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## ADOPTING A NEW APPROACH TO MEDICAL INFORMATION FOR ADOPTEES

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### I. INTRODUCTION

These days, it is commonplace to visit a doctor and, while completing and updating the seemingly endless pile of necessary papers, fill out a medical history report that includes information on both your medical past and your immediate family's. Due to relatively recent advances in science and medicine, doctors can use this history to diagnose, and sometimes preventatively treat, serious illnesses like cancer and heart disease. However, for a portion of America's population, recent family medical history is not available due to private adoptions at birth.

The confidentiality process in adoption records has gone through several changes since the founding of this country.<sup>1</sup> As it stands today, most states keep all adoption records confidential and closed to the public, as well as to all parties involved in the adoption, to ensure the best interests of the parties involved.<sup>2</sup> Not until approximately thirty years ago did adoption laws begin to reflect the idea that the State should provide an adoptee with basic medical information, both about himself and his birth, as well as a small amount of available medical information about his birth parents and immediate family members.<sup>3</sup> While this medical information has proven useful to adoptees in predicting some possible future health issues,<sup>4</sup> the recent advances in medicine and science have shown that simply providing adoptees with this information at birth is no longer enough to keep them on

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1. See generally Elizabeth J. Samuels, *The Idea of Adoption: An Inquiry into the History of Adult Adoptee Access to Birth Records*, 53 RUTGERS L. REV. 367 (2001) (discussing the historical changes made to adult adoptees' right to access birth records).

2. See generally *id.* at 371–72.

3. Jessica Ann Schlee, Comment, *Genetic Testing: Technology that is Changing the Adoption Process*, 18 N.Y.L. SCH. J. HUM. RTS. 133, 141–42 (2001).

4. See D. Marianne Brower Blair, *Lifting the Genealogical Veil: A Blueprint for Legislative Reform of the Disclosure of Health-Related Information in Adoption*, 70 N.C. L. REV. 681, 705 (1992).

an equal playing field with non-adoptees when it comes to their health.<sup>5</sup> Thus, “[f]or many, the future is blind without a sight of the past.”<sup>6</sup> The fact that scientists and doctors can use family health history to prevent or treat diseases through early testing makes it essential for adoptees to have a method of obtaining updated medical information past the year of their birth.

Some estimates indicate that at least six million adoptees lived in the United States in 1997.<sup>7</sup> “After factoring in birth parents and adoptive parents for each adoptee, the number of persons directly affected by the adoption process grows to over [twenty-four million] persons.”<sup>8</sup> States conducted many of these adoptions privately, particularly those that did not occur recently, so the parties remain anonymous to one another.<sup>9</sup> Thus, an enormous number of Americans are now struggling in a system built on antiquated law that is not very useful, and in fact might be harmful. This Comment proposes a solution to this overlooked dilemma.

First, Section II runs through a brief history of adoption record confidentiality to show that it was not always the policy to keep medical and other information from adult adoptees. Section III then discusses the current state of adoption records. Next, Sections IV and V analyze the key arguments for and against opening records, including how opening or not opening records impacts birth parents, adoptive parents, adoptees, and society as a whole. The sections give specific attention to the argument for quasi-confidentiality, to the extent of non-identifying medical records. In doing so, the Comment focuses on recent medical advancements and how they have affected adoptees. Section VI examines discussions surrounding the dilemma, as well as a limited number of suggestions to remedy the situation.<sup>10</sup> To conclude, Section VII proposes a way to address the issue that keeps the best interest of the child at heart, while still preserving the privacy needs of the adoptive and birth parents.

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5. *See id.* at 704–05.

6. Samuels, *supra* note 1, at 435 (citing *Bradey v. Children's Bureau*, S.C. Ct. Com. Pl., Apr. 9, 1979).

7. Mary L. Saenz Gutierrez, Comment, *Oklahoma's New Adoption Code & Disclosure of Identifying Information*, 34 TULSA L.J. 133, 142 (1998)

8. *Id.*

9. *See id.*

10. It is important to remember that all state laws regarding adoption are different, as well as each state's available options for adult adoptees to find information identifying their birth parents. Although analyzing state law specifics is beyond the scope of this Comment, it does include some generalizations.

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## II. THE HISTORY OF ADOPTION RECORD CONFIDENTIALITY

Adoption, though unknown at common law, has become a necessary element of society, seeking to provide all children with stable home environments even if their birth parents cannot or do not want to care for them.<sup>11</sup> The first prototypes for adoption in America were based on the apprenticeship model inherited from the Puritans in which the State either placed orphans with relatives or apprenticed them out to learn a trade, thereby fulfilling the interests of both the child and society.<sup>12</sup> However, economic interests in a booming America soon became dominant and resulted in severe child labor issues, prompting the need for the regulation of apprenticeships.<sup>13</sup> As a result, state legislatures began to develop and expand their supervisory role in the process,<sup>14</sup> and the term adoption came to be defined as “general child placement with both relatives and nonrelatives.”<sup>15</sup>

American adoption laws began to take shape in the late nineteenth century, with the first laws aiming to sever the child’s legal ties to birth parents and to establish those ties with the adoptive parents.<sup>16</sup> However, at that time, most states did not keep documents confirming these initial legal ties to the birth parents a secret to anyone, including the adoptee and the general public.<sup>17</sup> The 1930s and 1940s saw a growth in confidentiality provisions for members of the public, but parties involved in the adoption retained access.<sup>18</sup> Until the 1950s, most birth parents, adoptive parents, and adoptees could obtain court records of the birth and adoption proceedings.<sup>19</sup> In the 1950s, however, courts closed adoption records to all persons involved, but birth records, such as the original birth certificate, were still

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11. *Mills v. Atlantic City Dep’t of Vital Statistics*, 372 A.2d 646, 649 (N.J. Super. Ct. Ch. Div. 1977).

12. See generally Gutierrez, *supra* note 7, at 137–38 (providing a brief description of the apprenticeship model).

13. *Id.*

14. See *Mills*, 372 A.2d at 649.

15. Gutierrez, *supra* note 7, at 138.

16. *Does v. State*, 993 P.2d 822, 828 (Or. Ct. App. 1999).

