999).

177. See Rajkumar & Hartman *supra* note 175.

178. See *id.*

179. See Rosenthal & Puck, *supra* note 176, at 99.

180. See *GenRISK Testing Program Offers Patients Hope in Confronting Disease*, GENE THERAPY WKLY, Mar. 2, 1999, available in 1999 WL 11598221.

181. See *id.*

182. See *id.* (BRCA1 and BRCA2 stand for *B*Reast *C*ANcer Gene 1 and *B*Reast *C*ANcer Gene 2).

183. See *id.*

184. See Charles W. Henderson, *Testing Program Offers Patients New Hope in Confronting Disease*, CANCER WKLY. PLUS, July 26, 1999, available in 1999 WL 11805477.

185. See *id.*

186. See *id.*

the "prior probability" of finding a mutation.<sup>187</sup> The only way to determine the prior probability is to take a detailed family history.<sup>188</sup> The family history must include all cancer diagnoses, not just breast and ovarian cancer, as well as the ages at diagnosis and the patient's ethnicity.<sup>189</sup>

Perhaps the most important thing that women should know before testing for BRCA1 or BRCA2, the mutated genes, is that a positive test does not mean a patient will *definitely* develop cancer.<sup>190</sup> Most articles in the medical literature about BRCA1 and BRCA2 tests say that the risk of actually developing breast cancer with a positive genetic test is eighty-five percent.<sup>191</sup> There is, however, recent evidence that this risk figure may actually be much lower in individuals who do not have a very strong family history of cancer.<sup>192</sup>

An individual at increased risk for breast or ovarian cancer can make choices that may help reduce her risk of developing cancer or help her in detecting the disease at an early stage.<sup>193</sup> An individual at increased risk may choose to be monitored more closely for any sign of cancer.<sup>194</sup> This may include more frequent mammograms, breast exams by a doctor, breast self-exams, and an ultrasound exam of the ovaries.<sup>195</sup> An individual at increased risk may choose to have her healthy breasts removed.<sup>196</sup> A recent study has suggested that the removal of the ovaries decreases the chance of getting breast cancer for women who carry the BRCA1 mutation.<sup>197</sup>

### III. Court-Ordered HIV Testing and Its Implications for Genetic Testing Under Rule 35

Huntington's Disease, Alzheimer's Disease, and breast cancer often lead to death, usually in a very slow and sometimes painful man-

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187. See Elizabeth B. Claus et al., *Effect of BRCA1 and BRCA2 on the Association Between Breast Cancer Risk and Family History*, 90 J. NAT'L CANCER INST. 1824, 1824 (1998).

188. See *id.* at 1827-28.

189. See *id.*

190. See Wylie Burke, M.D., Ph.D. et al., *BRCA1 and BRCA2: A Small Part of the Puzzle*, 91 J. NAT'L CANCER INST. 904 (1999).

191. See *id.*

192. See *id.*

193. See Ellen Michaud, *Outsmart Your "Bad" Genes*, PREVENTION, Apr., 1999, at 122, 130-31.

194. See *id.* at 127.

195. See *id.*

196. See *id.* at 198.

197. See Timothy R. Rebbeck et al., *Breast Cancer Risk After Bilateral Prophylactic Oophorectomy in BRCA1 Mutation Carriers*, 91 J. NAT'L CANCER INST. 1475, 1475 (1999).

ner.<sup>198</sup> A positive test result for one of these diseases at the presymptomatic stage often tells the person that he or she is likely to develop symptoms later in life and eventually die prematurely, with little or nothing the person can do to stop the inevitable.<sup>199</sup> Because of the potentially traumatic nature of the information generated by genetic tests,<sup>200</sup> they bear a striking resemblance to HIV tests. The issues central to debates concerning HIV testing—such as discrimination, psychological trauma, and stigmatization—will reverberate in discussions surrounding genetic testing.<sup>201</sup>

### A. Cases of Court-Ordered HIV Testing

While public health officials and civil libertarians were debating how best to treat information concerning a person's HIV status, a number of courts have been confronted with similar informational privacy issues.<sup>202</sup> Courts have had to consider issues surrounding the discovery of medical records that contain confidential HIV information,<sup>203</sup> whether a doctor must divulge his HIV status,<sup>204</sup> and whether

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198. See *supra* Part II.B.

199. See *supra* Part II.B.

200. See Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 490 (1995) [hereinafter Gostin, *Health Information Privacy*].

201. See *id.*

202. See *id.* at 495–98 (providing an in-depth discussion of the privacy rights of individuals in disclosing various personal documents including health care records).

203. See *Woods v. White*, 689 F. Supp. 874, 875 (W.D. Wis. 1988) (extending the constitutional right to privacy to disclosure of a prisoner's HIV status by prison medical service personnel and holding that giving chaplains open access to patient medical records violated privacy rights of patients), *aff'd*, 899 F.2d 17 (7th Cir. 1990).

204. See, e.g., *Estate of Behringer v. Medical Ctr.*, 592 A.2d 1251, 1276–77 (N.J. Super. Ct. Law Div. 1991) (mandating disclosure of a doctor's HIV-positive status to patients as part of informed consent); see also Jane H. Barney, *A Health Care Worker's Duty to Undergo Routine Testing for HIV/AIDS and to Disclose Positive Results to Patients*, 52 LA. L. REV. 933, 956–60 (1992) (advocating a duty of health care workers to submit to routine HIV testing and to disclose a positive status to their patients); Michelle Wilcox DeBarge, *The Performance of Invasive Procedures by HIV-Infected Doctors: The Duty to Disclose Under the Informed Consent Doctrine*, 25 CONN. L. REV. 991, 992–93, 1007–11 (1993) (advocating that the *Behringer* court was correct in its determination that a doctor must disclose a positive HIV status whenever there is a material risk of doctor-to-patient HIV transmission and concluding that the *Behringer* court was correct in holding that the performance of surgical or invasive procedures by an HIV-infected doctor poses a material risk of HIV infection to the patient). For further discussions of doctors' and healthcare workers' obligation to disclose a positive HIV status, see Theodore R. LeBlang, *Obligations of HIV-Infected Health Professionals to Inform Patients of Their Serological Status: Evolving Theories of Liability*, 27 J. MARSHALL L. REV. 317, 319 (1994); Mary K. Logan, *Who's Afraid of Whom? Courts Require HIV-Infected Doctors to Obtain Informed Consent of Patients*, 44 DEPAUL L. REV. 483, 510–11 (1995); Phillip L. McIntosh, *When the Surgeon Has HIV: What to Tell Patients About the Risk of Exposure and the Risk of Transmission*, 44 U. KAN. L. REV. 315, 316–19, 326–27 (1996).

a party must submit to an HIV test under Rule 35.<sup>205</sup> When confronted with these discovery issues, particularly in motions for court-ordered HIV testing, courts have come to different conclusions depending upon the focus of their reasoning. More specifically, when faced with a motion to compel HIV testing, courts have been reluctant to order the test when they focus their analysis on the specific facts of HIV infection and the effects of the test. Those courts that focus on the facts of the case and on satisfying the “in controversy” requirement of Rule 35, rather than the effects of the test, have been more willing to order the test. Compelled HIV testing has occurred in several different circumstances, ranging from child custody issues to claims for future damages. The most far-reaching attempt to compel a plaintiff to undergo an HIV test has been to prove future damage claims by focusing on the tort claimant’s life expectancy.

### 1. HIV Testing to Reduce the Amount of Future Damages

Generally in these compelled HIV testing cases, the defendant may try to determine the HIV status of the plaintiff to ultimately reduce the amount of damages for future wages.<sup>206</sup> The defendant seeks a reduction of damages based on the theory that, if the plaintiff is HIV-positive, the plaintiff’s life expectancy will be dramatically shorter than that of a person not infected with the virus.<sup>207</sup> The defendant

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205. See Ugo Colella, *HIV-Related Information and the Tension Between Confidentiality and Liberal Discovery*, 16 J. LEGAL MED. 33, 69 (1995).

206. See *Sacramona v. Bridgestone/Firestone, Inc.*, 152 F.R.D. 428, 430 (D. Mass. 1993); *Pettyjohn v. Goodyear Tire & Rubber Co.*, No. 91-CV-2681, 1992 WL 105162, at \*1 (E.D. Pa., Apr. 29, 1992)).

207. See *Sacramona*, 152 F.R.D. at 430–31; see generally Mark A. Rothstein, *Preventing the Discovery of Plaintiff Genetic Profiles by Defendants Seeking to Limit Damages in Personal Injury Litigation*, 71 IND. L.J. 877 (1996) [hereinafter Rothstein, *Preventing the Discovery*]. Rothstein discusses how,

[u]nder the prevailing American rule, a tort victim suing for damages for permanent injuries is permitted to base his recovery ‘on his prospective earnings for the balance of his life expectancy at the time of his injury undiminished by any shortening of that expectancy as a result of the injury.’

*Id.* at 884 (quoting *Sea-Land Servs., Inc. v. Gaudet*, 414 U.S. 573, 594 (1974) (emphasis omitted) (quoting 2 FOWLER V. HARPER & FLEMING JAMES, JR., *THE LAW OF TORTS* § 24.6, at 1293–94 (1956))). “[R]ate of earning . . . is based on the plaintiff’s abilities, training, experience, and pre-injury earnings. Prospects for wage increases and loss of fringe benefits also are considered.” *Id.*

[D]etermining life expectancy[ ] is already more difficult, and it is likely to become increasingly complicated in the new era of genetics and predictive medicine. Currently, life expectancy is based initially on standard mortality tables. These tables, however, are merely the starting point for making a determination of life expectancy or work expectancy. ‘[S]uch evidence is not conclusive but

argues that, by making a claim for future lost wages, the plaintiff places his life expectancy at issue.<sup>208</sup> This may become an issue when the defendant learns through discovery that the plaintiff was a former drug user, shared hypodermic needles with people, or engaged in unprotected sex.<sup>209</sup> Arguing that the plaintiff placed his life expectancy in controversy and that the plaintiff engaged in activity that placed him at risk of contracting HIV, the defendant files a Rule 35 motion seeking to compel the plaintiff to undergo HIV testing.<sup>210</sup> One federal court rejected this argument by recognizing that the test would be an “extraordinary measure” and would have little relevance to the lawsuit.<sup>211</sup> The court found the relevance of the results to be so attenuated from the plaintiff’s personal injury cause of action that ordering the test would allow the defendant to engage in a fishing expedition.<sup>212</sup>

In a decision that has produced much contention among legal scholars, a federal court in Pennsylvania reached the opposite result in *Pettyjohn v. Goodyear Tire & Rubber Co.*<sup>213</sup> The plaintiff was a mechanic injured while working on a truck rim.<sup>214</sup> Explaining that the plaintiff placed his life expectancy in controversy by seeking future damages, the court ordered the plaintiff to undergo an HIV blood test, and further ordered him to forego his claims for loss of future wages, loss of earning capacity, and future medical expenses if he did not submit to HIV testing within five days.<sup>215</sup> Without any further explanation, the court ordered the plaintiff to undergo HIV testing.<sup>216</sup>

Extending this rule further, the same district court held in a separate lawsuit that a defendant could discover any medical records related to the plaintiff’s HIV status because plaintiff sought future damages.<sup>217</sup> As in *Pettyjohn*, the defendant wanted the information to more accurately measure the amount of future damages the plaintiff

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merely an aid to assist [the jury] in determining the present value of any future damages determined to be due . . . .’

