

Assembly Joint Resolution

No. 44

Introduced by Assembly Member Carter

**(Principal coauthors: Assembly Members Bradford, Davis, Hall,
Mitchell, and Swanson)**

(Principal coauthors: Senators Price and Wright)

August 6, 2012

Assembly Joint Resolution No. 44—Relative to Sickle Cell Anemia Awareness Month.

LEGISLATIVE COUNSEL'S DIGEST

AJR 44, as introduced, Carter. Sickle Cell Anemia Awareness Month

This measure would recognize the month of September 2013, and each September thereafter, as Sickle Cell Anemia Awareness Month in California, and would urge the President and the Congress of the United States to restore and continue funding for sickle cell anemia centers and research to make sickle cell anemia and other genetic hemoglobin disorders a public health priority.

Fiscal committee: no.

1 WHEREAS, Sickle cell anemia and sickle cell disease, used
2 interchangeably, refer to a group of inherited disorders that affect
3 the red blood cells; and

4 WHEREAS, Sickle cell anemia is a disease in which a person's
5 body produces abnormally shaped red blood cells that resemble a
6 crescent or sickle, and which do not last as long as normal, round
7 red blood cells, which leads to anemia. The sickle cells also get
8 stuck in blood vessels and block blood flow, which can cause pain
9 and organ damage; and

1 WHEREAS, Sickle cell anemia is a genetic disorder where
2 individuals with the disease are born with two sickle cell genes,
3 each inherited from one parent. An individual with only one sickle
4 cell gene has a “sickle cell trait,” which occurs in one out of every
5 12 African Americans and in one out of every 100 Latinos in the
6 United States; and

7 WHEREAS, It is estimated that more than 70,000 Americans
8 have sickle cell anemia. Sickle cell anemia occurs in one out of
9 every 400 African American births and in one out of every 36,000
10 Latino births; and

11 WHEREAS, Sickle cell anemia can be a life-threatening
12 condition, and access to comprehensive care can be limited by
13 social, economic, cultural, and geographic barriers; and

14 WHEREAS, The average cost of hospitalization for sickle cell
15 anemia in 2004 was \$6,223, for more than 84,000 hospital
16 admissions that year. Total hospitalization costs for individuals
17 with sickle cell anemia equaled \$488,000,000, of which 65 percent
18 were covered by Medicaid funds; and

19 WHEREAS, Individuals living with sickle cell anemia encounter
20 barriers to obtaining quality care and improving their quality of
21 life. These barriers include limitations in geographic access to
22 comprehensive care, the varied use of effective treatments, the
23 high reliance on emergency departments and on public health
24 programs, and the limited number of health care providers with
25 knowledge and experience to manage and treat sickle cell anemia.

26 WHEREAS, The Sickle Cell Anemia Control Act was signed
27 into law in 1972 by President Richard Nixon after pledging that
28 his administration would “reverse the record of neglect on the
29 dreaded disease” by increasing funding for and expanding sickle
30 cell anemia-related programs, including the development of
31 comprehensive sickle cell anemia centers; and

32 WHEREAS, In 1975, the Sickle Cell Disease Association of
33 America, Inc. and its member organizations began conducting
34 monthlong events in September to call attention to sickle cell
35 anemia and the need to address the problem at national and local
36 levels, and chose September as National Sickle Cell Awareness
37 Month in order for the public to reflect on the children and adults
38 whose lives, education, and careers have been affected by this
39 disease; and

1 WHEREAS, In 2003, the Sickle Cell Treatment Act was signed
2 into law; and

3 WHEREAS, The effort to officially recognize Sickle Cell
4 Anemia Awareness Month succeeded at the federal level in 1983
5 when the United States House of Representatives unanimously
6 passed, and President Ronald Reagan signed, the first resolution
7 introduced by the Congressional Black Caucus that recognized
8 September as National Sickle Cell Anemia Awareness Month;
9 now, therefore, be it

10 *Resolved by the Assembly and the Senate of the State of*
11 *California, jointly,* That the Legislature recognizes September
12 2013 and each September thereafter as Sickle Cell Anemia
13 Awareness Month; and be it further

14 *Resolved,* That the Legislature urges the Congress of the United
15 States to support the President's continuation of funding for the
16 Sickle Cell Anemia Demonstration Program, the Registry and
17 Surveillance System for Hemoglobinopathy Program Initiative,
18 and the Public Health Approach Disorders program, and to make
19 sickle cell anemia and other genetic hemoglobin disorders a public
20 health priority; and

21 *Resolved,* That the Chief Clerk of the Assembly transmit copies
22 of this resolution to the President and Vice President of the United
23 States, the Speaker of the United States House of Representatives,
24 the President pro Tempore of the United States Senate, each
25 Senator and Representative from California in the Congress of the
26 United States, and to the author for appropriate distribution.