Dear Friend:

Thank you for your recent inquiry about scleroderma. Our goal is to provide the most up-to-date information, including resources that provide a better understanding of scleroderma, as well as helpful strategies for coping with the challenges people with scleroderma may face. As you begin to learn about scleroderma, it is important to remember that its symptoms and the severity of the disease vary greatly from person to person.

**Become a Member**
You don't have to face scleroderma alone! By joining the Scleroderma Foundation, you become part of a nationwide family that is dedicated to supporting those affected by this disease and working to find a cure. Membership also ensures that you receive the most important and up-to-date information through our quarterly magazine, the *Scleroderma Voice*, plus, information about support group meetings, patient education programs, physician referrals, peer counseling and more. Don't miss these member benefits.

**What's Happening in Your Local Area**
The Scleroderma Foundation has a nationwide network of chapters and support groups that offers numerous opportunities that may be of interest to you. These include educational programs to learn more about the disease; networking with others who are living with scleroderma; opportunities to get involved in efforts to raise awareness about scleroderma; support patient education programs; and raise money to fund some of the most promising research to find a cause and cure. You'll find a list of chapters and support groups enclosed. If you live in an area served by a chapter or support group, we urge you to contact them to find out what's happening in your community.

**We Are Here for You**
We hope that you'll join us in supporting those living with this disease and working to find a cure by donating to the mission of the Scleroderma Foundation. Whether or not you become a member, we encourage you to contact the National Office or any of our chapters if we can be of assistance. Find out more about the Foundation and the disease on our website at www.scleroderma.org.

The Scleroderma Foundation is a national support system dedicated to helping each other - and working toward the day when a cure is found. Please join us!

Sincerely yours,

Robert J. Riggs
Chief Executive Officer
Scleroderma Facts

- Scleroderma is an autoimmune disease whose symptoms typically include some or all of the following: sensitivity to cold in extremities, thickening of the skin, shortness of breath, difficulty swallowing, joint stiffness and pain, and damage to internal organs.
- Autoimmune diseases, which affect more than 50 million Americans, are the third leading cause of death in the United States.
- 300,000 cases of scleroderma are estimated in the United States.
- 80% of scleroderma patients are female.
- Scleroderma typically strikes between the ages of 25 and 55.
- 95% of scleroderma cases begin with Raynaud Phenomenon (hands and feet abnormally sensitive to cold.)
- Federal research funding for scleroderma lags behind other diseases of similar prevalence.
- Misdagnosis 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.

The Scleroderma Foundation is here to help!

- The Scleroderma Foundation is a 501(c)(3) national non-profit organization serving the interests of persons with scleroderma. The Foundation’s 22 Chapters and more than 145 Support Groups nationwide help carry out its three-fold mission of support, education, and research. The Scleroderma Foundation is the leading non-profit support of scleroderma research.
- The Scleroderma Foundation has granted over $18.6 million in research grants since 1989 and continues to budget an average of $1 million annually for peer reviewed research funding —our single largest budgeted expense.
Our Three-Fold Mission Is
Support, Education and Research

SCLERODERMA: Overview and Causes

A publication of Scleroderma Foundation

The balance of collagen formation and collagen breakdown is altered so that too much collagen builds up. This results in fibrosis in the heart, lungs, and the muscles that line these organs. Collagen is made by fibroblasts (a type of cell that is involved in the production of extracellular matrix). In normal circumstances, the production of a scar is the result of an injury, and it is a temporary response to heal tissue damage. However, in scleroderma, the immune system can also produce collagen as part of an autoimmune response, which can cause tissue damage and lead to permanent scarring.

In response to injury, the immune system can produce collagen to heal tissue damage, as well as to activate the immune system. This can result in an autoimmune attack on the body's own tissues. Some of these autoantibodies are specific for a particular disease. The immune system is said to be "autoimmune" when it produces antibodies against its own tissues.

Autoantibodies specific to scleroderma have been identified, and they are often found in scleroderma patients. These autoantibodies are thought to play a role in the development of the disease.

