The Scleroderma Foundation of Southern California has moved! The new address is:
5855 Green Valley Circle Suite 200
Culver City, CA 90230
Our phone number will stay the same, for now: 310-287-0793
Please visit our Facebook Page http://www.facebook.com/sclerodermasocal
for an announcement about an open house.
www.sclerodermasocal.org
socachapter@scleroderma.org
The Scleroderma Foundation and Southern California Chapter are 501(c)(3) organizations. Contributions to the Foundation are tax exempt and should be mailed to the Culver City address. Federal tax ID #77-0229244

Stepping Out to Cure Scleroderma
This past June, patients, foundation members, family, friends, and volunteers came out to La Mirada Park to help raise awareness and funds for the Scleroderma Foundation of Southern California.

The 11th annual Stepping Out to Cure Scleroderma walk and family celebration was a community affair featuring music, food, and entertainment that brought people together from all over Southern California in the mission to raise money to fight scleroderma.

All told, this year’s Stepping Out saw over 900 walkers raise over $90,000. Major sponsors for the 2013 Stepping Out were Actelion, Coca Cola Company, Dasani, Southern California Gas, and Supervisor Don Knabe, Fourth District, County of Los Angeles. The Foundation also received wonderful cooperation from the City of La Mirada and La Mirada Regional Park.

Through our advanced online team building capability, we saw teams come together like Team Helen, Seiler’s Strollers, and Hal’s Dream Team to raise generous amounts of money and participation.

The annual Stepping Out event brings out people of all ages to volunteer, show support, and walk in an effort to help make this disease something of the past. Families and friends gather to celebrate those living with scleroderma, and remember those who have passed because of the disease.

To view photos, learn more about the event, or keep up to date with next year’s walk, follow us on Facebook at http://www.facebook.com/sclerodermasocal and you can find the separate Stepping Out to Cure Facebook Page link there
Upcoming Events

**National Patient Education Conference**
July 2014
Anaheim, CA

**Support Group Meetings**
Inland Empire (Corona)
October 26

Whittier Support Group
October 19

Sherman Oaks/ San Fernando Valley
November 10

**Patient Services Day**
October 22 - West Covina

**In Memory of and In Honor of Contributions:**

In order for the Southern California chapter to receive credit for contribution made in honor of, or in memory of an individual, please send the contribution directly to our office. If you are making the contribution online through scleroderma.org/socal, please notify our office so that we can assure proper credit and prepare acknowledgement letters.

**Charitable IRA Rollover Opportunity for Year-End Contributions**

The American Taxpayer Relief Act of 2012 reinstated the Charitable IRA Rollover retroactively for 2012 and extended it through December 31, 2013.

Originally enacted in 2006, the Charitable IRA Rollover allows individuals age 70 1/2 and older to make direct transfers up to $100,000 per year from individual retirement accounts to qualified charities without having to count the transfers as income for federal tax purposes. Since no tax is incurred on the withdrawal, gifts do not qualify for a charitable deduction, but may be counted toward an individual’s minimum required distribution.

**Recap of other provisions of the Charitable IRA Rollover:**

- Distributions must be made directly to a qualified charity by the plan administrator of an IRA. Retirement assets in 401(k), 403(b), SEP, or SIMPLE plans do not qualify, but may be rolled into a new or existing IRA and transferred to the charity.

- Distributions may only be made to 501(c)(3) tax exempt organizations and cannot be made to donor advised funds, private foundations or supporting organizations.

- Distributions may not be used to fund life-income gifts such as charitable gift annuities, charitable remainder trusts or pooled income funds.

For more information and to obtain a form to expedite your Charitable IRA Rollover contribution, please contact Interim Executive Director Jerold D Kappel CFRE at 310-287-0793 or email to socachapter@scleroderma.org.
2013 Fight for Lexi Golf Tournament

Golf, auctions, dinner, and comedy highlighted the 2013 Fight For Lexi Golf Tournament in Coto de Caza to help raise awareness and funds for the Scleroderma Foundation of Southern California.

Led by the president of the board, Chris Pettit, and his wife Melinda Pettit, the Fight for Lexi golf tournament saw 139 golfers try their hand at the difficult Dove Canyon golf course and later enjoy a reception and dinner with their families.

Fight for Lexi golf tournament, silent and live auction, and raffle donations will net over $65,000 for the support and education of scleroderma patients.

Lexi Pettit was diagnosed with Scleroderma at the young age of 16. Not wanting to stand on the sidelines, the Pettit family organized what has become a favorite fundraiser for the Scleroderma Foundation of Southern California.

Make sure you follow us on Facebook at Scleroderma Foundation, Southern California Chapter and the Fight for Lexi Facebook Page for up to date information on upcoming events and your chance to register for next year’s Fight for Lexi.

The Scleroderma Foundation and Lexi Pettit receive a $21,657 check from the Markham Mark of Distinction Program.

