

OUR MISSION:
SUPPORT, EDUCATION
AND RESEARCH



**SCLERODERMA
FOUNDATION**

SUPPORT • EDUCATION • RESEARCH

LISA'S STORY

Lisa Hendricks was just seven years old when her parents noticed she was limping and couldn't lay her hands flat on a table. She hadn't complained of any pain, or showed any signs that the stiffness in her fingers was slowing her down. In fact, she had just started to play the piano and seemed to love it. Yet her parents knew something was wrong.

Suddenly, Lisa was unable to get up from a sitting position. Her parents rushed her to the doctor, who immediately recognized the symptoms of the linear and morphea forms of scleroderma. Two months later, specialists at the University of California, San Francisco, confirmed the diagnosis.

And just like that, in the blink of an eye, Lisa had begun her life with scleroderma.

Lisa has recently finished college and is beginning her career as an elementary school teacher. She volunteers for her church, hangs out with friends and family, and still enjoys playing the piano. She just does it all with scleroderma.

Lisa first found the Scleroderma Foundation while she was doing research online about the disease and support groups that provide resources for patients. What she found in her research was life-changing.

“When you talk to other members of a Scleroderma Foundation support group, you know they understand what you are talking about. It's very comforting,” said Lisa, who belongs to the Foundation's support group in Sacramento. “We get together once a month, but really a lot of us are in constant contact. It's like I finally found where I belong.”

Support is a critical component of the Scleroderma Foundation's mission, but it isn't the only aspect that drives the organization. The Foundation educates patients, families, medical professionals and the public through awareness campaigns. The organization also works to raise much-needed funds for research to identify the cause, and ultimately a cure, for the disease. These components make up the Foundation's three-fold mission of support, education and research.

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– Lisa Hendricks

SUPPORT

Because scleroderma is rare (it is estimated that the disease affects about 300,000 people in the U.S., 80 percent of whom are women), people who are newly diagnosed often worry that they are alone with the disease. While health care providers administer medical therapies to aid a patient’s physical wellness, fellow patients play a significant role in the person’s mental and physical health.

It is that reason why the Foundation’s nationwide network of chapters and support groups exist: to make connections with others living with the disease. Here, people can find a safe and welcoming place to share, to learn, to cry, and to laugh.



For patients unable to connect in person, the Foundation has an active online support group through Inspire (www.inspire.com), where people living with scleroderma can chat in a secure environment 24/7. The Foundation also serves the community with support and resources on social media venues, such as Facebook and Twitter.

EDUCATION

Often times, scleroderma is difficult to diagnose because it mimics other diseases. It has many forms and varied symptoms. It is not a condition that easily can be categorized because it is so complex and affects people in such drastically different ways.

We realize the need to provide education to patients, family members, medical professionals and the public to foster a better understanding about scleroderma. We also want to help patients manage and cope with the disease.

The Foundation's national network of chapters and support groups hosts patient education events, including seminars with medical experts that offer patients access to information from some of the top clinicians and researchers working in the field. These events provide members, including patients and their families, the most up-to-date information about scleroderma treatments and research.

Through the Foundation's website (www.scleroderma.org) you can find valuable health information and frequently asked questions about the disease, learn about Foundation activities and events, access chapter and support groups, make a donation, and much more.

The "Scleroderma VOICE," a magazine published quarterly, is a patient/member-friendly tool designed to inform people about important scleroderma issues including research and advocacy. With a worldwide readership, the magazine is the leading publication dedicated to the scleroderma community. It is available to individuals who become members or supporters of the Scleroderma Foundation.

Each year, the Foundation, with the generous support of its sponsors, holds the National Patient Education Conference. This special event brings together scleroderma experts from around the country to lead workshops and panel discussions. The conference offers an invaluable experience for

attendees thanks to the network of people they meet who experience similar physical and emotional feelings, as well as the information they receive from medical and research experts.

Among the most effective tools the Foundation uses to provide education to its members is a weekly online newsletter. The eLetter provides current medical information, news about national and local Foundation events, and helpful articles taken from current sources as well as from its large medical archive.

The Foundation also has a toll-free hotline (1-800-722-HOPE) with a dedicated staff member available to help patients and their families find resources and information near their home.

A final component of education is through public awareness campaigns initiated on a national and local level.

RESEARCH

In addition to providing support and education to patients and promoting awareness, we also are a leading funder of scleroderma-related research. Currently, the Foundation provides at least \$1 million per year for research funding – our single largest budgeted expense. Each year, new and established investigators apply to receive a portion of that funding through the Foundation’s research program.

