

Become An Advocate!

Let's Start Talking About It!



While you may think that you are just one person, and your voice is too small to be heard, every effort makes a difference! In fact, it is essential that you write to your elected officials. That's how grass-roots lobbying has its largest impact. The greater number of people who write and call their representatives, the more influence we have in order to make a difference in the lives of those with affected by scleroderma.

Remember these facts to share with your representatives:

- Scleroderma is a chronic, autoimmune connective tissue disease whose symptoms typically include some or all of the following: sensitivity to cold in fingers and hands, thickening of the skin, shortness of breath, difficulty swallowing, joint stiffness and pain and damage to internal and external organs.
- Autoimmune diseases, which affect more than 50 million Americans, are the third leading cause of death in the United States.
 - The estimated impact of scleroderma in the US is \$1.5 billion annually.
 - The direct cost of treatment for patients is more than \$460 million annually.
 - 80% of patients are female.
- There are currently 12 newly diagnosis scleroderma patients being seen at the University of Michigan Scleroderma Clinics a week; and in Grand Rapids, Dr. Martin, treats at least 98

scleroderma patients in his practice. We know that scleroderma touches the lives of thousands of individuals in the state of MI.

- Scleroderma typically strikes between the ages of 25 and 55, but can affect even infants
- 95% of scleroderma cases begin with Raynaud's phenomenon (hands and feet abnormally sensitive to cold).
- Federal research funding for scleroderma lags behind other diseases of similar prevalence. We currently have the Scleroderma Research and Awareness Acts that we are working on and hoping to have passed in the 112th Congress. This legislation would establish a public awareness campaign highlighting disease symptoms, prevalence and the importance of early diagnosis. It would also expand research related to scleroderma and research of various secondary conditions.
- Misdiagnosis is common. It can take three years or more for an individual to be diagnosed and receive appropriate treatment, often due to lack of familiarity with the disease among medical professionals.

Scleroderma Patients Need Your Voice!



PLEASE HELP those whose lives are affected every day by scleroderma. These children, men, teens, and women are living in bodies that are hurting, weakening and some of their bodies are turning harder by the day. Scleroderma patients want to live a normal life. They want to go to the grocery store and be able to go into a freezer department without wearing protective gloves. They want to be able to zip their own clothing, button a jacket, put on makeup and do other household chores. Every day scleroderma patients face obstacles and struggles yet they work so hard to overcome them.

Share Your Voice



We need your support, your voice, your time, and most of all we need YOU! You do make a difference by picking up the phone, sending e-mails, and letters! Never doubt the difference one person can make! You can also ask your friends, co-workers, neighbors, and family to do the same. Every phone call that is made helps us get one step closer to the goal of finding a CURE!

Become A State Advocacy Coordinator Position Description



The **Scleroderma State Advocacy Coordinator** is a crucial volunteer leadership role that works with the Foundation's National Advocacy Committee to develop the advocacy program in each state.

The coordinator facilitates all activity that deals with Federal legislation and outreach.

In general, you will be the "go to" person in your State for organizing patients, family and friends, and others interested in helping our cause to obtain new co sponsors for scleroderma legislation per increased funding for medical research to find a cure.

A master spreadsheet has been compiled and will be provided to you with all of your state's Congressional Representatives and (2) Senators. You will be responsible for tracking and updating the status of efforts within your state to help achieve overall goals.

A packet will be provided with the bills and tips for advocating for our bills. You will need to develop and manage a plan to reach out to each of you congressman and senators.

This can include the following:

- Make a personal contact with the health legislative aide listed on the spreadsheet. Identify that you are the State Advocacy Coordinator and ask for their support for our bill.
- Identify constituents that can make contact with the legislative aide and encourage and help them to do so.
- Arrange for local meetings at the offices.
- Arrange for an advocacy table or presence at any event your chapter or support group may be hosting (educational forum, walk, etc.). These materials, including a banner and letters, are available through the SF National office.
- Forward any letters to the SF National Office in a timely manner.
- Keep a log of all activity and update the Master spreadsheet by the 1st of each month.
- Visit Thomas.loc.gov to identify any new co sponsors.
- Familiarize yourself with all the tools available on the SF National Advocacy website.
- Make yourself available as a contact for patients, family and friends in your state for advice/help in contacting their representatives.
- Participate once per month on a conference call held by the National Advocacy Committee

For more information on how you can get involved in the advocacy efforts of the Michigan Chapter, contact the office at (248) 595-8526.