

Privacy for Safety: The NCAA Sickle-Cell Trait Testing Policy and the Potential for Future Discrimination

Heather R. Quick*

ABSTRACT: Recent NCAA legislation requires incoming Division I student-athletes to: (1) submit to testing for the sickle-cell trait, (2) provide results of a previous test, or (3) waive out of testing and release the NCAA from any potential future liability. However, the legislation does not provide colleges and universities with guidance on the proper treatment of a student's genetic information. Furthermore, current federal laws do not provide sufficient protection against unwanted and unnecessary dissemination of this sensitive genetic information, especially considering that many schools have student-athletes sign waivers allowing the release of their medical information to the media. Public knowledge of this information can lead to discrimination in the future, especially in the employment context. The NCAA should either stop the testing program or take further steps to protect a student-athlete's privacy.

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* J.D. Candidate, The University of Iowa College of Law, 2012; B.A., Iowa State University, 2009.

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I. INTRODUCTION

Dale Lloyd II was a freshman football player for Rice University.¹ In September 2006, Dale collapsed on the field during practice after having completed sixteen consecutive 100-yard sprints.² Dale died at the hospital the following day.³ Doctors later determined that Dale's death resulted from acute exertional rhabdomyolysis—a consequence of complications associated with the sickle-cell trait.⁴ Dale had never been tested for the sickle-cell trait and was unaware of his status as a carrier.⁵

Following the loss of their son, Dale's parents, Bridgette and Dale Lloyd, sued Rice University and the National Collegiate Athletic Association ("NCAA") for wrongful death.⁶ The Lloyds asserted in their claim that the NCAA was negligent for failing to warn Dale about the risk of complications due to carrying the sickle-cell trait.⁷ All parties eventually settled.⁸ The settlement required the NCAA to formally recommend that all Division I schools test student-athletes for the sickle-cell trait before participating in intercollegiate athletics.⁹ Eventually, the NCAA decided to go further than a recommendation and implemented legislation on testing student-athletes for the sickle-cell trait.

Enacting legislation requiring sickle-cell testing of new student-athletes was not a simple process for the NCAA. Initially, the NCAA proposed requiring sickle-cell trait testing for all new student-athletes with no opt-out option.¹⁰ After recommendations from the Ivy League division, the NCAA later changed the proposed policy by adding an amendment that would allow student-athletes to forgo the test if the athlete: (1) provided proof of

1. Brett Zarda, *Lawsuit Prompts NCAA To Screen Athletes for Sickle Cell*, USA TODAY (July 2, 2010, 2:34 PM), http://www.usatoday.com/sports/college/2010-06-30-sickle-cell-ncaa-cover_N.htm.

2. *Id.*

3. *Id.*

4. Vence L. Bonham et al., *Screening Student Athletes for Sickle Cell Trait—A Social and Clinical Experiment*, 363 NEW ENG. J. MED. 997, 997 (2010).

5. Zarda, *supra* note 1.

6. *Id.*

7. Dennis Dodd, *NCAA To Recommend Schools Test for Sickle Cell Trait*, CBSSPORTS.COM (June 29, 2009), <http://www.cbssports.com/collegefootball/story/11903550>.

8. *Id.*

9. *Id.* Division I schools are the largest NCAA member institutions. In order to qualify as a Division I institution, a school must meet several criteria, including offering fourteen sports, two of which must be team sports, and also offer a sports team for the fall, winter, and spring seasons. *Differences Among the Three Divisions: Division I*, NCAA, <http://www.ncaa.org/wps/wcm/connect/public/ncaa/about+the+ncaa/who+we+are/differences+among+the+divisions/division+i/> (last visited Sept. 27, 2011).

10. Michelle Brutlag Hosick, *Protocol Decided for Sickle Cell Testing*, THE NCAA NEWS (Apr. 13, 2010), http://www.meacsports.com/fls/20800/Compliance/Bulletins/LoopApril152010.pdf?DB_OEM_ID=20800.

an earlier test; or (2) signed a waiver refusing the sickle-cell test and releasing the school from liability.¹¹

The NCAA eventually codified this policy in NCAA Division I Legislation 17.1.5.1, entitled “Sickle Cell Solubility Test,” which states: “The examination or evaluation of student-athletes who are beginning their initial season of eligibility and students who are trying out for a team shall include a sickle cell solubility test, unless documented results of a prior test are provided to the institution.”¹² The NCAA Council signed the legislation April 29, 2010 and required covered universities to begin implementing the regulation on August 1, 2010.¹³ The NCAA added language requiring sickle-cell testing to Division I legislation on mandatory medical examinations.¹⁴

As mentioned above, if students refuse the test or decline to provide the results of an earlier sickle-cell trait test, students can choose to opt out of the requirement.¹⁵ Each school creates its own waiver with the assistance of its legal department.¹⁶ Some Division I conferences, like the Big Ten Conference, create waivers and similar procedures for all participating schools to implement.¹⁷ The NCAA has stated that schools should not push for waivers but, instead, promote testing as much as possible.¹⁸ Many colleges and universities have followed suit with some even using language

11. *Id.*

12. 2011–2012 NCAA DIV. I MANUAL § 17.1.5.1 (2011) [hereinafter NCAA MANUAL].

13. Madison Park, *NCAA Genetic Screening Rule Sparks Discrimination Concerns*, CNNHEALTH (Aug. 4, 2010, 8:13 AM), <http://www.cnn.com/2010/HEALTH/08/04/ncaa.sickle.genetic.screening/index.html?ref=allsearch>.

14. NCAA MANUAL, *supra* note 12, at § 13.11.3.7.3 (requiring testing before prospective student-athletes can participate in weight training or conditioning workouts); *Id.* § 13.11.3.8.2 (requiring testing before participating in “weight training or conditioning workouts conducted by an institution’s strength and conditioning coach”); *Id.* § 13.11.3.9.3 (same); *Id.* § 13.11.3.10.1 (requiring testing before “voluntary individual workouts pursuant to the safety exception”).

15. *Id.* § 17.1.5.1. Students may argue under a Fourth Amendment analysis that the testing is not reasonable under the circumstances. This argument will likely fail so long as the waiver option remains available, and also only against the state schools as the NCAA is not considered a private actor. *NCAA v. Tarkanian*, 488 U.S. 179, 190–99 (1988) (finding that a state university’s compliance with NCAA regulations does not make the NCAA a state actor); Susan K. Menge, *Should Players Have to Pass to Play?: A Legal Analysis of Implementing Genetic Testing in the National Basketball Association*, 17 MARQ. SPORTS L. REV. 459, 466 (2006). As this claim would likely fail with the waiver option, this Note will focus on what actions should be taken to protect a student-athlete’s privacy right under the current policy.

16. THE NAT’L COLLEGIATE ATHLETIC ASS’N, QUESTION AND ANSWER DOCUMENT, NCAA DIVISION I PROPOSAL NO. 2009-75-B 2 (June 2, 2010), <http://www.ncaa.org/wps/wcm/connect/e833fc8042c462ce92bdfbfd1ce0240/NCAA+Division+I+Sickle+Cell+Trait+QA+for+institutions+5+25+2010.pdf?MOD=AJPERES&CACHEID=e833fc8042c462ce92bdfbfd1ce0240>.

17. Interview with Terrance G. Noonan, Director of Athletic Training Servs., Univ. of Iowa, in Iowa City, Iowa (Oct. 20, 2010).

18. THE NAT’L COLLEGIATE ATHLETIC ASS’N, *supra* note 16, at 2.

on their waiver forms to discourage students from waiving the privacy protection of sickle-cell trait testing results.¹⁹

The Lloyd family, the NCAA, and other organizations have justified concerns about the risks associated with the sickle-cell trait.²⁰ However, this mandated testing also creates potential privacy issues for student-athletes. Because this policy is new, colleges and universities likely do not understand its requirement, as many questions about the testing policy have yet to be answered.²¹

Congress enacted certain federal statutes intended to protect an individual's medical information from unwanted dissemination that might be able to alleviate some of the unforeseen consequences of mandated sickle-cell trait testing. One of the first federal statutes to provide protection of an individual's medical records, which can include the results of a genetic test, was the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), and more specifically the Standards for Privacy of Individually Identifiable Health Information (hereinafter "Privacy Rule") within that legislation.²² Also, the Family Educational Rights and Privacy Act ("FERPA") protects a student-athlete's medical information when a student's medical records are part of his or her educational records.²³ However, HIPAA, FERPA, and other statutes only have limited applicability and only cover certain entities in certain situations.²⁴

The need for increased privacy protection is great, as disclosure of a student-athlete's status as a sickle-cell trait carrier can lead to future discriminatory consequences—most notably in the employment context.²⁵

19. See *University of Vermont Athletic Medicine Department Sickle Cell Position Statement*, UNIV. OF VT., http://uvmathletics.com/sports/2010/12/15/athmed_1215105511.aspx?path=athleticmed (last visited Sept. 19, 2011) (click on the hyperlink "UVM Sickle Cell Position Statement," which will open a word document); *Sickle Cell Trait Fact Sheet*, PRINCETON UNIV., available at <http://www.princeton.edu/uhs/pdfs/Sickle-Cell-Trait-Fact-Sheet.pdf> ("The recommendation of the Princeton University Athletic Medicine . . . is that every student-athlete be tested or show proof of prior testing for sickle cell trait.").

