

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 906
(I-19)

Introduced by: Medical Student Section

Subject: Ensuring the Best In-School Care for Children with Sickle Cell Disease

Referred to: Reference Committee K
(_____, Chair)

Whereas, Sickle cell disease (SCD) affects approximately 1 in 100,000 Americans, particularly in communities of color where the incidence is 1 in 365 African Americans and 1 in 16,300 Hispanics in the U.S.¹; and

Whereas, 1 in 13 African Americans are born with sickle cell trait, making this autosomal recessive disease commonly inherited and highly prevalent in African American families and communities¹; and

Whereas, Youth with SCD miss on average 20-30 school days per year because of symptoms or complications of the disease²; and

Whereas, Adolescents with SCD report having important academic goals, and school absenteeism becomes an impediment of reaching these goals resulting in worse standardized test scores and history of repeated grade levels³; and

Whereas, Due to impaired kidney functions, those with SCD need constant access to hydration and liberal access to the bathroom, both of which are frequently monitored and restricted in the classroom⁴⁻⁷; and

Whereas, SCD can limit students' abilities to engage in the same intensity of aerobic physical activities as those not impacted by SCD due to increased fatigue and further, exercise-induced acidosis promotes red blood cell sickling⁴⁻⁸; and

Whereas, Educators' poor understanding of physical limitations and students' needs for accommodations, such as adequate hydration, can result in increased pain crises or stroke⁴⁻⁷; and

Whereas, In a study assessing the needs of educators working with students with chronic illnesses, researchers found that educators felt least supported and trained to work with students suffering from sickle cell disease, cystic fibrosis, and epilepsy⁹; and

Whereas, Studies show that teachers who understand medical conditions such as ADHD, asthma, and allergy tend to use more evidence-based approaches to accommodating students' classroom needs¹⁰⁻¹¹; and

Whereas, 25.2% of schools in the United States lack a school nurse, thus recognition and monitoring of potentially emergent medical complications, such as stroke, fall on teachers and non-healthcare staff in many schools¹²; and

Whereas, According to the American School Health Association, school professionals suggested a need for more support when working with students with conditions such as sickle cell disease, cystic fibrosis, and epilepsy⁹; and

Whereas, Existing AMA policy currently “recognizes sickle cell disease (SCD) as a chronic illness, (2) encourages educational efforts directed to health care providers and the public regarding the treatment and prevention of SCD” (H350.973); and

Whereas, Existing AMA policy currently urges “physicians, physicians-in-training, and medical students to serve as advocates for pediatric patients with diabetes to ensure that they receive the best in-school care, and are not discriminated against, based on current federal and state protections” (H-60.932); and

Whereas, Existing AMA policy currently “(1) urges all schools, from preschool through 12th grade, to: (a) develop Medical Emergency Response Plans” for children at risk for anaphylactic reactions; and “(5) urges physicians to work with parents and schools to ensure that all their patients with a food allergy have an individualized emergency plan” (D-60.976); therefore be it

RESOLVED, That our American Medical Association support the development of an individualized sickle cell emergency care plan by physicians for in-school use, especially during sickle cell crises (New HOD Policy); and be it further

RESOLVED, That our AMA support the education of teachers and school officials on policies and protocols, encouraging best practices for children with sickle cell disease, such as adequate access to the restroom and water, physical education modifications, seat accommodations during extreme temperature conditions, access to medications, and policies to support continuity of education during prolonged absences from school, in order to ensure that they receive the best in-school care, and are not discriminated against, based on current federal and state protections. (New HOD Policy)

Fiscal Note:

Received: 08/28/19

References:

