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IMPLICATIONS OF NCAA MANDATED GENETIC TESTING: LOOKING OUT FOR THE ATHLETES AND LOOKING TO THE FUTURE

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INTRODUCTION

In 2010, the NCAA initiated a mandatory program for all athletes to be screened for sickle cell trait, starting with Division I athletes.[1] A settlement agreement between Dale Lloyd II's family and the NCAA stipulated that the NCAA initiate testing of athletes to prevent future deaths, like the one their son suffered.[2] Lloyd, an NCAA athlete, died from complications of sickle cell trait after a football practice in 2006.[3] This article will show how mandatory genetic testing is a matter of great significance, and not just of legal utility for the NCAA. It will discuss what other tests the NCAA should initiate in the future and how genetic testing could change the face of college athletics. The article will then cover the history and future of genetic testing, the NCAA rules regarding genetic testing, and whether the Genetic Information Nondiscrimination Act of 2008 (GINA) impacts collegiate testing. Finally, this article will show how the NCAA can benefit from the major advances in genetic testing, and that testing by the NCAA is important for reasons other than a legal settlement agreement.

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[1] Susan L. Smith & Miriam Shuchman, *Sickle Cell Screening of College Athletes: Legal Obligations Fulfilled, Moral Obligations Lacking*, 92 OR. L. REV. 1127, 1127 (2014).

[2] *Id.* at 1128.

[3] *Id.*

I. HISTORY OF GENETIC TESTING

The first case of large scale genetic testing began in 1962 in Massachusetts.[4] The purpose was to test newborns for phenylketonuria (PKU), and soon after, other states followed Massachusetts' lead.[5] Over the years, genetic testing of infants continued to expand.[6] Government agencies now recommend that states test infants for thirty-two different genetic traits.[7] Testing is available for more than sixty different disorders and all fifty states test for sickle cell anemia.[8]

Sickle cell anemia is one form of sickle cell disease, but sickle cell trait is not considered a form of sickle cell disease.[9] Newborn screenings may show a sickle cell trait, but the parents may not be informed of the finding.[10] State-mandated newborn screenings are the most common type of mandated testing in the United States, covering about 4 million babies per year.[11] The NCAA's mandated testing of collegiate athletes is second in scope only to the infant testing required by states.[12] NCAA has

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[4] Leila Barraza & Lauren Burkhart, *The Expansion of Newborn Screening: Implications for Public Health and Policy*, ANNALS OF HEALTH L., Special Edition 2014, at 44, http://www.annalsofhealthlaw.com/annalsofhealthlaw/vol23issue2?pg=1#pg1.

[5] *Id.*

[6] *Id.* at 44–45.

[7] *See* BABY'S FIRST TEST, http://www.babysfirsttest.org (last visited Jan. 30, 2016). This website is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS).

[8] *Id.* This information was found by referencing the list of items tested for which appears when one clicks a state in the map of the United States.

[9] *Sickle cell Disease*, CDC, www.cdc.gov/sicklecell (last visited Jan. 30, 2016) (found under the Sickle cell trait Fact Sheet).

[10] *See* HRSA, www.hrsa.gov/advisory (last visited Nov. 8, 2016) (shows committees with the title Screening US College Athletes for their Sickle cell Disease Carrier Status on page 8–9).

[11] Barraza & Burkhart, *supra* note 4, at 44–45.

[12] Smith & Shuchman, *supra* note 1, at 1128.

tested more than 460,000 NCAA athletes.[13] No evidence of other large scale mandatory genetic testing was found.

The NCAA implemented phase one of its mandated testing for sickle cell trait among Division I athletes in 2010.[14] Phases two and three were implemented in 2012 and 2014, respectively.[15] Phase two included testing Division II athletes, and phase three included testing Division III athletes.[16] The results of those screenings and their impact on the NCAA are not publicly known. Each Division determined how it wanted to implement the mandatory testing.[17] Prior to this mandate, genetic testing for sickle cell trait was not done in college. Most college athletes are screened for sickle cell disease as newborns, but may be unaware of whether they carry the sickle cell trait.[18]

Currently, the NCAA tests for sickle cell trait as a condition resulting from the terms of its settlement with Lloyd's heirs; however, it also has the best interests of the athletes in mind.[19] Those opposed to the mandated test are concerned that the information will be used to discriminate against the affected athletes.[20] This worry stems from the 1970's, a time when mandated testing for sickle cell disease was used to discriminate

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[13] *See id.* at 1127–28 (stating that "[i]n 2010, the [NCAA] implemented a policy requiring all NCAA Division I athletes to be screened for . . . sickle cell . . ." and this requirement was extended to all athletes in 2014–2015, "placing it among the largest mandatory genetic screening programs in the United States."); *see also How The NCAA Works*, NCAA, http://www.ncaa.org/champion/how-ncaa-works (last viewed Oct. 20, 2016) (noting that the NCAA is composed of over 460,000 student-athletes).

[14] Smith & Shuchman, *supra* note 1, at 1127.

[15] *Id.* at 1128.

[16] *Id.*

[17] *See 2013 NCAA Division II Convention Legislative Proposals Question and Answer Guide*, NCAA 9–14, http://cdn.e2ma.net/userdata/1367819/assets/docs/2013qadocument_-_final.pdf (notes that Div. I and II have their own rule making boards, by asking how the proposal relates to Div I and II rules).

[18] Barraza & Burkhart, *supra* note 4, at 42–44.

[19] Smith & Schuchman, *supra* note 1, at 1128.