20. See *supra* Part I. Some have criticized the NCAA's decision to mandate this testing coming from a lawsuit settlement, including the Sickle Cell Association of America's chief medical officer Dr. Lanetta Jordan, who recently stated that the screening mandate was "not linked to screening for the purpose of genetic counseling or parenting. It's screening for protection of the universities, not protection of the athlete." See Hosick, *supra* note 10; see also Bonham et al., *supra* note 4, at 999 ("The fact the students can avoid the testing if they prove they have already been tested or sign a waiver releasing their university and the NCAA from liability suggests that it is designed primarily as a defensive legal measure.").

21. Bonham et al., *supra* note 4, at 998–99 (posing many questions the NCAA mandate has left unanswered, including how the university will protect a student's privacy).

22. 45 C.F.R. §§ 160, 164(A) & (E) (2010).

23. 20 U.S.C. § 1232g (2006).

24. See *infra* Part III.C.

25. A student-athlete being marked as a carrier of the sickle-cell trait can also have negative consequences when attempting to gain insurance. According to Title I of GINA, a group health plan or "a health insurance issuer offering group health insurance coverage in

The potential for discrimination in employment resulting from released genetic information is apparent, even with the recent steps taken to protect an individual's genetic information. In recent years, Congress has taken action to prevent discrimination resulting from one's genetic information with the Genetic Information Nondiscrimination Act of 2008 ("GINA").²⁶ However, GINA provides insufficient protection against all of the potential negative consequences.

This Note argues that the NCAA's legislation on sickle-cell trait testing does not provide the necessary privacy protections to make up for the shortfalls of HIPAA and FERPA and that, to sufficiently protect a student's privacy, one of the following actions must be taken: (1) repeal the legislation and take the necessary safety precautions for all student-athletes; or (2) either the NCAA or Congress take action to close the loopholes in this legislation and forbid the NCAA from asking students for authorization to release their medical information to the media.

To fully understand the problem, this Note first provides a background of the sickle-cell trait and the potential problems the trait creates for student-athletes. It then explores how HIPAA and FERPA apply in the NCAA context. More specifically, this Note analyzes how these statutes fail to properly protect student-athletes, and further discusses why the release of a student-athlete's sickle-cell trait test results could lead to future discriminatory problems.²⁷ This Note concludes by discussing possible actions either the NCAA or Congress should take to provide the medical privacy these student-athletes need.

connection with a group health plan" cannot use a person's "genetic information." Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881, 883 (2008) (codified as amended at 42 U.S.C. § 2000ff-8(a)(7) (Supp. 2008)). Yet GINA only provides protection for carriers who wish to obtain health insurance and fails to provide protection in "life insurance, disability insurance, or long-term care insurance." SECRETARY'S ADVISORY COMMITTEE ON HERITABLE DISORDERS IN NEWBORNS AND CHILDREN, SCREENING U.S. COLLEGE ATHLETES FOR THEIR SICKLE CELL DISEASE CARRIER STATUS 12 (2010) [hereinafter SECRETARY'S ADVISORY COMMITTEE], *available at* <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendations/correspondence/briefingcarrierstatus.pdf>.

26. 122 Stat. 881.

27. The NCAA mandates have also sparked many other concerns for student-athletes, including the potential for discrimination in the intercollegiate context. These topics are not within the boundaries of this Note. For a discussion on the mandates' potential problems with discrimination, see Bonham et al., *supra* note 4, at 998-99.

II. SICKLE-CELL TRAIT AND HOW TO TEST

A. DEFINITION OF THE SICKLE-CELL TRAIT AND POTENTIAL CONSEQUENCES OF THE TRAIT

Sickle-cell complications can cause problems within the blood stream by creating hemoglobin S in red blood cells.²⁸ Red blood cells that contain mostly hemoglobin S have a tendency to “become stiff, distorted in shape and have difficulty passing through the body’s small blood vessels.”²⁹ These cells can then block blood flow, which leads to damaged tissue and further health complications.³⁰

Being a carrier of the sickle-cell *trait* leads to different complications associated with production of hemoglobin S than those diagnosed with sickle-cell *disease*.³¹ People with sickle-cell *disease* are susceptible to more complications than those only with the *trait*.³² Unlike carriers of the *disease*, people with the sickle-cell *trait* are “generally healthy.”³³ While people with sickle-cell *disease* produce *only* hemoglobin S as opposed to A, those who are only carriers of the *trait* produce both hemoglobin S and A but always more A.³⁴ The sickle-cell trait is “inherited through a defective gene passed on by one of the parents.”³⁵

Many student-athletes who carry the sickle-cell trait participate in athletics without complication and have no idea that they carry the trait.³⁶ However, in rare instances, exertional activity, heat, altitude, or dehydration can lead to devastating complications for carriers of the trait.³⁷ For example, carriers of the trait can experience symptoms such as “muscle cramping, pain, swelling, weakness, difficulty breathing or fatigue.”³⁸ Since 2000, nine collegiate football players have died as a result of complications associated with the sickle-cell trait.³⁹

28. *What Is Sickle Cell Disease?*, SICKLE CELL DISEASE ASS’N OF AM., <http://www.sicklecelldisease.org/index.cfm?page=about-scd> (last visited Oct. 6, 2011).

29. *Id.*

30. *Id.*

31. *Id.*

32. *Id.*

33. *Id.*

34. *Id.*

35. Park, *supra* note 13.

36. *Id.*

37. *Id.*; Carlton Haywood Jr. & Michael Pena, *Sidelined by Sickle Cell Trait?*, JOHNS HOPKINS BERMAN INST. OF BIOETHICS (May 4, 2010), <http://bioethicsbulletin.org/archive/sickle-cell-trait/>.

38. *Background on Sickle Cell Trait and the NCAA*, NCAA.ORG (Sept. 9, 2010), <http://www.ncaa.org/wps/wcm/connect/public/NCAA/Resources/Latest+News/2010+news+stories/September+latest+news/Background+on+sickle+cell+trait+and+the+NCAA>.

39. Haywood Jr. & Pena, *supra* note 37.

B. TESTING PROCEDURES

Testing for the sickle-cell trait is not completed at birth, unlike testing for the sickle-cell disease.⁴⁰ Testing for the sickle-cell trait is a blood test.⁴¹ The sickle-cell test is only five dollars, yet confirmation tests are generally more expensive.⁴²

However, colleges and universities cannot solve the problem by testing alone.⁴³ To be effective, schools and their respective athletic programs *need* to follow-up with students about their test results and provide guidance on how to remain healthy and prevent potential future complications.⁴⁴

Requiring colleges and universities to test student-athletes for the sickle-cell trait and to perform follow-ups is not a new concept.⁴⁵ Some schools, like the University of Oklahoma, already required sickle-cell trait testing before the NCAA legislation.⁴⁶ Here, the athletic trainers educate the coaches and players about the risks associated with carrying the sickle-cell trait.⁴⁷ If a student athlete tests positive, the athletic trainers follow-up with the student-athlete and educate him or her about the trait and inform the student-athlete of the necessary precautions to prevent complications.⁴⁸ In fact, by 2006, twenty-one percent of schools already had sickle-cell trait testing requirements for all student-athletes.⁴⁹ Sickle-cell trait testing is currently the only health test required for student-athletes.⁵⁰

40. See Bonham et al., *supra* note 4, at 997–98; SECRETARY'S ADVISORY COMMITTEE, *supra* note 25, at 1–2.

41. Neil K. Kaneshiro, *Sickle Cell Test*, MEDLINEPLUS, <http://www.nlm.nih.gov/medlineplus/ency/article/003666.htm> (last visited Oct. 6, 2011).

42. Dodd, *supra* note 7; Hosick, *supra* note 10.

43. Zarda, *supra* note 1 (describing the necessary steps that need to be taken after testing to ensure the safety of sickle-cell trait carriers).

44. *Id.*; Hosick, *supra* note 10; SECRETARY'S ADVISORY COMMITTEE, *supra* note 25, at 8.

45. SECRETARY'S ADVISORY COMMITTEE, *supra* note 25, at 7–8 (analyzing the number of Division I athletic programs that tested for the sickle-cell trait prior to the NCAA mandate, including those institutions that only tested African Americans) (citing C.E. Clarke III et al., *Sickle Cell Trait Preparticipation Screening Practices of Collegiate Physicians*, 16 CLINICAL J. SPORT MED. 440 (2006)).

