

Screening U.S. College Athletes for Their Sickle Cell Disease Carrier Status

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This briefing paper outlines issues surrounding the screening of young athletes for their sickle cell disease carrier status (or sickle cell trait), a genetic condition. The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) has developed the report to advise the Secretary of the U.S. Department of Health and Human Services about the rule of the National Collegiate Athletic Association requiring testing for sickle cell trait in all incoming Division I student athletes.

Section 1: Introduction and Background

By the end of 2009, there were approximately 4 million people in the U.S. (1.31% of the population)¹ and an estimated more than 300 million people worldwide with sickle cell trait (AS).² Sickle cell trait occurs in high frequency among people of African or Middle Eastern descent but it is also common among those of Indian, or Mediterranean origin.³ For nearly three decades, screening for sickle cell disease and related hemoglobinopathies has been part of state-public health newborn screening programs in the U.S. An important aspect of the public health approach to screening is the recognition that screening for sickle cell disease, sickle cell trait, and related hemoglobinopathies, like all genetic testing, should include counseling to explain the benefits and risks of testing, and health education that explains the results and their implications.

SACHDNC shares the commitment of the athletic associations - National Collegiate Athletic Association (NCAA) and the National Athletic Trainers' Association (NATA) - to ensure the safety and health of college athletes, including those with sickle cell trait, and offers recommendations within this briefing paper that are based on the current state-of-knowledge about definite, probable, possible and unlikely associations of morbidity and mortality or health risks with sickle cell trait, and provides recommendations that may help prevent certain adverse events in all persons involved in collegiate sports, including those with sickle cell trait.

The Committee believes that it is within the public health protection and assurance responsibility of the Secretary to provide guidance to the nation and institutions, like athletic associations, on matters related to athletics and health. We recognize that the scientific evidence needed to fully judge the best practices related to the athlete with sickle cell trait has not been fully established. SACHDNC thinks informed opinion allows rational recommendations based on experience and knowledge of the pathophysiologic mechanisms underlying sickle cell conditions.

Finally, this briefing paper does not discuss implications of universal or population-based carrier screening for heritable disorders or conditions but is a limited discussion of the implications of genetic screening for a selected population presumably for its protection against physical harm in collegiate athletics.

Section 2: Research findings and reports on Health Outcomes of Sickle Cell Trait

Sickle cell trait is defined by the inheritance of a normal beta hemoglobin gene from one parent and a sickle cell gene from the other parent. In this condition, every red blood cell contains both hemoglobins A and S, and hemoglobin A is the predominant hemoglobin produced as opposed to sickle cell disease (SCD) in which sickle hemoglobin (S) is the predominant hemoglobin. Hemoglobins exist as tetramers but in their assembly, stable (alpha-beta) dimers are formed first. Sickle cell trait red cells therefore contain three main populations of hemoglobin tetramers: $\alpha^A_2\beta^A_2$ (Hb A), $\alpha^A_2\beta^S_2$ (Hb S), and the hybrid hemoglobin, $\alpha^A_2\beta^A\beta^S$ (Hb A/S).⁴ Both Hb S and Hb A/S participate in polymerization when deoxygenated. It is the presence of excess Hb A ($\alpha^A\beta^A$ dimers) that ensures that AS cells do not sickle under physiologic conditions. It is not surprising therefore that red blood cells from individuals with sickle cell trait can be induced to sickle *in vitro* under certain conditions such as deoxygenation.⁵ Furthermore, in situations or in tissues where high plasma osmolarity, severe acidosis, and/or hypoxia occur, such as the renal medulla, sickling is believed to occur in sickle cell trait. However, although sickle cell disease is characterized by chronic hemolytic anemia, vasculopathy, and acute vaso-occlusive events, sickle cell trait has not been associated with these features under normal physiologic conditions.

