



Scleroderma Foundation
Southeast Florida Chapter
6145 N.W. 123 Lane
Coral Springs, FL 33076

NON-PROFIT ORG.
U.S. POSTAGE
PAID
FT. LAUD. FL
PERMIT NO. 785

Please make checks payable to: Scleroderma Foundation-Southeast Florida Chapter (SF-SE FL Chapter)
Mail to: 6145 N.W. 123 Lane • Coral Springs, FL 33076

Gift enclosed \$ _____ Check Credit Card Date _____

Please charge my: Visa MasterCard Amer. Express Discover

Credit Card No. _____ Exp. Date _____

Gift From: (Name) _____

Address _____

City, State, Zip _____ Phone: _____

E-mail Address _____

Please notify the following of my gift:

Name _____

Address _____

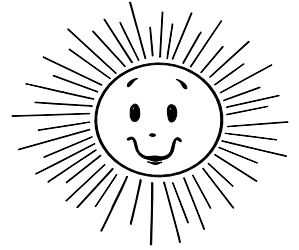
City, State, Zip _____

In honor of (occasion) _____

In memory of (name) _____

- Anniversary
- Bar/Bat Mitzvah
- Birth
- Birthday
- Congratulations
- Engagement
- Get Well
- Graduation
- Happy Holiday
- In Memory of
- Marriage
- In Honor of
- Thank You
- Generic
- Other _____

Scleroderma Foundation's E-Letter



...Humor....

Stop Sign

Driving my car one afternoon, I rolled through a stop sign. I was pulled over by a police officer who recognized me as his former English teacher. "Mrs. Brown," he said, "those stop signs are periods, not commas."

Sugar Worry

A fellow nurse at my hospital received a call from an anxious patient. "I'm diabetic and I'm afraid I've had too much sugar today," the caller said. "Are you light-headed?" my colleague asked. "No," the caller answered, "I'm a brunette."

Scales Don't Lie

A lady noticed her husband standing on the bathroom scale, sucking in his stomach. Thinking he was trying to weigh less with the maneuver, she commented, "I don't think that's going to help." "Sure it does," he said, "It's the only way I can see the numbers."

Sign up to keep informed on the latest news about Scleroderma research, treatments and information.

http://www.scleroderma.org/e_letter_signup.shtm

2009 MATCHING GIFTS

Many employers sponsor matching gift programs and will match any donation you make to us whether for the golf tournament, walk, a tribute or annual fund gift. Contact your employer's HR Department for matching gift paperwork and / or phone us at 954.255.8335 for assistance. Your gift to the Scleroderma Foundation Southeast Florida Chapter could be doubled!

Disclaimer

The Scleroderma Foundation in no way endorses any drugs, treatments, physicians, individuals or organizations reported in this newsletter. Material presented in this newsletter is for informational purposes only. Because the manifestations and severity of scleroderma vary among individuals, personalized healthcare management is essential. It is strongly recommended that all drugs and treatments be discussed with the reader's physician(s) for proper evaluation.

Handwritten calligraphy for
envelope addressing and placecard lettering

*Calligraphy
by Mona*

(954) 325-9092

MonasLine@aol.com

With All the Physical Problems, How Can I have a Good Sex Life Again?

Let's look at what a good sex life consists of. Generally you have to have a partner with whom you can talk, have fun and who you trust with your thoughts and feelings as well as your body. If you have this person already, you have a great start on getting your sensuality/sexuality back. If you don't have this person, it will take a bit of work on your part, but many people with Scleroderma have met their loved one and gone on to have a lovely time together.

In the event you and your partner are having trouble living with your Scleroderma, including the changes it's caused in your sexuality, there are resources for you to tap, such as couples therapists, counselors, and physicians specializing in sexual dysfunction. Remember, too, that your rheumatologist is concerned with your quality of life as well as your medications or lab work. Use these professionals to good advantage and get your joy back.

