



HOUSE JOINT RESOLUTION 17-1019

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also SENATOR(S) Kefalas and Smallwood, Aguilar, Baumgardner, Cooke, Court, Crowder, Donovan, Fenberg, Fields, Garcia, Gardner, Guzman, Holbert, Jahn, Jones, Kagan, Kerr, Lambert, Lundberg, Marble, Martinez Humenik, Merrifield, Moreno, Neville T., Priola, Sonnenberg, Tate, Todd, Williams A.

CONCERNING RECOGNIZING MARCH 24, 2017, AS "ALS AWARENESS DAY".

WHEREAS, Amyotrophic lateral sclerosis, or ALS, was first discovered in the 19th century, but it wasn't until the late 1930s, when the Yankees' Iron Horse, Lou Gehrig, was diagnosed that national attention was brought to this agonizing and lethal disease; and

WHEREAS, ALS attacks nerve cells, the building blocks of our nervous system, which send and receive electrical sparks of information; they begin to wither, as do the patients' muscles and their ability to speak, eat, swallow, and breathe; and

WHEREAS, According to the ALS Association, each day, approximately 15 people are told they have the disease--people who may have just gone to the doctor because they found themselves tripping more often or dropping things; and

WHEREAS, The disease has no boundaries and no bigotries--it affects more than approximately 30,000 people in the United States and has no known cause and, as of yet, no known cure; and

WHEREAS, For reasons that are not yet understood, ALS is twice as likely to afflict veterans; since 2008, the U.S. Department of Veterans Affairs has recognized ALS as a "service-connected disease"; and

WHEREAS, The voluntary ALS Registry, signed into law by Congress in 2008, was created to encourage ALS patients to securely submit information about their health; the data is collected to help the medical community advance research and understanding about the disease; though it has been underutilized, the Registry also serves as an important communications resource, providing updated information to patients about clinical trials; and

WHEREAS, Efforts to understand, treat, and cure ALS are also happening locally at clinics and hospitals and in hospital systems throughout Colorado; and

WHEREAS, Another treatment avenue for ALS patients was passed by the Colorado General Assembly in 2014; the Right to Try Bill, the first of its kind in the nation, gives patients access to experimental therapies and medicines that have not yet been approved by the Food and Drug Administration; and

WHEREAS, It is vitally important to increase awareness of ALS and to support public and private efforts taking place in Colorado and across the continents to continue the profound impact made by millions during the Ice Bucket Challenge in 2014, which was put on by the ALS Association; now, therefore,

Be It Resolved by the House of Representatives of the Seventy-first General Assembly of the State of Colorado, the Senate concurring herein:

That the Colorado General Assembly:

- (1) Urge pharmaceutical companies, through the Right to Try Law, to make experimental therapies and medicines available to people in Colorado with ALS;
- (2) Acknowledge the men and women who are collaborating to find the cause and the cure for ALS in Colorado and across the country and the world;
- (3) Encourage ALS patients to register with the federal ALS Registry;
- (4) Increase awareness of and education about ALS and the difficulties of living with it;
- (5) Recognize the courageous patients of this enigmatic and tragic disease and their equally courageous families and caregivers and do everything possible as a legislative body to help them; and
- (6) Increase efforts to encourage and work with the United States Congress to do everything possible to end ALS.

Crisanta Duran
SPEAKER OF THE HOUSE
OF REPRESENTATIVES

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