A formal process for adoption *centered around the interests of the child* was first enacted by the state of Massachusetts in 1851. This statute provided the basis for our modern view of adoption as “an institution whose purpose, ideally, is ‘to place a homeless child in a home as a complete and equal member of the family constellation, with all the rights, privileges, and responsibilities that accrue to parents’ natural children.’”

Gutierrez, *supra* note 7, at 139 (internal citations omitted).

17. See Samuels, *supra* note 1, at 374 (“In the mid-1920s, there were virtually no confidentiality or secrecy provisions in adoption law.”).

18. *Id.*

19. See *id.* at 377.

available to the adoptee upon reaching the age of majority.<sup>20</sup> The 1960s and 1970s saw the most significant shift in adoption law relating to the confidentiality of records; by 1960, twenty-eight of the forty-nine reporting states declared that both court and birth records only could be obtained through a court order, even by adult adoptees.<sup>21</sup> Finally, by 1990, every state, with the exception of two,<sup>22</sup> had made original birth and court records confidential to everyone, including parties to the adoption.<sup>23</sup>

### III. THE CURRENT STATE OF CONFIDENTIALITY IN ADOPTION RECORDS

Today, state sanctioned access to birth records or other identifying information about birth parents for adult adoptees varies widely from state to state. The simplest way adult adoptees may attempt to access identifying information about their birth parents is through state adoption registries, if available.<sup>24</sup> There are two primary types of state adoption registries: passive and active.<sup>25</sup> In a passive registry, sometimes called a mutual consent registry, both adoptees and birth parents must register their identifying information and consent to release it with the registry.<sup>26</sup> The registry then notifies the parties when two names match.<sup>27</sup> In active registries, sometimes called search and consent registries, once one party registers his or her information, an intermediary searches for the other party and requests his or her consent to release his or her identifying information.<sup>28</sup> If a match is never produced in a passive registry, or if the other party refuses to consent after an active registry search, the adult adoptee's only other option is to go through the courts.<sup>29</sup>

Those states with confidential adoption records usually allow for the release of identifying information of parties to the adoption if there is a "judicial finding of good cause."<sup>30</sup> This "good cause" typically needs to be

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20. *See id.* at 377–78. "Approving these uniform law recommendations, a 1955 *Iowa Law Review* article described as 'the prevailing modern view' the provisions that court records were to be opened only by a court order while original birth records could be inspected by adult adoptees." *Id.* at 378.

21. *Id.*

22. *See id.* at 378, 380. Alaska and Kansas have not closed their records. *Id.* at 378–80.

23. *See id.* at 378–84 (detailing the states' statutory developments).

24. *See generally* Brett S. Silverman, *The Winds of Change in Adoption Laws: Should Adoptees Have Access to Adoption Records?*, 39 *FAM. CT. REV.* 85, 88 (2001) (describing the two main types of adoption registries).

25. *Id.*

26. *Id.*

27. *Id.*

28. *Id.*

29. *Id.*

30. *Id.* at 87.

something beyond just “mere curiosity,” such as a medical or psychological necessity to open the records.<sup>31</sup> Also, the adult adoptee’s “wishes and needs” must be balanced against the interests of others involved in the process, including the adoptive and birth parents, as well as the needs of society to maintain the adoption process in a functioning way.<sup>32</sup>

Birth parents can control the release of their identifying information before the adoptee begins searching in two ways.<sup>33</sup> If the birth parent consents to the release of her identifying information to the adoptee when the adoptee reaches the age of eighteen, the parent may sign an affidavit “indicating [her] prior consent to the release of identifying information.”<sup>34</sup> If the birth parent does not consent to the release of identifying information, the parent may file papers blocking others from accessing the information.<sup>35</sup>

#### IV. ARGUMENTS TO KEEP ADOPTION RECORDS CLOSED

##### A. Social History and Policy

Originally, confidentiality of birth records only applied to the public to legitimize the adoption process,<sup>36</sup> thus keeping the adoptee’s best interests in mind.<sup>37</sup> Putting the original birth certificate under seal and creating a new one with the adoptive parents’ names signified the “rebirth” of the child as a member of his or her new family.<sup>38</sup> Thus, the threat and concern of having the stigma of illegitimacy revealed to the public, which could in turn cause the child humiliation or disgrace, was reduced.<sup>39</sup> Later, the Children’s Bureau published a study addressing concerns that, in the future, the birth parents might intrude upon the adoptive family if identifying information was provided to them.<sup>40</sup> It was not until much later that

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31. See *Golan v. Louise Wise Servs.*, 507 N.E.2d 275, 277 (N.Y. 1987).

32. *Id.* (citing *In re Linda F.M.*, 418 N.E.2d 1302, 1303 (N.Y. 1981)). “Finally, society’s interest in providing children with substitute families through the adoption process, which may be damaged by disclosure, is of importance.” *Id.* (internal citations omitted).

33. See generally Silverman, *supra* note 24, at 88–89.

34. *Id.* at 88.

35. *Id.* at 89. These papers are sometimes called a request for nondisclosure. *Id.*

36. See generally Gutierrez, *supra* note 7, at 140.

37. Silverman, *supra* note 24, at 90.

38. Gutierrez, *supra* note 7, at 140; see also Samuels, *supra* note 1, at 376 (“During the 1930s states began to provide for new birth certificates with the adoptive parents’ names substituted for the birth parents’ names.”).

39. *Id.*; see also Brower Blair, *supra* note 4, at 696.

