



Three Principles for Meaningful Healthcare Reform

The Scleroderma Foundation (SF) is a nonprofit organization dedicated to help patients and their families cope with scleroderma through mutual support programs, peer counseling, physician referrals, and educational information; to promote public awareness and education through patient and health professional seminars, literature, and publicity campaigns; and to stimulate and support research to improve treatment and ultimately find the cause of and cure for scleroderma and related diseases. SF is lead by a network of health professionals, community leaders, patients, and their families who work tirelessly to improve health outcomes for those who suffer from scleroderma.

Scleroderma is an autoimmune disease which causes the soft tissues of the body to harden and contract. The hardening and contraction of soft tissues can occur both inside and outside the body, affecting the skin and internal organs. Scleroderma affects approximately 300,000 individuals, and often leads to other conditions, including pulmonary hypertension, gastrological orders, and respiratory difficulties. About three to four times more women than men develop the disease. Unfortunately, the underlying causes of scleroderma remain unknown and treatment options are limited.

Due to the debilitating affects of scleroderma, many patients are unable to work and find themselves on disability. Highlighting the need to invest in medical research is the increased number of individuals on disability which results in a significant economic burden. However, the current 24 month waiting period to receive coverage under Medicare for an individual on disability can cause economic ruin to the patient and their family. Many patients forgo treatment while in this uncovered period, exacerbating health problems while they are without care, causing increased costs to Medicare.

SF recommends the following three principles for consideration as the dialogue over healthcare reform moves forward:

- The federal investment in medical research must be increased substantially and in a systematic fashion to ensure that innovative discoveries are translated to patient-aiding treatments in a timely manner.
- Increased education is needed to ensure that health care providers can accurately and quickly diagnose serious medical conditions, such as scleroderma.
- Increased means of providing coverage individuals on Social Security Disability Insurance to eliminate the coverage gap for individuals disabled due to chronic medical conditions.