Research continues to assemble the pieces of the scleroderma puzzle to identify the susceptibility genes, which may contribute to the development of the disease. The Scleroderma Foundation thanks Maureen Mayes, M.D., M.P.H., University of Texas/Houston and John Varga, M.D., Northwestern University, for their assistance in the preparation of this brochure.
SCLERODERMA OVERVIEW

Introduction

Scleroderma is an autoimmune disease which means that it is a condition in which the body’s immune system attacks its own tissues. The normal role of the immune system is to provide protection from invaders such as viruses. In autoimmune disorders, this ability to distinguish foreign from self is compromised. As immune cells attack the body’s own tissue, inflammation and damage result. Scleroderma (the name means “hard skin”) can vary a great deal in terms of severity. For some, it is a mild condition; for others it can be life-threatening. Although there are medications to slow down disease progression and help with symptoms, right now there is no cure for scleroderma.

TYPES OF SCLERODERMA

There are two main forms of scleroderma: systemic (systemic sclerosis, SSc) that usually affects the internal organs or internal systems of the body as well as the skin, and localized that affects a local area of skin either in patches (morphea) or in a line down an arm or leg (linear scleroderma), or as a line down the forehead (scleroderma en coup de sabre). It is very unusual for localized scleroderma to develop into the systemic form.

SYSTEMIC SCLEROSIS (SSC)

To make matters more confusing, there are two major types of systemic sclerosis or SSc: limited cutaneous SSc and diffuse cutaneous SSc. The difference between limited cutaneous and diffuse cutaneous SSc is the extent of skin involvement. In limited SSc, skin thickening only involves the hands and forearms, lower legs and feet. In diffuse cutaneous disease, the hands, forearms, the upper arms, thighs, or trunk are affected. The face can be affected in both forms. The importance of making the distinction between limited and diffuse disease is that the extent of skin involvement tends to reflect the degree of internal organ involvement.

Scleroderma sine sclerosis refers to the unusual occurrence (only about 5% of all cases) in which there is evidence of internal organ complications of SSc but no skin thickening.
Several clinical features occur in both limited and diffuse cutaneous SSc. Raynaud phenomenon, for example, occurs in both. Raynaud phenomenon is a condition in which the fingers turn pale or blue upon cold exposure, and then become ruddy or red upon warming up. These episodes are caused by a spasm of the small blood vessels in the fingers. As time goes on, these small blood vessels become damaged to the point that they are totally blocked. This can lead to ulcerations of the fingertips. Raynaud phenomenon occurs in almost all (95%) SSc patients with either limited or diffuse disease, and painful finger ulcers can also be seen in both forms.

The esophagus is also affected in almost all SSc patients with loss of the usual movement. As a result, food can “hang up” in the esophagus, and stomach acid can reflux back up into the esophagus, causing heartburn.

Telangiectasias are small red spots that appear on the hands, arms, face, and/or trunk. These are tiny blood vessels in the skin that have widened. They are usually not dangerous in themselves, but are cosmetically unpleasing, particularly if they occur on the face. Some people have telangiectasias in the esophagus, stomach, and bowel that can be a source of bleeding.

People with the diffuse form of SSc are at a greater risk of developing pulmonary fibrosis (scar tissue in the lungs that interferes with breathing, also called interstitial lung disease), kidney disease, and bowel disease.

All patients with SSc should have periodic pulmonary function tests to monitor for the development of pulmonary fibrosis. Symptoms of pulmonary disease include a dry cough and shortness of breath. However, in the early stages there may not be any symptoms at all.

Kidney involvement occurs more frequently in the diffuse than in the limited form of SSc, especially in the first five years post-diagnosis, and typically takes the form of a sudden increase in blood pressure. As is the case with usual high blood pressure, there are no symptoms at first. However, if undetected and untreated, this high blood pressure can damage the kidneys in a matter of weeks, which is why it is called scleroderma renal crisis. The key to management and prevention of permanent kidney damage is early detection and treatment with ACE inhibitors.
The risk of extensive gut involvement, with slowing of the movement or motility of the stomach and bowel, is higher in those with diffuse rather than limited SSc. Symptoms include feeling bloated after eating, diarrhea, or alternating diarrhea and constipation.

