

107TH CONGRESS
1ST SESSION

S. CON. RES. 69

Expressing support for tuberous sclerosis awareness.

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 21, 2001

Mr. WARNER (for himself and Mr. HAGEL) submitted the following concurrent resolution; which was referred to the Committee on Health, Education, Labor, and Pensions

CONCURRENT RESOLUTION

Expressing support for tuberous sclerosis awareness.

Whereas at least two children born each day will be affected with tuberous sclerosis;

Whereas nearly one million people worldwide are known to have tuberous sclerosis;

Whereas tuberous sclerosis affects all races and ethnic groups equally;

Whereas tuberous sclerosis is caused by either an inherited autosomal disorder or by a spontaneous genetic mutation;

Whereas when tuberous sclerosis is genetically transmitted as an autosomal dominant disorder, a child with a parent with the gene will have a 50-percent chance of inheriting the disease;

Whereas two-thirds of the cases of tuberous sclerosis are believed to be a result of spontaneous mutation, although the cause of such mutations is a mystery;

Whereas diagnosis takes an average of 90 days with consultation of at least three specialists;

Whereas tuberous sclerosis frequently goes undiagnosed because of the obscurity of the disease and the mild form the symptoms may take; and

Whereas the Congress as an institution, and Members of Congress as individuals, are in unique positions to help raise public awareness about the need for increased funding for research, detection, and treatment of tuberous sclerosis and to support the fight against tuberous sclerosis: Now, therefore, be it

1 *Resolved by the Senate (the House of Representatives*
2 *concurring), That it is the sense of Congress that—*

3 (1) all Americans should take an active role in
4 the fight against tuberous sclerosis by all means
5 available to them, including early and complete clin-
6 ical testing and investigating family histories;

7 (2) the role played by national and community
8 organizations and health care providers in promoting
9 awareness of the importance of early diagnosis, test-
10 ing, and ongoing screening should be recognized and
11 applauded;

12 (3) the Federal Government has a responsibility
13 to—

1 (A) endeavor to raise awareness about the
2 importance of the early detection of, and proper
3 treatment for, tuberous sclerosis;

4 (B) increase funding for research so that
5 the causes of, and improved treatment for, tu-
6 berous sclerosis may be discovered; and

7 (C) continue to consider ways to improve
8 access to, and the quality of, health care serv-
9 ices for detecting and treating tuberous scle-
10 rosis; and

11 (4) the Director of the National Institutes of
12 Health should take a leadership role in the fight
13 against tuberous sclerosis by acting with appropriate
14 offices within the National Institutes of Health to
15 provide to the Congress a five-year research plan for
16 tuberous sclerosis.

Q