

5 Top Tips for People with Scleroderma Who HATE to Cook!

by Rose Payne, CHHC



If you have been diagnosed with Scleroderma and suffer from fatigue, muscle pain, digestive problems, tightening of the skin or Raynaud's, (just to name a few complications) it may seem challenging to prioritize eating

well. If you consider any of the research that demonstrates the use of food choices as a protocol and the seemingly dramatic improvement to response rates and overall improvement of health to scleroderma patients you may want to make a shift in your priorities. I know after a long physically challenging day the last thing you want to do is spend time in your kitchen! But what if those few minutes led to reduced pain in your hands and legs, or improved your digestion, relieved your GERD or gave you more flexibility and less tightening of the skin? There is no substitute for the health benefits of a home-cooked meal comprised of good food choices. Try adopting some of my top tips for having a better relationship with your kitchen and saving time, energy and making the most of your efforts.

1. Cook once and then eat many meals from it. You've probably heard this before but now it's time to actually do it. Cook larger batches of soups, stew or grains and freeze in small batches for the start of another meal. Cooked grains freeze very well in zip lock bags and can be thawed easily.
2. Invest in a few time saving tools for your kitchen:
 - ❖ Wide handled pots, utensils and knives
 - ❖ Food processor with slicing blades to do the work of chopping

- ❖ Steamer basket
 - ❖ Well-seasoned wok and a crock-pot - think one-pot meals!
3. Make a menu plan for the week. Don't resist this very important part of keeping on track with your commitment to eating well. Having a plan is a key component and will ensure you have the necessary foods in your pantry when you are ready to cook. Remember to include pure carrot juice a couple of times a week for skin softening.
 4. Make your time in the kitchen as enjoyable as possible.
 - ❖ Reorganize your working space to make it efficient, keeping counters clean and clutter free.
 - ❖ Spend a few hours cooking with a friend on a non-workday and divide up the food for the week.
 - ❖ Play music or listen to a book on tape while you are cooking.
 - ❖ Focus on the positive health benefits and congratulate yourself on your accomplishments.
 5. Keep it simple
 - ❖ Focus on the quality & choice of health supportive ingredients you chose, not the quantity of dishes you prepare.
 - ❖ Don't be so serious, feel the pleasure of nourishing yourself!

I welcome your questions and comments!
Contact me at
rose@HighLevelWellnessOnline.com.

Get your free e-book "The 7 Secrets of Highly Energetic People" at
www.HighLevelWellnessOnline.com

Rose Payne will be one of our guest speakers at the Joint Educational Conference on October 15, 2011, in Somerville, NJ. Save the Date!

Compassionate Allowances Outreach Hearing on Autoimmune Diseases

The Social Security Administration (SSA) has a list of what is called Compassionate Allowance Conditions. What this means is that the disease entities on this list clearly qualify for Social Security and Supplemental Social Security Income disability benefits which allows the SSA to electronically target and make speedy decisions for those people suffering with these diseases. This is the groundwork that should result in faster approval times for those applying for Social Security benefits and less paperwork.

On March 16, 2011, the SSA held an Outreach Hearing on Autoimmune Diseases in Baltimore, Maryland. The purpose of this hearing was to educate administrators in the SSA so that diseases including scleroderma, lupus, rheumatoid arthritis, and multiple sclerosis, can be listed as compassionate allowance conditions. Dr. Virginia Steen from Georgetown University was one of the speakers on behalf of scleroderma, as well as Rosemary Markoff, a patient and Board member from the Tri-State chapter. Two patients from the SFDV, John Keegan and Marsha Niederman, attended the hearing and were able to meet several commissioners from the SSA. They were able to impress upon them the fact that living with scleroderma demands lifestyle changes often leading to total disability. According to Mr. Art Spencer, Associate Commissioner of the Office of Disability Program, scleroderma is likely to be listed as early as June. This is very good news for anyone thinking of applying for disability.

Annual MacCutcheon Lacy Memorial Golf Tournament raises over \$12,000 for the SFDV



On June 13, 2011, the Annual MacCutcheon Lacy Golf Tournament was held at Rossmoor Country Club in Monroe, NJ, in memory of Bruce MacCutcheon and Marilyn Lacy, who both suffered from and lost their battles with scleroderma. This tournament featured 18 holes of golf, breakfast, lunch, dinner, and prizes. 110 golfers and multiple sponsors gave generously to raise over \$12,000 in one day. Many of them have supported this event since it started over 10 years ago. We thank them all and especially thank the MacCutcheon and Lacy families for their time and dedication in supporting the SFDV.