Calcinosi s refers to the presence of calcium deposits in, or just under, the skin. This takes the form of firm nodules or lumps that tend to occur on the fingers or forearms, but can occur anywhere on the body. These calcium deposits can sometimes break out to the skin surface and drain whitish material (described as having the consistency of toothpaste).

Pulmonary hypertension (PH) is high blood pressure in the blood vessels of the lungs. It is totally independent of the usual blood pressure that is taken in the arm. This tends to develop in patients with limited SSc after several years of disease. The most common symptom is shortness of breath on exertion. However, several tests need to be done to determine if PH is the real culprit. If the ultrasound of the heart, called an echocardiogram, is abnormal, then a right heart catheterization needs to be done to actually measure the pressure in the lung blood vessel (pulmonary artery) and to test for other abnormalities that can cause PH. Because there are now many medications to treat PH, the earlier it is detected and treated, the better the result will be.

**LOCALIZED SCLERODERMA**

**Morphea**

Morphea consists of patches of thickened skin that can vary from half an inch to six inches or more in diameter. Some people have only one or a few such patches, while others have multiple ones all over the body. The patches can be lighter or darker than the surrounding skin and thus tend to stand out. Also there is usually a loss of the fatty layer underneath the morphea spots. Morphea, as well as the other forms of localized scleroderma, does not affect internal organs.

**Linear scleroderma**

Linear scleroderma consists of a line of thickened skin down an arm or leg on one side. The fatty layer under the skin can be lost, so the affected limb is thinner than
the other one. In growing children, the affected arm or leg can be shorter than the other.

**Scleroderma en coup de sabre**

Scleroderma en coup de sabre is a form of linear scleroderma in which the line of skin thickening occurs on the forehead or elsewhere on the face. In growing children, both linear scleroderma and en coup de sabre can result in distortion of the growing limb or lack of symmetry of both sides of the face.

**WHAT CAUSES SCLERODERMA?**

The cause of scleroderma is unknown. However, we do understand a great deal about the biological processes involved. In localized scleroderma, the underlying problem is the overproduction of collagen (scar tissue) in the involved areas of skin. In systemic sclerosis, there are three processes at work: blood vessel abnormalities, fibrosis (which is overproduction of collagen) and immune system dysfunction, or autoimmunity.

In systemic sclerosis, the small blood vessels are damaged and become narrowed. This is what is responsible for Raynaud phenomenon and the painful ulcers that can occur on the fingers. This vascular damage also occurs in the internal organs and is responsible for scleroderma renal crisis and PH.

The small arteries are normally capable of constricting (narrowing) or dilating (relaxing) to adjust blood flow to the needs of the body. For example, in very cold weather the blood vessels to the hands and feet narrow in order to maintain central body warmth. However, in SSc the blood vessel loses its normal method of relaxation, becoming prone to episodes of vasospasm (contraction of the muscle wall that closes the vessel). The vessels become overly sensitive to cold temperatures and other stimuli like emotional stress, which results in Raynaud attacks.

The thickened skin in scleroderma is caused by overproduction of collagen, which is the basic component of scar tissue. Abnormal accumulation of collagen is called fibrosis. Collagen is a normal part
Types of Scleroderma

Scleroderma is an autoimmune disease which means that it is a condition in which the body’s immune system incorrectly recognizes healthy tissue as foreign. In response, the immune system makes antibodies that attack the body’s own tissue. This inflammation and damage result. Scleroderma (the name means “hard skin”) is the name given to these infiltrations because of the thickening and hardening of the skin that can result. As immune cells attack the body’s own tissue, the body’s ability to distinguish foreign from self is compromised. The body’s immune system can attack internal organs or internal systems of the body as well as the skin. The result is an abnormal proliferation of the connective tissue called collagen which thickens the skin, blood vessels, and internal organs. Raynaud phenomenon, for example, can cause the skin to lose its blood supply, leading to blanching and a numbing sensation. 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:

- Funding an average of $1 million in original research grants awarded to investigators annually.
- 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 publicity campaigns.