Medically, sickle cell trait is known as a powerful protector of young children from mortality and severe morbidity from acute falciparum malaria infection through reduced parasite density.⁶ And, in malaria endemic populations, sickle cell trait has a broad positive effect on child survival. In other populations, there is no evidence of such a beneficial effect of sickle cell trait. In a large study of 65,514 “Black” patients admitted consecutively to 13 Veterans Administration hospital in the 1970s, 7.8% of them were found on blood tests to have sickle cell trait.⁷ The inpatient records of 24,616 members of the tested cohort - 18,294 with no abnormal hemoglobins, 4,900 with sickle cell trait, and 1,422 with hemoglobin C trait – were reviewed. The study concluded that, “sickle cell trait had no effect on average age at hospitalization or death, overall mortality, length of hospitalization on medical and surgical wards, and frequency of any diagnosis, except essential hematuria and pulmonary embolism. Although, historically, sickle cell trait was thought to be an asymptomatic condition, hyposthenuria⁸, hematuria⁹, and an increased risk for glaucoma after traumatic hyphema are now accepted as complications of sickle cell trait.¹⁰ In addition, splenic infarction has been reported in individuals with sickle cell trait traveling to high altitudes.¹¹ Over the last two decades, renal medullary carcinoma, a rare aggressive kidney tumor, has been reported to be associated with sickle cell trait.¹² These reports, combined with continual

reports of sudden death in individuals with sickle cell trait undergoing physical exertion, have fueled the controversy over the issue of the impact of sickle cell trait on the health of the individual.

There has been growing concern over the past several decades about the association of sickle cell trait and exercise-related morbidity and mortality in collegiate athletes and military recruits. The strongest epidemiological data supporting that association was a study of over 2 million military recruits in which the risk of sudden unexplained death in recruits with sickle cell trait (hemoglobin AS) was compared with that in recruits without hemoglobin S¹³. The retrospective review of 1977-1981 demonstrated that among "Black" recruits, those with sickle cell trait (AS) were 27.6 times more likely to suffer sudden unexplained death than those without hemoglobin S; and, among all recruits ("Black" and "Non-Black"), those with sickle cell trait were 39.8 times more likely to suffer sudden unexplained death than those without hemoglobin S. Over the 5-year period reviewed, there were 12 unexplained sudden deaths in 37,300 "Black" recruits with sickle cell trait, none in 1,300 "Non-Black" recruits with sickle cell trait, and 5 in 429,000 "Black" and 11 in 1,617,000 "Non-Black" recruits without hemoglobin S. All the 12 sudden unexpected deaths in recruits with sickle cell trait were related to exercise with five of the 12 classified as "sudden unexplained cardiac deaths".

Kark's retrospective report from the US military suggested strongly that exertional heat illness might account for increased incidence of sudden death in military recruits, especially those with sickle cell trait, who were training under extreme conditions. In a 10-year (1982-1991) follow-up prospective trial of modified training regimen that included enforced hydration and close monitoring of environmental conditions, there was overall decrease in sudden expected deaths in the 2.3 million recruits, with none occurring in 40,000 recruits with sickle cell trait.¹⁴ Training centers not participating in the trial had rates of sudden unexpected deaths similar to those reported in the 1977-1981 review. Based on this study, testing for sickle cell trait was removed as a requirement for military accession in 1996. There have not been similar epidemiologic studies or intervention trials in collegiate or any other group of athletes.

However, although exercise related injury and death are rare generally, there continues to be concern over the concentration of deaths among athletes with sickle cell trait. The issue of how to manage exercise in people with sickle cell trait has been debated in two articles that summarize much of the debate.^{15,16} There have been 15 reports of sudden deaths in college athletes with sickle cell trait over the last 15 years. These cases have received a great deal of media attention. However, because there is

no systematic reporting or registry of the exercise-related deaths, and the diagnosis of sickle cell trait is often unclear, the true incidence is unknown. Since many of these cases were settled out of court, the medical details have neither been revealed nor subjected to scientific review. Without well-designed epidemiologic studies, the number of deaths and injury, their causes, possible underlying pathophysiologic mechanisms, and true attributable risks in individuals with sickle cell trait remain unclear. Therefore, medical scientists have had great difficulty determining whether there is increased risk of sudden death in individuals with sickle cell trait.

However, there are common clinical themes. Many of the deaths occurred after strenuous exercise in unconditioned military recruits or deconditioned athletes in pre-season. Some reports suggest that milder episodes of heat-related illness occurred previously in the subjects.¹⁷ Clinical description of fatal cases are often incomplete and anecdotal. The exercise routine leading to the acute illness is often easier to document in organized athletic activities. It has been suggested that increased risk of morbidity/mortality is related to repeated exercise with great physical effort over a short period of time rather than sustained mild to moderate physical effort over a long period.

