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Lori B. Andrews

Nanette Elster

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# ARTICLES

## ADOPTION, REPRODUCTIVE TECHNOLOGIES, AND GENETIC INFORMATION

*Lori B. Andrews*<sup>†</sup>

*Nanette Elster*<sup>††</sup>

### I. INTRODUCTION

AFTER I GAVE A SPEECH at an American Fertility Society meeting a few years ago, a physician called me aside, and in hushed tones, asked my advice.<sup>1</sup> He had just learned that one of his sperm donors had been arrested for murder. He wanted to know whether he had a legal duty to inform the women who used the man's sperm of this new development.

Several thoughts ran through my mind as I attempted to answer the question, which seemed to hover on the precipitous divide in the nature/nurture debate. In the way he posed the question, the physician implied that this was genetic information akin to telling the recipient that the donor had a family history of early coronary artery disease or breast cancer, relevant due to the information it provided about the child's nature. But as I tried to envision the impact of that information on the recipient and the child, my concern focused entirely on its influence on nurture. I wondered whether, each time the

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<sup>†</sup> Professor, Chicago-Kent College of Law, Illinois Institute of Technology. B.A., Yale College; J.D., Yale Law School, 1978.

<sup>††</sup> Visiting Assistant Clinical Professor, Chicago-Kent College of Law, Illinois Institute of Technology. B.A., University of Illinois; J.D., Loyola University of Chicago; M.P.H., Boston University.

1. References in the first person in this Article refer to the experiences of Lori Andrews.

child lashed out in anger at a playmate, the mother would freeze in horror at the idea that her child's genetic predisposition was unfolding. She might rush in and prevent the child from engaging in any number of normal behaviors in an attempt to avert the creation of a criminal.

I could not think of any legal reason why such information should be disclosed, and I could think of any number of social reasons why it should not be revealed. The incident raised in my mind a larger question of the type of information about the child's genetic progenitors to which parents (and the child himself or herself) might be entitled. Such questions arise in the areas of adoption, egg donation, sperm donation, embryo donation, and surrogate motherhood.

There are some instances in which giving genetic information to the rearing parents can be beneficial to the child. A classic case is screening newborns for phenylketonuria (PKU). If this genetic disease is diagnosed in a newborn, appropriate treatment with a special diet can prevent mental retardation in the child. For a limited number of diseases, such as heart disease, family history may help the parents and, later in life, the child, engage in preventive strategies for the child's benefit.

On the other hand, there are many instances in which a child might be stigmatized or harmed by genetic information. A child may not be adopted at all if the potential parents know that the child has the gene for a serious late-onset disorder such as Huntington's disease. Such a possibility led Dorothy Wertz, Joanna Fanos, and Philip Reilly to recommend restrictions on the use of genetic testing in the adoption context.<sup>2</sup> They suggest that testing should be limited to situations in which the adoptee may benefit from preventive measures or treatment: "Testing for untreatable adult-onset disorders prior to adoption makes the child into a commodity undergoing quality control."<sup>3</sup>

Concerns are raised, even outside the adoption context, about giving biological parents information about their child's

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2. Dorothy C. Wertz et al., *Genetic Testing for Children and Adolescents: Who Decides?*, 272 JAMA 875, 880 (1994) (suggesting that genetic testing in the context of adoption should be restricted).

3. *Id.*

genetic status, other than in cases where such information is necessary for immediate health care treatment or prevention. Genetic information can have psychological, social, and financial implications; some commentators suggest that, except in limited circumstances where genetic information is needed for immediate treatment and prevention, the decision about whether to undergo a genetic test should be postponed until the child reaches maturity and can make that decision himself or herself.<sup>4</sup> Accordingly, it would not seem appropriate that adoptive parents should have more information about their child than biological parents.

Given the overemphasis our culture places on genetic explanations for behavior, generating more genetic information about a child might not necessarily be good for the child. As Dorothy Nelkin and Susan Lindee ably demonstrate in their recent book, *The DNA Mystique*, our contemporary culture appears to place greater weight on nature over nurture, and is inclined to find an explanation for all things in a person's genes.<sup>5</sup> They note that since 1983, when the subject heading "behavioral genetics" first appeared in the *Reader's Guide to Periodic Literature*, hundreds of articles on that topic have appeared, and "among the traits attributed to heredity have been mental illness, aggression, homosexuality, exhibitionism, dyslexia, addiction, job and educational success, arson, tendency to tease, propensity for risk taking, timidity, social potency, tendency to giggle or to use hurtful words, traditionalism, and zest for life."<sup>6</sup> The authors also discuss how these ideas entered popular culture in novels, movies, soap operas, and advertisements.

With respect to parenting, Nelkin and Lindee point out that in the 1970s, childrearing manuals emphasized the importance of nurturing, while today such manuals indicate that a child's personality is predestined genetically. Of particular note

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4. See COMMITTEE ON ASSESSING GENETIC RISKS, INST. OF MED., *ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY* 10, 260-64 (Lori B. Andrews et al. eds., 1994).

5. DOROTHY NELKIN & M. SUSAN LINDEE, *THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON* 104-06 (1995) (suggesting that there is a "general public conversion to the idea that differences between men and women are genetically determined").

6. *Id.* at 82.

is Nelkin and Lindee's description of a 1993 television movie, *Tainted Blood*, in which an adopted boy kills his parents.<sup>7</sup> In the movie, a reporter learns that the boy's mother killed her own parents, too. When the reporter also discovers the boy had a twin sister, she begins a desperate search for the girl with "tainted blood" (who indeed committed murder herself).<sup>8</sup>

Nelkin and Lindee explain that, despite scientific limitations to such information, genetic explanations for a person's behavior are readily accepted by the public since "they can relieve personal guilt by implying compulsion, an inborn inability to resist specific behavior."<sup>9</sup> Such explanations may relieve societal guilt and provide an excuse to reduce social services by deflecting attention away from social and economic influences on behavior.<sup>10</sup> The authors maintain that "the gene has been transformed. Instead of a piece of hereditary information, it has become the key to human relationships and the basis of family cohesion. Instead of a string of punches and pyrimidines, it has become the essence of identity and the source of social difference."<sup>11</sup>

Given the ascendancy of genetic information, parents rearing an adopted child may feel that their child's future is preordained by the genetic information they are provided.

Nevertheless, an individual's genetic family history increasingly is being viewed as an important tool in medical diagnosis and treatment. Such recognition led state legislatures to create statutes requiring the collection of genetic information in the adoption context. A 1987 survey by the American Society of Human Genetics found that fifteen states had such statutes.<sup>12</sup> Much has changed since 1987. The collection of genetic information is becoming easier, and technology has increased the number of genetic conditions which are identifiable through testing. These changes are reflected in the adoption

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7. *Tainted Blood* (USA television broadcast, Mar. 3, 1993).

8. NELKIN & LINDEE, *supra* note 5, at 86-87.

9. *Id.* at 145.

10. *See id.* *See also* MARQUE-LUISA MIRINGOFF, THE SOCIAL COSTS OF GENETIC WELFARE (1991) (promoting the notion that society readily accepts genetic rationalizations for a person's behavior, especially if that behavior is anti-social or criminal).

11. NELKIN & LINDEE, *supra* note 5, at 198.

12. Diane Plumridge et al., *ASHG Activities Relative to Education: Heredity and Adoption: A Survey of State Adoption Agencies*, 46 AM J. HUM. GENETICS 208, 208-09.

laws of many states.

## II. STATE POLICIES REQUIRING COLLECTION OF GENETIC INFORMATION

At least twelve states require compilation of a social history when one is obtainable;<sup>13</sup> thirty-four, a medical history;<sup>14</sup> twenty-four, a genetic history or history of hereditary conditions;<sup>15</sup> and twenty-one, a health history.<sup>16</sup> Such disclosures

13. ARK. STAT. ANN. § 9-9-505 (Michie 1993); COLO. REV. STAT. §§ 19-1-103(80), 19-5-207 (1997); FLA. STAT. ANN. § 63.022 (2) (g) (West 1997); KAN. STAT. ANN. § 59-2130 (1994); MISS. CODE ANN. § 93-17-205(1) (1994); N.M. STAT. ANN. §§ 32A-5-3, 32A-5-14 (Michie 1978 & Supp. 1995); OHIO REV. CODE ANN. § 3107.12 (Banks-Baldwin Supp. 1996) OKLA. STAT. ANN. tit. 10, § 7504-1.1 (West Supp. 1998); R.I. GEN. LAWS § 15-7.2-2 (1996); UTAH CODE ANN. § 78-30-17 (1) (1996); WASH. REV. CODE ANN. § 26.33.380 (West 1997); W. VA. CODE § 48-4-7 (1996).