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.
Our Three-Fold Mission Is
Support, Education and Research

SCLERODERMA: Overview and Causes

A publication of Scleroderma Foundation

If you’re one of the millions of people suffering from skin conditions, you may be wondering what scleroderma is. Scleroderma (literally meaning “hard skin”) is a group of connective tissue disorders that cause increased collagen deposition in the skin and other tissues. Collagen is a protein that forms the connective tissue matrix, providing strength and elasticity. In scleroderma, the balance of collagen formation and collagen breakdown is altered so that too much collagen builds up.

Collagen is made by fibroblasts (a type of cell that is normal in wounds and during scarring). Collagen is also made by immune cells in response to injury. Under normal circumstances, the production of a scar is the immune system to produce collagen as part of the wound healing process. For example, the production of a scar following surgery is due to the production of collagen by fibroblasts and immune cells. Some of these autoantibodies are specific for a particular disease.

The Scleroderma Foundation thanks Maureen Mayes, M.D., M.P.H., University of Texas/Houston and John Varga, M.D., Northwestern University, for their assistance in the preparation of this brochure.

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:  VISA  MasterCard  American Express  Discover)
Exp. Date:______________CVV Code:_____
Name on Card:____________________________________
of skin and many organs. However, in scleroderma the balance of collagen formation and collagen breakdown is altered so that too much collagen builds up. In localized scleroderma this process is confined to some areas of the skin. In SSc, excess collagen causes fibrosis in the heart, lungs, and the muscles that line the GI tract.

Collagen is made by fibroblasts (a type of cell that is part of almost every tissue in the body) which can be provoked or activated to make more collagen. Under normal circumstances, the production of a scar is the last step in healing following an injury or an infection, for example, the production of a scar following a cut in the skin. Fibroblasts are activated by the immune system to produce collagen as part of the normal healing process. However, in SSc fibroblasts are activated for no apparent reason. The resulting scar causes tissue damage, decreased flexibility, and malfunction of the organ involved.

The third problem in SSc is the dysregulation of the immune system resulting in an immune attack on the body’s own tissues. Some of these autoantibodies are found in several autoimmune diseases, while others are specific for a particular disease.

One way to detect activation of the immune system is to find antibodies (proteins made by immune cells, the bullets of our immune army) in the blood that targets the body’s own tissue (autoantibodies). A very specific set of autoantibodies is found in scleroderma. These autoantibodies can be thought of as footprints of the scleroderma disease process because they are only made under very specific conditions. It is not clear what role these autoantibodies play in damaging the blood vessels or stimulating collagen overproduction.

**WHO GETS SCLERODERMA?**

There are many clues that define susceptibility to develop scleroderma. A genetic basis for the disease has been suggested by the fact that SSc is more common among patients whose family members have other autoimmune diseases (such as lupus).
In rare cases, SSc runs in families, although for the vast majority of patients there is no other family member affected. Scleroderma can affect some Native Americans and African Americans more severely than Caucasians.

Women are more likely to get SSc. Environmental factors may trigger the disease in the susceptible host. For example, silica exposure (as in coal mining or sand blasting) has been associated with systemic scleroderma and certain drugs can cause scleroderma-like reactions. Localized scleroderma is more common in children, whereas SSc is more common in adults. However, both can occur at any age.

PUTTING IT ALL TOGETHER

Research suggests that the susceptible host for scleroderma is someone with a genetic predisposition to injury from some external agent, such as a viral or bacterial infection or a substance in the environment. In localized scleroderma, the resulting damage is confined to the skin. In SSc, the process causes injury to blood vessels, or indirectly perturbs the blood vessels by activating the immune system. Fibroblasts are activated as part of the response to tissue injury. Interacting networks of immune inflammation and injury from inadequate blood supply drive the process, so it becomes chronic. Collagen made in excess interferes with normal organ function, sometimes leading to organ failure. In many cases, the process goes into remission after some years of activity. Research continues to assemble the pieces of the scleroderma puzzle to identify the susceptibility genes, to find the external trigger and cellular proteins driving fibrosis, and to interrupt the networks that perpetuate the disease.

