

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)

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

4 Whereas, 1 in 13 African Americans are born with sickle cell trait, making this autosomal  
5 recessive disease commonly inherited and highly prevalent in African American families and  
6 communities<sup>1</sup>; and

7 Whereas, Youth with SCD miss on average 20-30 school days per year because of symptoms  
8 or complications of the disease<sup>2</sup>; and

9 Whereas, Adolescents with SCD report having important academic goals, and school  
10 absenteeism becomes an impediment of reaching these goals resulting in worse standardized  
11 test scores and history of repeated grade levels<sup>3</sup>; and

12 Whereas, Due to impaired kidney functions, those with SCD need constant access to hydration  
13 and liberal access to the bathroom, both of which are frequently monitored and restricted in the  
14 classroom<sup>4-7</sup>; and

15 Whereas, SCD can limit students' abilities to engage in the same intensity of aerobic physical  
16 activities as those not impacted by SCD due to increased fatigue and further, exercise-induced  
17 acidosis promotes red blood cell sickling<sup>4-8</sup>; and

18 Whereas, Educators' poor understanding of physical limitations and students' needs for  
19 accommodations, such as adequate hydration, can result in increased pain crises or stroke<sup>4-7</sup>;  
20 and

21 Whereas, In a study assessing the needs of educators working with students with chronic  
22 illnesses, researchers found that educators felt least supported and trained to work with  
23 students suffering from sickle cell disease, cystic fibrosis, and epilepsy<sup>9</sup>; and

24 Whereas, Studies show that teachers who understand medical conditions such as ADHD,  
25 asthma, and allergy tend to use more evidence-based approaches to accommodating students'  
26 classroom needs<sup>10-11</sup>; and

27 Whereas, 25.2% of schools in the United States lack a school nurse, thus recognition and  
28 monitoring of potentially emergent medical complications, such as stroke, fall on teachers and  
29 non-healthcare staff in many schools<sup>12</sup>; and

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1 Whereas, According to the American School Health Association, school professionals  
2 suggested a need for more support when working with students with conditions such as sickle  
3 cell disease, cystic fibrosis, and epilepsy<sup>9</sup>; and  
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5 Whereas, Existing AMA policy currently “recognizes sickle cell disease (SCD) as a chronic  
6 illness, (2) encourages educational efforts directed to health care providers and the public  
7 regarding the treatment and prevention of SCD” (H350.973); and  
8  
9 Whereas, Existing AMA policy currently urges “physicians, physicians-in-training, and medical  
10 students to serve as advocates for pediatric patients with diabetes to ensure that they receive  
11 the best in-school care, and are not discriminated against, based on current federal and state  
12 protections” (H-60.932); and  
13  
14 Whereas, Existing AMA policy currently “(1) urges all schools, from preschool through 12th  
15 grade, to: (a) develop Medical Emergency Response Plans” for children at risk for anaphylactic  
16 reactions; and “(5) urges physicians to work with parents and schools to ensure that all their  
17 patients with a food allergy have an individualized emergency plan” (D-60.976); therefore be it  
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19 RESOLVED, That our American Medical Association support the development of an  
20 individualized sickle cell emergency care plan by physicians for in-school use, especially during  
21 sickle cell crises (New HOD Policy); and be it further  
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23 RESOLVED, That our AMA support the education of teachers and school officials on policies  
24 and protocols, encouraging best practices for children with sickle cell disease, such as adequate  
25 access to the restroom and water, physical education modifications, seat accommodations  
26 during extreme temperature conditions, access to medications, and policies to support  
27 continuity of education during prolonged absences from school, in order to ensure that they  
28 receive the best in-school care, and are not discriminated against, based on current federal and  
29 state protections. (New HOD Policy)

Fiscal Note:

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**References:**

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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)