[20] Madison Park, *NCAA Genetic Screening Rule Sparks Discrimination Concerns,* CNN (Aug. 4, 2010), http://www.cnn.com/2010/HEALTH/08/04/ncaa.sickle.genetic.screening.

against African-Americans, since they are at highest risk for the disease.[21] Beth Tarini and her associates took data from the 2007-08 academic year to determine the number of athletes impacted by the new testing policy.[22] Tarini and her associates worked with Health Services Research and estimated 2,147 Division I athletes would test positive for sickle cell trait during the 2007-08 academic year.[23] Tarini concluded, "[a]longside a 100 percent effective intervention, screening could prevent the deaths of seven student-athletes over a 10-year period."[24]

Seven deaths over the span of ten years does not seem sufficient to warrant the cost and controversy of mandating genetic testing of all athletes before they participate in or condition for an NCAA sport; however, saving almost one athlete per year is worth the trouble, not only financially and legally, but also in changing training protocols to better protect athletes from harm.[25] The costs of genetic testing will be discussed later in this article. The NCAA wants to ensure player safety, and mandated testing is one of many safety precautions in place to accomplish this end.

Athletes are not the only ones to suffer from the normally innate sickle cell trait. A study conducted in the 1980's showed sickle cell trait contributed to issues with military personnel during the physical exertion of basic training, leading to unexplained deaths.[26] The military did not implement mandatory genetic testing of all military personnel and recruits, but instead changed its training regimen to better incorporate guidelines for hydration, rest monitoring, and increased awareness of heat related illnesses, all of which reduce the chances of blood cell sickling in those with Sickle cell trait.[27]

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[21] *See* H.R. REP. NO. 110–28, at § 2(3) (2007).

[22] Beth A. Tarini et al., *A Policy Impact Analysis of the Mandatory NCAA Sickle cell trait Screening Program*, 47 HEALTH SERV. RES. 446, 446–61 (2012).

[23] *Id.* at 452.

[24] *Id.* at 453.

[25] *See generally id.* at 446, 447, 453.

[26] Alexis A. Thompson, *Sickle cell trait Testing and Athletic Participation: A Solution in Search of a Problem?*, 2013 SPORTS MED. IN HEMATOLOGY 632, 632–37 (2013).

[27] *Id.* at 634.

Universal precautions and changes in training regimens were not available as options to the NCAA due to the settlement agreement reached with Lloyd's family.[28] Those opposed to the mandatory testing look to the military's response as a solution that the NCAA should follow instead of its current mandated testing protocol.[29] Perhaps if the NCAA had taken a more proactive position to protect athletes from sudden death, universal precautions would be in place instead of mandatory testing. During settlement negotiations with the Lloyd family, the NCAA could have looked at best practices from the military or other areas to determine the best way to avoid mandatory genetic testing, the concern of discrimination based on genetic testing results, and being seen as not having the athletes' best interests in mind. However, mandatory testing does not preclude the NCAA from initiating universal training protocols to better protect all athletes. NCAA implementation of universal training protocols would help silence critic concerns about discrimination against those athletes in need of abridged training, as well as critics saying that testing is not in the best interest of the athletes.

The NCAA faced harsh criticism from a number of groups including the American Society of Hematology, the Sickle Cell Disease Association of America, and the American Academy of Pediatrics.[30] Their position is that mandated testing would lead to discrimination, and the link between sickle cell trait and death is not strong enough to require mandated testing.[31] Although there are other ways to protect athletes with sickle cell trait, the settlement agreement with the Lloyd family calls for testing athletes to determine potential health risks.[32] The critics of the mandated testing raise valid points, but the NCAA is not at liberty to go against the terms of its settlement agreement.

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[28] Smith & Shuchman, *supra* note 1.

[29] Thompson, *supra* note 26, at 634.

[30] Rosalie Ferrari et al., *Sickle cell trait Screening of Collegiate Athletes: Ethical Reasons for Program Reform,* 24 J. OF GENETIC COUNSELING 873, 874 (2015).

[31] *Id.*

[32] Smith & Shuchman, *supra* note 1, at 1127–28.

II. NCAA RULES FOR GENETIC TESTING

The NCAA now requires all student-athletes to either know of or be tested for sickle cell trait prior to participating in college sports, including weight training prior to the sport season.[33] Each division implemented this testing requirement at different times, and each division has chosen slightly different methods of implementation.[34]

Division III of the NCAA has made education a large part of its sickle cell trait screenings.[35] The rule gives an athlete three options: (1) to present documentation of the athlete's sickle cell status; (2) to have testing of sickle cell status pending, which requires a waiver to participate until the results are known; or (3) to opt out of testing all together, which also requires a waiver to participate.[36] Options two and three also have the additional requirement of education before the waiver is signed.[37] The increased education about the trait not only benefits the athlete, but the NCAA hopes that it will keep the number of athletes who opt-out of testing low.[38] Jack Ohle, the vice chair of the NCAA President's Council believes that sickle cell screening is essential, stating, "[t]he key point is that our student-athletes are safer knowing their status and allowing our institutions to accommodate for that status. For a small, yet equally important, number of student-athletes, this knowledge is a matter of life or death."[39]

Division I and Division II have adopted similar requirements, but Division III is the only one with a strong

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[33] *Sickle cell trait*, NCAA, http://www.ncaa.org/health-and-safety/medical-conditions/sickle-cell-trait (last updated Jan. 17, 2014).