Please note that this brochure is provided for educational purposes only. It is not intended to substitute for informed medical advice.

The Scleroderma Foundation thanks Maureen Mayes, M.D., M.P.H., University of Texas/Houston and John Varga, M.D., Northwestern University, for their assistance in the preparation of this brochure.
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.
Our Three-Fold Mission Is Support, Education and Research

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.
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.
“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. 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.” — 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.
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

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• 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.

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

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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:  □ VISA  □ MASTERCARD  □ AMERICAN EXPRESS  □ DISCOVER)

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.

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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.

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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

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

Our Three-Fold Mission Is Support, Education and Research

Pulmonary Hypertension in Scleroderma

A publication of the Scleroderma Foundation

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April 2014

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Putting it all together

Pulmonary hypertension is not the only type of lung disease that can occur in patients with scleroderma. Interstitial lung disease (ILD), also called pulmonary fibrosis, is another serious complication. Please contact the Scleroderma Foundation for information on pulmonary fibrosis.

It is important to note that patients can have significant pulmonary involvement from their scleroderma before signs and symptoms appear. Therefore, it is important to have routine screening for possible pulmonary involvement, in particular pulmonary arterial hypertension and interstitial lung disease.

Due to the complexity of the diagnosis and treatment of scleroderma lung disease, strong consideration should be given to referral of patients to physicians with expertise in scleroderma, interstitial lung disease, and PH. This requires close collaboration between you, your rheumatologist, pulmonologist, and cardiologist.

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The Scleroderma Foundation wishes to thank Kristin Highland, M.D., Richard Silver, M.D., and David Badesh, M.D., for their input on this brochure.

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Pulmonary hypertension (PH) is high blood pressure in the blood vessels of the lungs. If the high blood pressure in the lungs is due to narrowing of the pulmonary arteries leading to increased pulmonary vascular resistance, it is known as pulmonary arterial hypertension (PAH). When the blood pressure inside the pulmonary vessels is high, the right side of the heart has to pump harder to move blood into the lungs to pick up oxygen. This can lead to failure of the right side of the heart. Patients with scleroderma are at increased risk for developing PH from several mechanisms. Frequently patients with scleroderma have multiple causes of their PH.

Patients who have limited cutaneous scleroderma (formerly known as CREST syndrome) are more likely to have PAH than those patients who have diffuse cutaneous systemic sclerosis. PAH may be the result of the same processes that cause damage to small blood vessels in the systemic circulation of patients with scleroderma. The lining cells of the blood vessels (endothelial cells) are injured and excessive connective tissue is laid down inside the blood vessel walls. The muscle that constricts the blood vessel may overgrow and narrow the blood vessel.

Other scleroderma patients may have PH because they have significant scarring (fibrosis) of their lungs. This reduces the blood oxygen level, which in turn, may cause a reflex increase in blood pressure in the pulmonary arteries.

WHAT ARE THE SYMPTOMS OF PULMONARY HYPERTENSION?

Patients with mild PH may have no symptoms. Patients with moderate or severe PH usually notice shortness of breath (dyspnea), especially with exercise. Patients may also notice unusual chest pains and symptoms of right-sided heart failure, such as worsening shortness of breath and swelling of the feet and legs. Other symptoms that patients cite include a cough, lightheadedness or fainting, palpitations (heart racing or fluttering), and swelling.

HOW IS PULMONARY HYPERTENSION DIAGNOSED?

