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ACR-286 Sickle Cell Disease Awareness Month. (2017-2018)

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Assembly Concurrent Resolution No. 286

CHAPTER 223

Relative to Sickle Cell Disease Awareness Month.

[Filed with Secretary of State September 11, 2018.]

LEGISLATIVE COUNSEL'S DIGEST

ACR 286, Kamlager-Dove. Sickle Cell Disease Awareness Month.

This measure would recognize the month of September 2018 as Sickle Cell Disease Awareness Month in California.

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 disease 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 disease 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 disease, 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 disease. Sickle cell disease occurs in one out of every 500 African American births and in one out of every 36,000 Latino births; and

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

WHEREAS, This disease is severe and can mean a high number of hospital inpatient stays. Additionally, pain crises bring patients to the emergency room when severe. That means the statewide cost for sickle cell is very high. Billed charges for sickle cell inpatient stays in 2014, not including health maintenance organization systems, totaled over four hundred million dollars (\$400,000,000), and about half of those charges were covered by Medi-Cal alone. The remainder were paid by dual eligible for Medi-Cal and Medicare, private payer, some other government program, or self pay. Estimates combining state emergency room treatment and release visit data and federal "typical charge" data tell us that there were 10,790 visits to the emergency room for sickle cell-related causes in California in 2014 that did not result in admission, totaling \$338 million in charges; and

WHEREAS, Individuals living with sickle cell disease 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 disease; 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 disease-related programs, including the development of comprehensive sickle cell disease 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 disease 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 of the State of California, the Senate thereof concurring, That the Legislature recognizes September 2018 as Sickle Cell Disease Awareness Month, and that the residents of the State of California are encouraged to join together in raising awareness and heightening public knowledge of this disease; and be it further

Resolved, That the Chief Clerk of the Assembly transmit copies of this resolution to the author for appropriate distribution.