

TEXAS TALK

Scleroderma Foundation – The Texas Bluebonnet Chapter Newsletter

Summer 2011



**SCLERODERMA
FOUNDATION**

SUPPORT • EDUCATION • RESEARCH



Shaking

things up for Scleroderma

**Scleroderma
Foundation**
Texas Bluebonnet Chapter



BOARD OF DIRECTORS

Denise Roberson, President
Marianne Nelkin, Vice President
Treasurer, Tina Villegas
Secretary, Larry Preston

Virginia Browne
Dr. Chelsea Clinton
Ne'Cauje Turner
Emily Woods
Amber Paris

EXECUTIVE DIRECTOR

Cindi Brannum

MEDICAL ADVISORY BOARD

Frank C. Arnett, MD, Rheumatologist
Bruce A. Baethge, MD, Rheumatologist
Gowri Balachandar, MD, Gastroenterologist
Trish Borman, PhD, Psychologist
Chelsea Clinton, MD, Internal Medicine
Melissa Costner, MD, Dermatologist
Alexander Duarte, MD, Pulmonologist
Heidi Jacobe, MD, Dermatologist
Mark D. Khorsandi, MD, Hand Surgeon
Maureen D. Mayes, MD, Rheumatologist
Philip L. Nauert, DDS, Dentist
John C. Paris, DMD, Dental
Larry D. Scott, MD, Gastroenterologist

Disclaimer: The Scleroderma Foundation in no way endorses any drugs or treatments reported in this newsletter. Information is provided to keep readers informed. 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 the reader's physician (s) for proper evaluation and treatment.



Letter From Our President

Page 2

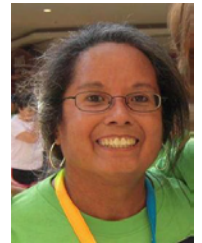
We have had a GREAT start to this year. We hosted the first gala of the year with the Hula for Hope, we have held a state wide garage sale, and we have many more events to go!!

There are so many ways to get involved with the Texas Chapter and YOU can make a difference. Attend a walk, host a garage sale, help with a support group, write a letter to your Senator and ask for their support, or come and hear Dr. Maureen Mayes speak in Amarillo.

Big or small, everything counts in helping us find a cure for Scleroderma. Come and join us this year, because YOU are what makes Texas great!

Keep Shining,
Denise Roberson

Executive Director's Corner



Since January, the chapter has been planning and prepping for upcoming events.

The all state garage sales have rallied the SG leadership and their members in a cohesive manner and many look to hosting one again next year. Currently we are coordinating our own garage sale in Allen next weekend as well as prepping for the Dallas walk in June.

I want to take this time to thank all the volunteers who continue to serve the Texas Chapter through their leadership of a support group and/or by being a member who faithfully participates in chapter events in their local city. We do need you and appreciate all you do!

Looking forward to a fantastic 2011!
Cindi Brannum

Calendar of Events

Corpus Christi	Stepping out to Cure Walk	June 11 th
Dallas Forth Worth	Stepping out to Cure Walk	June 25 th
Houston	Stepping out to Cure Walk	July 23 rd
Patient Education Day	Dr. Maureen Mayes in Amarillo, TX	August 6th
Longview	Stepping out to Cure Walk	October 8th
Patient Forum	Hosted in Allen, TX	November 12th
Corpus Christi	Tennis Tournament	December 3rd & 4th



Ms. Woods Goes to Washington

Last year we were rallying for a Bill that was never heard on the Senate floor and it did not get passed. Because it was never heard, we have to start over again this year with the same process. The Bill is the same Bill, The Scleroderma Research and Awareness Act, but it has a different Bill number for 2011. The Senate Bill is now **The Scleroderma Research and Awareness Act (S. 649)**. We need YOUR support. Please call our two Texas State Senators and asking for their support for this very important step in finding a cure for Scleroderma. Read below to find out how you can support this Bill.

SCLERODERMA RESEARCH AND AWARENESS ACT" (S. 649)

Senator Kirsten Gillibrand (D-NY) has **reintroduced** legislation in the U.S. Senate to increase federal funding for Scleroderma research and begin the first ever federal public awareness program on scleroderma. **The Scleroderma Research and Awareness Act (S. 649)** is an excellent opportunity to raise awareness of scleroderma among members of Congress and other policymakers in Washington. All Scleroderma Foundation advocates are urged to contact their Senators (2) and ask them to become a co-sponsor of **The Scleroderma Research and Awareness Act (S. 649)**.