Another aspect to a good sex life is physical comfort. Here are some ways to make sure you're physically comfortable enough for physical intimacy:

- Attitude counts. One good attitude to have is that intercourse is not the goal, being together and feeling close physically is the goal. The sexiest part of your body is your mind.
- Communication between you and your partner is key to experimenting with new ways of making love.
- Think about having intimacy for intimacy's sake. Having a cuddle in front of the fire might lead to intercourse but if it doesn't, the cuddle and chat can be almost as loving and lovely.
- If you can, go away to a hotel for a day or two so you can reconnect and get away from the everyday. Bring candles and candle holders, have a good dinner, prepare for your comfort as below. If intercourse occurs, fine. If not, fine.
- Take your medicine for pain, GERD, anti-inflammatory at least 30 minutes before. This can add to the comfort and reduce your worry about your physical symptoms.
- Take a warm bath, light candles, put on music, get a massage with oils, make up the bed with clean sheets earlier in the day or do it together (this can be a good stretching exercise), heat up the electric blanket in advance.,
- Use Replens, Astroglide, or KY Jelly for moisture.
- Use helpful devices for sex just as you use devices to help you in other aspects of your life.
- Stretch the vagina with plenty of lubricant. You may also use other appliances for this. It's the same principal as stretching the mouth or fingers with appliances.

The Sexual Positions We're Used to Are Painful Now Because of My Tight Skin and Arthritis in my Joints.

What Do You Suggest?

There are resources (see the end of this article) that can give you some options for positions that might be more comfortable for you and require less strenuous activity while providing intimacy.

Remember that any experimentation will require increased communication between you and your partner in order to determine what feels good and what doesn't work for the two of you.

Principles to Ponder:

1. A positive, can-do attitude and loving communication make good things happen between people.
2. Living well with Scleroderma requires a lot of adjustment, both for the person with the disease as well as his or her relationships with loved ones. This is true of the sexual relationship as well.
3. A first-rate quality of life includes sexuality and sensuality as well as pain control, disability control and reduction of acute symptoms.
4. Good sex makes people feel good about themselves in addition to increasing physical relaxation, reduction of pain, relief of depression and fostering a sense of enjoyment.
5. Use the skills you've developed to cope with Scleroderma, such as information gathering and support groups, to help improve your sex life.

SEXUALITY and SCLERODERMA

By Elaine Furst, R.N., MA, BSN

Tight skin, dry mouth, curled fingers, painful joints, heartburn, fatigue...this doesn't sound very sexy, does it?

Along with all the other things Scleroderma may have taken from you, your ability to have satisfying sex might seem to be one of them. It's easy to see how physical discomfort can take the sexy out of sexual relations, especially when pain and fatigue are compounded by what you consider to be an unattractive face and body due to your disease. Some of you might even have decided to give up sex altogether.

This article will discuss ways to have a satisfying physical relationship even though you may have some or all of the symptoms listed above, or maybe a few more in addition.

Some Definitions First

It is often thought that sexuality means sexual intercourse and that's it. But sexuality is more than that. Your sexuality is part of how you think of yourself, especially regarding your desirability as a person and your views on love.

Sexuality Encompasses:

- The person you feel you are
- How you feel as a man or a woman
- The way you act
- Your body
- The way you dress, move and speak
- How you feel about other people

In addition to ideas about sexuality, sensuality plays an important part in a person's sex life, although it doesn't only mean sexual pleasure. Sensuality encompasses pleasure of all kinds, not only sexual pleasure. Think about how wonderful it is to savor something delicious or smell fresh flowers or luxuriate in a steamy bath. These things are examples of sensual pleasure.

What Good Is Having Sex Anyway?

In general, having pleasurable experiences of all kinds increases your quality of life. Think about the last time you had fun and how good it felt; pain decreased, self confidence went up, optimism increased, and so forth. A satisfying sex life can do even more by increasing exercise, increasing endorphins, increasing healthy sleep, and increasing blood circulation to extremities.

What Causes Sexuality Problems in People with Scleroderma?

Not surprisingly, the physical symptoms that most affect sexual functioning are the tight skin on the hands and face, pain, fatigue, dry mouth, and vaginal dryness. Men with Scleroderma can have problems with erection due to decreased blood flow to the penis and penile malformation due to tight skin, both of which can cause problems in sexual relationships.

Also not surprisingly, people with Scleroderma have difficulty with how they look, difficulty in their relationships due to disability and who are angry and depressed over their illness have more trouble having satisfying sexual relationships.