[34] Gary Brown, *Education Campaign Informs DIII Decision on Sickle Cell Legislation,* NCAA (Nov. 8, 2012, 12:00 AM), http://www.ncaa.org/about/resources/media-center/news/education-campaign-informs-diii-decision-sickle-cell-trait [hereinafter Brown, *Education Campaign*].

[35] *Id.*

[36] *Id.*

[37] *Id.*

[38] *Id.*

[39] Gary Brown, *Division III Approves Sickle Cell Measure,* NCAA (Jan. 19, 2013, 12:00 AM), http://www.ncaa.org/about/resources/media-center/news/diii-approves-sickle-cell-measure.

educational component.[40] The NCAA believes it is in the best interest of all student-athletes to know their status.[41] Brian Hainline, Chief Medical Officer for the NCAA, stated, "[s]ometimes we just have to go forward with proposals we believe are protective of not only the athletes but also the institutions. And that is what the NCAA has done in this case."[42] At the NCAA Division III annual meeting, the issue of privacy for the student-athlete was discussed, where opponents to the mandatory testing looked to discrimination and privacy as reasons justifying their opposition.[43] Livingston Alexander addressed these issues:

> Athletic trainers already deal with medically sensitive issues every day. We have established procedures to handle confidential information in a professional manner that is still in the best interests of the student-athlete. There is no reason to suggest we would not address sickle cell trait status in the same professional manner.[44]

Division III's requirement that all student-athletes be educated about sickle cell trait makes the mandated testing less discriminatory.[45] In its education program initiated before screening, the NCAA included information that anyone can be a carrier of sickle cell trait, regardless of their race.[46]

III. THE FUTURE OF GENETIC TESTING

As genetic testing becomes more specialized and accurate, the NCAA should expand its genetic testing to include risk factors for a variety of injuries to develop better training protocols for all student-athletes. These training protocols would help athletes with sickle cell trait or a variety of other conditions that lead to a higher occurrence of grave harm including

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[40] *Id.*

[41] *Id.*

[42] *Id.*

[43] *Id.*

[44] *Id.*

[45] Brown, *Education Campaign*, *supra* note 34.

[46] *See id.*; *see also* Brown, *Division III Approves Sickle Cell Measure*, *supra* note 39.

concussion susceptibility, the risk of injury to major tendons (tendinopathy)[47] Marfan Syndrome,[48] and Hypertrophic Cardiomyopathy.[49] If the NCAA took a more proactive approach in checking athletes for these types of conditions, it could avoid potential harm to its reputation from another lawsuit for negligence in caring for its athletes.

A. CONCUSSION SUSCEPTIBILITY

A 2013 study on how genes relate to a person's ability to recover from a concussion found that certain people have a harder time recovering from head injuries than others because of genetic factors.[50] These findings will have a dramatic impact on sports such as football and soccer.[51] This information can help determine which players are at greater risk for a longer recovery and a potentially career ending head trauma.[52] This information will also change the way those athletes train for the sport.[53] Increased monitoring and greater precautions can be taken by athletic trainers for soccer and football players at greater risk for long-term damage.

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[47] *See* Roger Collier, *Genetic Tests for Athletic Ability: Science or Snake Oil?*, 184 CAN. MED. ASS'N. J. 43, 43 (2012); *see generally* Nicola Maffulli, et al., *The Genetics of Sports Injuries and Athletic Performance,* 3 MUSCLE, LIGAMENTS, AND TENDONS J. 173, 173 (2013) (discussing tendinopathy susceptibility in athletics).

[48] *What is Marfan Syndrome?*, NAT'L HEART, LUNG, AND BLOOD INST. (Oct. 1, 2010), http://www.nhlbi.nih.gov/health/health-topics/topics/mar#.

[49] Martha Pyron, *Hypertrophic Cardiomyopathy: A Cause of Athlete Sudden Death*, AM. C. OF SPORTS MED. (Oct. 7, 2016), http://www.acsm.org/public-information/articles/2016/10/07/hypertrophic-cardiomyopathy-a-cause-of-athlete-sudden-death.

[50] Eric Niiler, *Finding a Link Between Genes and Brain Injury: Are Some People Predisposed to Trauma*, WASH. POST (May 5, 2014), https://www.washingtonpost.com/national/health-science/finding-a-link-between-genes-and-brain-injury-are-some-people-predisposed-to-trauma/2014/05/05/c2d9dd06-c49e-11e3-bcec-b71ee10e9bc3_story.html.

[51] *See id.*

[52] *See id.*

[53] *See id.*

Granted, all sports have inherent risks; however, if an athlete can be more informed about how those risks relate to his or her genetic makeup, the amount of sport-injury related lawsuits and overall athlete suffering will likely decrease. The more information an athlete has about her genetic makeup, the more likely she will be able to determine the safest sports to be engaged in. This will lead to more informed decisions for participation in sports.

Here, the NCAA can get ahead of the game in protecting its athletes from the serious repercussions of concussions. The scientific discovery of the Apolipoprotein E (APOE) gene,[54] and how it affects concussion susceptibility, should be the next area of testing mandated by the NCAA. Although the NCAA would be wise to wait until the science is more conclusive before putting funds into testing all soccer and football players, it would be unwise to wait too long and risk not being on top of critical safety measures that protect athletes. College football is a huge revenue source,[55] and the member colleges and universities of the NCAA need to stay informed of the ever-changing science in concussion prevention to maintain its image of caring for the safety of all its athletes.

