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# Genetic Information Discrimination in Public Schools: A Common-Sense Exception

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# Genetic Information Discrimination in Public Schools: A Common-Sense Exception

*Tyler Wood*[*]

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## I. INTRODUCTION

When Colman Chadam's parents learned their son had genetic markers consistent with cystic fibrosis (CF), they probably did not realize that those markers would one day affect what school Colman could attend.[1] Unfortunately,

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1. Sarah Zhang, *DNA Got a Kid Kicked out of School–and It Will Happen Again*, WIRED (Feb. 1, 2016, 7:00 AM), https://www.wired.com/2016/02/schools-kicked-boy-based-dna/ (on file with *The University of the Pacific Law Review*).

that is exactly what happened in 2012 when school officials at Jordan Middle School in Palo Alto, California learned of Colman's genetic markers.[2] The school officials decided to send him to another school because they feared he, and two other students with CF, posed cross-threats to each other.[3] People were outraged when they heard the story, and some saw the story as a harbinger of a dystopian future in which genetics determines all aspects of life.[4] In California, however, such a dystopian future may not be as inevitable as Chadam's situation might suggest, because California law may already prohibit public schools from treating Chadam as Jordan Middle School did.[5] This Comment uses the facts of Chadam's case as a framework for exploring whether CalGINA, California's Genetic Information Non-Discrimination Act, does in fact prohibit Jordan Middle School's conduct.[6]

First, however, some background information on genetics is in order because it will provide valuable context for analyzing whether CalGINA applies to Chadam's situation.[7] Accordingly, Part II(A) provides a brief history of the study of genetics.[8] Part II(B) discusses what genetic information discrimination is, its history, and its existence today.[9] Part III details existing legislation protecting against genetic information discrimination in the United States, California, and two other states, respectively.[10] Parts IV and V discuss Chadam's case and whether CalGINA applies to his situation.[11] Assuming CalGINA does apply to public schools, this Comment explores whether existing law furnishes an exception that exempts the school from CalGINA's requirements.[12] Finally, a variation of the facts in Chadam's case demonstrates the need for an exception to genetic information nondiscrimination laws that allows schools to discriminate on the basis of genetic information when a

2. *Id*.

3. *Id*.

4. *See* Barry Starr, *Palo Alto Student Asked to Leave School Because of His DNA*, KQED (Feb. 8, 2016) http://ww2.kqed.org/futureofyou/2016/02/08/student-was-asked-to-leave-school-because-of-his-dna/ (on file with *The University of the Pacific Law Review*) (referencing Gattaca, a movie that portrays a world in which people who are not genetically engineered are considered "in-valids," precluded from various professions, and relegated to menial jobs).

5. *See infra* Parts V.A–B (discussing whether CalGINA applies to public schools and if so, whether the school's conduct falls within the scope of what CalGINA prohibits).

6. *See infra* Part V.A. (discussing whether CalGINA applies to public schools); *infra* Part V.B (discussing whether the school's conduct in Chadam's case falls within the scope of what CalGINA prohibits).

7. *See infra* Part II.A–B, III (discussing, respectively, genetics, the study thereof, the history of genetic information discrimination, and existing legislation).

8. *See infra* Part II.A (discussing the history of genetics).

9. *See infra* Part II.B (discussing historical and more recent instances of genetic information discrimination).

10. *See infra* Part III (discussing existing legislation).

11. *See infra* Part IV (describing the facts of Chadam's case); Part V (exploring whether CalGINA applies to public schools and whether the school's conduct constituted discrimination).

12. *See infra* Part V.B.3 (discussing whether there is an existing exception that would have justified Jordan Middle School's conduct); *see also infra* Part VII (proposing an exception to existing law that would have justified Jordan Middle School's conduct if Chadam had actually had CF).

school learns, through genetic information, that a student poses an imminent threat to other students, teachers, or staff. [13]

## II. GENETICS

Analyzing CalGINA and whether it applies to Chadam's case warrants a discussion of the history of genetics and genetic information discrimination.[14]

### *A. Heredity's Heritage*

Gregor Mendel is considered the "father of genetics."[15] During his famous pea-plant experiments in the 1860s, Mendel discovered dominant and recessive traits and the principles that govern inheritance.[16] While at the time Charles Darwin's theory of evolution overshadowed Mendel's work, scientists rediscovered Mendel's research and theories on inheritance in the early 1900s and consider them foundational principles in both biology and genetics.[17]

Throughout the late 19th and early 20th centuries, scientists continued learning more about inheritance and genetics.[18] Importantly, in 1944, Oswald Avery concluded that DNA was the medium through which people inherit traits.[19] Seven years later, a century's worth of work culminated in Watson and Crick's discovery of the shape of DNA: the now-iconic double helix.[20]

In 1990, the National Institute of Health and the Department of Energy launched the Human Genome Project.[21] The Project's goal was to sequence each of the 3 billion base pairs that comprise the human genome.[22] They completed the project in 2003.[23] Since then, researchers have discovered more than 1800 disease genes and developed more than 2000 genetic tests for various human conditions.[24] Although these discoveries produced immense medical and scientific benefits, many people worry that easy access to genetic information

13. *See infra* Part VII (proposing an exception to existing law that would have justified Jordan Middle School's conduct if Chadam had actually had CF).

14. *See infra* Part II.A–B (providing the context for the legal and social landscape in which the Chadam's case takes place).

15. Abigail Lauren Perdue, *Justifying GINA*, 78 TENN. L. REV. 1051, 1055 (2011).

16. *Id.*

17. *Id.*

18. *Genetics*, BRITANNICA, https://www.britannica.com/science/genetics (last visited Nov. 13, 2016) (on file with *The University of the Pacific Law Review*).

19. *Id.*

20. J.D. Watson & F.H. Crick, *Molecular Structure of Nucleic Acids: A Structure for Deoxyribose Nucleic Acid*, 4356 NATURE 737, 737–38 (1953).

21. *Human Genome Project*, NAT'L INST. HEALTH https://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=45 (last visited Nov. 13, 2016) (on file with *The University of the Pacific Law Review*).

22. *Id.*; Perdue, *supra* note 15, at 1057–58.

23. NAT'L INST. HEALTH *supra* note 21.

24. *Id.*

will provide a new basis for discrimination.[25] Because our understanding of genetics is relatively new, it is no surprise that genetic information discrimination is not rampant—but it does exist.[26]

### *B. Genetic Information Discrimination*

There is great debate about the extent to which people discriminate against each other because of genetic information.[27] According to the Council for Responsible Genetics, there are hundreds of documented cases of genetic information discrimination, most of which occur in the employment and insurance contexts.[28] Some examples include: "seven-year-old Danny," who had "a gene predisposing him to a heart disorder," which an insurance company used to justify denying him coverage despite the fact that, other than taking medication to minimize the risk of a heart attack, he was healthy; Jonathon, whose health coverage was eliminated when he was diagnosed with Fragile X Syndrome, which forced his mother to quit her job so they could qualify for Medicaid; and Kim, who was fired one week after her employer discovered that her mother died of Huntington's disease, despite her receiving outstanding performance reviews.[29] Critics, however, emphasize the need to investigate whether claims like these are legitimate because they are often based on subjective, unverified, individual accounts.[30] Often implicit in such criticism is the sentiment that non-discrimination laws are premature.[31] But proponents of genetic nondiscrimination laws argue their rather preemptive nature cuts the other way, extolling the benefits of addressing discrimination before it becomes rampant.[32] But regardless of the extent to which genetic discrimination exists today, there is a history of genetic discrimination in the United States,[33] and there are at least some recent instances of genetic information discrimination, both of

25. Rivka Jungreis, Comment, *Fearing Fear Itself: The Proposed Genetic Information Nondiscrimination Act*, 15 J. L. POL'Y 211, 212 (2007).