Find the magic of giving back!

Saturday, August 27, 2011

Since 2006, Macy's Shop For A Cause Event has partnered with non-profit organizations nationwide to raise more than \$38 million for their ongoing charitable efforts. This is your chance to be part of this monumental event on Saturday, August 27, 2011.

Shop For A Cause gives you the opportunity to give back to your community and to help our organization. Purchase a \$5 Shopping Pass* for exclusive savings in every Macy's store and online at macys.com on Saturday, August 27th, and the Scleroderma Foundation Delaware Valley Chapter keeps 100% of the proceeds. Plus, you can enter to win a \$500 Macy's Gift Card.

Find the magic of giving back, as Macy's celebrates a national day of support for our community.

*Some exclusions and restrictions apply.

For more information or to purchase a pass contact the SFDV office at 866-675-5545 or at dvchapter@scleroderma.org

Jenny's Journey

In 1999 my sister, Mary Jane Sister, lost her battle with Scleroderma. After donating to the cause in her memory, I received a newsletter about the Scleroderma Walk and decided to participate in her honor. As the years went by more and more family joined me, including Mary Jane's husband, children, and grandchildren. My cousin's daughter has since bought a house in Belmar and graciously started hosting a family picnic after the walk. Currently, 4 generations of Mary Jane's loved ones, from our parents to our grandchildren and everyone in between, totaling 35+ family members travel from 4 different states to walk in her memory. It has become an annual family event.

Our team name, "Jenny's Journey" is taken from Mary Jane's nickname, Jenny, and her inspirational journey. She always had a beautiful smile and kind, encouraging words for the people around her, no matter how ill she was. "A dime at a time" is our motto. Before Mary Jane died, when she needed a positive reminder most, she'd find dimes and believed her late mother-in-law "dropped" them for her. After Mary Jane passed the rest of us started finding dimes, too, everywhere, and always when we need them most, no doubt from Mary Jane. At this point, we all have stacks and jars of dimes around our homes that remind us she's watching over us and we can do anything we put our minds to. Mary Jane was a wonderful, strong, positive woman and we're honored to come together for a good cause and to honor her memory.

Submitted by The Decker Family



Lupus and Scleroderma in African Americans: Overlap and Understanding



The Scleroderma Foundation Delaware Valley Chapter and Lupus Foundation of American Philadelphia TriState Chapter joined forces on March 29, 2011, in Bala Cynwyd, PA, at the Bala Cynwyd Public Library to present a panel discussion focusing on these two autoimmune diseases and their overlap in African Americans. Dr. Nora Sandorfi from the Department of Rheumatology at Thomas Jefferson University Hospital gave an insightful presentation on this complex and frustrating diagnosis. In addition two patients active in the lupus and scleroderma community participated on the panel adding their personal experiences and insights in dealing with this overlap syndrome. Our program included a lively Q&A session between our presenters and the audience touching on many subjects. It is clear that lupus and scleroderma presents differently in African Americans, but the need for more information through research and clinical studies is critical in helping understand these differences leading to better detection methods and treatments.

Our chapter enjoyed being able to work with the Lupus Foundation of America Philadelphia TriState Chapter in making this discussion possible. We thank Dr. Nora Sandorfi and our two patient panelists for sharing their expertise and look

forward to similar programs in the future. We would also like to thank Jean Knapp, Head Librarian at the Bala Cynwyd Library, for providing their meeting room for our seminar.

Please note that the National Scleroderma Foundation will be hosting a program on Scleroderma in the African-American population this fall.

African-American Scleroderma Education Program

The Scleroderma Foundation is proud to announce a new program coming this fall. On Saturday, Sept. 24, we are teaming up with Virginia Steen, M.D., and Laura Hummers, M.D., ScM, to present the first African-American Scleroderma Education Program.

This special event for patients, caregivers and family members will be held at the Tremont Plaza Hotel, 222 St. Paul Place, in Baltimore, Md.

Dr. Steen is a member of the Foundation's Medical Advisory Board and is a professor at Georgetown University Medical Center in Washington, D.C. Dr. Hummers is co-director of Johns Hopkins Scleroderma Center, and assistant professor at Johns Hopkins University School of Medicine in Baltimore.

