



Tell Me More

A Question and Answer session with:

JULIANN NEDEROSTEK, RN, MAED, BC

Clinical Nurse Specialist, Thomas Jefferson University

Hospital Care – What Should I Know?

Juliann Nederostek is a nurse educator at Thomas Jefferson University Hospital who is also a scleroderma patient. She presented “Scleroderma – A Nurse’s Perspective” at the Hospital of the University of Pennsylvania patient education seminar on March 10, 2012 and understands the special needs of scleroderma patients while receiving care in a hospital or clinic. Juliann likes to call her rheumatologist every year on her birthday to say, “I’m another year older and it’s your fault.” Growing old is a sign of good medical care for Scleroderma.

How can I prepare better for my hospital visit?

You might want to prepare a bag with your individual needs to be organized. It is a very stressful time when you anticipate a hospital admission, and just like the expectant Mom, having your needs packed in advance may help. Have a list of your medication prepared, including any creams or lotions.

What warning signs should I let my nurse know immediately?

If your room is cold, have the nurse arrange for your room temperature to be warmer for you. If you need socks or extra blankets, or the weight of the covers “tucked in” is uncomfortable, inform the nurse. If you utilize a heating pad, have the doctor order one for you at the bedside. Hospital heating pads are temperature controlled and will not burn your skin. If you have difficulty swallowing, request to speak to the dietician to discuss your food preferences. If you are having pain for any reason, communicate this issue immediately. If you have “assistive devices” such as a cane, walker, or a commode communicate this as well.

Editor’s Note: Don’t be shy about informing your medical professional whether it be your nurse, physical therapist, or doctor about your specific needs. The more they know the more they can help you.

How can I make my skin more comfortable?

Dry, itching skin may be an ongoing issue. Your rheumatologist needs to refer you to a dermatologist who is sensitive to a scleroderma patient’s skin issues. It is very difficult to explain the itching, burning, and achy symptoms, if they are not familiar with this disease. Dove soap was recommended by my dermatologist for daily care. Creams and lotions are ordered or recommended by your Dermatologist, after a thorough evaluation.

What things should my nurse be aware of relating to my scleroderma?

You should tell your nurse ANYTHING you may need for your safety and comfort, for example your mouth care needs, where is a good site for blood draws, and what you use for your appetite or gastrointestinal issues.

What should I do if I get a severe Raynaud’s attack?

If the normal interventions do not relieve your attack (medication, warm water, paraffin bath, someone suggested warm sand) notify your rheumatologist immediately!

How can I help my shortness of breath while in the hospital?

Make sure you communicate what works for you – the head of the bed being elevated; use of oxygen therapy continuously or just at night. Plan to pace activity for morning care or ambulation. If you need a commode at the bedside for urgency or reduced physical stress, ask for one to be ordered. If you use an ambulatory aid (cane, walker,) let your nurse know that as well. Do not use the furniture to lean on as hospital furniture has wheels, and may not be locked. This is a safety issue as well.

Will scleroderma affect my healing after a procedure?

Yes it might. If you are also on immunosuppressant drugs, you could also be prone to an increase in wound infection. Dental patients need to take antibiotics before and after oral surgery or periodontal treatment.

ALWAYS, inform the doctor of your diagnosis and medications.

Tell Me More *(from page 1)*

Do nurse's need or get any special training to take care of scleroderma patients?

Nurses learn about autoimmune diseases in general. Scleroderma is very rare, so it is not stressed in their nursing education. The general symptoms of scleroderma patients are familiar to the nurse, such as: shortness of breath, dry skin, circulation issues, frequent mouth care, and GERD do present as separate medical issues. The intervention for the patient does not change. If you have specific care related to these issues, communicate these needs.

How can I communicate better at my doctor's appointment?