14. ALA. CODE § 26-10A-31(g)(2) (1992); ALASKA STAT. § 18.50.510(a)(3) (Michie 1996); CAL. FAM. CODE § 8706 (West 1994 & Supp. 1998); COLO. REV. STAT. §§ 19-1-103 (80), 19-5-207, 402 (1997); FLA. STAT. ANN. § 63.022 (2) (g) (West 1997); HAW. REV. STAT. § 578-14.5 (1993); IDAHO CODE § 16.1506 (Supp. 1997); 750 ILL. COMP. STAT. ANN. 50/18.4a (West 1993); IND. CODE ANN. § 31-3-1-2 (West Supp. 1997); IOWA CODE ANN. § 600.8 (West 1996); KAN. STAT. ANN. § 59-2130 (1994); LA. CHILD. CODE art. 1125(A)(2) (West 1995); MD. CODE ANN., FAM. LAW § 5-328(a) (1991 & Supp. 1997); MASS. GEN. LAWS ANN. ch. 210, § 5D(a) (West 1987); MICH. COMP. LAWS ANN.14. § 710.27(1)(b)&(c) (West Supp. 1997); MISS. CODE ANN. § 93-17-205(1); MO. ANN. STAT. § 453.121(1)(5) (West 1997); NEB. REV. STAT. § 43-107 (2) (1993 & Supp. 1997); N.H. REV. STAT. ANN. § 170-B:15 (1994); N.J. STAT. ANN. § 9:3-41.1(a) (West Supp. 1997); N.M. STAT. ANN. § 32A-5-40 (Michie 1995); N.Y. DOM. REL. LAW § 114(1) (McKinney 1988 & Supp. 1998); N.Y. SOC. SERV. LAW § 373-a (McKinney 1992); OHIO REV. CODE ANN. § 3107.12 (Anderson Supp. 1996); OKLA. STAT. ANN. tit. 10, § 7504-1.1 (West Supp. 1998); OR. REV. STAT. § 109.342 (1997); 23 PA. CONS. STAT. ANN. § 2533(b)(12) (West 1991); R.I. GEN. LAWS § 15-7.2-2 (1996); S.C. CODE ANN. § 20-7-1740 (Law. Co-op 1996); TEX. FAM. CODE ANN. § 162.007 (West 1996); UTAH CODE ANN. § 78-30-17 (1) (1996); WASH. CODE ANN. § 26.33.350 (West 1997); W. VA. CODE § 48-4-7 (1996); WIS. STAT. ANN. § 48.425 (West 1997); WYO. STAT. ANN. § 1-22-116 (Michie 1997).

15. ARIZ. REV. STAT. ANN. § 8-129(A) (West 1989); ARK. CODE ANN. § 9-9-505 (1993); CAL. FAM. CODE § 8706 (West 1994 & Supp. 1998); COLO. REV. STAT. § 19-5-207 (1997); HAW. REV. STAT. § 578-14.5 (1993); IDAHO CODE § 16-1506 (Supp. 1997); 750 ILL. COMP. STAT. ANN. 50/18.4a (West 1993); IOWA CODE ANN. § 600.8 (West 1996); KAN. STAT. ANN. § 59-2130 (1994); LA. CHILD. CODE art. 1125(A)(2) (West 1995); MINN. STAT. ANN. § 259.79(1) (West Supp. 1998); MISS. CODE ANN. § 93-17-205(1); N.J. STAT. ANN. § 9:3-41.1 (West 1993); N.M. STAT. ANN. §§ 32A-5-3, 32A-5-14 (Michie 1978 & Supp. 1995); N.Y. DOM. REL. LAW § 114(1) (McKinney 1988 & Supp. 1998); N.Y. SOC. SERV. LAW § 373-a (McKinney 1992); OHIO REV. CODE ANN. § 3107.09 (Banks-Baldwin Supp. 1996); OKLA. STAT. ANN. tit. 10, § 7504-1.1(A) (West Supp. 1998); OR. REV. STAT. § 109.342 (1997); R.I. GEN. LAWS § 15-7.2-2 (1996); S.C. CODE ANN. § 20-7-1740 (Law Co-op. 1996); TEX. FAM. CODE ANN. § 162.007 (West 1996); UTAH CODE ANN. §§ 78-30-17 (1) (1996); WISC. STAT. ANN. § 48.425 (West 1997); WYO. STAT. ANN. § 1-22-116 (Michie 1997).

16. ALA. CODE § 26-10A-31(g)(2) (1992); ARIZ. REV. STAT. ANN. § 8-129(A) (West 1989); ARK. CODE ANN. § 9-9-505(a) (1993); CONN. GEN. STAT. ANN. § 45a-746 (West 1993 & Supp. 1997); KY. REV. STAT. ANN. § 199.520 (Banks-Baldwin 1994 & Supp. 1996) (requiring a health history of the biological parents and relatives to be given to adoptive parents); MINN. STAT.

can occur without revealing the identity of the adoptee's biological parents. Not only is this information compiled, but some states require its disclosure early in the adoption process. Twenty-three states require disclosure of the known medical history<sup>17</sup> of the adoptee and his or her biological parents by the state or county department of social services, licensed child placing agency, or the court. This disclosure must be made to the adoptive parents before or soon after finalization of the adoption.<sup>18</sup> Nine states have statutes which require disclosure of the biological parents' health or medical histories.<sup>19</sup>

ANN. § 257.01 (West 1992); N.H. REV. STAT. ANN. § 170-B:19 (1994) (requiring the division or agency involved in an adoption to release the health history of the natural parent and blood relatives upon request of an adoptee over 21 or an adoptive parent); N.M. STAT. ANN. §§ 32A-5-3, 32A-5-14 (Michie 1978 & Supp. 1995) (requiring that the pre-placement study include full disclosure of the adoptee's health history if known); N.Y. Dom. Rel. Law § 114 (McKinney Supp. 1997); N.C. GEN. STAT. § 48-3-205 (1997) (requiring that biological parents supply a health history of the child for review by prospective adoptive parents); N.Y. DOM. REL. LAW § 114(1) (McKinney 1988 & Supp. 1998) (requiring any "information which may be a factor influencing the child's present or future health" be included in the order of adoption); R.I. GEN. LAWS § 15-7.2-2 (1996); TEX. FAM. CODE ANN. § 162.005 (West 1996); UTAH CODE ANN. § 78-30-17 (1) (1996) (requiring a health history to be filed in the final adoption report); VT. STAT. ANN. tit. 15A, § 2-105(a) (Supp. 1997); WASH. REV. CODE ANN. § 26.33.350 (West 1997).

17. This term is utilized herein to include all health and genetic information.

18. See ALA. CODE § 26-10A-19(C)(6) (1992); ARK. CODE ANN. §§ 9-9-501, 9-9-505 (Michie 1993); CAL. FAM. CODE § 8706 (West 1994 & Supp. 1998); FLA. STAT. ANN. § 63.082 (3) (a) (West 1997); 750 ILL. COMP. STAT. ANN. 50/18.4 (West 1993); IND. CODE ANN. § 31-19-17-2 (West Supp. 1997); IOWA CODE ANN. § 600.8 (West 1996); NEB. REV. STAT. § 43-107 (2) (1993 & Supp. 1997), 43-128 (Supp. 1996); N.J. STAT. ANN. § 9:3-41.1 (West Supp. 1997); N.M. STAT. ANN. §§ 32A-5-3, 32A-5-14 (Michie 1978 & Supp. 1995); N.Y. DOM. REL. LAW § 114(1) (McKinney 1988 & Supp. 1998); OHIO REV. CODE ANN. § 3107.12 (Banks-Baldwin 1994) ("shall be filed with the court"); OKLA. STAT. ANN. tit. 10, § 7504-1.1 (West Supp. 1998); OR. REV. STAT. § 109.342 (1997); 23 PA. CONS. STAT. ANN. § 2909(a) (West 1991 & Supp. 1997); TEX. FAM. CODE ANN. § 162.008 (West 1996); UTAH CODE ANN. § 78-30-17 (1996); VA. CODE ANN. § 63.1-223 (Michie 1995); WASH. REV. CODE ANN. § 26.33.350 (West 1997); W. VA. CODE §§ 48-4-6, 48-4A-6 (1996); WIS. STAT. ANN. §§ 48.93 (1r), 48.425 (1) (am); WYO. STAT. ANN. § 1-22-116 (Michie 1997).

