



SCLERODERMA ADVOCATE

Western Pennsylvania chapter

V13: Issue 1

February 2008

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UPCOMING EVENTS

As you may recall, the Spring 2007 Educational Seminar in Greensburg unfortunately had to be cancelled, primarily because of the dearth of positive RSVPs. No future meetings have been planned at this time. If you enjoy these gatherings and want them to continue, you **MUST** call, write, or e-mail the Board to let us know. Please call Jennifer Jablon at 412-383-8674, or send an e-mail to jablonj@dom.pitt.edu. The address for US mail is to the left on this page.

ELECTION OF NEW BOARD MEMBERS

The Western PA Chapter Board members would like to say a fond farewell to two of our Board Members. Carol Blair, RN, and Sandra Fennyach. We appreciate their contributions and wish them well.

This leaves two more empty spaces on our Board. If anyone is interested in joining, please call 412-383-8674 for further information about meeting times, locations, etc. We will be holding elections for Executive Members (President, Vice President, Treasurer, and Secretary) at our next Board meeting. All are welcome and encouraged to participate. Board meetings are informal and can be held at any location that is convenient and mutually agreed upon by the attendees.

SUPPORT GROUP MEETINGS

South Hills/Mon Valley
Southminster Presbyterian Church
799 Washington Road (room 11)
Mt. Lebanon, PA
1st Wednesday of each month
7:00-8:00pm
for further details -
call Tom at 412-571-2889

Beaver Valley
Christ Episcopal Church,
1217 3rd Ave (use 4th Ave entrance)
New Brighton, PA
2nd Tuesday of each month, 2:00pm
for further details -
call Ann at 724-846-1497
or Eileen at 724-827-2985

The drugs and treatments reported in this newsletter are by no means an endorsement by the Scleroderma Foundation of Western Pennsylvania or its Medical Advisory Board. All drugs and treatments should be discussed with your personal physician prior to use.

News From National

The following three articles have been copied in their entirety from www.scleroderma.org.

CALIFORNIA HERE WE COME!

SAVE THE DATE: July 25–27, 2008

The Scleroderma Foundation and the Southern California Chapter are pleased to announce that the 2008 National Conference will be held July 25–27 in Manhattan Beach, Calif.

The Foundation is committed to helping you learn about scleroderma and how it affects you and your family, it is also an event that allows you to reconnect with friends, and establish new relationships as well.

If you haven't attended a National Conference, this is the year to come. The Manhattan Beach Marriott www.marriott.com/hotels/travel/laxmn-manhattan-beach-marriott will serve as the host hotel in sunny California.

Registration forms will appear in the March issue of the "Scleroderma VOICE" magazine.

Hotel highlights:

- This hotel is nonsmoking
- Located close to LAX, beaches, shopping, dining and entertainment
- Great location with a 9 hole, par 3 executive golf course on site
- All guest rooms are specifically designed to fit all business and leisure needs

Workshop highlights:

We're offering over 40 workshops this year, including some of your favorites such as:

- Dental issues
- Scleroderma 101
- Gastrointestinal issues
- Nutrition
- Sexuality
- Coping
- Yoga

The Foundation is also excited to report that Cindy Coney, who led the "Maximizing Life, Minimizing Stress" workshop at the 2007 Conference, will serve as opening keynote speaker. A person living with lupus, Coney, who also serves on the Lupus Foundation of America board, is a dynamic and humorous speaker. She received rave reviews following her 2007 conference workshop.

Legislative Action Alert

Support Scleroderma Postage Stamp Resolution in the House of Representatives

In December, Congressman Stephen Lynch (D-MA) introduced legislation in the U.S. House of Representatives ("House Concurrent Resolution 268") calling for a commemorative postage stamp highlighting scleroderma. The resolution seeks the support of Congress for a postal stamp to be issued to "promote public awareness of, and additional research relating to, scleroderma." This legislation is an excellent opportunity to raise awareness of scleroderma among members of Congress and other policymakers in Washington.

All SF advocates are urged to contact their Representative and ask them to co-sponsor H. Con. Res. 268.

To find your Representative, simply visit www.congress.org and enter your zip code.

