



ALASKA STATE LEGISLATURE

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Education Committee Chair

EDUCATION
HEALTH & SOCIAL SERVICES
JUDICIARY
TRANSPORTATION

Sponsor Statement

SB 60

Senate Bill 60 establishes May 12 as Myalgic Encephalomyelitis (ME) Awareness Day to help spread knowledge of the disease, the need for research and appropriate medical care, and to support individuals and their families living with Myalgic Encephalomyelitis.

Myalgic Encephalomyelitis, also known as chronic fatigue syndrome (CFS) or ME/CFS, is a serious, chronic, neurologic disease affecting as many as nine million Americans of all ages, including children. ME/CFS causes dysfunction across all body systems that severely impacts quality of life and ability to work.

ME/CFS often causes a lifetime of disability, with 75% of people unable to work or attend school and 25% of people housebound or bedbound. As many as 90% of people with ME/CFS are undiagnosed. Covid has increased the prevalence of ME/CFS three to five times since 2020 with 50% of Long Covid cases meeting the diagnostic criteria for ME/CFS. Long Covid is affecting as many as 56 million Americans with an estimated economic impact of \$3.7 trillion dollars.

ME/CFS is underfunded relative to disease burden and has no known treatments or cures. Experts and advocates for years have been requesting increased funding, research, medical education, and multidisciplinary collaboration. Medical education pertaining to ME/CFS is lacking. According to the U.S. Center for Disease Control and Prevention most medical schools in the United States do not have ME/CFS as part of their physician training. This leaves the average medical practitioner untrained and unprepared to treat people with ME/CFS & associated diseases.

Establishing May 12 as Myalgic Encephalomyelitis Awareness Day in Alaska mirrors the international designation, chosen to memorialize the birth date of Florence Nightingale, the English army nurse who inspired the founding of the International Red Cross, and who was believed to have contracted a chronic immunological and neurological illness in her mid-thirties and spent the last 50 years of her life virtually bedridden.

This day of recognition will lead to increased awareness of ME/CFS in Alaska. It is our hope that this recognition will lead to increased funding for research by the federal government and private entities, directed clinical education of the disease, and development of diagnostic testing and appropriate treatments, resulting in better medical care for those living with ME/CFS.