Always talk to your doctor fully dressed. Being dressed, you are seen as a person, not just a patient. This also helps you to have

the dignity and feel secure to initiate conversation for the questions and information that is necessary for your care. If you are seeing multiple specialists, it is easy to lose track of what you should ask. Make a list to be sure your questions relate to the physician specialist you are seeing. You need to tell the doctor your specific symptoms. The doctor is only as good as the information you, the patient, add to the clinical evaluation. Your rheumatologist should help you coordinate your care.

How has being a scleroderma patient helped you become a better nurse?

I credit having scleroderma for meeting wonderful, caring, and patient health care professionals. My research nurse was so supportive; she made picking up my clinical trial medications as convenient as possible. My rheumatologist was honest, as well as encouraging, to the point that I pursued a change of professional position with success. I am much more patient

Living with Scleroderma: Eating, sitting, bending, healing can be hard

Written By KELLY BOTHUM *The News Journal*



Alvin Crowl lives with scleroderma (which sometimes means he can't enjoy his GTO as much), and he and wife Angie are organizing a cruise night to help raise awareness of the autoimmune disorder.

Alvin Crowl doesn't get frustrated when people ask him the reason for his tan in the middle of the winter. For Crowl, it's an opportunity to explain the many ways his autoimmune disease affects his body.

Crowl, 62, of Wilmington, has scleroderma, which causes his skin to harden and take on a darker hue. His fingers are so sensitive to cold -- and sometimes develop ulcers on the tips -- that he wears gloves almost year-round. It's too hard for him to bend over, so he uses a piece of plastic to help put his socks on. He wears shoes without tie-up laces.

But those are just the symptoms people can see. Crowl also suffers from

digestive problems related to the condition. Last year, he was hospitalized with heart failure and internal bleeding related to his scleroderma. He received eight infusions of iron.

"He doesn't do much in the winter," said his wife, Angie, who is helping to organize a fund raiser next month to raise money and awareness of the disease. "Even when the weather is better, he's still affected. On a cold, rainy day in the spring, it's the same as if it was 20 degrees out for him."

Tough diagnosis

Named from the Greek words meaning "hard skin," scleroderma can be a frustrating disease for patients and physicians alike. It's caused by an excessive accumulation of scar tissue in different parts of the body, from the skin to small blood vessels. For reasons not completely understood, the mechanisms that usually control the accumulation of this tissue go awry, said Dr. Sergio A. Jimenez, director of the Scleroderma Center at Thomas Jefferson University Hospital in Philadelphia.

"So it keeps piling up. Just like strong, tough scar tissues can't be removed, it causes the skin to get thicker and affect the mobility of joints," said Jimenez, whose center draws people from across



the globe who have already been diagnosed or who need confirmation of the disease. "It can also go to the internal organs, lungs, where it can affect the transfer of oxygen, so they can't breathe well. Many other organs are affected, resulting in renal failure, renal crisis, heart failure and problems in the intestinal tract."

That range of symptoms can make it hard for people to get the care they need. It can take five to 10 years for someone to be diagnosed with scleroderma, often because the symptoms aren't seen as being related, said Christine Gaydos, executive director of the Delaware Valley chapter of the Scleroderma Foundation. About 300,000 people are estimated to have the disease in the U.S. Women are disproportionately affected, about six to eight times more often diagnosed than men.

"I think in the beginning it can mimic other disorders, like rheumatoid arthritis or just pain in the joints," Jimenez said.

(continued on page 3)

Living with Scleroderma: *(from page 2)*

"It takes a person who is aware of the disorder to actually make the diagnosis."

How it began

Crowl first experienced skin symptoms years ago, when he was working on airplane engines for the Delaware Air National Guard. He thought the color change in his hands -- from pink to white and blue in the winter -- was the result of working with jet fuel and other chemicals. But in 1997, he found out the discoloration was the result of Raynaud's phenomenon, which occurs in about 90 percent of scleroderma patients.

Two years later, he found out the bigger issue was scleroderma. As his skin has thickened, he has lost some mobility, particularly with bending over. He also has had to deal with hard-to-heal wounds and ulcers on his body, including one that kept him from sitting for more than half a year. That was difficult, his wife said, because it meant the car enthusiast couldn't spend hours behind the wheel of his 1972 GTO.