26. *See infra* Part II.B (discussing both historical and more modern instances of genetic discrimination).

27. Jeffrey Morrow, *Insuring Fairness: The Popular Creation of Genetic Antidiscrimination*, 98 GEO. L.J. 215, 222 (2009); *see* Jungreis, *supra* note 25, at 226–27.

28. COUNCIL FOR RESPONSIBLE GENETICS, GENETIC DISCRIMINATION: POSITION PAPER (2001), *available at* http://www.councilforresponsiblegenetics.org/pageDocuments/2RSW5M2HJ2.pdf (on file with *The University of the Pacific Law Review*).

29. *Id*.

30. *Cases of Genetic Information Discrimination*, NAT'L HUMAN GENOME RESEARCH INST., https://www.genome.gov/12513976/cases-of-genetic-discrimination/ (last visited Nov. 13, 2016) (on file with *The University of the Pacific Law Review*).

31. *See Health Law–Genetics–Congress Restricts Use of Genetic Information by Insurers and Employers*, 122 HARV. L. REV. 1038, 1043 (2009) (concluding that GINA was premature); Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 441 (2010).

32. Roberts, *supra* note 31, at 441.

33. *Infra* Part II.B.1 (describing historical genetic discrimination in the United States).

which inform and frame the current policy debate.[34] The following two sections address, respectively, the history of genetic information discrimination in the United States and some recent instances thereof.[35]

*1. A History of Genetic Discrimination*

In the early 1900s, the United States embraced the "eugenics" movement's goal of "improving the quality of the stock."[36] Proponents of eugenics sought to accomplish this goal by discouraging procreation amongst the so-called "genetic underclass" (those who were physically or intellectually inferior) through coerced sterilization and promoting procreation between those considered genetically superior (those who were physically or intellectually superior).[37] As one eugenicist put it, "The superficially sympathetic man flings a coin to the beggar; the more deeply sympathetic man builds an almshouse for him so that he need no longer beg; but perhaps the most radically sympathetic of all is the man who arranges that the beggar not be born."[38]

Starting with Indiana in 1907, many states passed sterilization laws.[39] In *Buck v. Bell*, America's most famous instance of forced sterilization, the Supreme Court upheld a Virginia sterilization statute as it was applied to Ms. Carrie Buck, who, as the court put it, was an 18-year-old "feeble minded" woman who was the daughter of a "feeble-minded" woman and the mother of a "feeble-minded child."[40] In *Buck*, Justice Holmes, expressing a sentiment similar to that of the "sympathetic man" described above, noted "it is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind . . . . Three generations of imbeciles are enough."[41]

In 1910, the Department of Genetics of the Carnegie Institution of Washington established the Eugenics Records Office that conducted genetic research on both cacogenic[42] and unsocial families and aristogenic[43] families[44] to

34. *Infra* Part II.B.2 (discussing some more modern instances of genetic information in the United States).

35. *Infra* Part II.B.1–2 (discussing, respectively, historic and modern instances of genetic discrimination in the United States).

36. Perdue, *supra* note 15, at 1098.

37. *Id*.

38. *Id*.

39. *Id*.

40. Buck v. Bell, 274 U.S. 200 (1927).

41. *Id*. at 207.

42. Webster's defines "cacogenic" as "dysgenic" or "relating to Cacogenesis." *Cacogenic*, WEBSTER'S DICTIONARY, https://www.merriam-webster.com/dictionary/cacogenic (last visited Oct. 6, 2017) (on file with *The University of the Pacific Law Review*). "Dysgenic" is further defined as "tending to promote survival of or reproduction by less well-adapted individuals (as the weak or diseased) especially at the expense of well-adapted individuals (as the strong or healthy)." *Dysgenic*, WEBSTER'S DICTIONARY, https://www.merriam-webster.com/dictionary/dysgenic (last visited Oct. 6, 2017) (on file with *The University of the Pacific Law Review*). "Cacogenesis" is defined as an "inability to produce hybrids that are both viable and fertile" or "racial

give advice on who was "fit for marriage."[45] While the atrocities the Nazis committed during WWII to advance eugenics ultimately turned public opinion against the movement,[46] even as late as 1971, the geneticist Bentley Glass supported "the right of every child to be born with a sound physical and mental constitution, based on a sound genotype."[47] He claimed parents would one day have no "right to burden society with a malformed or a mentally incompetent child."[48] Fortunately, Glass's prophecy has not come true, but this history of eugenics demonstrates genetic information is not entirely new and provides a foundation for concern as our understanding of and ability to alter DNA continues to develop.[49]

### *2. Genetic Information Discrimination Today*

There are more recent instances of genetic information discrimination as well.[50] In *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, the plaintiffs, both current and former employees of Lawrence Berkeley Laboratory (LBL), brought ADA, Title VII, and privacy claims against LBL, alleging that the employer tested their blood and urine for sickle-cell disease, syphilis, and pregnancy without their knowledge or consent.[51] The District Court for the Northern District of California dismissed all of the claims as barred by the statutes of limitations, but the Ninth Circuit reversed and remanded the Title VII and constitutional claims.[52] LBL eventually settled with the plaintiffs.[53]

Another example involved the Burlington Northern Santa Fe Railroad.[54] The

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deterioration especially when due to the retention of inferior breeding stock." *Cacogenesis*, WEBSTER'S DICTIONARY, https://www.merriam-webster.com/dictionary/cacogenesis (last visited Oct. 6, 2017) (on file with *The University of the Pacific Law Review*).

43. "Aristogenic" is the adjective form of "aristogenesis," which Webster's defines as "a theory now not widely accepted in biology: evolution is the product of a continuous orderly creative faculty innate in living matter and manifested in response to external stimuli at such a rate that perfection of an adaptation anticipates the need of that adaptation." *Aristogenic*, WEBSTER'S DICTIONARY, https://www.merriam-webster.com/dictionary/aristogenic (last visited Oct. 6, 2017) (on file with *The University of the Pacific Law Review*).

44. Charles B. Davenport, *The Work of the Eugenics Records Office*, 15 EUGENICS REV. 305, 315 (Apr. 1923).

45. Perdue, *supra* note 15, at 1098.

46. *Health Law–Genetics*, *supra* note 31, at 1039.

47. Perdue, *supra* note 15, at 1098.

48. *Id.*

49. *Supra* Part II.B.1 (discussing the history of genetic information discrimination in the United States).

50. *Infra* Part II.B.2 (discussing more modern instances of genetic information discrimination in the United States).

51. Norman-Bloodsaw v. Lawrence Berkeley Laboratory, 135 F.3d 1260 (9th Cir. 1998).

52. *Id.*

53. Roberts, supra note 31, at 465.

54. Press Release, Equal Emp't Opportunity Comm'n, EEOC Settles ADA Suit Against BNSF for Genetic Bias (Apr. 18, 2001), https://www.eeoc.gov/eeoc/newsroom/release/4-18-01.cfm (on file with *The University of the Pacific Law Review*).

