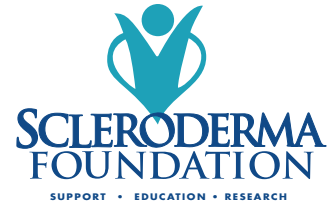


NOT ALONE

Texas Bluebonnet Chapter Newsletter

July 2008



Walking, Walking, Walking!!!

This year Texas increased the number of fundraising walks from two to three. Houston, our longest continuing walk, was held on April 27th and hosted 162 participants for the 6th annual walk.

The Corpus Christi walk shortly followed on May 10th, with 29 participants at their 3rd annual walk.

And we are very proud to welcome the DFW walk, which will be held as this goes to press, on June 28th. The Texas Chapter is excited to add this walk to our annual walk events and will report on the outcome of this walk in the next newsletter!

The 6th Annual Houston Walk

April 27, 2008 was promised by the weatherman to be a very cold and rainy morning. But that did not stop the West Houston and Conroe support groups of the Texas Bluebonnet Chapter from setting up for their 6th annual 5K walk and fun run. The walk committee showed up at Bear Creek Park eagerly at 5:30 am, and the volunteers and sponsors showed up soon after.

Dr. Maureen Mayes was the honorary guest runner and wore bib #1. She took time to shake hands and mingle with patients, most of whom she knew, and meet their families.

The walk went in three stages: the runners, the kids, and then the walkers. At 8:00, the runners were off! And then it was time for the 1K kids run. Children from two to twelve years old ran to their markers and back across the finish line along with clowns Suzzala and Sunshine. Each child received a medal for completing the race. Last, but not least, the 5K walkers, which included families with children and grandparents alike, lined up and walked the double loop through the shady park.

As the participants finished the walk, everyone congregated in the pavilion for food, and the awarding of sponsor gifts and door prizes. Somehow the rain held off and the event was enjoyed by all!



Dr. Mayes, #1 honorary guest runner, and others get ready for the run!

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Overall, 162 walkers and runners showed up in support of the Scleroderma Foundation! We cannot thank all of these participants enough, as well as the 60 volunteers, 18 sponsors and all of the donors for making this event a huge social and fundraising success! Together we raised awareness for this disease which is part of the Scleroderma Foundation's three-fold mission and we couldn't have done it without you!



Right: Houston 1K kid participants and clowns Suzzala and Sunshine show off their medals.

The 3rd Annual Corpus Christi Walk



Above: Walkers enjoy the scenery and the USS Lexington, a Corpus landmark. **Below:** Out-of-state participants walk in memory of a loved one.



On May 10th, Corpus Christi held their walk along the seawall of the Gulf of Mexico. Participants traveled from all over Texas as well as the nation, including Delaware, Kentucky, California, Virginia and Michigan! Patients, care givers, friends, and family members walked in honor and memory of loved ones.

Everyone was eager to share how Scleroderma has affected them, and there were many heartwarming stories. The walk was held the day before Mother's Day making the whole event even more touching.

Gina Stimson, patient and owner of *Absolutely Everything* in Port Aransas, saw an advertisement for the walk and immediately registered and started a Firstgiving fundraising page online. She was the top fundraiser! Gina's sons, Jared from Ft. Worth and Chase from Waco, surprised their mother by arriving the night before to support her. They walked alongside Gina and her husband, Larry, in her honor.



Above: Gina Stimson and her family.

Another woman, vacationing from out-of-state, saw the walk advertised on Corpus Christi's online calendar of events. She lost her mother to scleroderma years earlier and 'escapes' each year on Mother's Day weekend. She and her friend felt impelled to spend their morning running in memory "4 MOM" and "4 GAIL."

The weather and people attending made for a lovely walk. And, we raised nearly \$5,000. Thank you to all the sponsors, volunteers, and the entire Villarreal family for your participation in making the Corpus Christi walk a success, 3 years in a row!

