

Assembly Joint Resolution

No. 51

**Introduced by Assembly Member Brown
(Principal coauthor: Assembly Member Bradford)**

August 7, 2014

Assembly Joint Resolution No. 51—Relative to Sickle Cell Anemia Awareness Month.

LEGISLATIVE COUNSEL'S DIGEST

AJR 51, as introduced, Brown. Sickle Cell Anemia Awareness Month.

This measure would recognize the month of September 2014, 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 that do not last as long as normal round red
7 blood cells, which leads to anemia. The sickle cells also get stuck
8 in blood vessels and block blood flow, which can cause pain and
9 organ damage; and
10 WHEREAS, Sickle cell anemia is a genetic disorder where
11 individuals with the disease are born with two sickle cell genes,

1 each inherited from one parent. An individual with only one sickle
2 cell gene has a “sickle cell trait,” which occurs in one out of every
3 12 African Americans and in one out of every 100 Latinos in the
4 United States; and

5 WHEREAS, According to the United States Department of
6 Health and Human Services Office of Minority Health,
7 approximately two million Americans carry the sickle cell trait
8 and unlike most people with sickle cell anemia, most people who
9 have sickle cell trait never know they have it and can live their
10 entire lives without any complications from it; and

11 WHEREAS, Serious problems associated with sickle cell trait
12 are rare. However, exercise-related sudden death in individuals
13 who have a sickle cell trait most commonly occurs in those
14 undergoing intense physical exertion, such as military recruits in
15 basic training and athletes during conditioning workouts; and

16 WHEREAS, Individuals with a sickle cell trait should not be
17 excluded from physical activity, including sports, unless
18 recommended by medical personnel. Instead, people should be
19 educated about precautions that should be taken, including drinking
20 adequate amounts of fluids, pacing training with longer periods
21 of rest and recovery, avoiding participation in performance tests
22 such as sprints and mile runs, and, most importantly, being familiar
23 with the symptoms of overexertion; and

24 WHEREAS, According to the United States Centers for Disease
25 Control and Prevention, it is estimated that more than 90,000
26 Americans have sickle cell anemia. Sickle cell anemia occurs in
27 one out of every 500 African American births and in one out of
28 every 36,000 Latino births; and

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

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

37 WHEREAS, Individuals living with sickle cell anemia encounter
38 barriers to obtaining quality care and improving their quality of
39 life. These barriers include limitations in geographic access to
40 comprehensive care, the varied use of effective treatments, the

1 high reliance on emergency care and on public health programs,
2 and the limited number of health care providers with knowledge
3 and experience to manage and treat sickle cell anemia; and

4 WHEREAS, The Sickle Cell Anemia Control Act was signed
5 into law in 1972 by President Richard Nixon after pledging that
6 his administration would “reverse the record of neglect of the
7 dreaded disease” by increasing funding for and expanding sickle
8 cell anemia-related programs, including the development of
9 comprehensive sickle cell anemia centers; and

10 WHEREAS, In 1975, the Sickle Cell Disease Association of
11 America, Inc., and its member organizations began conducting
12 monthlong events in September to call attention to sickle cell
13 anemia and the need to address the problem at national and local
14 levels, and chose September as National Sickle Cell Awareness
15 Month in order for the public to reflect on the children and adults
16 whose lives, education, and careers have been affected by this
17 disease; and

18 WHEREAS, Sickle cell disease is a chronic condition that can
19 affect any organ, including the kidneys, lungs, and spleen. Research
20 indicates that patients experience many severe complications,
21 including stroke, infections, and pulmonary embolism; and

22 WHEREAS, Pain is the most common complication of sickle
23 cell disease and the primary reason that people with the disease
24 go to the emergency room or hospital; and

25 WHEREAS, While there is no widely available cure for sickle
26 cell disease, emerging treatments, including medications that
27 prevent blood cells from sickling, are being studied; and

28 WHEREAS, A potentially groundbreaking investigational drug,
29 GMI 1070, designed to treat painful vaso-occlusive crises, which
30 occur when red blood cells lump together and impede blood flow
31 in sickle cell patients, has been found to be safe following a clinical
32 trial at the University of California, Davis; and

33 WHEREAS, In 2003, the Sickle Cell Treatment Act was signed
34 into law; and

35 WHEREAS, The effort to officially recognize Sickle Cell
36 Anemia Awareness Month succeeded at the federal level in 1983
37 when the United States House of Representatives unanimously
38 passed, and President Ronald Reagan signed, the first resolution
39 introduced by the Congressional Black Caucus that recognized

1 September as National Sickle Cell Anemia Awareness Month;
2 now, therefore, be it

3 *Resolved by the Assembly and the Senate of the State of*
4 *California, jointly,* That the Legislature recognizes September
5 2014, and each September thereafter, as Sickle Cell Anemia
6 Awareness Month; and be it further

7 *Resolved,* That the Legislature urges the Congress of the United
8 States to support the President's continuation of funding for the
9 Sickle Cell Anemia Demonstration Program, the Registry and
10 Surveillance System for Hemoglobinopathy Program Initiative,
11 and the Public Health Approach Disorders program, and to make
12 sickle cell anemia and other genetic hemoglobin disorders a public
13 health priority; and be it further

14 *Resolved,* That the Chief Clerk of the Assembly transmit copies
15 of this resolution to the President and Vice President of the United
16 States, the Speaker of the United States House of Representatives,
17 the Majority Leader of the United States Senate, each Senator and
18 Representative from California in the Congress of the United
19 States, and to the author for appropriate distribution.