AMENDED IN ASSEMBLY AUGUST 18, 2014

CALIFORNIA LEGISLATURE—2013–14 REGULAR SESSION

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 amended, 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.

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

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

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

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

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

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

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

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

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

WHEREAS, Individuals living with sickle cell anemia encounter barriers to obtaining quality care and improving their quality of

life. These barriers include limitations in geographic access to comprehensive care, the varied use of effective treatments, the high reliance on emergency care and on public health programs, and the limited number of health care providers with knowledge and experience to manage and treat sickle cell anemia; and

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

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

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

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

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

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

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

WHEREAS, The effort to officially recognize Sickle Cell Anemia Awareness Month succeeded at the federal level in 1983 when the United States House of Representatives unanimously passed, and President Ronald Reagan signed, the first resolution

introduced by the Congressional Black Caucus that recognized September as National Sickle Cell Anemia Awareness Month; now, therefore, be it

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

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

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

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