Finally, the symptoms of Scleroderma can be difficult in terms of physical discomfort and disability, but sometimes the very medications needed to treat those symptoms can get in the way of physical intimacy and pleasure. The following medications chart on medications gives a summary of the problems they might cause. Be sure to talk to your doctor about possible remedies for the side effects that might be affecting your sex drive or physical comfort.

Continued on page 10

Support Group Information

We are excited to report that all of the Southeast Florida Chapters support groups are up and running. Please take advantage of these meetings, as they are a wonderful resource for caregivers and individuals dealing with Scleroderma. It is an opportunity to share feelings, get up to date information on medications, research and how other people deal with their symptoms and side effects.

Listed to the right are all of our Support Groups, locations, times and leaders. Please take the time to find the one closest to you and attend. We have a very exciting new curriculum planned with great topics, guest speakers and updated research information.

DADE COUNTY

Baptist Hospital of Miami:

*8900 North Kendall Drive,
Main Bldg. in the Cafeteria
Miami, Florida 33176*
2nd Saturday of EACH month 11:00 - 1:00 p.m.
(Feel free to bring a lunch or snack with you)

For more information call
Christina Thrailkill at (786) 413-7372
or email to teena968@juno.com



BROWARD COUNTY

Margate:

*Northwest Medical Center
2801 North State Road 7 Conference Room 1
Margate, Florida
Main Hospital Entrance
3rd Saturday of EACH month
11:00 a.m. - 1:00 p.m.*

**PLEASE NOTE THERE IS NO MEETING FOR
THE MONTHS OF JULY AND AUGUST**

(Feel free to bring a lunch or snack with you)
For more information call
Berna Falkoff at (954) 978-9918
or Sharla Slappey at (954) 755-8579

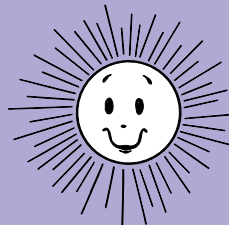
PALM BEACH COUNTY



North Palm Beach County

*John F. Kennedy Hospital
5301 South Congress Avenue
Atlantis, Florida
Conference Room 1
1st Saturday of EACH month
(with some exceptions)
11:45 a.m. - 1:45 p.m.*

(Feel free to bring a lunch or snack with you)
For more information call
Ann Potts (561) 798-1925 or
email her at dapotts50@aol.com



South Palm Beach County

*New Church
10621 El Clair Ranch Road
Boynton Beach, Florida
Boker room
3rd Saturday of EACH month
11:00 a.m. - 1:00 p.m.*

(Feel free to bring a lunch or snack with you)
For more information call
Rachel Ebert (561) 279-1021, (561) 523-6895
or email her at racebert@bellsouth.net
Parking located behind the church

Be aware that some drugs sold online

- Are too old, too strong, or too weak
- Aren't made using safe standards
- Aren't labeled, stored, or shipped correctly
- Aren't FDA-approved
- Aren't safe to use with other medicines or products
- May be counterfeit

COUNTERFEIT DRUGS

Counterfeit drugs are fake or copycat products can be difficult to identify. The deliberate and fraudulent practice of counterfeiting can apply to both brand names and generic products, where the identity of the source is often mislabeled in a way that suggests it is the authentic approved product.

Counterfeit drugs may:

- Be contaminated
- Lead to dangerous side effects
- Be made with the wrong amounts of ingredients
- Be packaged in phony packaging that looks legitimate
- Not help the condition or disease the medicine is intended to treat
- Contain the wrong active ingredient
- Contain no active ingredients at all or contain too much of an active ingredient

For example, counterfeit versions of the FDA-approved weight loss drug Xenical, which contains the active ingredient orlistat, recently were obtained by three consumers from two different Web sites.

Laboratory analysis showed that the capsules that the consumers received contained the wrong active ingredient, sibutramine. Sibutramine is the active ingredient of a different medicine called Meridia, a prescription drug also approved by FDA to help obese people lose weight and maintain weight loss. In addition, sibutramine is classified as a controlled substance by the Drug Enforcement Administration (DEA) because of its potential for abuse and misuse.

Using medicine that contains an active ingredient that wasn't prescribed by your licensed health care provider may be harmful.