Equal Employment Opportunity Commission (EEOC) filed suit against the railroad because it was testing employees, without their knowledge or consent, for a genetic condition that caused carpel tunnel syndrome.[55] The Railroad quickly settled with the EEOC and agreed to all of the EEOC's demands.[56]

While neither case resulted in a court ruling, both highlight how genetic information potentially presents a new means of discriminating.[57] Both cases also provide a contextual backdrop for the circumstances in which Congress passed GINA, the first major legislation addressing genetic information discrimination.[58]

## III. GENETIC INFORMATION DISCRIMINATION LAWS

Various states began prohibiting genetic information laws in the mid-1990s, but the federal government did not follow suit until 2008 when it passed the Genetic Information Nondiscrimination Act (GINA).[59] In 2011, California passed its own genetic information protection law, commonly known as CalGINA.[60] Other states have similar laws that extend protections to a wide variety of extents.[61]

### *A. GINA: History and Substance*

Congresswoman Louise Slaughter and Senator Olympia Snowe first attempted to address genetic information discrimination with the Genetic Information Nondiscrimination Act in Health Insurance of 1995.[62] The bill failed to pass either house.[63] Various iterations of the bill were reintroduced in each of the next five legislative sessions, but Congress did not pass any of them.[64] With time, however, the political climate tilted in favor of GINA.[65] In 2008, the Genetic Information Nondiscrimination Act garnered broad support and passed

55. *Id*.

56. *Id*.

57. *See supra* Part III.B (describing the facts of the Lawrence Berkeley Laboratory and Burlington Northern Santa Fe Railroad cases, both of which are instances of employers using genetic information to make certain decisions).

58. *See infra* Part IV (discussing GINA).

59. *President Bush Signed GINA into Law!*, COALITION FOR GENETIC FAIRNESS, http://www.geneticfairness.org/act.html (last visited Jan. 7, 2017) (on file with *The University of the Pacific Law Review*).

60. SB 559, 2011 Leg., 2011–2012 Sess., (Cal. 2011) (enacted by Chapter 261) (on file with *The University of the Pacific Law Review*).

61. *See infra* Part III.C (describing the laws of West Virginia and Utah).

62. *Genetic Discrimination*, NAT'L HUMAN GENOME RESEARCH INST., https://www.genome.gov/10002077/#al-4 (last visited Nov. 13, 2016) (on file with *The University of the Pacific Law Review*).

63. *Id*.

64. *Id*.

65. *The New Genetic Nondiscrimination Act*, COUNCIL FOR RESPONSIBLE GENETICS, http://www.councilforresponsiblegenetics.org/pageDocuments/PGWOGJ2F3O.pdf (last visited Jan. 7, 2017) (on file with *The University of the Pacific Law Review*).

in the House 414–1 and in the Senate 95–0, and President Bush signed the bill into law shortly thereafter.[66] "Senator Ted Kennedy applauded GINA as 'the first civil rights bill of the [21st] century.'"[67]

GINA defines genetic information as "information about (i) [an] individual's genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual."[68] It further defines genetics tests as "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes."[69]

Title I of GINA prohibits group plans and individual health insurers from discriminating based on genetic information in health insurance.[70] Specifically, insurers are not allowed to require, request, or purchase genetic information to use in eligibility, coverage, underwriting, or premium decisions.[71] Additionally, insurers may not require genetic tests, nor can insurers request genetic tests outside of a few narrowly defined circumstances.[72] Title II prohibits similar conduct in the employment context.[73] It prevents employers from using genetic information in firing, hiring, promotion, or pay decisions and does not allow them to require or request genetic tests as a condition of employment unless certain narrow exceptions apply.[74]

Legislators faced many difficulties trying to pass this bill.[75] Opponents of GINA worried about the burdens GINA might place on industry.[76] In addition, the lack of documented cases of genetic discrimination prompted some to question whether the bill was even necessary.[77] Proponents, on the other hand, believed that protecting against genetic information discrimination would assuage the public's fears of this discrimination, thereby prompting them to take advantage of genetic testing benefits and ultimately ushering in a new era of personalized medicine.[78] But given that only 6% of adults have ever undergone

66. NAT'L HUMAN GENOME RESEARCH INST., *supra* note 63.

67. COALITION FOR GENETIC FAIRNESS, *supra* note 60.

68. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 101(d)(7)(A), 122 Stat. 881, 885.

69. *Id*.

70. *Id*. at 883.

71. *Id*. at 883, 888, 896.

72. *Id*. at 883–84, 888–89, 896–97.

73. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 101(d)(7)(A), 122 Stat. 881, 907–13.

74. *Id*. at 907–13. It is worth noting here that GINA would likely have protected Danny, Jonathon, and Kim, the examples mentioned above from the Council for Responsible Genetics.

75. COUNCIL FOR RESPONSIBLE GENETICS, *supra* note 66.

76. *Congress Restricts Use of Genetic Information by Insurers and Employers*, *supra* note 31; COUNCIL FOR RESPONSIBLE GENETICS, *supra* note 66.

77. *See* Zhang, *supra* note 1.

78. Press Release, Rep Slaughter Celebrates Signing of GINA Bill, (May 21, 2008), https://louise.house.gov/media-center/press-releases/may-21-2008-rep-slaughter-celebrates-signing-gina-bill (on file with *The*

genetic testing, it is clear society has not yet realized that vision of a new era of personalized medicine.[79] That statistic, however, is not necessarily a condemnation of GINA's effectiveness so much as it may be a result of the lack of treatments for conditions genetic testing might discover.[80] Indeed, it is difficult, if not impossible, to gauge GINA's effectiveness because it is largely a preemptive law.[81] Nonetheless, it seems the more people find out about GINA, the more they use it.[82] Since GINA became law in 2008, people have notified the EEOC of over 1,000 GINA violations,[83] and when the EEOC took its first case to trial in 2015, the court awarded two employees $2.25 million.[84] This suggests that the law has had some effect.[85] Still, many claim GINA does not go far enough and alternative methods are superior.[86] For example, some scholars advocate for a privacy rights based approach to protecting against genetic information discrimination.[87] Other scholars believe GINA should include disparate impact provisions.[88] Additionally, some scholars highlight the need for extending protections to additional contexts and broadening the scope of the protections themselves.[89] While states' approaches to protecting against genetic

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79. HARVARD T. H. CHAN SCH. OF PUB. HEALTH, THE PUBLIC AND GENETIC EDITING, TESTING, AND THERAPY (2017), *available at* https://cdn1.sph.harvard.edu/wp-content/uploads/sites/94/2016/01/STAT-Harvard-Poll-Jan-2016-Genetic-Technology.pdf (on file with *The University of the Pacific Law Review*).

80. Sharon Begley, *Consumers Aren't Wild About Genetic Testing–Nor Are Doctors*, STAT (Feb. 12, 2016), https://www.statnews.com/2016/02/12/consumers-arent-wild-genetic-testing-doctors/ (on file with *The University of the Pacific Law Review*).

81. Roberts, *supra* note 83.

82. Natasha Gilbert, *Why the Devious Defecator Case is a Landmark for US Genetic-Privacy Law*, NATURE (June 25, 2015), http://www.nature.com/news/why-the-devious-defecator-case-is-a-landmark-for-us-genetic-privacy-law-1.17857 (on file with *The University of the Pacific Law Review*).

83. *Genetic Information Non-Discrimination Act Charges*, EEOC, ghttps://www.eeoc.gov/eeoc/statistics/enforcement/genetic.cfm (last visited Jan. 7, 2017) (on file with *The University of the Pacific Law Review*).

