

NORTHERN CALIFORNIA CHAPTER

2ND ANNUAL SAN JOSE

“STEPPING OUT TO CURE SCLERODERMA” SUNDAY MAY 15, 2011

Scleroderma is a chronic autoimmune disease that affects more than 300,000 Americans. Four times as many women as men have this disease, which can strike at any age. Scleroderma is characterized by an overproduction of collagen that can harden skin and attack internal organs. It is a highly individualized disease, with symptoms ranging from mild to life-threatening. There is no cure yet but there are many treatments available.



Registration is now open for the 2nd Annual San Jose "Stepping Out to Cure Scleroderma" 2 Mile Walk/Family Fun Run & 10K Competitive, Accurately Timed Run. New for 2011 is "Professional Course Management" including a measured and accurate course. This exciting event raised nearly \$50,000 last year and with your help we hope to increase that amount in 2011!

It will be held Sunday May 15, 2011 at the Almaden Lake Park and adjacent trails, 15652 Almaden Expressway in San Jose. Registration starts at 8am and the walk/run starts at 9am.

There are 2 ways to register. **Register Online** and build your own personal fundraising page at:

www.firstgiving.com/scl-northernca

To Register by Mail you can download and print the registration form, linked to the above page and mail it to our chapter office, or bring it on race day. If you would like to have a registration form mailed to you contact the chapter office.

You must register by **April 27** to be guaranteed a Stepping Out T-Shirt or Reusable Shopping Bag and to take advantage of

special pricing detailed on above registration links.

There will be music, food, a silent auction & raffle including SF Giants tickets and many other prizes. It is a great way to have fun while increasing the awareness of scleroderma and raising \$\$\$ to help find the cause and cure of this life changing and potentially fatal autoimmune disease.



OUR PURPOSE

The **PURPOSE** of the Chapter is to help patients make contact with each other through Support Groups, Newsletters & Activities;

To **EDUCATE** and **INFORM** the public about scleroderma, its meaning, and its consequences through a central base;

To **ENCOURAGE** more awareness within the medical profession;

To **PROMOTE** medical research toward finding a cause and cure;

To **ACCEPT** donations, bequests, memorials, and grants from our generous supporters.

NATIONAL PATIENT EDUCATION CONFERENCE FINANCIAL ASSISTANCE AVAILABLE

The Scleroderma Foundation and the Northern California Chapter are pleased to announce that the 2011 "Bridge To Hope" National Patient Education Conference will be held July 8-10 at the Hilton Union Square in San Francisco.

We are committed to helping you learn about scleroderma and how it affects you and your family. The National Conference is an event that allows you to reconnect with friends and establish new relationships with other patients and their families. You will meet and learn from world renowned scleroderma researchers and clinicians.

The Northern California Chapter may be able to offer you **financial assistance** to help cover the cost of registration. To qualify you must be a current member of the Scleroderma Foundation with dues paid up to date. If interested please email us at nocachapter@scleroderma.org or call 916-832-1102 and tell us why you need help.

For more information and to register go online to www.scleroderma.org and follow the links. You must register yourself even if you qualify for a scholarship and you will be reimbursed. Also book your hotel room as soon as possible as they often sell out.

**SCLERODERMA
FOUNDATION
NORTHERN CALIFORNIA
CHAPTER**

**P.O. BOX 601313
SACRAMENTO, CA
95860**

**916-832-1102
800-722-HOPE**

**NoCAchapter
@scleroderma.org**

**WWW.SCLERODERMA.ORG/
CHAPTER/NO_CALIF**



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WALK SEASON 2011

If you have ever wondered what goes on behind the scenes to make *Stepping Out To Cure Scleroderma* work – now is the time to volunteer and solve the mystery. Every walk committee needs industrious and committed people to help. Typical committee duties include food, entertainment, registration, raffles/silent auctions, giveaways (shirts and bags), set-up, clean-up and taking pictures. Most committees meet four to six times before their walks to make sure everything is organized and working smoothly.

If you are interested in helping, please call (916) 832-1102 or email nocachapter@scleroderma.org and we can answer your questions and help you get in touch with the walk committee chair in your area. The old saying “many hands make light work” is never more evident than at *Stepping Out To Cure Scleroderma*. Without the many hands your walk could not happen!



RECOMMEND DOCTORS FOR OUR REFERRAL LIST

Do you know a doctor that has been a big help to you or other scleroderma patients? Recommend him or her for our referral list to help those in the Northern California area get the medical assistance they need. We are especially seeking dentists, pulmonologists and rheumatologists. Call (916) 832-1102 or email nocachapter@scleroderma.org with your recommendations. Thank you!

MATCHING GIFTS BENEFIT THE FOUNDATION

As many members of the Northern California Chapter of the Scleroderma Foundation have discovered, their employers and other organizations often sponsor Matching Gift Programs for their employees and associates, and will match the charitable donations they make whether it's for our annual Stepping Out For a Cure Walks or personal annual gifts to the Foundation and Chapter. Contact your employer's HR Department for information regarding their participation in a Matching Gift Program. Your donations to the Chapter, always appreciated, could very well be doubled!



From left: Cathy Eddy, Victoria Chavez, Kari Connolly MD, Kate Hannon, Tamiko Katsumoto MD, Jayme Kornfeld at Fall Patient Education Conference

Follow us now on Facebook!

Just search under Scleroderma Foundation Northern California Chapter to find out what is happening in our area. See photos from past walks, start a discussion, or just comment on something important to you. Make sure to click the "thumbs up" to "like" our page, and you will receive all future posts.

See you there!