Sport related concussions account for up to 3.8 million injuries annually.[56] A 2010 study of the APOE gene looked at three different alleles associated with the gene.[57] The researchers found that if an athlete carries the promotor allele, they are more likely to suffer more concussions.[58] "In our sample, 89% (8 of 9) of athletes with multiple concussions carried the promoter rare allele . . . ."[59] Another study of the APOE alleles conducted at

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[54] Ryan T. Tierney et al., *Apolipoprotein E Genotype and Concussion in College Athletes*, 20 CLINICAL J. OF SPORTS MED. 464, 464 (2010).

[55] *See* Chris Smith, *College Football's Most Valuable Teams 2015: Texas, Notre Dame And . . . Tennessee?*, FORBES (Dec. 22, 2015, 12:00 PM), http://www.forbes.com/sites/chrissmith/2015/12/22/college-footballs-most-valuable-teams-2015-texas-notre-dame-and-tennessee/#f923cb551300.

[56] Tierney et al., *supra* note 54.

[57] *Id.*

[58] *Id.* at 466.

[59] *Id.*

Penn State University shows a link between the e4 allele and more severe symptoms associated with concussions.[60]

Arizona State University (ASU) has teamed up with Riddell and Translational Genomics Research Institute (TGen) for three consecutive years to research the connection between genetics and concussions in football players.[61] The research project uses the Riddell Sideline Response System (SRS) along with genetic samples from participating athletes to determine how the body responds to different head impacts.[62] These studies are an example of the continued research on the connection of genetics and concussion recovery.

The program is beneficial for all three entities involved. Riddell hopes to use this information to build a helmet that is better able to protect the athlete from concussions.[63] Dan Arment, President of Riddell, said, "[t]ogether we are advancing player protection and furthering important research that has the potential to forever change athlete concussion diagnosis and treatment in football and beyond."[64] Riddell's commitment is to "Smarter Football."[65] TGen will use the information gathered to further its research on concussion susceptibility and to "develop a definitive test that will objectively define when an athlete is injured."[66]

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[60] Kristie Auman-Bauer, *Genetics Affects Concussion Recovery*, PENN ST. NEWS (Nov. 20, 2015), http://news.psu.edu/story/381653/2015/11/20/research/genetics-affects-concussion-recovery.

[61] *Riddell and TGen Begin Third Year of Research Collaboration with Arizona State University's Football Program*, RIDELL NEWSROOM (Sep. 8, 2015), http://news.riddell.com/info/releases/riddell-and-tgen-begin-third-year-of-research-collaboration-with-arizona-state-universitys-football-program [hereinafter *Riddell*].

[62] *Riddell and TGen Team Up with Arizona State University's Football Program to Further Genetic Research into Athlete Concussion Detection and Treatment*, TRANSLATIONAL GENOMICS RES. INST. (Aug. 25, 2014), https://www.tgen.org/home/news/archive/2014-media-releases/riddell-and-tgen-team-up-with-arizona-state-universitys-football-program-to-further-genetic-research-into-athlete-concussion-detection-and-treatment.aspx#.WBZWoZMrJE4.

[63] *Id.*

[64] *Riddell*, *supra* note 61.

[65] *Id.*

[66] *Id.*

ASU hopes the information gained by the other two entities will translate into better equipment to keep ASU football players safe.[67] Ray Anderson, ASU's Athletics Director, stated, "[w]e pride ourselves on being innovative and on our willingness to help further a game we all value, and, along with industry leaders Riddell and TGen, we are looking forward to spending another season helping shape the future of football."[68] The NCAA needs to stay apprised of current research, such as that conducted by ASU, TGen, and Riddell, and do all it can to protect the future of its athletes. More programs, like the one ASU is involved with, will bring greater information to the equipment makers who, in turn, can make sports safer because their equipment is of higher quality.

This program works for football, but concussions in soccer still needs to be addressed. Genetic testing of soccer players for concussion susceptibility or risk for severe symptoms is important information for coaches and athletic trainers to have to best serve the student-athlete. When TGen develops the definitive test for concussions, it will be of great value to all sports.

B. TENDINOPATHY

The NCAA can also follow the studies describing the different tendon issues that arise in sports and how genetics can be used to determine an athlete's risk of developing such a tendon injury.[69] Once the specific genes responsible for tendon injury susceptibility can be isolated along with the genes that control the body's ability to heal, then genetic information will have huge implications for athletes and their careers. The potential is phenomenal. Genetic testing can be used to adjust training programs specifically to the athlete. Genetic technology can help the athlete heal quicker and more efficiently. The draw back to this future ideal is that athletes who can afford individualized training and the best genetic treatments will be able to play longer, whereas the athletes without those means will be at a disadvantage. Regulations on use of the information, and the types of treatment available, would need improvement to

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[67] *See id.*

[68] *Id.*

[69] *See* Maffulli, *supra* note 47.

better protect the individual and the sport. If the wealthy alone can afford to play sports longer due to the genetic information they could take advantage of, then sports will suffer, and those less advantaged will lose the opportunity to play.