46. Park, *supra* note 13.

47. Luke Atkinson, *University of Oklahoma Trainer Leads Research To Protect Athletes with Sickle Cell Trait*, OKLA. DAILY, Sept. 16, 2009, available at <http://www.foxnews.com/story/0,2933,549283,00.html>.

48. *Id.*

49. Zarda, *supra* note 1.

50. *Id.* This is despite the fact that heart disease was the leading cause of death for college athletes according to a 2008 study by the National Center for Catastrophic Sports Injury Research. *Id.* However, the testing for heart disease is much more costly, which may explain why schools have not required testing for this disease. *Id.* Another possibility is that the driving reason behind requiring the sickle-cell trait testing is that the NCAA was sued, a criticism many have made against the policy. See Park, *supra* note 13 and accompanying text.

III. APPLICABLE STATUTES: HIPAA AND FERPA

Two federal statutes can protect a student–athlete’s sickle-cell trait test results: HIPAA and FERPA.⁵¹ HIPAA and FERPA do not offer the same level of protections and cover different types of situations.⁵² In addition, both statutes cannot apply at the same time, or stated another way, a student–athlete cannot receive double coverage.⁵³ Determining which statute applies depends on the academic institution and how it handles administering the sickle-cell trait test, stores the medical records, and bills for insurance.⁵⁴ Below, this Note analyzes both statutes, attempting to discern which statute applies in different situations.

A. HIPAA AND THE PRIVACY RULE

In the majority of circumstances, HIPAA covers a student–athlete’s sickle-cell trait test results.⁵⁵ With the increase of computerized medical records, Congress passed HIPAA in 1996 to protect an individual’s privacy with regard to medical records while still ensuring that medical personnel could transmit an individual’s medical information when necessary for adequate medical care.⁵⁶

51. Family Educational Rights and Privacy Act (FERPA), 20 U.S.C. § 1232(g) (2006); Health Insurance Portability and Accountability Act (HIPAA) of 1996, Pub. L. No. 104-191, 110 Stat. 2033. The Fourteenth Amendment does not prevent the NCAA from asking for a student–athlete’s genetic information in this situation, as the NCAA is not considered a state actor. *NCAA v. Tarkanian*, 488 U.S. 179, 193–99 (1988). HIPAA and FERPA allow states to enact statutes that offer more protection. Not all states offer further protection, however, and if they do the statutes usually only cover employment situations and further limit what constitutes genetic information. Amy Foster, Note, *Critical Dilemmas in Genetic Testing: Why Regulations To Protect the Confidentiality of Genetic Information Should Be Expanded*, 62 BAYLOR L. REV. 537, 551–53 (2010). FERPA also allows states to enact statutes providing more protection, but the level of protection also varies from state to state. See generally Susan P. Stuart, *A Local Distinction: State Education Privacy Laws for Public Schoolchildren*, 108 W. VA. L. REV. 361 (2005) (discussing how states have enacted more privacy laws in an attempt to make up for the downfalls of FERPA).

52. Charles O’Hara, *HIPAA Privacy Standards and University Athletic Departments*, CATS NEWSLETTER, (Coll. Athletic Trainers Soc’y, Pittsburg, PA), Spring 2003, at 9–11, available at <http://www.collegeathletictrainer.org/newsletter/getfile.php?fetch=5-1>.

53. U.S. DEPT. OF HEALTH & HUMAN SERVICES & U.S. DEPT. OF EDUCATION, JOINT GUIDANCE ON THE APPLICATION OF THE FAMILY EDUCATIONAL RIGHTS AND PRIVACY ACT (FERPA) AND THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996 (HIPAA) TO STUDENT HEALTH RECORDS 3–4 (Nov. 2008) [hereinafter JOINT GUIDANCE], available at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/hipaaferpajointguide.pdf>.

54. *Id.*

55. See James Blake Hike, Note, *An Athlete’s Right to Privacy Regarding Sport-Related Injuries: HIPAA and the Creation of the Mysterious Injury*, 6 IND. HEALTH L. REV. 47, 53–54 (2009).

56. U.S. DEPT. HEALTH & HUMAN SERVICES, OFFICE FOR CIVIL RIGHTS PRIVACY BRIEF: SUMMARY OF THE HIPAA PRIVACY RULE 1–2 (2003) [hereinafter SUMMARY OF THE HIPAA PRIVACY RULE], available at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/privacysummary.pdf>.

As a part of HIPAA, Congress mandated that the Secretary of Health and Human Services (“HHS”) provide guidelines on how to protect the privacy of an individual’s health information.⁵⁷ After Congress declined to create these guidelines,⁵⁸ HHS then promulgated the Privacy Rule, which went into effect on April 14, 2003.⁵⁹ The Privacy Rule only covers “protected health information” (“PHI”) and only regulates “covered entities.”⁶⁰ This Part defines both of these terms below.

1. Protected Health Information

The Privacy Rule defines PHI as “individually identifiable health information . . . that is: (i) [t]ransmitted by electronic media; (ii) [m]aintained in electronic media; or (iii) [t]ransmitted or maintained in any other form or medium.”⁶¹ Excluded from this definition are medical records under FERPA⁶² and employment records.⁶³ PHI can “include[] any demographic or personally identifiable data relating to physical or mental health conditions, as well as information relating to the provision of health care and payment.”⁶⁴ As a part of GINA, Congress mandated the HHS to amend the Privacy Rule to treat genetic information as PHI by 2009, which would thus include sickle-cell trait testing results.⁶⁵

2. Covered Entities

Many, but not all, universities are covered entities under HIPAA. A covered entity can either be “(1) [a] health plan[;] (2) [a] health care clearinghouse . . . [;] or] . . . (3) [a] health care provider who transmits any health information in electronic form in connection with a transaction covered by [HIPAA].”⁶⁶ First, a school qualifies as a health-care provider if it

57. Health Insurance Portability and Accountability Act (HIPAA) of 1996, Pub. L. No. 104-191 § 264, 110 Stat. 2033; *see also* SUMMARY OF THE HIPAA PRIVACY RULE, *supra* note 56, at 1–2 (2003).

58. SUMMARY OF THE HIPAA PRIVACY RULE, *supra* note 56, at 1–2.

59. *Id.* at 20.

60. 45 C.F.R. § 160.103 (2010).

61. *Id.*

62. *Id.*; JOINT GUIDANCE, *supra* note 53, at 3.

63. 45 C.F.R. § 160.103; JOINT GUIDANCE, *supra* note 53, at 3.

64. Richard Bell et al., *The Impact of the HIPAA Privacy Rule on Collegiate Sport Professionals*, 11(2) SPORT J. (2008) (citing David Jones, *HIPAA: Friend or Foe to Athletic Trainers?* ATHLETIC THERAPY TODAY, Mar. 2003, at 17, 17–19 (2008)), *available at* <http://www.thesportjournal.org/article/impact-hipaa-privacy-rule-collegiate-sport-professionals>.

65. Stephen K. Phillips, *A Legal Research Guide to HIPAA*, 3 J. HEALTH & LIFE SCI. L. 134, 140 (2010) (citing 42 U.S.C. § 1320d-9 (2006)).

66. 45 C.F.R. § 160.103 (2002). The Centers for Medicare and Medicaid Services have issued a flow chart in an attempt to help entities determine whether they are covered entities under HIPAA. *Covered Entity Charts*, CTRS. FOR MEDICARE & MEDICAID SERVS., *available at* <http://www.cms.gov/HIPAAGenInfo/Downloads/CoveredEntitycharts.pdf> (last visited Sept. 19, 2011).

“furnish[es], bill[s] or get[s] paid for health care . . . or employ[s] a provider of medical or health services.”⁶⁷ Second, a school completes a transaction under HIPAA if it transmits “information between two parties to carry out financial or administrative activities related to health care.”⁶⁸ For example, if a university bills the cost of the sickle-cell test to an insurance company, the medical information then falls within the scope of the privacy rule.⁶⁹ If a school’s athletic department is a covered entity, HIPAA requires the school to provide student–athletes with a notice of its privacy practices.⁷⁰

The NCAA did not explicitly state who should pay for the test, and schools are handling the payment process differently.⁷¹ For example, the University of Iowa’s athletic programs first attempts to have the student–athlete’s insurance carrier pay for the test, but if this is not possible the University covers the cost.⁷² In most cases, if the athletic program is testing during a student–athlete’s required medical examination, as recommended by the NCAA,⁷³ the college or university will bill either the student’s or the school’s insurance, thus electronically transmitting the information and becoming a covered entity.

B. FERPA

FERPA may also cover a student–athlete’s medical information kept by a university. FERPA applies to all postsecondary institutions that receive funding under any U.S. Department of Education program.⁷⁴ If even one department of the educational institution receives funding, FERPA covers all

67. THOMAS N. SHORTER, UNDERSTANDING HIPAA: A GUIDE TO SCHOOL DISTRICT PRIVACY OBLIGATIONS 17–18 (2004) (internal quotation marks omitted); 45 C.F.R. § 160.103.

