

108TH CONGRESS
1ST SESSION

S. CON. RES. 33

Expressing the sense of the Congress regarding scleroderma.

IN THE SENATE OF THE UNITED STATES

APRIL 7, 2003

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

A BILL

Expressing the sense of the Congress regarding scleroderma.

Whereas scleroderma is a debilitating and potentially fatal autoimmune disease with a broad range of symptoms which 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 of tasks;

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

Whereas scleroderma is the 5th 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; 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 the Congress that—

3 (1) private organizations and health care pro-
4 viders should be recognized for their efforts to pro-
5 mote awareness of and research on scleroderma;

6 (2) the people of the United States, including
7 the medical community, should make themselves
8 aware of the symptoms of scleroderma and con-
9 tribute to the fight against scleroderma;

1 (3) the Federal Government has a responsibility
2 to promote awareness regarding scleroderma, to ade-
3 quately fund research projects regarding
4 scleroderma, and to continue to consider ways to im-
5 prove the quality of health care services provided for
6 scleroderma patients, including making prescription
7 medication more affordable;

8 (4) the National Institutes of Health should
9 continue to play a leadership role in the fight
10 against scleroderma by—

11 (A) working more closely with private or-
12 ganizations and researchers to find a cure for
13 scleroderma;

14 (B) funding research projects regarding
15 scleroderma conducted by private organizations
16 and researchers;

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

22 (D) supporting the formation of small
23 workgroups composed of experts from diverse
24 but related scientific fields to study
25 scleroderma;

1 (E) conducting more genetic, environ-
2 mental, and clinical research regarding
3 scleroderma;

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

6 (G) providing for better dissemination of
7 the information learned from such research;
8 and

9 (5) the Centers for Disease Control and Preven-
10 tion should give priority consideration to the estab-
11 lishment of a national epidemiological study to bet-
12 ter track the incidence of scleroderma and to gather
13 information about the disease that could lead to a
14 cure.

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