84. The case, *Lowe v. Atlas Logistics Group*, 102 F. Supp. 3d 1360, 1363–64 (N.D. Ga. 2015), gained some notoriety because of its colorful facts. An employer was trying to figure out which of his employees were leaving human feces in a warehouse that stored produce. The employer suspected one of the plaintiffs was, as the court put it, the "devious defecator" and asked the employees to do a cheek-swab. The plaintiffs' DNA did not match the DNA of the feces. Despite the reasonableness of wanting to determine who was defecating in the warehouse, the court held that asking for the cheek-swabs violated GINA. Julie Beck, *Genetic Privacy, as Explained by Mystery Poopers*, ATLANTIC (Aug. 3, 2015), http://www.theatlantic.com/technology/archive/2015/08/the-case-of-the-mystery-pooper-dna-privacy/400355/ (on file with *The University of the Pacific Law Review*); Lowe v. Atlas Logistics Group, 102 F.Supp.3d 1360, 1363–64 (N.D. GA 2015).

85. *Genetic Information Non-Discrimination Act Charges*, *supra* note 83; Beck, *supra* note 86.

86. Robert C. Green, Denise Lautenbach & Amy L. McGuire, *GINA, Genetic Discrimination, and Genomic Medicine*, NEW ENG. J. MED. (Jan. 29, 2015).

87. *See* Morrow *supra* note 27, at 237–39.

88. Ifeoma Ajunwa, *Genetic Data and Civil Rights*, HARV. CIV. RTS.-CIV. LIBERTIES J. (2016) (on file with *The University of the Pacific Law Review*).

89. Anya Price, *Comprehensive Protection of Genetic Information One Size Privacy Models May Not Fit All*, 79 BROOK. L. REV. 175, 177 (2013).

information discrimination vary widely, California has secured broader protections against genetic information discrimination.[90]

### *B. CalGINA*

Like many states, California has its own genetic information nondiscrimination law.[91] California's law goes further than federal law, extending protections in many additional contexts.[92] CalGINA's legislative history suggests the "range of protections [under federal GINA] incomplete for Californians" and that the state had a "compelling public interest in realizing the medical promise of genomics[,] . . . relieving the fear of discrimination[,] and in prohibiting its actual practice."[93] Much like GINA, CalGINA defines genetic information as follows:

> information about (i) [an] individual's genetic tests, (ii) The genetic tests of family members of the individual (iii) The manifestation of a disease or disorder in family members of the individual . . . [and] includes any request for, or receipt of, genetic services, or participation in clinical research that includes genetic services, by an individual or any family member of the individual.[94]

Where GINA prohibits discrimination on the basis of genetic information only in the health insurance and employment contexts, CalGINA extends that protection to the following areas: (1) "all business establishments of every kind whatsoever;"[95] (2) access to any "program or activity that is conducted, operated, or administered by the state or by any state agency, is funded directly by the state, or receives any financial assistance from the state;"[96] (3) housing, including mortgage lending and restrictive covenants;[97] and (4) the provision of emergency medical care and services.[98] CalGINA also amended the Education Code to ensure that schools have access to more resources so they can more readily combat genetic information bias.[99] While many states have some level of genetic

90. *See infra* Part V (discussing CalGINA).

91. *See* SB 559, 2011 Leg., 2011–2012 Sess., (Cal. 2011) (enacted by Chapter 261) (adding genetic information as a protected basis in a number of different contexts).

92. *Id*.

93. *Id.* § 1.

94. *Id*. § 3.

95. *Id*. 3(b).

96. *Id*. 6(a).

97. SB 559, 2011 Leg., 2011–2012 Sess., § 16–16.5 (Cal. 2011) (enacted by Chapter 261).

98. *Id*. § 3–3.5.

99. *Id*. § 4(a).

information discrimination protections in place, most states do not extend them to public schools.[100]

### *C. Genetic Information Discrimination Laws in Other States*

Most states have genetic information nondiscrimination laws that are commensurate with federal law.[101] Indeed, 35 states ban genetic information discrimination in both the health insurance and employment contexts.[102] Another 13 states ban genetic information discrimination only in health insurance, which brings the number of states prohibiting this discrimination to 48.[103] In addition, 17 states extend protections to disability insurance, and 15 states provide protection in the life insurance context.[104] Meanwhile, only nine states prohibit discrimination on the basis of genetic information in long-term care insurance.[105]

Most states do not prohibit genetic information discrimination in public schools.[106] West Virginia may come the closest since it prohibits collecting "confidential student information," which includes genetic information.[107] The West Virginia statute does not address whether or how a school can use genetic information if it inadvertently obtains it.[108] Not only do most states not extend protections to public schools, but some appear to expressly authorize use of genetic information in public schools.[109]

For example, Utah authorizes collecting students' biometric identifiers or information on certain conditions.[110] The definition of biometric identifier includes a "human biological sample used for valid scientific testing or screening," and the definition of biometric information includes "information . . . based on an individual's biometric identifier; and [information] used to identify [an] individual."[111] Arguably, these definitions would include genetic information because genetic information is information that can be used to identify an individual.[112] Thus, Utah appears to expressly authorize collecting genetic

100. *See infra* Part III.C (describing the laws in other states).

101. Price, *supra* note 91.

102. NAT'L HUMAN GENOME RESEARCH INST., *supra* note 63.

103. *Id.*

104. *Id.*

105. *Id.*

106. *Genome Statute and Legislation Database Search*, NAT'L HUM. GENOME RES. INST., https://www.genome.gov/policyethics/legdatabase/pubsearchresult.cfm?content_type=1&content_type_id=1&topic_id=1&source_id=1&keyword=education&search=Search (last visited Nov. 13, 2016) (on file with *The University of the Pacific Law Review*).

107. W. VA. CODE ANN. § 18-2-5h(c)(9) (West, Westlaw through 2016 Regular Session).

108. *Id.*

109. UTAH CODE ANN. § 53A-1-1406(6) (West, Westlaw through 2016 Fourth Special Session).

110. *Id.*

111. *Id.* § 53A-1-1402(3)–(4).

112. *See id.* § 53A-1-1402 (using the definitions, human biological samples, and information based on biometric identifiers, both of would seem to include genetic information since DNA is a biological sample and

information in public schools, and although it regulates the use of that information, the regulations primarily relate to maintaining disciplinary records and schedules for expunging.[113] California, on the other hand, prohibits denying access to any "program or activity that is conducted, operated, or administered by the state or by any state agency, is funded directly by the state, or receives any financial assistance from the state" on the basis of genetic information discrimination.[114] If that provision includes public schools, then California may be the only state to extend genetic information protection to public schools.[115]

## IV. CHADAM V. PALO ALTO UNIFIED SCHOOL DISTRICT

In 2012, a Palo Alto school teacher learned one of her students, Colman Chadam, had genetic markers consistent with Cystic Fibrosis (CF).[116] Chadam did not have CF,[117] but two other students at his school did. [118] People with CF are not supposed to be around each other because they can easily transmit to and contract from each other a certain kind of bacteria that CF causes them to carry in their lungs.[119] The teacher incorrectly told these other students' parents that Chadam had CF, and the parents asked the administration to send Chadam to another school.[120] Although Chadam did not have CF and posed no threat to the students with CF, the administration complied and sent him to another school.[121]

Initially, Chadam's parents sought an injunction in state court but settled with the school district.[122] It appears once the school learned Chadam did not actually have CF, they let him return to his original school. [123] Ultimately, Chadam attended the other school for only 11 days before his original school

is used to identify people).

113. *Id*. § 53A-1-1407.

114. CAL. GOV'T CODE § 11135(a) (West, Westlaw current with all 2016 Reg. Sess., Ch. 8 of 2015–2016 2nd Ex. Sess., and all propositions on 2016 ballot).

115. *Supra* Part III.B–C (discussing genetic information protection in California and the rest of the United States).

