

107TH CONGRESS
2^D SESSION

S. CON. RES. 126

Expressing the sense of Congress regarding Scleroderma.

IN THE SENATE OF THE UNITED STATES

JUNE 27, 2002

Mr. REID (for himself, Mr. CRAIG, Ms. FEINSTEIN, and Ms. STABENOW) submitted the following concurrent resolution; which was referred to the Committee on Health, Education, Labor, and Pensions

CONCURRENT RESOLUTION

Expressing the sense of Congress regarding Scleroderma.

Whereas Scleroderma is a debilitating and potentially fatal autoimmune disease with a broad range of symptoms that may be either localized or systemic;

Whereas Scleroderma may attack vital internal organs, including the heart, esophagus, lungs, and kidneys, and may do so without causing any external symptoms;

Whereas more than 300,000 people in the United States suffer from Scleroderma;

Whereas the symptoms of Scleroderma include hardening and thickening of the skin, swelling, disfigurement of the hands, spasms of blood vessels causing severe discomfort in the fingers and toes, weight loss, joint pain, difficulty

swallowing, extreme fatigue, and ulcerations on the fingertips which are slow to heal;

Whereas people with advanced Scleroderma may be unable to perform even the simplest tasks;

Whereas 80 percent of the people suffering from Scleroderma are women between the ages of 25 and 55;

Whereas Scleroderma is the fifth leading cause of death among all autoimmune diseases for women who are 65 years old or younger;

Whereas the wide range of symptoms and localized and systemic variations of Scleroderma make it difficult to diagnose;

Whereas the average diagnosis of Scleroderma is made 5 years after the onset of symptoms;

Whereas the cause of Scleroderma is still unknown and there is no known cure;

Whereas Federal funding for Scleroderma research is less than for other diseases of similar prevalence; and

Whereas the estimated annual direct and indirect costs of Scleroderma in the United States are \$1,500,000,000:
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) private organizations and health care pro-
4 viders should be recognized for their efforts to pro-
5 mote awareness and research of Scleroderma;

1 (2) the people of the United States should make
2 themselves aware of the symptoms of Scleroderma
3 and contribute to the fight against Scleroderma;

4 (3) the Federal Government should promote
5 awareness regarding Scleroderma, adequately fund
6 research projects regarding Scleroderma within the
7 fiscal budget, and continue to consider ways to im-
8 prove the quality of health care services provided for
9 Scleroderma patients, including making prescription
10 medication more affordable;

11 (4) the National Institutes of Health should
12 continue to play a leadership role in the fight
13 against Scleroderma by—

14 (A) working more closely with private or-
15 ganizations and researchers to find a cure for
16 Scleroderma;

17 (B) funding research projects regarding
18 Scleroderma conducted by private organizations
19 and researchers;

20 (C) holding a Scleroderma symposium
21 which would bring together distinguished sci-
22 entists and clinicians from across the United
23 States to determine the most important prior-
24 ities in Scleroderma research;

1 (D) supporting the formation of small
2 workgroups composed of experts from diverse
3 but related scientific fields to study
4 Scleroderma;

5 (E) conducting more genetic, environ-
6 mental, and clinical research regarding
7 Scleroderma;

8 (F) training more basic and clinical sci-
9 entists to carry out such research; and

10 (G) providing for better dissemination of
11 the information learned from such research;
12 and

13 (5) the Centers for Disease Control and Preven-
14 tion should give priority to the establishment of a
15 national epidemiological study to better track the in-
16 cidence of Scleroderma and to gather information
17 about the disease that could lead to a cure.

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