40. Samuels, *supra* note 1, at 386.

The study spoke approvingly of a trend toward closing the court records of adoption proceedings to

concerns about birth parents' privacy became an issue.<sup>41</sup> Though the privacy of the birth parents was not initially a reason for confidentiality, it has become the primary reason for denying access to records.<sup>42</sup>

## B. Current Arguments

### 1. Concerns of Birth Parents

The primary concern of birth parents who advocate for the continued confidentiality of adoption records is maintaining their anonymity.<sup>43</sup> "The assurance of secrecy regarding the identity of the natural parents enables them to place the child for adoption with a reputable agency, with the knowledge that their actions and motivations will not become public knowledge."<sup>44</sup> This can be a traumatic experience for many birth parents and, for some, a sense of a new beginning is imperative.<sup>45</sup> Many who give children up for adoption are unmarried at the time; the sudden reappearance of a child after many years could significantly alter the new lives the birth parent may have rebuilt since that adoption.<sup>46</sup> In some cases, the child may be a result of a rape,<sup>47</sup> or the birth parents may have considered the option of abortion, for health or other reasons.<sup>48</sup> Reopening these emotional wounds could be extremely painful for the birth parent.<sup>49</sup> In extreme cases,

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public inspection, noting that "parties in interest," who are generally permitted access to the records, might better be termed "parties of record" to ensure that birth parents whose rights have been terminated would not have access. The suggestion was that "harm may be done" if "such a parent learns the whereabouts of the child after adoption."

*Id.* (quoting MARY RUTH COLBY, DEP'T OF LABOR, PROBLEMS AND PROCEDURE IN ADOPTION 118-20 (1941)).

41. *See id.* at 424.

These opinions and commentaries made it seem as if there had never been long periods in many states, only recently concluded in some and ongoing in others, when the recommendation for allowing adult adoptees access had been followed without apparent harm to either individuals or to the institution of adoption.

*Id.*

42. *See id.* at 424-25.

43. *See Golan v. Louise Wise Servs.*, 507 N.E.2d 275, 277 (N.Y. 1987).

44. *Mills v. Atlantic City Dep't of Vital Statistics*, 372 A.2d 646, 649 (N.J. Super. Ct. Ch. Div. 1977).

45. Silverman, *supra* note 24, at 91.

46. *Golan*, 507 N.E.2d at 277 (citing *In re Linda F.M.*, 418 N.E.2d 1302, 1303 (N.Y. 1981)); *see also Mills*, 372 A.2d at 651 (noting the possibility that the birth parent has not revealed the adoptee's existence).

47. *See Silverman*, *supra* note 24, at 92.

48. *See id.* at 93 ("Jane does not want to have to tell a curious adoptee that he or she would have been aborted barring the danger, especially after four decades.").

49. *Golan*, 507 N.E.2d at 277; *see Silverman*, *supra* note 24, at 91-92.

birth parents could fear being blackmailed by the child or others to keep the adoption a secret.<sup>50</sup>

Some birth parents have argued that a contract was made between them and the state to maintain confidentiality.<sup>51</sup> Though some courts recognize that the mutual agreements necessary to adoptions, combined with state regulations, may present a sort of contractual arrangement,<sup>52</sup> at least one court has rejected the idea that adoption law contains “unambiguous promises” by the state leading to a statutory contract.<sup>53</sup> Another state court has recognized that birth parents are assured a right of privacy by the state and opening records may violate that promise.<sup>54</sup> As previously mentioned, state statutes differ on their regulations and promises.

Regardless, the Supreme Court of the United States has recognized the right to privacy.<sup>55</sup> Specifically, the right to be “let alone” was recognized as a vital interest in *Stanley v. Georgia*.<sup>56</sup> Freedom from government intrusion is protected by the Bill of Rights, but freedom from intrusion by other people is left up to the individual states.<sup>57</sup> As a result, many courts have suggested that “the states’ important interest in protecting the privacy of birth parents might itself be ‘compelling’ in constitutional terms.”<sup>58</sup> Although studies and surveys show the percentage of birth parents who are

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50. See *Golan*, 507 N.E.2d at 277.

51. See *Does v. Oregon*, 993 P.2d 822, 828 (Or. Ct. App. 1999). In this case, the plaintiffs were birth mothers seeking to declare Oregon’s Measure 58 invalid. *Id.* at 825. Measure 58, if passed by the voters, would allow adopted persons over the age of twenty-one to gain access to original birth certificates. *Id.* When the Oregon legislature created the state’s voluntary registry system, a provision said, “The state fully recognizes the right to privacy and confidentiality of birth parents whose children were adopted, the adoptees, and the adoptive parents.” *Id.* at 829.

52. See *id.* at 830.

Despite the difficulties in characterizing an adoption in terms of “general principles of contract law,” we accept for present purposes that the mutual agreements required of birth and adoptive parents in completing adoptions, coupled with the pervasive state regulation and, indeed, the state’s dictation of the terms of the agreements, create a species of agreement that may be cognizable . . .

*Id.* at 830.

53. *Id.* at 831.

54. *Mills v. Atlantic City Dep’t of Vital Statistics*, 372 A.2d 646, 649 (N.J. Super. Ct. Ch. Div. 1977) (“Assured of this privacy by the State, the natural parents are free to move on and attempt to rebuild their lives after what must be a traumatic and emotionally tormenting episode in their lives.”).

55. *Griswold v. Connecticut*, 381 U.S. 479, 484–85 (1965).

56. 394 U.S. 557, 564 (1969) (quoting *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting)).

57. *Mills*, 372 A.2d at 651.

58. *Samuels, supra* note 1, at 426 (citing *ALMA Soc’y Inc. v. Mellon*, 601 F.2d 1225, 1236 (2d Cir. 1979)).

insistent on confidentiality for life is very small,<sup>59</sup> that small percentage has resulted in the current system that mainly requires confidential records.<sup>60</sup>

## 2. Concerns of Adoptive Parents

Though the birth parents' right to privacy dominates the confidentiality debate, both birth and adoptive parents have compelling arguments to keep records confidential to all parties, including the adoptee as a child or adult.<sup>61</sup> One concern for adoptive parents is keeping the adoptive relationship as close to a natural family as possible, without the interference of the birth parents.<sup>62</sup> The unexpected, or perhaps undesired, appearance of birth parents, especially when a child is young, could create confusion as to which parents are the "correct" ones.<sup>63</sup> Confidentiality allows a closer bond to develop between the adoptee and the adoptive parents without interference from birth parents or the public.<sup>64</sup>

## 3. Concerns of the General Public

The general public has a stake in maintaining confidentiality in adoptions as well.<sup>65</sup> Adoption has become a way of creating families where it might be biologically impossible to do so.<sup>66</sup> Though acceptance of lifestyles without children has grown throughout the years, there is still a perspective that living a life without children is incomplete or somehow wrong.<sup>67</sup> Childless couples sometimes face pressure to have children, and adoption is a socially acceptable method of doing what sometimes cannot be done biologically.<sup>68</sup> Society also has an interest in "providing children with substitute families through the adoption process...."<sup>69</sup> Single parent families are typically more unstable financially, and if the child ends up in the state child welfare system, he or she is supported by taxpayers.<sup>70</sup> In addition, on

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59. See Silverman, *supra* note 24, at 92–93.

