



## **About the Scleroderma Foundation**

### ***History***

The Scleroderma Foundation, Inc., was established Jan. 1, 1998, after a merger between the West coast-based United Scleroderma Foundation and the East coast-based Scleroderma Federation, each of which can trace their founding dates back to the early 1970s. The two organizations shared similar missions, goals and programs, and collaborated to fund medical research grants through a joint peer review process modeled after those of the National Institutes of Health.

In 1996, the leadership of both groups began negotiations to merge the two into one organization that would be national in scope and that eliminated duplication of effort and overlapping services. Most importantly, a merger would diminish competition for much-needed financial support. Within 18 months of starting this dialogue, the two organizations came together with a combined board of directors, shared staff and a united vision to serve the scleroderma community.

### ***The Foundation Today***

The Scleroderma Foundation, Inc., is a 501(c)(3) nonprofit organization, incorporated under the laws of the State of Illinois. It is headquartered in Danvers, Mass., in the metro Boston area.

An 11-person Board of Directors that meets on a quarterly basis governs the Foundation, and it employs a professional staff to manage the day-to-day operations. An active Medical Advisory Board, comprised of distinguished researchers and clinicians in scleroderma and related fields, assists the Foundation to provide research and medical-related information for patients and other interested parties. An independent Peer Review Committee comprised of leading medical experts reviews, evaluates and scores research grant applications to ensure the Foundation funds are used to support the most promising research initiatives taking place across the country.

In addition to the National Office, the Foundation has a network of 23 chapters and 168 support groups throughout the U.S. that are dedicated to carrying out the Foundation's mission.

The Foundation has an annual operating budget of approximately \$4 million. Its single, largest annual budgeted expense is \$1 million for scleroderma research.

### ***Mission and Work of the Foundation***

The Foundation has a three-fold mission of support, education and research. This mission is the cornerstone upon which its programs and services are built.

### ***Support***

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The Foundation provides support for people living with scleroderma and their families through programs such as peer counseling, physician referrals and educational information.

Scleroderma-related news and information is distributed through a quarterly member magazine, the *Scleroderma Voice*. The publication features research updates, clinical trials and treatment modalities, as well as articles by the leading doctors and health care professionals. Along with practical tips for coping with scleroderma, answers to medical questions and patient profiles, the *Scleroderma Voice* serves as an important tool to inform the Foundation's members about its efforts to fund more research, advance public awareness and advocate for more federal funding of scleroderma-specific research.

The Foundation operates a toll-free telephone hotline for patients, concerned individuals and medical professionals to request information and speak with an informed, lay consultant about issues and concerns. You can access the helpline at (800) 722-HOPE (4673).

The Foundation produces a variety of literature to help people better understand, manage and cope with the many symptoms of scleroderma. Members of the Medical Advisory Board regularly update the organization's brochure series and other information.

The Foundation's network of 23 chapters and 168 support groups offer patient education programs and facilitated meetings for patients and their families in communities across the country. For those who live outside of a chapter or support group territory and cannot easily access those services in their area, or whose health prevents them from participation, the Foundation participates in Web-based social networking on Facebook, Twitter and Inspire. Each site provides a forum for collaborative communication, peer support and encouragement.

### *Education*

Beyond the patient services described above, a part of the Foundation's mission is to provide education about the disease to patients, families, the medical community and the public through a variety of awareness programs at both the grassroots and national levels. Such programs include public relations activities, patient advocate trainings and organized visits to legislators on Capitol Hill.

By promoting public awareness about scleroderma, the Foundation hopes to generate more funding for medical research, as well as foster a greater understanding about the complications faced by people living with the disease.

To accomplish its education goals, the Foundation operates a Web site ([www.scleroderma.org](http://www.scleroderma.org)) that is filled with information to help inform patients and the public about scleroderma. Medical articles are routinely posted on the site along with links to other relevant information. The average number of visits to the site is 50,000 per day.

Foundation members also receive an electronic newsletter. The weekly eLetter provides scleroderma-related information. It is available by subscription only and reaches an average of 10,000 people each week.

The Foundation offers support and educational information to its Chapter and Support Group leaders around the country through another Web-based newsletter, *Direct Connection*. This newsletter is published bi-monthly and is geared toward our volunteer leadership throughout the U.S.

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The annual National Patient Education Conference, held each summer in a major U.S. city, brings an average of 500 patients and the world's leading medical experts together for a two-day program. It features a wide-range of workshops on topics such as the latest research initiatives, coping and disease management skills, caregiver support and exercise techniques. All of the workshops and seminars are conducted by medical professionals with direct knowledge of scleroderma and the challenge faced by patients. The annual conference is also an important opportunity for patients to come together in a mutually-supportive environment to establish friendships and share information on living with scleroderma.

Physicians and researchers dedicated to treating and curing scleroderma can learn from each other through the Foundation's Medical Professionals Program. Members can access the latest research studies, treatment modalities and resources. They receive news articles, pamphlets and information packets free. The medical community also benefits from being listed on the Physician Member section of the Foundation's Web site, and receive eLetter updates on new or advancing research.

### *Research*

Although patient support programs and education are a large part of the Scleroderma Foundation's mission and programming, the heart of the organization is based in the third part of its mission - research.

There is no known cause or cure for scleroderma. Current treatments are geared toward managing a broad spectrum of symptoms, and the Foundation is dedicated to funding the best research to find the cause and cure. To that end, the Foundation awards an average of \$1 million in research grants annually through its nationally-recognized peer review process, which is modeled after those of the National Institutes of Health. The Scleroderma Foundation provides grants to support qualified initiatives at universities and other research institutions.

### ***Funding***

The principal means of support for the Foundation's work comes from individuals with a connection to the disease, as a patient, family member or close friend who battles scleroderma. Nationally, the Foundation engages in a variety of fundraising activities including events, direct mail campaigns, corporate solicitations and workplace giving campaigns such as the Combined Federal Campaign. On the local level, the Foundation's chapters engage in various fundraising activities. Monies raised at the local level stay with the chapter to help support patient services. Thirty percent of all funds raised through the chapters are given to the National Office to support its operations. If a gift is received at the National Office from a donor living in a chapter territory, the National Office returns those funds to the local chapter for its use, unless otherwise directed by the donor. Chapters also support the Foundation's research program by making annual gifts to the research fund that is administered by the National Office.

Foundation membership is \$25 per year. These funds support the costs to produce and mail the quarterly magazine, send information packets, and help underwrite the costs associated with operating the toll-free patient helpline. The Foundation relies on the generosity of individuals, corporations and philanthropic organizations to underwrite its programs and services. The Foundation does not receive federal or local government support.

***For more information about scleroderma, visit [www.scleroderma.org](http://www.scleroderma.org) or call (800) 722-HOPE (4673).***