68. See SHORTER, *supra* note 67, at A-7 (defining transaction under HIPAA).

69. The institution would be a covered entity because they are transmitting the medical information. See *infra* Part III.A.

70. 45 C.F.R. § 164.502 (a)–(b); SUMMARY OF THE HIPAA PRIVACY RULE, *supra* note 56, at 11.

71. SECRETARY’S ADVISORY COMMITTEE, *supra* note 25, at 9.

72. Interview with Terrance G. Noonan, *supra* note 17. Some athletic departments cover the cost of testing all athletes. *Report: N.C. A&T Trainer Urged Against Sickle Cell Test*, USA TODAY (January 7, 2011 2:50 PM), http://www.usatoday.com/sports/college/2011-01-07-nc-at-student-dies_N.htm (quoting the school’s chief athletic director as stating “[p]lease make sure the [athlete is] actually on the team before this test is done. The reason for this is that the student health center is charging the athletic department for this test to be done.” (internal quotation marks omitted)).

73. SECRETARY’S ADVISORY COMMITTEE, *supra* note 25, at 7. Even if the athletic-training departments do not need to bill insurance and transmit documents electronically in that instance, the departments likely will do so for some other reason as they provide services in a variety of circumstances.

74. 34 C.F.R. § 99.1(d) (2011); JOINT GUIDANCE, *supra* note 53, at 1.

parts of the institution.⁷⁵ Because of this, FERPA is wide-ranging and covers most public and private postsecondary institutions.⁷⁶

FERPA covers all information in a student's "educational records," defined as records "(1) [d]irectly related to a student; and (2) [m]aintained by an educational agency or institution or by a party acting for the agency or institution."⁷⁷ Excluded from the definition of "educational records" are "treatment records," defined as:

[r]ecords on a student who is . . . attending an institution of postsecondary education, that are:

- (i) [m]ade or maintained by a physician . . . or other recognized professional or paraprofessional acting in his or her professional capacity or assisting in a paraprofessional capacity;
- (ii) [m]ade, maintained, or used only in connection with treatment of the student; and
- (iii) [d]isclosed only to individuals providing the treatment.⁷⁸

Such records can be personally reviewed by a physician or other appropriate professional of the student's choice.⁷⁹ Treatment records become educational records when shared with someone that is a part of the institution other than the treating physician, even if that person is the student.⁸⁰

As the goal of mandating the sickle-cell trait test is to prevent health complications, the college physician or team athletic trainer will have to share this information with the student and relevant coaches. Therefore, if the prevention process is done correctly, the results of the sickle-cell trait test will fall under "educational records," not "treatment records," and FERPA will apply.

C. HIPAA AND FERPA OVERLAP

Either FERPA or HIPAA may protect a student-athlete's genetic information, but not both. Determining which statute applies is a confusing and complicated process; various scholars have had little success in discerning when which statute applies.⁸¹ After the passage of HIPAA and the Privacy Rule, many colleges and universities were unclear about which statute applied to them, leading the HHS to release the *Joint Guidance on the*

75. JOINT GUIDANCE, *supra* note 53, at 1.

76. *Id.*

77. 34 C.F.R. § 99.3; *see also* JOINT GUIDANCE, *supra* note 53, at 1–2.

78. 34 C.F.R. § 99.3(4).

79. 34 C.F.R. § 99.11(f).

80. JOINT GUIDANCE, *supra* note 53, at 7.

81. *Id.* at 1.

Application of the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act (HIPAA) to Student Health Records in an attempt to clarify which statute applied when.⁸²

HIPAA covers most Division I colleges and universities, as most of these institutions bill services to health-insurance providers or are health-care providers.⁸³ However, a postsecondary institution can be a covered entity under HIPAA but still have records exempt from the Privacy Rule because those records are considered “educational records” and are, therefore, covered by FERPA instead.⁸⁴ In this situation, it is important to note that any record that does not fall within the definition of “educational record” is considered PHI and HIPAA governs, meaning a university can have both FERPA-covered records *and* HIPAA-covered records.⁸⁵

Yet if a student’s medical records, including genetic information, are released to the media, this takes the records out of FERPA’s definition of “educational records” because they no longer meet the traditional definition as being used for treatment only.⁸⁶ Also, if the university shares this information with another HIPAA-covered entity, for example a health-insurance company or hospital, FERPA no longer covers these medical records, but instead, HIPAA covers them because the records are no longer confined to FERPA-regulated institutions.⁸⁷

D. SHORTCOMINGS OF HIPAA AND FERPA

As discussed, HIPAA and FERPA provide many protections but not enough to sufficiently protect a student–athlete’s privacy. In short, these statutes allow for unauthorized disclosures, fail to provide remedies sufficient to have a deterrent effect, and do not remove the possibility of an institution asking for a waiver that would allow the release of the student’s medical information to the media.

1. Exceptions That Allow Unauthorized Disclosures

HIPAA does not prevent the disclosure of PHI in all circumstances. A covered entity may always disclose individually identifiable information if

82. *Id.*

83. Hike, *supra* note 55, at 54; *see also* Susan M. Pitz, *HIPAA and the Sports Media: Separating Fiction from Reality*, NEV. LAW., Aug. 2003, at 12, 12.

84. JOINT GUIDANCE, *supra* note 53, at 3, 7; *see also* John L. Nicholson & Meighan E. O’Reardon, *Data Protection Basics: A Primer for College and University Counsel*, 36 J.C. & U.L. 101, 111 (2009).

85. *See supra* note 81.

86. Hike, *supra* note 55, at 54 (“[I]ntercollegiate athletic organizations constitute ‘covered entities’ under HIPAA when they engage in non-traditional operations and release an athlete’s PHI to third parties.”).

87. CLIFFORD A. RAMIREZ, *FERPA CLEAR AND SIMPLE: THE COLLEGE PROFESSIONAL’S GUIDE TO COMPLIANCE* 41 (2009).

that information has been “de-identified.”⁸⁸ De-identified information “does not identify an individual” [] or provide “a reasonable basis to believe that the information can be used to identify an individual.”⁸⁹ However, research shows that de-identified records can easily be re-identified.⁹⁰ Further, the Privacy Rule’s de-identification guidelines do not require covered entities to remove the patient’s “hospital name, diagnosis, year of visit, patient’s age, [or] the first three digits of ZIP code.”⁹¹ A person could easily determine the identity of someone with this information still available.⁹²

A covered entity can also disclose a person’s PHI without an individual’s authorization for research: (1) if the entity obtains documented Institutional Review Board (“IRB”) or Privacy Board approval; (2) if it is preparatory to research; (3) if the PHI requested is of decedents; or (4) if the covered entity only discloses limited data sets due to a data use agreement.⁹³ With Division I schools participating actively in research, a student–athlete’s genetic information may appeal to university researchers and the transfer of information may become commonplace.⁹⁴ For instance, at the University of Southern California, researchers often use PHI in their research, obtaining medical information from university hospitals and clinics.⁹⁵

Like HIPAA, FERPA has loopholes that allow for the release of a student–athlete’s medical information. Still, FERPA provides students who are eighteen years old and older (and for the parents of those under eighteen) with many rights regarding the information in these educational records.⁹⁶ Still, like HIPAA, FERPA contains exceptions where schools can release a student’s educational records to certain individuals without the student’s authorization, including:

School officials [including teachers] with legitimate educational interest; Other schools to which a student is transferring; Specified

88. 45 C.F.R. § 164.502(d)(2) (2010); *see also* 45 C.F.R. §§ 164.502 & 164.514(a)–(b); Stacey A. Tovino, *The Use and Disclosure of Protected Health Information for Research Under the HIPAA Privacy Rule: Unrealized Patient Autonomy and Burdensome Government Regulation*, 49 S.D. L. REV. 447, 455–56 (2004).

89. Paul Ohm, *Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization*, 57 UCLA L. REV. 1701, 1737 (2010) (citations omitted).

90. *Id.* at 1742–43.

91. *Id.* at 1740.

92. *See id.*

93. 45 C.F.R. §§ 164.512(i)(1)(i)–(iii); SUMMARY OF THE HIPAA PRIVACY RULE, *supra* note 56 at 8; U.S. DEP’T OF HEALTH & HUMAN SERVS., HEALTH INFORMATION PRIVACY: RESEARCH (Apr. 3, 2003), *available at* <http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/research/research.pdf>. *See also* Tovino, *supra* note 88, at 455.

94. *See* OFFICE OF RESEARCH COMPLIANCE, IMPACT OF HIPAA MEDICAL PRIVACY RULE ON RESEARCH AT USC (2003), *available at* <http://orc.research.sc.edu/PDF/HIPAAoverview.pdf>.