The Johnson Sistas

The Johnson Sistas (Michelle Sanderson, Maria Shelton, Laura Varney, Kim Miller, Deanna Girard, and Maria Smith) are a group of military wives that came together at Fort Knox, Kentucky in 2004. We all lived in the Johnson housing area and hung out at the park everyday while our kids played. We became as close as sisters. Most military families lose touch after they move away from each other, but we have all maintained contact and have committed to an annual girlfriend reunion to coincide with a Scleroderma Walk in a different state over a 50 year period.

The Scleroderma Walks started when we noticed that Michelle's hands, nose and mouth looked a little different than ours. She explained her disease and what it could do to her. We knew that she was chosen to be a Scleroderma pioneer to help find a cure and we knew we were chosen to be her helpers. We could all make a bigger difference if we pulled together and spread the word, raised

money for research and were proactive in the cause. We are a loud bunch, so talking about Scleroderma to anyone that will listen is no problem at all! We all regularly wear our t-shirts from past walks and make the Scleroderma disease a part of everyday conversation. We just celebrated our 3rd annual girlfriend reunion with a Scleroderma walk in Corpus Christi, Texas. The first year we walked in Nashville, Tennessee and the second year we walked in



Left to Right: Tina Villegas (CC Support Group Leader), Cindi Brannum (SFTBC President), Sherry Sterling (Actelion Patient Representative) and the Johnson Sistas!

Birmingham, Michigan. Every year the group grows a little bigger. Melissa Dowd, a long time friend of Michelle's, became an honorary Johnson Sista at the Michigan walk and is committed to the 50 year plan.

Special Recognition to a past participant!

In May 2008, the national office of the Scleroderma Foundation announced the winner of the most funds raised by an individual for walks held during 2007 nationwide. And the winner is.... Joe Palumbo!

Joe Palumbo ran in the 2007 Stepping Out to Cure Scleroderma 5K Run in Houston. He ran in honor of his mother and his sister, both Scleroderma patients. Joe's mother lives in Houston and his sister lives in New York.



Joe Palumbo at the 2007 walk in Houston.

Joe registered for the walk online and created a Firstgiving pledge page. Once pledges began coming in, a friendly competition started between Texas and New York. The winner was the Texas Bluebonnet Chapter! Joe raised nearly \$15,000 to help the foundation with their three-fold mission of support, education, and research.

The Texas Bluebonnet Chapter would like to congratulate and thank Joe for his hard work and dedication to this cause!

Our advice to other folks with this horrible disease is to take it day by day, make sure to do your hand exercises, always wear an oven mitt while reaching into the refrigerator, laugh out loud A LOT and spread the word about Scleroderma. Ironically, this disease has brought our group to a higher level of appreciation. All of our lives are different now. We have a stronger belief, more reasons to smile and don't let the little things bother us. We live with the fear that this disease will take our friend, but that just makes us stronger in the fight!

- Maria Smith

A Patient's Journey

At first, it was a good excuse to quit playing the flute. I was 14, in junior high, and suffering like all adolescents with a need to



find an identity, and band geek was not it. When I began to get small calcifications or ulcers on the tips of my fingers, I complained to my mother that playing the flute was painful. I wasn't any good at my instrument anymore anyways, as my lips were begin-

ning to thin out, not good for the pucker of a flautist. I was thrilled when they allowed me to sit in the choir room and play music computer games with the boy with a broken arm instead of participating in band class.

Luckily, my mother worked for a dermatologist at this time, and her boss was able to piece together my symptoms. I had been diagnosed with Raynaud's the previous year, and now I had the calcifications on the tips of my fingers. They sent me to a rheumatologist in Denver, and I spent the day getting x-rays and skin biopsies. All of my tests verified the dermatologist's initial diagnosis... Scleroderma.

