

May 11, 1999

70th OREGON LEGISLATIVE ASSEMBLY--1999 Regular Session

Senate Joint Memorial 8

Sponsored by COMMITTEE ON HEALTH AND HUMAN SERVICES (at the request of Mike Dallum, Brownsville, OR; Mike Cunningham, Albany, OR; Chad and Beth Risley, Roseburg, OR)

SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure as introduced.

Urges Congress to increase support for research into the cause, prevention, early diagnosis, treatment and cure of amyotrophic lateral sclerosis.

JOINT MEMORIAL

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To the President of the United States and the Senate and the House of Representatives of the United States of America, in Congress assembled:

We, your memorialists, the Seventieth Legislative Assembly of the State of Oregon, in legislative session assembled, respectfully represent as follows:

Whereas amyotrophic lateral sclerosis (ALS), often referred to as Lou Gehrig's disease, is a progressive neurologic disease resulting in weakness, wasting and paralysis; and

Whereas ALS affects people in the prime of life, typically in the fifth or sixth decade; and

Whereas ALS deprives families and communities of vitally important and beloved members; and

Whereas ALS leads to severe disability and death within three to five years after diagnosis; and

Whereas an estimated 30,000 Americans, including 150 Oregonians, are affected by ALS; and

Whereas ALS kills an estimated 5,400 Americans each year, including 60 Oregonians; and

Whereas 300,000 Americans who are now alive and well will eventually die of ALS; and

Whereas ALS is not a rare disease, with an incidence five times greater than that of Huntington's disease and equal to that of multiple sclerosis; and

Whereas the financial cost to families of persons with ALS is exceedingly high, and in the advanced stages care can cost up to \$200,000 a year; and

Whereas the cause of ALS is not known and no cure exists; now, therefore,

Be It Resolved by the Legislative Assembly of the State of Oregon:

(1) We encourage the President and Congress of the United States to adequately support research into the causes, prevention, early diagnosis, treatment and ultimate cure of amyotrophic lateral sclerosis.

(2) A copy of this memorial shall be sent to the President of the United States and to each member of the Oregon Congressional Delegation.

NOTE: Matter in boldfaced type in an amended section is new; matter [italic and bracketed] is existing law to be omitted. New sections are in boldfaced type.

LC 3334

My name is Mike Dallum and I want to testify about Amyotrophic Lateral Sclerosis, or Lou Gerhig's Disease. My life has changed dramatically since I was diagnosed in October of 1997.

Until I had a tracheotomy I was an editor for *The Times* in Brownsville, a weekly newspaper. I am now reliant on a nurse and family to care for me. It is a relentless illness, as I now am fed through a tube in my stomach. I breathe with a ventilator and I have lost the ability to speak.

I am here to ask you to help by asking for more research to find a cure. Right now the Federal Drug Administration is holding a medicine called Myotrophin that may help people with Lou Gerhig's Disease.

The intrusion into my life and the way it has affected my family is traumatic. Anything you can do to help would be appreciated.