*See id.* at 884–85 (quoting *Brodie v. Philadelphia Transp. Co.*, 203 A.2d 657, 660 (Pa. 1964)).

208. *See Sacramona*, 152 F.R.D. at 431.

209. *See id.* at 430.

210. *See id.*

211. *See id.* at 431.

212. *See id.*

213. No. 91-CV-2681, 1992 WL 105162, at \*1 (E.D. Pa. 1992).

214. *See id.*

215. *See Pettyjohn*, 1992 WL 105162, at \*1.

216. *See id.*

217. *See Agosto v. Trusswal Sys. Corp.*, 142 F.R.D. 118, 121 (E.D. Pa. 1992).

was entitled to recover.<sup>218</sup> The court reasoned that it would be manifestly unfair to permit a plaintiff to recover for damages for a life span that he may never live out.<sup>219</sup> The court opined that discovering evidence of plaintiff's HIV status was necessary to adequately defend against future damages.<sup>220</sup>

## 2. HIV Testing in Child Custody Cases

In addition to claims for future damages, parties have filed motions to compel HIV testing in child custody cases, arguing that a person's HIV status is an important factor in determining his ability to raise the child.<sup>221</sup> In *Doe v. Roe*,<sup>222</sup> a 1988 case from New York, grandparents of two minor children sought to gain custody from the father.<sup>223</sup> Under New York court rules, a movant must generally show that the plaintiff placed his physical condition in controversy and that the evidence is material and relevant to the action before the court orders a physical examination.<sup>224</sup> With most of the opinion discussing the mechanics of HIV testing and the nature of HIV and AIDS, a New York family law court extended the general requirements for ordering a physical examination in cases of HIV testing by stating that litigants must also prove a compelling need for the test before it is ordered.<sup>225</sup> Realizing the need for more stringent boundaries for HIV testing to protect against the stigmatization associated with AIDS, to prevent the

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218. See *Agosto*, 142 F.R.D. at 120.

219. See *id.* (stating that "basic fairness dictates that Plaintiff should not be allowed to make a potentially large recovery against [Defendant] based on an average life span when, in reality, Plaintiff may well have a shorter than average life expectancy").

220. See *id.* But see *Colella*, *supra* note 205, at 68 (discussing the case of *Herbert v. Amrex-Zetron*, No. C 709912 (L.A. Sup. Ct. filed Dec. 30, 1988), which held that an employer "could not discover the HIV status of a non-party or 'any other aspect of [the non-party's] medical condition which might reveal whether or not [the non-party] is infected with HIV or has or does not have any other symptoms of Acquired Immune Deficiency Syndrome'" (alterations in original)). For an article on setting boundaries for use of HIV information in court, see *Colella*, *supra* note 205, at 45 ("The threshold question in any discovery dispute involving HIV-related information should be whether the information is critical to the requesting party's case.").

221. See *Doe v. Roe*, 526 N.Y.S.2d 718, 726 (Sup. Ct. 1988); see generally *Steven L. v. Dawn J.*, 561 N.Y.S.2d 322, 324 (N.Y. Fam. Ct. 1990) (determining whether HIV status is important to custody issues).

222. 526 N.Y.S.2d 718 (Sup. Ct. 1988).

223. See *id.* at 719–20.

224. See N.Y. C.P.L.R. § 3121(a) (McKinney 1991) ("After commencement of an action in which the mental or physical condition or the blood relationship of a party . . . is in controversy, any party may serve notice on another party to submit to a physical, mental or blood examination by a designated physician.").

225. See *Doe*, 526 N.Y.S.2d at 725.

potential discrimination suffered by people living with AIDS, and to protect the privacy of those living with HIV or AIDS, the court required the party seeking the test to show a compelling need for the test instead of the traditional "good cause" requirement.<sup>226</sup>

### 3. HIV Testing in "Fear of AIDS" Cases

The most difficult type of case that courts face arises when the HIV status of one of the parties is central to the lawsuit. This occurs particularly in "fear of AIDS" cases. A "fear of AIDS" case is one in which a plaintiff sues on the basis of possible exposure to AIDS or HIV by a person who intentionally or negligently exposed the plaintiff to the risk.<sup>227</sup> These cases rarely focus on the actual results of the test. Rather, the focus is on whether the plaintiff can make her case without the test by showing a reasonable fear of infection regardless of actual transmission of the virus. In one Wisconsin case, the plaintiff was a social worker suing a former client who became violent at a hearing.<sup>228</sup> The defendant bit the plaintiff during the altercation and immediately told the plaintiff that she had AIDS.<sup>229</sup> The plaintiff brought a lawsuit claiming assault and battery, including a claim for pain and suffering damages.<sup>230</sup> To prove her damages, both emo-

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226. See *id.* at 726. New York courts have continued to give special protection to the use of HIV information in child custody cases. Even in a case where only HIV medical records were sought, a New York court held that HIV status did not necessarily change a person's ability to raise a child because an individual who is HIV-positive can be quite healthy and remain so for many years. See *Steven L.*, 561 N.Y.S.2d at 326 (recognizing that not all people who are HIV-positive will develop AIDS within a particular time).

227. See, e.g., *Syring v. Tucker*, 498 N.W.2d 370 (Wis. 1993) (discussing how defendant allegedly bit plaintiff and immediately stated that she had AIDS). For a general discussion on AIDS phobia cases, see Wendy Allison Reese, *Tort Law: Actual Exposure or Possible Exposure?: The AIDS Phobia Debate—Are Courts Opening the Litigation Floodgates or Illustrating Judicial Proscription?* 22 AM. J. TRIAL ADVOC. 495, 495 (1998) (stating that presently most jurisdictions are unwilling to allow a plaintiff to recover in AIDS phobia cases absent a showing of actual exposure to the HIV virus); see also *Pendergist v. Pendergrass*, 961 S.W.2d 919, 926 (Mo. Ct. App. 1998) (holding that absent proof of actual exposure to the HIV virus as a result of a defendant's negligent conduct, that is, proof of both a scientifically accepted method, or channel, of transmission and the presence of the HIV virus, the fear of contracting AIDS is unreasonable as a matter of law and, therefore, not a legally compensable injury). But see *Hartwig v. Oregon Trail Eye Clinic*, 580 N.W.2d 86 (Neb. 1998) (representing the minority viewpoint). The Nebraska Supreme Court held that actual exposure to HIV was not necessary and stated that "it is not unreasonable to fear HIV infection or AIDS when one . . . is exposed via a medically sufficient channel of transmission to the tissue, blood, or body fluid of another and it is impossible or impracticable to ascertain whether that tissue, blood, or body fluid is in fact HIV positive." *Id.* at 91.

228. See *Syring*, 498 N.W.2d at 371.

229. See *id.*

230. See *id.*

tional and physical, and out of concern that she may have contracted HIV, the plaintiff asked the court to compel the defendant to undergo HIV testing.<sup>231</sup> The court ordered the test and the defendant refused to comply.<sup>232</sup> The court then ordered the defendant to pay twenty-thousand dollars for mental distress under the presumption that HIV was not transmitted, but based on the fear and anxiety the plaintiff suffered from the possibility that she may have contracted the virus.<sup>233</sup> The plaintiff appealed on the grounds that the lower court should have taken further steps to force the defendant to undergo an HIV test before it awarded a minimal amount of damages.<sup>234</sup> The appellate court agreed and ordered a new hearing on damages after the defendant submitted to an HIV test.<sup>235</sup> In its opinion, the court recognized the privacy concerns associated with making the defendant's HIV status open to the court, but stated that the defendant waived her privacy claim when she yelled out that she had AIDS after biting the plaintiff.<sup>236</sup> Nevertheless, the court applied a more stringent standard and held that the plaintiff demonstrated a compelling need for the test based on the fact that a negative test would eliminate the anxiety and uncertainty that the plaintiff lives with daily.<sup>237</sup>

In *Brown v. New York City Health and Hosp. Corp.*,<sup>238</sup> another fear of AIDS case, defendant requested that the court order the plaintiff to undergo HIV testing to diminish the damages for her AIDS-phobia claim.<sup>239</sup> In this case, a nurse sustained a deep puncture wound to her thumb from a needle that was taken out of a baby who was HIV positive.<sup>240</sup> The court stated that if the plaintiff were actually claiming to have contracted the virus, the court would have ordered the test.<sup>241</sup> If the plaintiff files a lawsuit seeking damages for having contracted AIDS, she "places her HIV status in issue and may not thereafter re-

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231. See *id.* at 372.

232. See *id.*

233. See *id.* at 372-73.

234. See *id.* at 373.

235. See *id.* at 377-78.

236. See *id.* at 378.

237. See *id.* The court failed to realize other means of getting the information, such as ordering the plaintiff to undergo an HIV test six months after the incident. Six months is generally considered the maximum time that HIV antibodies develop if a person is exposed to HIV. *Diagnostics (HIV) New Device Enables Earlier HIV Detection*, AIDS WEEKLY PLUS, Oct. 20, 1997, available in 1997 WL 14714713. A negative result at that time, therefore, would mean that the plaintiff had not contracted HIV. See *id.*

238. 624 N.Y.S.2d 768, 769 (N.Y. Sup. Ct. 1995).

239. See *Brown*, 624 N.Y.S.2d at 769.

240. See *id.* at 770.

241. See *id.* at 771.



fuse to submit to a definitive HIV-antibody test.”<sup>242</sup> The court, however, denied the motion for a blood test of the plaintiff because the case was an AIDS-phobia case, which does not require a showing of actual transmission, only exposure.<sup>243</sup>

## B. HIV Testing and AIDS Policies—Exceptionalists Versus Traditionalists

As illustrated by the above HIV testing cases, courts are less likely to order testing when they make a determination that, because of the stigmatization surrounding the disease, AIDS is different from other diseases. Courts that do order HIV tests, however, are ignoring the concerns expressed by many public health officials who oppose mandatory HIV testing. Although the public health debate does not usually involve court-ordered HIV testing, the arguments are very similar in both contexts. In debating the idea of mandatory HIV testing, public health officials and civil libertarians have had to decide how to treat AIDS while also addressing individual privacy issues. In doing so, they have had to decide to what extent HIV should receive special legal attention. The debate is generally divided between exceptionalists and traditionalists.<sup>244</sup> The discourse involving the special nature of HIV testing highlights the differences between these two groups and their views regarding mandatory HIV testing.

### 1. Exceptionalist View—HIV Is Unique

Policymakers clearly recognized the unique nature of HIV and AIDS during the infancy of the disease.<sup>245</sup> To civil libertarians and gay

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242. *Id.*

243. *See id.* at 769–70.

