
Introduced by Senator Glazer
(Coauthor: Assembly Member Baker)

April 17, 2017

Senate Concurrent Resolution No. 40—Relative to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Awareness Month.

LEGISLATIVE COUNSEL’S DIGEST

SCR 40, as introduced, 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.

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

9 WHEREAS, Between 100,000 and 300,000 Californians of all
10 ages, races, and sexes are estimated to be afflicted with ME/CFS,
11 with an estimated 836,000 to 2.5 million Americans afflicted and
12 17 million worldwide; and

13 WHEREAS, ME/CFS has been found by the National Academy
14 of Medicine to be “a serious, chronic, complex, and systemic

1 disease that frequently and dramatically limits the activities of
2 affected patients,” leaving them with a lower quality of life than
3 patients with multiple sclerosis, stroke, renal failure, heart failure,
4 and other chronic diseases; and

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

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

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

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

19 WHEREAS, The National Academy of Science’s Institute of
20 Medicine has stated that there is a “paucity of research to date,
21 remarkably little research funding, that more research is essential,
22 and that the level of current research does not reflect disease
23 burden, prevalence, and economic cost to society”; and

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

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

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

38 WHEREAS, The cause of ME/CFS is unknown, there is no
39 diagnostic test and no federal Food and Drug Administration
40 (FDA)-approved treatments, and most patients have no access to

1 doctors with expertise in ME/CFS since there is no training about
2 the disease at most medical schools; and

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

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

12 *Resolved by the Senate of the State of California, the Assembly*
13 *thereof concurring*, That the Legislature hereby proclaims May
14 12, 2017, as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
15 Awareness Day, and declares the month of May 2017, and each
16 May thereafter, as Myalgic Encephalomyelitis/Chronic Fatigue
17 Syndrome Awareness Month, to help spread awareness of the
18 disease and the need for increased research funding, and to support
19 individuals living with ME/CFS; and be it further

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

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

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