95. *Id.*

96. For example, students have the right to access the information in their file and review it. A student can also challenge any information in their file he or she believes is inaccurate. 34 C.F.R. §§ 99.10–99.12, .20–.22 (2011).

officials for audit or evaluation purposes; Appropriate parties in connection with financial aid to a student; Organizations conducting certain studies for or on behalf of the school; Accrediting organizations; To comply with a judicial order or lawfully issued subpoena; Appropriate officials in cases of health and safety emergencies; and State and local authorities, within a juvenile justice system, pursuant to specific State law.⁹⁷

Despite the congressional intent to protect a student's records, unauthorized access of medical records happen. Researchers and the media see a student's records as valuable, and some go to the lengths of computer hacking to reach the information.⁹⁸ In fact, the problem has become so prevalent that many colleges name security and privacy of student records as a main technology concern.⁹⁹ For example, in 2009, hackers gained access to the University of California at Berkeley's medical database, which included health care information for "160,000 students, alumni, and their families."¹⁰⁰

2. Lack of Remedy To Provide a Deterrent Effect

Moreover, a student-athlete's lack of legal recourse if a school violates his or her privacy rights provides little deterrent effect to colleges and universities. HIPAA does not provide victims a private right of action against unauthorized disclosures.¹⁰¹ Violations of HIPAA and the Privacy Rule are subject to criminal sanctions, but enforcement actions are rarely brought and usually deal with someone stealing an individual's identity information.¹⁰²

Similar to HIPAA, "FERPA lacks a remedial provision, provides for no private right of action, and does not create a privacy interest that is

97. *Family Educational Rights and Privacy Act (FERPA)*, ED.GOV, <http://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html> (last visited Sept. 19, 2011); *see also* 20 U.S.C. § 1232g(b) (2006); 34 C.F.R. § 99.31 (2011).

98. Lynn M. Daggett, *FERPA in the Twenty-First Century: Failure to Effectively Regulate Privacy for All Students*, 58 CATH. U. L. REV. 59, 101 (2008).

99. *Id.* (citing Marisol Bello, *Securing Students' Data Top Tech Issue*, USA TODAY, Mar. 20, 2008, at A3).

100. Stefanie Hoffman, *UC Berkeley Database Hacked, 160,000 Records Compromised*, CRN (May 11, 2009, 5:45 PM), <http://www.crn.com/news/security/217400303/uc-berkeley-database-hacked-160-000-records-compromised.htm?itc=refresh>.

101. Nicolas P. Terry, *What's Wrong with Health Privacy?*, 5 J. HEALTH & BIOMEDICAL L. 1, 7 (2009); Phillips, *supra* note 65, at 171 (citing multiple federal circuit- and state-court cases that have determined there is no private right of action for HIPAA Privacy Rule violations). New regulations do allow state attorneys general to sue on behalf of residents of a state for violations of the Privacy Rule. LaToya Rembert-Lang, *New HIPAA Rules Go into Effect February 17, 2010: Are You Ready?*, MARKETING RESEARCH ASS'N (Jan. 11, 2010), <http://www.marketingresearch.org/news/2010/01/11/new-hipaa-rules-go-into-effect-february-17-2010-are-you-ready>.

102. Phillips, *supra* note 65, at 169-70 (detailing cases in which the federal government has brought criminal charges for breaching confidentiality under HIPAA).

cognizable under 42 U.S.C. § 1983,” a civil rights statute.¹⁰³ Schools only face punishment for policies that lead to the unlawful disclosure of educational records, not individual instances of unlawful disclosure.¹⁰⁴ If an educational institution does have a policy that leads to unlawful disclosure, first, the institution is given a chance to change the policy before any reprimand.¹⁰⁵ Then, if the institution fails to change the policy, it loses funding under the Department of Education programs that put them under the reach of FERPA.¹⁰⁶ Thus, schools are in the clear so long as they change the policies when directed. Perhaps more importantly, a student-athlete whose privacy rights are violated has no remedy whatsoever as schools face no consequences for nonpolicy-related incidents of disclosure.

Because of this, violations of FERPA often are not penalized at all, including unauthorized disclosure of medical information.¹⁰⁷ Unauthorized disclosures in the athletics context have occurred, including recent instances where a coach disclosed to an entire team an athlete’s bipolar disorder and another incident where a coach disclosed a student-athlete’s disciplinary record to boosters.¹⁰⁸ Overall, these policies provide little incentive to closely follow the privacy requirements of HIPAA or FERPA.

3. Neither Statute Prevents Schools from Asking for a Media-Release Waiver

Both HIPAA and FERPA allow disclosure of medical information to the media *if the student-athlete has authorized the disclosure in advance*.¹⁰⁹ HIPAA allows for more blanket-type disclosures than FERPA.¹¹⁰ For example, HIPAA does not require that the waiver specify the purpose of the disclosure, but rather requires that the waiver simply state who is allowed to make the disclosure and to whom the person or entity is allowed to disclose the information.¹¹¹ FERPA provides more stringent requirements for a valid waiver. The waiver must: (1) be written and signed, (2) specify what records

103. Stephanie Humphries, Note, *Institutes of Higher Education, Safety Swords, and Privacy Shields: Reconciling FERPA and the Common Law*, 35 J.C. & U.L. 145, 157 (2008) (citing *Gonzaga Univ. v. Doe*, 536 U.S. 273, 283–91 (2002)).

104. *Id.* at 157–58.

105. *Id.* at 158.

106. *Id.*

107. Daggett, *supra* note 98, at 111–12.

108. *Id.*

109. O’Hara, *supra* note 52, at 5.

110. See 45 C.F.R. § 164.508(c) (2010) (detailing the requirements for written authorization to release PHI); O’Hara, *supra* note 52, at 5.

111. 45 C.F.R. § 164.508(c). Because of this, many HIPAA covered universities have their waivers written very generally. For example, Iowa State University’s waiver form lists many entities that the school can release medical information to, including coaching staff and the media. See *infra* note 122.

will be disclosed, (3) give the reason for disclosure, and (4) identify to whom the information will be disclosed.¹¹²

Some colleges and universities have students sign such waivers when filling out other necessary medical information, circumventing any privacy goal of HIPAA or FERPA.¹¹³ These waivers often authorize the release of any medical information, past or present, relevant to the student-athlete's participation in athletics at the college or university.¹¹⁴

IV. INSUFFICIENT SAFEGUARDS AND INSUFFICIENT INFORMATION

If schools implement the sickle-cell trait testing plan as hoped by proponents of the plan, a student-athlete's genetic information will be in the hands of multiple people, as well as permanently in his or her medical record.¹¹⁵ The current federal laws include too many loopholes that allow schools to release this information and do not provide strict enough sanctions for improper disclosures.

A. INCREASED OPPORTUNITIES FOR A SCHOOL TO RELEASE A STUDENT-ATHLETE'S GENETIC INFORMATION

NCAA legislation 17.1.5.1 provides little guidance on how a school should conduct testing and who should have access to that information.¹¹⁶ The NCAA has left the process of obtaining the sickle-cell trait test results, results from prior tests, and waivers up to each individual school.¹¹⁷ The results have led to a wide variety of disclosure forms and waivers.¹¹⁸ Some schools do not even provide information on the possibility of waiving the test at all on their websites.¹¹⁹

112. RAMIREZ, *supra* note 97, at 51.

113. *See supra* Part III.D.3.

114. *Id.*

115. Interview with Terrance G. Noonan, *supra* note 17.

116. *See* NCAA MANUAL, *supra* note 12, 17.1.5.1.

117. NAT'L COLLEGIATE ATHLETIC ASS'N, NCAA DIVISION I PROPOSAL NO. 2009-75-B QUESTION AND ANSWER DOCUMENT 1-2 (2010), available at <http://www.ncaa.org/wps/wcm/connect/e833fc8042c462ce92bdfbfd1ce0240/NCAA+Division+I+Sickle+Cell+Trait+QA+for+institutions+5+25+2010.pdf?MOD=AJPERES&CACHEID=e833fc8042c462ce92bdfbfd1ce0240>. After announcing the legislation, and after the publication of the *New England Journal of Medicine* article critiquing the mandate, the NCAA responded with slightly more comprehensive guidelines for when a student-athlete tests positive, but still left much up to the individual athletic programs. The NCAA recommended that athletic programs follow the *Sports Medicine Handbook* when a student-athlete tests positive for the trait and gave further vague instructions like "[d]evelop a year-round strength and conditioning program" and "allow[] longer periods of rest and recovery." *Background on Sickle Cell Trait*, *supra* note 38. The NCAA also provided a video on dealing with student-athletes that test positive for the sickle-cell trait. *Id.*

118. *See supra* Part I (detailing that the NCAA mandate allows universities to make the waivers as they see fit and describing certain waivers).