60. See *Does v. State*, 993 P.2d 822, 827–28 (Or. Ct. App. 1999).

61. See *Golan v. Louise Wise Servs.*, 507 N.E.2d 275, 277 (N.Y. 1987).

62. See *id.*

63. See Samuels, *supra* note 1, at 386; see also Silverman, *supra* note 24, at 93 ("Furthermore, the adoptee is 'protected from confusion of knowing two families and the anxiety of choosing to which family they belong.'").

64. Silverman, *supra* note 24, at 90.

65. See Samuels, *supra* note 1, at 407.

66. See *id.*

67. See *id.*

68. See *id.*

69. *Golan v. Louise Wise Servs.*, 507 N.E.2d 275, 277 (N.Y. 1987).

70. See generally Samuels, *supra* note 1, at 408–10 (noting that the social stigma of unwed, single mothers, extreme in the 1950s, still remains to some extent).



the public policy side, many feel that allowing adoption procedures to remain confidential may give pregnant women more incentive to choose adoption over abortion.<sup>71</sup>

## V. ARGUMENTS TO OPEN RECORDS

While the justification for keeping records confidential has been to protect all parties involved, including the adoptee, this fails to take into account the eventual interest many adoptees have in discovering their birth heritage.<sup>72</sup> The social revolution of the 1960s and 1970s resulted in a culture much more accepting of single parenthood and blended families.<sup>73</sup> One effect of the social change is a lessening of the illegitimacy stigma that was for so long associated with adoption.<sup>74</sup> As a result, adoptees in today's society generally feel more comfortable in expressing a desire to search for their birth parents.<sup>75</sup> Since the 1960s, many adult adoptees have petitioned courts and legislatures to gain access to their birth records.<sup>76</sup>

### A. Arguments to Gain Access to All Records, Including Identifying Information

One argument of adult adoptees is that since they are adults, society's interest in maintaining a normal home for a child through adoption is no longer a valid interest.<sup>77</sup> They argue that the identifying information surrounding their births is necessary to complete their identities as a human beings.<sup>78</sup> Adoptees can feel a sense of "genealogical bewilderment" due to a lack of access to information about their birth history.<sup>79</sup> "The adoptee's

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71. Silverman, *supra* note 40, at 90 ("Confidentiality in the adoption process could be the catalyst that brings a traumatized biological parent to place a child up for adoption rather than 'resort to less desirable means of dealing with the prospective parenthood.") (quoting *Bradey v. Children's Bureau*, 274 S.E.2d 418, 421 (S.C. 1981)).

72. Gutierrez, *supra* note 7, at 141.

73. Samuels, *supra* note 1, at 416.

74. *Id.*

75. *Id.*

76. *See id.* at 417.

77. *See Mills v. Atlantic City Dep't of Vital Statistics*, 372 A.2d 646, 649 (N.J. Super. Ct. Ch. Div. 1977) (presenting adult adoptee plaintiffs' argument that the "family relationship which the State has created and protected has grown to maturity.").

78. *Id.* at 650; *see also* Gutierrez, *supra* note 7, at 141 ("Sealing records in adoption blocks the formation of a child's identity by denying her need to be 'connected with [her] biological and historical past.'").

79. Silverman, *supra* note 24, at 93.

sense of identity and ability to develop relationships with others are strongly affected by the separation from the biological parents.”<sup>80</sup>

### 1. The “Right to Know” Argument

Adoptees argue it is fundamentally unfair to deny access to information of which they are “co-owners.”<sup>81</sup> They claim they have a “right to know” the information.<sup>82</sup> However, courts have held that where a state has a compelling interest, the state may regulate an adoptee’s ability to view adoption records as the records are not public information.<sup>83</sup> In states where adoption records are kept confidential, the compelling state interest is now the birth parent’s privacy.<sup>84</sup> A showing of “good cause” typically will override the birth parent’s privacy intent.<sup>85</sup> Courts have held consistently that “while information regarding the heritage, background[,] and physical and psychological heredity of any person is essential to that person’s identity and self image, nevertheless it is not so intimately personal as to fall within the zones of privacy implicitly protected in the penumbra of the Bill of Rights.”<sup>86</sup>

### 2. The Equal Protection Argument

Adoptees have also argued that requiring adoptees to obtain a court order by showing “good cause” to access records violates the equal protection guaranteed by the Fourteenth Amendment.<sup>87</sup> However, courts have held that “constitutional principles of equal protection do not require that all persons be treated identically.”<sup>88</sup> The Equal Protection Clause is not violated when people are treated differently as long as the State gives a reasonable basis that is rationally related to the treatment.<sup>89</sup> Only when the group of individuals are in a “suspect” class must the State show a legitimate interest in sustaining the different treatment.<sup>90</sup> The prevailing

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80. *Id.*

81. *Id.* at 94.

82. *Id.*

83. *Mills*, 372 A.2d at 650; *see Silverman*, *supra* note 24, at 94.

84. *See Mills*, 372 A.2d at 651.

85. *See Golan v. Louise Wise Servs.*, 507 N.E.2d 275, 278 (N.Y. 1987) (“Even in the face of consent by all parties, the court must independently satisfy itself that ‘good cause’ for disclosure has been shown and possible limitations on the use of the information have been explored before allowing access.”).

86. *Mills*, 372 A.2d at 650.

87. *Id.* at 652.