Talking Points for calling your Representative's Office:

- Ask to speak with the staff member who handles health issues.
- Explain what scleroderma is (*please see below for scleroderma information*) and briefly tell your story about living with the disease.
- Explain that Congressman Stephen Lynch from Massachusetts has introduced a resolution in the House (H. Con. Res. 268) that calls for a scleroderma postage stamp.
- Ask them to contact Rep. Lynch's office and co-sponsor H. Con. Res. 268.
- Thank them for their time and ask them to advise you of the action they took in response to your request (leave your contact information).

After contacting your Representative's office, please let the Scleroderma Foundation know by sending a brief e-mail including who you spoke with and any questions they may have to advocacy@scleroderma.org.



March on Washington

December 12, 2007

Members and staff from the Scleroderma Foundation traveled to Washington, D.C. to meet with elected and appointed federal officials to advocate the need for increased federal funding for scleroderma.

The visit kicked off when Foundation CEO Frannie Waldron and Foundation board member and researcher Dr. Carol Feghali-Bostwick attended a meeting of National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). The coalition, which attracted more than 80 representatives from many health organizations, touched on subjects including collaborative partnerships, research, and updates on NIAMS. The day-long event also provided Waldron and Feghali-Bostwick the opportunity to network with colleagues.

Later that evening, Stephen Katz, M.D., Ph.D, the director of NIAMS, held an exclusive, 75-minute meeting with the Foundation, an event Foundation board member Cindy Nolen called "phenomenal."

"He was very giving of his time, down to earth, and he genuinely cared what we had to say," Nolen said.

The next day staff and members of the Foundation's Advocacy Committee met with Congressional staff from the states of California, Illinois, Missouri, Iowa, Wisconsin, New York, New Hampshire, Massachusetts, and Pennsylvania. During these meetings, committee members and staff were given the chance to stress the importance of increased funding for scleroderma research in the National Institutes of Health budget. (NIAMS is a part of NIH). Raising awareness of scleroderma and the struggle researchers face in gaining funding were key points made during the visits.

"The goal of these meetings was to express our legislative priorities, keep ourselves in front of these legislative staffers, and hopefully we may have a larger Capitol Hill Day," said Nolen who is a person living with scleroderma, and was a SF Board Member and Chair of the Advocacy Committee.



From left: Roger Brechner, SF Chapter and Support Group Manager, Carol Feghali-Bostwick, SF Board Member, and Frannie Waldron, SF CEO at Senator Arlen Specter's office

LOCAL NEWS FROM 2007

Carol Blair retires

From time to time, we take notice of the contribution that one individual has made to some aspect of our lives. Carol Blair, RN, is such an individual. For over 25 years, Carol devotedly served patients with rheumatic diseases and especially systemic sclerosis (SSc, or scleroderma) at the University of Pittsburgh outpatient Arthritis Center. She worked with Dr. Thomas Medsger as both a nurse and research coordinator providing education and study information to patients, arranging appointments and providing needed support and encouragement to hundreds of patients who were newly diagnosed or daily dealing with their disease. After months of deliberating, Carol retired in April 2007.

Carol moved to Pittsburgh from the Bronx, New York City with her husband and family in 1970. She began working with Dr. Medsger in the Division of Rheumatology and Clinical Immunology at the University of Pittsburgh in 1982, juggling her home life with 5 children and her position as "scleroderma nurse." It was obvious to those who know Carol that both her family and her work with scleroderma patients were very important to her.

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Carol Blair, continued from page 3....

She was well known to the rheumatology faculty and fellows with whom she worked in obtaining medical records for new patients and supporting them in their clinical roles. Her gift for meeting new people and making them feel at ease in an instant with her personal touch and warmth was especially appreciated by patients and staff.

When not in the Arthritis outpatient office, Carol spent much of her time on the phone with patients who had questions or fears regarding their diagnosis. She also scheduled new appointments and coordinated specialist appointments for SSc patients who came from some distance to UPMC. She often invited out of town patients to stay at her home during their trips to Pittsburgh. One of her other jobs was to serve as the coordinator for research studies. She was always happiest working directly with people. She served our local SF Chapter as Secretary and Board Member for a number of years.

Those of us who have had the opportunity to work with Carol in any capacity miss her New York accent and easy manner, and we wish her the best in her retirement years.