"But even with everything that comes up, he still keeps a good attitude," she said. "You'd never know what was going on." Because scleroderma is considered a spectrum disease, patients can experience a range of severity depending on what parts of the body are affected. Less-severe forms include hardened skin on hands and forearms, but more crippling cases can impact kidney, lung and heart function. Scarring also can

damage the esophagus, causing problems with swallowing and acid reflux. In the intestines, it can cause bloating, gas and constipation that last for days. The only part of the body not affected by scleroderma is the brain.

"I have my days when my stomach doesn't feel right, so I won't eat. When I really have it bad, I can't eat for a week or two weeks -- I just throw everything up," said Crowl, who lost 30 pounds during an episode last year.

Jimenez said although there is no cure for scleroderma, there has been progress in treating its complications, improving the quality of life for patients. In some cases, patients have had symptoms go into remission or their progression halted.

In the past, patients died from kidney related problems caused by scleroderma. But better treatment control, including dialysis, has reduced the number of deaths. These days, patients with scleroderma face the most risk from lung related complications, such as pulmonary hypertension, which occurs when the vessels in the lungs tighten, reducing the circulation of blood.

In addition to their symptoms, patients also have to deal with the challenges of living with a rare condition, Gaydos said, noting that scleroderma is considered by the National Institutes of Health to be a rare disease. That means educating people.

"People say, 'I've heard of it, but I really don't know a whole lot about it,'" Gaydos said.

WHAT IS SCLERODERMA?

Scleroderma is an autoimmune disease that affects connective tissues in the body. It causes changes in the skin, blood vessels, muscles and internal organs.

Hardening of the skin is one of the most visible signs of the disease, but this thickening of collagen also can happen to internal organs, including the lungs, heart and kidneys. It also can affect the intestinal tract, making it difficult to eat, swallow or get rid of waste in the body. About 300,000 people in the United States are estimated to have scleroderma. Women are six to eight times more likely to develop the disease than men.

Symptoms may include fingers or toes that turn blue or white in response to hot or cold temperatures (a condition known as Raynaud's phenomenon), joint pain and ulcers on the fingertips or toes, shrinking muscles and injured tendons. Patients frequently lose movement in their joints, especially the hands. The long-term prognosis for scleroderma patients depends on the severity of symptoms.

Contact Kelly Bothum at 324-2962 or kbothum@delawareonline.com.
SOURCES: Scleroderma Foundation, PubMed Health

Patient Education Seminar at the University of Pennsylvania

On March 10, 2012, the Scleroderma Foundation Delaware Valley Chapter sponsored a patient education seminar at the Hospital of the University of Pennsylvania. Over 80 patients and their families attended the seminar.



Thank you to Dr. Peter Merkel who gave an update on Scleroderma Research and Therapy, Dr. Chris Derk who spoke about Raynaud's disease, and Mrs. Juliann Niderostek, who spoke about scleroderma care from a nurse's perspective (see page 1). A power point presentation is available for Mrs. Niderostek's talk on our chapter website. Dr. Merkel, Chief of Rheumatology at the Hospital of the University of Pennsylvania, has recently arrived in Philadelphia from Boston University where he was a key member of the Boston University Scleroderma program. Dr. Derk, Associate Professor of Clinical Medicine and Fellowship Program Director at the Hospital of the University of Pennsylvania, worked for many years at the Scleroderma Center at Thomas Jefferson University. Mrs. Niderostek is a Clinical Nurse Specialist at Thomas Jefferson University. Again, we thank all of our speakers for sharing ways to cope with scleroderma and hope for a better future.

This program was made possible, in part, by unrestricted grants from Gilead Sciences.