FDA also became aware recently of a number of people who placed orders over the internet for one of the following prescriptions:

- Ambien (zolpidem tartrate)
- Lexapro (escitalopram oxalate)
- Xanax (alprazolam)
- Ativan (lorazepam)

Instead of receiving the drug they ordered, several customers received a product that contained haloperidol, a powerful anti-psychotic drug. As a result, these customers needed emergency medical treatment for symptoms such as difficulty in breathing, muscle spasms and muscle stiffness - all problems that can occur with haloperidol.

FDA continues to proactively protect consumers from counterfeit drugs. The agency is working with drug manufacturers, wholesalers and retailers to identify and prevent counterfeit drugs. FDA is also exploring the use of modern technologies and other measures that will make it more difficult for counterfeit drugs to get mixed up with, or deliberately substituted for, safe and effective medicines.

HOW TO PROTECT YOURSELF

1. Only buy from state-licensed pharmacy Web sites located in the U.S.
2. Don't buy from Web sites that sell prescription drugs without a prescription.
3. Don't buy from Web sites that offer to prescribe a drug for the first time without a physical exam by your doctor or by answering an online questionnaire..
4. Check with your state board of pharmacy of the National Association of Boards of Pharmacy to see if an online pharmacy has a valid pharmacy license and meets state quality standards.
5. Look for privacy and security policies that are easy to find and easy to understand.
6. Don't give any personal information, such as a social security number, credit card information, or medical or health history, unless you are sure the Web site will keep your information safe and private.
7. Use legitimate Web sites that the Web site will not sell your personal information, unless you agree.

Report unsafe or suspicious sites to FDA by going to www.fda.gov/buyonline and clicking on "Report problem Web sites."

ALERT: For a list of drugs that you should NOT buy online because of special safety restrictions visit www.fda.gov/cder/consumerinfo/don'tbuyonnet.htm.

The Possible Dangers of Buying Medicines Over the Internet

The Food and Drug Administration (FDA) wants to warn consumers about the possible dangers of buying medicines over the Internet. Some Web sites see prescription and over-the-counter drugs that may not be safe to use and could put people's health at risk.

So how can you protect yourself? FDA says that consumers should know how to recognize a legal Internet pharmacy and how to buy medicines online safely,.

DON'T BE DECEIVED

Buying prescription and over-the-counter drugs on the Internet from a company you don't know means you may not know exactly what you're getting.

There are many Web sites that operate legally and offer convenience, privacy, and safeguards for purchasing medicines. But there are also many "rogue Web sites" that offer to sell potentially dangerous drugs that have not been checked for safety and effectiveness. Through a rogue site may look professional and legitimate, it could actually be an illegal operation.

These rogue sites often sell unapproved drugs, drugs that contain the wrong active ingredient, drugs that may contain too much or too little of the active ingredient, or drugs that contain dangerous ingredients. Some Web sites sell counterfeit drugs that may look exactly like the real FDA-approved medicines, but their quality and safety are unknown.

Signs of a trustworthy Web site:

- It's located in the United States.
- It's licensed by the state board of pharmacy where the Web site is operating (visit www.napb.info for a list of state boards of pharmacy).
- It has a licensed pharmacist available to answer your questions.
- It requires a prescription for prescription medicines from your doctor or another health care professional who is licensed to prescribe medicines.
- It provides contact information and allows you to talk to a person if you have problems or questions.

Another way to check on a Web site is to look for the National Association of Boards of Pharmacy's (NABP) Verified Internet Pharmacy Practice Sites Seal, also known as VIPPS Seal.

This seal means that the internet pharmacy is safe to use because it has met state licensure requirements, as well as other NABP criteria. Legitimate pharmacies that carry the VIPPS seal are listed at www.vipps.info.

Signs of an unsafe Web site:

- It sends you drugs with unknown quality or origin.
- It gives you the wrong drug or another dangerous product for your illness.
- It doesn't provide a way to contact the Web site by phone.
- It offers prices that are dramatically lower than the competition.
- It may offer to sell prescription drugs without a prescription - this is against the law!
- It may not protect your personal information.

KNOW YOUR MEDICINES

Before you get any new medicines for the first time, talk to your doctor or pharmacist about any special steps you need to take to fill your prescription.