88. *Id.* (citing *State v. Krol*, 344 A.2d 289 (N.J. 1975)).

89. *Id.* at 653.

90. *Id.*

opinion is that being an adoptee does not put one into a “suspect” class,<sup>91</sup> so the State must only show a rational basis for the difference, which is usually the State’s interest in regulating adoption procedures.<sup>92</sup>

### 3. The Birth Parent Argument

According to many birth parents, the reluctance to initiate open records results largely from “spoken and unspoken prohibitions coming from adoption caseworkers, family members, mental health workers, the religious community, and society in general.”<sup>93</sup> Many birth parents claim that the agency told them that the memory of the experience would disappear eventually and that confidential records were for the best.<sup>94</sup>

In reality, “[a] large majority of birth parents are reported to be open to or actually desire contact with adoptees.”<sup>95</sup> Birth mothers may suffer long-term psychological consequences as a result of placing a child up for adoption.<sup>96</sup> These psychological consequences may develop from an “enduring preoccupation” with concerns about the child’s well being.<sup>97</sup> Many birth parents want to relieve those fears, preoccupations, and any guilt by conveying to the adoptee that they made the decision based on the adoptee’s best interest and not out of rejection.<sup>98</sup> Many others want to reconnect with the child they placed for adoption, with the full

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91. *Id.*

An adoptee does not derive that status from an accident of birth but as the result of a legal proceeding which has as the very essence of its purpose the protection of that adoptee’s best interest. Rather than vilify or relegate the adoptee to an inferior status, the adoption process of which the challenged statutes are an integral part often improves the situation of the child, insuring a home, family unit and loving care which might otherwise not be guaranteed.

*Id.* at 653.

92. *Id.*

The state has more than a rational basis, it has a compelling interest in regulating the access sought here. An adoptive child, like the child of a divorce, is not a ‘normal’ child. His or her life has been affected by the intervention of a court proceeding. The State has become involved in the creation of the child’s home life.

*Id.*

93. Samuels, *supra* note 1, at 419 (citing Anne B. Broadzinsky, *Surrendering an Infant for Adoption: The Birthmother Experience*, in *THE PSYCHOLOGY OF ADOPTION* 295, 298–99 (David M. Prodzinsky & Marshall D. Schecter, eds., 1990)).

94. *See* Silverman, *supra* note 24, at 92.

95. Samuels, *supra* note 1, at 416; *see* Silverman, *supra* note 24, at 92–93 (“Concerning the release of identifying information to adoptees, almost [ninety percent] of the birth mothers surveyed said they favored the unsealing of the adoption information.”).

96. Samuels, *supra* note 1, at 418; *see* Silverman, *supra* note 24, at 92 (“The aftermath of adoption leaves the birth parent with feelings of guilt, anger, grief, and depression.”).

97. Samuels, *supra* note 1, at 418.

98. Silverman, *supra* note 24, at 92–93.

understanding that they have no legal claim to the adoptee.<sup>99</sup>

#### B. Arguments for Access to Non-Identifying Information, Like Medical Records

While the above arguments for opening all records note the possible concerns and fears of all parties involved, this Comment focuses on the adult adoptee's arguments to open records in order to obtain his or her biological or family medical history.<sup>100</sup> Currently, in order to access these records, an adoptee must typically have a medical emergency or medical condition which necessitates access to the adoptee's family history.<sup>101</sup> Sometimes an even more serious condition is present, such as organ failure, where it might be necessary to gather identifying information and actually contact the birth parents.<sup>102</sup> The current state of medical treatment shows that a medical emergency is not the only condition where access to one's family medical history is necessary.

Mental health history, though often ignored, is also a powerful reason for access to family medical information.<sup>103</sup> Studies show that many mental illnesses such as substance abuse, bipolar disorder, and eating disorders can be based in part on a genetic predisposition.<sup>104</sup> Courts have held that mental health problems can establish the "good cause" necessary to open adoption files at least to non-identifying information about medical history.<sup>105</sup> Initial access to adoptee's family medical history, however, could save time and

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99. *Id.* at 93.

100. *See Golan v. Louise Wise Servs.*, 507 N.E.2d 275, 276 (N.Y. 1987) (noting an adoptee commenced action because he was suffering from a heart condition and the genetic information would be useful in his treatment).

101. *See id.* at 276. In *Golan*, the plaintiff suffered from a heart condition that caused him to have a heart attack and subsequently lose his commercial pilot's license. *Id.* To get his license back, the plaintiff needed more family medical history information from his biological parents because he had an unknown nature of risk. *Id.*

102. *See Doe v. Ward Law Firm, P.A.*, 579 S.E. 303, 305 (S.C. 2003) ("We held a party could not show the required good cause absent a compelling need for identifying information about the biological parents.").

103. *See id.* at 304–08. In *Ward*, the adopted child's mental health began to deteriorate around the age of thirteen. *Id.* at 304. The child threatened several members of the family, and after several years of psychiatric care the child's doctors suggested that a complete family medical and psychological history would be helpful. *Id.*

104. *See Anorexia Nervosa May be Genetic*, NEWS-MEDICAL.NET, Feb. 21, 2007, <http://www.news-medical.net/?id=22075> (discussing the results of a ten year study on anorexia nervosa and how the researchers performing the study suggest that many sufferers may have a genetic predisposition to the disease); *see also* Brower Blair, *supra* note 4, at 703–05 (discussing how disclosure of medical history can lead to early diagnoses of mental illness in children).

105. *See Ward*, 579 S.E.2d at 305.

money in diagnosing the problem, rather than petitioning for a court's decision.