Finally, experts do not agree on the possible underlying pathophysiologic mechanisms that may lead to sudden death in individuals with sickle cell trait who undergo strenuous exercise. Some believe that red cell sickling is the primary event leading to vascular occlusion, muscle infarction, and rhabdomyolysis. Almost all reports of unexplained death in people with hemoglobin S cite the presence of sickled red blood cells at autopsy as causation of death. However, the presence of sickled cells in post-mortem tissue specimens from a person with hemoglobin S does not imply pre-mortem sickling. In fact, the tissue hypoxia and acidosis associated with death are expected to induce deoxygenation and polymerization of sickle hemoglobin and red cell sickling soon after death. Therefore, sickling seen in post-mortem samples is most likely an artifact of death. Hyposthenuria, a known feature of sickle cell trait, has been suggested as a factor that may increase the risk of dehydration leading to rhabdomyolysis. Sickling of a few red cells has been observed in experimental subjects with sickle cell trait undergoing strenuous exercise under conditions of heat and restricted hydration.¹⁸

Athletes with sickle cell trait can and have performed at the highest level of sports. In reports from several countries, including the U.S., on professional and international athletes in several sports, the prevalence rates of sickle cell trait were similar to those in the general population. In addition, exercise

in individuals with mild or severe forms of sickle cell disease does not seem to be associated with serious adverse outcomes, making a biological link between sudden death and sickling much more difficult to suspect in those with sickle cell trait. However, those with the most severe forms of sickle cell disease may be incapable of or prohibited from participating in strenuous exercise to the degree where adverse outcomes may be seen.

In summary, there is evidence for the occurrence of exercise and/or heat-related acute illness in people with sickle cell trait. Some of these events are severe and fulminant enough to cause death. However, the prevalence of exercise-related illness and death in people with sickle cell trait is too small to affect the overall survival or morbidity of the condition. The possibility that an unidentified, rare, genetic defect found in a subset of people with sickle cell trait is either solely or partially responsible for the increased risk of exercise and/or heat-related death can only be ruled out through well-organized, large-scale genetic epidemiology studies.

Section 3: Public Health Implications of the National Collegiate Athletic Association Rule

NCAA Rule on Testing for Athletes for Sickle Cell Trait

In June of 2009, the NCAA Committee on Competitive Safeguards and Medical Aspects of Sports adopted the recommendation that its member colleges and universities test student-athletes to confirm their sickle cell trait status if that information is not already known. Subsequently the NCAA amended its Sports Medicine Handbook to recommend that athletics departments confirm sickle cell trait status in all student-athletes during their required medical examinations.¹⁹ In April 2010, the NCAA Division I Legislative Council decided that effective from the 2010-11 academic year, “all incoming Division I student-athletes must be tested for sickle cell trait, show proof of a prior test or sign a waiver releasing an institution from liability if they decline to be tested.”²⁰ This is a rule, not a recommendation.

The original 2009 legislation requiring all incoming student-athletes to be tested before participating in athletic activities was part of a legal settlement between Rice University and the parents of Dale Lloyd, a football student-athlete whose death a day after he collapsed during a workout in September 2006 was attributed to sickle cell trait.²¹ The NCAA cited the 2007 recommendations of the National Athletic Trainers’ Association (NATA)²² and the College of American Pathologists (CAP) in making their 2009 recommendations. The NCAA, NATA, and CAP all state that athletes with sickle cell trait would not be disqualified.

A critical concern with both voluntary and mandated screening for sickle cell trait as a prerequisite for participation in organized sports is protection of the rights of the individual. This includes protection of privacy and protection against actions of a discriminatory nature, such as labeling or prevention from participation in competitive sports. With regard to the NCAA rule, the benefit of screening thousands of collegiate students as prerequisite for participation in sports is unproven and should be carefully weighed against the consequential risk of stigmatization, misinformation, and unwitting denial of access to potentially successful athletic careers for those who happen to have sickle cell trait. Such consequences would be prejudicial against students found to have sickle cell trait.