Additional program speakers will be announced in the future. For more information about this program, email Kerri Connolly, Director of Programs and Services, at kconnolly@scleroderma.org.

Pulmonary Arterial Hypertension Seminar in Allentown, PA

The SFDV along with *Gilead Sciences* was pleased to present a seminar on pulmonary arterial hypertension in the setting of scleroderma on May 7, 2011, in Allentown, PA. Dr. Paul Forfia, Director of the Pulmonary Hypertension Program at the Hospital of the University of Pennsylvania, was our guest speaker. He spoke in depth about the causes, symptoms, detection, and treatment of this serious and life threatening condition. He emphasized the importance of evaluating the right side of the heart, especially when doing echocardiograms. We all came away



knowing that with the medications available today the effects of pulmonary arterial hypertension can be managed leading to a better quality of life. As with most complications, early detection is key in providing successful management.

We would like to thank Dr. Forfia for taking time out of his weekend schedule to speak for us. We would also like to thank Mick Dungan and Melissa Anderson from Gilead Sciences for making this program happen.

Annual Shore Walk

The Beach Walkway in Manasquan, NJ, was at capacity on June 5, 2011, when 426 walkers participated in the 11th annual "Stepping Out to Cure Scleroderma" Walk. This year's walk was held in memory of Pat Allee whose family came out to support each other and along with everyone else, walked for the hope of finding a cure for this terrible disease. An estimated \$40,000 was raised which will support the Scleroderma Foundation Delaware Valley Chapter's mission of support, education, and research.



The 11th Annual Shore Walk was thankful to have several generous sponsors including:



We would like to thank Scott Ritchie and Ocean Trophies who year after year donate our beautiful award plaques. We would also like to thank Enriche Ramirez and Entenmann Bakery in Brick, NJ for their generous donation of baked goods.

We had the pleasure of recognizing several teams – those who raised the most money at the 2010 Shore Walk and those with the most walkers in 2011.

Most Money Raised in 2010

- 1st Place, Helen's Angels – \$5525
- 2nd Place, Grandma Doris' Kids – \$3181
- 3rd Place, Jenny's Journey – \$2320

Most Walkers in 2011

- 1st Place (59 Walkers)
Patty's Wild Orchids
- 2nd Place (46 Walkers)
Team Snow White
- 3rd Place (43 walkers)
Jenny's Journey

Thank you volunteers!

Our 30+ volunteers were at the heart of the entire event. They arrived early, set up all the tables, sold promotional items and 50/50 raffles, provided information, handed out refreshments, and even cleaned up!! As always we are indebted to them – there would be no walk without them.

As always we thank the Borough of Manasquan and Wally Wall, Beach Manager, for providing a safe and clean venue for us to make our home on a Sunday morning in June.

To view all the Shore Walk Photos go to https://picasaweb.google.com/112635125257565869578/2011SclerodermaShoreWalk?authkey=Gv1sRgCO_12Yax1v6smAE&feat=directlink
We have also posted a few short videos on FB and You Tube.





2nd Annual Delaware 5K Run and Walk

Scleroderma patients and supporters from the greater Wilmington, Delaware area came out on a cold and rainy day to hold its 2nd Annual 5K Run and Walk in Brandywine Park on April 16, 2011. The sun did not come out, but our volunteers found creative ways to keep things dry and the 5K went off on schedule. Jon and Mike from Races2Run directed the race and the Wilmington police led our runners through the local streets and safely back to the finish line in the park. The teams that raised the most money in 2010 and those with the most “walkers” in 2011 were awarded plaques for their achievements.

Most money raised in 2010

- 1st Place – Team Personti
- 2nd Place – Crowl’s Crawlers
- 3rd Place – Team Sharon



Most walkers in 2011

- 1st Place – Team Sharon
- 2nd Place – Waffy’s Walkers
- 3rd Place – Barbara’s Angels

We want to thank everyone who came out to volunteer and participate with smiles on their faces despite the dismal weather. We are grateful for your continued commitment.