In a patient with scleroderma, the development of unexplained shortness of breath should lead to consideration of possible PH.
A laboratory clue that a patient might have PH is a reduced diffusing capacity (DLCO) on pulmonary function tests (PFTs). The DLCO measures the ability of gas to move from the air, across the lung tissue and blood vessel wall, into the blood. In the absence of lung fibrosis, if the DLCO is less than 50 percent of its predicted value, this is a clue that PH may be present. Another test commonly used to screen patients for PH is the echocardiogram. It can estimate the pulmonary artery pressure fairly well in most patients in a noninvasive manner.

The physician may order a cardiac catheterization to measure the actual pressure in the pulmonary arteries. This invasive test is done to more accurately measure the pressures in the lung blood vessels; to assess the blood flow generated by the heart (the cardiac output); to exclude an underlying leak or shunt contributing to the PH; to assess the function of the left side of the heart; and possibly to assess the patient’s responsiveness to vasodilator therapy. The results of this test may change the therapy prescribed by the physician. Right heart catheterization is the “gold standard” for diagnosing PAH.

An exercise test known as the six-minute walk test is often helpful in assessing exercise capacity in patients with PH. In addition, a Functional Class is often assigned to patients based on their activity tolerance, ranging from Class I to IV (with I being mildest and IV the most severe).

**WHAT IS THE TYPICAL COURSE OF PAH IN SCLERODERMA?**

It was previously thought that the development of PAH in patients with scleroderma was always associated with a poor prognosis. However, ongoing educational efforts regarding the risk of PAH in scleroderma has led to earlier diagnosis. Studies now suggest that patients identified with mild or early PAH will fare better if drug therapy is started before symptoms and exercise capacity worsen.

**WHAT IS THE TREATMENT OF PAH?**

Supplemental oxygen, anticoagulation (blood thinners), and diuretics are often important parts of treatment for PAH. If the oxygen level at rest, with exercise, or during sleep is low, supplemental oxygen therapy may be given. The decision to treat with anticoagulation is made on an
individual basis by the patient and their physician, based on the potential risk of bleeding.

Calcium channel blockers (such as amlodipine, diltiazem or nifedipine) can help a small proportion of patients with PAH. Such treatment is successful in only a minority of scleroderma patients with PAH.

**PAH SPECIFIC MEDICATIONS**

The list of drugs for treating PAH continues to expand and include the following FDA-approved drugs: epoprostenol (Flolan® and Veletri®), treprostinil SQ or IV (Remodulin®), treprostinil inhaled (Tyvaso®), treprostinil oral (Orenitram®) iloprost (Ventavis®), bosentan (Tracleer®), ambrisentan (Letairis®), macitentan (Opsumit®), sildenafil (Revatio®), tadalafil (Adcirca®), and riociguat (Adempas®). Each of these drugs falls within one of four separate categories based on different mechanisms of action. These drugs are used alone or in combination with drugs in one or more other classes. Each will be briefly reviewed below.

**Prostacyclin Analogs**

**Epoprostenol**

Epoprostenol (Flolan®, Veletri®) is a potent vasodilator that must be given by a constant intravenous infusion. This requires an indwelling central venous catheter and an infusion pump. In a multicenter, randomized, controlled clinical trial of chronic intravenous epoprostenol, in patients with PAH and scleroderma, there was improvement in exercise capacity and hemodynamics. A survival benefit was not seen in this population over the period of study, but the study was not designed to detect a difference in survival. Common side effects of epoprostenol therapy include headache, flushing, jaw pain with initial chewing, diarrhea, and bone pain. Other side effects include the potential for serious infection associated with the catheter. Chronic intravenous epoprostenol has been approved by the FDA for the treatment of patients in Functional Class III and IV PAH related to scleroderma.

**Treprostinil**

Due to the complexity of chronic intravenous epoprostenol therapy, studies have since been undertaken with various analogues of prostacyclin being administered via the subcutaneous (under the skin), oral, and inhaled routes. Continuous subcutaneous infusion of treprostinil (Remodulin®) resulted in a slight
improvement in exercise capacity, which was greater in sicker patients and was dose-related. The use of subcutaneous treprostinil may be limited by infusion site pain and redness. Treprostinil is approved for intravenous or subcutaneous delivery for the treatment of patients in Functional Class II, III, and IV PAH. Inhaled trepostinil (Tyvaso®), when administered four times daily, has been shown to improve exercise capacity in patients with Class III PAH. An oral form of treprostinil (Orenitram®) was approved by the FDA in December 2013.