Prior to the 2009 NCAA recommendation, testing for sickle cell trait was not uncommon in NCAA Division 1-A colleges. In a 2006 survey reported by Clarke and colleagues in 2007, 59 (64%) of 92

participating colleges in Division 1 Football Bowl Subdivision were screening athletes for sickle cell trait. Of those, 44 colleges (76%) targeted screening to African American athletes, and 9 (21%) screened all athletes.²³ Certified athletic trainers, strength/conditioning coaches, and coaches were notified of sickle cell trait test results the majority of the time, according to Clarke's findings. Screening results were primarily used to counsel athletes with sickle cell trait about potential risks during exercise while genetic counseling was provided at a substantially lesser percentage of colleges. Of the colleges that screened, 13 (22%) reported they had directly treated athletes for a complication of sickle cell trait during exercise. Forty-seven (80%) of the screening colleges reported that they screened in order to initiate preventive measures but, of 33 schools that did not screen, 24 (73%) said there was "lack of evidence-based data supporting such screening", and 13 (39%) thought screening was cost prohibitive.

The NCAA states in its Sports Medicine Handbook "if screening is done, it may be done on a voluntary basis with the informed consent of the student-athlete and should be offered to all student-athletes, "...because sickle cell trait occurs in all populations".¹⁹ If a screening test is positive, the student athlete should be offered counseling on the implications of sickle cell trait, including health, athletics and family planning. Confirmatory testing should be recommended to verify the screening result. Screening can be used as a gateway to targeted precautions."⁵ The NCAA suggests that knowledge of a student-athlete's sickle cell trait status "should facilitate prompt and appropriate medical care during a medical emergency." However even prior to the new NCAA testing policy of April 2010, many problematic aspects of the rule began to emerge.

There are two options for providing results on sickle cell screening: provision of results from prior testing or from new testing. Based on informal reports from community physicians, sickle cell centers, sickle cell disease counseling programs and sickle cell disease community-based organizations, both options have encountered problems. In the first option, some athletic departments are encouraging families to obtain newborn screening results. Parents have been contacting their newborn-screening programs to obtain test results. Unfortunately, once the family has obtained the test results, follow-up counseling or education may be unavailable or inadequate. Research has shown that some pediatricians and family physicians do not feel competent to discuss conditions included in newborn screening panels.²⁴ Evaluation of the skills of pediatric residents in relaying newborn screening results has shown that, indeed, their explanations may be too complex for some parents²⁵ and even incorrect or

misleading.^{26,27} An additional problem is that in some states, universal newborn screening for sickle cell disease may have started too late to include all children currently of college age.

The option of new testing is also presenting some difficulties. Some colleges are offering testing and, in order to save costs, they have selected inexpensive screening tests that do not provide accurate diagnosis of sickle cell trait or other common hemoglobin disorders. Athletes who test positive on the inexpensive screening test are referred for further confirmatory testing with a more definitive test. This approach will of course result in a missed opportunity to detect other hemoglobin variants in athletes testing negative for hemoglobin S, giving them the false impression of having no abnormal hemoglobins.

Other barriers encountered in the college-based testing have included unavailability of coaches and athletic trainers for education sessions about sickle cell trait and exercise-related illness, the source of payment for the testing – college or student, and targeting of testing at some athletes and sports as a cost-saving measure.

In a more organized approach, one sickle cell center partnered with a local university to provide testing, on-site counseling and education about sickle cell trait to student-athletes²⁸. Testing was voluntary and included pre-test counseling with each student-athlete. Post-test telephone counseling was provided regardless of trait status. Sickle cell center staff met with coaches, athletic trainers and administrators to provide education about sickle cell trait, methods to prevent heat and exercise-related injury, and counseling to help prevent stigmatization of student-athletes found to have sickle cell trait.

Management of the Student Athlete with Sickle Cell Trait

The NCAA recommends that student-athletes with sickle cell trait should set their own pace; engage in slow and gradual pre-season conditioning; use adequate rest and recovery between repetitions; be excused from some performance tests; stop activity when struggling or experiencing symptoms such as muscle pain, abnormal weakness, undue fatigue or breathlessness; stay well hydrated, especially in hot and humid conditions; refrain from extreme exercise when ill; access supplemental oxygen at [high] altitudes when needed; and seek prompt medical care when experiencing unusual distress. These guidelines place the burden on the athlete to design his/her own training program and monitor his/her condition during strenuous activity, and gradually become acclimated to drills that are more strenuous.

However, athletes do not usually make their own training schedule or exercise routines. If athletic officials need to know the sickle cell status of athletes, they should also bear the responsibility to ensure safety of the athlete. On the other hand, the guidelines do not address the potential of the coach to limit the practice or play time of the athlete with sickle cell trait, consciously or unconsciously, out of concern for the safety of the athlete or for potential personal liability. The guidelines also do not address the culture of sports where athletes are pushed beyond their limits and those who cannot keep up are not given the same opportunities.