Mary Lucas, RN
Research Assistant to Dr. Medsger

National Studies of Local Interest

The University of Pittsburgh, Division of Rheumatology is a participating center in the **SCOT – Scleroderma: Cyclophosphamide or Transplantation** study, sponsored by the NIH. SCOT is under the direction, locally, by Dr. Thomas A. Medsger, Jr. The main purpose of this study is to compare two ways of treating diffuse systemic sclerosis.

One group of study participants will have stem cell transplantation. With this treatment, they will first have hematopoietic stem cells removed from their blood. They then will receive high doses of chemotherapy and radiation to eliminate their presumably abnormal immune system, followed by the reintroduction of the purified stem cells to re-establish their immune system.

The other group of will receive Cyclophosphamide (CTX), which is often used to treat autoimmune diseases. However, the dose used in the SCOT study is higher than what doctors typically prescribe, and the length of treatment is longer. In the high-dose CTX arm, 12 monthly doses of CTX are administered intravenously.

Participants will be randomly assigned to one of the two arms after eligibility is confirmed. Visits to a rheumatology center in addition to visits to a regional transplant center will be required, so patients must be able and willing to travel to participate in this trial. Currently, 7 transplant centers and 21 rheumatology centers across the U.S., all leaders in the fields of either transplantation or scleroderma, are participating in this research.

Beaver Valley Support Group Activities

The Beaver Valley Support Group had a very productive year, filled with events and outings. On a lovely Saturday morning, June 30th, we stepped out to cure scleroderma at the 2nd annual Walk-a-thon at Brady's Run Park in Beaver County. We would like to thank the following sponsors for their generosity and support.

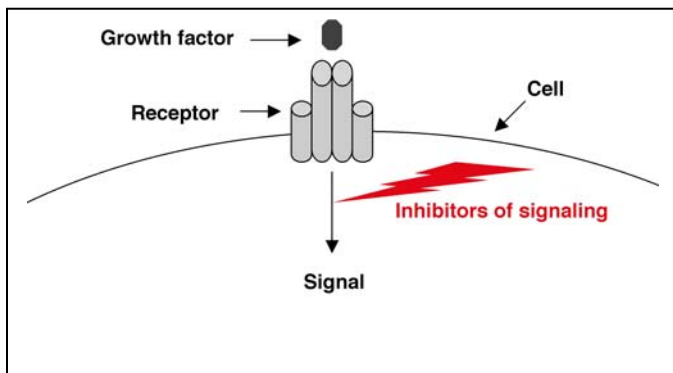
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ADVANCES IN SCLERODERMA RESEARCH in 2007

by Carol Feghali-Bostwick, PhD

The 2007 national meeting of the American College of Rheumatology (ACR) held November 6-11, 2007, in Boston MA, highlighted presentations on clinical and basic research by investigators from the US and abroad. New observations on systemic sclerosis (SSc) were described in the format of posters and oral presentations.

Several presentations focused on the role of growth factors in the development of fibrosis. These growth factors, such as transforming growth factor-beta and platelet-derived growth factor (PDGF), when added to fibroblasts (cells grown from the skin of healthy donors and patients with scleroderma), signal into the cell to 'turn on' certain genes such as those responsible for producing collagen, making normal fibroblasts behave like scleroderma fibroblasts. Investigators are now focusing on blocking the effect of these growth factors via a variety of approaches, thus preventing them from signaling into the cell (see figure below).



Approaches include using antibodies that neutralize the activity of the growth factor, chemical inhibitors that block the ability of these factors to signal into the cell, and drugs that are currently used for the treatment of various cancers and which are also known to inhibit the signaling of these growth factors. As with any drug, there are both beneficial and potentially harmful effects when blocking these molecules.

Several SSc-associated autoantibodies have been thoroughly described in SSc patients. They include anti-topoisomerase I (Scl-70), anti-RNA polymerases, anti-centromere, anti-ribonucleoprotein (RNP), anti-Th/To, and more recently anti-U11/U12 RNP antibodies. New antibodies were described at the Boston meeting. An antibody directed against peroxiredoxin I, an antioxidant enzyme, was detected in the blood of 40% of Japanese SSc patients. Antibodies against another antioxidant repair enzyme, methionine sulfoxide reductase A

(MSRA) were detected in another study in 33% of SSc patients and were associated with pulmonary fibrosis and kidney damage. Antibodies against p53, a tumor suppressor protein that regulates cell function, were also detected in patients with SSc. Levels of this antibody were higher in patients with limited skin involvement compared to those with diffuse skin involvement.