119. Drake Athletic Training Staff, *Sickle Cell Trait Test Information*, GODRAKEBULLDOGS.COM (June 9, 2010), http://www.godrakebulldogs.com/ViewArticle.dbml?DB_OEM_ID=15700&

Furthermore, potential sanctions against an athletic program are not likely to create much pressure on the program. The Committee on Infractions determines punishment for violations of NCAA rules.¹²⁰ Different levels of violations come with different levels of punishment, with the most serious punishment being a *major infraction*.¹²¹ Major infractions usually involve conduct that would provide an institution with “extensive recruiting or competitive advantage.”¹²² It is unclear what actions, if any, the NCAA would take against a violation of the sickle-cell legislation.

The NCAA’s lack of guidance, coupled with the lack of clarity on NCAA sanctions for failure to follow the legislation, create more problems when analyzing the collateral consequences. For example, some universities, such as the University of Nebraska-Lincoln, have student-athletes sign a waiver allowing the school to release their health information to the media.¹²³ As discussed, this is allowable under HIPAA and FERPA.¹²⁴ The health of these athletes, especially in high-profile sports such as football, is crucial. A media release allows a school to publicize a student’s health information but still comply with the governing statutes—even if it is in a backwards way that defeats the purpose of both statutes.¹²⁵ If these students, uninformed about the importance of keeping genetic information private, release their sickle-cell trait test results this information could potentially be released to the media and beyond.

College football and many other college sports receive great media attention. If, for example, a college football player who is a carrier of the trait is pulled from a game because he is suffering from sickle-cell trait related symptoms, the media and fans are likely going to want to know the reason.¹²⁶ If the student-athlete signed a waiver allowing the school to

KEY=&ATCLID=204957972&SPID=39420&SPSID=602748 (requiring students to provide test results, without mentioning the option of a waiver). However, whether these schools are notifying each student individually of their rights is unknown. Regardless, this information is not publicized on their website to current or potential student-athletes.

120. *Glossary of Terms*, NCAA.ORG, <http://www.ncaa.org/wps/wcm/connect/public/NCAA/Issues/Enforcement/Rules+Enforcement+glossary+of+terms#major> (last visited Oct. 6, 2011).

121. *Id.*

122. *Id.*

123. For the waiver form used, see University of Nebraska, Medical History for Student Athletes, *available at* http://www.huskers.com/pdf6/80708.pdf?SPSID=184&SPID=41&DB_OEM_ID=100; *see also* Iowa State University, Authorization for Release of Medical Information, *available at* http://www.cycloneathletictraining.com/documents/filelibrary/forms/Authorization_for_Release_of_Medica_EB56D9oAF4BDo.pdf (showing the waiver form used by Iowa State University).

124. *See supra* Part III.D.3.

125. Pitz, *supra* note 83, at 12–13.

126. Hike, *supra* note 55, at 48–50. For example, the hospitalization of thirteen University of Iowa football players for rhabdomyolysis recently received national attention. *See* Pat Forde, *Leadership Lacking in Latest Mess*, ESPN (Jan. 18, 2011), <http://sports.espn.go.com/ncf/>

release his medical information to the media, coaches will be able to disclose why the student–athlete left the game. This could result in the coach simply stating that the student–athlete showed symptoms as a result of carrying the sickle-cell trait and they took him out as a precaution. On the other hand, the coach could disclose the symptoms and allow scouts and the public at large to reach the conclusion on their own that this resulted from complications due to the sickle-cell trait. Any scout or future employer would then have this information and the potential to use it in making hiring or recruiting decisions.

B. DRAWBACKS OF RELEASING GENETIC INFORMATION

The future consequences of releasing this genetic information to a college or university can be devastating to a student–athlete. A person’s “genetic information should be handled with the utmost care in order to avoid unwarranted infringements of the principle of self-determination and the right to privacy.”¹²⁷ In the past, sickle-cell trait testing has been associated with violations of privacy with some individuals being tested without their knowledge, sometimes by their employer.¹²⁸ A student–athlete’s status as a carrier of the sickle-cell trait may affect their employment opportunities.

For example, a student–athlete is more susceptible to discrimination if the employer believes carrying the trait makes a candidate less qualified, a possibility not completely prevented by GINA.¹²⁹ In the past, employers have fired trait carriers because certain industries banned carriers of the sickle-cell trait from working with them.¹³⁰ Employers have various reasons to be hesitant to hire a carrier of the sickle-cell trait—whether valid or not. For example, an employer may believe that the potential complications due to the trait, such as shortness of breath with exertional exercise, may make it difficult for the employee to perform his or her job.¹³¹ These types of jobs

columns/story?columnist=forde_pat&id=6069090 (criticizing University of Iowa coaches for their handling of football players’ hospitalizations). In fact, curiosity about the University of Iowa players’ medical condition was so high that University of Iowa Hospitals and Clinics staff illegally accessed the players’ files in violation of HIPAA. *UI Investigating Access to Players’ Medical Data*, KCCCL.COM (Jan. 28, 2011, 4:37 PM), <http://www.kcci.com/sports/26653381/detail.html>.

127. J.H. GERARDS ET AL., GENETIC DISCRIMINATION AND GENETIC PRIVACY IN A COMPARATIVE PERSPECTIVE 12 (2005).

128. SECRETARY’S ADVISORY COMMITTEE, *supra* note 25, at 11 (citing the case of Lawrence Berkeley Laboratory testing employees for “sickle cell trait, syphilis, and pregnancy without their knowledge.”). Also, testing for a genetic marker like the sickle-cell trait also reveals information about the potential genetic information of family members, leading to non-consensual disclosure in some cases. *Id.* at 10–11.

129. Rhonda B. Evans, Recent Development, “Striking Out”: *The Genetic Information Nondiscrimination Act of 2008 and Title II’s Impact on Professional Sports Employers*, 11 N.C. J.L. & TECH. 205, 220 (2009).

130. Haywood Jr. & Pena, *supra* note 37.

131. *Id.*

can include more than being a professional athlete, including any job that requires working in the heat for extended hours or exercise—like walking—without many breaks.

An employer could also see an employee or potential employee with the sickle-cell trait as a financial burden. An employer may be afraid that because a potential employee is a carrier of the sickle-cell trait, future potential complications will create much higher health-insurance costs.¹³² Further, an employer may believe that carrying the sickle-cell trait could require “frequent and expensive absences from work and may lead to reduced employee efficiency and productivity.”¹³³

Congress enacted GINA with the goal of preventing discrimination due to an individual’s genetics in both the employment and health-insurance contexts by providing a legal remedy to those who are discriminated against due to their genetic information.¹³⁴ The use of “genetic information” in employment situations is covered by Title II.¹³⁵ GINA does not allow employers to condition employment on taking or the results of genetic tests.¹³⁶ These employers include the NFL and other professional-sports organizations.¹³⁷ For example, the Major League Baseball recently received

132. Mark A. Rothstein, *Discrimination Based on Genetic Information*, 33 JURIMETRICS J. 13, 14–15 (1992).

133. GERARDS ET AL., *supra* note 126, at 18 (discussing why employers are interested in a potential employee’s genetic information).

134. Daniel Schlein, *New Frontiers for Genetic Privacy Law: The Genetic Information Nondiscrimination Act of 2008*, 19 GEO. MASON U. C.R. L.J. 311, 313–14 (2009). In fact, part of the motivation for passing GINA was the history of widespread testing for sickle cell in the 1960–70s and the discrimination that African Americans received as a result. SECRETARY’S ADVISORY COMMITTEE, *supra* note 25, at 11. This discrimination against African Americans who carried the sickle-cell trait also led to the passage of the Sickle Cell Anemia Control Act, “which withholds federal funds from States unless sickle-cell testing is voluntary.” Pub. L. No. 110-233, 122 Stat. 881 (2008) (codified as amended at 42 U.S.C. § 2000ff (Supp. II 2008)). Because the sickle-cell trait is much more predominant in African Americans, employers would use the positive test result as a reason to not hire an African American, when the end goal was to simply discriminate against a person because of his or her race. SECRETARY’S ADVISORY COMMITTEE, *supra* note 25 at 11 (citing National Sickle Cell Anemia Control Act, Pub. L. No. 92-294, § 2, 86 Stat. 136 (1972) (codified as amended at 42 U.S.C. 300b (2006))); *see also* GERARDS ET AL., *supra* note 126, at 13 (“[T]he fact that differentiation that is based on genetic information may easily result in indirect discrimination against vulnerable groups.”).

135. Evans, *supra* note 129, at 207; Foster, *supra* note 51, at 545.

136. *See* Evans, *supra* note 129, at 207.