If guidelines similar to those guidelines instituted by the Department of Defense were applied to prevent dehydration and exercise-related illness for all student-athletes,²⁹ the need for sickle cell trait testing would be negated and all students would be better protected. Formal responses from the Sickle Cell Disease Association of America, Inc. and the American Academy of Pediatrics (AAP) to the NCAA rule do not support carrier screening as a means to reduce heat related illness or death. Hord and Rice's editorial in the AAP newsletter indicated that the risk of illness will be reduced for all individuals as training and fitness standards are modified. The authors noted that successful training modifications have occurred in military, firefighter, and police trainee programs. Continued assessment and modification of collegiate training protocols, development and implementation of educational and awareness programs and a clear chain of administrative responsibility to actively address illness and injury prevention will benefit all athletes.³⁰

Genetic Privacy

Genetics and genomics have provided the ability to reveal the 'invisible' part of heredity at the molecular level.³¹ Genetic information is different from information on cholesterol level or blood pressure. However, because genetic information discloses information beyond the perception of the individual tested, many scientists, lawyers and ethicists have described genetic information as unique and qualitatively different, deserving of "exceptional or special" consideration.

In the case of student athletes, mandatory identification of sickle cell status not only discloses information about the individual athlete, but may also disclose information about paternity and genetic carrier status of family members, raising an important question. Are an athlete's right to genetic privacy invaded if the athlete is required to undergo a test to determine sickle cell status? The result of the test

discloses genetic information that may reach beyond the individual, potentially yielding non-consensual genetic information about the athlete's family members.

Sickle cell anemia, the first "molecular disease", has provided a case study for the exploration of the legal, ethical and social implications of genetic screening programs. Mandatory screening programs, as a condition for school attendance and marriage licenses, are a part of the history of sickle cell screening. Many sickle cell screening programs in the late 1960s and 1970s were later judged shortsighted with limited or no benefit.³² The history of sickle cell testing has been fraught with abuse of human rights, including the modern right to genetic privacy, with examples of individuals being screened for sickle cell trait without their knowledge. In response to the case of Norman-Bloodsaw versus Lawrence Berkeley Laboratory, in which employees were tested for sickle cell trait, syphilis, and pregnancy without their knowledge, and other examples of invasion of genetic privacy, many states enacted genetic privacy and non-discrimination laws.³³

Genetic Discrimination

A patchwork of state law was enacted addressing employment and insurance discrimination and genetic privacy rights. On May 21, 2008, President Bush signed the United States Genetic Information Nondiscrimination Act of 2008 ("GINA").^{34, 35} The Congressional Findings in support of the law highlighted the mass screening of African Americans for sickle cell carrier status and the resulting discrimination that occurred during the 1960s and 1970s as a rationale for the Act:

"(3) Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Because some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information. This form of discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease that afflicts African Americans. Once again, State legislatures began to enact discriminatory laws in the area, and in the early 1970s, began mandating genetic screening of all African Americans for sickle cell anemia, leading to discrimination and unnecessary fear. To alleviate some of this stigma, Congress in 1972 passed the National Sickle Cell Anemia Control Act, which withholds Federal funding from States unless sickle cell testing is voluntary".³⁴

The Act was the accomplishment of a “13-year legislative saga” where leaders on both sides of the aisle in Congress finally came together to draft and pass a genetic information nondiscrimination bill. The reach of GINA is limited to employment and health insurance discrimination. GINA does not address life insurance, disability insurance, or long-term care insurance. GINA specifically excludes the military, where historically there have been examples of genetic discrimination against individuals with sickle cell trait.³⁶ Covered entities include health insurers and employers; organizations such as the NCAA are not explicitly covered.

The Act became effective on November 21, 2009. A legal question that will likely be adjudicated is what is meant by “manifested disease or a manifested condition”. As the scientific understanding of what it means to be a carrier of a genetic condition (including sickle cell trait) is developed (specifically, when there is phenotypic expression or clinical complications), the federal judiciary may be confronted with interpretation of the term “manifested” when dealing with genetic carrier status and the potential phenotypic expression pursuant to GINA.³⁴

A limitation of the Act is that GINA prohibits discrimination based on genotype, but not phenotype.³⁷ Thus, GINA only applies to individuals who are asymptomatic (non-manifested condition). However, the current debate that sickle cell trait is associated with significant clinical indications during intense exercise can be argued as establishing a manifested genetic condition and excluded under GINA. This is only a legal theory for speculation today but may be the interpretation of the law tomorrow.