Currently, the NCAA mandates only sickle cell trait testing.[70] The sections above discuss two areas of potential growth, but these health issues do not cause death. There are other genetic diseases that can lead to death among athletes if undiscovered.[71] In the future, the NCAA should consider including screenings for other genetic diseases, along with the sickle cell trait, known to cause death to student-athletes. If it is mandating the test for the health and welfare of its athletes, just as the states mandate newborn screenings for the welfare of its citizens, the NCAA needs to consider expanding its testing to include other genetic conditions which also lead to sudden death in athletes. Two such diseases are Marfan syndrome and hypertrophic cardiomyopathy.[72]

C. MARFAN SYNDROME

Marfan syndrome is a genetic condition that causes the connective tissue of the heart and blood vessels to be weak and prone to bursting.[73] This can lead to the aorta rupturing and sudden death.[74] Although Marfan syndrome is a genetic condition, twenty-five percent of the time it can occur without inheriting the condition.[75] Marfan syndrome also affects the long bones of the body, which causes outward signs of the condition, including longer than normal arms, fingers, and legs.[76] These traits are useful to basketball players, such as Isaiah Austin,[77] yet his basketball career ended in college due to a pre NBA-draft

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[70] *See* Brown, *Division III Approves Sickle Cell Measure*, *supra* note 39.

[71] *See* NAT'L HEART, LUNG, AND BLOOD INST., *supra* note 48.

[72] *Id.*; *see also* Pyron, *supra* note 49.

[73] *Id.*

[74] *Id.*

[75] *Id.*

[76] *See id.*

[77] *See* Miriam Falco, *What is Marfan Syndrome?*, CNN (June 23. 2014, 6:25 PM), http://www.cnn.com/2014/06/23/health/marfan-syndrome-nba-player.

physical which showed he had Marfan syndrome.[78] He was told he would not be able to play competitive basketball any longer, ending his hopes of playing in the NBA.[79] Austin played for Baylor University and was unaware of his condition until the NBA tested him during the pre-NBA draft physical.[80] If the NCAA had tested him as part of their pre-entry physical, Austin would have known earlier that a career in the NBA would not be in his future. The choice to play for Baylor University would have been a better-informed choice had Austin known his medical status.

Austin played for Baylor not knowing his heart could rupture during physical exertion. The NCAA is lucky Austin's heart did not rupture during game-play or it would have potentially faced another lawsuit like the action brought by Dale Lloyd II's family. Critics of the mandated sickle cell trait screening claim that the NCAA is protecting its own interests, not those of the athletes.[81] Since the mandate to test arose from the settlement of a negligence lawsuit, the NCAA's response is perceived as an appeasement of a family who suffered the untimely loss of their son, which could have been avoided.[82] The NCAA wants mandated testing to be perceived as a result of concern for their athletes. If this is true, the NCAA should also be testing for Marfan Syndrome and Hypertrophic Cardiomyopathy to protect itself from future liability lawsuits.

D. HYPERTROPHIC CARDIOMYOPATHY

Hypertrophic cardiomyopathy (HCM) is another genetic condition that can cause sudden death in athletes.[83] Dr. Martha Pyron, in an article for the American College of Sports Medicine states, "[hypertrophic cardiomyopathy is the leading cause of sudden death in young athletes."[84] An athlete suffering from

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[78] *Id.*

[79] *Id.*

[80] *Id.*

[81] Madison Park, *NCAA Genetic Screening Rule Sparks Discrimination Concerns*, CNN (Aug. 4, 2010, 8:13 AM), http://www.cnn.com/2010/HEALTH/08/04/ncaa.sickle.genetic.screening.

[82] *See id.*

[83] Pyron, *supra* note 51.

[84] *Id.*

HCM has an enlarged heart, which, if left undiscovered and untreated, eventually causes the heart muscle itself to block the flow of blood to the body.[85] This reaction can cause ventricular fibrillation which leads to death.[86] The severity of the condition varies and can become more significant over time.[87] People with this condition are "likely to be held from all athletic activity."[88] However, having this condition does not mean that the athlete can no longer play the sport they love. In fact, with proper monitoring and training regimens, the athlete can still play at a high level.[89] NCAA screening for this condition could save lives or promote the monitoring of the condition.

Cuttino Mobley is one example of an athlete with HCM who still played at a competitive level without the effects of his disease manifesting during his career.[90] Mobley acts as an exception to the rule of withholding persons with HCM from participating in athletics.[91] Mobley, who was diagnosed with HCM, played in the NBA from 1998 until 2008.[92] After ten years in the league, two separate cardiologists declared Mobley unfit to play in the NBA.[93] Both cardiologists are opposed to allowing people with HCM to participate in athletics.[94] Allegedly, these two specific cardiologists were chosen by the New York Knicks to find Mobley unfit to play to avoid paying a luxury tax for being above the salary cap.[95] Mobley's story illustrates both sides of the genetic testing issue, namely the protection of the athlete versus the use of the genetic information to discriminate against the player, which is the fear of critics of the mandated NCAA screening. This is another example of why regulations

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[85] *Id.*

[86] *Id.*

[87] *Id.*

[88] *Id.*

[89] *See, e.g.*, Mobley v. Madison Square Garden LP, 11 Civ. 8290 (DAB), 2013 U.S. Dist. LEXIS 46341, at *2 (S.D.N.Y. Mar. 15, 2013).

[90] *Id.*

[91] *Id.*

[92] *Id.* at *3–*4.

[93] *Id.*

[94] *Id.*

[95] *Id.* at *5–*6.

need to be in place to protect the genetic information of all people tested so the information cannot be used to harm them.

