

AMENDMENT TO H. CON. RES. 320
OFFERED BY MR. TAUZIN

Strike all after the resolving clause and insert the following:

1 That it is the sense of the Congress that—

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

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

9 (3) the National Institutes of Health should
10 continue to take a leadership role in research efforts
11 regarding the fight against Scleroderma and should
12 allow for broad dissemination of the information
13 learned from such research; and

14 (4) the Centers for Disease Control and Preven-
15 tion should consider additional methods to improve
16 disease surveillance of Scleroderma.



Strike the preamble and insert the following:

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

4 Whereas Scleroderma may attack vital internal organs, in-
5 cluding the heart, esophagus, lungs, and kidneys, and
6 may do so without causing any external symptoms;

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

9 Whereas the symptoms of Scleroderma include hardening
10 and thickening of the skin, swelling, disfigurement of
11 the hands, spasms of blood vessels causing severe dis-
12 comfort in the fingers and toes, weight loss, joint pain,
13 difficulty swallowing, extreme fatigue, and ulcerations
14 on the fingertips which are slow to heal;

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

17 Whereas 80 percent of the people suffering from
18 Scleroderma are women between the ages of 25 and
19 55;

20 Whereas Scleroderma is the 5th leading cause of death
21 among all autoimmune diseases for women who are
22 65 years old or younger;



1 Whereas the wide range of symptoms and localized and
2 systemic variations of Scleroderma make it difficult
3 to diagnose;
4 Whereas the average diagnosis of Scleroderma is made 5
5 years after the onset of symptoms;
6 Whereas the cause of Scleroderma is still unknown and
7 there is no known cure; and
8 Whereas the estimated annual direct and indirect costs of
9 Scleroderma in the United States are \$1,500,000,000:
10 Now, therefore, be it