### 1. History of Access to Medical Information

“For most of the twentieth century adoption agencies commonly gave very limited information about the medical and social background of a child and the child's biological family to adoptive parents.”<sup>106</sup> However, in the mid-1970s, people on all sides of the adoption debate began to recognize that providing full disclosure of the adoptee's medical, family, and social history offered “psychological and practical benefits to both the adoptee and the adoptive family.”<sup>107</sup> The majority of adoption experts now agree that full disclosure is necessary and endorse it as a policy for adoption professionals.<sup>108</sup>

Currently, no national standard exists, and instead state legislatures decide whether and how an adoptee's medical or family health history information is disclosed.<sup>109</sup> As such, state procedures differ in the degree of specificity that needs to be applied in obtaining and releasing that information.<sup>110</sup> As of 2001, only twenty-three states required disclosure of the information to the adoptive parents before or within a reasonable time after the adoption is finalized.<sup>111</sup>

Unfortunately, more than half the states do not require the information to be given to adoptive parents, who in turn could pass it on to the adoptee.<sup>112</sup> Additionally, in many states that do require disclosure of the information, adoption agencies often leave vital, usually negative, information out of the history.<sup>113</sup> Usually, this results out of a concern that a child with negative medical information or family history might not be placed with adoptive parents.<sup>114</sup> “Selective disclosure of this nature has been a particular problem for many families who adopted older children from state agencies,

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106. Brower Blair, *supra* note 4, at 695.

107. Schlee, *supra* note 3, at 141.

108. Brower Blair, *supra* note 4, at 698–99.

109. Schlee, *supra* note 3, at 142.

110. *Id.* at 142–43 (“Typically, state adoption statutes simply refer to the collection and disclosure of health information that is ‘known,’ ‘available,’ ‘obtainable,’ or ‘reasonably known.’”).

111. *Id.* at 145.

112. See Brower Blair, *supra* note 4, at 695–96; Schlee, *supra* note 3, at 145.

113. See Brower Blair, *supra* note 4, at 696.

114. *Id.* (“Richard Hochstra, director of Michigan's public adoption services, explained: ‘You want the best for these children. So it is easy to withhold information, not in a malicious sense, but in the sense that you are highlighting some of the best in these children, and you tend to leave out some of the problems.’”).

only to discover subsequently a long history of psychiatric disorders.<sup>115</sup> Agencies are also concerned about harm caused to the adoptee's self-esteem and self-image because of the knowledge of a genetic predisposition to a certain disease or health problem.<sup>116</sup>

## 2. Advances in Medical Treatments of Preventative Disease

With every passing year, scientific and medical advances are made to treat, and even prevent, potentially fatal diseases and conditions.<sup>117</sup> The Office of Public Health Genomics has stated that family medical history can play a vital role in preventing many health problems.<sup>118</sup> Some diseases are genetic, including well-known conditions such as heart disease, breast cancer, colon cancer, diabetes, and high blood pressure, as well as less common conditions such as hemophilia, cystic fibrosis, and sickle cell anemia.<sup>119</sup> The public has taken note of this, as a recent survey by the U.S. Surgeon General found that ninety-six percent of Americans believe knowing their family health history is important.<sup>120</sup>

Knowledge of family history of a certain health problem can help a doctor decide how to better treat a patient.<sup>121</sup> The doctor may choose to run a screening test for early detection of a disease, such as an early mammogram for breast cancer, if a family history indicates that it might be important.<sup>122</sup> Knowledge of family history of an illness might also prompt a doctor more earnestly to suggest lifestyle changes such as quitting smoking, working out, or eating better in order to reduce the risk of illness.<sup>123</sup> In extreme cases, a screening may suggest more radical alternatives to prevent a disease, such as a premature mastectomy to prevent breast cancer, or removing a colon to prevent colon cancer.<sup>124</sup>

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115. *Id.*

116. *See id.* at 697.

117. *See generally* Human Genome Project Information, Medicine and the New Genetics, <http://www.ornl.gov/sci/techresources/Human-Genome/medicine/medicine.shtml> (last visited Feb. 8, 2009) (describing the role of genetics in medical diagnosis).

118. CTR. FOR DISEASE CONTROL, NAT'L OFFICE OF PUB. HEALTH GENOMICS, FAMILY HISTORY: RESOURCES AND TOOLS, <http://www.cdc.gov/genomics/public/famhix/faq.htm> (last visited Feb. 8, 2009).

119. *See id.*; *see also* U.S. DEP'T OF HEALTH & HUMAN SERVS., U.S. SURGEON GENERAL'S FAMILY HISTORY INITIATIVE, <http://www.hhs.gov/familyhistory> (last visited Feb. 8, 2009).

120. U.S. DEP'T OF HEALTH & HUMAN SERVS., *supra* note 119.

121. CTR. FOR DISEASE CONTROL, *supra* note 117.

122. *See id.*

123. *See id.*

124. *See* UNIV. OF MICH. HEALTH SYS., COLON CANCER RISK: IT'S OFTEN ALL IN THE FAMILY (2007), available at <http://www.newswise.com/articles/view/527643/?sc=rsmn>.

### 3. The Current Issue in Regard to Adoptees

While adoptees have gained more access to medical health history at the time of birth, a problem lies in the fact that many diseases and conditions, for which updated information could be useful, may not develop until later in a person's life.<sup>125</sup> Although an adoptee might receive medical information and a family health history at birth or at the time of adoption, this information can be premature.

For example, if "Sara" is adopted when she is three months old, her adoptive parents may receive, and pass on to her, medical information including any known conditions of her birth parents, grandparents, and possibly even great-grandparents. However, perhaps when Sara is ten years old, her biological maternal grandmother develops breast cancer. Then, when she is fourteen, her biological maternal great-aunt develops breast cancer, and when she is in her twenties and thirties her birth mother and her birth mother's sister develop breast cancer. None of this information will have been provided in the medical information, even if it contains a family medical history, because that genetic predisposition to breast cancer was not yet known at the time of Sara's adoption. Yet, knowing of this seemingly obvious predisposition to breast cancer could potentially save Sara's life. Regardless of whether adoption records are open to adult adoptees or not, a system to provide adoptees with any new family medical history should exist.

## VI. PREVIOUSLY PROPOSED PLANS

There have been a few proposals to deal with this dilemma. The first way is to keep the system as it is now, where medical information may be updated anonymously when deemed necessary by either the birth parents, adoptive parents, or adoptee.<sup>126</sup> The second way is the relatively new technology of genetic testing, which could be useful in obtaining necessary medical information.<sup>127</sup>

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125. See generally Schlee, *supra* note 3, at 136 (discussing the ability to predict "adult onset" disorders).