Additional potential disease markers were described at this year's annual ACR meeting. Two markers were found to correlate with pulmonary hypertension in SSc. Brain natriuretic peptide (BNP), has been used as a predictor of heart failure. BNP is a hormone that is released by the heart in response to stretching. A second marker, uric acid, has been found in increased amounts in the blood of patients with pulmonary arterial hypertension with no underlying connective tissue disease and correlates with pulmonary artery pressures. Both BNP and uric acid levels were found to be elevated in SSc patients with PAH compared to SSc patients without PAH suggesting that these markers may potentially predict PAH in SSc. Another potential marker of PAH is von Willebrand factor (vWF). A group in England has observed that increased levels of vWF correlate with PAH. Although it is not likely that any of these markers will independently be able to predict PAH, a combination of them may be more effective in determining which patients are at greatest risk to develop PAH. Serum levels of COMP, a protein found primarily in cartilage, were increased in patients with SSc and correlated with the extent of skin involvement. COMP levels in blood may serve as markers of progressive skin thickening.

One of the initial injuries in SSc is damage to endothelial cells that line blood vessels. These cells can be released into the blood and their presence in the circulation is speculated to indicate cell damage. The number of circulating endothelial precursor cells (CEP) is greater in SSc patients than in healthy individuals. Precursors of monocytes (mCEP) were studied by a group of investigators in Tokyo, Japan. The cells are known for their ability to promote angiogenesis (new blood vessel formation). The number of circulating mCEP in the blood of patients with SSc was increased, but their ability to promote new blood vessel formation was impaired, suggesting that factors produced locally in the tissues block the function of these cells.

Endothelial cell damage and narrowing of the blood vessels are believed to be the underlying cause of one of the first symptoms of SSc, Raynaud phenomenon. Investigators examined the frequency of Raynaud affecting the thumbs compared to the other fingers. Results indicated that in both primary Raynaud phenomenon (Raynaud with no underlying connective

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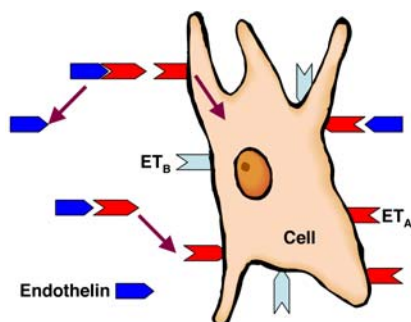
ADVANCES IN SCLERODERMA*continued from page 5*

tissue disease) and in Raynaud phenomenon secondary to scleroderma and other connective tissues diseases, the thumb was often spared. The reason why thumb involvement is not as common as other finger involvement is unclear.

Results of several clinical trials in SSc patients were also presented at the annual meeting in Boston. Finger ulcers cause significant pain and disability in SSc; they can become infected and often take weeks to months to heal. They are due to blood vessel narrowing and endothelial cell injury. The effect of a new topical formulation of nitroglycerin, MQX-503, was assessed in patients with Raynaud phenomenon. Currently, patients with RP are treated with calcium channel blockers and nitroglycerin ointments that are applied to the fingers. MQX-503 is applied similarly but is more rapidly absorbed. Side effects included headaches, dizziness, skin ulcers, and skin irritation. Overall, MQX-503 was deemed safe. Patients applied the drug to their fingers daily for 4 weeks for a maximum of 4 applications/day. RP patients had a 15% improvement in their symptoms compared to 1% of the placebo-treated group. This improvement is not as frequent as the 60% observed with other nitroglycerin ointments, but side effects such as headache were much less common with MQX-503.

Investigators examined the discharge records from a database that contains information from representative hospitals in the U.S. Obstetric hospitalizations from 2002-2004 in patients with SSc and PAH were reviewed. Of 13.9 million obstetric hospitalizations from 2002-2004, 700 occurred in women with SSc. Findings suggested that women with SSc had increased risk of hypertensive disorders and an increased risk for longer hospital length of stay compared to the general population.