116. Andrew Hanson, *Genetic Discrimination: A New Frontier*, HARV. C.R.–C. L. L. REV. (Feb. 28, 2016), http://harvardcrcl.org/genetic-discrimination-a-new-frontier/ (on file with *The University of the Pacific Law Review*).

117. Starr, *supra* note 4.

118. Zhang, *supra* note 1.

119. *Cross-Infection*, CYSTIC FIBROSIS TRUST, https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/cross-infection (last visited Jan. 8, 2016) (on file with *The University of the Pacific Law Review*).

120. Zhang, *supra* note 1.

121. Jill Tucker, *Boy in School Flap Over Cystic Fibrosis*, SFGATE (Nov. 6, 2016, 8:48 AM), http://www.sfgate.com/health/article/Boy-in-school-flap-over-cystic-fibrosis-3944802.php (on file with *The University of the Pacific Law Review*).

122. Sue Dremann, *Palo Alto DNA-Privacy Case Could Have Wide Implications*, PALO ALTO ONLINE (Jan. 24, 2016, 7:03 AM), http://www.paloaltoonline.com/news/2016/01/24/palo-alto-dna-privacy-case-could-have-wide-implications (on file with *The University of the Pacific Law Review*).

123. *Id.*

allowed him to return.[124] Despite settling with the school over the original injunction, the family is later sued the school in federal court, claiming, among other things, the school violated the Americans with Disabilities Act (ADA).[125] Specifically, the parents argue that genetic information consistent with a certain disease constitutes a perceived disability for ADA purposes. [126] The United States Ninth Circuit Court of Appeals rejected the school district's motion to dismiss and let the ADA claim proceed, which means the argument may prove successful.[127] Because Chadam and the school district settled the initial dispute and are now litigating the ADA theory, no court has ruled on whether the school's conduct was permissible under CalGINA .[128] The next Part, therefore, explores whether CalGINA prohibits the school district's conduct.[129]

## V. CALGINA'S APPLICATION TO CHADAM'S SITUATION?

In determining whether CalGINA applied to Chadam's situation, the first issue is whether public schools fall into one of the additional contexts to which California extends genetic information discrimination protections.[130] Then, assuming CalGINA does apply to public schools, the next issue is whether CalGINA prohibited the school's conduct.[131]

### *A. Does CalGINA Apply to Public Schools?*

CalGINA adds genetic information to the list of protected bases in California Government Code section 11135.[132] Section 11135, therefore, prohibits "unlawfully den[ying] full and equal access to . . . or . . . discrimination" on the basis of, among other things, genetic information in "program[s] or activit[ies] that [are] conducted, operated, or administered by the state or by any state agency, is funded directly by the state, or receives any financial assistance from the state."[133] California Code of Regulations section 11150 defines "funded

124. Tucker, *supra* note 123.

125. Dremann, *supra* note 124.

126. Chadam v. Palo Alto Unified Sch. Dist., 666 F. App'x 615, 616 (9th Cir. 2016).

127. *Id.* at 617.

128. *See supra* Part III.B CalGINA (explaining the provision in CalGINA protecting against discrimination in programs or activities operated or funded by the state, a definition which presumably covers public schools). As of April 4, 2017, the court had ordered a settlement conference to take place on July 28, 2017. Order Scheduling Settlement Conference at 1, Chadam v. Palo Alto Unified Sch. Dist., No. C 13-4129 CW, 2014 WL 5694080 (N.D. Cal. Apr. 4, 2017).

129. *Infra* Part V.

130. *See supra* Part V.A (explaining that California may be the only state that extends genetic information protections to students in public school).

131. *Infra* Part V.B (discussing whether CalGINA prohibits the school's conduct in Chadam's case).

132. SB 559, 2011 Leg., 2011–2012 Sess., § 6(a) (Cal. 2011) (enacted by Chapter 261); CAL. GOV'T CODE § 11135(a).

133. CAL. GOV'T CODE § 11135(a).

directly by the state" as "any payment, transfer, or allocation of State funds to any recipient."[134] "Recipient" is further defined as, among other things, a "local agency . . . who regularly employs five or more persons and who receives State support, as defined in [section 11150], in an amount in excess of $10,000 in the aggregate per State fiscal year or in an amount in excess of $1000 per transaction."[135] Finally, the definition of "local agency" includes "school district."[136] Therefore, as long as a school district regularly employs five or more people and receives more than $10,000 per year from the state, the school district will be subject to the law.[137]

Although it is possible for public schools or school districts to not qualify as a "recipient" either by: (1) not regularly employing five or more people or (2) not receiving $10,000 during a fiscal year, it seems highly unlikely.[138] Even the smallest California school district, Alpine County Unified School District, employs at least five people.[139] Further, although public schools receive some funds from local sources, given that the state furnishes nearly 60% of the public school system's budget,[140] it is hard to imagine the smallest school district not receiving the requisite $10,000.[141] Therefore, the vast majority of public schools, including Palo Alto Unified School District, satisfy the definition of "recipient."[142] The next issue is whether public schools are "programs" or "activities" as defined in CalGINA.[143]

California Government Code section 11135 prohibits discrimination on the basis of, among other things, genetic information in "program[s] or activit[ies] that [are] conducted, operated, or administered by the state or by any state agency, is funded directly by the state, or receives any financial assistance from the state."[144] The California Code of Regulations includes "provision of

134. CAL. CODE REGS. tit. 2, § 11150 (2017).

135. *Id.*

136. *Id.*

137. *See* SB 559, 2011 Leg., 2011–2012 Sess., § 6(a) (Cal. 2011) (enacted by Chapter 261) (prohibiting discrimination on the basis of genetic information in "program[s] or activit[ies]" that are, among other things, "funded directly by the state"); *see also id*. (defining "funded directly by the state" and "recipient").

138. *See Administration*, ALPINE COUNTY UNIFIED SCH. DISTRICT, http://alpinecoe.k12.ca.us/administration/ (last visited Jan. 8, 2017) (on file with *The University of the Pacific Law Review*) (showing that the administration for the smallest school district in the state employs at least six people in its administration, which does not include the employees at its three schools).

139. *Id.* (showing that the administration for the smallest school district in the state employs at least six people in its administration, which does not include the employees at its three schools).

140. *Education Budget Facts–CalEdFacts*, CAL. DEP'T EDUC., http://www.cde.ca.gov/fg/fr/eb/cefedbudget.asp (last visited Jan. 8, 2017) (on file with *The University of the Pacific Law Review*).

141. *Administration*, *supra* note 138; CAL. DEP'T EDUC., *supra* note 140.

142. *Administration*, *supra* note 138 (showing that the administration for the smallest school district in the state employs at least six people in its administration, which does not include the employees at its three schools).

143. *See* CAL. GOV'T CODE § 11135(a) (requiring that in order to be subject to the section there must be a program or activity that is receiving government funds).