Pictured from left to right: Jerold Kappel, Director of Scleroderma Foundation; Steve King, V.P. SWS Chains; Chris Pettit, V.P. National Accounts (SWS), President of the Board, Lexi Pettit, Mike Hanskat, Southern California Regional Supervisor, Markham Vineyards, Ken Snyder, Director of Wine/SWS; and James Bradney, VP-GM/SWS of SoCal.

Vertical Cure

Vertical Cure raised over $25,000. This is the 12th Vertical Cure, and it has now raised over $250,000. Congratulations to Chris Corman, John Crayton, and all the skiers that have skied 2,367 vertical miles to support scleroderma research and patient services.

The ScleroSun Fall 2013
I was diagnosed with scleroderma 13 years ago. My son, Evan, was 16 and still in high school, and my daughter, Jennifer, had just finished college. When I was diagnosed there wasn’t much known about the disease, and everything I read or heard about the disease was doom and gloom, with little to no hope.

It started in 1999, when I had a hysterectomy. During the pre-op physical, my doctor detected some shading on my lungs. He suggested after my recuperation to return and have it checked out. The only symptoms I experienced at the time were shortness of breath and a chronic cough, which to me had become a normal part of life. Reflecting back, I didn’t realize how bad it was until people would comment when they called me at home by saying, “were you running to answer the phone?”

I belonged to Cedars Sinai at the time and was referred to a pulmonologist who ordered scans and tests. He also suggested that I undergo an “Open Lung Biopsy” to rule out some possibilities. After the biopsy, the doctors were still puzzled and did not have a clear diagnosis and were still asking why there was fibrosis of the lungs and where had it come from?

Things got worse following the open lung biopsy. The procedure left me with cracked ribs causing pain and discomfort for a long period of time; something I didn’t know was a possible biopsy side effect. I was left feeling highly anxious and worried.
that something went wrong with my procedure or that perhaps my condition needed urgent treatment. After seeing me in so much pain, my brother urged me to see his friend, a pulmonologist at UCLA, to get a second opinion.

While reviewing the images, I could see a concerned look on the face of this new physician as he looked at my scans and x-rays. I asked him directly what he saw and his answer was painfully honest. He told me I had Pulmonary Fibrosis. I had never been told how serious this disease was, only that I had ‘interstitial lung disease’, a general term for fibrosis of the lungs. When I asked if it could be reversed with treatment or drugs, his response was that only a lung transplant would cure it. When I asked if removing only one lung would be possible (as I knew someone living with only one lung) the doctor informed me both lungs were badly scarred. After our consultation, my husband and I were both shocked and terribly scared, plus we were completely uninformed about lung disease and could only imagine the worst.

In 2000, we met with Dr. Ross about being put on the lung transplant list. At the time, transplantation authorities were hesitant to hold a place in line for anyone with a preexisting autoimmune condition. While updating some family members about my situation – I had not yet shared the nature or seriousness of my condition with my children - a dear cousin became determined to be my champion. She decided her mission would be to get to the root of the problem, get my condition diagnosed, get it treated and get me cured. No matter what it took, Sheila spared no resource – time, money, or energy - on my behalf. At this point, my husband Ron and I were numb and we gladly welcomed any help my cousin offered. She turned out to be the perfect patient advocate.

After extensive research with the pulmonary staff at Scripps Hospital in San Diego, my cousin learned of two prominent physicians, both located out of state. The first, Dr. Ganesh Raghu of the University of Washington in Seattle and the second, Dr. Kevin Brown, an autoimmune lung diseases specialist at National Jewish in Denver, Colorado.

Even before our expedition to Denver and Seattle, I had no understanding of the seriousness of my condition or even a name for my illness. I remember sitting in my office when my physician’s assistant faxed me my file for my trip. As I looked over my charts, I came upon a letter my doctor wrote describing my situation: I had a survival rate of two years.

The appointment with Dr. Raghu in Seattle went well. Dr. Raghu reviewed my files and scans, examined me, and diagnosed me with Scleroderma. Our next appointment was at the National Jewish with Dr. Brown. I was an outpatient there for several days and went through a series of comprehensive tests ordered by Dr. Brown where he then concurred with Dr. Raghu’s diagnosis of scleroderma. Dr. Brown referred me to Dr. Robert Strieter, who at the time was a Pulmonologist at UCLA. It was Dr. Strieter who coordinated my care with a team of specialists for every organ in my body. It was good news and bad news; good because after all we went through, I was finally diagnosed; bad news because the disease was an ugly, progressive illness with a bad prognosis.

How am I doing today? I have my share of discomfort and struggles, mostly with the chronic cough and shortness of breath, which causes fatigue. But none of this is enough to stop me from having a wonderful quality of life. I credit my continued good health to the most wonderfully caring team at UCLA who closely monitor my condition, my wonderful husband, family, and friends who have been supportive over the last 13 years, the Southern California Scleroderma Chapter community, and last but not least my positive outlook.