Approximately 10% of SSc patients develop PAH, a potentially fatal complication. Bosentan has been shown in clinical trials to be beneficial for patients with PAH. Bosentan is considered to be a dual endothelin receptor blocker in that it can block both type A and B receptors of endothelin (ET_A and ET_B) that are found on the surface of cells (see figure below).



Endothelin can cause constriction (narrowing) of blood vessels and plays a role in the development of PAH in patients with and without SSc. An international group of investigators reported on the long-term effects of bosentan treatment in patients with PHT secondary to connective tissue diseases including SSc. A total of 53 patients were followed for two years after the start of treatment. Patients treated with bosentan had increased survival (82.4%) at two years compared to patients given placebo. More recently other endothelin receptor blockers have been developed and include atrasentan, sitaxsentan, ambrisentan, and darusentan. The advantages of these drugs is that they only block the type A receptor, which participates in blood vessel narrowing, and do not block the type B receptor which is involved in blood vessel widening. A recent study with ambrisentan, known as the ARIES trial, included both patients with primary PAH and patients with PAH secondary to connective tissue diseases such as SSc, HIV disease, and use of appetite suppressants. Patients treated with 5 mg or 10 mg ambrisentan once daily, but not those given 2.5 mg, had increased exercise capacity, measured as the distance they could walk in 6 minutes (6-minute walk test).

Pulmonary fibrosis is another complication of SSc. Investigators in New Orleans, LA, evaluated mycophenolate mofetil (MMF) in the treatment of lung fibrosis in patients who could not tolerate cyclophosphamide (Cytoxan). MMF (CellCept) is an immunosuppressive drug used for the treatment of autoimmune hepatitis and to prevent rejection in patients who have received liver transplants. Overall, MMF was well tolerated. Although a small number of patients were treated with MMF for 3-9 months, they all showed improvement of their symptoms with increased activity level. Some patients on oxygen could discontinue oxygen use following MMF treatment and patients on prednisone were able to either discontinue or reduce their prednisone dose.

Cardiac involvement in SSc is often asymptomatic and can occur as a primary complication or secondary to PAH or kidney disease. A group from France completed an assessment of heart involvement in 50 patients with SSc and concluded that cardiac magnetic resonance imaging (MRI) may be a more sensitive test for the detection of cardiac problems even in patients who have no clinical symptoms of heart involvement.

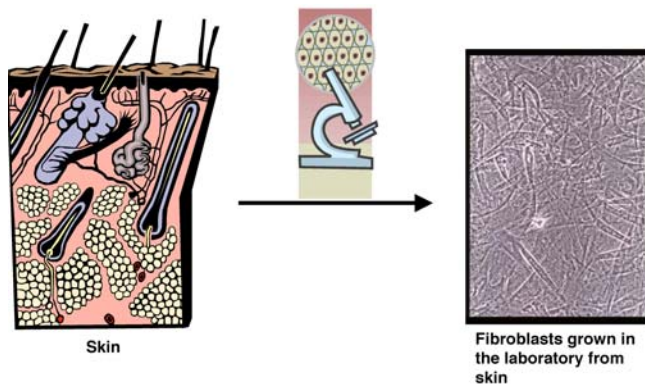
Recently, several investigators have shown that B lymphocytes, a subgroup of white blood cells involved in the immune response, are present in tissues of patients with SSc. Clusters of these cells have been recently detected in the lungs of patients with pulmonary fibrosis. Studies using a mouse model of fibrosis known as the tight skin mouse (TSK) has shown that eliminating B cells decreases the amount of skin fibrosis.

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To eliminate B cells, investigators use antibodies against markers found on the surface of these cells. One such marker is known as CD20. A group from Rome, Italy, determined the effect of removing B cells in patients with SSc. Three patients with diffuse skin involvement and one patient with limited skin involvement participated in the study. Patients were given antibodies against CD20. After 12 months, all four SSc patients had improvement in the severity and activity of their skin disease. Controlled trials involving a larger number of patients would be needed before determining whether the use of anti-CD20 antibodies is effective in SSc.



Results of several studies on the epidemiology of scleroderma were presented. A study conducted in the Netherlands examined the prevalence of atherosclerosis in SSc patients. An increased frequency of atherosclerosis has been observed in some rheumatic diseases such as systemic lupus erythematosus (SLE). Unlike patients with SLE, patients with SSc did not have increased signs of atherosclerosis.