244. Ronald Bayer discusses how civil libertarians and gay activists have dominated the discourse regarding HIV policy, terming these individuals HIV exceptionalists. *See* Ronald Bayer, Ph.D., *Public Health Policy and the AIDS Epidemic: An End to HIV Exceptionalism?*, 324 *NEW ENG. J. MED.* 1500, 1501 (1991). To see how the HIV policy debate has divided into two groups, see Marcia Angell, *A Dual Approach to the AIDS Epidemic*, 324 *NEW ENG. J. MED.* 1498, 1499 (1991); Scott Burris, *Public Health, “AIDS Exceptionalism” and the Law*, 27 *J. MARSHALL L. REV.* 251, 251–54 (1994); Stephen C. Joseph, M.D., M.P.H., *Premarital AIDS Testing: Public Policy Abandoned at the Altar*, 261 *JAMA* 3456, 3456 (1989).

245. A great deal of the policy regarding HIV was determined in the 1980s and early 1990s when the public was still relatively ignorant as to how HIV is transmitted, what HIV testing will determine, and the types of treatment available to persons infected with HIV. This ignorance added to the fears associated with the disease, inducing a higher level of fear among the public. *See* Jon Van, *Ignorance: Knowledge Gap Thwarts Prevention, Treatment*, *ORANGE COUNTY REC.*, Sept. 17, 1989, at L09 (discussing how significant gaps in scientific understanding are hampering efforts to protect individuals from the virus and to provide those who contract it with useful therapies); *see also* Charles Petit, *S.F. Pupils Get Mixed*

activists, the unique nature of AIDS was readily apparent.<sup>246</sup> AIDS was instantly characterized as this generation's plague, which quickly manifested itself in fear and prejudice.<sup>247</sup> Being HIV-positive has always been equated with being given a "death sentence."<sup>248</sup> Even today, a fear is attached to the disease because it remains incurable, although certain treatments have helped slow the inevitable nature of the disease.<sup>249</sup> As well as being labeled a lethal disease, HIV has usually been associated with homosexuals, intravenous-drug users, or those with high-risk sex lives.<sup>250</sup> As a result, those with HIV are often isolated and subjected to disparate treatment.<sup>251</sup> Since the discovery of HIV, people with AIDS have been denied medical treatment, denied access to schools, fired from their jobs and denied health insurance.<sup>252</sup>

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*Marks in AIDS Survey*, S.F. CHRON., Jan. 2, 1987, at 7 (reporting that most San Francisco high school students in 1987 knew that AIDS is contracted mainly from sex, but an alarmingly high proportion did not know much about avoiding it).

246. See Peter H. Berge, *Setting Limits on Involuntary HIV Antibody Testing Under Rule 35 and State Independent Medical Examination Statutes*, 44 FLA. L. REV. 767, 777-78 (1992).

247. See *id.* at 778.

248. *Id.* at 779.

249. See Henry L. Davis, *Many Living Longer with AIDS Face Challenges*, BUFFALO NEWS, Apr. 17, 1998, at A1 (discussing how attitudes of people with HIV are changing now that infected individuals are living longer with the development of successful drug treatments, such as protease inhibitors). Instead of making plans to die, infected individuals are worrying about what to do with the rest of their lives. The article reports that in a Buffalo-area survey, a majority of infected individuals said that they want to go back to work. See *id.* A change in attitude could be gauged by the dozens of people who packed a recent seminar that offered employment advice to the HIV-infected. See *id.* See also Sandra Mathers, *AIDS Treatment Center Marks 10 Years of Radical Change in Public Attitudes*, ORLANDO SENTINEL, Feb. 5, 1998, at 11 (discussing how attitudes of individuals infected by AIDS or HIV in central Florida have changed, but noting that infected people still need support centers because they are living longer thanks to a new generation of more effective AIDS drugs). Many of those who are now finding out that they are infected are deciding to keep their jobs, while a number of infected individuals, extremely ill for years, now are stable and thinking of going back to work. See *id.* See generally Lynda Richardson, *Wave of New AIDS Laws Seeks to Protect Public; Focus Shifts as Attitudes About Disease Change*, CINCINNATI ENQUIRER, Sept. 27, 1998, at A18 (discussing how public perception of AIDS and HIV has changed because new AIDS drugs have transformed what was seen as a fatal disease into a chronic condition for many people, making early testing and treatment more important).

250. See Tracy E. Hopkins, *AIDS: The Professional Killer*, BLACK PROFESSIONAL, Fall 1994, at 34, available in 1994 WL 14531057; Robert J. Paul & James B. Townsend, *AIDS in the Workplace: Balancing Employer and Employee Rights*, 18 REV. BUS. 9 (1997), available in 1999 WL 18073947.

251. See Hopkins, *supra* note 250, at 34; Paul & Townsend, *supra* note 250, at 9.

252. See Cheryl Frank, *AIDS Victims Are Wary of Discrimination*, A.B.A. J., Nov. 1985, at 19 (stating that paramedics refused to give aid to a heart attack victim when they thought, wrongly, that he had AIDS); *Municipal Hospital in Bronx Fined on Care of AIDS Victim*, N.Y. TIMES, Jan. 16, 1986, at B10 (reporting that a hospital was fined for refusing to give adequate care to a man with AIDS); see also *Leckelt v. Board of Comm'rs*, 909 F.2d 820 (5th Cir. 1990) (allowing a nurse to be discharged for not disclosing HIV test results); *Doe v.*

Because AIDS has often been associated with homosexuality, it produces a fear in people who are HIV positive that they will also suffer from discrimination based on the assumption that they are homosexual.<sup>253</sup> Many homosexuals have also been afraid of being tested, not only out of fear of dying, but also out of the fear of being outed. In an effort to encourage people to get tested, to quell the rapid growth of the disease, and to alleviate the fears associated with AIDS, states have enacted statutes mandating that testing be anonymous and voluntary and that the results remain confidential.<sup>254</sup> However, even with the general acceptance of the premise that HIV is unique and that HIV testing should be voluntary, courts have still compelled HIV

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Ball, 725 F. Supp. 1210 (M.D. Fla. 1988), *aff'd sub nom.*, Doe v. Garrett, 903 F.2d 1455 (11th Cir. 1989), *cert. denied*, 499 U.S. 904 (1991) (allowing a member of the Naval Reserve to be released because of a positive HIV test); Ray v. School Dist., 666 F. Supp. 1524 (M.D. Fla.1987) (seeking a preliminary injunction to prevent a school from segregating three hemophiliac school children who tested positive for HIV); White v. Western Sch. Corp., No. IP-85-1192-C (S.D. Ind. Aug. 23, 1985) (LEXIS, Genfed Library, Dist. File) (holding that a child with HIV must exhaust all administrative remedies prior to seeking a preliminary injunction to prevent the school from segregating the child); Aviles v. United States, 696 F. Supp. 217 (E.D. La.1988) (compelling a member of the Coast Guard to retire because of a positive HIV test result); District 27 Community Sch. Bd. v. Board of Educ., 502 N.Y.S.2d 325 (Sup. Ct. 1986) (holding that education officials and health commissioners were not required by law to exclude children with AIDS from the classroom); Doe v. Rice, 769 F. Supp. 440 (D.P.R.1991) (requesting evidentiary hearing to determine whether a member of the National Guard to be discharged after testing positive for HIV); Sierra Perez v. United States, 779 F. Supp. 637 (D.P.R.1991) (allowing a hospital employee to be discharged after testing positive for HIV); Plowman v. United States Dep't of Army, 698 F. Supp. 627 (E.D. Va. 1988) (allowing a civilian musician employed by the Army to be dismissed after testing positive for HIV); Faye A. Silas, *Is School for All?*, A.B.A. J., Nov. 1985, at 18 (discussing the case of Ryan White who was not allowed to attend school because he had AIDS); Pamela Washington-Carter, Comment, *AIDS and Disability-Based Discrimination in Employer-Provided Health Insurance: The ADA Imposes Liability for Broken Promises*, 20 S.U. L. REV. 457, 457-58 (1993).

253. See Angell, *supra* note 244, at 1498; see generally Burris, *supra* note 244, at 264 (discussing AIDS fear and discrimination).

254. See, e.g., Tracy Jackson Smith, *AIDS and the Law: Protecting the HIV-Infected Employee from Discrimination*, 57 Tenn. L. Rev. 539 (1990) (arguing for laws that protect the confidentiality of HIV information in order to protect against discrimination); Frederick T. Smith, *AIDS-Based Employment Discrimination in the American and Canadian Workplace*, 10 COMP. LAB. L.J. 531, 545 (1989) (discussing state laws which protect individuals infected by HIV and AIDS).

HIV-infected persons in the United States may be protected by state statutes modeled after the Federal Rehabilitation Act, which prohibit discrimination against the handicapped. All fifty states and the District of Columbia have either statutes or executive orders which ban discrimination in the workplace based on an individual's physical handicap or disability. Unlike the federal act, most state statutes cover all employers, public or private, with more than a certain minimum number of employees.

*Id.*

testing. Only those courts that have recognized the unique consequences of HIV testing have been less inclined to order it.

## 2. Traditionalist's View—HIV Is No Different from Other Communicative Diseases

Arguing against this special treatment of HIV and HIV testing, Ronald Bayer, a leading public health commentator, began to question the need for granting HIV this exceptional status. In discussing how the exceptional treatment afforded HIV will wane as treatments become more successful,<sup>255</sup> Bayer is one of the first to characterize the participants in the debate as exceptionalist or traditionalist.<sup>256</sup> Exceptionalists are those who advocate for the special treatment of HIV and HIV testing,<sup>257</sup> while traditionalists believe that HIV should be treated like all other lethal and communicative diseases.<sup>258</sup>

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255. See Bayer, *supra* note 244, at 1503.

256. See *id.* at 1501.

257. The universally accepted manner in controlling the disease included voluntary, anonymous testing that was to remain confidential. See *Anonymous Tests Lead to Earlier AIDS Treatment; CDC Studies Results Before and After States Required Names*, BALTIMORE SUN, OCT. 28, 1998, at 8A; Dorine Bethea, *Early Test for HIV is Key to Control*, RICHMOND TIMES-DISPATCH, June 25, 1999, at B1; Jeffrey Levi, Ph.D. et al., *Anonymous HIV Testing and Medical Care*, JAMA, June 23, 1999, at 2282; *Testing (HIV) Confidential vs. Anonymous Testing May Make a Difference*, AIDS WKLY. PLUS, Nov. 9, 1998.

258. See Bayer, *supra* note 244, at 1503. Bayer continuously makes pointed references to the "well-organized gay community," seeming to imply that the traditional practices of public health were implemented solely because of the strong lobby of gay activists:

In the first years of the AIDS epidemic, U.S. officials had no alternative but to negotiate the course of AIDS policy with representatives of a well-organized gay community and their allies in the medical and political establishments. In this process, many of the traditional practices of public health that might have been brought to bear were dismissed as inappropriate. As the first decade of the epidemic came to an end, public health officials began to reassert their professional dominance over the policy-making process and in so doing began to rediscover the relevance of their own professional traditions to the control of AIDS.