19. ARIZ. REV. STAT. ANN. § 8-129(A) (West 1989); CONN. GEN. STAT. ANN. § 45a-746 (West 1993 & Supp. 1997); IDAHO CODE § 16-1506 (Supp. 1997) (stating that an "investigative report including reasonably known or available medical and genetic information regarding both natural parents and sources of such information" shall be available to the adopting family); KY. REV. STAT. ANN. § 199.520 (Banks-Baldwin 1994 & Supp. 1996) (requiring that a health history of biological parents and their relatives be given to adoptive parents); LA. CHILD CODE arts. 1124-1126 (West Supp. 1998); MO. ANN. STAT. § 453.121(3) (allowing medical history to be released to adoptive parents or adopted adult upon written request); N.H. REV. STAT. ANN. § 170-B:19 (1994) (requiring the division or agency involved in an adoption to release the health history of the natural parent and blood relatives upon request of an adoptee over 21 or an adoptive parent); N.C. GEN. STAT. § 48-3-205 (1997) (requiring health history of biological parents that is "relevant to the adoption decision"); N.D. CENT. CODE §§ 14-15-01(7)(j)-(16)(s) (1997) (requiring that nonidentifying information of the genetic parents be furnished to the adoptive parents and adopted adult). 1997).

These laws are in keeping with the recommendations of a number of professional organizations. The American Society of Human Genetics (ASHG) states that genetic history should be included in an adoptee's record, asserting that "[e]very person should have the right to gain access to his or her medical record, including genetic data . . . ."20 The ASHG recommends that "[w]hen medically appropriate, genetic data may be shared among the adoptive parents, biological parents and adoptees."<sup>21</sup> The Child Welfare League of America similarly recommends disclosing known hereditary conditions of the biological parents and the child to the adoptive parents.<sup>22</sup>

Some state agencies use special questionnaires to gather genetic information about parents, siblings, half-siblings, grandparents, aunts, uncles, and cousins. The Wisconsin Department of Human Services collects information regarding nearly seventy specific conditions.<sup>23</sup> In Illinois, an adoption intake form is used by a state agency to ask questions about biological parents and their biological relatives. However, there is no national standardized form to record the health information of biological parents, adoptees, and other relatives.

Currently, no statutes require that biological parents actually undergo genetic testing. Instead, the statutes refer to a collection of information that is "known," "available," "obtainable," or "reasonably known."<sup>24</sup> In Virginia, for example,

20. American Society of Human Genetics, *American Society of Human Genetics Social Issues Committee Report on Genetics and Adoption: Points to Consider*, 48 AM. J. HUM. GENETICS 1009, 1010 (1991) (stating the ASHG position on the collection genetic information for adopted children).

21. *Id.*

22. Child Welfare League of America, *Standards for Adoption Service*, § 4.13, Washington, D.C.: CWLA, 1988. The recommendation is somewhat limiting, though. It reads:

Except as limited by statute, special circumstances, or the wishes of the parties to the adoption, adoptive parents should be given full disclosure of information about the birth parents and the child to be adopted. . . .

This information should include:

Known hereditary and other conditions — problems that may either appear later or adversely affect future development (the advice of appropriate consultants is important both to determine scientifically any risks and to know how to interpret them).

23. Department of Health and Human Serv., Div. of Community Serv., State of Wisconsin Family History Questionnaire: Medical/Genetic, DCS-149 (Rev. 4/93).

24. See, e.g., ARIZ. REV. STAT. ANN. § 8-129(A) (West 1989) ("reasonably available"); ARK. CODE ANN. § 9-9-501 (Michie 1993) ("When obtainable"); CAL. FAM. CODE § 8706 (West 1994 & Supp. 1998) ("if available; . . . so far as ascertainable"); COLO. REV. STAT. § 19-5-207



when a petition for adoption is filed with the court, a report must be filed including, among other things, "relevant physical and mental history of the parents if known to the person making the report. However, nothing in this subsection shall require that an investigation be made."<sup>25</sup> Some states do attempt to gain access to birth parents' medical records.<sup>26</sup> In some states, the adoption report must include a report of any physical exam which either birth parent had within one year before

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(1997) ("if obtainable"); CONN. GEN. STAT. ANN. § 45a-746 (West 1993 & Supp. 1997) ("to the extent reasonably available"); FLA. STAT. ANN. § 63.022 (2) (g) (West 1997) ("when available"); HAW. REV. STAT. § 578-14.5 (1993) ("if known"); IDAHO CODE § 16-1506 (Supp. 1997) ("reasonably known or available"); 750 ILL. COMP. STAT. ANN. 50/18.4 (West 1993) ("known"); IOWA CODE ANN. § 600.08 (West 1996) ("known"); KAN. STAT. ANN. § 59-2130 (1994) (requiring a complete genetic, medical, and social history of the child and the parents, and if the information is not available, then an affidavit explaining the reasons why the information is not filed must be included); KY. REV. STAT. ANN. § 199.529(1) (Banks-Baldwin Supp. 1997) (stating that if the agency receives written data concerning genetic biological information about biological relatives, the agency will make a diligent effort to pass it on to the adoptive parent); LA. CHILD CODE art. 1125(A) (West 1995) ("if known"); *Id.* at art. 1126 (requiring a "good faith effort to obtain"); MICH. COMP. LAWS ANN. § 710.27 (West Supp. 1997) ("reasonably obtainable"); MO. ANN. STAT. § 453.121 (West 1997) ("if known"); NEB. REV. STAT. § 43-146.02 (1993) ("available"); N.H. REV. STAT. ANN. § 170-B:15 (1994) ("reasonably available"); N.J. STAT. ANN. § 9:3-41.1 (West 1993 & Supp. 1997) ("available"); N.M. STAT. ANN. § 32A-5-3 (Michie 1978 & Supp. 1995) ("known"); N.Y. DOM. REL. LAW 114(1) (McKinney 1988 & Supp. 1998) ("available"); N.C. GEN. STAT. § 48-3-205 (1997) ("known"); OHIO REV. CODE ANN. § 3107.12 (Banks-Baldwin Supp. 1996) ("if known"); OKLA. STAT. ANN. tit. 10, § 7504.1.1(A)(1)(a) (West Supp. 1998) ("reasonably available"); OR. REV. STAT. § 109.342 (1997) (requiring the medical history to be "as complete as possible under the circumstances" and listing information to be included "[w]hen possible"); S.C. CODE ANN. § 20-7-1740 (Law. Co-op. 1996) ("known"); S.D. CODIFIED LAWS § 25-6-15.2 (Michie 1992) ("if known"); TENN. CODE ANN. § 36-1-133 (1996) ("available"); TEX. FAM. CODE ANN. § 162.007 (West 1996) ("available"); UTAH CODE ANN. § 78-30-16 91(g) (1996) ("when obtainable"); VA. CODE ANN. § 63.1-223(D) (Michie 1995) ("known"); WASH. REV. CODE ANN. § 26.33.350 (2) (West 1997) ("known or available"); W. VA. CODE § 48-4-6 (Supp. 1997) (entitling adoptive parent or parents access to all "known circumstances" surrounding the birth and the medical history of the child); WYO. STAT. ANN. § 1-22-116 (Michie 1997) ("available").

Several states do not qualify the information. *See* ALA. CODE § 26-10A-19 (1992); IND. CODE ANN. § 31-3-1-2 (Michie Supp. 1994); MD. CODE ANN., FAM. LAW § 5-328 (1991 & Supp. 1997) (amended 1992, removing "whenever possible" language); WISC. STAT. ANN. § 48.425 (West 1997).

25. VA. CODE ANN. § 63.1-223(D) (Michie 1995) (omitting any statutory requirement that biological parents actually undergo genetic testing).