For your convenience the numbers for your 2 Senators are listed below:

1. Kay Bailey Hutchison - 202-224-5922
2. John Cornyn - 202-224-2934

Talking Points for calling your Senator's Office:

- ◆ Identify yourself as a constituent and ask to speak with the staff member who handles health issues.
- ◆ Explain what scleroderma is and briefly tell your story about living with the disease.
- ◆ Explain that Senator Gillibrand from New York has introduced a bill calling for increased funding for scleroderma and the first ever public awareness program on scleroderma and that it is designated as S. 649.
- ◆ Ask them to contact Karina Cabrera in Senator Gillibrand's office and become a co-sponsor of S. 649 at (202) 224-4451.
- ◆ Thank them for their time and ask them to advise you of the action they took in response to your request (leave your contact information).
- ◆ If you would prefer to send an email to your senators instead, information on how to do this is available on each senator's webpage by following the instructions below. To go to Kay Bailey Hutchison's or John Cornyn's personal website: http://www.senate.gov/general/contact_information/senators_cfm.cfm?State=TX. Fill out the required information, choose **Healthcare** in the subject drop down menu, enter **Scleroderma** as the subject of your message. Write your brief compelling story and how the "Scleroderma and Research and Awareness Act" S. 649 relates to you in the message block. In closing, ask them to support **The Scleroderma Research and Awareness Act (S. 649)** - then click the "Submit Information" tab and you are done.

A Walk Around TEXAS



Carl and Joey Briggs celebrated their 38 years of "happily ever after" on April 15th at Morton's Steakhouse in Dallas. They had won the Dining Out package in

the silent auction at the Texas Chapter's Hula for Hope on New Year's Eve. It contained several wonderful dining gift cards, including the one for Morton's, and they had saved the card for this special occasion. Joey is a support group leader for the Allen/Collin County support group.

your dedication and hard work! We appreciate and love you!"

HULA FOR HOPE New Year's Eve 2010



The Texas Chapter held its first gala event, a benefit luau this past New Year's Eve.

The "Hula for Hope" luau chose the beautiful Cooper Conference Center in Dallas, better known for its health and wellness programs created by Dr. Kenneth Cooper. We celebrated the turning of a new year and enjoyed all the Chapter festivities which included an authentic hula show brought in by Keola Hula Halau, the 50/50 Cash Prize Raffle, and a very hotly contested Silent Auction (21 entries). Several support groups within Texas sent up their auction basket to show representation of their cities. A huge 'shout out' goes to our newest support group in the Rio Grande Valley, whose donors sent up a variety of home-grown items from the southern most tip of Texas.

We look forward to our next NYE "Hula for Hope" luau benefit at the end of this year. Y'all come join us!! Aloha pumehana (warm-hearted love)! To see all the great moments from the Hula for Hope luau, check out the video link below:

<http://www.youtube.com/watch?v=oojz11anpHE>

STATE WIDE GARAGE SALES!

On April 30th the Texas Bluebonnet Chapter held a state wide garage sale in which the Chapter's support groups held a garage sale in their own city all on the same day. We had six support groups host their own garage sales: Austin, Corpus Christi, Longview, Paris, Rio Grande Valley, and San Antonio. All together they raised over \$4,000!! Way to go Texas!! At the Rio Grande Valley garage sale they had people showing up and they hadn't finished even setting up yet. At the Longview garage sale, the E.L.K.S. Lodge donated their building to host the garage sale on Friday and Saturday. So after you do your spring cleaning, you can have a garage sale too and help us raise awareness and funds for the Texas Chapter Scleroderma Foundation.