*Id.* at 1502. Bayer's article summarily dismisses the reasons for the special treatment given to AIDS. See *id.* at 1501-04. By doing so, he inappropriately underestimates the potential stigma and discrimination suffered by HIV-positive people (most of whom are gay), the argument that was the cornerstone of the "exceptionalist" policy. During the 1980s, and even today, gay men suffer discrimination and are often the subject of hate crimes. Recent reports show that AIDS discrimination has continued to be a problem. See Lisa Van Proyen, *Study Reveals Discrimination Against Area People with HIV*, L.A. DAILY NEWS, Sept. 18, 1998, at N11 (reporting that discrimination is still very much an issue for those seeking employment in the Los Angeles area). The study analyzed employment issues for Los Angeles residents living with HIV and AIDS. See *id.* "The survey was mailed to 5,685 people with HIV or AIDS who are case-managed by Los Angeles-area AIDS service organizations. . . . About 67% of those not working said they are unemployed or disabled, with a majority reporting that they are thinking about returning to the work force to increase their income and feel useful to society. While the law states that no HIV-infected person can be denied employ-

In developing policies with sometimes conflicting interests, the debate has often centered on the mechanics of HIV testing: rules protecting anonymity, voluntariness, and confidentiality. Some medical and public health officials have advocated that AIDS should be treated as all communicable diseases are treated: documenting test results, notifying the sex partners of those infected, reporting the names of HIV infected individuals, and criminalizing the knowing transmission of the disease.<sup>259</sup> They argue that these steps were effectively used in treating past diseases and are now necessary to slow the spread of HIV, whereas additional protections would allow the disease to grow at a rapid pace.<sup>260</sup>

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ment because of the disease, many fear that they will lose their current health insurance . . . and will not obtain adequate insurance from a new employer." *Id.* Los Angeles mayor Richard Riordan vowed to encourage health insurers to cover all employees, including those with AIDS. *See id.* "Their medications alone can cost \$12,000 to \$16,000 a year." *Id.* *See also AIDS; Patient Discrimination Becoming a Global Problem*, DAYTON DAILY NEWS, July 3, 1998, at 16A. The article reported that the World AIDS Congress conducted a study which revealed that:

Many HIV-positive people face bias throughout the world, including denial of the right to marry, refusal of medication and other treatment and job discrimination. . . . [F]ear of being branded an outcast keeps many from litigating and also stops some from getting tested, helping fuel the spread of the virus. . . . In a study of 100 [individuals] who complained of HIV discrimination in Mexico, only 21 went to court. . . .

*Id.*

Because this discrimination is still present, privacy concerns should remain a major part of the debate surrounding AIDS. However, the change from AIDS being a "life sentence" to a manageable disease, because of the more effective treatments available, should also factor into the debate. The availability of treatments will likely change the policy surrounding HIV testing, but the public's continued misperception of AIDS should play a factor in shaping this debate as well. *See Richardson, supra* note 249, at A18. The article reported that

[f]ifty-five percent of Americans believed in 1997 that they could become infected by sharing a drinking glass with an infected person, compared with 48 percent in 1991, according to [a] survey by researchers at the University of California at Davis. Forty-one percent believed that AIDS might be contracted from a public toilet, compared with 34 percent in 1991.

*Id.* According to Dr. Gregory Herek, a social psychologist, "such erosion in knowledge about HIV may reflect the fact that recent public health campaigns have not emphasized that the disease is transmitted through sexual contact, tainted hypodermic needles or blood." *Id.*

259. *See Bayer, supra* note 244, at 1501-02; Chandler Burr, *The AIDS Exception: Privacy vs. Public Health*, ATLANTIC MONTHLY, June 1997, at 57, 57-58. *But see* Gabriel Rotello, Editorial, *AIDS Is Still an Exceptional Disease*, N.Y. TIMES, Aug. 22, 1997, at A23 (advocating that a move away from AIDS exceptionalism "should proceed with caution, and with a healthy sense of what we still don't know, and what we need to find out").

260. *See Bayer, supra* note 244, at 1501-03.

### C. The Implications of HIV Testing and AIDS Policies for Genetic Testing Under Rule 35

The categorization of the public health debate as exceptionalists versus traditionalists has also encompassed discussions surrounding genetic testing. "Genetic exceptionalists," those who advocate for the special treatment of genetic information, believe that genetic information is uniquely private information and more personal than even a person's HIV status.<sup>261</sup> Thomas Murray, the first to use the term "genetic exceptionalism," claims that the drafters of the GPA<sup>262</sup> are the leaders in the exceptionalist camp.<sup>263</sup> He bases his claim on the substance of the GPA, which is designed to protect the confidentiality and personal nature of genetic information by limiting the use of the information, protecting against genetic discrimination, limiting the use of DNA databases, and setting forth stringent rules regarding the collection, analysis and storage of DNA and genetic information.<sup>264</sup>

#### 1. Genetic Exceptionalists—Genetic Information Is Unique

In claiming that genetic information is unique, the drafters of the GPA found information contained in DNA to be highly personal and distinct for a number of reasons. These reasons include the fact that genetic information can sometimes predict a person's likelihood of developing a disease and that genetic tests divulge information about a person's parents, siblings, and children.<sup>265</sup> Because genes are inherited, a positive result from a genetic test will likely give information about the medical condition of the person's family.<sup>266</sup> Another important distinction advanced by genetic exceptionalists is that genetic information may be used to discriminate against a person in the areas of employment and insurance.<sup>267</sup>

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261. See Mark A. Rothstein, *Discrimination Based on Genetic Information*, 33 JURIMETRICS J. 13, 13–18 (1992) [hereinafter Rothstein, *Discrimination Based on Genetic Information*]; Thomas H. Murray, *Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?*, in GENETIC SECRETS, PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 60, 60–62 (1997).

262. See Murray, *supra* note 261, at 61. The model Genetic Privacy Act was introduced in Congress, hearings were held, but no action was taken. See S. RES. 89, 105th Cong. § 9811 (1997); H.R. RES. 306, 105th Cong. § 713 (1997); S. RES. 1045, 105th Cong. (1997); S. RES. 1694, 104th Cong. § 2 (1996); H.R. RES 2748, 104th Cong. (1995).

263. See Murray, *supra* note 261, at 61.

264. See *id.* at 60–62.

265. See Annas et al., *Drafting the Genetic Privacy Act*, *supra* note 103, at 360.

266. See *id.*

267. See Meredith A. Jagutis, *Insurer's Access to Genetic Information: The Call for Comprehensive Federal Legislation*, 82 MARQ. L. REV. 429, 435 (1999); Melinda B. Kaufmann, *Genetic*

Along with the drafters of the GPA, other public health officials and civil libertarians have argued for the exceptional treatment of genetic information in debating the level of legal protections needed to guard against genetic discrimination and in discussing ways to research genetic information without violating individual privacy.<sup>268</sup> These genetic exceptionalists, agreeing with the GPA's drafters, have argued against mandatory genetic testing. Instead, they have advocated for voluntary genetic testing only after the individual has been fully informed of the nature of the tests and the informational risks associated with the results.<sup>269</sup>

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*Discrimination in the Workplace: An Overview of Existing Protections*, 30 *LOV. U. CHI. L.J.* 393, 393 (1999); Rothstein, *Discrimination Based on Genetic Information*, *supra* note 261, at 13.

268. See Kaufmann, *supra* note 267 (arguing that genetic information deserves more protection than other forms of medical information because it is uniquely personal). According to Kaufmann:

The information available through our genes, including the potential to unlock secrets unknown even to the individual, highlights the unique nature of genetic information. In addition, genetic information carries implications not only for the individual but also for his or her family. History, therefore, should be a guide to determine the scope of privacy applicable to genetic information. Specifically, the release of genetic information conjures up the specters of social stigma, employment and insurance discrimination, and ultimately creates a genetic underclass.

*Id.* at 430; see also Lori B. Andrews & Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 *AM. J.L. & MED.* 75, 77 (1991) (arguing that "genetic information is particularly sensitive because genetic screening and monitoring reveal much more personal information about the individual than other types of medical surveillance used by employers"); Elizabeth B. Cooper, *Testing for Genetic Traits: The Need for a New Legal Doctrine of Informed Consent*, 58 *MD. L. REV.* 346, 362-64 (1999):

Although scientific breakthroughs make testing a viable option for some individuals at risk for genetically linked disease, the indeterminate nature of test results combined with various concerns—about lack of disease-appropriate treatment, or access thereto; potential psychological harm to the person being tested; ramifications for other family members; possible breaches of privacy; and the risk of discrimination based on positive results—must be considered by clinicians who plan to offer genetic testing.

*Id.* at 363-64. See also Lawrence O. Gostin, *Genetic Privacy*, 23 *J.L. MED. & ETHICS* 320, 324-26 (1995) (arguing that an individual's genetic information may have far-reaching implications for those in the same racial or ethnic group) [hereinafter Gostin, *Genetic Privacy*]; Gostin, *Health Information Privacy*, *supra* note 200, at 491 (stating that "[t]he current and likely future proliferation of genetic databases means that holders of these genomic data will possess vast amounts of information" and that "[g]enetic information does not simply reveal important health and personal characteristics of individuals, but also provides important biological facts about their parents, siblings, and children"); Mark A. Rothstein, *Should Genetic Information Be Used to Predict Life Expectancy of Plaintiffs in Tort Cases?* 34 *HOUS. LAW.* 49, 50-51 (Oct. 1996) (arguing that genetic information should be subject to greater protection than other kinds of medical information).

269. See Cooper, *supra* note 268, at 419.

## 2. Genetic Traditionalists—Genetic Information Is No Different from Other Medical Information

Not until the last few years have people argued against special protections for genetic information. These genetic traditionalists have begun to question the need for additional protections against discrimination, believing that discrimination based on a genetic disorder would be covered by the Americans with Disabilities Act (“ADA”), a position held by the Equal Employment Opportunity Commission (“EEOC”).<sup>270</sup> Other traditionalists believe that genetic information is no different than other medical information.<sup>271</sup> Those who do not see any real difference between “regular” medical information and genetic information either believe that medical privacy laws already adequately cover genetic information,<sup>272</sup> or they believe that the whole genetic privacy debate is just a symptom of the inadequacies of the current state of medical privacy laws, and that policymakers should not limit their focus to genetic privacy laws.<sup>273</sup>

### a. Genetic Information: No More Predictive of Future Diseases Than Other Medical Information

In Murray’s article *Genetic Exceptionalism and Future Diaries*, he attempts to show that the GPA’s drafters are incorrect in declaring that genetics is “so uniquely powerful and uniquely personal” that it

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270. See Equal Employment Opportunity Comm’n, 2 EEOC COMPLIANCE MANUAL § 902.8, at 902–45 (1995) (the definition of the term “disability” provides that an individual who is subject to discrimination based on genetic predisposition is regarded as an individual with a disability and thus covered under the ADA). In March of 1995, the EEOC issued regulations clarifying the definition of “disability” under the ADA. The EEOC regulations prohibit an employer from discriminating against a worker on the basis of his genetic make-up. See *id.* The provision extends coverage to include “individuals who are subject to discrimination on the basis of genetic information relating to illness, disease, or other disorders.” *Id.*

271. See Murray, *supra* note 261, at 61.

272. See *id.* at 61–62; Robert Wachbroit, *The Question Not Asked: The Challenge of Pleiotropic Genetic Tests*, 8 KENNEDY INST. ETHICS J. 131, 140 (1998) (“[T]o insist that counseling should be routinely provided whenever the medical test is genetic leads to a mystique surrounding the idea of genes that encourages misunderstandings about what genes are and distorts their significance.”).