A Peer-Review Research Committee, composed of scleroderma experts from around the country, evaluates research proposals using a model based on best practices established by the National Institutes of Health (NIH). The committee determines which proposals receive funding each year through an objective critique and ranking of all applications.

Key to the Foundation’s research program is the goal of fostering new research and young investigators. Through the years, the Foundation’s research

BECOME A MEMBER OF THE SCLERODERMA FOUNDATION

When you become a member of the Scleroderma Foundation, you support the organization's mission of support, education and research. Your donation helps pay for programs in each of those three areas, including:



- We budget at least \$1 million annually for research.
- Helping patients and their families cope with scleroderma through mutual support groups, physician referrals and the National Patient Education Conference.
- Promoting public education of the disease through publications, seminars, patient education events and awareness activities.

As a member of the Scleroderma Foundation, you will receive:

- Our quarterly magazine, the “Scleroderma VOICE.” The magazine includes updates on the latest scleroderma research and treatments, positive and uplifting stories from patients living with the disease; and tips about how to manage living with scleroderma.
- Information and educational offerings from your local chapter.
- Discounted registration fees to the annual National Patient Education Conference.

Please consider joining the Scleroderma Foundation today. A membership form is attached on the reverse side of this panel.

To become a member of the Scleroderma Foundation, fill out this form, tear at perforation and send with your check or credit card information to:

Scleroderma Foundation
Attn: Donations
300 Rosewood Drive, Suite 105
Danvers, MA 01923

I would like to become a member and help support the Scleroderma Foundation's efforts to improve the lives of those with scleroderma, and to assist in the search for a cause and cure. Enclosed please find my check (or credit card information) in the amount of \$_____.

Donations of \$25 or more can be acknowledged as members (\$35 or more for international members).

- I am not interested in members benefits.
- However, I would like to make a contribution in the amount of \$_____.

Name: _____

Address: _____

City: _____

State/ZIP: _____

Country: _____

Telephone: _____

Email: _____

Credit Card: _____

Credit Card No.: _____

(Circle One:    )

Exp. Date: _____ CVV Code: _____

Name on Card: _____

program has provided vital “seed” funding that has allowed new investigators to advance to a level that makes it possible for him or her to receive greater amounts of funding through the National Institutes of Health and other entities. For this reason, the Scleroderma Foundation takes seriously its role as a catalyst to fund and stimulate new research and ideas.

Thanks to recent advances in research and treatment, scleroderma patients now can expect to live longer and more productive lives – with increased hope for the future. A cure for scleroderma, however, remains elusive. Research costs continue to climb. Modern laboratory staff, equipment and supplies are expensive. Laboratories and clinical research programs must look outside their own facilities for financial support.

ADVOCACY

Each area of our mission comes together in the area of advocacy. Our advocates volunteer to carry important messages from the scleroderma community to elected and appointed officials on the state and federal levels. It is our collective goal and hope to educate public officials about the critical need for public funding of scleroderma research.

The Scleroderma Foundation enlists the support of legislators and other decision makers to establish a higher profile for scleroderma and the needs of patients. We work to support broad health care priorities in Washington, D.C., including health insurance reform, and the expansion of federal orphan drug research and development programs.

SUPPORTING THE FOUNDATION

The Scleroderma Foundation, like all charitable organizations, must rely on the generosity of donors who support its three-fold mission. Without the support of its donors, the Foundation cannot fulfill its mission of service to patients, their families and the medical community working to find a cure. It is

the hope of a cure that drives us forward to fund the most promising peer-reviewed medical research. We strive to be a leader in patient education and support services, and a resource for researchers working to eradicate this disease.

In addition to the fundraising efforts conducted by the national organization, the Foundation's network of chapters and support groups engage in a variety of fundraising activities. One such successful program is Stepping Out to Cure Scleroderma. These walk-a-thons held throughout the country bring together thousands of walkers to raise money through pledged donations that support the Foundation's mission.

From volunteering in your local chapter, getting involved in fundraising initiatives, to being an advocate, you can become involved and support our work and mission in numerous ways.

LEARN MORE

For more information about the programs and services of the Scleroderma Foundation, including how you can help, please call 1-800-722-HOPE (4673) or visit www.scleroderma.org.



OUR THREE-FOLD MISSION IS SUPPORT, EDUCATION AND RESEARCH

Support: To help patients and their families cope with scleroderma through mutual support programs, peer counseling, physician referrals, and educational information.

Education: To promote public awareness and education through patient and health professional seminars, literature, and publicity campaigns.

Research: To stimulate and support research to improve treatment and ultimately find the cause of and cure for scleroderma and related diseases.



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