Any time you get a prescription refilled

- Check the physical appearance of the medicine (color, texture, shape and packaging)
- Check to see if it smells and tastes the same when you use it.
- Alert your pharmacist or whoever is providing treatment to anything that is different.



Second Annual South Miami Medical Symposium 8:00 am - 1:00 pm

On Saturday, October 3, 2009 the Scleroderma Foundation will be hosting its **Second Annual Medical Symposium** at South Miami Hospital. The event is expected to be a huge success. We anticipate a full house so register early.

The line-up of speakers is going to be very interesting, an educational event you won't want to miss.

Please mark your calendar for Saturday, October 3rd you should expect a formal registration brochure in the mail soon or you can fill out the one below. The event is free of charge.

Name _____

Address _____

Address _____

City _____ State _____ Zip _____

Phone (_____) _____ E-mail _____

If you have any questions, call the Scleroderma Foundation at 954.255.8335

NOTE: We are unable to control the temperature in the conference room and it does get cold. Please bring appropriate clothing, gloves and jackets with you so that you will be comfortable.

At A Glance:

Saturday, July 4th



Happy Birthday
AMERICA



Friday, July 17th
through
Sunday, July 19th
Scleroderma
National
Conference
St. Louis, MO

Monday, August 24th
School Starts in
Broward County



Monday, Sept. 7th
Labor Day

Friday, September 18th
Rosh Hashana begins

Sunday, September 27th
Yom Kippur

Saturday, October 3rd
Miami Medical Symposium
South Miami Hospital
8:00 - 1:00



Monday, October 12th
Columbus Day

Saturday, October 31st
Halloween



Saturday, November 7th
Sixth Annual Stepping out to
Cure Scleroderma Walk,
Tradewinds Park, Coconut Creek
9 am Registration



12th Annual Ellen Ehrhart Medical Symposium

Sponsored by



On Saturday, June 6, 2009 over 50 people came out to North Broward Medical Center for the Scleroderma Foundations 12th Annual Ellen Ehrhart Medical symposium sponsored by Actelion Pharmaceuticals. The day was a huge success and everyone in attendance was very excited with the wealth of information that was presented.

We would like to thank all of our guest speakers for volunteering their time on a Saturday to educate all of our attendees. These highly renowned medical professionals presented and discussed topics dealing with the rehab, dental problems and pain management. Following each presentation, audience members were given the opportunity to ask specific questions related to their own Scleroderma issues. This question and answer period was extremely helpful.

On behalf of the Scleroderma Foundation, I would like to express our most sincere gratitude to the following speakers: Dr. Harold Menchel, Dr. Eugene Lustgarten and Dawn Brown-Cross. Thank you goes out to Actelion Pharmaceuticals for making this event possible.

Mission Statement

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.



The Sixth Annual Stepping Out to Cure Scleroderma Walk is set for **Saturday, November 7th** at Tradewinds Park in Coconut Creek, Florida. The preparations are well underway and we have some really exciting things going on.

Come walk with your friends, neighbors, family and co-workers on a beautiful sunny day in Florida. Not only will you get the opportunity to socialize, exercise and be entertained, you will feel great about raising money for people suffering with Scleroderma.

We need your help to make this year's event bigger and better than ever. Our goal is to raise \$30,000 and have over 400 volunteers and walkers come out and support the Foundation. Set a fundraising goal and begin asking friends, family, co-workers and neighbors to sponsor you or participate and make a team. The day will be filled with music, food, friends and entertainment, an event not to be missed! We want everyone to:

Get ready...Get set...Participate

Mark your calendars;

Start putting your teams together and raise pledges.

This year's goal is \$30,000

Help us achieve it!

Call the Scleroderma Foundation at 954.255.8335 for more details on sponsorship, putting a team together or volunteering that day. Go ahead and set up your own fundraising page at www.firstgiving.com. It's not too early to begin.

Third Party Events

A third party event is an event that you decide to do and make the Scleroderma Foundation the beneficiary of the dollars that you raise. Why not host a party at your home, a car wash, a wine tasting or something that interests you. The Foundation would be happy to provide support to help get things going.

Please call the office if you have any questions or ideas.