MEET OUR MEMBERS

Roz Sandler is a survivor. Diagnosed in 1980 when she developed a finger ulcer infection that would not heal, Roz joined the ranks of those who have refused to let scleroderma take over their lives. She had never even heard of the disease before her diagnosis, which, she has since realized, turned her life "inside out." In the last 31 years, however, Roz has seen many changes in the world of scleroderma research and treatment. She notes that the disease is now being diagnosed earlier and that more medical practitioners are aware of its symptoms and their effects upon patients. "The medical team that takes care of me," she says, "is smart about my health ... finally!"



Roz has learned to manage scleroderma and advocate for herself on a daily basis. She listens to her body and knows when she has to set limits, especially when, at those times when she can't even move, to say "no." The secret of her success? Relax about all the medical appointments, labs and tests; remember that you are chronically ill; and make peace with the routines the disease makes necessary. Some of the treatments she has found most helpful in treating her symptoms are passive range of motion, biofeedback, and pain management.

When asked what advice she would give to other scleroderma patients, Roz recommends finding a support group. "It is wonderful to talk to people who understand without needing explanation," she claims. "It helps keep me sane." At first she participated in an online support network, but when a local support group was formed in Santa Rosa, where she lives, she became a charter member. "Another important thing" she says, "is to find a doctor you trust and respect, who gives you 'time' during an appointment." As with most scleroderma patients, Roz has a variety of doctors, who, she says "absolutely must be team players." She keeps notes on her medical information because she knows she won't remember what was said during an appointment, no matter how important or seemingly insignificant the information and how sure she is that she will remember. She often brings a friend along to medical appointments, especially when she is nervous or apprehensive about her condition. "It is easier on me than having a family member present because I feel freer to ask all the hard questions."

In educating herself about scleroderma Roz has attended five Scleroderma Foundation National Patient Education Conferences, such as the one coming up this July in San Francisco. She remembers them as positive experiences during which she has made lifelong friends and acquired indispensable information about scleroderma. She even got to meet one of her medical heroes, Dr Maureen Mayes. "In that one afternoon, she alleviated many of my fears," says Roz of the experience.

As part of her survival methodology, involvement in the Scleroderma Foundation is important to Roz because her membership keeps her connected to the greater scleroderma community. "When I run out of steam," she says, "they don't. Most importantly, the Foundation lets you know that you are not alone and makes sure you are educating yourself about your disease."

Roz Sandler's tough-minded and courageous strategies teach us all what we, too, must do to survive scleroderma.

CALENDAR

MAY 15, 2011

2ND ANNUAL
"STEPPING OUT TO CURE
SCLERODERMA" WALK/RUN
SAN JOSE, CA

JUNE 25, 2011

CALIFORNIA PH FORUM
REDWOOD CITY, CA

JULY 8-10, 2011

NATIONAL PATIENT
EDUCATION CONFERENCE
HILTON UNION SQUARE
SAN FRANCISCO, CA

SEPTEMBER 10-11, 2011

SCLERODERMA AWARENESS
WEEKEND
"LIVING WELL WITH
SCLERODERMA" PATIENT
EDUCATION CONFERENCE
AND
"STEPPING OUT TO CURE
SCLERODERMA" WALK/5RUN
SACRAMENTO, CA

Have you paid your dues? Your dues help to support our educational meetings, along with awareness and research for scleroderma. Won't you mail yours today?



Membership and Tributes: I would like to support the Northern California Chapter of the Scleroderma Foundation to help fund patient support, education and research!

*All contributions of \$25 or more include **annual** membership dues and all chapter publications unless requested otherwise. Please make checks payable to Scleroderma Foundation- Northern California Chapter.*

Benefactor....\$1000 _____	Contributor.....\$100 _____
Patron.....\$500 _____	Supporter.....\$50 _____
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**SCLERODERMA
FOUNDATION**

SUPPORT · EDUCATION · RESEARCH

NORTHERN CALIFORNIA CHAPTER

P.O. Box 601313
Sacramento, CA 95860

***New Support
Groups-***

We are always looking for new leaders to open up more support groups in Northern California. It is a great way to connect with others and share information.

We are ready to help you help us!

Change of address or want to be removed from the mailing list?

Send an email to:
nocachapter@scleroderma.org

NORTHERN CALIFORNIA SUPPORT GROUPS

<p><i>Sacramento</i> 451 Parkfair Drive Suite 3 Sacramento, CA 95864</p>	<p>Last Saturday of each month except Nov. and Dec. 10 am-12 pm <i>Holiday Party Dec. 4</i> Watch Website for details!</p>	<p>Theresa Parulan (916) 481-7950 tpsclero@comcast.net Victoria Chavez (916) 359-0976 vicknbob@surewest.net</p>
<p><i>San Francisco</i> Western Addition Branch SF Public Library 1550 Scott St. San Francisco, CA 94115 (corner of Scott & Geary)</p>	<p>Alternating Saturdays– Contact Jayme for definite dates. 10:30 am-12:00 pm</p>	<p>Jayme Kornfeld (415) 256-9004 j_kornfeld@comcast.net</p>
<p><i>Santa Rosa</i> New Vintage Church 3300 Sonoma Ave Santa Rosa, CA 95404</p>	<p>Fourth Saturday of each month except Nov. & Dec. 10 am-12 pm <i>Holiday Party Dec. 3</i> Watch Website for details!</p>	<p>Cathy Eddy (707) 538-9193 eddy@c@sbcglobal.net</p>
<p><i>Telephone Support Group</i> Conference Call– Calls are free, however long distance charges may apply.</p>	<p>Please contact Chapter Office for dates, times and call in number.</p>	<p>Chapter Office (916) 832-1102 nocachapter@scleroderma.org</p>

**** Schedule subject to change, please call or email leader to confirm meetings.***