273. See Angela Liang, *The Argument Against A Physician’s Duty to Warn for Genetic Diseases: The Conflicts Created by Safer v. Estate of Pack*, 1 J. HEALTH CARE L. & POL’Y 437, 441 (1998) (discussing a physician’s conflicting duties under New Jersey law between confidentiality and warning a patient’s family members about the patient’s genetically-transferable condition); Paul A. Lombardo, *Genetic Confidentiality: What’s the Big Secret?*, 3 U. CHI. L. SCH. ROUNDTABLE 589 (1996) (arguing that genetic confidentiality law is not the cure to the health care access crisis).



should be distinguished from other medical information.<sup>274</sup> He attacks each of the arguments put forth by the privacy advocates and decries the plea to treat genetic information differently as an “overly dramatic view of the significance of genetic information in our lives”:<sup>275</sup>

It implies that the contents of that future diary reflect what is most intimate, central, and important about us—that it reveals, in some fundamental way, our social and personal identity, our loves and interests, and our actions. In fact, our genomes have little or nothing to say about any of these crucial matters.<sup>276</sup>

In making his argument that genetic information is not distinctive enough to warrant special treatment, Murray sees no difference in the ability of genetic information to be more predictive in mapping a person’s future health than other medical information.<sup>277</sup> For instance, information about one’s cholesterol level or a chronic hepatitis B infection are often hidden but are no less predictive of a person’s future health than genetic information, and these risks have not been given special protection.<sup>278</sup> They are only medical facts that are covered by existing medical privacy laws.<sup>279</sup>

#### **b. Genetic Information: No More Traumatic than Other Medical Information**

The argument that a person’s family is affected by the information is also not distinctive according to Murray.<sup>280</sup> He compares genetic information to knowledge that a member of a family suffers from heart disease or tuberculosis.<sup>281</sup> The fact that a family member has tuberculosis is of special importance to the family because they could easily be infected with tuberculosis, and the family of a heart patient has an interest in the information to better prepare for the individual’s death or disability.<sup>282</sup> The stress associated with informing family members about difficult medical information may be no different where it is genetically related.<sup>283</sup>

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274. Murray, *supra* note 261, at 62.

275. *Id.* at 71.

276. *Id.* at 67.

277. *See id.* at 64.

278. *See id.* at 64–65.

279. *See id.*

280. *See id.* at 65.

281. *See id.*

282. *See id.*

283. *See id.*

### c. Genetic Information: Not Unique in Leading to Discrimination

In terms of discrimination, Murray believes that genetic information is not unique.<sup>284</sup> Institutions and individuals have used all kinds of information that can lead to discrimination.<sup>285</sup> Insurance companies constantly assess an individual's risk for future health threats by examining family history and past medical problems<sup>286</sup>—insurance is often denied on that basis.<sup>287</sup> Genetic information is not exceptional in that regard. Murray states that it is not reasonable to allow an insurance company to discriminate on the basis of a current health condition that is not genetically related and then to carve out an exception for genetic discrimination.<sup>288</sup> Practically, this would be very difficult anyway. Many genetic diseases may be affected by environmental factors, so it is difficult to distinguish between a disease that is genetic and one that is non-genetic.<sup>289</sup> For example, if a person is a heavy smoker and also has a genetic predisposition to cancer, should an insurance company be prohibited from denying coverage because a link to cancer is probably going to be genetically related but it could also be caused by the heavy use of cigarettes? Where should the line be drawn? Huntington's Disease is a purely genetic disease.<sup>290</sup> Getting hit by a bus is purely non-genetic. Those are easy examples, but a problem occurs for conditions like heart disease that sometimes are partially caused by a person's genes and partially caused by other environmental factors.<sup>291</sup> Cholesterol is a risk factor and can be con-

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284. See *id.* at 65–66.

285. See *id.*

286. See *id.*

287. See *id.*; see also Gary Schuman, *Health and Life Insurance Applications: Their Role in the Claims Review Process*, 62 DEF. COUNS. J. 225, 225 (1995). Schuman notes:

[I]nsurance companies are permitted to select their risks and to restrict or even deny coverage for life and health insurance to individuals when, in the opinion of the insurer, restriction is necessitated by the applicant's medical condition or personal history. The goal is not equal treatment of policyholders, but equitable treatment based on the risk that applicants represent to the insurer. Insurance, by its very nature, is recognized as being 'discriminatory.'

*Id.* at 225 (citing *Imperial Casualty & Indem. Co. v. Sogomonian*, 243 Cal. Rptr. 639, 645 (1988) (holding that the insured's failure to disclose earth movement and subsidence amounted to material fraud thus giving the insurer a right to rescind the homeowner's policy) and *Robinson v. Occidental Life Ins. Co.*, 281 P.2d 39, 42 (Cal. App. 1955) (examining the insurer's right to reject a claim or rescind a policy because of the decedent's false representations on his life insurance application)).

288. See Murray, *supra* note 261, at 65.

289. See *supra* Part II.A (discussing how both genetic and environmental factors can contribute to the onset of certain diseases and disorders).

290. See *supra* Part II.B.1.

291. See Murray, *supra* note 261, at 67–68.

trolled, but our genes have as much to do with heart problems as do other factors, making labeling almost impossible.<sup>292</sup>

Murray finds the fact that a person's genetic composition is something that they cannot control to be irrelevant: "If we are less inclined to worry about discrimination on the basis of health risk factors that are open to modification and individual choice, then let us recognize *that* as the relevant difference, and not confuse it with the distinction between genetic and non-genetic factors."<sup>293</sup> Murray also argues that providing a person with health care should not hinge on whether a disease is based on genetic or non-genetic factors because it is most likely that the need for health care is a product of both factors.<sup>294</sup> As one of these factors is not controllable, the distinction between non-genetic and genetic factors is not important.<sup>295</sup>

#### d. **Mystique of Genetic Information**

Murray concludes that we only consider genetic information special because of a certain mystery associated with it.<sup>296</sup> Others have agreed with this assessment. The book *The DNA Mystique: The Gene as a Cultural Icon*<sup>297</sup> explains how genes have become a cultural phenomenon.<sup>298</sup> The glorified use of genetics in movies, television shows, and science fiction stories that highlight the scary possibility of eugenics and genetic cleansing and show the extremes of genetic determinism have greatly exaggerated the relevance and importance of genetics to society.<sup>299</sup>

#### D. **A Proposal: Testing Policy Should Be Based on the Characteristics That Make Each Disease Unique**

Using the categories detailed by Bayer and Murray in the medical exceptionalism debate, however, gives little guidance on the proper methods of dealing with diseases and their corresponding tests. In the HIV testing and genetic testing areas, courts and policymakers should

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292. *See id.* at 68.

293. *Id.* at 66.

294. *See id.* at 69.

295. *See id.*

296. *See id.* at 71.

297. DOROTHY NELKIN & SUSAN LINDEE, *THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON* (1995).

298. *See id.* at 198-99.

299. *See id.* at 198-99; *see also* MARK H. HALLER, *EUGENICS: HEREDITARIAN ATTITUDES IN AMERICAN THOUGHT* 77-78 (1963); KENNETH M. LUDMERER, *GENETICS AND AMERICAN SOCIETY: A HISTORICAL APPRAISAL* 2 (1972); *The Road to Eugenics*, 3 U. CHI. L. SCH. ROUNDTABLE 491, 493 (1996).

not have to first go through the cognitive step of determining whether or not something is exceptional before mandating a test. A more pragmatic approach is to accept that each disease has some unique qualities that separate it from other diseases, and that its corresponding test will produce different types of information. For example, a positive result for an HIV test means something quite different than a positive test for tuberculosis. Both are infectious diseases, but the transmission and subsequent treatments are quite different. The results, therefore, send a completely different message to the individual—unlike a positive tuberculosis test, a positive HIV test may be considered a death sentence.<sup>300</sup> Because these tests send different messages, they are likely to cause different social and psychological harms. As a result, decisions regarding the testing for diseases should focus on these variances.

Treating every disease and its corresponding test as unique has also been advocated in the HIV context.<sup>301</sup> Scott Burris argues in his article on HIV exceptionalism that HIV has not been treated differently from other comparable health threats.<sup>302</sup> Rather, all feared diseases rightfully get their own unique response.<sup>303</sup> Burris argues that relying on a single set of public health policies is not warranted.<sup>304</sup> Burris found the public health's treatment of HIV over the past fifteen to twenty years to be an appropriate balance between managing the disease and dealing with the fears associated with it.<sup>305</sup> The approach advocated by traditionalists, where all communicative or lethal diseases get the same treatment, lacks a social commitment to protecting people with the disease. The traditionalists do not understand how people respond to epidemics, thereby hurting the public's health and infringe civil rights.<sup>306</sup>

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300. See Mark Taylor, *TB Outbreak Fallout: ER Doc Who Contracted Disease Sues Hospital for Lack of Warning, Precautions*, MOD. HEALTHCARE, May 10, 1999, at 40, 42, available in 1999 WL8771423 (discussing how TB is a curable disease). According to a CDC public health advisor, "We [the CDC] don't expect anyone to die of TB. So when a death does occur, it's abnormal." *Id.* See also *Acute HIV Syndrome*, 60 AM. FAM. PHYSICIAN, Aug. 1, 1999, available in 1999 WL 24104710 (discussing how there is still no cure for the HIV virus).

301. See Burris, *supra* note 244, at 251.

302. See *id.* at 272.

303. See *id.* at 261–62.

304. See *id.* at 272.

305. See *id.* at 254–64.

306. See *id.* at 271.

#### IV. An "Examination of the Examination" Approach to Rule 35

Examining the specific characteristics of each disease in developing public health policies also has value to courts in deciding whether to order a genetic test under Rule 35. With new tests for certain lethal diseases and genetic testing becoming more commonplace, the current fact-based approach to Rule 35, where the court's main focus is on the "in controversy" and "good cause" requirements, is outdated. Given that genetic testing may reveal traumatic information or be interpreted in several ways, genetic tests are significantly different than the traditional physical and psychological examinations contemplated by Rule 35.

Some courts have held that a party's request for a Rule 35 examination forces courts to balance the rights of civil litigants to discover relevant facts against the privacy interests of persons subject to discovery.<sup>307</sup> By adding this balancing test to the "in controversy" and "good cause" requirements of Rule 35, these courts have accepted the proposition that certain examinations are so intrusive that they should not be ordered.

With the changing uses of Rule 35 to include tests for a wide range of diseases, many of which are lethal and untreatable, courts need to continue their fact-based analyses of the "in controversy" and "good cause" requirements. However, they should extend this to include a thorough "examination of the examination," where the focus is on the mechanics of the procedure, what information the test will produce, and the potential consequences of obtaining those results. An "examination of the examination" analysis, therefore, requires courts to focus on: (1) the informational risks associated with the test, and (2) the actual value of the test for the purposes sought. This totality of the circumstances approach does not limit courts to a simple analysis of the "in controversy" and "good cause" requirements. Rather, it requires courts to evaluate the impact of the order on the person subject to the examination, as well as on third parties and society in general.