Life is Merely What I Call It! Poem By: Shirul Patel

Lazy days
Hungry days
Tearful days
Friend days
Sleepy days
Brownie days
Uplifting days
Pill days
Movie days
Cold days
Wine days
Sunny days

Energetic days
Sad days
Tempting days
Family days
Bad-hair days
School days
Ulcer days
Frustration days
Rainy days
Restful days
Stomach day

PARIS SUPPORT GROUP



We have just had our 2nd Anniversary ! Our group was formed by Jean Shannon, who was diagnosed with Scleroderma a few years ago. She wanted to meet others with her disease and learn more about it. So she placed a tiny little ad in a local Penny Saver type newspaper and paid for it herself. The ad read: **Do you have Scleroderma? If interested in joining a Support Group call 903-739-9578.**

Our group is small and intimate, and we are like family. On behalf of the Paris Support Group we would like to say, "Thank you Bluebonnet Chapter, the Scleroderma Foundation, and last but not least, Jean for



What's for Sale?

TBC Storehouse

SF Letter Opener	\$1.00 each
SF Awareness Pin	\$2.00 each
SF Rubber Wristband	\$2 each
SF Koozie	\$3.00 each
SF Car Magnet	\$3.00 each
SF Flashlight Key Chain	\$3.00 each
SF Nylon Drawstring Bag	\$5.00
SF Stainless Water Bottle	\$10.00
Scleroderma Cookbook	\$10.00
SF Glass Tumblers, etched logo	set of 2, \$10.00
SF Umbrella (navy & white)	\$15.00
SF Roll-Up Blanket	\$15.00
SF Lunch Tote (black, grey, blue)	\$15.00
Ladies SF Polo Shirt	\$20.00
The Scleroderma Book	\$20.00
Yoga & Caregiver DVD	\$30.00
SF Awareness Silver Bracelet	\$50.00

Buy your own polo or denim shirt and we will have the SF logo put on it for \$5 plus the postage (Postage is \$2 for the first shirt and \$1 postage for each additional shirt)

To place an order or for more information on any of the items for sale, please contact the Texas Chapter Office.

Contact Us

Scleroderma Foundation
Texas Bluebonnet Chapter
101 W McDermott, Suite 117
PO Box 1836
Allen, Texas 75013

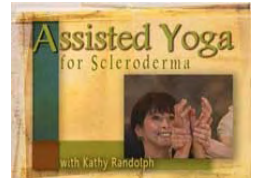
972.396.9400 OR
1.866.LEARNSF

FAX: 972.649.7910

EMAIL:
TXChapter@scleroderma.org

Assisted Yoga for Scleroderma with Kathy Randolph

A therapeutic program of yoga poses and breathing techniques selected for the benefit of those more severely affected with the symptoms of scleroderma. All sequences are performed at three levels of assistance, with complete instruction for both the individual and the assistant. Kathy Randolph is a certified instructor of Yoga for the Special Child™, a Certified Hatha Yoga Instructor, and co-owner of The Yoga Center in Reno, Nevada. 2 DVD set.



Scleroderma Awareness Silver Bracelet

Byzantine is one of the most beautiful and most complex chain weaves in the world. This handcrafted bracelet is made of 18 gauge base metal coated with a layer that is .15 to .25 mil of silver. The jump rings are interwoven into this ornate patterned design. This is a 3-hour weaving process! The bracelet is finished off with faceted round Swarovski crystals, with the Scleroderma awareness charm in teal blue and connected with a sterling silver antique Bali magnetic clasp. This beautiful bracelet will be a treasured heirloom for years to come!

(Design and hand craftsmanship by Pam Carcido whose sister is our own E.D. Cindi Brannum)



These programs are made possible, in part, by an unrestricted grant from Actelion Pharmaceuticals, U.S.

ALLEN/COLLIN COUNTY, Allen Support Group: Meets the first Sunday of every month, 3–5:00 p.m. at Texas Health Resources Hospital. The meetings will be held in Conference Room #1 (main floor, right hall), Refreshments will be provided. **Support Group Leaders:** Emily Woods, 972-342-7797, Joey Briggs, 972-234-8899, or Jean Brown, 972-390-8258, allen@scleroderma.org

AUSTIN, Austin Support Group: Meets the third Sunday of every month, 2:30–4 p.m. at North Austin Medical Center, 12221 Mopac Expressway N., at the Parmer Lane Exit, Austin, Texas, in Classrooms one and two, 2nd floor, at the main entrance (signs on doors). **Support Group Leaders:** Scott and Julie Tefft, 512-863-0039, Joan Maril, 512-301-8869, austin@scleroderma.org