**Iloprost**

Iloprost (Ventavis®) is a prostacyclin analog delivered by inhalation 6–9 times daily that has been shown to improve a composite measure of exercise capacity and functional class. Inhaled iloprost has been studied in patients who remain symptomatic while on stable ERA (bosentan) therapy for at least three months. There was a borderline significant improvement in exercise capacity, and improvement in functional class. Combination therapy appeared to be safe and well tolerated. Inhaled iloprost has been approved by the FDA for treatment of patients with Functional Class III and IV PAH.

**Endothelin Receptor Antagonists (ERA)**

**Bosentan**

Bosentan (Tracleer®) is an oral endothelin receptor antagonist (ERA). In a pilot study, bosentan was shown to improve exercise capacity and cardio-pulmonary hemodynamics in patients with Functional Class III and IV PAH. A larger study confirmed improvement in exercise capacity and showed a reduction in clinical worsening. While oral bosentan therapy is clearly simpler than chronic intravenous epoprostenol or subcutaneously infused treprostinil, there is a potential for liver injury with bosentan, and monthly blood tests are required while receiving treatment. Bosentan is likely to produce major birth defects if used by pregnant women. Pregnancy must be prevented, and monthly pregnancy tests are required while taking bosentan.

**Ambrisentan**

Ambrisentan (Letairis®), like bosentan, is an FDA-approved ERA drug treatment for patients with PAH. To be taken once daily for patients in Functional Class II or III, this drug has shown improvement in exercise capacity. Similar to bosentan, ambrisentan should not
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:

- Funding an average of $1 million in original research grants awarded to investigators annually.

- 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 publicity campaigns.

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.
Our Three-Fold Mission Is Support, Education and Research

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A publication of Scleroderma Foundation
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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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Join Now!

Your tax-deductible gift of $25 or more makes you a member.
The Scleroderma Foundation’s Mission: Support, Education and Research

Support. The Foundation helps patients and their families cope with scleroderma through various support programs, peer counseling, physician referrals, and educational information offered by our nationwide network of chapters and support groups.

Education. We promote public awareness and education through patient and health professional seminars, scleroderma-related literature and publicity campaigns. A toll-free information line is offered in addition to patient education information and a comprehensive website containing medical articles, research and support information.

Research. The Foundation aims to stimulate and support research to improve treatment and, ultimately, find the cause of and cure for scleroderma. As the leading nonprofit supporter of scleroderma research, our peer-review based program budgets $1 million each year for scleroderma-related research.

Membership: For only $25 a year, you can become a member, support our mission and receive our quarterly magazine, Scleroderma Voice, that includes:

- Updates on the latest scleroderma research and treatments
- Articles by leading doctors and other health professionals
- Answers to your medical questions by health professionals
- Practical tips on coping with scleroderma
- Heartwarming stories by and about people with scleroderma, describing how they have met and overcome their challenges
- Articles about what the Scleroderma Foundation is doing for you - such as funding new research, advocating for more federal research funding on Capitol Hill, and working nationwide, year-round to raise public awareness of scleroderma and its impact on individuals and their families

It’s easy to give! You have many options:

1. **Call the Scleroderma Foundation toll-free** at 1-800-722-4673 and make your gift via credit card.
2. **Give online** via our secure server. Visit our website at [www.scleroderma.org](http://www.scleroderma.org) and click on the Donate box on the upper right side.
3. **Mail your gift** (check or credit card) to the Scleroderma Foundation at the address below.
4. Give through **payroll deduction** at work through the Combined Federal Campaign (CFC), United Way or your employer’s workplace giving program. Our CFC # is 2615.

**Thank you for your support!**
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- Scleroderma Ribbon Jar Opener: $2.00

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