

EXPRESSING THE SENSE OF THE CONGRESS REGARDING
TUBEROUS SCLEROSIS

AUGUST 1, 2001.—Referred to the House Calendar and ordered to be printed

Mr. TAUZIN, from the Committee on Energy and Commerce,
submitted the following

REPORT

[To accompany H. Con. Res. 25]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the concurrent resolution (H. Con. Res. 25) expressing the sense of the Congress regarding tuberous sclerosis, having considered the same, report favorably thereon with an amendment and recommend that the concurrent resolution as amended be agreed to.

CONTENTS

	Page
Amendment	1
Purpose and Summary	2
Background and Need for Legislation	2
Hearings	3
Committee Consideration	3
Committee Votes	3
Committee Oversight Findings	3
Statement of General Performance Goals and Objectives	3
New Budget Authority, Entitlement Authority, and Tax Expenditures	3
Committee Cost Estimate	3
Congressional Budget Office Estimate	4
Federal Mandates Statement	4
Advisory Committee Statement	4
Constitutional Authority Statement	5
Applicability to Legislative Branch	5
Section-by-Section Analysis of the Legislation	5
Changes in Existing Law Made by the Bill, as Reported	5

AMENDMENT

The amendment strikes the preamble and inserts a new preamble which appears in italic type in the reported concurrent resolution.

The following shows the preamble and the subsequent provisions of the reported concurrent resolution:

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

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

(2) the role played by national and community organizations and health care providers in promoting awareness of the importance of early diagnosis, testing, and ongoing screening should be recognized and applauded;

(3) the Federal Government has a responsibility to—

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

(B) increase funding for research so that the causes of, and improved treatment for, tuberous sclerosis may be discovered; and

(C) continue to consider ways to improve access to, and the quality of, health care services for detecting and treating tuberous sclerosis; and

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

PURPOSE AND SUMMARY

H. Con. Res. 25 encourages the Federal government to increase public awareness of tuberous sclerosis.

BACKGROUND AND NEED FOR LEGISLATION

Tuberous sclerosis complex (TSC) is a genetic disorder characterized by seizures and tumor growth in vital organs such as the brain, heart, kidneys, lungs, and skin. Individuals with tuberous sclerosis commonly begin having seizures during the first year of life, and conventional epilepsy therapies often do not control the seizure activity in infants, children or adults. Seizures, as well as brain tumors, contribute to cognitive impairment. As a result, a majority of those afflicted with tuberous sclerosis experience some form of learning disability and behavioral problem.

There are at least one million people worldwide who are known to have tuberous sclerosis. The Committee endeavors to raise awareness about the importance of the early detection of and proper treatment for tuberous sclerosis. Further, the Committee believes the resources of the Federal government's health and research institutes, through a coordinated effort, can accelerate the understanding of the biological mechanisms causing tuberous sclerosis. Working in partnership with other research initiatives, this

Nation can help lessen the long-term impact of this devastating disease.

H. Con. Res. 25 takes an important step in the fight against tuberous sclerosis.

HEARINGS

The Subcommittee on Health held a hearing entitled, “Advancing the Health of the American People: Addressing Various Public Health Needs” on June 27, 2001. The Subcommittee heard testimony on H. Con. Res. 25 at the hearing. The witness testifying on the bill was Mr. Michael Coburn, President and CEO, Tuberous Sclerosis Alliance.

COMMITTEE CONSIDERATION

On Wednesday, July 11, 2001, the Subcommittee on Health met in an open markup session and approved H. Con. Res. 25 for Full Committee consideration, as amended, by voice vote, a quorum being present. On Wednesday, July 18, 2001, the Full Committee met in open markup session and ordered H. Con. Res. 25 favorably reported to the House, as amended, by unanimous consent, a quorum being present.

COMMITTEE VOTES

Clause 3(b) of rule XIII of the Rules of the House of Representatives requires the Committee to list the record votes on the motion to report legislation and amendments thereto. There were no record votes taken in connection with ordering H. Con. Res. 25 reported. A motion by Mr. Tauzin to order H. Con. Res. 25 reported to the House, as amended, was agreed to by unanimous consent.

COMMITTEE OVERSIGHT FINDINGS

Pursuant to clause 3(c)(1) of rule XIII of the Rules of the House of Representatives, the Committee held a legislative hearing and made findings that are reflected in this report.

STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

The goal of H. Con. Res. 25 is to encourage all Americans and the Federal government to take an active role in the fight against tuberous sclerosis.

NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

In compliance with clause 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee finds that H. Con. Res. 25, a concurrent resolution expressing the sense of the Congress regarding tuberous sclerosis, would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

COMMITTEE COST ESTIMATE

The Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII of the Rules of the House of Representatives, the following is the cost estimate provided by the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974:

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, July 30, 2001.

Hon. W.J. "BILLY" TAUZIN,
*Chairman, Committee on Energy and Commerce,
House of Representatives, Washington, DC.*

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimates for the following Concurrent Resolutions approved by the Committee on Energy and Commerce:

—H. Con. Res. 25, expressing the sense of the Congress regarding tuberous sclerosis.

—H. Con. Res. 36, urging increased federal funding for juvenile (Type I) diabetes research.

—H. Con. Res. 61, expressing support for a National Reflex Sympathetic Dystrophy (RSD) Awareness Month.

If you wish further details on these estimates, we will be pleased to provide them. The CBO staff contact is Charles Betley.

Sincerely,

BARRY B. ANDERSON
(For Dan L. Crippen, Director).

Enclosure.

H. Con. Res. 25—Expressing the sense of the Congress regarding tuberous sclerosis

H. Con. Res. 25 would express the support of the Congress for efforts to encourage early and complete clinical testing for tuberous sclerosis, to raise awareness of the needs for clinical testing, and to increase research to improve the detection and treatment of tuberous sclerosis. The resolution also would urge the Director of the National Institutes of Health to develop a five-year research plan for improving detection and treatment of tuberous sclerosis. CBO estimates that passing H. Con. Res. 25 would result in no significant cost to the federal government. The resolution would not affect direct spending or receipts; therefore, pay-as-you-go procedures would not apply.

The CBO staff contact is Charles Betley. This estimate was approved by Peter H. Fontaine, Deputy Assistant Director for Budget Analysis.

FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act were created by this legislation.

CONSTITUTIONAL AUTHORITY STATEMENT

Pursuant to clause 3(d)(1) of rule XIII of the Rules of the House of Representatives, the Committee finds that the Constitutional authority for this legislation is provided in Article I, section 8, clause 3, which grants Congress the power to regulate commerce with foreign nations, among the several States, and with the Indian tribes.

APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

H. Con. Res. 25 expresses the sense of the Congress that the Federal government has a responsibility to raise public awareness of tuberous sclerosis and educate all Americans about the importance of the early detection of, and proper treatment for, tuberous sclerosis. In addition, the resolution urges an increase in funding for research on tuberous sclerosis. Finally, H. Con. Res. 25 urges the National Institutes of Health to take a leadership role and to provide a five-year research plan in the fight against tuberous sclerosis.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

This legislation does not amend any existing Federal statute.