The ethical and social considerations of the NCAA rule on screening Division I athletes for sickle cell trait have recently been reviewed by Bonham et al., in a *New England Journal of Medicine Perspective*.³⁸ One of the notable points made by the authors addresses the motivation of the new NCAA rule: “The fact [that] 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.”

Accessing Newborn Screening Results and/or its Residual Blood Spots

As of 2007, all states include sickle cell disease as part of their newborn screening panel. In one form or another, states are engaged in efforts to ensure that the results of state-mandated newborn screening

are retained securely, made known to identified medical personnel (pediatrician of record) and parents and guardians of tested newborns. With regard to sickle cell trait, short and long-term follow-up procedures vary from state to state with most states engaging only in the initial notification through letters. In some states, community-based organizations serving persons with sickle cell disease are contracted to provide counseling and education for the families of newborns with sickle cell disease or trait.

Because newborn screening for sickle cell disease in the United States is universal and an integral part of state public health systems, the cost of retrieving test results should be covered by the state. It has been argued that screening need only occur once, in the newborn period, with the understanding that states would maintain permanent databases and systems that would enable results to be retrieved at a later date. Unfortunately, databases for retrieval of the results of newborn screening have not always been implemented widely and even physicians have not always been able to access past results easily. Past results may not have been retained long enough to be available to young adults. Even if the problem of the cost of retrieving newborn screening results becomes resolved, the issue of providing appropriate education and counseling regarding the results would need to be addressed.

It is highly unlikely that student health staff, coaches, and athletic trainers will work with physicians, nurses, genetic counselors, and others trained about sickle cell trait to:

- help the student athlete and parents to understand better sickle cell trait and related genetic disorders of relevance to them;
- become educated and trained continually on how best to identify, prevent, and treat the rare exercise-related complications that may affect the athlete; and,
- ensure that the athlete with sickle cell trait is not handled in a manner that may lead to stigmatization or discrimination and that measures are in place to address such issues if they were to occur.

Section 4: Recommendations of SACHDNC to the Secretary, U.S. Department of Health and Human Services on Screening of Student Athletes for Sickle Cell Trait

It is agreed that all individuals should be given the opportunity to find out whether or not they have sickle cell trait, and they should understand what the medical and genetic consequences of having sickle cell trait are. Recent events such as the decision by the NCAA to recommend screening for sickle cell trait in athletes in its Division I schools will probably result in greater awareness of sickle cell trait than many other efforts to date. However, this awareness may unwittingly also lead to misinformation, undue alarm, stigmatization, and discrimination. Although very uncommon, persons with sickle cell trait may develop symptoms associated with heat stroke and muscle breakdown, also called rhabdomyolysis, when undergoing strenuous exercise as in military training, or sports. However, these problems, not exclusive to sickle cell trait, have simple and practical solutions that were universally applied successfully enough in the military to lead to the removal of screening for sickle cell trait as a requirement for military accession.

The recommendation by athletic organizations that student athletes be tested for sickle cell trait is not backed by empirical scientific evidence. 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. In response to the recommendation to screen students for sickle cell trait because of concerns that those with sickle cell trait might be at greater risk of exercise or heat-related illness compared with other student athletes, SACHDNC recommends:

1. All individuals should have the opportunity to find out their risk for various medical disorders, including their carrier status for genetic conditions such as sickle cell disease.
2. Evaluation and testing for sickle cell disease and other genetic conditions should take place within the individual's medical home. That evaluation should include counseling regarding the implications of the information for the individual and assurance of the privacy of genetic information. Genetic testing should not be a pre-requisite for participation in sports, unless deemed medically necessary.

3. As part of the individual's annual medical evaluation for participation in sports, all potential athletes should receive education on safe practices for prevention of exercise and heat related illnesses.
4. The Secretary, HHS, instruct SACHDNC to work with the SCDA, relevant federal HHS agencies, athletic associations, community based and health care professional organizations to develop guidelines and educational resources about screening for sickle cell trait in all persons, including athletes.
5. The National Institutes of Health and the Centers for Disease Control and Prevention conduct research to ascertain if some athletes with sickle cell trait are at increased risk of exercise-related sudden death.

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