126. See Silverman, *supra* note 24, at 96-97.

127. See Human Genome Project Information, Gene Testing, [http://www.ornl.gov/sci/techresources/Human\\_Genome/medicine/genetest.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetest.shtml) (last visited Feb. 8, 2009) [hereinafter Human Genome Project Information, Gene].

### A. Keeping the Current System

Many argue that keeping the system the way it is will be the only way to protect those birth parents and adoptees who oppose open records.<sup>128</sup> Medical privacy and confidentiality is an important issue to consider when contemplating a medical information disclosure system.<sup>129</sup> In some jurisdictions, there even has been a recent recognition of a tort known as the “breach of the duty of medical confidentiality.”<sup>130</sup>

The underlying rationale for the duty of medical confidentiality is two-fold: first, protection of the patient’s right to determine who has access to personal information, and second, the concern that patients will be less likely to seek medical treatment or provide complete and accurate information to medical personnel without an assurance of confidentiality.<sup>131</sup>

If a birth parent will not voluntarily provide the information necessary, it would be difficult to make the disclosure of the information mandatory or investigate their medical records without running into privacy issues.<sup>132</sup> Some argue that asking for more than a birth parent is willing to give could prompt some birth parents to seek a different option, “such as abortion or turning to black-market adoption.”<sup>133</sup>

While some have advocated sanctions on the birth parents or adoption agencies if an accurate and complete medical history is not provided, others argue that any attempt to do so “would likely prove ineffective and could raise significant privacy concerns.”<sup>134</sup> In some situations, the only way to know that a birth parent is giving inaccurate or incomplete information would be to run diagnostic tests on the parent and possibly on his or her immediate family.<sup>135</sup> Those against sanctions argue that “reasonable efforts” to obtain the necessary information should be enough to put the adoptee on sufficiently equal footing with non-adoptees in the area of family health history.<sup>136</sup> If future medical information were needed or required, “correspondence through a guardian ad litem may often prove a

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128. See generally Silverman, *supra* note 20, at 97.

129. See Brower Blair, *supra* note 4, at 693.

130. *Id.* at 692.

131. *Id.* at 692–93.

132. See *id.* at 751.

133. *Id.* at 746.

134. *Id.* at 763.

135. See *id.* at 760–63.

136. *Id.* at 761 (“‘Reasonable efforts’ to investigate should in most instances provide adoptive and prospective adoptive parents with the information available to the birth parent.”).



solution.”<sup>137</sup> If birth parents want to communicate this medical information to the adoptee voluntarily, some courts allow them to petition the court to appoint an intermediary to provide updated medical history to the adoptee, regardless of age.<sup>138</sup> It is unknown, however, how many birth parents are aware of this option.

### B. Genetic Testing

With the advances in medicine has come the ability to test one’s genes for predispositions to certain genetic diseases; this is known as gene testing.<sup>139</sup> When a genetic predisposition for a disease exists, there will be a mutated sequence of deoxyribonucleic acid (“DNA”) in the system.<sup>140</sup> Scientists have developed short DNA strands called “probes” which complement the mutated strands of genes, and when they inject those probes into the person’s DNA sample, the probes will bind to a mutated strand, if present.<sup>141</sup> By directly examining the DNA molecules, a scientist can predict the chance of an adult-onset of diseases such as cancer, Alzheimer’s, or Huntington’s.<sup>142</sup> Currently, over one thousand of these genetic tests exist.<sup>143</sup>

Gene testing can be incredibly helpful in clarifying a specific diagnosis or guiding a doctor to the most appropriate treatment available.<sup>144</sup> Gene testing has also proven to be helpful in the case of adoptive children, who would otherwise have a very limited medical history or none at all.<sup>145</sup> In fact, many adoptive parents have started to request genetic tests prior to adopting a child in order to get a full understanding of any future medical conditions that might arise.<sup>146</sup> Adoption agencies generally allow genetic testing, especially when the child’s medical records are inadequate.<sup>147</sup> In fact, “[m]any adoption agencies welcome these genetic tests in hopes it will promote more adoptions and reduce wrongful adoption suits caused by a lack of medical information supplied at the time of adoption.”<sup>148</sup>

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137. *Golan v. Louise Wise Servs.*, 507 N.E.2d 275, 278 (1987) (internal citations omitted).

138. *In re Baby Boy “S.S.”*, 719 N.Y.S. 2d 311, 313 (N.Y. App. Div. 2001).

139. See Human Genome Project Information, Gene, *supra* note 127.

140. *Id.*

141. *Id.*

142. *Id.*

143. *Id.*

144. See *id.*

145. See Schlee, *supra* note 3, at 133.

146. See *id.* at 150.

147. *Id.*

148. *Id.*

However, negative consequences may result from genetic testing on minor adoptees prior to adoption.<sup>149</sup> First, the adoptee has no choice in this testing, so his or her right to privacy may be abridged.<sup>150</sup> Second, if the test results do show a genetic predisposition, the child can be injured “psychologically, personally, and socially.”<sup>151</sup> Adoptees risk stigmatization by future employers and insurance agencies because an involuntary genetic test is part of their permanent medical record.<sup>152</sup> Additionally, the primary public concern is that potential adoptive parents will attempt to “strive for the perfect child” by testing prospective adopted children, and possibly deciding not to adopt any children who have been labeled as unhealthy.<sup>153</sup> “This runs contrary to public policy, which is to promote the best interest of the child, the basis of the current legal standard in adoption proceedings.”<sup>154</sup>

#### VII. A MODERN PROPOSAL

As has been shown, “[t]here is no way to create adoption legislation that will appease each sect of the triad—birth parents, adoptees, and adoptive parents.”<sup>155</sup> While there is clearly an increasing need for a better method of disclosing family health history and updated medical information to adoptees, instituting a new or improved system involves weighing the interests of several different parties, as well as dealing with complex issues of privacy.<sup>156</sup> Perhaps it is time to try a uniform system that affects all states that keep adoption records closed. Allowing different state social service departments and agencies to control the dissemination of information might lead to the “continuation of the same practices that generate disrupted adoptions, untreated or misdiagnosed children, and myriad wrongful adoption suits.”<sup>157</sup>

“In a sociological study of birth parents in the mid-1970s, ninety-five percent of the respondents indicated an interest in updating information

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149. *See generally id.* at 151–82 (discussing negative effects genetic testing may have on potential adoptees).