Teri's Run Raises \$9500 for Scleroderma Research



The 10th Annual Teri's Run was held on September 9, 2011, in Downingtown, PA. This annual event is held in memory of Teri Valocchi who lost her battle with scleroderma. Over 500 people came out to participate in the 5K, Kid's Fun Run, and Walk. The organizers of Teri's Run transform downtown Downingtown into a family fun night and raise awareness of scleroderma at the same time. Money raised for research enables the Scleroderma Foundation to fund approximately \$1,000,000 in grants each year. We would like to thank the organizers and participants of Teri's Run for their generous donation.

Stepping Out To Cure Scleroderma 2012

WALK DATES ARE SET!!



SAVE THE DATE

Manasquan, New Jersey
York, Pennsylvania
Philadelphia, Pennsylvania

June 3, 2012
August 11, 2012
October 14, 2012

- **Walk to honor a family member or friend living with scleroderma****
- **Walk in memory of a loved one who battled scleroderma****
- **Walk to raise money for scleroderma research****
- **Walk to support patient education programs and support groups****
- **Walk to raise scleroderma awareness****

Form a Team on First Giving www.firstgiving.com/scl-dv

Download a Brochure from our website

All proceeds support the SFDV programs of scleroderma patient education, scleroderma awareness campaigns, and funding for research.

We need sponsors, volunteers, and walkers. For more information:

Website: scleroderma.org/chapter/Delaware_valley

Phone: 866-675-5545

Email: dvchapter@scleroderma.org

SCLERODERMA

Delaware Events



DELAWARE FUNDRAISERS

3rd Annual Delaware 5K Run and Walk April 15, 2012

Bellevue State Park in Wilmington, Delaware, was the site of the 3rd Annual "Stepping Out To Cure" Scleroderma 5K Run and Walk. Volunteers and participants came together to raise scleroderma awareness and raise funding for educational programs and research. Trophies were awarded to the top male and female runners, as well as medals for specific age categories. Frank and Catherine from Run The Day officiated the 5K cross country course and did a great job of making sure all the runners found their way to the finish line along the beautiful course. Once again we recognized the team with the most walkers - Team Sammons, and the team raising the most money in 2011, Crowl's Cruisers.

As always we would like to thank our volunteers who helped set up Pavilion #3 with refreshments, information, and T-shirts. Charlette Fletcher of my1stchoicechiropractic.com manned the lengthy 5K course. Lastly we thank our Scleroderma Board volunteers Joan Forrer, Tina Eckenrode, and Maddy Rudolph for handling the registration table.



Cruise for a Cure April 15, 2012

Congratulations to the Delaware Support Group who organized a highly successful car show, Cruise for a Cure, held at Mt. Pleasant High School in Wilmington. Over 120 cars entered this show to benefit the SFDV showing off their hard work restoring their cars and hoping to win a trophy in their car class or even Best in Show - Amazing for a show in its first year!! Great food from Backyard Louie's BBQ and TJ's Coffees, Inc., raffles including a handmade quilt by Annmarie Auld, music by DJ Jimmy Jet, a 50/50, and lots of sunshine rounded out a perfect day. Beautiful trophies were donated by local sponsors including the People's Choice award in memory of Roseanne Auld Krantz.

The best part of all is that no one left the show without becoming aware of scleroderma. The SFDV is thankful to everyone who took part in Cruise For a Cure 2012.



What is a Scleroderma Center?

The Delaware Valley Chapter is privileged to have two Scleroderma Centers in its territory, one at Thomas Jefferson University Hospital in Philadelphia, PA, and one at Robert Wood Johnson Medical Center in New Brunswick, NJ. There are many rheumatologists and specialists throughout the the SFDV region who treat patients with scleroderma, however, *what makes a Scleroderma Center?*



As scleroderma patients suffer from the effects of scleroderma in many different organs, they will most likely be treated by 2, 3, or more specialists. This may include a gastroenterologist, dermatologist, pulmonologist, or a cardiologist. The core of a Scleroderma Center is its Department of Rheumatology and the experts there. As a patient needs to be evaluated by other specialists, the Scleroderma Center provides access to these other doctors and nurses as part of a network. The specialists working together in a Scleroderma Center have also chosen scleroderma as part of their career focus, but more importantly, are part of a loop of care that comes back to the rheumatologist. A procedure by radiology and testing in the clinical laboratory are also part of the patient care loop and is centralized in a Scleroderma Center.