This is a tremendous shock for everyone who is newly diagnosed. No one has heard of it, the doctors don't know what causes it, and they really don't know what to do to treat it. The word chronic at the age of 14 has no relative meaning. I was petrified; however, more than this, I did not want to be different than my peers, so I hid it. I ignored it. Only my best friends even knew I was sick. I rarely took my medication, and I went about my days like any rebellious teenager.

Luckily, my disease progression was slow and allowed this... to a point. My second year of college, during final

exams, my kidneys failed. At this point, I could no longer ignore my illness. It demanded my attention. Through the next couple of years, usually during final exams, I began to lose circulation in my fingers spontaneously, like spontaneous frostbite. It is a painful experience, which they have little success in treating, and usually ends in partial loss of the fingertips. Throughout these trials and all of the other symptoms that Scleroderma can throw at you, mainly gastric, I managed to continue leading my life. Through nerve blocks, IV drips, nitroglycerin paste, TPA, hyperbaric chamber treatments, and finally a move to Texas and a lower elevation, I managed to maintain a balance, giving Scleroderma the front seat when it absolutely required it, but pushing it to the back whenever possible.

Although I often had to take my exams at a later time, I completed my Bachelor's Degree from the University of Colorado. I enjoyed college thoroughly and received good grades. I fell in love, and I got married to a wonderful man. Four years ago, we had a baby girl, who is the joy of our life. Also, I've always been able to work, until very recently. It's been an amazing life so far. It may not be a "normal" life, but whose is?



Above: Amber and her daughter, Jacelyn.

I think people often feel sorry for me. If I'm going to be honest, sometimes I even feel sorry for myself. However, I learned very early that Scleroderma has been a blessing in my life, and I'll tell you why. My family is the closest family I have ever seen. We do not take each other for granted. I do not take life for granted. All of the accomplishments

I listed above and many more, including recently committing to co-lead my local support group, are amazing to me. They are treasures that I am so thankful for. If I were a healthy, "normal" individual, I might regard these events as normal and as my right. However, growing up dealing with this disease, I can clearly see how lucky I am every day, and that is a true blessing in itself.

- Amber Paris

2007 PASS TOURNAMENT

The Patty Ann Spence Schreckenbach (PASS) mixed doubles charity tennis tournament has been held the first weekend in December for the last three years in loving memory of Patty Schreckenbach, who passed away peacefully on April 16, 2005 after complications from scleroderma. Patty had many interests and talents,



Above: 2007 Junior division participant.

one of which was her love of tennis. She was a member of the United States Tennis Association (USTA) and helped her team win the State Tennis Championships at level 4.0.

Since 2005, Patty's husband, Pat, has helped organize the annual PASS tournament

held in Corpus Christi, TX at the Al Kruse Tennis Center. Proceeds and donations received equally benefit the Scleroderma Foundation and the Dr. Shelby Torrance Youth Tennis Fund. In December 2007, \$3,500 was raised for the charities!

The Director of the tournament is Ms. Susan Torrance, a USPTA member, and major tournament support is provided by Mrs. Diana Sherer. Ms. Susan Torrance was Patty's tennis coach who brought her to a 4.0 level, and was also her friend. Patty did not start playing tennis until she was 32 years young.

The tournament, which is a "see your own level," non-elimination format, has both an adult and junior division. Everyone plays five matches over the two-to-three day event. The adult division is initially divided into nine flights based upon each team's initial level of play determination. Each flight is named after one of Santa's reindeer. As a team wins or loses, it moves upward toward or down from the "Rudolph" flight. The first and second place winners of each final flight receive an award trophy, which are Christmas tree ornaments purchased from the Make-A-Wish Foundation.

There are also generous drawings for prizes. In addition, juniors receive awards such as racquet bags, extra strings and free racquet restringing.

If you are interested in participating in the 2008 event, the tournament will be held on December 6th & 7th. For more information, please write to:

Al Kruse Tennis Center
C/O Susan Torrance
502 King Street
Corpus Christi, TX 78401

Honoring

It was a beautiful, sunny day at the Houston Arboretum. There were over 40 in attendance as the Texas Bluebonnet Chapter dedicated a bench in memory of our founders, Fran Waranius and Linda Pecot. Their planting, nurturing and service to this chapter will never be forgotten. Thank you to the family and friends of Fran and Linda for helping make it such a special affair and to Paulette Levine for coordinating this chapter event.