26. Only a few states make specific reference to obtaining the birth parents' medical records. *See* HAW. REV. STAT. § 578-14.5 (1993) (obtaining from natural parents the written consent to release information); MISS. CODE ANN. § 93-17-205(1)(b) (1994) ("A report of any medical examination which either birth parent had within one (1) year before the petition for adoption, if available"); PA. CONS. STAT. ANN. § 2102 (West 1991 & Supp. 1997) (including the medical records and other information of an adoptee's natural family in the definition of "[m]edical history information"); WISC. STAT. ANN. § 48.425(1)(am)(1) (West 1997) (requiring the medical and genetic history of the birth parents).

the petition for adoption.<sup>27</sup>

The fact that generally there is no affirmative duty to order tests on the child or parents as a way to collect genetic information is illustrated by *Foster v. Bass*,<sup>28</sup> which exemplifies courts' reluctance to find such a duty owed by adoption agencies. In *Foster*, the adoptive father of an child severely retarded as a result of phenylketonuria filed suit against doctors, the hospital, and the private adoption agency asserting the negligence of all defendants in failing to test the child for PKU.<sup>29</sup> Catholic Charities, the adoption agency, gave the adoptive parents a standard medical information form which provided spaces for information about the baby's race, sex, blood type, and other information including PKU test results.<sup>30</sup> The PKU space, though, was left blank on the adopted child's form. The Fosters brought the form to their pediatrician when they took the child for an examination. Catholic Charities also gave the parents a Placement Examination Report form. This form was to be given to the physician for completion and returned to the agency as part of the adoption procedures, Catholic Charities required the Fosters to obtain certification from their own pediatrician that the baby was in good health.<sup>31</sup> The Fosters' pediatrician noticed the blank left beside PKU on the form and presumed the results had not yet been received.<sup>32</sup> Based on his presumption, the doctor did not order PKU testing. At the time of the child's birth, PKU testing was not required by statute,<sup>33</sup> however, Catholic Charities and the Fosters' pediatrician were aware of the test's availability as

27. See MISS. CODE ANN. § 93-17-205(1)(b) (1994); WISC. STAT. ANN. § 48.425(1)(am)(2) (West 1997) (requiring "report of any medical examination which either birth parent had within one year before the date of the petition").

28. 575 So.2d 967 (Miss. 1990) (upholding summary judgment in a case in which the father of an adopted child sued an adoption agency for failing to test the child for phenylketonuria).

29. *Id.* at 968.

30. *See id.* at 970.

31. *See id.* at 976 (noting that since the adoption agency had no doctors on its staff, it was allowed to rely on the expertise of physicians with regard to a child's health).

32. *See id.* at 970-71 (noting that Dr. Nichols, a PKU-testing advocate, insisted that he would have performed a PKU test if he had known the child had not been given one, yet he took no affirmative steps to discover what the blank line on the form actually meant). Tests may take as long as 2 months to be returned. *See id.* at 971.

33. *See id.* at 976 (noting that PKU testing became mandatory "with the enactment of MISS. CODE ANN. § 41-21-203, and its subsequent amendment in 1985").

indicated by Catholic Charities' inclusion of it on the medical information form and the doctor's own involvement with instituting mandatory screening at a local hospital.<sup>34</sup>

The court found, however, that "creation of the medical information form does not obligate Catholic Charities to make sure it is completed and that all things on the form are examined."<sup>35</sup> The court found no duty on the part of Catholic Charities to conduct the test.<sup>36</sup> It was not disputed that if Catholic Charities had known the information it would have had a duty to disclose such information, but, according to the court, "Catholic Charities had no information about PKU testing to convey to anyone."<sup>37</sup> This rationale seems to encourage ignorance; if agencies do not inquire, they do not have to disclose. Realizing that children with health problems are more difficult to place, it would not be surprising if agencies were reluctant to probe into a child's medical background, let alone take the initiative in performing diagnostic tests. The court's concluding comments support agency passivity: "There is no evidence of misrepresentation or fraud. Neither is there evidence that Catholic Charities did not do all that it could. It disclosed what information it had."<sup>38</sup> The court feared that finding Catholic Charities liable would bring about much litigation which would inhibit agencies from continuing to provide services. In a footnote, the court opined that "[w]hen tragedies such as this occur, we can not put an agency at fault because a child did not conform to specifications that adopting parents desire . . . . [Agencies] could not afford an unreasonable responsibility of guaranteeing the health of a child. Even natural parents are without this guarantee."<sup>39</sup>

Information collected at the time of the child's adoption may be of limited value. Parents who surrender children for adoption are often young. Therefore there is only a limited amount of information known about the biological parents'

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34. *Foster v. Bass*, 575 So.2d 971 (Miss. 1990).

35. *Id.* at 978 (noting the court dismissed the form as merely a tool "to assist the parents and their personal pediatricians").

36. *See id.* at 977.

37. *Id.* at 983.

38. *Id.* at 983-84.

39. *Id.* at 984 n.22.

own health; many diseases will not be manifested at that time. Requiring information about other family members, such as grandparents (as is done in at least ten states),<sup>40</sup> will provide further clues, but the lack of a mechanism for updating this information will limit the potential benefits to the child of possessing this genetic information. Currently, Texas is the only state that mandates updating health information.<sup>41</sup> The Texas law states:

The department, licensed child-placing agency, parent, guardian, person, or entity who prepares and files the original report is required to furnish supplemental medical, psychological, and psychiatric information to the adoptive parents if that information becomes available and to file the supplemental information where the original report is filed.<sup>42</sup>

Although no penalties are imposed by the statute for failing to supplement the record, the language emphasizes the importance placed on updating medical information. A Delaware statute, although not requiring affirmative steps to amass updated information, does require that:

If [the] Family Court receives a report stating that a birth parent, another offspring of the birth parent or the adoptee has a genetically transmitted disorder or family pattern of a disease, Family Court shall instruct the agency that was involved with the adoption . . . to conduct a diligent search for the adult adoptee, adoptive parents of a minor adoptee or birth parent(s) to inform them of the report.<sup>43</sup>

A similar situation exists in the context of most reproductive technologies. A few state statutes require the collection of genetic information about sperm donors,<sup>44</sup> and in one case egg

40. ARK. CODE ANN. §§ 9-9-501(8)-9-9-505 (Michie 1993); CONN. GEN. STAT. ANN. § 45a-746 (West 1993 & Supp. 1997); HAW. REV. STAT. § 578-14.5 (1993); MISS. CODE ANN. § 93-17-205(1) (1994); NEB. REV. STAT. § 43-107(2) (1993 & Supp. 1997); OKLA. STAT. ANN. tit. 10, § 7504-1.1(B)(2)(b) (West Supp. 1998); R.I. GEN. LAWS § 15-7.2-2 (1996); TEX. FAM. CODE ANN. § 162.007(d) (West 1996); UTAH CODE ANN. § 78-30-16 (1) (g) (1996); WIS. STAT. ANN. § 48.425(1)(am)(1) (West 1997).

41. See TEX. FAM. CODE ANN. § 162.005(f) (West 1996) (mandating that adoptive parents be furnished with updated medical information regarding the adopted child).

42. *Id.*

43. DEL. CODE ANN. tit. 13, § 924 (Supp. 1996) (requiring that the court records of any adoption be kept "strictly confidential").

44. See, e.g., OHIO REV. CODE ANN. § 3111.35(A)(2)(a) (Banks-Baldwin 1995) (requiring disclosure of genetic information by all parties involved in artificial insemination).

donors,<sup>45</sup> but such information generally is not for the purpose of informing the recipient or the resulting child. Rather, it is to exclude as donors those men, or women, with particular genetic mutations, such as Tay-Sachs. Florida, Virginia, and New Hampshire have statutes requiring medical screening of surrogate mothers.<sup>46</sup> Beyond the few statutes on point, there is a medical standard of care, created by the practice of genetic screening of donors and the standards embodied in the Ethical Considerations of the New Reproductive Technologies of the American Fertility Society.<sup>47</sup> The guidelines require the taking of a genetic history and the provision of certain genetic tests for the purpose of excluding potential sperm donors, egg donors, embryo donors, or surrogates who are thought to present high risks such as men or women who carry the Tay-Sachs gene.<sup>48</sup> In addition, the guidelines provide that the genetic information collected without identifying information should be available on request to the infertile couple and the resulting child.<sup>49</sup> As with the adoption statutes, no provision is made for updating the information. The only exception is with respect to surrogate motherhood which, ironically, is handled by lawyers, not physicians. Lawyers have required the surrogate mothers to keep them informed of any address changes for the next eighteen years in case the child needs additional information.<sup>50</sup>

In states that do not provide adoptees, or the children born of reproductive technologies, with a statutory right to genetic

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45. N.H. REV. STAT. ANN. § 168-B:14 (1994 & Supp. 1997) (requiring gamete donors to be "medically acceptable").

46. FLA. STAT. ANN. § 742.15 (2) (b) (West 1997) (requiring that the surrogate agree to submit to "reasonable medical evaluation and treatment"); VA. CODE ANN. § 20-160 (Michie 1995) (setting forth the requirements for the petition and hearing for court approval of the surrogacy contract); N.H. REV. STAT. ANN. § 168-B:13 (1994 & Supp. 1997) (requiring a woman who undergoes in vitro fertilization to be medically acceptable).

47. The Ethics Committee of the American Fertility Society, *Ethical Considerations of the New Reproductive Technologies*, 46 FERTILITY AND STERILITY 1s, 83s-45s (Supp. 1 1986).

