

**First Regular Session
Seventy-first General Assembly
STATE OF COLORADO**

INTRODUCED

LLS NO. R17-0862.01 Jessica Wigent x3701

HJR17-1019

HOUSE SPONSORSHIP

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HOUSE JOINT RESOLUTION 17-1019

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

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

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

9 WHEREAS, According to the ALS Association, each day,
10 approximately 15 people are told they have the disease--people who may

Shading denotes HOUSE amendment. Double underlining denotes SENATE amendment.
Capital letters indicate new material to be added to existing statute.
Dashes through the words indicate deletions from existing statute.

1 have just gone to the doctor because they found themselves tripping more
2 often or dropping things; and

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

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

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

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

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

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

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

31 That the Colorado General Assembly:

32 (1) Urge pharmaceutical companies, through the Right to Try
33 Law, to make experimental therapies and medicines available to people

1 in Colorado with ALS;

2 (2) Acknowledge the men and women who are collaborating to
3 find the cause and the cure for ALS in Colorado and across the country
4 and the world;

5 (3) Encourage ALS patients to register with the federal ALS
6 Registry;

7 (4) Increase awareness of and education about ALS and the
8 difficulties of living with it;

9 (5) Recognize the courageous patients of this enigmatic and tragic
10 disease and their equally courageous families and caregivers and do
11 everything possible as a legislative body to help them; and

12 (6) Increase efforts to encourage and work with the United States
13 Congress to do everything possible to end ALS.