137. Some argue GINA may not cover any employment where physical capabilities are relevant to the job description, including in professional-sports leagues. The argument is that GINA might not apply because (1) GINA assumes that a person’s genetic information has no bearing on a potential employee’s ability to perform the job, and this is not the case with professional football, and (2) GINA also assumes that genetic information deals with concerns of future risk because of a genetic disposition, while the NFL is concerned with current risk due to the trait. Adam Y. Siegel & Frank Alvarez, *Sickle-Cell Testing and the Implications of GINA*, SPORTS LITIG. ALERT, May 21, 2010, available at <http://www.hackneypublications.com/sla/archive/001055.php>. The NFL tests for the trait during the annual scouting combine but

criticism for DNA testing of potential baseball recruits to determine age, as many saw this as a violation of GINA.¹³⁸

Still, GINA does not prevent all possible discrimination due to a person's genetic information. An employer can have access to a person's genetic information when that information is publicly available.¹³⁹ For example, an employer who finds information in a newspaper or in another media resource does not violate GINA.¹⁴⁰ Therefore, if a student signed a media waiver and his or her status as a carrier of the sickle-cell trait is made public, a future employer is not punished for its knowledge of this situation.

GINA prohibits an employer from using this information to discriminate against an employee, even if it obtained the genetic information legally.¹⁴¹ Yet, proving that an employer based an employment decision on knowledge of the employee's, or potential employee's, sickle-cell status is extremely difficult.¹⁴² GINA is modeled after Title VII, which uses a balancing test that federal courts will likely apply to GINA claims.¹⁴³ In applying this balancing test, it will likely be "difficult for a plaintiff to prove that a termination, lack of advancement, or other form of adverse action was due not to the employer's purported legitimate business rationale, but rather to specific knowledge of the litigant's genetic makeup."¹⁴⁴

Further, GINA does not allow disparate-impact claims for at least six years, and at that time, Congress will only create a committee to determine if

leaves the decision whether to test all players up to each individual team. Katie Thomas & Brett Zarda, *In N.C.A.A., Question of Bias over a Test for a Genetic Trait*, N.Y. TIMES, Apr. 12, 2010, <http://www.nytimes.com/2010/04/12/sports/12sickle.html>. Previously, this type of situation would have been regulated by the Americans with Disabilities Act. In *Chevron U.S.A. Inc. v. Echazabal*, the Court upheld the EEOC's regulation which stated that a company may refuse to hire an individual because performing the job would be a danger to his or her health. 536 U.S. 73, 76 (2002). This regulation would have possibly allowed professional-sports organizations to refuse to hire athletes if they carried a gene that would make them more susceptible to negative health consequences. However, GINA does not have a "direct threat" defense—as the ADA did—which would allow an employer "to terminate or reassign an employee with a known predisposition or medical condition that might make him harmful to himself." Schlein, *supra* note 134, at 366. Any notion that professional sports teams can test for genetic predispositions is only "a legal theory for speculation today." SECRETARY'S ADVISORY COMMITTEE, *supra* note 25, at 12.

138. Michael S. Schmidt & Alan Schwarz, *Baseball's Use of DNA Raises Questions*, N.Y. TIMES, July 21, 2009, <http://www.nytimes.com/2009/07/22/sports/baseball/22dna.html>.

139. 42 U.S.C. § 2000ff-1(b)(4) (Supp. III 2010); *How Does GINA Impact ME?*, COAL. FOR GENETIC FAIRNESS, http://www.geneticfairness.org/ginaresource_impact.html (last updated Nov. 10, 2008).

140. 42 U.S.C. § 2000ff-1(b)(4).

141. 42 U.S.C. § 2000ff(a).

142. Gregory Katz & Stuart O. Schweitzer, *Implications of Genetic Testing for Health Policy*, 10 YALE J. HEALTH POL'Y L. & ETHICS 90, 108 (2010) (discussing how proving unlawful discrimination under GINA will be difficult "because of loopholes in the law").

143. Schlein, *supra* note 134, at 365.

144. *Id.* at 365–66.

allowing disparate-impact claims are necessary.¹⁴⁵ The inability to bring a disparate-impact claim means that “GINA would effectively block the ability of the federal courts to process . . . claims efficiently and cost-effectively as a class action”¹⁴⁶

Finally, GINA is limited in applicability. The statute includes an exemption for employers “not ‘affecting commerce’ or that have 15 or fewer employees.”¹⁴⁷

In fact, discrimination in the employment context due to being a carrier of the sickle-cell trait can happen and has. For example, Ryan Clark, an NFL player for the Pittsburgh Steelers, recently suffered the consequences of teams knowing that he carried the sickle-cell trait.¹⁴⁸ In 2007, Clark had his spleen and gallbladder removed after a game in Denver because of complications from sickle-cell trait, exacerbated by the high altitude.¹⁴⁹ His status as a carrier of the sickle-cell trait adversely affected him during his free agency during the 2009 off-season, as some teams questioned whether he could play at high altitudes.¹⁵⁰

The drawbacks could be overcome if this testing policy were to substantially benefit the student-athlete, but this is likely not the case. Before the legislation, schools involved in four of the eight deaths in college football linked to the sickle-cell trait knew the student carried the trait.¹⁵¹ Some argue that there is no data to support that screening can save lives.¹⁵²

V. STOP TESTING OR REQUIRE MORE PROTECTIONS FOR STUDENT-ATHLETES

As shown by the discussion in Part IV, HIPAA and FERPA are riddled with too many loopholes that allow schools to release sensitive genetic information. Further, even where the statutes provide protection, the guidelines are likely too complicated for colleges and universities to properly follow them. Because of this, the NCAA should repeal the testing policy. If testing is seen as vital to protect against complications of the trait,

145. *Id.* at 365. In a disparate-impact claim, an employee does not need to prove intent to discriminate but simply that an employer’s policy or practice leads to discrimination. *Smith v. City of Jackson, Miss.*, 544 U.S. 228, 241 (2005).

146. Schlein, *supra* note 134, at 365.

147. *Id.* at 364–65.

148. Thomas & Zarda, *supra* note 137.

149. *Id.*

150. *Id.*

151. *Id.*

152. *Id.* (“There’s not any data that shows that screening can save lives. . . . A lot of the kids who have died, they’ve known they have sickle-cell trait and they still run them to death. It should just be a change in the training program to protect everyone and not just the kids with sickle.” (quoting Dr. William Roberts) (internal quotation marks omitted)).

either the NCAA or Congress must provide further privacy protections, especially as genetic testing becomes more prevalent and accessible.¹⁵³

A. *PROHIBIT TESTING AND SIMPLY CHANGE WORKOUT PROCEDURES FOR ALL STUDENT-ATHLETES*

Implementing protections during workouts for *all* student-athletes provides the clearest option to prevent unnecessary deaths while protecting the privacy of student-athletes. The United States Armed Forces adopted this solution to problems associated with the sickle-cell trait.¹⁵⁴ In the early 1970s, multiple divisions of the armed forces discovered that soldiers were dying as a result of complications due to the sickle-cell trait.¹⁵⁵ A 1987 study by the *New England Journal of Medicine* revealed that African-American soldiers were 40% more likely to die during basic training as a result of complications with the sickle-cell trait.¹⁵⁶

The armed forces first implemented a program similar to the NCAA legislation, testing all soldiers for the trait.¹⁵⁷ The armed forces then removed soldiers who tested positive from certain activities that increase the likelihood of adverse health effects.¹⁵⁸ This policy led to discrimination against those who carried the trait, most of whom were African American. For instance, after a positive testing for the trait, the armed forces banned these soldiers from completing certain duties.¹⁵⁹ Once the armed forces discovered it could avoid these complications with “appropriate hydration and modification of training,” they changed their policy, removing the ban for trait carriers and implementing the prevention policy for all soldiers.¹⁶⁰

Soon after the NCAA sickle-cell legislation went into effect, the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (the “Committee”) released a recommendation to the U.S. Department of Health and Human Services on the legislation.¹⁶¹ The Committee recommended that the NCAA forgo requiring testing and instead follow the lead of the armed forces and simply take the necessary precautions for everyone.¹⁶² The Committee determined:

153. Katz & Schweitzer, *supra* note 142, at 93–94 (“According to a 2003 survey . . . the expansion of genetic testing is staggering: between 2000 and 2002, the number of genetic tests conducted in 827 hospitals nearly doubled.”).

154. See Mary L. Anzalone et al., *Sickle Cell Trait and Fatal Rhabdomyolysis in Football Training: A Case Study*, 42 *MED. & SCI. SPORTS & EXERCISE* 3, 6 (2010).

155. *Id.* at 3–4.

156. *Id.* at 6 (citing J. A. Kark et al., *Sickle-Cell Trait as a Risk Factor for Sudden Death in Physical Training*, 317 *NEW ENG. J. MED.* 781, 781–87 (1987)); see also Zarda, *supra* note 1.

157. Bonham et al., *supra* note 4, at 998.

158. *Id.*

159. *Id.*

160. *Id.*

161. SECRETARY’S ADVISORY COMMITTEE, *supra* note 25.

162. *Id.* at 14–15.