48. *Id.*

49. *Id.*

50. See LORI B. ANDREWS, *NEW CONCEPTIONS: A CONSUMER'S GUIDE TO THE NEWEST INFERTILITY TREATMENTS, INCLUDING IN VITRO FERTILIZATION, ARTIFICIAL INSEMINATION, AND SURROGATE MOTHERHOOD* 280-81 (1984) (giving example of a provision in surrogate mother contract developed by attorneys); see also LORI B. ANDREWS, *BETWEEN STRANGERS: SURROGATE MOTHERS, EXPECTANT FATHERS, & BRAVE NEW BABIES* (1989) (discussing relationships among all parties in surrogate mothering context).

information, and in all states in which the offspring later desires additional genetic information such as when the individual himself or herself reaches reproductive age and wants to know about genetic risks to select prenatal tests or make other reproductive decisions, questions arise regarding whether the individual can sue to obtain that information.

When identifying information is sought, most states permit disclosure only if good cause is shown,<sup>51</sup> the court determines the information is necessary,<sup>52</sup> or the interested parties mutually consented to such disclosure.<sup>53</sup> Under the "good cause" standard, adoptees are able to get certain non-identifying information, such as health insurance information, but not information that identifies individuals. In a frequently cited case involving disclosure, the court suggested that "[a] need to have access to family medical histories or information regarding the child's heredity may constitute good cause where the evidence presented in court shows a valid justifiable need to obtain the information requested."<sup>54</sup> The court noted further: "[r]equests for medical, hereditary or ethnic background information should be granted, absent some showing of compelling reasons *not* to reveal the information."<sup>55</sup> Another court suggested that "[u]pon an appropriate showing of psychological trauma, medical need, or of a religious identity crisis . . . the New York courts would appear required under their own Statute to grant permission to release all or part of the sealed adoption records."<sup>56</sup> Thus, these cases, like the statutes, would appear to support disclosure of genetic information in at least some instances.

51. See, e.g., ARK. CODE ANN. § 9-9-217(2)(A) (Michie 1997) (requiring a court order finding good cause for disclosure); WIS. STAT. ANN. § 48.93 (1d) (West 1997) (stating that records may be disclosed "by order of the court for good cause shown").

52. See, e.g., DEL. CODE ANN. tit. 13, § 925 (Supp. 1996); CAL. FAM. CODE § 9203 (West Supp. 1994).

53. See, e.g., ALA. CODE § 26-10A-31(C) (1992); WIS. STAT. ANN. § 48.433 (West 1997) (providing the statutory limits and requirements for gaining access to identifying information about parents).

54. *Mills v. Atlantic City Dept. of Vital Statistics*, 372 A.2d 646, 654 (N.J. Super. Ct. Ch. Div. 1977) (holding that psychological need may constitute good cause to reveal information to adoptees where the state fails to show a compelling reason not to reveal the information).

55. *Id.* at 655.

56. *ALMA Society, Inc. v. Mellon*, 601 F.2d 1225, 1233 (2d Cir. 1979) (footnote omitted) (requiring a showing of "good cause" before adoption records can be released).

In at least eighteen states, the artificial insemination laws, like the adoption laws, allow access to records under the good cause standard or similar proof of compelling reasons.<sup>57</sup> Thus, the court cases from the adoption realm could be applied by analogy to children conceived through sperm donation. However, the type of information children of artificial insemination would receive might be of a lesser scope. Since state agencies are not involved in artificial insemination, it may be difficult to determine where the record is located and, because physicians attempt to protect the anonymity of donors, the record is unlikely to contain any identifying information that would allow the resulting child, or even the physician providing the insemination, to recontact the donor for information.

Despite statutes, case law, and practices encouraging the collection of information, the information is only as good as the people collecting it. Unless those collecting the information are familiar with genetics, they may not be able to probe adequately. The form used in Illinois includes inquiries about physical descriptions and inquiries about specific medical conditions in various categories including: Congenital Impairments; Allergies; Eye, Ear, Developmental Disorders; Circulatory Disorders; Hormonal Disorders; Respiratory Disorders; Lymphatic Disorders; Nervous System Disorders; Infection, Hospitalization; and Other Impairment, Allergy Disorder, or Disease.<sup>58</sup> Such forms purport to amass a great deal of significant information for adoptees and adoptive parents, but unless all the questions are asked and the respondent is questioned in a way he or she understands, these inquiries will not produce information that benefits the adoptee.

There are a number of ways that the collection of genetic information in the adoption context could be enhanced. Disclosure of known or available information is a step in the right

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57. Access to the file seems to be disallowed by some states. See IDAHO CODE § 39-5403(2) (1993) (restricting access to artificial insemination files to research and statistical purposes only, unless pursuant to a court order); N.M. STAT. ANN. § 40-11-6 (Michie 1994) (providing that where a woman is artificially inseminated from sperm other than her husband's, the husband's signature of consent will be "kept confidential and in a sealed file" with the health services division of the department of health and is subject to inspection upon an order of the court for good cause shown).

58. DEPARTMENT OF CHILDREN AND FAM. SERV., STATE OF ILLINOIS, ADOPTION INTAKE FORMS.

direction, but to make such disclosure meaningful, those collecting the information need to know what questions to ask to elicit useful responses. One possible mechanism for gaining accurate and comprehensive medical information would be to enlist medical student volunteers to conduct medical interviews of biological parents during the intake process. Another potential solution may be to develop a uniform training program with the assistance of physicians from various disciplines, genetic counselors, and social workers, and then require all intake workers to undergo training. As important to determining what should be included in such an effort is what activity should be excluded. Genetic testing of the child should not be undertaken unless immediate treatment or preventive therapy is available. Genetic testing of the biological parents should not be required. Neither should biological parents and adoptees have any obligation to undergo genetic testing in order to collect health, medical, or genetic information.<sup>59</sup>

### III. ACCESS TO IDENTIFYING INFORMATION

In the adoption setting, children may gain access to information not enumerated in the statute only if they can demonstrate "good cause" for wanting access.<sup>60</sup> Case law indicates that "good cause" is a stringent requirement when the adoptee is attempting to obtain *identifying* information.<sup>61</sup> To determine whether an adoptee has shown good cause, the interests of all parties concerned are considered, and the biological parents' right to privacy is not easily overcome.<sup>62</sup> The state's interest in maintaining the integrity and effectiveness of the adoption process is linked closely to the interests of the biological

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59. See, e.g., Lori B. Andrews, *Gen-etiquette: Genetic Information, Family Relationships and Adoption*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN A GENETIC ERA 255 (Mark Rothstein ed., 1997) (discussing reasons why genetic testing of adults and children should not be required).

60. See, e.g., *Alma Society v. Mellon*, 601 F.2d 1225 (2d Cir. 1979) (finding New York statute which allowed the release of adoption records to an adult adoptee constitutional, upon a showing of "good cause," which included upon psychological trauma, medical need, and religious identity crises).

61. *Id.* (considering whether "good cause" is a sufficient requirement for allowing the release of otherwise sealed identification information about biological parents who may maintain an expectation of privacy).

62. See, e.g., *In re George*, 630 S.W.2d 684 (Mo. Ct. App. 1982).



parents: "It has been assumed that birth parents . . . want to erase the adoption from their lives . . . and confidentiality protects the natural parents' lives from future disruption."<sup>63</sup> In order to assure the birth mother that she may indeed go on with her life without the stigma of having borne an illegitimate child, or being unable to care for a child, and to insure that she may live free from fear of disruption, the states enacted the sealed records statutes.

The rationales offered for maintaining the confidentiality of the adoption record are as follows: assuring the biological parents an opportunity to "move on and attempt to rebuild their lives;"<sup>64</sup> enabling adoptive parents to raise the "child without fear of interference from the natural parents and without fear that the birth status of an illegitimate child will be revealed or used as a means of harming the child or themselves;"<sup>65</sup> and protecting "the child from any possible stigma of illegitimacy . . . insur[ing] that the relationship with his or her new parents can develop into a loving and cohesive family unit uninvaded by a natural parent who later wishes to intrude into the relationship."<sup>66</sup>

During the 1930s and 1940s, social workers and adoptive parents supported legislation limiting access to adoption records and, by 1950, most state laws required sealed adoption records.<sup>67</sup> Until recently, "each member of the adoption triangle was stigmatized: the birth mother was 'promiscuous,' the child a 'bastard,' the adoptive parents 'barren.'"<sup>68</sup> The stigma associated with adoption is one of the reasons why the process

63. Sarah E. Nugent, Comment, *The Release of Nonidentifying Information to Adopted Children: Striking a Balance Between the Rights of Biological Parents and Adopted Children*, 23 RUTGERS L.J. 709, 712-13 (1992) (comparing a natural parent's right to privacy with the rights of the adoptee).

