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SCR-40 Myalgic Encephalomyelitis Awareness Month. (2017-2018)

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Senate Concurrent Resolution No. 40

CHAPTER 102

Relative to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Awareness Month.

[Filed with Secretary of State July 12, 2017.]

LEGISLATIVE COUNSEL'S DIGEST

SCR 40, Glazer. Myalgic Encephalomyelitis Awareness Month.

This measure would proclaim May 12, 2017, as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Awareness Day and declare the month of May 2017, and each May thereafter, as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Awareness Month.

Fiscal Committee: yes

WHEREAS, Myalgic Encephalomyelitis (ME), sometimes called Chronic Fatigue Syndrome (ME/CFS), is a neuroimmune disease characterized by overwhelming fatigue, "brain fog," pain, postexertional malaise, headaches, cardiac symptoms, immune dysfunction, hypometabolism, lack of energy production at a cellular level, orthostatic intolerance, severe dizziness and balance problems, increased morbidity, and higher risk of suicide due to lack of treatments and neglect; and

WHEREAS, Between 100,000 and 300,000 Californians of all ages, races, and sexes are estimated to be afflicted with ME/CFS, with an estimated 836,000 to 2.5 million Americans afflicted and 17 million worldwide; and

WHEREAS, ME/CFS has been found by the National Academy of Medicine to be "a serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients," leaving them with a lower quality of life than patients with multiple sclerosis, stroke, renal failure, heart failure, and other chronic diseases; and

WHEREAS, ME/CFS affects men, women, and children of all backgrounds, who are often ill for years or a lifetime. Most patients never recover fully. One-quarter of patients are housebound or bedridden, often for years, while one-half to three-quarters of patients are unable to work or attend school; and

WHEREAS, ME/CFS is perhaps the most common chronic disease causing students to drop out of high school and college, sometimes indefinitely; and

WHEREAS, ME/CFS is a tragic and disabling disease that destroys the lives of many patients and imposes a severe toll on their families, friends, and caretakers; and

WHEREAS, The federal Centers for Disease Control and Prevention (CDC) estimates that 84 percent of those with ME/CFS are either misdiagnosed or not diagnosed at all; and

WHEREAS, The National Academy of Science's Institute of Medicine has stated that there is a "paucity of research to date, remarkably little research funding, that more research is essential, and that the level of current research does not reflect disease burden, prevalence, and economic cost to society"; and

WHEREAS, The economic impact of ME/CFS in the United States is estimated to be \$20 billion to \$50 billion per year (CDC February 2016) and likely costs the California economy billions of dollars in health care costs, patient care, lost productivity, and lost tax revenues; and

WHEREAS, Increased public awareness of the severity of ME/CFS will decrease the misplaced stigma and discrimination that accompanies the disease and will lead to increased National Institutes of Health (NIH) funding and private funding for research, treatment, and clinical education; and

WHEREAS, Because California is internationally recognized as a hub for all types of cutting-edge research, we are uniquely positioned to contribute to the development of diagnostic tests and treatments for the disease; and

WHEREAS, The cause of ME/CFS is unknown, there is no diagnostic test and no federal Food and Drug Administration (FDA)-approved treatments, and most patients have no access to doctors with expertise in ME/CFS since there is no training about the disease at most medical schools; and

WHEREAS, The lack of tracking for ME/CFS by the CDC and the grossly inadequate NIH funding for research based on disease burden have hindered progress in diagnosing and treating ME/CFS, such that there is no FDA-approved treatment for the disease; and

WHEREAS, These efforts are expected to contribute to a healthier, more productive California, United States, and world, and are expected to reduce health care costs by finding better treatments and an eventual cure for ME/CFS; now, therefore, be it

Resolved by the Senate of the State of California, the Assembly thereof concurring, That the Legislature hereby proclaims May 12, 2017, as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Awareness Day, and declares the month of May 2017, and each May thereafter, as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Awareness Month, to help spread awareness of the disease and the need for increased research funding, and to support individuals living with ME/CFS; and be it further

Resolved, That the Legislature urges state agencies, medical service providers, health care agencies, research facilities, medical schools, and the NIH, CDC, and FDA to work toward increasing clinical care, supportive care, and medical education and research funding for ME/CFS to a level commensurate with similarly prevalent diseases; and be it further

Resolved, That the Legislature encourages schools, colleges, and media organizations to inform the public about ME/CFS; and be it further

Resolved, That the Secretary of the Senate transmit copies of this resolution to the author for appropriate distribution.