In a study conducted in Canada, investigators determined whether autoimmune diseases occurred more frequently in families of 352 patients with SSc. Their findings suggest that autoimmune diseases such as SLE, rheumatoid arthritis, myositis, Sjogren syndrome, and autoimmune thyroid disease occur more frequently in families of SSc patients. In addition, SSc occurred in 2.3% of family members. These findings suggest that a shared inherited genetic background may predispose family members to autoimmune conditions.

Researchers from Padua, Italy, and the University of Pittsburgh, PA, described similarities and differences between children and adults with SSc. Approximately 4% of SSc patients have onset of their disease in childhood. The distribution of autoantibodies in the blood, which serve as markers of SSc, differs in children and adults. These antibodies are also associated with

higher risk of involvement of particular internal organs such as kidneys and lung. For example, anti-RNA polymerase and anti-centromere antibodies are less frequent in children while anti-U1 RNP and anti-PM-Scl antibodies are more common. As a result, kidney involvement and pulmonary arterial hypertension are less common in children with SSc while overlap with myositis (muscle involvement) is more common. Cardiac involvement seemed to occur more often in children than adults, but in spite of that, survival was found to be improved in children with SSc with 90% of patients surviving 10 years after their illness begins.

Polymorphisms are changes in the sequence of DNA that are individual-specific. Some occur more frequently in individuals with autoimmune diseases, suggesting that disease susceptibility may be increased in persons with certain polymorphisms. Specific polymorphisms may be one of the reasons why some individuals respond to a particular drug while others do not. A polymorphism in the surfactant protein-B (SP-B) gene was found to protect SSc patients from pulmonary fibrosis. Carriers of this polymorphism had a reduced risk of developing pulmonary fibrosis compared to SSc patients who did not have this SP-B sequence.

A recently described disease which has increased skin thickness reminiscent of scleroderma is nephrogenic fibrosing dermopathy (NFD) or nephrogenic systemic fibrosis (NSF). This disease occurs in patients with end-stage kidney disease who are receiving hemodialysis or peritoneal dialysis. Most cases are associated with the prior administration of gadolinium, a dye used by radiologists for a variety of diagnostic studies which require "contrast". Unlike SSc, patients with NFD do not have Raynaud phenomenon. NFD can also affect the lungs, heart, blood vessels, and muscles. Investigators from Boston, MA, treated two patients with NSF with imatinib mesylate (Gleevec). After 15 weeks, both patients had softening of their skin. Gleevec is currently being considered for the treatment of SSc as it inhibits growth factor signaling in cells.

Both basic and clinical research conducted by investigators from many different countries have led to new insights into the mechanisms involved in the development of SSc and potential new therapies that may be effective for SSc patients. This information has helped us add new pieces to the scleroderma puzzle.

If you have any suggestions for future articles, or any questions for the 'Ask the Doctor' series, please contact the editorial staff for the ADVOCATE at 412-383-8674.

The Scleroderma Advocate is published three times each year by the Scleroderma Foundation Western Pennsylvania Chapter, a non-profit organization of dedicated volunteers; and is made possible by dues of local chapter members. The Chapter's United Way Contributor's Choice identification number is 4787.

Membership dues and correspondence should be mailed to the address below. Membership in the local chapter also guarantees your membership to the National Foundation. The only way to ensure that our Chapter will be notified that your annual dues have been paid is to return your membership renewal form and payment to us directly.

We want to insure that you continue to receive The Advocate and other important mailings, such as those for Education Seminars, so please inform us if you have a change of address.

The Western Pennsylvania Chapter of the Scleroderma Foundation can also be reached on the web at <http://www.scleroderma.org/chapter/wpenn/htm>

The Scleroderma Foundation is a 501(c)(3) national nonprofit organization serving the interests of persons with scleroderma. The Foundation's 24 chapters and 158 support groups nationwide help to carry out its three-fold mission of support, education, and research. The Scleroderma Foundation is the leading nonprofit supporter of scleroderma research, funding over \$1 million of new grants each year to find the cause and cure of scleroderma.

Website: www.scleroderma.org.
Toll-free number: 800-722-HOPE.

The Scleroderma Foundation's Mission

- ❖ 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
- ❖ To stimulate and support research to improve treatment and ultimately find the cause and cure of scleroderma and related diseases.



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