64. *Mills v. Atlantic City Dept. of Vital Statistics*, 372 A.2d 646, 649 (N.J. Super. Ct. Ch. Div. 1977) (describing a rationale for the privacy provided by the state during a "traumatic and emotionally tormenting" period in parents' lives).

65. *Id.*

66. *Id.*

67. See Susan K. Goodman, *Adoption of What? Information Policy for Records of Adoption in the U.S.*, REC. MGMT. Q., Apr. 1993, at 3, 8 (documenting legislative trends in keeping adoption records sealed).

68. Janet Hopkins Dickson, *The Emerging Rights of Adoptive Parents: Substance or Spector?*, 38 UCLA L. REV. 917, 926 (1991) (explaining that this historical stigmatization still shapes adoption law and practice).

has been cloaked in secrecy. To protect the interests of all parties concerned, adoption records were sealed and specific authorization was required for disclosure.<sup>69</sup>

The theory underlying sealed records was that such secrecy would promote and protect the interests of all parties involved. For example, it was assumed that the state's interests in promoting adoption would be hampered without the assurance of confidentiality. Even today, some commentators suggest that without the guarantee of privacy, "the natural parents will resort to abortions or to the black market, or they will fail to divulge personal information necessary to the adoption proceedings."<sup>70</sup> Moreover, some commentators argue that "confidentiality protects the natural parent's lives from future disruption,"<sup>71</sup> as well as the lives of the adoptive parents who may feel threatened by the adoptive child's contact with his or her biological parents.<sup>72</sup> Other commentators, though, argue that disclosure may actually prevent disruption of the adoptive parents' lives. "[W]hat many are beginning to realize . . . is that increased disclosure gives adoptive parents the opportunity to make an informed decision regarding their emotional and financial ability to adopt the particular child."<sup>73</sup>

Only Virginia purports to define what constitutes "good cause" for disclosure. The term "good cause" is defined as "a showing of a compelling and necessitous need for identifying information."<sup>74</sup> Florida, however, does enumerate factors to be considered in assessing "good cause" which are far more specific than the definition set forth in the Virginia legislation. The Florida statute reads:

In determining whether good cause exists, the court shall give primary consideration to the best interests of the adoptee, but must also give due consideration to the interests of the adoptive

69. See Gloria L. Kelly, , *Getting to Know You: Disclosure of Information Contained in Sealed Adoption Records Under Connecticut Public Act 87-555*, 5 CONN. PROB. L.J. 81, 84-85 (1989).

70. Nugent, *supra* note 63, at 712.

71. *Id.* at 713.

72. *See id.*

73. Marci J. Blank, Note, *Adoption Nightmares Prompt Judicial Recognition of the Tort of Wrongful Adoption: Will New York Follow Suit?*, 15 CARDOZO L.R. 1687, 1716 (1994) (citation omitted).

74. VA. CODE ANN. § 63.1-236 (Michie 1995) (defining the condition upon which the commissioner will disclose identifying information from an adoption file).

and birth parents. Factors to be considered in determining whether good cause exists include, but are not limited to:

1. The reason the information is sought;
2. The existence of means available to obtain the desired information without disclosing the identity of the birth parents, such as by having the court, a person appointed by the court, the department, or the licensed child-placing agency contact the birth parents and request specific information;
3. The desires, to the extent known, of the adoptee, the adoptive parents and the birth parents;
4. The age, maturity, judgment and expressed needs of the adoptee; and
5. The recommendation of the department, licensed child-placing agency, or professional which prepared the preliminary study and home investigation, or the department if no such study was prepared, concerning the advisability of disclosure.<sup>75</sup>

In trying to establish good cause to receive identifying information, mere curiosity is not enough.<sup>76</sup> Some adoptees have tried to show that their need to know has had a disturbing effect on their lives that can only be relieved by receiving identifying information, but courts have not readily granted such requests. In one case, the court did not find an adoptee's need to know to be sufficiently strong because, although he argued that he had "a deep personal need to know the truth"<sup>77</sup> and was distracted by not knowing, he had not received medical or psychological assistance, nor had his professional life been affected adversely by his distress.<sup>78</sup> In another case, a woman argued that her profound depression was due to not knowing the identities of her biological parents,<sup>79</sup> but the court refused to release the information. The court was influenced by the fact that although an expert witness indicated that the release of the information would help her recover from her

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75. FLA. STAT. ANN. § 63.162(4) (West 1997).

76. See *Linda F.M. v. Department of Health of New York*, 418 N.E.2d 1302, 1304 (N.Y. 1981) (declining to grant access to birth records based solely on an adopted child's curiosity).

77. *Bradey v. Children's Bureau*, 274 S.E.2d 418, 420 (S.C. 1981) (finding that the adoptee failed to provide a compelling interest for the release of confidential identifying information).

78. See *id.*

79. See *Dixon v. Department of Pub. Health*, 323 N.W.2d 549, 552-53 (Mich. Ct. App. 1982) (holding that the plaintiff failed to make a sufficient showing of good cause to allow the opening of the records).

depression, the expert also indicated that the depth of her depression resulted from her treatment in the adoptive home, not from a lack of information about her biological parents.<sup>80</sup> Another court also rejected an adoptee's assertion that she had a psychological need to know by holding that "[s]he [was] not suffering from any mental or physical ailment due to her lack of knowledge . . . ."<sup>81</sup>

Even when an adoptee shows good cause for contacting a biological parent, courts are reluctant to provide identifying information. In *Application of George*, the applicant, an adult adoptee, was suffering from leukemia.<sup>82</sup> His disease was in remission due to drug therapy, but once the drug treatment ceased to be effective, the only other therapy to induce remission would have been a bone marrow transplant. The procedure is most effective when the donor is a blood-related sibling.<sup>83</sup> In attempting to locate his closest genetic match, the applicant sought the identities of his biological parents. The trial court denied his request for disclosure, and the court of appeals affirmed.

The court reasoned that the trial court must "exert every proper effort to either obtain consent to disclosure or obtain if possible necessary information without disclosure"<sup>84</sup> and such efforts were made in the case at bar. In a previous opinion, the court of appeals found that the petitioner had established good cause. In reaching this decision, the court balanced the following interests:

- (1) the nature of the circumstances dictating the need for release of the identity of the birth parents; (2) the circumstances and desires of the adoptive parents; and (3) "the circumstances of the birth parents and their desire or at least the desire to the birth mother not to be identified;" and (4) the interests of the

80. *See id.* at 552.

81. *In re Assalone*, 512 A.2d 1383, 1389 (R.I. 1986) (holding that curiosity and a desire to discover one's natural identity are insufficient reasons to merit disclosure of adoption records). Petitioner was preoccupied with learning the identities of her biological parents and this preoccupation affected her social adjustment according to the trial court. *See id.* at 1387 (reviewing the trial court's findings).

82. 630 S.W.2d 614 (Mo. Ct. App. 1982) (regarding an adult leukemic adoptee's attempt to search for a compatible bone marrow match from his natural family using the assistance of the court system).

83. *See id.* at 615.

84. *Id.* at 620.

state in maintaining a viable system of adoption by the assurance of confidentiality.<sup>85</sup>

Based on the finding of good cause, the court ordered the trial court "to determine if possible, the existence of genetically appropriate donors and to attempt to obtain consent to disclosure."<sup>86</sup> Following the court's mandate, the trial court judge personally attempted to gain consent from the biological parents. Having discovered the name of the biological father on the birth certificate, the judge and the judge's wife met with the alleged father several times in an effort to gain his consent to disclose his identity to the adoptee. The alleged father denied paternity and would not submit to a blood test to determine if he was an appropriate genetic match. The judge went so far as to offer that he and his wife would also be tested and he assured the alleged father that no test of paternity would be done on the blood sample.<sup>87</sup> This offer, however, was refused by the alleged father.

With regard to the biological mother, the judge arranged to have her and her daughter tested to determine if they were potential genetic matches. An unidentified nurse performed the test so as to preserve the secrecy of the birth mother's identity. The results revealed that the applicant's mother and half-sister were not appropriate matches.<sup>88</sup> Based on the information he gleaned, the trial court judge found that the identity of the biological parents should not be disclosed. He recited for the record "that a confrontation with the natural father would be 'counter productive' whether by the 'court,' the 'applicant,' or 'anyone else.'"<sup>89</sup> The court of appeals affirmed, finding that "[t]he evidence amply demonstrates that the possibility that disclosure would result in any benefit to the applicant is so remote as to be very nearly non-existent."<sup>90</sup> The court noted that,

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85. *In re George*, 625 S.W.2d 151, 156 (Mo. Ct. App. 1981) (listing the balancing of interests used by the trial judge and determining that the natural father should be contacted before a decision to disclose, if possible).