##### A. Informational Risks

The "examination of the examination" approach to Rule 35 first requires an assessment of the informational risks associated with the

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307. See *Crowe v. Nivison*, 145 F.R.D. 657, 658 (D.C. Md. 1993); *Lowe v. Philadelphia Newspapers, Inc.*, 101 F.R.D. 296, 298 (E.D. Pa. 1983).

procedure.<sup>308</sup> The risks usually associated with medical procedures involve risks to the human body through surgery or medicine. The primary risk posed by a genetic test, however, is the actual information produced by the test.<sup>309</sup> This informational risk manifests itself in several ways, including “anxiety, distress, and other psychological harms to subjects who learn that they carry genes that may predispose them to serious medical problems.”<sup>310</sup> These risks become even more prevalent when the genetic information reveals a disease or disorder that is incurable or untreatable. Without an analysis of the informational risks, courts fail to fully understand the depth of intrusiveness caused by the Rule 35 examination.

Analyzing the informational risks associated with the test requires a close examination of the potential impact that the information garnered from the test could have on the individual being tested. The impact may be psychological trauma to the individual tested, as well as a violation of privacy through disclosure of the results to sources outside of the litigation.

Aside from genetic testing, the most poignant example of informational risks can be seen in HIV testing. The information produced by an HIV test can cause severe psychological trauma to the person tested, and it can have a detrimental effect if the HIV-positive status is disclosed to others. Among the detrimental effects that the tested person may experience are: discrimination in employment, schooling, and insurance;<sup>311</sup> severe stigmatization by society;<sup>312</sup> and fears of being classified as a homosexual, drug user, or sexual deviant.<sup>313</sup> Similar

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308. The term “informational risks” was first detailed in Ronald Green & A. Mathew Thomas, *DNA: Five Distinguishing Features for Policy Analysis*, 11 HARV. J.L. & TECH. 571, 572 (1998).

309. *See id.*

310. *Id.*

311. *See* Jagutis, *supra* note 267, at 433; Kaufmann, *supra* note 267, at 400–04; Rothstein, *Discrimination Based on Genetic Information*, *supra* note 261, at 14–16; Washington-Carter, *supra* note 252, at 457–58.

312. *See* Paul R. Billings, M.D. et al., *Discrimination as a Consequence of Genetic Screening*, 50 AM. J. HUM. GENETICS 476–82 (describing anecdotal evidence of discrimination against individuals based on “apparent or perceived” genetic abnormalities); Karen L. Chadwick, *Fear of AIDS: The Catalyst for Expanding Judicial Recognition of a Duty to Prevent Emotional Distress Beyond Traditional Bounds*, 25 N.M. L. REV. 143, 159 (1995).

313. *See* Eric J. Knapp, *Tort Law—Turning Blood into Whine: “Fear of Aids” as a Cognizable Cause of Action in New Mexico—Madrid v. Lincoln County Med. Ctr.*, 28 N.M. L. REV. 165, 188 (1998). The author states:

Anxiety arising from the possibility of contracting HIV and developing AIDS generally reflects public misperceptions, misinformation, and ignorance about the disease. Furthermore, ignorance about HIV and AIDS promotes hysteria and irrational fears, as well as prejudice, stigmatization and discrimination against those

informational risks occur with genetic tests for lethal diseases, including: the potential to unlock secrets that are currently unknown about the person; the unique quality of the information enabling certain identification of the individual; the stability of DNA rendering distant future applications possible; the ability to generalize the data to families, genetically related communities, and ethnic and racial populations.<sup>314</sup>

Informational risks may also impact third parties. Just as a positive HIV test result can have implications for the individual's sex partner, a genetic test result may impact the individual's family. The very idea of genetic information implies inheritance, so a genetic test result often gives information about the family of the individual tested, many of whom would not otherwise be affected by the lawsuit. Further, genetic test results can impact society by stigmatizing a certain racial or ethnic group based upon a common genetic characteristic attributable only to that group.

### 1. Risks to the Individual Tested: Impact of Learning the Results

The most extreme example of an informational risk involves the discovery of a lethal disease. The effect the results have on the individual depends on the kind of information the test produces. A positive test result for an incurable and untreatable disease is going to affect the individual differently than a positive result for a disease that can be easily treated with medication. One of the informational risks feared from forcing a person to undergo an HIV test is the impact that the results will have on the person being tested. Individuals who have tested positive for HIV have suffered severe emotional trauma, sometimes attempting suicide.<sup>315</sup> However, as HIV and AIDS have become more treatable and have allowed people to live longer lives, the psychological effects have become somewhat less traumatic.<sup>316</sup>

#### a. Risks of Discovering an Untreatable Disease

Depending on the level of trauma likely to be produced by a court-ordered genetic test, the informational risks will vary widely according to the treatments available, the severity of the symptoms, the

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infected with HIV. For example, most people still believe that HIV can be transmitted through casual contact, [and] that AIDS remains primarily a 'gay disease.'

*Id.*

314. See Gostin, *Genetic Privacy*, *supra* note 268, at 320–28.

315. See Chadwick, *supra* note 312, at 159.

316. See *supra* note 245 and accompanying text.

prognosis for the disease, and the mathematical probability of getting the disease. In arguing that genetic information is less than extraordinary, traditionalists fail to recognize one key piece of the puzzle—many people refuse to take a genetic test for fear that they may learn that they have a disease which they cannot control, treat, or cure, a view they likely will not change just because they filed a lawsuit. For example, before the test for HD became available, a majority of people at risk said that they would take the test.<sup>317</sup> However, currently only ten to fifteen percent of those at risk choose to be tested.<sup>318</sup> The five reasons cited by researchers who have studied the low numbers of test-takers include “(1) if the results were adverse, the risk of developing [HD] for existing children would increase, (2) the absence of an effective cure, (3) potential loss of health insurance, (4) financial costs of testing, and (5) inability to ‘undo’ the knowledge.”<sup>319</sup> Because there is no cure for HD, people opted not to take the test for fear of suffering these negative consequences. People choose not to take genetic tests for several reasons, but mostly because of the informational risks associated with the tests, such as the potential for stigmatization and discrimination, the fear that they may not be able to obtain health or life insurance, the stress of having to possibly disclose negative information to family members, and the basic fear and anxiety associated with dying.<sup>320</sup> Also, knowing whether one is a carrier of a disease adds to the already difficult decision to reproduce, as well as adding to the stress of deciding whether to disclose the information to other family members.<sup>321</sup>

An analysis of the informational risks in the context of genetic testing, therefore, requires the court to ask a series of questions about the medical test. Will a positive result mean that the individual will likely die from an incurable and untreatable disease? Is there a cure? Are there significant treatments? How will the lack of treatment or cure affect the individual when she receives the results? Has the individual avoided taking a genetic test previously? If so, for what reasons?

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317. See Rothstein, *Preventing the Discovery*, *supra* note 207, at 895.

318. See Dorothy C. Wertz, Ph.D., *Society and the Not-So-New Genetics: What Are We Afraid of? Some Future Predictions from a Social Scientist*, 13 J. CONTEMP. HEALTH L. & POL’Y 299, 319 (1997).

319. *Id.*

320. Because the information for each disease is different, the impact on the individual being tested will vary based on the possible interpretations of the results. See Eliot Marshall, *Gene Tests Get Tested*, 275 SCI. 782 (1997). Courts, therefore, need to be cognizant of these differences before ordering a test. See *supra* Part II.B.3.

321. See Wertz, *supra* note 318, at 319–21.



## b. Seeking Discovery of Unavailable Information

In asking these questions, courts also need to understand the significant distinction between court-ordered genetic testing and other forms of discovery. Generally, in discovery, a litigant is seeking information that exists and is already available to the litigants.<sup>322</sup> But in a compelled genetic test, the litigant is seeking information that is not already known or available. The person being tested is, therefore, used as a vehicle to obtain this unavailable information. In the typical court-ordered medical or psychological exam, the information sought is not likely to reveal unknown information, or information which will have a significant impact on the individual's future. A medical examination under Rule 35 is usually based on the plaintiff's claim that he or she suffers from an illness or injury.<sup>323</sup> The medical examination is ordered to verify the injury.<sup>324</sup> The same is true for a psychological examination where a person is claiming a mental injury and the psychological exam is used to confirm or discount that claim.<sup>325</sup> Unless a Rule 35 motion is centered on a claim for genetic damage, currently an unlikely prospect, the genetic test is not used to confirm or discount an injury, but to determine information not readily available, known, or possibly even suspected by the individual being tested. As a result, the litigant may be forced to learn about her future health or impending doom.

## c. Proposal: Voluntary Testing with Informed Consent

The fears associated with learning that one has a life-threatening condition have prompted most genetic medical and ethical scholars to advocate voluntary testing with informed consent.<sup>326</sup> Many public

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322. In a request for production, a litigant is trying to obtain documents, records, or other tangible objects. See FED. R. CIV. P. 34(a). In a deposition, the litigant is trying to obtain information known to the deponent. See FED. R. CIV. P. 30.

323. See *supra* Part I.

324. See *supra* Part I.

325. See *supra* Part I.

326. See generally *Cobbs v. Grant*, 502 P.2d 1, 9 (Cal. 1972) (holding that a person of adult years and of sound mind has the right, in exercise of control over his own body, to determine whether or not to submit to lawful medical treatment); see also A.M. Capron, *Informed Consent in Catastrophic Disease Research and Treatment*, 123 U. PA. L. REV., 341-438 (1974); Larry R. Churchill et al., *Genetic Research as Therapy: Implications of "Gene Therapy" for Informed Consent*, 26 J.L. MED. & ETHICS 38, 45 (1998); Cooper, *supra* note 268, at 352; JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* xiv (1984). Seven states have enacted laws requiring informed consent for using genetic information. See ARIZ. REV. STAT. ANN. § 20-448.02 (West 1998); CAL. INS. CODE § 10148 (West Supp. 1999); MINN. STAT. § 72A.139 (1998); N.J. STAT. ANN. § 10:5-45 (1998); N.M. STAT. ANN. §§ 24-21-3 TO -4 (Michie Supp.

health advocates agree that genetic testing should only occur after the person has been fully informed of the potential results and consequences of the test and the person has been given post-result counseling regardless of the results:

Although scientific breakthroughs make testing a viable option for some individuals at risk for genetically linked disease, the indeterminate nature of test results combined with various concerns—about lack of disease-appropriate treatment, or access thereto; potential psychological harm to the person being tested; ramifications for other family members; possible breaches of privacy; and the risk of discrimination based on positive results—must be considered by clinicians who plan to offer genetic testing. Indeed, the ability to conduct such a test, particularly when viewed in conjunction with the repercussions of being tested, highlight the importance of the pre-test counseling process and a genuine expression of informed consent . . . . These dilemmas are extraordinary. Indeed, if nothing else, they point out the need for a new legal doctrine of informed consent to provide a framework for patients to consider carefully, with their physicians, a decision to undergo genetic testing.<sup>327</sup>

#### d. Special Concerns for Testing Children

Another area where medical and ethical scholars have strongly discouraged the use of mandatory or forced genetic testing involves parents testing their children for genetic defects. Many have advocated limiting the situations in which a parent can have his or her child tested for the same reasons that mandatory testing should not be allowed in adults—it may cause psychological trauma without offering any benefit in terms of treatments or cures.<sup>328</sup> The fear of giving children information about their possible medical destiny is what has prompted medical and legal institutions to uniformly oppose the testing of minors unless there is a clear benefit to the minor.<sup>329</sup> These institutions point to “the possibility of lowered self-esteem, stigmatization, [and] family conflict.”<sup>330</sup>

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1999); N.Y. INS. LAW § 2612 (McKinney Supp. 1999–2000); OR. REV. STAT. § 746.135 (1998).