The phone number is

954.255.8335

Quote attributed to Eleanor Roosevelt

“Many people will walk in and out of your life, but only true friends will leave footprints in your heart. To handle yourself, use your head; to handle others use your heart. Anger is only one letter from danger. If someone betrays you once, it is his fault; if he betrays you twice it is your fault. Great minds discuss ideas; average minds discuss events and small minds discuss people. He, who loses money, loses much; he, who loses a friend, loses much more; he who loses faith loses all. Beautiful young people are accidents of nature; but beautiful old people are works of art. Learn from the mistakes of others; you can't live long enough to make them all yourself.

See challenges as opportunities; and adversity as a potential blessing in disguise.

Hello Scleroderma Members, Family, and Friends!

This year The Scleroderma Foundation, Southeast Florida Chapter has its own Internet shopping Website with over 600+ retailers and 80 Green Stores to Help All of Us in our fundraising efforts.

You are just doing what you already do everyday - SHOPPING. It's Simple, Convenient and a Time Saver!

By going to www.ShoptoEarn.net/sclerodermaseflorida, we receive 1%-40% of that purchase towards our fundraising efforts. No need to “sell” anything.

It helps You and Your Family Be More Earth Friendly by Saving Time, Money, and Gas All Year Long!

No Sales Tax on .Com Stores such as [Drug Store.com](http://DrugStore.com), Restaurant.com, Diapers.com, [Gift Certificates.com](http://GiftCertificates.com). Pass this on to your family, and friends.

Free shipping and Internet-only Discounts on many of the Shopping Sites!

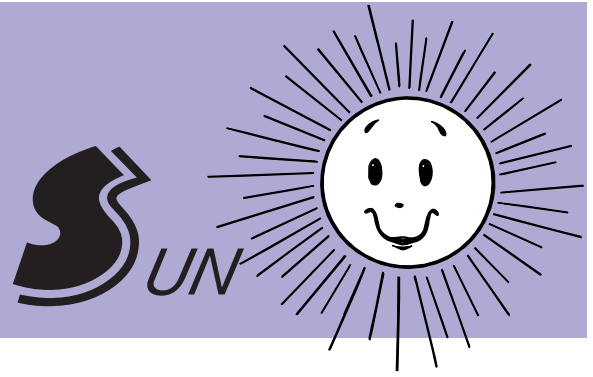
We ask for your support to help our community:

www.ShoptoEarn.net/sclerodermaseflorida for all your purchases.

Any Website-use questions, please call Jodi @ 954.255.8335.

*Thanks again,
Scleroderma Foundation
Southeast Florida Chapter*

SOUTH **F**FLORIDA
SCLERODERMA



July August September 2009

Officers
President

Ruth Greenspan

Vice President
Jerry Lance

Secretary
Ferne Robin

Treasurer
Sharla Slappey

Directors
Fred Auman
Berna Falkoff
Chris Miller
Robert Slappey
Dr. Howard Meridy

Executive Director

Jodi Danois
Office Address

Scleroderma Foundation
6145 N.W. 123 Lane
Coral Springs, FL 33076
(p) 954-255-8335
(f) 954-255-8081

Sclerodermasofl@bellsouth.net
www.scleroderma.org/chapter/seflorida



**SCLERODERMA
FOUNDATION**
SUPPORT • EDUCATION • RESEARCH

SOUTHEAST FLORIDA CHAPTER

Newsletter by:
Dawn Janosik

President's Message

“Summertime And The Living Is Easy”. George Gershwin thought so and I truly hope and think so. As far as our chapter is concerned the year, thus far, has not been easy, BUT most successful. So far this year Jodi and our Board of Directors have done a masterful job in accomplishing two Medical Symposiums, a wonderful golf tournament and an elegant tea party. Kudos to all of you who helped and participated in these events.

Summertime in South Florida is not the easiest place to be. The heat is too intense, the rain is too often and too wet and the fear of hurricanes too threatening. Therefore, I suggest we all stay well and thank Mother Nature for being so good to us. We do not have snow, sleet or frigid temperatures.

While we are not as active during the summer we are here and ready to help you in any way we can. The office is always open and we are busily preparing for our Sixth Annual Stepping Out to Cure Scleroderma Walk scheduled for Saturday, November 7th.

Please have a healthy summer and in remembrance of the Gershwin brothers make sure “Your Living is Easy”.

*Ruth Greenspan
President*