150. *See id.* at 152–53.

151. *Id.* at 156.

152. *See generally id.* at 167–76.

153. *Id.* at 158.

154. *Id.* at 159.

155. Silverman, *supra* note 24, at 96 (“Each group is very different, and they all have their own specific needs. Unfortunately, these needs not only do not line up but also are in direct conflict with each other.”).

156. Brower Blair, *supra* note 4, at 694.

157. *Id.* at 714–15.

about themselves in the agency records.”<sup>158</sup> This is a very positive statistic for instituting a system in which birth parents are required to update their family health history on an annual or biannual basis. There are, of course, privacy concerns, which is why the system would need to remain anonymous and records would need to be sealed to the public. State social services agencies and private adoption agencies could send a standardized form to the birth parents on record, requesting any updated medical information to be returned to the agency. While issues of honesty and accuracy would still be a problem, statistics show that this would likely be in a minority of cases.<sup>159</sup> The previously noted study suggests that allowing birth parents this opportunity could provide them an outlet through which they could receive some peace of mind that the child they relinquished remains healthy and alive, maybe even in part through their efforts.

Getting in touch with birth parents could also be an issue, especially if they have moved or started a new family, from whom they want to keep the adoption a secret. There are, however, ways to maintain anonymity. For instance, the birth parent could keep a separate post office box to receive the necessary forms, they could be reminded by electronic mail at an anonymous account, or they could contact the agency or state to make the necessary updates. Simple logistical issues should not keep states from instituting a necessary system for updating the medical information.

The system should be as mandatory as possible, to ensure that birth parents know this is a serious matter, while still guaranteeing privacy. To ensure that birth and adoptive parents are aware the system is in the best interest of the child, counseling for both sets of parents at the time of adoption should be mandatory. As far as the adoptive parents are concerned, this system would pre-empt any need for invasive genetic testing, as frequently updated medical information would allow for the discovery of any possible medical problems as quickly as adoptive parents might discover such health problems in their biological families.

It should be acceptable, if they desire, for adoptive parents to keep the information from the adoptee during childhood. This might facilitate the idea of keeping the adoptive family as natural as possible. Adoptive parents could be concerned about the attachment their adopted child might make to the birth parents if the child is bombarded yearly with new information about his or her birth parents. However, these records should be turned over to the adoptee upon reaching adulthood, either by the adoptive parents

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158. *Id.* at 711.

159. *See id.*

or by the State, as it is necessary for adoptees to have this information to make informed medical and reproductive decisions in the future.<sup>160</sup>

As far as un-cooperative birth or adoptive parents, extreme cases could warrant sanctions and fines if counseling has not worked to promote the message. Much like a birth parent who does not pay court-ordered child support, a birth parent who chooses to give a child up for adoption still should have a responsibility when it comes to that child's health. Recent medical advancements have made this evolution in adoption law necessary to try to put adoptees on equal footing with non-adoptees.

Furthermore, a system like this could possibly end the legal arguments surrounding open records. Arguing for a system of completely open records over-generalizes the issue of adoption records into a case for those who have a mere curiosity rather than a necessity to be exposed to certain types of information. Even if a state is convinced that open adoption records are necessary, it will most likely apply this proactively, such that any adoptions taking place from the point of legislation forward will have open records.<sup>161</sup> This would not help those who have been adopted up to this point in time.

A new system requiring updated information annually or biannually would give agencies and state social service systems the opportunity to send a form to the birth parents or adult adoptee giving both birth parents and adoptees the change to send in identifying information about themselves, if they desire. This would facilitate a system that brings more attention to passive registries, which would cut down on search and consent costs.

One of the primary problems with registries, and the reason why they have such a low success rate, is that not many people are informed of them. This is typically because any contact with adoptees and birth parents from agencies is extremely limited after the first year following adoption. Instituting a system like this would provide an opportunity to update vital medical information while still protecting the privacy of those who want the protection provided by the laws now in place. At the same time, the majority would have a state sanctioned outlet through which they could voluntarily send in identifying information. All parties would be aware of the passive registry, and if the identifying information was not given, then it could be assumed the party in question did not desire to communicate with the other party.

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160. *Id.* at 705–06.

161. *See* Gutierrez, *supra* note 6, at 145–46 (discussing Oklahoma's amended Adoption Code which permits "only adult persons whose adoptions are finalized after November 1, 1997 (the effective date of the Code) to obtain copies of their original birth certificates").

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### VIII. CONCLUSION

The system designed to promote and control adoption needs to remember its primary focus: the best interest of the child. As times have changed, so have the interests of the adoptee and how the adoptee relates to others in the world. While everything possible is done to ensure that the adoptee finds a loving home that will be the best possible substitute for a natural family, there is still a biological and genetic connection to the birth parents that may need to be regulated, especially in the areas of health and medicine. The most recent medical advances have left many adoptees wondering where they fit in with this new system of preventative medicine and procedures.

The adoption system needs to adapt to the times and find a way to provide adoptees with this information, which sometimes may just be precautionary, but at other times may save a life. The arguments to open and close records are relevant in bringing up possible concerns and fears, but records do not have to be open to maintain a system designed to update medical information. An efficiently designed system would be able to maintain anonymity while still providing the necessary information. As a bonus, it could provide an outlet for birth parents and adoptees to reunite if desired without the expense to the adoptee, birth parent, or State of using a search and consent registry.

In 1979, a South Carolina judge wrote: “The law must be constant with life.”<sup>162</sup> As life changes and progresses, so must the law.

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162. Samuels, *supra* note 1, at 435 (citing *Bradey v. Children's Bureau*, S.C. Ct. Com. Pl., Apr. 9, 1979).