IV. GINA'S IMPACT ON COLLEGE ATHLETICS

A small step toward the protection of people's genetic test results comes from the Genetic Information Nondiscrimination Act of 2008, known as GINA.[96] Large scale mandated genetic testing is not found outside of newborn screenings and the NCAA due, in part, to GINA.[97] The federal government's implementation of GINA took place over several years and prohibits employers and health insurance companies from discriminating on the basis of genetic test results, including family members' genetic results.[98] However, GINA does not protect people's genetic information from other types of insurance coverage evaluation or areas of life.[99] It only protects the information from employers and health insurance.[100]

GINA was originally introduced in both the House of Representatives and the Senate in 2003.[101] It was brought up again in 2005.[102] In 2007, GINA was introduced in the House of Representatives once again.[103] After many subcommittee hearings and testimony from various industries, the bill was

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[96] 1 HEALTH CARE REFORM: LAW AND PRACTICE § 9.04 (Matthew Bender).

[97] *Screening U.S. College Athletes for their Sickle cell Disease Carrier Status*, SEC'Y'S ADVISORY COMM. ON HERITABLE DISORDERS IN NEWBORNS AND CHILDREN (Oct. 11, 2010), http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendations/correspondence/briefingcarrierstatus.pdf.

[98] Amanda L. Laedtke et al., *Family Physicians' Awareness and Knowledge of the Genetic Information Non-Discrimination Act (GINA)*, 21 J. GENETIC COUNSELING 345, 346 (2012).

[99] *Id.*

[100] *Id.*

[101] Genetic Nondiscrimination in Health Insurance and Employment Act, H.R. 1910, 108th Cong. (2003); Genetic Information Nondiscrimination Act of 2003, S. 1053, 108th Cong. (2003).

[102] Genetic Information Nondiscrimination Act of 2005, H.R. 1227, 109th Cong. (2005); Genetic Information Nondiscrimination Act of 2005, S. 306, 109th Cong. (2005).

[103] Genetic Information Nondiscrimination Act of 2008, H.R. 493, 110th Cong. (2007).

passed and sent to the Senate for a vote.[104] The Senate amended the bill and approved it, sending it back to the House of Representatives for another vote, and finally to President George Bush for his signature, making it law.[105] The two sides of the debate came from insurance companies and actuaries against the promoters of genetic testing, civil rights, the disabled, and the public's ability to not fear using the science available to them.[106]

The need for genetic information to be protected stems from state laws of the 1900's which allowed for the sterilization of people with certain defects.[107] These laws continued in one form or another until the 1980's and included discrimination against African-Americans due to their sickle cell tendency.[108] In 1972, Congress passed the National Sickle Cell Anemia Control Act to discourage states from maintaining laws requiring mandatory testing for sickle cell by withholding funding.[109] Since GINA's protection is limited, its impact on college athletics is not readily apparent. However, GINA plays a role when a university or college under the NCAA insures an athlete's future earnings.[110] This type of insurance coverage is a long-term disability policy, not a health insurance policy.[111] Since it is not health insurance, any and all genetic test results are available for the insurance company to consider in its decision of whether to insure an athlete. This leaves the athlete open to discrimination outside of employment and health insurance protections of GINA due to the mandatory testing.

Even though GINA is just one part of understanding and dealing with the need for protection of genetic information, it is not enough to protect people from having their genetic information used against them. The NCAA is trying to protect its athletes from harm, but because of lack of regulation regarding

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[104] *Id.*

[105] *Id.*

[106] H.R. REP. NO. 110-28, pt. 3, at 30 (2007); H.R. Rep. No. 110-28, pt. 1, at 28–29 (2007).

[107] H.R. REP. NO. 110-28, pt. 1, at 39–40 (2007).

[108] H.R. REP. NO. 110-28, pt. 2, at 2 (2007).

[109] *See id.*

[110] *Loss of Value White Paper Insurance Programs to Protect Future Earnings*, NCAA, http://www.ncaa.org/about/resources/insurance/loss-value-white-paper (last visited Feb. 1, 2016).

[111] *See id.*

access to genetic test results, the mandated testing could harm the exceptional college athlete looking to enter professional sports. GINA would protect that athlete once the athlete is an employee of a professional sports franchise, but by then it may be too late. If at some point college athletes are considered employees of the university's sports programs, then GINA would apply based on the university's employer status, protecting the information the NCAA is requiring the athletes to provide.

V. COSTS OF GENETIC TESTING

Genetic testing comes at a price. There are, of course, financial costs. However, there are also numerous social costs that attach themselves to genetic testing, even without touching genetic enhancements.

The financial costs are easier to address than the emotional and social costs. The NCAA, through a deal with Quest Diagnostics, tests the athletes for sickle cell trait for $8.50, with some tests ranging up to $32.50.[112] The NCAA does not require the schools to pay for the test; it leaves the choice of who pays up to the individual institutions.[113] The NCAA has also granted a one-time payment in the amount of $500.00 to institutions to help defray the cost of testing.[114] The price of the testing for sickle cell trait is minimal enough for the student-athletes to pay for the testing themselves.

Prior to the mandate and disclosure of sickle cell trait, schools took into account the cost of a lawsuit brought by families of student-athletes who died during training.[115] One family was awarded ten million dollars by a Florida jury.[116] However, the Court of Appeals found that the University of

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[112] *NCAA Sickle cell trait (SCT) Testing – What You Need to Know*, NCAA (2014), https://www.ncaa.org/sites/default/files/SCT%20testing%20brief%202014.pdf.

[113] Brown, *Division III Approves Sickle Cell Measure*, *supra* note 39.

[114] *See id*.

[115] Alicia Jessop, *A Costly Decision: Sickle cell trait Testing of NCAA Student-Athletes*, THE BUS. OF C. SPORTS (July 21, 2011), http://businessofcollegesports.com/2011/07/21/a-costly-decision-sickle-cell-trait-testing-of-ncaa-student-athletes.