86. *In re George*, 630 S.W.2d at 620 (discussing an earlier opinion in this case).

87. *See id.* at 618.

88. *See id.* at 617.

89. *Id.* at 618.

90. *Id.* at 622-23.

[b]ecause of [the] unfortunate circumstances of the rarity of the blood characteristics of the natural mother, the chance that any half sibling on the father's side might provide a suitable match theoretically seems to be less than one in a million . . . .<sup>91</sup>

This case exemplifies the great lengths that courts will go to in order to preserve the privacy interests of biological parents. The trial court judge, acting as a confidential intermediary, undertook to do what the plaintiff would have done: determine if a family member would be an appropriate genetic match. Finding the possibility of a match with the mother and her child so slight and the possibility of convincing the alleged father to give blood highly unlikely, the trial court did not find plaintiff's circumstances outweighed the policy interest of the state in maintaining a viable system of adoption through maintaining anonymity. This decision suggests that few, if any, instances exist where an adoptee has a compelling reason to know the identity of his or her biological parents. If the information needed can be obtained without information that discloses the biological parents' identities, it appears courts will take this approach.

Nor have adoptees been successful in trying to create constitutional rights to access to identifying genetic information. Courts have rejected arguments that "by refusing automatic access to birth records that nonadopted persons have, [the court] is abridging a constitutionally protected right to privacy and to receive important information,"<sup>92</sup> as well as the First Amendment right of adoptees to receive information,<sup>93</sup> their right to equal protection of laws, which they argued would entitle them to the same information that non-adopteds can receive about their natural parents,<sup>94</sup> and their fundamental liberty interest in learning the identity of their biological family.<sup>95</sup> Courts have found constitutional sealed record statutes and

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91. *Id.* at 619.

92. *Mills v. Atlantic City Dept. of Vital Statistics*, 372 A.2d 646, 650 (N.J. Super. Ct. Ch. Div. 1977) (discussing the difficulty in striking a balance between the right to privacy and the adoptee's interest in learning the identity of his or her biological parents).

93. *See id.* at 652.

94. *Id.*

95. *ALMA Society, Inc. v. Mellon*, 601 F.2d 1255, 1230 (2nd Cir. 1979) (rejecting the argument that learning "the identity of one's natural family is a fundamental right under the Due

their attendant requirement of a showing of good cause before allowing access to the information in the adoption record. According to the Supreme Court of Illinois, in *In re Roger B.*, there do not seem to be any "case[s] holding that the right of an adoptee to determine his genealogical origin is explicitly or implicitly guaranteed by the Constitution"<sup>96</sup> and even if such a right were recognized, it would not be absolute, but subject to limitations based on a compelling state need.<sup>97</sup>

Although collection of genetic information is becoming more routine, lessening the need to disclose the names and/or whereabouts of biological parents to obtain such information, half the states still do not require collection of genetic information. Even in states which require the collection of information, those adoptees placed before such information was collected regularly still need to learn such information directly from their biological parents. One court specifically considered a request by an individual to learn his biological parents' identities to obtain genetic information. In *Golan v. Louise Wise Services*, an adult adoptee suffering from a heart condition sought the identities of his birth parents.<sup>98</sup> According to the plaintiff's affidavits, access to genetic information would help in treating his condition and evaluating its severity.<sup>99</sup> The plaintiff was adopted in 1932, and the information in the adoption record most likely was scant. Therefore, he needed to seek the answers to his questions directly from his biological parents. Additionally, because of the "unknown nature of the risk posed by plaintiff's condition,"<sup>100</sup> plaintiff alleged in his affidavits that the Federal Aviation Administration required his family medical history to continue his certification as a commercial pilot.<sup>101</sup> The court found that the plaintiff's asserted need for

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Process clause of the Fourteenth Amendment").

96. *In re Roger B.*, 418 N.E.2d 751, 753 (Ill. 1981) (holding that adoptees do not have a fundamental right to examine their adoption records).

97. *See, e.g., Mills*, 372 A.2d at 650-651 (discussing a state's ability to regulate the right to privacy).

98. *Golan v. Louise Wise Serv.*, 507 N.E.2d 275 (N.Y. 1987) (holding that an adopted person's need for genetic information for treatment of a heart condition did not automatically give the adopted person a right to disclosure of the identities of the biological parents). Plaintiff had obtained a copy of the adoption decree containing the identity of his biological mother and a reference to the surname of his father. *See id.* at 276, n.1.

99. *Id.* at 276.

100. *Id.* at 277.

101. *See id.* at 276-77. (Telephone interview with Stephen Tulin, Defendant's attorney (Nov.

genetic information did not automatically entitle him to learn the identities of his biological parents.<sup>102</sup> Before such information can be disclosed, the interests of the adoptee, adoptive parents, biological parents, and society must be balanced.<sup>103</sup> The court determined that even though a "preliminary showing of 'good cause' has been made on the papers, the court may hold a hearing to determine the effect of disclosure on other interested parties."<sup>104</sup> The court suggested that the information plaintiff required may be obtained by utilizing a guardian ad litem as an intermediary to avoid disclosing the identities of his biological parents while obtaining the information required by the plaintiff.<sup>105</sup>

Some states have mechanisms to ease access of adoptees to identifying information about biological parents, with the latter parties' implicit or explicit consent. In Michigan, for example, an adoptee of a post-1980 adoption may obtain identifying information upon request, unless either biological parent has filed a written request with the state that the information *not* be released. If one parent has requested that identifying information not be released, identifying information about that parent will not be disclosed.<sup>106</sup>

At least twenty states have formal consent registries<sup>107</sup> whereby biological parents and adoptees can learn one another's identities if there is mutual consent. The purpose of these registries is to assist birth parents and adoptees in finding

30, 1994)).

102. *Id.* at 279.

103. *See id.* at 277.

104. Golan v. Louise Wise Serv., 507 N.E.2d 275 (N.Y. 1987).

105. *Id.* at 279.

106. *See* MICH. COMP. LAWS ANN. § 710.68(7) (West, Supp. 1997); 750 ILL. COMP. STAT. ANN. 50/18.3 (West 1993) (providing that a confidential intermediary may be used for purposes of contact).

107. The following are states with formal registries. ARK. CODE ANN. § 9-9-503(a) (Michie 1997); COLO. REV. STAT. § 25-2-113.5 (1997); CONN. GEN. STAT. ANN. § 45a-755 (West 1993 & Supp. 1997); GA. CODE ANN. § 19-8-23 (Supp. 1997); 750 ILL. COMP. STAT. ANN. 50/18.3 (West 1993); IDAHO CODE § 39-259A (1993); LA. CHILD. CODE ANN. art. 1270 (West Supp. 1998); ME. REV. STAT. ANN. tit. 22, § 2706-A (West 1992); MD. CODE ANN., FAM. LAW § 5-4A-02 (1991); MISS. CODE ANN. § 93-17-205 (1994); MO. ANN. STAT. § 453.121(10) (West 1997); NEV. REV. STAT. § 127.007 (1987); N.Y. PUB. HEALTH LAW § 4138-c(1)-(2) (McKinney 1997); OR. REV. STAT. §§ 109.425-109.507 (1995); R.I. GEN. LAWS §§ 15-7.2-2 to -15 (1996); S.C. Code Ann. § 20-17-1780 (Law. Co-op. 1993); S.D. CODIFIED LAWS § 25-6-15.3 (Michie 1992); TEX. FAM. CODE ANN. § 162.401; 162.403 (West 1996); UTAH CODE ANN. § 78-30-18 (1996); W. VA. CODE ANN. §§ 48-4A-1-48-4A-8 (1996).



one another.<sup>108</sup>

Another mechanism used by states to gain access to identifying information is to employ confidential intermediaries to obtain the consent of the person whose identity is sought.<sup>109</sup> Under the Washington statute, “[t]he intermediary shall search for and discreetly contact the birth parent or adopted person . . . . If the confidential intermediary locates the person being sought, a discreet and confidential inquiry shall be made as to whether or not that person will consent to having his or her present identity disclosed to the petitioner.”<sup>110</sup> Confidential intermediaries, entitled to reimbursement for actual expenses from the petitioner,<sup>111</sup> are used as either a way to gain consent for disclosure or as a way to obtain requested or necessary information without disclosing a person’s identity. This essentially was the role played by the judge in *Application of George*,<sup>112</sup> where the petitioner sought to locate his biological parents in the hope of finding a bone marrow donor.