From the first day I was diagnosed, I never let the disease get me down. I pushed through the times when I didn’t feel so great and still kept active. I enjoy living every day to it’s fullest and always see the positive side of things. Going from a two-year survival time in 2000 to where I am today, 13 years later and in remission, I consider myself one lucky lady. I remember praying to see my son get to college, for his sake. So imagine my profound joy on the day I walked him down the aisle at his wedding two years ago!

I am a true believer that if you have the three gifts that I have; a great team of doctors, a great support system from family and friends, and most importantly a great positive attitude, you can beat all odds.
The Scleroderma Foundation of Southern California is on the move. But we moved just a few miles south, and we are still in Culver City. As the recession has slowly eased, rents have increased for “creative space”, so we needed to control our administrative overhead and secure a longer lease period. With the continued support of the foundation’s members and donors, the new office will allow us to offer more services and support—such as a renewal of Westside support group meetings—and contribute more to scleroderma research.

If you do follow the Scleroderma Foundation/SoCal on Facebook, you know that the 2014 National Patient Education Conference will be held at the Marriott in Anaheim. As the host organization, the Southern California affiliate chapter will provide volunteers for the conference and host a reception for chapter leadership from across the nation. If you are interested in being a host volunteer, please email or telephone the office. The Georgia chapter did a wonderful job hosting the 2013 conference in Atlanta this past July, so we have a benchmark to meet.

Special recognition goes to Karen Gottesman, Patient Services Director, for the teleseminars that garnered the SoCal affiliate chapter the 2013 Outstanding Patient Education Program. These complimentary teleseminars, archived on scleroderma.org/so cal, are made possible because healthcare and other professionals volunteer their time to prepare and present their work and findings. The same goes for Patient Education Days for which medical professionals and patients give of their time, experience and expertise.

Another reason to visit the foundation’s Facebook page is that important articles and news items relating to scleroderma are posted there continually. Elaine Furst, Outreach Director, has been very helpful in providing this information. Speaking of outstanding volunteers, support group leaders are critically important to achieving the foundation’s mission. Please join me in thanking them during the upcoming Holiday season.

As we approach the end of 2013 and the foundation’s fiscal year, please consider a new or increased annual gift. The foundation is in better financial position than in the past, but to meet current and future program goals it will require the support of all who are invested in its mission and vision.

Jerold D. Kappel, CFRE Interim Executive Director
From the Desk of the Patient Services Director

By Karen Gottesman

It’s been a busy year thus far as we continue to expand our reach to help scleroderma patients in need. A new area of focus has been on reaching out to new rheumatologists as well as Community clinics that care for the underserved in an effort to educate them on the importance of early diagnosis. Due to the importance of early intervention, it’s critical that we all work together within the community to reach as many patients as possible. Another program that’s underway is a caregiver program with the goal of meeting the needs of all those who give so much to the patients they love.

As many of us have just returned from the National Conference in Atlanta, I’d like to take a moment to mention what an excellent conference it was this year. Kudos to the folks at our National office, in addition to the Atlanta Chapter, for a job well done. This year, my Canadian colleagues and I had the pleasure of presenting a session on SPIN — the Scleroderma Patient-centered Intervention Network. SPIN is an international collaboration of clinicians, researchers, and patients with the primary goal of designing testing, and disseminating evidence-based interventions to improve the health-related quality of life for scleroderma patients worldwide. Do remember the name SPIN as you will undoubtedly be hearing much more about it in the years to come.

One of the more exciting highlights of the conference was the recognition of one of our chapter’s educational programs. The Southern California Chapter won the year’s Outstanding Education Program for our national Teleseminar Series. As creator of the program, I am especially proud; but a big bravo and thank you to all those involved in helping make this program so successful.

And while we’re on the topic, if you haven’t already heard, next year’s conference will be held on our home turf! Get your mouse ears ready, Anaheim here we come.

In the meantime, reach me anytime with questions or concerns at karen@sclerodermasocal.org.

—Karen Gottesman

Legacy Giving

The end of the year is the time that many people review their estate plans in light of changes in the law, changes in family or financial circumstances, or a wish to leave a legacy to a charity for which there is a particular commitment. Our hope is that the Scleroderma Foundation of Southern California is a charity for which you have that special commitment. To discuss how your bequest or charitable trust can fulfill your desire to help scleroderma and support those that fight the disease everyday of their life, please contact Jerold D Kappel, Interim Executive Director and Certified Fundraising Executive, at the foundation offices - (310) 287-0793 or email socachapter@scleroderma.org.
Southern California Support Groups

Antelope Valley
Betty Power
(661) 860-3697
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Crescenta Valley
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Inland Empire
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Los Angeles
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coupons/specials

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