[116] *See id*.

Central Florida Athletic Association was a part of the University and thus was eligible for limited sovereign immunity, and therefore was protected from the large jury award.[117] However, the cost of litigation is still a consideration.

The costs associated with the implementation of the mandated testing include the test itself, the required educational component, and genetic counseling after testing positive for sickle cell trait. The NCAA has developed videos and pamphlets outlining why testing is important and basic information about sickle cell trait.[118] The focus is having student-athletes make educated decisions regarding their sickle cell trait status, and the implications their status can have on their participation in their given sport.[119] Each school has an athletic training staff to help ensure all athletes, not just those with sickle cell trait, stay well-hydrated during workouts.[120] Maintaining hydration and preventing heat related illnesses are key to keeping blood cells from sickling.[121] Trainers also watch for signs associated with complications from sickle cell trait and let athletes or coaches know when a break is required as a matter of safety.

The mandate by the NCAA protects its schools from any further liability in the area of negligence due to an athlete's unknown sickle cell trait status.[122] The waiver, if signed by the non-tested athlete, prohibits the athlete or their estate from bringing a suit against the school.[123] Even though the athlete could pay for the test herself, it is in the best interest of the school to make testing or waiver as easy as possible so as to further protect the school's financial interests and the best interests of its athletes.

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[117] UCF Ath. Ass'n v. Plancher, 121 So. 3d 1097 (Fla. Dist. Ct. App. 2013).

[118] *Sickle cell trait*, NCAA, http://www.ncaa.org/health-and-safety/medical-conditions/sickle-cell-trait (last updated Jan. 17, 2014) [hereinafter NCAA].

[119] *See id.*

[120] *See id.*

[121] Kevin M. Conley et al., *National Athletic Trainers' Association Position Statement: Pre-participation Physical Examinations and Disqualifying Conditions*, 49 J. ATHLETIC TRAINING 112, 112 (2014).

[122] *See* NCAA, *supra* note 118.

[123] *See id.*

Marfan syndrome testing is much more expensive than the cost of sickle cell testing and not as reliable.[124] The cost for a Marfan syndrome test for the first person in a family is $1,400 to $2,000, with insurance coverage varying.[125] Once the family genetic mutation is found, the cost for testing other family members decreases to between $250 and $400.[126]

The reliability of the Marfan genetic test is also in question.[127] To determine if someone has Marfan, the genetic tests are evaluated to find a mutation in the FBN1 gene.[128] However, in five to ten percent of individuals with clinical traits of Marfan syndrome, there is no genetic finding of the disease.[129] The reliability is also affected by other conditions showing up on the same gene sequence as Marfan syndrome.[130] Perhaps the limitations of cost and reliability are why the NCAA has not mandated athletes to be tested for Marfan. Clinical diagnosis may be more effective, followed by testing to validate, instead of testing first. Clinical diagnosis may be more effective, followed by testing to validate, instead of testing first. Since testing misses five to ten percent of clear-cut cases of Marfan, clinical evaluation is essential. Marfan syndrome is missed in many cases, which led to a letter from 26 members of Congress urging the U.S. Department of Health and Human Services and the Department of Education to do a better job screening high school students for Marfan syndrome.[131] Perhaps the NCAA will not need to test for the syndrome if it is done at the high school level instead.

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[124] *Genetic Testing and Marfan Syndrome,* THE MARFAN FOUND. 4, https://www.marfan.org/download/file/fid/968/Genetic%20Testing%20and%20Marfan%20Syndrome.pdf (last visited April 24, 2016).

[125] *Id.* at 4.

[126] *Id.* at 4.

[127] *See id.* at 4, 6.

[128] *See id*. at 1–3.

[129] *Id.* at 3.

[130] *Id*. at 3–5.

[131] *Congressional Representatives Take Steps Towards Enhanced Athletic Screening*, THE MARFAN FOUND., https://www.marfan.org/about-us/news/2016/03/03/congressional-representatives-take-steps-towards-enhanced-athletic (last visited Apr. 24, 2016).

The cost of genetic testing for HCM is around $3,000.[132] Traditionally, HCM was diagnosed and evaluated by a series of echocardiographs.[133] This may still be the most cost effective way to test for the disease since it causes mutations on eight different genes.[134] In Europe, countries recommend that testing for HCM not be done on athletes.[135] "Genetic testing is not recommended for diagnosis of HCM . . . outside the setting of expert clinical and detailed family assessment (e.g. to evaluate an athlete's heart)."[136] The critical impact that Europeans place upon the need for genetic testing to be done via families illustrates the costs outside the financial realm. These non-financial costs are discussed below.

For concussion susceptibility, the cost for an APOE genetic test is $250 to $300.[137] The danger of incorporating this testing into the NCAA protocol is that APOE allele 4 is associated with Alzheimer's Disease as well as concussion susceptibility.[138] If testing is mandated, this genetic information could be used by long term care insurance to discriminate against the athlete or their family members.

The NCAA has the best interests of its student-athletes in mind by requiring education regarding sickle cell trait and the

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[132] Thomas H. Hauser & Warren J. Manning, *Screening for Hypertrophic Cardiomyopathy: A Cost Analysis of Echocardiography, Cardiac Magnetic Resonance and Genetic Testing,* J. OF CARDIOVASCULAR MAGNETIC RESONANCE, Jan. – Feb. 2009, at 57.