1. Data & Statistics on Sickle Cell Disease | CDC. Centers for Disease Control and Prevention. <http://www.cdc.gov/ncbddd/sicklecell/data.html>. Accessed March 27, 2019.
2. Day S, Chismark E. The cognitive and academic impact of sickle cell disease. J Sch Nurs. 2006;22(6):330-5.
3. Schwartz LA, Radcliffe J, Barakat LP. Associates of school absenteeism in adolescents with sickle cell disease. Pediatr Blood Cancer. 2009;52(1):92-6.
4. Sickle Cell Disease: A Practical Guide for Teachers. AboutKidsHealth. <http://www.aboutkidshealth.ca/Article?contentid=652&language=English>. Published March 17, 2011. Accessed March 27, 2019.
5. Center for Disease Control and Prevention. Tips for Supporting Students with Sickle Cell Disease. Tips for Supporting Students with Sickle Cell Disease [Brochure].
6. St. Jude Children's Research Hospital. Educator's Guide to Sickle Cell Disease. Educator's Guide to Sickle Cell Disease [Brochure]. 2011.
7. UAB Division of Hematology at Children's Hospital. Facts About Sickle Cell Disease for: School Teachers & Nurses. Facts About Sickle Cell Disease for: School Teachers & Nurses [Brochure].
8. Chatel B, Messonnier LA, Bendahan D. Do we have to consider acidosis induced by exercise as deleterious in sickle cell disease? Exp Physiol. 2018;103(9):1213-1220.
9. Berger C, Valenzuela J, Tsikis J, Fletcher C. School Professionals' Knowledge and Beliefs About Youth With Chronic Illness. J Sch Health. 2018;88(8):615-623.
10. Cicutto L, Conti E, Evans H, et al. Creating asthma-friendly schools: a public health approach. J Sch Health. 2006;76(6):255-8.
11. Hawkins KE. Assessing Teachers' Confidence in Implementing Food Allergy Emergency Plans. 2017:1-153.
12. National Association of School Nurses. School Nurses in the U.S.[Brochure]. School Nurses in the US[Brochure]. 2017.

RELEVANT AMA POLICY

Sickle Cell Disease H-350.973

Our AMA: (1) recognizes sickle cell disease (SCD) as a chronic illness, (2) encourages educational efforts directed to health care providers and the public regarding the treatment and prevention of SCD; (3) supports the inclusion of SCD in newborn screening programs and encourages genetic counseling for parents of SCD patients and for young adults who are affected, carriers, or at risk of being carriers; (4) supports ongoing and new research designed to speed the clinical implementation of new SCD treatments; and (5) recommends that SCD research programs have input in the planning stage from the local African American community, SCD patient advocacy groups, and others affected by SCD.

Citation: (CLRPD Rep. 3, I-98; Reaffirmed: CLRPD Rep. 1, A-08; Modified: BOT Rep. 12, A-11)

Ensuring the Best In-School Care for Children with Diabetes H-60.932

Our AMA policy is that physicians, physicians-in-training, and medical students should serve as advocates for pediatric patients with diabetes to ensure that they receive the best in-school care, and are not discriminated against, based on current federal and state protections.

Citation: CSAPH Rep. 4, A-08; Reaffirmed: CSAPH Rep. 01, A-18

Childhood Anaphylactic Reactions D-60.976

Our AMA will: (1) urge all schools, from preschool through 12th grade, to: (a) develop Medical Emergency Response Plans (MERP); (b) practice these plans in order to identify potential barriers and strategies for improvement; (c) ensure that school campuses have a direct communication link with an emergency medical system (EMS); (d) identify students at risk for life-threatening emergencies and ensure these children have an individual emergency care plan that is formulated with input by a physician; (e) designate roles and responsibilities among school staff for handling potential life-threatening emergencies, including administering medications, working with EMS and local emergency departments, and contacting families; (f) train school personnel in cardiopulmonary resuscitation; (g) adopt the School Guidelines for Managing Students with Food Allergies distributed by FARE (Food Allergy Research & Education); and (h) ensure that appropriate emergency equipment to deal with anaphylaxis and acute asthmatic reactions is available and that assigned staff are familiar with using this equipment; (2) work to expand to all states laws permitting students to carry prescribed epinephrine or other medications prescribed by their physician for asthma or anaphylaxis; (3) support increased research to better understand the causes, epidemiology, and effective treatment of anaphylaxis; (4) urge the Centers for Disease Control and Prevention to study the adequacy of school personnel and services to address asthma and anaphylactic emergencies; (5) urge physicians to work with parents and schools to ensure that all their patients with a food allergy have an individualized emergency plan; and (6) work to allow all first responders to carry and administer epinephrine in suspected cases of anaphylaxis.

Citation: (CSAPH Rep. 1, A-07; Modified: CCB/CLRPD Rep. 2, A-14)