Research is also an important aspect of a Scleroderma Center. There are multiple clinical trials such as studies to evaluate new medications and treatments being performed at Scleroderma Centers. Some of these studies are National studies being conducted at other Centers as well. Many doctors and scientists are also doing basic research such as studies in mice or in tissue culture. They come together to focus on scleroderma and other autoimmune diseases with the hope of finding the path to a cure.

For more information about the Delaware Valley Chapter Scleroderma Centers contact:

University of Medicine and Dentistry of New Jersey

Robert Wood Johnson Scleroderma Program, 125 Paterson St., 5th floor, Clinical Academic Building, Robert Wood Johnson Medical School (RWJMS), New Brunswick, NJ 08903

Clinic Information: Adult patients seen with morphea localized and scleroderma spectrum disorders

Hours: New patients seen on Tuesdays 8 AM to 12 noon. Follow up patients seen on Wednesdays 8 AM to 5 PM.

Appointments and information: (732) 235-7217 Fax: (732) 235-6526

Physician inquiries: (732) 235-7217. Leave a message or ask for the nurse

Physicians Affiliated with this Center: Vivien M. Hsu, M.D. Director, UMDNJ Scleroderma Program

Research Information: We are actively involved with multiple clinical trials of novel treatments and anti-fibrotic agents for systemic sclerosis. Our research aims to find better treatment options for pulmonary fibrosis, pulmonary hypertension, Raynaud's, digital ulcers, myopathy, and other complications seen with this devastating disease.

Contact: Research coordinators: Debbie McCloskey, R.N. (Nurse Manager, Clinical research Center), Helina Malveax, and Fei Chen at (732) 418-8484

Thomas Jefferson University Hospital, Philadelphia, PA

The Scleroderma Center, 833 Chestnut Street, Suite 740, Philadelphia, PA 19107

Appointments and Inquiries: 215-955-6680

Physician Inquiries: 215-503-5042

Physicians Affiliated with this Center: Sergio Jimenez, M.D., M.A.C.R.

Division of Rheumatology, 211 S. 9th Street, Suite 600, Philadelphia, PA 19107; 225 E. City Line Avenue, Suite 109, Bala Cynwyd, PA 19004

Clinic Information: Pediatric and adult patients with systemic and localized scleroderma are seen, as well as patients with other fibrotic autoimmune connective disorders

Website: jeffersonhospital.org/rheumatology/index.html

Hours: Monday-Friday 8 AM to 5 PM (hours may vary in each clinic)

Appointments: Philadelphia Clinic 215-955-8430 Bala Cynwyd Clinic 610-664-0134

Physician Inquiries: 215-955-1410

Physicians Affiliated with this Center: Nora Sandorfi, M.D. Nora.Sandorfi@jefferson.edu

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)

Kathleen Sammons, 302-482-2890, waffy606@aol.com or Angie Crowl, 302-425-5054, anglcrowl@aol.com
Once a month on Wednesdays at 6:15 pm – next meeting May 16
Woodlawn Library, 2020 West 9th Street
Wilmington, DE 19805
302-571-7425

NEW JERSEY

Cherry Hill, New Jersey (Burl-Cam)

John Keegan, 856-767-4783, johnkeegan@comcast.net 2nd Thursday of every other month starting in January at 1:30 pm – May meeting is 3rd Thurs on May 17th
385 Kings Highway North, Cherry Professional Building, Cherry Hill, NJ 08034
856-779-7225

Warren, New Jersey (Watchung Hills)