While the value of screening athletes for sickle cell trait remains to be determined, the recommendation fails to acknowledge that testing for sickle cell trait is genetic screening and does not include clear guidelines about follow up counseling and education and mechanisms to protect the privacy of the student athlete, and prevent stigmatization and discrimination. The recommendation shows a lack of sensitivity to an historical context within which sickle cell carrier screening took place in the U.S., and a lack of sensitivity to the real possibility of stigma and loss of opportunities for student athletes who are identified as having sickle cell trait.¹⁶³

Instead of risking the dissemination of student-athletes' private genetic information, the NCAA should follow the example of the United States Armed Forces and simply require all participating schools to implement procedures for *all* student-athletes that would prevent complications due to the sickle-cell trait. Complications from the sickle-cell trait result when student-athletes are not allowed to rest during long conditioning exercises.¹⁶⁴ The common-sense solution would be to allow these students to rest and hydrate, regardless of their genetics. If the students who test positive for the trait can be monitored and the appropriate precautions taken, schools should just take the same precautions for all athletes.

B. REQUIREMENTS SIMILAR TO FERPA ARE NECESSARY TO PROTECT THE PRIVACY OF STUDENT-ATHLETES, WITH PROTECTIONS AGAINST RELEASE OF A STUDENT-ATHLETE'S MEDICAL INFORMATION TO THE MEDIA

A clear-cut rule applicable to all schools that administer sickle-cell trait testing would be the next best option to protect the privacy interests of student-athletes. The most effective mode would be by NCAA legislation, but if not through that, then by congressional legislative action.

1. By NCAA Legislation

NCAA legislation would likely provide the most coverage, as the NCAA should simply provide guidelines with the mandated testing. To best protect the genetic information of student-athletes, the NCAA should restrict the disclosure of a student-athlete's test results to the team physician, coaches, and athletic trainers who work with the student-athlete. Also, the NCAA should require schools to prohibit the release of a student-athlete's medical information—including the symptoms—to the media, or exempt genetic information from this release. This would remove any problem with determining what colleges and universities are covered by FERPA, as not all receive the type of funding that allows coverage under the statute, or HIPAA, as not all are "covered entities."

163. *Id.* at 14.

164. Atkinson, *supra* note 47.

However, the problem with this approach is enforcement, as the consequences of not following NCAA protocol on sickle-cell trait testing are unclear and minimal at best and likely would not provide any remedy to students whose privacy rights were violated.¹⁶⁵ As previously mentioned, the stricter regulations focus on violations dealing with recruiting.¹⁶⁶

Still, breaking NCAA protocol can lead to severe consequences for those who fail to follow regulations.¹⁶⁷ On August 19, 2010, only nineteen days after the mandated sickle-cell trait testing went into effect, Jospin “Andre” Milandu, a freshman at North Carolina Agricultural and Technological State University (“NC A&T”), died during a track and field tryout from complications associated with the sickle-cell trait.¹⁶⁸ NC A&T, a Division I university,¹⁶⁹ failed to test Milandu and the twenty-eight other participants for the sickle-cell trait.¹⁷⁰ After the release of the autopsy information, the school fired Athletic Director Wheeler Brown for failing to comply with the NCAA legislation.¹⁷¹

The swift and harsh response to Miandu’s death shows that college and university administrators take the sickle-cell trait testing requirements seriously. However, failing to comply with privacy rules alone, unlike failing to test and then a resulting death, will likely not have the devastating results as with Milandu. Moreover, NC A&T took this action, not the NCAA.

Also, the NCAA should not only mandate that schools follow these procedures, but could also require schools to promise student–athletes that they will not release the information at all. Under the Privacy Rule, if a covered entity, like a college or university’s athletic department, agrees to more restrictions, then it must follow these restrictions.¹⁷²

2. By Federal Statute

If the NCAA fails to adopt legislation that increases the privacy protection of student–athletes’ genetic information, the next best option would be for Congress to amend FERPA to ensure that the results of the sickle-cell trait test fall under the “educational records” definition and,

165. *See supra* Part III.D.2.

166. *See supra* Part IV.A.

167. *North Carolina A&T Fires Athletic Director over Student Death*, USA TODAY (Oct. 15, 2010, 7:52 PM), http://www.usatoday.com/sports/college/2010-10-15-ncat-athletics-director-fired_N.htm [hereinafter *North Carolina*].

168. *Id.*

169. *A&T Welcome*, OFFICIAL SITE OF AGGIE ATHLETICS: N.C. A&T, http://www.ncataggies.com/ViewArticle.dbml?DB_OEM_ID=24500&ATCLID=204937491 (last visited Oct. 6, 2011); *see also NCAA Members by Division*, NCAA.ORG, <http://web1.ncaa.org/onlineDir/exec/divisionListing> (last visited Oct. 6, 2011).

170. *North Carolina, supra* note 167.

171. *Id.*; *see also* Memorandum from Chancellor Harold L. Martin, Sr. to the University Community (Oct. 15, 2010), *available at* <http://www.ncataggies.com//pdf8/716820.pdf>.

172. 45 C.F.R. § 164.502(c) (2010).

therefore, are exempt from coverage under the Privacy Rule. This is desirable because FERPA provides more protections than HIPAA. This amendment may require that all team physicians be employed in some capacity by the student-health center.¹⁷³ FERPA should allow for the information on the student's status as a carrier of the trait to be discussed with the necessary team personnel, meaning the coach, strength and conditioning coaches, team physician and athletic trainers, but this would still provide more protections than HIPAA.¹⁷⁴

Still, as already discussed, FERPA does not provide sufficient protections to prevent all instances of unauthorized release, as this statute is meant to provide coverage in a variety of instances and is not tailored to intercollegiate athletics.¹⁷⁵ Further, amending either of the current privacy statutes still does not change the fact that the results of this genetic test will be in a student-athlete's permanent medical record, regardless of whether the student-athlete wants it there.¹⁷⁶ Whether this information falls under the definition of an educational record or PHI, athletic trainers and physicians are required to put this information in the permanent medical file.¹⁷⁷ Finally, this does not fix issues with enforceability.¹⁷⁸

C. WAIVER POLICY IS NOT ENOUGH TO ENSURE THE PRIVACY AND AUTONOMY OF STUDENT-ATHLETES

One obvious counterargument to this privacy issue is that student-athletes can opt out of testing. This means that student-athletes concerned about the possibility of being a sickle-cell trait carrier and who want to be tested are penalized because testing means having the results susceptible to unwanted disclosure. Further, the legislation was originally proposed without the waiver option,¹⁷⁹ and a criticism of the legislation is that the waiver option circumvents the whole rationale for implementing the policy.¹⁸⁰ Whether the legislation will continue to allow for the waiver option is unclear.

Considering that the NCAA and many colleges and universities push for the release of the information and not the waiver, student-athletes will likely follow this influence and forgo the waiver option. Incoming student-athletes

173. Hike, *supra* note 55, at 53.

174. *Id.* at 53-54.

175. *See supra* Part III.B.

176. GARY HARRELSON ET AL., ADMINISTRATIVE TOPICS IN ATHLETIC TRAINING: CONCEPTS TO PRACTICE 112 (2009).

177. *Id.*

178. *See supra* Part III.D.2.

179. Hosick, *supra* note 10.

180. *See supra* note 20 and accompanying text.

are already under an enormous amount of pressure,¹⁸¹ and privacy concerns or implications of handing over genetic information are likely the last concerns on their minds. Student-athletes not only face the pressures of attempting to perform at a higher level of competition but also attempting to achieve a higher level of education.¹⁸² Also, student-athletes hope to create strong relationships with their coaches.¹⁸³ In an attempt to create these relationships, student-athletes are more likely to follow the recommendations of these people without thinking of the consequences.

Unlike other levels of competition, college athletes are not able to have a vote in the eligibility rules—which include the legislation on sickle-cell trait testing—and have no outside representation looking out solely for their interests.¹⁸⁴ Not only do these student-athletes not have someone looking out solely for their interests at the time of releasing their information, they do not have a representative at the stage of the formation of the testing policy making sure their privacy is protected.

VI. CONCLUSION

The NCAA legislation on sickle-cell trait testing shows the lack of privacy protections available to student-athletes and opens the door for future discrimination due to a student-athlete's genetic information. The threat of complications due to carrying the sickle-cell trait does not justify testing, as schools could take the same precautions for all student-athletes regardless of their status. If not, the NCAA or Congress must provide sufficient guidelines similar to FERPA, while also removing the option of allowing a student-athlete to authorize release of their medical information to the media. These options will better protect both a student-athlete's privacy and health.

181. Eric A. Storch et al., *Self-Reported Psychopathology in Athletes: A Comparison of Intercollegiate Student-Athletes and Non-Athletes*, 28 J. SPORT BEHAV. 86, 87 (2005).

182. *Id.*

183. *Id.*

184. Matthew J. Mitten & Timothy Davis, *Athlete Eligibility Requirements and Legal Protection of Sports Participation Opportunities*, 8 VA. SPORTS & ENT. L.J. 71, 116 (2008).