144. *Id.*

education" in its definition of "program or activities."[145] Therefore, because public schools provide education, they are a "program or activity" within the purview of CalGINA.[146] Accordingly, because public schools receive state funding and are a "program" or "activity" for the purposes of CalGINA, they are subject to the law and cannot unlawfully discriminate on the basis of genetic information.[147] The question that remains then is whether the school's conduct in Chadam's case constituted genetic discrimination under CalGINA.[148]

### *B. Does CalGINA Prohibit the School's Conduct in the Chadam Case?*

Whether Chadam's school violated CalGINA would, it seems, have turned on: (1) whether the information the school used—the genetic markers—fits the definition of genetic information in CalGINA; (2) if it does, whether its actions qualified as discrimination or a denial of equal access to a program or activity; and (3) if so, whether another law justified its actions.[149]

The first issue is whether the information the school used falls within CalGINA's definition of genetic information.[150] CalGINA defines genetic information as, in part, "information about . . . [an] individual's genetic tests."[151] It is significant that Chadam had genetic markers consistent with CF.[152] Moreover, a genetic test discovered the information.[153] Thus, this information is most likely genetic information under CalGINA.[154]

The next issue is whether the school's use of the information violated CalGINA.[155] CalGINA does not allow programs and activities that receive government funding to unlawfully deny full and equal access or unlawfully discriminate on the basis of genetic information.[156] In Chadam's case, the school's actions arguably fit both the denying access and discrimination prongs

145. CAL. CODE REGS. tit. 2, § 11150 (2017).

146. *See id.* (including in its definition of "program or activities" the "provision of education," which schools do); *see also* CAL. GOV'T CODE § 11135(a) (prohibiting discrimination on the basis of genetic information in "programs or activities" receiving government funding).

147. *Education Budget Facts–CalEdFacts*, *supra* note 142; CAL. CODE REGS. tit. 2, § 11150 (2017); CAL. GOV'T CODE § 11135(a).

148. *See* CAL. GOV'T CODE § 11135(a) (prohibiting discrimination, which the school would not have violated if they did not discriminate notwithstanding the fact that they are subject to CalGINA).

149. *Id.*

150. *Id.*

151. *See id.* (defining genetic information the same way section 51 of the Civil Code does); *see also* SB 559, 2011 Leg., 2011–2012 Sess., § 6(a) (Cal. 2011) (enacted by Chapter 261) (defining genetic information).

152. Hanson, *supra* note 118.

153. *Id.*

154. *See* Starr, *supra* note 4 (explaining that doctors completed genetic tests on Chadam as a young child when they were trying to diagnose a heart condition, and that his mother volunteered this information to the school when she enrolled him there).

155. *Infra* Part V.B.2 (discussing whether the school's use of Chadam's information violated CalGINA).

156. CAL. GOV'T CODE § 11135(a).

because he was denied access to the school he was attending because of his genetic information.[157] The school district, on the other hand, could have argued that Chadam retained access to a school—just not Jordan Middle School.[158] But Chadam might nonetheless have countered that being allowed in every school except one is not full and equal access under CalGINA.[159] Regardless, even if the school district successfully proved it did not unlawfully deny Chadam full and equal access, Chadam still would have had an excellent argument that the school district discriminated against him because of his genetic information.[160] It is unclear exactly how a court would have decided the case, but the fact that Chadam's family and PAUSD settled after the family originally sought an injunction might suggest that the school district did not think it had strong case.[161] In addition, given that the school district's belief that Chadam had CF was the impetus behind sending him to another school, it appears as though the reason they later reversed course is because they learned that Chadam did not actually have CF.[162] Ultimately, given the language of the statute and the facts of Chadam's case, the school likely violated CalGINA.[163]

Assuming the school district unlawfully discriminated against Chadam on the basis of his genetic information, the issue remains whether there is an exception that might have justified the school's actions.[164] For example, the California Education Code authorizes school officials to send a student home if "there is a good reason to believe that the child is suffering from a recognized contagious or infectious disease."[165] Such a student "shall not be permitted to return until the school authorities are satisfied that any contagious or infectious disease does not exist."[166] It seems, therefore, that the school district not only had the authority to send Chadam home or, presumably, to another school, but also had an affirmative duty to prevent his return until it knew he was no longer

157. *See supra* Part IV (describing Chadam's story and how Jordan Middle School sent him to another school for 11 days because of his genetic information).

158. *See supra* Part IV (describing that PAUSD did not deny Chadam access to all schools in the district—just the one he currently attended).

159. *See* CAL. GOV'T CODE § 11135(a) (prohibiting denial of full and equal access to public schools on the basis of genetic information).

160. *See id.* (prohibiting denial of full and equal access to public schools on the basis of genetic information).

161. *See supra* Part IV (noting that the family settled with PAUSD after filing an injunction); *see also supra* Part V.B.2 (discussing whether the school's actions violated CalGINA).

162. Dremann, *supra* note 124.

163. *See* CAL. GOV'T CODE § 11135(a) (prohibiting denial of full and equal access to public schools on the basis of genetic information); *see also supra* Part VII (describing how Chadam's school sent him to another school for 11 days because of his genetic information).

164. *Infra* Part VIII.B.3.

165. CAL. EDUC. CODE § 49451 (West, Westlaw current with all 2016 Reg. Sess., Ch. 8 of 2015–2016 2nd Ex. Sess., and all propositions on 2016 ballot).

166. *Id.*

contagious.[167] The school district raised this defense before the U.S. District Court for the Northern District of California, but the court dismissed the case on other grounds and did not rule on that issue.[168] The lack of a ruling on how section 49451 relates to CalGINA warrants a brief discussion of whether section 49451 might have justified the school's actions.[169]

Chadam did not have CF.[170] Therefore, there was no contagious or infectious disease.[171] Nonetheless, the fact that Chadam did not actually have CF does not render this defense moot because the statute is based, in part, on the school's reasonable belief.[172] Thus, if the school reasonably believed that Chadam had CF, its conduct seems to fall under section 49451.[173] But as the Chadams point out in their brief to the Ninth Circuit, once the students with CF's parents found out about Chadam's genetic markers, the school waited nearly a month before it sent him to the other school.[174] Had they sent him to another school immediately, perhaps PAUSD would have had a strong argument that they reasonably believed Chadam posed a risk of infection to the other students with CF.[175] But this delay cuts against the proposition that section 49451 justified PAUSD's conduct because it suggests they did not actually believe he posed an imminent threat to the other students with CF.[176] Moreover, even if the school district did subjectively and honestly believe Chadam posed some sort of threat to other students, such belief seems considerably less reasonable in light of the month-long delay.[177] This delay demonstrates PAUSD had time to learn the truth it ultimately discovered: Chadam did not actually have CF and, therefore, posed no threat to the other students.[178] Therefore, it seems highly unlikely that section 49451 alone would exonerate PAUSD.[179]

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167. *Id.*

168. Chadam v. Palo Alto Unified Sch. Dist., No. C 13-4129 CW, 2014 WL 5694080, at *7 (N.D. Cal. Nov. 4, 2014), *a'ff'd in part, r'ev'd in part and remanded*, Chadam v. Palo Alto Unified School District, 666 F. App'x 615, 617 (9th Cir. 2016); *see also* Chadam, *supra* note 128, at 617 (not addressing the district court's decision to not address the argument based on California Education Code § 49451).

169. *See* Chadam, *supra* note 128, at 617 (not addressing the district court's decision to not address the argument based on California Education Code section 49451).

170. *Id.*.

171. *Id.*; *Chadam v. Palo Alto Unified Sch. Dist.,* No. C 13-4129 CW, 2014 WL 5694080, at *7 (N.D. Cal. Nov. 4, 2014), *a'ff'd in part, r'ev'd in part and remanded*).

172. *See* CAL. EDUC. CODE § 49451 (using the language "good reason to believe").

173. *See id*. (using the language "good reason to believe").

174. Brief for Petitioner at *5–10, Chadam v. Palo Alto Unified Sch. Dist., No. 14-17384, 2016 WL 6694941 (9th Cir. Nov. 15, 2016) (detailing the timeline between when the school and parents found out about Chadam's genetic markers and when the school pulled Chadam from class).

175. *See* CAL. EDUC. CODE § 49451 (using the language "good reason to believe").

176. *See id.* (using the language "good reason to believe"); *see* Brief for Petitioner, *supra* note 176, at *5–10 (detailing the timeline between when the school and parents found out about Chadam's genetic markers and when the school pulled Chadam from class).