CORPUS CHRISTI, Corpus Christi Support Group: Please call for meeting dates and times. Meetings at The Heart Hospital, 7002 Williams Dr., Corpus Christi, Texas. **Support Group Leaders:** Shawn Sullinger, 361-547-3281 or Steve Armijo, 361-937-5563, corpuschristi@scleroderma.org

EL PASO, El Paso Support Group: Meeting dates are on even numbered months from 10:30am-12:30pm at the United Blood Services, 424 S. Mesa Hills, in the Community Room. **Support Group Leaders:** Manny Guterres, 915-584-2506, Billy McCain, 915-591-4075, Marianne Nelkin, 915.584.6504, elpaso@scleroderma.org

FT WORTH, Ft Worth Support Group: **Support Group Leaders:** Marion McAllister, 817-924-7591, Gay Jordon, 817-713-3942, and Amber Paris, 817-577-7020

HOUSTON, Houston Support Group: Meets on the second Sunday of every other month from 2-4 p.m. at Memorial Hermann NW, 1635 North Loop West, South Tower, Meeting Rm. B. **Support Group Leaders:** Shirul Patel, 281-773-6916 and Bhoomieka Patel, 832-613-2131, houston@scleroderma.org

LONGVIEW, Longview/Piney Woods Support Group: Please call for meeting dates. Meetings are from 2–4 p.m. at the Regional Hospital, Senior Circle, 3000 North 4th Street, Longview, Texas. **Support Group Leader:** Shirley Sawyer, 903-987-1822, Larry Preston, 903-734-1210, longview@scleroderma.org

LUBBOCK, Lubbock Support Group: Meets on even numbered months from 1–3 p.m. at Knipling Educational & Conference Center, corner of Louisville and 21st. **Support Group Leader:** Mickey Goodwin 806.794.1507, Dahlia Ponciano, Chris Zavala, 806-368-6777, lubbock@scleroderma.org

PARIS, Paris Support Group: Meets every other month from 3–5 p.m. at Paris Regional Medical Center, 820 Clarksville St. south campus conference room C, 903-785-4521, . **Support Group Leaders:** Jean Shannon, 903-739-9578, or Laurie Badgley, 903-715-0215, paris@scleroderma.org

WESLACO, Rio Grande Valley Support Group: Please call for meeting dates and times. Meet at the Knapp Medical Center, 1401 E. 8th St., Conf Room 9. **Support Group Leaders:** Berty Valdez, 956-874-3897, Carol Good, 956-607-1189, and Lorena Vasquez, 956-328-6898, rgv@scleroderma.org

SAN ANTONIO, San Antonio Support Group: Meetings are every 3rd Sunday per month from 3-5 p.m. at University Hospital, 4502 Medical Drive, Cafeteria 3rd Floor “Foundation Room” (unless otherwise directed), 210-358-4889, **Support Group Leaders:** Jovana Desarden, 210-909-9375; Denise Horan, 210-380-6162, Debbie Charlton, 210-690-2224, sanantonio@scleroderma.org

WACO, Waco Support Group: Meets on odd numbered months from 3–5 p.m., at Providence Medical Center, Classroom 3 & 4, 6901 Medical Parkway. Support Group Leader: Sue Fitch, 254-799-3222, **Support Group Leader:** Jennifer Andrews, 254-235-3952, waco@scleroderma.org

Support Groups provide a forum to share feelings, concerns, information, and as well as a place to offer peer support and encouragement. Solicitations or research projects are not conducted at support group meetings. Support groups often feature speakers specializing in scleroderma or related topics. To find out information about upcoming speakers or meeting topics, please contact the support group leader or chapter office. This schedule is subject to change. Before attending a group for the first time, please call to verify date and time. Groups are free of charge and open to everyone.



SPOTLIGHT



Story by Caroline Clemens

While waiting for the ferry to tour Alcatraz, my grandmother and I treated ourselves to a couple of Cokes on a beautiful summer day in San Francisco. The air was warm, the vacation was fun, and we were excited to tour every inch of the celebrated city. I didn't think much when I had to ask her to open the plastic Coke bottle.