327. Cooper, *supra* note 268, at 363–69.

328. See *Abstracts*, 15 ISSUES L. & MED. 227, 228 (1999) (reviewing Heather S. Cline, *Genetic Testing of Children: An Issue of Ethical and Legal Concern*, PEDIATRIC NURSING, Jan.–Feb. 1999, at 61).

329. See Wertz, *supra* note 318, at 322. Statements have been made by the American Society of Human Genetics, the American College of Medical Genetics, the American Medical Association, and the Clinical Genetics Society in the United Kingdom. See *id.*

330. *Id.*

## 2. Risks to the Individual: Disclosure to Persons Outside the Litigation

### a. Fear of Discrimination

A court will also need to look at the risks associated with the potential disclosure of the genetic information to persons outside of the litigation. The actual act of testing produces information that has the potential of being disclosed to people outside the lawsuit, possibly resulting in negative consequences for the person tested. An additional psychological burden results from societal discrimination and the labeling of the individual with the genetic defect.<sup>331</sup> Individuals may feel stigmatized or depressed because of their newly discovered status of being genetically abnormal.<sup>332</sup> Most importantly, these individuals may be denied insurance coverage or employment because of their disease, or they may be ridiculed or scorned by a society that neither sympathizes with, nor understands, their condition.<sup>333</sup> As a result of persistent discrimination against them, these persons might feel less worthy or unwanted by society.<sup>334</sup> This negative treatment, coupled with the nature of the future illness, could lead them to experience feelings of worthlessness and depression, and could even make them suicidal.<sup>335</sup> The effects of stigmatization, along with the potential for a future devastating illness, therefore, have severe psychological implications for the individuals involved.<sup>336</sup>

### b. Identifier in Criminal Investigations

Another risk associated with the disclosure of genetic information is the use of genetics as an identifier in criminal investigations. Often, companies that perform genetic testing maintain the results in a database.<sup>337</sup> The results of a court-ordered genetic test may be stored, sometimes without the person's knowledge, and later used to identify that individual by comparison testing.<sup>338</sup> This information has previously been used by the Federal Bureau of Investigations and other law

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331. See Kirke D. Weaver, J.D., *Genetic Screening and the Right Not to Know*, 13 ISSUES L. & MED. 243, 256 (1997); Billings et al., *supra* note 312, at 476.

332. See Billings et al., *supra* note 312, at 479.

333. See *id.* at 476-79.

334. See *id.* at 479.

335. See *id.* at 252-57.

336. See *id.*

337. See Green & Thomas, *supra* note 308, at 577.

338. See *id.* at 578-80.

enforcement agencies in capturing criminals.<sup>339</sup> In theory, the information in the database can be used outside of the law enforcement area, violating the privacy of the person tested.<sup>340</sup> When genetic science becomes more precise and sophisticated, it could lead to someone being identified solely by their genetic make-up, alleviating the need for other types of identifiers. This type of identification is not possible with the use of the medical records or ordinary medical information currently available.

### c. Protective Order Not an Adequate Remedy

A court may alleviate some of the risks associated with disclosing genetic information by issuing a protective order. However, a protective order is not likely to cover the situation in which an insurance company asks the applicant questions related to any known diseases or genetic defects. A court cannot issue a protective order allowing the person to lie or commit fraud while trying to obtain insurance. Even if a person refuses to answer a question about genetic conditions because of the protective order, the insurance company is likely to infer that a defect does exist and deny the application.<sup>341</sup> The potential difficulty of obtaining insurance is a major reason people choose not to be genetically tested.<sup>342</sup> Without any test results or any knowledge of a genetic disorder, the individual has no information to give to these entities.

The same concerns regarding the disclosure of private medical information attached to HIV testing. A fundamental reason public health officials have advocated for anonymous, voluntary, and confidential testing is that people would not get tested if they knew the information would be disclosed to their employers or insurance companies.<sup>343</sup> Many people would go to independent HIV testing centers that had no connection to an insurance company out of fear that their own doctor would have to report the information to the insurance company.<sup>344</sup> The only way that people would get tested is if these pro-

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339. See Peter Donnelly, D. Phil. & Richard D. Friedman, J.D., *DNA Database Searches and the Legal Consumption of Scientific Evidence*, 97 MICH. L. REV. 931, 932-33 (1999).

340. For a more detailed examination of the DNA database debate, see Donnelly & Friedman, *supra* note 339, at 934-62.

341. See generally Christine Gorman, *The Doctor's Crystal Ball*, TIME, Apr. 10, 1995, at 61 (explaining how numerous people of African and Mediterranean descent lost their insurance because they participated in a screening campaign for sickle-cell anemia).

342. See Billings et al., *supra* note 312, at 481.

343. See *supra* Part III.B.

344. See Wertz, *supra* note 318, at 308.

tections were in place. These same policy reasons have been advanced by public health officials when they advocate for voluntary genetic testing after the patient has been fully informed of the potential consequences.<sup>345</sup>

### 3. Informational Risks to Third Parties Outside the Lawsuit

The informational risks also impact people not involved in the lawsuit, something a court must recognize and understand fully before mandating genetic testing. Because genes are inherited, genetic information about an individual is also information about her children, parents, and siblings.<sup>346</sup> In addition to the tested individual suffering from increased anxiety and stress, a family member may suffer severe psychological and emotional trauma from this information. The family member, who is not a party to the litigation, has no legal standing to prevent the test from occurring. The test may cause internal family strife because the family member has no control over the decision to determine this medical information.<sup>347</sup> Further, the genetic information generated by the test could be used by employers and insurance companies to discriminate against any blood relative of the tested individual.<sup>348</sup> A genetic test, therefore, impacts an entire family and exposes its members to psychological, physical, and social harms without their individual consent.<sup>349</sup> Although results from a genetic test may not be affirmative proof of a genetic disorder, family members may still suffer severe psychological harm from being forced to decide whether to be tested themselves after a relative has tested positive for a particular disease.<sup>350</sup>

Psychological trauma is usually associated with a positive test result, but could also occur with a negative result. A negative result may mean a positive result for some member of the family. For example, a negative result could mean a child has tested positive for a genetic disease. Because of the child's test result, the mother decides to get tested and the result is negative. It then follows that the father is the person who passed the defective gene to the child. Sometimes a negative result of one sibling is coupled with a positive result of another

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345. See *supra* Part III.C.

346. See Green & Thomas, *supra* note 308, at 580.

347. See *id.* at 580–81.

348. See *id.* at 573, 580.

349. See *id.* at 580–84.

350. See *id.*

sibling. The negative child will want to show joy and happiness, but is unable to because of feelings of guilt for getting the “good” genes.<sup>351</sup>

#### 4. Informational Risks to Society

Another unique feature of genetic information, and a factor that courts must analyze, is its potential to be a common characteristic within the subject’s racial or ethnic community. For example, Tay-Sachs disease is a genetically related disease that is associated with persons of Ashkenazi Jewish heritage.<sup>352</sup> Thus, a minority group could suffer stigmatization and discrimination not only based upon the person’s heritage, but also because of the group’s common genetic composition. Genetic determinism may be the root of developing repressive laws that will lead to a more entrenched course of discrimination.<sup>353</sup> Common genetic traits within a community, therefore, could be used to justify a society’s discrimination toward a certain racial group or underclass. In particular, the information received from a genetic test could be used by a court or a jury to further stigmatize and stereotype an ethnic or racial minority because it is common to the entire class. The informational risk to society is another factor that should impact the ordering of a genetic test.

### B. The Probative Value of the Information to the Court

#### 1. The Admissibility of the Evidence

In addition to requiring courts to assess the informational risks associated with ordering a test under Rule 35, the “examination of the examination” approach requires the court to thoroughly evaluate the usefulness of the genetic information to the lawsuit. Because discovery requires that the information sought “be reasonably calculated to lead to the discovery of admissible evidence,”<sup>354</sup> courts theoretically should begin evaluating the likelihood that the results will be admissible before the test is even ordered. The broad scope of discovery, how-

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351. See Weaver, *supra* note 331, at 244.

352. See Rachael Myerowitz & Norman D. Hogikyan, *Different Mutations in Ashkenazi Jewish and Non-Jewish French Canadians with Tay-Sachs Disease*, 232 SCI. 1646, 1646 (1989), available in 1986 WL 2338023.

353. See generally George P. Smith II, J.D. & Thaddeus J. Burns, J.D., *Genetic Determinism or Genetic Discrimination?* 11 J. CONTEMP. HEALTH L. & POL’Y 23, 25 (1994) (stating that abuse engendered by the mapping of the human genome and emergent DNA technology “may result from discrimination based on the dissemination of key information about the genotype of an individual—information revealing the risk factors inherent in that individual”).

354. FED. R. CIV. P. 26(b)(1).

ever, does not require that the determination of admissibility be made before ordering an examination. One applicable rule for determining the admissibility of genetic evidence is Federal Rule of Evidence 403.<sup>355</sup> Pursuant to this rule, a court may determine that the test will produce relevant information but still decide not to order the test if the probative value of such information "is substantially outweighed by the danger of unfair prejudice, confusion of the issues, or misleading the jury."<sup>356</sup> A federal court in Illinois applied this same analysis in denying a Rule 35 motion by finding that the psychological tests sought by the motion involved evaluative techniques that were not useful to the court.<sup>357</sup>

Evaluating the evidentiary importance of the test results before ordering the test would prevent the court from forcing a party to undergo a potentially traumatic test that will produce inadmissible evidence. Ordering a test that could cause severe psychological trauma and then not using the results during trial has no benefit to the movant, the person tested, or the litigation itself. Requiring the court to determine whether the information sought is admissible before ordering a test, therefore, forces an immediate analysis of the usefulness of this scientific evidence for purposes of the litigation.

Given that genetic tests for presymptomatic diseases do not produce definitive results, they can confuse or mislead the jury and cause undue prejudice to the party opposing the test. This possibility is exacerbated by the already widespread use of science in the courtroom and the public's perception that science is exact, reliable, and determinative.<sup>358</sup> Many applications of science and technology are already widely used in criminal cases and these procedures are beginning to make their way into civil cases.<sup>359</sup> These applications seemingly involve all branches of medical technology: blood typing, hair identification, genetic screening, X-rays, neutron activation (chemical analysis of materials by bombarding neutrons and detecting the uniquely characteristic radiations that different chemical elements produce after neutron capture), delicate organic chemistry (to determine cause of death in poison cases), and identification by voice screening (mathe-

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355. FED. R. EVID. 403.