Photos from the 2nd Annual “Stepping Out To Cure Scleroderma” 5K Run and Walk in Wilmington, Delaware are available at <https://picasaweb.google.com/nmbhagat62/2ndAnnual2011Delaware5kRunWalk?feat=email#>



SCLERODERMA FOUNDATION DELAWARE VALLEY CHAPTER SUPPORT GROUP CALENDAR

August

- 10 – Philadelphia Support Group at 1:30 pm
- 13 – Monmouth Support Group at 10:00 am
- 22 – Doylestown Support Group at 6:30 pm
- 22 – North Delaware Support Group at 6:00 pm

September

- 6 – Woodbury Support Group at 7:00 pm
- 7 – Williamsport Support Group at 1:00 pm
- 7 – Bucks County Support Group at 7:00 pm
- 7 – York Support Group at 7:00 pm
- 8 – Burl-Cam Support Group at 1:30 pm
- 10 – Reading Support Group at 10:00 am
- 14 – Philadelphia Support Group at 1:30 pm
- 17 – Monmouth Support Group at 10:00 am (3rd week)
- 26 – Doylestown Support Group at 6:30 pm
- 26 – North Delaware Support Group at 6:00 pm

October

- 5 – Williamsport Support Group at 1:00 pm
- 8 – Monmouth Support Group at 10:00 am
- 11 – Watchung Hills Support Group at 2:00 pm

- 12 – Philadelphia Support Group at 1:30 pm
- 24 – Doylestown Support Group at 6:30 pm
- 24 – North Delaware Support Group at 6:00 pm

November

- 2 – Williamsport Support Group at 1:00 pm
- 9 – Philadelphia Support Group at 1:30 pm
- 10 – Burl-Cam Support Group at 1:30 pm
- 12 – Monmouth Support Group at 10:00 am
- 12 – Reading Support Group at 10:00 am
- 28 – Doylestown Support Group at 6:30 pm
- 28 – North Delaware Support Group at 6:00 pm

December

- 6 – Woodbury Support Group at 7:00 pm
- 7 – Williamsport Support Group at 1:00 pm
- 7 – Bucks County Support Group at 7:00 pm
- 10 – Monmouth Support Group at 10:00 am
- 14 – Philadelphia Support Group at 1:30 pm
- 26 – Doylestown Support Group at 6:30 pm
- 26 – North Delaware Support Group at 6:00 pm

Disclaimer: The Scleroderma Foundation in no way endorses any drugs or treatments reported in this newsletter or at SFDV sponsored meetings. Information is provided as a resource to be used with discretion. Because the manifestations and severity of scleroderma vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with one's physician to assure proper evaluation and treatment.

Support Group Meeting Locations

DELAWARE

Wilmington, Delaware (North Delaware)

Support Group Leader: Debra Wagner,
610-255-5768 or 610-864-6669,
scleroderma.desupport@comcast.net
4th Monday of every month at 6:00 pm
Kirkwood Library, 6000 Kirkwood Hwy
Wilmington, DE 19808-4817
302-995-7663

NEW JERSEY

Cherry Hill, New Jersey (Burl-Cam)

Support Group Leader: John Keegan,
856-767-4783, johnkeegan@comcast.net
2nd Thursday of every other month starting
in January at 1:30 pm
385 Kings Highway North, Cherry
Professional Building, Cherry Hill, NJ 08034
856-779-7225

Monmouth, New Jersey

Support Group Leader: Marsha Niederman,
732-276-5807, mjniiederman@optonline.net
2nd Saturday of the month at 10:00 am
except Sept. (meeting being held on Sept. 17
– 3rd Saturday of the month)
Neptune Twp Public Library
2nd floor conference room
25 Neptune Blvd., Neptune, NJ 07753
732-775-8241

Warren, New Jersey (Watchung Hills)

Support Group Leader: Ellen Waldstein,
908-647-7266, ellw@optonline.net
Support Group Co-Leader: Chris Frascella,
908-604-6054, co-leader
Tuesday at 2:00 pm, quarterly - January 18,
March 8, June 7 (luncheon meeting at
another location), October 11
Trinity United Church
118 King George Road, Warren, NJ 07059
732-469-5044

Woodbury, New Jersey

Support Group Leader: Mary Nuzzo,
856-582-6456, marynuzz@msn.com
1st Tuesday of the month, quarterly at 7:00
pm – March 8, June 7, September 6,
December 6
Underwood Memorial Hospital
Dining Room B, 1st Floor
(December meeting)
Medical Arts Building (adjoining building) –
Suite 14 (March, June &
September meetings)

