

**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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2009 WALK RAISES \$25,000

A great big THANK YOU to all who participated in the Northern California Chapter's 7th Annual "Stepping Out to Cure Scleroderma" Walk in Sacramento. The walk was a great success. There were a many familiar faces and also many new faces. Scleroderma patients, along with their families and friends, were there as we spread awareness in our green walk shirts. Some created their own shirts for their "walking team". There were cheerleaders, great music and even a dance instructor that warmed us up with some Zumba moves before the walk. We had many raffle prizes and a cruiser bike that was auctioned off. And of course, we had our delicious BBQ after the walk.



Theresa Parulan with husband Dexter who is the Sacramento walk chairman, Hannah, Jacob and Noodles.

“This sure was a great time to catch up and get to know other scleroderma patients. It has the feeling of an annual scleroderma family reunion,” said Sacramento support group leader Theresa Parulan. Theresa was also the top fundraiser gathering over \$5000 in donations on her personal Firstgiving page.

If you or someone you know is interested in becoming more involved with the walk, please let us know. “It is really such a wonderful and rewarding feeling to be a part of something very special, which is very dear to all our hearts,” states Theresa. “We are here to make sure every single person we come across learns about scleroderma and that we want a cure for it NOW!”

THANK YOU TO OUR DONORS AND VOLUNTEERS

The Scleroderma Foundation Northern California Chapter recognizes the individuals and families, companies and organizations whose contributions play a critical role in the success of our walk, and in the work of the foundation. Every gift regardless of size, is important to the Scleroderma Foundation. Every donor plays an important role in the fight to eradicate this disease and support those whose lives have been affected by scleroderma until the cure can be found.

To each and every donor and volunteer, we extend our most sincere gratitude for your generosity and gracious support.

2009 BUSINESS SPONSORS

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STARBUCK'S
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DE VEGA/PARULAN FAMILY**

**HARRAH'S
ALHAMBRA
LEFT BANK
DJ EDDIE SOLORIO
NORTH BAY PUBLISHING SOLUTIONS
PINNACLE ASSETT MANAGEMENT
HOLIDAY INN CAPITOL PLAZA**

MEET OUR MEMBERS

Meet Jane Johnson from the San Francisco Support Group. Born and raised in Michigan, Jane has been in San Jose for 18 years, and is a wife and mother to a 10 year old son, Jack, and a 7 year old daughter, Jannika. Jane had a successful career and an active lifestyle. Over a short period of time, Jane's hands started to turn colors, and by February 2008, were very swollen. After her general practitioner told her that this "must be hormonal," Jane went to see a hand surgeon. He directed her to a rheumatologist who suspected her problems were either lupus or scleroderma. Jane attended the 2008 Education Conference in Manhattan Beach, where she met doctors who later confirmed her diagnosis of aggressive diffuse scleroderma.



Rapidly, Jane's health was declining. She was exhausted all the time, her skin was rapidly hardening, and her GI tract was quickly affected with esophageal ulcers and GAVE (watermelon stomach). She was also experiencing shortness of breath, and soon was diagnosed with interstitial lung disease. "It felt like something was taking over my body and trying to eat me from the outside in."

Her doctors tried different medications, and Jane was accepted into the SCOT trial, to compare the chemotherapy drug, Cytoxan to a stem cell transplant. During the long insurance battle for approval, Jane's health continued to decline. Her doctors placed her onto a Cytoxan regimen due to her severe lung condition. After 4 months she began to feel like something was improving. In fact, within 6 months the Cytoxan had such a positive effect that she was no longer eligible for the study.

Today, Jane is continuing to show improvement. She is very grateful for the help of her family and friends, who have stood by her side during this difficult period. She calls her husband Dan a "superstar," and he and her children help with the everyday chores and tasks she can't do herself. Her extended family and friends provide words of encouragement and hope for the future, and they have stepped in at critical times when needed. Right now, Jane's hope is to continue to improve and spend quality time enjoying activities with her children and husband. She even looks forward to playing with grandchildren one day!

While struggling with her disease, Jane, with the help of other members of the Northern California Chapter, has taken on a new project: the 1st Annual San Jose Walk/10K Run for a Cure. Her goal for the event is to raise as much money for research as we can. Ultimately, she hopes that "a cure is found for this horrid disease and that it reverses damage already done. I hope that it happens in my lifetime and that all of us afflicted with scleroderma can benefit from it."

CALENDAR

MAY 16, 2010

INAUGURAL
"STEPPING OUT TO CURE
SCLERODERMA"
2 MILE WALK & 10K RUN
SAN JOSE, CA

MAY 22, 2010

EDUCATION SEMINAR
SAN FRANCISCO, CA

JULY 30-AUG. 1, 2010

NATIONAL SCLERODERMA
CONFERENCE
BOSTON, MA

SEPT. 25-26, 2010

8TH ANNUAL
"STEPPING OUT TO CURE
SCLERODERMA" WALK
& EDUCATION
SEMINAR
SACRAMENTO, CA

Do you know about the PG&E Discount?

With scleroderma, we have special needs regarding heat. You can apply to PG&E for a "Medical Baseline Discount." Just call and request a form for your doctor to fill out. Mail it back, and in a few weeks the discount will appear on your bill.



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 _____
Sponsor.....\$250 _____ Donor.....\$25 _____

This gift is in honor of _____

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Name: _____

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Would you like to receive publications by email? Y N

Phone: _____



P.O. Box 601313
 Sacramento, CA 95860

New Telephone Support Group

In an effort to provide support to those who are unable to attend regular support group meetings, we are starting a monthly call in support group. Please contact Cheryl George (see box to right) for more information.

Change of address?

Please notify the foundation.
 To be removed from the mailing list please Call 1-916-832-1102

NORTHERN CALIFORNIA SUPPORT GROUPS

<p><i>Sacramento</i> 451 Parkfair Drive Suite 3 Sacramento, CA 95864</p>	<p>Last Saturday of each month 10 am-12 pm July- <i>Summer Party</i>– No meeting in November 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-12:30 pm</p>	<p>Jayme Kornfeld (415) 256-9004 Jkornfeld@sbcglobal.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 May & Nov. 10 am-12 pm July – <i>Summer BBQ</i>– Watch Website for details!</p>	<p>Cathy Eddy (707) 538-9193 eddyc@sbcglobal.net</p>
<p><i>Telephone Support Group</i> Conference Call– Calls are free, however long distance charges may apply.</p>	<p>Please contact Cheryl for dates, times and call in number.</p>	<p>Cheryl George (209) 928-4332 cjgeorge3786@frontiernet.net</p>

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