356. *Id.*

357. *See Usher v. Lakewood Eng'g & Mfg Co.*, 158 F.R.D. 411, 413 (N.D. Ill. 1994).

358. *See generally* Renee A. Forinash, *Analyzing Scientific Evidence: From Validity to Reliability with a Two-Step Approach*, 24 ST. MARY'S L.J. 223, 245-54 (1992) (noting that jurors are lulled by flawed scientific evidence introduced by expert witnesses).

359. *See* 1 MCCORMICK ON EVIDENCE ch. 20, 360-88 (John W. Strong, ed., 4th ed. 1992).

mathematical analysis of speech patterns).<sup>360</sup> As one legal scholar has stated, “[i]n litigation, as in contemporary society, we have come to avert to scientific and technological information with increasing frequency and even dependence.”<sup>361</sup> One report claims that scientific evidence is used in nearly thirty percent of all court cases and that demand for scientific expert testimony has risen dramatically.<sup>362</sup>

## 2. Confusion of Issues, Misleading the Jury, and Undue Prejudice

The increased courtroom reliance on scientific evidence has been accompanied by growing concerns. In particular, both the scientific and the legal community have questioned the customary courtroom presentations of scientific testimony, which characteristically involve experts hired by adversaries who offer diametrically opposed opinions.<sup>363</sup> Serious questions have arisen concerning the ability of judges and lay jurors to evaluate and assign appropriate weight to DNA evidence.<sup>364</sup> The goal of genetic experts, to provide the court with nonpartisan scientific explanations of evidence through DNA evidence, may be compromised by legal adversaries who are not as interested in scientific truth as in winning their cases. It is probable that zealous attorneys will attempt to obtain genetic information about the opposing party and use their experts to interpret the genetic data for the jury. For example, defense attorneys in personal injury cases have a high stake in trying to admit genetic evidence into court if it shows that the life expectancy of the plaintiff is likely to be diminished.

Critics also believe judges do not have the necessary training, time, or motivation to make accurate scientific judgments.<sup>365</sup> Too often, lawyers and judges, as well as juries, look to the credentials of scientific expert witnesses to validate scientific procedures instead of educating themselves about these procedures.<sup>366</sup> Studies of jurors’ abilities to perceive, understand, and weigh scientific evidence have yielded mixed results, with some showing that mock-jurors are unable

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360. *See id.*

361. MICHAEL J. SAKS & RICHARD VAN DUIZEND, *THE USE OF SCIENTIFIC EVIDENCE IN LITIGATION* 3 (1983).

362. *See* Joannie M. Schrof, *Courtroom Conundrum*, U.S. NEWS & WORLD REP. Oct. 26, (1992) at 67–68.

363. *See* Howard T. Markey, *Science and Law: A Dialogue on Understanding*, 68 A.B.A. J. 154, 156–57 (1982).

364. *See* Randolph N. Jonakait, J.D., *Forensic Science: The Need for Regulation*, 4 HARV. J.L. & TECH. 109, 170–72 (1991).

365. *See id.*

366. *See id.* at 168.



to interpret statistical testimony properly.<sup>367</sup> Genetic test results are based on statistical probabilities, which will require expert explanations, and will likely make the results difficult to understand.

As illustrated by the highly publicized use of genetic or DNA technology in the courtroom, scientific evidence has been generally viewed as meriting greater weight than other types of evidence due to its perceived reliability.<sup>368</sup> Since the basic structure of the DNA molecule was discovered in 1953, scientific research has produced a wide range of applications of DNA technology, including the development of reproductive technology, pharmaceuticals, human disease-treatment methods, and other applications.<sup>369</sup> These highly-publicized uses of genetic evidence in criminal cases have sensitized the public, as well as members of the legal community, to the scientific breakthroughs of DNA technology.<sup>370</sup>

The mystique of genetic information and the increasing use of genetic information to solve crimes have caused people to view all genetic information as exact and reliable. The public is unlikely to readily discern the differences between DNA-typing used in criminal cases with the less accurate genetic screening for presymptomatic diseases. Because genetic screening for diseases is not always accurate, the resulting information may not improve the accuracy of the fact-finding mission of the court and may even confuse the trier of fact.

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367. See Steven M. Egesdal, Note, *The Frye Doctrine and Relevancy Approach Controversy: An Empirical Evaluation*, 74 GEO. L.J. 1769, 1775-78 (1986).

368. See Kenneth R. Kreiling, *Scientific Evidence: Toward Providing the Lay Trier with the Comprehensible and Reliable Evidence Necessary to Meet the Goals of the Rules of Evidence*, 32 ARIZ. L. REV. 915, 920-24 (1990).

369. See e.g., Lawrence M. Fisher, *Smoother Road from Lab to Sales; DNA Technique Aims to Predict Whom a Drug Will Benefit*, N.Y. TIMES, Feb. 25, 1998, at D1 (discussing one company's plans to use a comprehensive gene map to develop drugs); Gina Kolata, *For Some Infertility Experts, Human Cloning Is a Dream*, N.Y. TIMES, June 7, 1997, at A8 (discussing human cloning); Gina Kolata, *Scientists Face New Ethical Quandaries in Baby-Making*, N.Y. TIMES, Aug. 19, 1997, at C1 (discussing genetic research in embryology); Timothy L. O'Brien, *Vical Gets a Fast Start in New Drive Against Disease*, WALL ST. J., Jan. 3, 1994, at A10 (discussing one company's foray into development of "gene therapy" treatments for a wide range of diseases); J. D. Watson & F. H. C. Crick, *Molecular Structure of Nucleic Acid: A Structure for Deoxyribose Nucleic Acid*, 171 NATURE 737 (1953) (announcing the discovery that would later win the researchers the Nobel Prize).

370. See e.g., *Commonwealth v. Daggett*, 622 N.E.2d 272, 274-76 (Mass. 1993) (holding DNA evidence on blood recovered at the alleged crime scene inadmissible and finding that the erroneous admission of DNA test results of blood recovered from defendant's place of work was harmless); see generally *United States v. Bonds*, 12 F.3d 540 (3d. Cir. 1993) (discussing the admissibility of DNA evidence and the FBI procedures for declaring DNA matches).

Any debate regarding the use of complicated scientific evidence has always involved an examination of how the evidence will help the trier of fact, a determination required under Federal Rule of Evidence 403.<sup>371</sup> Genetic testing highlights the danger of allowing litigants to use what appears to the court to be an objective tool in finding the truth, when in reality the information produced by the tests is open to a wide variety of interpretations. Courts must deconstruct the established view that all uses of genetic science are accurate methods of finding the truth sought in a lawsuit. In determining genetic science's value in the courtroom, courts need to balance the potential positive effects of the scientific innovation and the litigants' expectation of fairness with the goal of deconstructing any preconceived notions of the technology.<sup>372</sup> The current state of genetic testing makes this process quite difficult for the court, but it is necessary given the grave dangers of ordering a person to submit to a test for a terminal genetic condition.

### 3. The Probative Value of Genetic Information to the Court

Scientists have developed and will continue to develop genetic tests that determine different levels of risk for genetic conditions. These conditions may have symptoms ranging from mild to severe, they may have evolving treatments, and they may appear at widely varying ages, if at all.<sup>373</sup> The many ethical problems with mandating such tests revolve around these uncertainties. The fewer the uncertainties that exist about a test, the more useful the information will be to the litigation.

The most likely use of genetic information will be in determining life expectancy. With the aid of mortality tables, statistics on the death rates related to cancer, heart disease or tobacco use have all been admitted to prove diminished life expectancy.<sup>374</sup> However, genetic testing for most diseases is still too uncertain to evaluate a person's life span.<sup>375</sup> Often, these genetic tests precede any symptoms, and the test result is generally too speculative as to when the disease will manifest itself and its potential severity.<sup>376</sup> Further, even though a cure may not be available for a particular disease when the test is sought, it does not

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371. See Fed. R. Evid. 403.

372. See Sheila Jasanoff, *Science at the Bar* 210–18 (1995).

373. See *supra* Parts II.A–II.B.

374. See Rothstein, *Preventing the Discovery*, *supra* note 207, at 884–86.

375. See Kording & DuMontelle, *supra* note 34, at 690.

376. See *id.* at 699.

preclude the discovery of a cure within the lifetime of the individual tested.<sup>377</sup> A positive test result, therefore, is usually too attenuated from the claim of future damages to be useful to determine lifespan.<sup>378</sup>

As illustrated by the three diseases discussed in Part II, the corresponding genetic tests will prove to have different levels of usefulness to the court. For example, the test for Alzheimer's Disease is not likely to be valuable to the court given that at least half of the patients with the disease do not test positive for the e4 allele, the mutation that shows a susceptibility to Alzheimer's.<sup>379</sup> Meanwhile, many with the allele never develop the disease.<sup>380</sup> Based on the unreliability of the test for Alzheimer's, the results are likely to mislead and confuse the jury. A test for HD, where the test is more accurate,<sup>381</sup> may be more valuable to the trier of fact. The accuracy of the test, however, does not necessarily tell the court anything about the severity of the disease or exactly when death will occur.<sup>382</sup> Geneticists hope that one day they will be able to refine the tests to eliminate these variables, and thus alleviate the ethical concerns associated with these tests. Development of greater predictive value will then place genetic testing firmly in the realm of other medical information. Until that happens, courts must exercise great caution in ordering a test that will do nothing to promote a more fair process for litigants.

## Conclusion

With the constant influx of new genetic technology in our everyday lives, it is no surprise that genetic information is beginning to pervade our courtrooms. However, genetic information has great potential to cause significant harm to the individual being tested and to society as a whole. There are times when genetic information will be of obvious benefit to courts, as illustrated by the wide and successful use of DNA evidence in criminal cases. The use of this technology, however, does not necessarily mean that the process will aid the fact-finding mission of the court. A balance needs to be struck between

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377. See *id.* at 691.

378. See *id.* at 702 (arguing that, because there is always a possibility that a cure could be found, "a positive predictive genetic result is probably too remote to be relevant" in proving that future damages should be lowered).

379. See Richard Mayeux, M.D., M.S.E. & Nicole Schupf, Ph.D., Dr.P.H., *Apolipoprotein E and Alzheimer's Disease: The Implications of Progress in Molecular Medicine*, 85 AM. J. PUB. HEALTH 1280, 1281 (1995).

380. See *id.*

381. See McMenemy, *supra* note 96, at ch. 2.

382. See *supra* Part II.B.1.

the usefulness of the information to the courts and the potentially damaging psychological and physical effects of the information.

The ease with which HIV testing has been ordered and the perceived reliability of genetic tests should give genetic and legal ethicists great cause for concern. As courts have generally focused on the “in controversy” and “good cause” requirements of Rule 35, they rarely examine the procedures to be used in the examination and the information that will be produced. This simple analysis is outdated by the advent of genetic tests for presymptomatic diseases. As each genetic test produces a variety of types of information, sometimes revealing a life-threatening condition, courts must extend their analysis to include a thorough “examination of the examination.” Otherwise, courts may be faced with the prospect of giving a civil litigant a “death sentence” while providing no substantial benefit to the administration of justice.