[133] *See id.*

[134] Michael J. Ackerman et al., *HRS/ EHRA Expert Consensus Statement on the State of Genetic Testing for the Channelopathies and Cardiomyopathies,* 13 EUROPACE 1077, 1091 (2011).

[135] *Id.* at 1082.

[136] *Id.* at 1092.

[137] Christina Domingues, *Doctors: Genetic Test Can Determine if Your Child is Concussion-Prone*, TIME WARNER CABLE NEWS (Apr. 28, 2015, 5:24 PM), http://www.twcnews.com/nys/rochester/news/2015/04/28/concussion-gene.html; Ben Locwin, *Sports and War: When it Comes to Concussions, Not Much Difference Between Football and Fighting*, GENETIC LITERACY PROJECT (Jan. 11, 2016), https://www.geneticliteracyproject.org/2016/01/11/sports-war-comes-concussions-not-much-difference-football-fighting (noting that the $250 test is offered by the Rochester Holistic Center and both tests are cheek swabs that test for alleles of the APOE gene).

[138] Locwin, *supra* note 137.

dangers associated with not knowing one's status before allowing the athlete to sign a waiver.[139] The schools are not only looking to protect their financial interests, but want to make sure they provide a safe training environment for their athletes.

Genetic testing by its nature does not only affect the individual athlete, but, potentially, their entire family and future generations. Since NCAA testing deals with genetic traits that can lead to death if not monitored correctly, the biggest social implication is the psychological impact upon the athletes and their families.[140] Other social concerns include discrimination and family implications.[141] These non-financial costs are just as, if not more, important than the financial costs.

Psychological concerns include the fear associated with not being able to play a sport any longer after loving the game for so long and investing countless hours. Another concern that weighs heavily on the psyche is the financial repercussions. If an athlete were no longer eligible to play, the university must determine what happens to the athlete's athletic scholarship. One must also consider the psychological damage of the loss of hope to play professionally, along with the income that profession provides. Not all of these psychological factors apply to sickle cell trait, since athletes are allowed to continue playing with altered training and closer monitoring.[142] However, for Marfan syndrome and HCM, the discovery of the condition usually means the end of a career in the sport.[143]

There can also be a heavy psychological burden upon the athlete in worrying about what other family members may be affected. Jeffrey Botkin's article describes how adult siblings of the person tested have strong feelings about whether they want to know their carrier status.[144] This can cause anxiety and

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[139] *See* UCF Ath. Ass'n v. Plancher, 121 So. 3d 1097, 1104 (Fla. Dist. Ct. App. 2013).

[140] Jeffrey R. Botkin, et.al., *Points to Consider: Ethical, Legal and Psychosocial Implications of Genetic Testing in Children and Adolescents*, 57 AM. J. OF HUM. GENETICS 1233, 1234 (2015).

[141] *Id.*

[142] *See* Heather R. Quick, *Privacy for Safety: The NCAA Sickle-Cell Trait Testing Policy and the Potential for Future Discrimination,* 97 IOWA L. REV. 665, 672 (2012).

[143] Ferrari, *supra* note 30; Pyron, *supra* note 49.

[144] Botkin*, supra* note 140, at 10.

depression for all involved.[145] The athlete may also have concerns about being treated differently by their teammates or fear the loss of camaraderie that comes along with athletic participation.

Along with the psychological impact, there is the difficulty of finding balance. The balance is between the benefits of knowing about the genetic condition so proper treatment can begin, against the love of playing a sport and the economic impact that not playing will have upon a family. For some athletes, this is not a challenge; the loss of life is far greater than the loss of playing a sport. Yet for others, the impact of the loss of income and the sport is a more difficult adjustment.

CONCLUSION

In the spirit of care and concern for its athletes, the NCAA needs to be more aware of other genetic conditions that can cause sudden death in athletes. Marfan syndrome and HCM are deadly if undetected.[146] Since genetic testing for these two conditions is not feasible for the NCAA at this time, the NCAA needs to be proactive by establishing screening programs to assess athletes for these conditions. This will help protect the NCAA from further negligence lawsuits as well as protect the athletes. Educational programs that address these other genetic diseases, along with screenings, can be just as effective in reducing athlete deaths as mandatory testing. The more information an athlete has about a condition, the more aware the athlete can be as to whether there is a need to consider that condition further on a personal level beyond the possible screenings. The NCAA also needs to follow the current research regarding the connection between genetics and concussion susceptibility and recovery times. By being aware of the risks and the current research, the NCAA and its members will be best prepared to protect the athletes and everyone's best interests.

To make the sickle cell trait testing more effective, the NCAA needs to improve how athletes are informed about the genetic tests. Some athletes did not even realize they had been

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[145] *Id.*

[146] NATIONAL HEART, LUNG, AND BLOOD INSTITUTE, s*upra* note 71.

tested.[147] Genetic counseling should also be included as part of the genetic testing.[148] NCAA member schools all have training staff and team physicians; perhaps a genetic counselor can be added to that list of medical personnel. Without better-informed students, the NCAA will continue to have the appearance of only caring about the outcome of lawsuits, not the athletes themselves.

With implementation of better informed consent for the athletes and counseling for the athletes and their families regarding the benefits and risks of testing, the NCAA will gain greater respect from the athletes it serves, as well as from the larger community. With the knowledge gained through such mass testing, better and safer training programs can be established, and there will be better outcomes for all involved.

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[147] Smith & Shuchman, *supra* note 1, at 1140–41.

[148] *Id.* at 1135–36.