

House Calendar No. 67

107TH CONGRESS
1ST SESSION

H. CON. RES. 25

[Report No. 107-181]

Expressing the sense of the Congress regarding tuberous sclerosis.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 8, 2001

Mrs. KELLY submitted the following concurrent resolution; which was referred to the Committee on Energy and Commerce

AUGUST 1, 2001

Additional sponsors: Mr. PASCARELL, Mr. WALSH, Ms. RIVERS, Mr. HILLIARD, Mr. PRICE of North Carolina, Mr. GEORGE MILLER of California, Mr. DOYLE, Mr. SHADEGG, Mr. TANCREDO, Ms. CARSON of Indiana, Mr. GUTIERREZ, Mr. McDERMOTT, Mr. ENGLISH, Mr. FOSSELLA, Mr. WELDON of Pennsylvania, Mr. KING, Mrs. MALONEY of New York, Mr. HILL, Mr. WELLER, Mr. STARK, Mr. ROTHMAN, Mr. CRANE, Mr. COX, Ms. SANCHEZ, Mr. ROYCE, Mr. WEXLER, Ms. LEE, Mr. BEREUTER, Ms. MCKINNEY, Mr. MORAN of Virginia, Mr. WOLF, Mr. BURTON of Indiana, Mr. WAMP, Mr. LUTHER, and Mr. COYNE

AUGUST 1, 2001

Reported with an amendment, referred to the House Calendar and ordered to be printed

[Strike out the preamble and insert the part printed in *italic*]

CONCURRENT RESOLUTION

Expressing the sense of the Congress regarding tuberous sclerosis.

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 is the largest known genetic cause of epilepsy;

Whereas tuberous sclerosis is now the second largest identifiable genetic cause of autism;

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

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

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

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

10 (3) the Federal Government has a responsibility
11 to—

12 (A) endeavor to raise awareness about the
13 importance of the early detection of, and proper
14 treatment for, tuberous sclerosis;

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

18 (C) continue to consider ways to improve
19 access to, and the quality of, health care serv-
20 ices for detecting and treating tuberous sele-
21 rosis; and

22 (4) the Director of the National Institutes of
23 Health should take a leadership role in the fight
24 against tuberous sclerosis by acting with appropriate
25 offices within the National Institutes of Health to

- 1 provide to the Congress a five-year research plan for
- 2 tuberous sclerosis.

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