177. *See* Brief for Petitioner, *supra* note 176, at *5–10 (detailing the timeline between when the school and parents found out about Chadam's genetic markers and when the school pulled Chadam from class).

178. *Id.* (detailing the timeline between when the school and parents found out about Chadam's genetic

In sum, there is a compelling argument that CalGINA applies to public schools and would have prohibited PAUSD's conduct.[180] Why the Chadams did not pursue a claim under CalGINA is not perfectly clear.[181] Regardless, because Chadam did not actually have CF, one cannot help but wonder what the outcome would have been if Chadam had actually had CF.[182] The remainder of this Comment uses a factual variation of Chadam's case—in which Chadam has CF—to explore whether an applicable exception to CalGINA that would have permitted the school's conduct exists, and if not, whether one should, and what it should be.[183]

## VI. WHAT IF CHADAM HAD CYSTIC FIBROSIS?

Had Chadam been diagnosed with CF, he would have posed a risk to students with CF at his school because people with CF often have various strands of a bacteria in their lungs that are commonly called pseudomonas.[184] Pseudomonas are generally not a threat to people who do not have CF, but people with the condition are especially capable of both transmitting pseudomonas to other people with CF and particularly susceptible to contracting pseudomonas from other people with CF.[185] Consequently, it is generally recommended that people with CF not meet face to face and keep at least six feet away from each other.[186] Therefore, if Chadam had CF, the school would have had to keep him and other students with CF separate from each other.[187] Perhaps this would have

markers and when the school pulled Chadam from class).

179. *See* CAL. EDUC. CODE § 49451 (using the language "good reason to believe"); *see* Brief for Petitioner, *supra* note 176, at *5–10 (detailing the timeline between when the school and parents found out about Chadam's genetic markers and when the school pulled Chadam from class).

180. *See supra* Part V.B.1 (concluding that the school used genetic information); Part V(B)(2) (concluding that the school's actions violated CalGINA); Part V.B.3 (concluding that section 49451 does not provide an independent justification for the school's actions).

181. Jennifer Wagner, *Genetic Discrimination Case Against School District is Appealed to Ninth Circuit*, GENOMICS L. REP. (Feb. 2, 2016), http://www.genomicslawreport.com/index.php/2016/02/02/genetic-discrimination-case-against-school-district-is-appealed-to-ninth-circuit/ (on file with *The University of the Pacific Law Review*); *but see* Jon Brooks, *Alleged Genetic Discrimination at California School Strikes a Nerve, Raises More Questions*, KQED SCIENCE (Feb. 10, 2016), https://ww2.kqed.org/futureofyou/2016/02/10/alleged-genetic-discrimination-at-california-school-strikes-a-nerve-and-raises-more-questions/ (on file with *The University of the Pacific Law Review*) (noting that Chadam's attorney wants a ruling that will affect more than just California).

182. *See supra* Part V.B.3 (discussing the impact of, among other things, the fact that Chadam did not have CF).

183. *See infra* Part VI, VII (discussing what would have happened if Chadam did have CF and proposing language for an exception that would justify the school's conduct if he had).

184. *Cross-Infection*, *supra* note 121.

185. *Id.*

186. Dr. Daniel J. James, *Cystic Fibrosis Patients Losing a Connection*, BOS. GLOBE (Nov. 11, 2013), https://www.bostonglobe.com/lifestyle/health-wellness/2013/11/18/cystic-fibrosis-patients-losing-connection/vl06v1Je4DiI5CLjNLMrMP/story.html (on file with *The University of the Pacific Law Review*).

187. *Id.*

been possible at Chadam's school, but to foster a CalGINA analysis and any potential exceptions that might apply to this hypothetical situation, this Comment assumes ensuring Chadam and the other students with CF were never within six feet of each other was unfeasible, unrealistic, or too risky.[188] Moreover, this Comment will not explore whether there were other options the school might have taken, but will instead focus on whether there is an exception that would have justified sending Chadam to another school, and if not, whether an exception should be created.[189] The following section addresses whether section 49451 would have justified the school's conduct if Chadam had CF.[190]

### *A. Would Section 49451 Have Justified PAUSD's Conduct if Chadam Had Cystic Fibrosis?*

Curently, CalGINA does not provide an exemption that would allow a school to discriminate against a student based on genetic information in certain circumstances where it would otherwise be prohibited.[191] Therefore, if there is an exemption that might have justified PAUSD sending a student with CF to another school, it would be in a source independent of CalGINA.[192] Section 49451 of the California Education Code is relevant because it permits school officials to send students home when they have "good reason to believe that the child is suffering from a recognized contagious or infectious disease," and the student "shall not be permitted to return until the school authorities are satisfied that any contagious or infectious disease does not exist."[193] While the analysis of section 49451 in the actual case turned on the reasonableness of the school's belief,[194] this hypothetical does not because the student has CF.[195] Rather, the key issue is simply whether the school's conduct would otherwise have satisfied the statute.[196]

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188. *Infra* Part VI, VII (discussing, respectively, what would have happened if Chadam did have CF and a proposed exception).

189. *Infra* Parts VI, VII (discussing what would have happened if Chadam had CF and if there should be an exception that would have justified the school's conduct if he did).

190. *Infra* Part VI.A (discussing whether California Education Code § 49451 would have functioned as an exception to CalGINA that would have justified the school's conduct).

191. CAL. GOV'T CODE § 11135(a).

192. *See id.* (prohibiting only unlawful denial of access to or discrimination within programs and activities receiving government funding).

193. CAL. EDUC. CODE § 49451.

194. *See supra* Part V.B.3 (discussing § 49451's application to Chadam's case).

195. *See* CAL. EDUC. CODE § 49451 (permitting schools to send a student home if the school has good reason to believe the student has a "contagious or infectious disease," which is effectively satisfied if the student does indeed have such a disease).

196. *See id*. (permitting schools to send a student home if the school has good reason to believe the student has a "contagious or infectious disease," which is effectively satisfied if the student does indeed have such a disease).

An in-depth and medically technical discussion on whether CF constitutes a contagious or infectious disease could easily mire this analysis.[197] This is especially true because our hypothetical student is at risk of transmitting the bacteria CF causes him to retain in his lungs, rather than CF itself.[198] Because people with CF can easily transmit the pseudomonas bacteria to each other, this comment assumes the pseudomonas bacteria constitutes an infectious or contagious disease.[199] Moreover, although neither section 49451 nor the Education Code defines an "infectious or contagious disease," section 1250.4 of the California Health & Safety Code defines "[c]ommunicable, contagious, or infectious disease" as "any disease that is capable of being transmitted from person to person with or without contact and as established by the State Department of Health Services pursuant to California Code of Regulations, Title 17, sections 120130 and 2500."[200] Assuming that the definition in section 1250.4 or a similar definition is the relevant standard, the pseudomonas probably satisfy the definition because people with CF can transmit them so easily between one another.[201]

Assuming the terms of section 49451 are satisfied, the next issue is how section 49451 and CalGINA interact.[202] Notwithstanding CalGINA, the power to send kids home under section 49451 focuses a school's authority when a parent has not consented to their child's physical exam, rather than a school's decision based on genetic information.[203] It is important to note California Government Code section 11135, the section where CalGINA added genetic information as a protected basis, only prohibits "*unlawful[]* deni[al of] full and equal access to . . . [and] . . . *unlawful[]* . . . discrimination [within] any program or activity that is conducted, operated, or administered by the state or by any state agency, is funded directly by the state, or receives any financial assistance from the state (emphasis added)."[204] Sending a student home under the authority of section

197. *See id*. (permitting schools to send a student home if the student has a "contagious or infectious disease").