Above: Linda's husband, Joe Pecot, and Fran's dear friend, Olivia Cook, unveil the honorary bench. Right: Close-up of the bench plaque.



Our Founders

Membership and Tributes

I would like to support the Texas Bluebonnet Chapter of the Scleroderma Foundation to help fund patient support, education and research!

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Patron.....\$500_____

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All contributions of \$25 or more include annual membership dues and all TBC publications unless requested otherwise. Please make checks payable to SF - Texas Bluebonnet Chapter.

Phone: _____

I do not want this contribution to apply to annual membership or to receive TBC publications.

Saying Goodbye

We have lost several of our friends and family, and would like to say good-bye to:

Cindy Lisa James: July 2007

Donna Lea Russo: December 2007

Bridgette Rawls: December 2007 - Houston Support Group

Clo Sturm: January 2008 –
Greater North Dallas & Tarrant County Support Groups

Mary Lopez: January 2008 - Austin Support Group

Louis S. Garcia: February 2008

Cookie Senior: March 2008

Erma Artis: May 2008 – Grand Prairie Support Group

Susan Dale: June 2008 - W. Houston Support Group

Buddy Dooley: June 2008 –
Greater North Dallas & Tarrant County Support Groups

April Ramirez: June 2008 – Greater North Dallas Support Group

Bruce Wallace Reid, Jr.: June 2008

If we have missed anyone, we are so very sorry. Please let us know who we've missed so we can say goodbye in our next newsletter.

Ask The Doctor!

Do you have questions about scleroderma or connective tissues diseases that you have not been able to find the answers to?

We have a Medical Advisory Board (MAB) standing by to answer your questions!

One or more questions will be chosen to print in the next newsletter, and if yours is chosen, we will send you some Texas Bluebonnet Chapter swag!

Please send all questions to:
txchapter@scleroderma.org
with subject: Ask the Doctor
and they will be submitted to the MAB.

Your TBC Board of Directors

Our Mission

The mission of the SF Texas Bluebonnet Chapter is threefold:

- To provide education and emotional support to people with scleroderma and their families.
- To stimulate and support research designed to identify the cause and cure of scleroderma as well as improve methods of treatment.
- To enhance the public's awareness of this disease.

Do you have questions, concerns, or comments? We would love to hear from you!

Toll Free: 866-LEARNSF (532-7673)

DFW area: 972.396.9400

Fax: 972.649.7910

Email: txchapter@scleroderma.org

Mailing Address: PO Box 1836

Allen, TX 75013

Farewell

We'd like to say thank you to four of our Board Members who have recently left their board positions:

Mike Beck
Bill Hubregs
Don McCullough
Larry Smith

Your hard work and dedication to this Chapter are very appreciated!

What is Scleroderma?

Scleroderma is a chronic, autoimmune connective tissue disease, and the word scleroderma literally means hard skin.

Common symptoms include hardening and thickening of the skin, one of the most visible manifestations of the disease. Other symptoms include Raynaud's disease (abnormal sensitivity to cold in the extremities), swelling of the hands and feet, pain and stiffness of the joints, joint contractures, digestive system and gastrointestinal tract problems, oral, facial and dental problems, and kidney, heart and lung involvement.

Characteristics of the disease include on over-production of collagen and damage to blood vessels. Approximately 300,000 people in the United States suffer from Scleroderma. Scleroderma primarily affects women between the ages of 25 and 55. There is currently no known cause or cure.

Officers

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INTERNATIONAL PAPER

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We appreciate your support in underwriting the Texas Bluebonnet Chapter's patient programs and for sponsoring individual support group presentations around the state!

Thank You to Our Sponsors!



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