509 North Broad Street,
Woodbury, NJ 08096
856-845-0100
Please contact support group leader prior to
attending meeting.

PENNSYLVANIA

Doylestown, Pennsylvania

Support Group Leader: Mary Gocek,
908-256-3408, marygocek@gmail.com
4th Monday of each month at 6:30 pm
Doylestown Hospital
1st floor – North Wing – Conference Room B
595 West State Street, Doylestown, PA 18901
215-345-2200

Langhorne, Pennsylvania (Bucks County)

Support Group Leader: Ilene Nusblatt, 215-
321-1670, inusblatt@comcast.net
(June and December meetings)
Support Group Leader: Sharon Durham,
215-638-2771, icoachjoy@hotmail.com
(March and September meetings)
First Wednesdays quarterly at 7:00 pm –
March 2, June 1, September 7, December 7
Aria Health - Bucks County
Conference Room C – ground floor
380 N. Oxford Valley Road,
Langhorne, PA 19047
215-949-5000

Philadelphia, Pennsylvania

Support Group Leader: Joyce Roby-
Washington, 215-474-0259 or 267-516-6987,
joycerw757@msn.com
2nd Wednesday of the month at 1:30 pm
Presbyterian Medical Center, University of
Pennsylvania Health System
39th and Market Streets,

Wright Saunders Building
Gardner Conference Room 128-C
Philadelphia, PA 19104
215-662-8000

Reading, Pennsylvania

Support Group Leader: Dawn Batzel, 610-
287-1445, happy81070@verizon.net
2nd Saturday of every other month at 10:00
am – March 12, May 14, July 9,
September 10, November 12
Reading Pediatrics office
40 Berkshire Court, Wyomissing, PA 19610
610-374-7400

Williamsport, Pennsylvania

Support Group Leader: Jayne Young,
570-323-4228, weyclu@sunlink.net
Gayle Bullock, 570-398-0551 (co-leader)
1st Wednesday of the month at 1:00 pm
(except January, February, July & August)
Life Center in the Lycoming Mall
300 Lycoming Mall Cir #3021,
Muncy, PA 17756
570-546-6879

York, Pennsylvania

Support Group Leader: Kathleen Gaskell-
Blankenship, 717-428-1464,
karlkathleen@earthlink.net
Meets quarterly on Wednesdays at
7:00 pm – September 7
Elmwood Mansion Conference Center
400 Elmwood Blvd. (Corner of S. Belmont
St & Elmwood Blvd), York, PA 17402
800-436-4326



We have started an e-mail support group for those patients and families that are not close to one of our existing support groups or those who would like to participate in addition to attending a support group. There is a weekly topic of discussion by email and everyone is free to comment or ask a question at any time. You can participate as little or as much as you like. If you are interested in being part of an email support group, please contact the office at 856-779-7225 or via e-mail at cferara@scleroderma.org.

Support Group Leaders Needed

We are always looking to expand our support groups into new areas. Please contact our office if you are interested in becoming a Support Group Leader.

Delaware
Southern DE Area

New Jersey
Cape May Area
Toms River Area

Pennsylvania
Carlisle/Harrisburg Area
Lehigh Valley Area
Delaware County Area
Norristown Area

NEWSLETTER OF THE SCLERODERMA FOUNDATION
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UPCOMING EVENTS

July 30, 2011 – Health Fair Christian Stronghold Church – Philadelphia, PA

August 13, 2011 – 7th Annual “Stepping Out to Cure Scleroderma” Walk – York, PA

August 21, 2011 – Lakewood Blue Claws Baseball Game – Scleroderma Awareness

September 9, 2011 – 10th Annual “Teri’s Run” – Downingtown, PA

September 24, 2011 – Camden County Women’s Health Conference, Eastern Regional High School, Voorhees, NJ

October 9, 2011 – 22nd Annual “Stepping Out to Cure Scleroderma” Walk – Philadelphia, PA

October 15, 2011 – Joint Educational Patient Conference – Somerville, NJ

Check our website at scleroderma.org/chapter/Delaware_valley for news and information. Check out our Facebook page for frequent postings www.facebook.com/pages/Delaware-Valley-Chapter-for-Scleroderma-Foundation.

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.

SFDV Office

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Delaware Valley Chapter
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