198. *Cross-Infection*, *supra* note 121.

199. *Id*.; CAL. EDU. CODE § 49451.

200. CAL. HEALTH & SAFETY CODE § 1250.4 (West, Westlaw current with urgency legislation through Ch. 4 of 2017 Reg. Sess.). Section 2500 of Title 17 of the California Code of regulations further defines 'communicable disease' as "an illness due to a specific microbiological or parasitic agent or its toxic products which arises through transmission of that agent or its products from an infected person, animal, or inanimate reservoir to a susceptible host, either directly or indirectly through an intermediate plant or animal host, vector, or the inanimate environment." CAL. CODE REGS. tit. 17, § 2500 (2017). Pursuant to § 120130 of the California Health and Safety Code, the California State Department of Health and Safety Code developed a list of diseases (also found in Title 17 of the California Code of Regulations), and the list does not appear to expressly mention the pseudomonas associated with CF. CAL. CODE REGS. tit. 17, § 2550–2640 (2017).

201. *Cross-Infection*, *supra* note 121.

202. *See* CAL. GOV'T CODE § 11135(a) (failing to reference section 49451 of the California Education Code); CAL. EDUC. CODE § 49451 (failing to reference California government Code section 11135).

203. CAL. EDUC. CODE § 49451.

204. CAL. GOV'T CODE § 11135(a).

49451 would be lawful.[205] Therefore, if the reason a school sends a student home is a genetic condition, such as CF, which the school learned of through genetic information they lawfully possessed, it would seem the school's conduct, although technically discriminatory, would constitute "lawful discrimination" and be permitted under CalGINA .[206] Nonetheless, the exceptions to CalGINA should be clearer.[207] Accordingly, the next Part discusses what an appropriate exception to CalGINA or a similar prospective statute in other states might look like.[208]

## VII. A BETTER WAY

Schools should be able to protect students who are put at risk by another student because of a disease or condition the other student has.[209] The fact that a school learns such information from genetic information should not preclude the school from protecting students.[210] Admittedly, California Education Code section 49451 may furnish an exception to CalGINA that would have permitted the school's conduct if Chadam actually had CF.[211] But legislators should add an explicit exception to CalGINA for clarity and simplicity.[212] In addition, states considering legislation similar to CalGINA should take note of Chadam's situation and include an exception that would authorize schools to protect students where a school learns through genetic information that a student has a disease or condition that puts other students at risk.[213] While there seems to be a dearth of examples of cases similar to Chadam's, that dearth is most likely attributable to the fact that California is the only state that prohibits genetic information discrimination in public schools.[214]

Of course, genetic information discrimination laws should provide a level of protection sufficient to ensure students are not mindlessly, maliciously, or arbitrarily removed from their schools under the pretext of a dangerous medical

205. CAL. EDUC. CODE § 49451.

206. *Id.*; CAL. GOV'T CODE § 11135(a).

207. *See supra* Part VI (explaining the potential relationship between California Government Code section 11135 and California Education Code section 49451, neither of which reference each other).

208. *See infra* Part VII (proposing language for a clearer exception to CalGINA or to be included in similar legislation elsewhere).

209. *See supra* Part VI (discussing the dangers that people with cystic fibrosis pose to each other).

210. *See supra* Part VI (explaining that existing California law probably prevents this, but noting that it could be ensured by creating an explicit exception within CalGINA).

211. *See supra* Part VI.A (exploring the how §49451 would have applied if Chadam did have CF).

212. *See supra* Part VI (discussing what would have happened if Chadam had actually had CF and thereby demonstrating the need for a clearer cut exception to CalGINA).

213. *See supra* Part III.B (explaining that there do not appear to be any other states that extend genetic information protections to public schools).

214. *See supra* Part III.B (explaining that California is the only state that prohibits genetic information discrimination in public schools).

condition.[215] Therefore, the exception should be narrow.[216] But the risks of a dystopian, genetically engineered future should not prevent legislators from ensuring that schools can protect students from legitimate risks posed by other students, even if doing so would otherwise constitute genetic information discrimination.[217] One standard that might suffice is that of section 49451, under which a school must have "good reason to believe that a student has a recognized contagious or infectious disease" before the school can send the student home.[218] Although the words "contagious" and "infectious" may imply there must be a risk of harm to other students to meet the standard, adding an "imminent risk of harm" component would be prudent to ensure students are only removed if there is truly a reason to do so.[219] In addition, since California Government Code section 11135 is phrased in terms of prohibiting "unlawful" discrimination, the exception should be phrased in terms of what constitutes lawful genetic information discrimination in public schools.[220] A model exception that California should add to CalGINA and that other states should include in similar prospective legislation might read as follows: "Conduct that would otherwise qualify as discrimination on the basis of genetic information in public schools under CalGINA is lawful if school officials learn or reasonably believe, through or because of genetic information, a student has a contagious or infectious disease or condition that poses an imminent risk of harm to another student or students."[221] This language ensures that a school with multiple students who have CF could act to protect those students without risking a genetic information discrimination suit.[222]

## VIII. CONCLUSION

Breakthroughs in genetic research promise great benefits in the form of personalized medical treatment, but also pose potential risks because genetic

215. *See supra* Part IV (detailing the facts of Chadam's case, which is exactly what prospective legislation should prevent).

216. *See supra* Part IV (detailing the facts of Chadam's case, which is exactly what prospective legislation should prevent and should not be allowed to occur through an overly broad exception).

217. *See supra* Part VI (explaining the risks that students with CF pose to each other, a danger schools should be allowed to take actions to avoid).

218. *See supra* Part VI.A (concluding that the language in § 49451 is probably sufficient to justify a school's conduct in a situation like that of PAUSD if Chadam had actually had CF as lawful discrimination pursuant to section 11135 of the California Government Code).

219. *See* CAL. EDUC. CODE § 49451 (not explicitly conditioning the authority to send a student home for medical reasons on the risk that student's condition poses to other students).

220. CAL. GOV'T CODE § 11135(a).

221. *See supra* Part VI, VII (explaining what would happen if Chadam had actually had CF, which demonstrates the need for an exception to existing law, which this language would accomplish).

222. *See supra* Part X (explaining the need for a clearer exception in California law and in prospective legislation elsewhere).

information can be used as a basis for discrimination.[223] Laws at both the federal and state level ban discrimination on the basis of genetic information in a variety of contexts.[224] California law extends this protection to public schools.[225] California Education Code section 49451 did not permit PAUSD's conduct in Chadam's case.[226] Had Chadam been diagnosed with CF, however, section 49451 may have justified the school's conduct because of the risk he and the other students with CF would have posed to each other.[227] Nonetheless, while protecting students in public schools from genetic information discrimination is an admirable goal, California and other state legislatures considering similar legislation should fashion an explicit and narrow exception that allows schools to protect students from legitimate medical risks.[228]

223. *See* Jungreis, *supra* note 25, at 211–12.

224. *See supra* Part III (exploring federal, California, Utah, and West Virginia law, and describing some general trends across the rest of the states).

225. *See supra* Part V.A (concluding that CalGINA applies to public schools).

226. *See supra* Part V.B.3 (discussing whether § 49451 justified the school's conduct in Chadam's case).

227. *See supra* Part VI.A (explaining that § 49451 might have justified the school's conduct if Chadam had actually had CF).

228. *See supra* Part VII (proposing language that would have justified the school's conduct in Chadam's case if he had actually had CF).