Adoption registries and the use of confidential intermediaries are recent developments and reflect a trend of lifting the veil of secrecy previously shrouding the adoption process,<sup>113</sup> and similarly may be implemented by programs at fertility centers. One example is the Sperm Bank of California’s “Yes” donor program. As part of the program, donors can agree to

108. See, e.g., LA. CHILD. CODE art. 1270(B) (West 1998) (stating that “[t]he purpose of this registry shall be to facilitate voluntary contact between the adopted person and the biological parents.”); OR. REV. STAT. § 109.430(1) (1995) (stating that the purpose of the section is to “[s]et up a voluntary adoption registry where birth parents and adult adoptees may register their willingness to the release of identifying information to each other”).

109. See, e.g., 23 PA. CONS. STAT. ANN. § 2905(c) (West 1991); WASH. REV. CODE ANN. § 26.33.343 (West 1997); WYO. STAT. ANN. § 1-22-203 (Michie 1997).

110. WASH. REV. CODE ANN. § 26.33.343(1) & (5) (West 1997).

111. See *id.* § 26.33.343(2)(c).

112. *In re George*, 630 S.W.2d 614 (Mo. Ct. App. 1982) (describing a court’s attempts to assist an adult adoptee with leukemia in his search for a compatible bone marrow match among his biological family).

113. See, e.g., Committee on Early Childhood, American Academy of Pediatrics, Adoption and Dependent Care, *Issues of Confidentiality in Adoption: The Role of the Pediatrician*, 93 PEDIATRICS 339, 339-41 (1994); Pamela Manson, *Courts Reunite Arizona Adoptees, Birth Parents*, ARIZ. REPUBLIC, Aug. 22, 1993, at B1 (describing Arizona’s Confidential Intermediary Program which facilitates the reconnection of birth parents and adoptees, if mutually desired). In 1980, only 10 states had mutual consent registries. See Jeffrey Rosenberg, *1988 Survey of State Laws on Access to Adoption Records*, 14 FAM. L. REP. 3017, 3019 (1988) (discussing legislative trends towards “mutual consent voluntary adoption registries,” whereby persons directly involved in adoptions can register their willingness to meet).

have their identities disclosed to their offspring upon the child's request when the child reaches the age of eighteen.<sup>114</sup> In addition, recent technological advances highlight the importance of access to certain information so that the benefits of such technology can be realized. Maintenance of an ongoing adoption registry and the development of standardized forms on which biological familial health information is recorded are important steps in providing biological parents, adoptees, and their children with necessary information upon which to base health, reproductive, and lifestyle decisions. However, more must be done to collect this significant information. Steps also must be taken to ensure that such information is accurate, but that collection does not stray beyond areas of medical relevance.

In the future, courts may be faced with the question of whether adoptees and children conceived with donor gametes should have access to genetic parents' identities so that they may update their genetic histories. The possibility of using an intermediary, such as the judge in the *George* case, might seem less appealing in such a situation. Since every adoptee could make a similar claim for a need to updated genetic information, the demand on judges' time would be great. Courts, swayed by stories in the popular and scientific press, might be inclined to grant such requests. After all, nary a day goes by when the newspapers do not report a new gene purported to be linked to a variety of diseases, conditions, and behaviors from breast cancer,<sup>115</sup> attempted rape,<sup>116</sup> homosexuality,<sup>117</sup> and

114. See Susan V. Seligson, *Seeds of Doubt*, ATLANTIC MONTHLY, March 1995, at 28 (discussing a program where sperm donors can agree to have their identities released to their offspring who have attained the age of 18).

115. Cf. Gina Kolata, *Breast Cancer Gene in 1% of U.S. Jews*, N.Y. TIMES, Sept. 29, 1995, at A24 (announcing the discovery of a mutation in the BRCA 1 gene linking one percent of the Jewish women in the United States to breast cancer); Bob Kuska, *BRCA1 Alteration Found in Eastern European Jews*, 87 J. NAT'L CANCER INST. 1505 (1995) (announcing that a study of Eastern European Jews showed that an alteration in BRCA 1 gene is present at measurable levels in the general population).

116. Carmen Lee, *Gene May Be a Cause of Being Overweight*, PITTSBURGH POST-GAZETTE, Aug. 31, 1995, at C6 (explaining that a mutated gene was discovered that makes people gain weight faster).

117. See Robert Pool, *Evidence for a Homosexuality Gene*, 261 SCIENCE 291 (1993) (suggesting that an uncovered region on the x chromosome appears to contain a gene or genes for homosexuality).

obesity.<sup>118</sup>

In recent years, a few courts have begun to show a willingness to order genetic testing outside of the criminal law context. In a case involving a tort claim, a court ordered Fragile X testing on a young boy based on the defendant company's attempt to show that the boy's retardation was genetic, and not due to the company's toxin.<sup>119</sup>

Yet forcing people to undergo genetic testing runs afoul of the Fourth Amendment,<sup>120</sup> of existing precedents regarding the right to refuse medical interventions,<sup>121</sup> and of the recommendations of national commissions<sup>122</sup> and conferences<sup>123</sup> not to order genetic testing on biological parents.<sup>124</sup> In our opinion, judges should also refrain from disclosing parents' identities in order to allow their adult children to update genetic information. Our opinion is not based on the view that the biological parents' privacy is sacrosanct; in general, we view parents as owing a great deal to the children they bring into the world. Rather, we would like to prevent a genetically deter-

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118. Charles C. Mann, *Behavioral Genetics in Transition*, 264 SCI. 1686, 1687 (1994) (discussing behavioral genetic research, including naming conditions and behaviors occurring as a result of genetic mutations).

119. *Severson v. KTI Chemicals Inc.*, No. 698517 (Cal. Super. Ct. May 9, 1994) (ordering plaintiff to give blood samples for DNA and high-resolution chromosomal analysis). For a published source describing the case and subsequent appeal, see *Chromosome Testing Order Appealed by Child Alleging In Utero Workplace Chemical Exposure*, CHEM. REG. DAILY (BNA), June 16, 1994 (LEXIS, BNA Library, CRD file) (describing the appeal of the California Superior Court decision in *Severson v. KTI Chemicals, Inc.* compelling chromosome testing of a child afflicted with microcephaly who alleges his condition was caused by his mother's occupational exposure to chemicals).

120. *Cf. Barlow v. Ground*, 943 F.2d 1132, 1137-39 (9th Cir. 1991) (holding that warrantless seizure of blood drawn from gay arrestee who had bitten police officer [to test for HIV] violated 4th Amendment).

121. See LORI ANDREWS, *MEDICAL GENETICS: A LEGAL FRONTIER* 105-12 (1987) (discussing the role of communication in the doctor-patient relationship, informed consent, and other duties to disclose); *In re A.C.*, 573 A.2d 1235, 1246 (D.C. 1990) (holding that a competent pregnant patient has the right to reject medical delivery procedure); *Baby Boy Doe v. Mother Doe*, 632 N. E. 2d 326 (Ill. App. Ct. 1994) (holding that a mother cannot be forced to undergo a cesarean section to benefit her viable fetus).

122. See COMMITTEE ON ASSESSING GENETIC RISKS, INSTITUTE OF MEDICINE, *supra* note 4, at 10, 260-64, 276-77.

123. National Institutes of Health Workshop Statement, *Reproductive Genetic Testing: Impact on Women*, in *WOMEN & PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY* 295 app. at 297 (Karen H. Rothberg & Elizabeth J. Thomson eds., 1994).

124. See generally Lori B. Andrews, *Prenatal Screening and the Culture of Motherhood*, 47 HASTINGS L.J. 967, 996-99 (1996) (describing the protections available against mandatory genetic testing of a fetus or its mother).

ministic view of people as nothing more than a packet of unfolding genes. Nelkin and Lindee ably demonstrate that such a view is taking hold. We can envision judges finding that children have a right, and perhaps even an obligation,<sup>125</sup> to learn everything they can about their genetic makeup. The child who feels shadowed by a gene for breast cancer, obesity, attempted rape — or even murder — may have trouble flourishing no matter what other genes he or she received in the genetic shuffle and no matter what other relationships and environmental influences exist in his or her life.

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125. In a letter to the editor of the JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, B. Meredith Burke argued that adolescents should have a duty to learn their genetic makeup. *Genetic Testing for Children and Adolescents*, 273 JAMA 1089 (1995) (letter to the editor from B. Meredith Burke). Burke took issue with an article that stated that adolescents have a “negative right” of deciding not to know. *See id.* Burke pointed out that 7.4% of girls between ages 15 through 17 become pregnant and argued that giving them the right not to know their genetic makeup “downplays the moral and legal obligation to protect an innocent bystander.” *Id.* (referring to the child who might be born with a genetic disease).

