

CINDY NOLEN'S STORY

Cindy Nolen is not only living with scleroderma, she is thriving. Complications from the disease nearly ended her life on two separate occasions, yet she survived and is making a difference in the lives of others dealing with this rare and painful condition.

A year after Nolen was diagnosed with the disease, a friend told her to call the toll-free number of the Scleroderma Foundation. The Foundation put Nolen in touch with her local support group, and soon she became actively involved in her disease—learning more from those who were experiencing similar symptoms, and also giving and receiving support.

After the initial diagnosis, the skin on Nolen's face and fingers began to tighten. She developed ulcers on two fingers, which eventually had to be amputated. Joint pain and stiffness made it difficult for her to move.

Then, her condition took a drastic turn for the worse. One night she was found convulsing on a floor, the result of a huge spike in blood pressure that induced seizures, putting her in a coma for three days. She came through that episode, but a short time later, she returned to the hospital and was in a coma for five days. Her kidneys were failing, and a doctor told her family to prepare for her funeral.

Nolen survived the coma, and soon began to improve. Her improvement was so significant, in fact, that she was able to take on the task of being president of the Nevada Chapter of the Scleroderma Foundation. Later, a member of the National Board of Directors asked her to consider serving on the Board, and she agreed.

"This disease is the worst thing and the best thing that has happened to me," she said. "While scleroderma is difficult, becoming involved with the Scleroderma Foundation has enabled me to establish wonderful friendships with staff and develop a huge network of friends that I can call upon whenever I need them for support."

Support is a critical component of the Scleroderma Foundation's mission, but it is not the only aspect that drives the non-profit. Providing education to patients,

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families, and the public, raising awareness of the disease, and providing funding for much-needed research to identify a cause and ultimately a cure is what drives the Foundation.

SUPPORT

Because scleroderma is rare, (it is estimated that it 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 healthcare 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 fellow people living with the disease. Here, people can find a safe and welcoming area to share, a place to cry, and—sometimes—a place to laugh.

"People at support groups, more so than friends and family members, recognize small feats, and emphasize the positive," said Christina Thrailkill of Florida. "When you have a setback, they don't focus on it. It makes you feel good to hear that."

For people unable to receive support in person, the Foundation has an active on-line bulletin board called *Get Connected* where people with the disease can chat in a secure environment. This popular tool is a 24/7 site where people can provide on-line support to each other—just another way the Foundation is serving people with scleroderma.

EDUCATION

Scleroderma is a disease that is often difficult to diagnose because it mimics other diseases and has many forms and varied symptoms. It is not a condition that is easily categorized because it is so complex and affects people in such drastically different ways.

The Foundation realizes the vast need to provide education to patients, family members, and the public to foster a better understanding of scleroderma and 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 are designed to give members, patients, and their families the best and latest information on scleroderma treatments and research.

The Foundation Web site (www.scleroderma.org) is another vehicle where individuals can find topical health information, learn about Foundation activities, access its chapters and support groups, make a donation, and much more. Well over 125,000 visits are made to the site each month.

The *Scleroderma VOICE*, a magazine published on a quarterly basis, is a patient/member-friendly tool designed to help people stay up-to-date on scleroderma issues important to their lives. The magazine has an international readership and is the leading publication dedicated to the scleroderma community. It is available to those who become members or supporters of the Scleroderma Foundation.

On a national level, the Foundation, with the generous support of its sponsors, holds an annual patient education conference, bringing in scleroderma experts from around the country to lead workshops. Attendees find the conference to be invaluable thanks to the network of people they meet who experience similar physical and emotional feelings, as well as the information they receive from the assembled 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, through its toll-free number (1-800-722-HOPE), has a dedicated staff member available to answer the telephone and direct patients and their families to resources and information near their home.

"The educational resources of the Foundation are phenomenal," Nolen said.

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, the Foundation is also a leading funder of scleroderma-related research.

Currently, the Foundation budgets about \$1 million annually for research funding—its largest single expense. Each year, established investigators vie for a portion of that funding through the Foundation's research program. Using a model based on best practices established by the National Institutes of Health, research proposals are evaluated through a peer review process. A committee, composed of scleroderma experts from around the country, determines which proposals will be funded each year by reading, critiquing, and ranking all applications. The research proposals are the end product of an open process that features national competition.

Key to the Foundation's research program is the goal of fostering new research and young investigators. Through the years, the Foundation's research program has provided vital "seed" funding that has allowed new investigators and new researchers to advance to a level that made it possible for them to receive greater amounts of funding through the National Institutes of

BECOME A MEMBER OF THE SCLERODERMA FOUNDATION

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



- funding over \$1 million in original research grants awarded to investigators annually
- helping patients and their families cope with scleroderma through mutual support groups and physician referrals
- promoting public education of the disease through patient literature, health professional seminars and publicity campaigns

Your membership gives you the following benefits:

- our quarterly magazine, the *Scleroderma Voice*. The magazine includes updates on the latest scleroderma research and treatments, profiles of patients who are overcoming their condition to live productive lives; tips on how to manage your disease
- newsletters and informational and educational offerings from your local chapter
- discounted registration fees to the Foundation's National Conference

Please consider joining the 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.

- 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: _____

E-mail: _____

Credit Card: _____

Credit Card #: _____

Exp. Date: _____

Name on Card: _____

Health and other entities. For this reason, the Scleroderma Foundation takes seriously its role as a catalyst to fund and to stimulate new research and new ideas. Thanks to recent advances in research and treatment, scleroderma patients as a group can now 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

In a very real sense, each of the three portions of the Foundation's mission comes together in the area of advocacy. Advocates of the Foundation volunteer to carry messages of importance of the scleroderma community to elected and appointed officials on the state and federal levels. It is their collective goal and hope to educate these officials on the critical need for public funding of scleroderma research. The Scleroderma Foundation is enlisting the support of legislators and other decision makers to establish a higher profile for scleroderma and the needs of patients.

The Foundation also works in support of broader health care priorities in Washington, D.C., including health insurance reform, and 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 the Foundation forward in funding the most promising, peer-reviewed medical research happening throughout the country. It continues 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 nationwide network of chapters and support groups engage in a variety of fundraising activities. One such successful program is the *Stepping Out to Cure Scleroderma* walks held throughout the country. Thousands of walkers raise money through pledged donations to benefit the Foundation during these events.

From individual volunteers around the U.S. who engage in fundraising activities to support the Foundation, to major initiatives such as the annual National Gala, there are countless ways in which you can become involved and support the work of the Scleroderma Foundation. You can turn to its Web site (www.scleroderma.org) to learn more. The staff can also direct you to events happening at its chapters.

"This disease hits more people than you think," Nolen said. "We need to find a cure, and I believe we will in my lifetime."

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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SCLERODERMA FOUNDATION



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