Shortly thereafter I returned home to start my third year teaching high school English in Allen, Texas. A new year brought new hope. This year was going to be a great year. And it was. I had no complaints, school-wise. At home however, mundane chores started to take their toll. Drying my hair became increasingly difficult. Turning my steering wheel was a daily reminder of a bizarre stiffness. So, I took action and spoke to my general physician who later referred me to a rheumatologist. A few months later I had a diagnosis – arthritis. It bemused me, but I could handle it. So what; I take a few pills a day and I feel fine. At 23, I found it odd to be diagnosed with arthritis, but I could handle it. Two years passed and I took my pills, went to my appointments, and continued teaching. It took two years for my rheumatologist to even mention the word Scleroderma. I'll never understand why it took that long, but when compared to some of my friends with Scleroderma, two years of misdiagnosis isn't that uncommon.

In the meantime, the

years passed and I worked hard at teaching. It was my dream job. I loved my connection with students, my friendships with colleagues, and my ability to pass on my love of learning. Life was great again, minus taking a few pills here and there.

Then, in 2007, teaching wasn't really enjoyable anymore. Walking upstairs to my classroom became a difficult task, and suddenly, walking to the front of the classroom left me breathless. At home doing the laundry, tying my shoes, dressing myself – all of these ordinary tasks took the wind out of me, and it wasn't long before walking down the halls in my school became tiresome and daunting. I couldn't even walk up the handicap ramp from my car to the school's entrance without stopping to catch my breath. Under the guidance of my new rheumatologist, I took my first Pulmonary Function Test. What followed were a series of tests that were foreign to me. Echocardiogram. Cardiac MRI. Right Heart Catheterization. And they all showed what had been bothering me. The diagnosis meant little to me, as I had never heard the term before – Pulmonary Hypertension secondary to my Scleroderma.

More pills. At first, they made me feel better, but eventually I had to add more and more. Between a handful of pills and a horrid clinical trial that left me grossly underweight, in 2008 I ended up on a continuous IV medicine called Flolan.

It was then that life was good again. I could breathe! I could walk! I could do anything! I loved teaching all over again. Mixing my medicine every night was a chore, but it was absolutely worth it to have my life back. I thanked God for my doctors, my medicine, and my newfound freedom.

Sadly, only a year passed and my health started to decline again. With Scleroderma, Pulmonary Hypertension, and a continuous IV, I didn't know it could get worse, but it did. September 6, 2009 marked my first day of an extended stay in the hospital, and forty three days later, I left University of Texas Southwestern Medical Center with a new peritoneal catheter for at-home dialysis. Losing my kidneys early in the school year set me back more so than I imagined and I began what would be a year of sporadic teaching. Nightly ten hour dialysis took every ounce of energy out of me. Likewise, between cleaning my two catheters (one for my Flolan and one for dialysis) and mixing my IV medicine for my PH, my boyfriend and I spent at least an hour at home prepping for my life saving daily therapy. My body and mind were weak and exhausted.

I lied to myself and said I could return to teaching in January and I did. My school had hired a co-teacher and together we taught. I only lasted two and a half months before my stroke. My ICU nurses welcomed me back with open

arms. Two weeks of my life had passed before I came-to in my hospital bed. Recovery, rehabilitation, and physical therapy were imminent and I quietly spent the rest of the school year at home.

My body had been through so much. My mind was mush. I was shockingly skinny and frail.

I suppose I could look back at all my misfortune and feel sorry for myself. Early on in this adventure I'd ask, "Why me?" But those thoughts have since left my mind. Living with Scleroderma, battling Pulmonary Hypertension, losing my kidneys, surviving a stroke – these are all merely chapters in my life. They don't define me. I'm not a sick person. For me, Scleroderma was the birth of a thousand tears, a handful of painful memories, and a few mental and physical scars. But, it has also served as a vehicle for my religious awakening, my intensely close relationships with my family and friends, and my eternal positive outlook on life.

It is overwhelming to think of where I've been and where I am now. Today I'm back, working full time, living the life that I want, so grateful to be able to share my time with my students, family, and friends. And now, instead of asking "Why me?," I ask, "Why not me?" After all, people keep saying that I'm a living miracle, and I'm beginning to believe them.