Ellen Waldstein, 908-647-7266, ellw@optonline.net
Chris Frascella, 908-604-6054 (co-leader)
Tuesday at 1:00 pm, quarterly – June 12 at 12:00 pm* (potluck lunch at leader's home), September 11, November 13
Trinity United Church
118 King George Road
Warren, NJ 07059
732-469-5044

Woodbury, New Jersey

Mary Nuzzo, 856-582-6456, marynuzz@msn.com
1st Tuesday (or Monday) of the month, quarterly at 7:00 pm – June 4 (Monday), September 4 & December 4
Underwood Memorial Hospital
Medical Arts Building (adjoining building) – Suite 14
509 North Broad Street
Woodbury, NJ 08096
856-845-0100
Please contact support group leader prior to attending meeting.

PENNSYLVANIA

Doylestown, Pennsylvania

Mary Gocek, 908-256-3408 or Desiree Bleam, 215-249-1132, desireealan@verizon.net
4th Monday of the month, quarterly at 6:30 pm – June 25, September 24, November 26
Doylestown Hospital
Conference Room G (main entrance elevators to ground floor, go right off elevator)
595 West State Street
Doylestown, PA 18901
215-345-2200

Langhorne, Pennsylvania (Bucks County)

Telephone contacts for support:
Ilene Nusblatt, 215-321-1670, inusblatt@comcast.net
Sharon Durham, 215-638-2771

Philadelphia, Pennsylvania

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

Dawn Batzel, 610-287-1445, happy81070@verizon.net
2nd Saturday of every other month at 10:00 am – May 12, July 14, September 8, November 10
Reading Pediatrics office
40 Berkshire Court, Wyomissing, PA 19610
610-374-7400

Williamsport, Pennsylvania

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
June and December meetings held at 1:15 pm at Grace Buffet, 811 N. Loyalsock Ave., Montoursville, PA 368-8666

York, Pennsylvania

Kathleen Gaskell-Blankenship, 717-428-1464, karlkathleen@earthlink.net
Meets quarterly on Wednesdays at 7:00 pm – May 2
Elmwood Mansion Conference Center
400 Elmwood Blvd. (Corner of S. Belmont St & Elmwood Blvd), York, PA 17402
800-436-4326



E-mail Support Group

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
Co-leader for Ocean County/
Toms River Area
Monmouth County Area
New Brunswick Area

Pennsylvania

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

**NEWSLETTER OF THE SCLERODERMA FOUNDATION
DELAWARE VALLEY CHAPTER
385 KINGS HIGHWAY NORTH
CHERRY PROFESSIONAL BUILDING
CHERRY HILL, NJ 08034**

UPCOMING EVENTS

April 28 – Bike Run, Wilmington to Smyrna, DE

May 5 – Sjogren's Health Fair, Philadelphia Zoo, PA

May 16 – Health Fair, Cherry Hill, NJ

June 3 – Stepping Out to Cure Scleroderma Walk, Manasquan, NJ

June 11 – MacCutcheon/Lacy Golf Outing, Monroe, NJ

July 27-29 – National Conference in Dallas, TX

August 11 – Stepping Out to Cure Scleroderma Walk, York, PA

September 7 – Teri's Run, Downingtown, PA

October 14 – Stepping Out to Cure Scleroderma Walk, Philadelphia, PA

October 27 – Educational seminar, New Brunswick, NJ

November 22 – Thanksgiving Parade, Philadelphia, PA

TBD – Scleroderma Day at the River Sharks, Camden, NJ

Check our website at www.scleroderma.org/chapter/Delaware_valley for news and information. Check out our Facebook page for frequent postings at www.facebook.com/pages/Delaware-Valley-Chapterfor-Scleroderma-Foundation/179200360685

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

Scleroderma Foundation
Delaware Valley Chapter
385 Kings Highway North
Cherry Professional Building
Cherry Hill, NJ 08034
856-779-7225
866-675-5545
DVchapter@scleroderma.org
www.scleroderma.org/chapter/delaware_valley

