A FAMILY’S RIBBONS OF LOVE AND HOPE

Five members of the Homen family got tattoos to raise awareness - and to show support

By KELLY HOMEN

I have scleroderma.
I am 48 years old and I was diagnosed with systemic scleroderma in February, 2002.
The onset was progressively rapid and an overlap with polymyositis rendered me bedridden for several months to follow.

At the time, my daughters were pretty young. Hailey was 10, Jaimey was 7 and Nickey was 6.

My husband, Andrew, became caregiver to me and took on the role of mom and dad, taking care of our girls most of the time. When he was at work, Hailey, the oldest, became mom to her sisters and caregiver to me as well.

During those months that I was bedridden, I had many moments when I questioned whether I would live.

During this time and many years that followed I prayed to God to just let me live long enough to see my three daughters graduate high school. Eventually, my medications started to help and my desire to be a wife and mother motivated me to try to just keep putting one foot forward every day.

It has been a long road, and it is never ending.
I still have many doctor visits, tests, and medications not to mention fatigue, pain, fibrosis of many areas of my body, and side effects of all the medications.

However, I try to not let scleroderma be the thing that defines me.

During these many years, my family really grew together to take care of me and each other. This disease gives our family a different perspective. We have come to value the little things in life.

So this summer God answered my prayers and I watched my baby girl, Nickey, graduate high school. She will attend the same college as her sister, Jaimey, in the fall. I also got to see

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Nearly 1,500 men, women and children participated in the Chapter’s two annual “Stepping Out” fundraising events in 2013, raising more than $100,000. (That’s right: 1,500 people!!)

The walk, runs and silent auction at Sacramento’s William Land Park on June 29 raised more than $52,400!
Top participants: Josie Garcia ($3,950), Rebecca Ottersbach ($3,500), Diana Luiz ($3,290), Julie Reid ($1,295) and Kate Hannon ($1,080)
Top teams: Team Jag ($10,130), Team Nina ($5,570), Beca’s Besties ($4,085), Diana Luiz’s Team ($3,780) and The Fighting YaYas ($3,220).
The walk, runs and silent auction at San Jose’s Almaden Lake Park on September 29 raised more than $54,500!
Top participants: Steve Dunlap ($2,680), Dario DuQue ($2,035), Corrine Schneider ($1,670), Heidi Mann ($1,500) and Yvonne Spitz ($1,390).
Top teams: Team Spitz ($3,201), Colleen’s Angels ($3,190), M92 ($3,040), In Memoriam of Sherry Clifford ($2,575) and Team Heidi ($1,920).

Thank You to ALL participants and volunteers for making these wonderful and important, high-profile events such huge successes!
Hope to see you all at next year’s Stepping Out events!
(PS: Urge family and friends to start tossing loose change into special jars for next year’s Stepping Out!)
TATTOOS
From Page 1

my oldest daughter, Hailey, graduate college! My husband and I also celebrated our 25th wedding anniversary in June!

We celebrated by taking a family vacation to Florida. On that trip to commemorate all these milestones, we all got scleroderma ribbon tattoos.

It was a first tattoo for all of us, and I battled with the idea for a long time. I checked with my doctor first to make sure we both thought it would heal properly.

These tattoos are all different but they all have the scleroderma ribbon and the teal color of the Scleroderma Foundation logo. They represent our journey and the love and support my family has for me.

I feel honored that they would get these tattoos on their bodies for me. It is also creating a lot of awareness about scleroderma.

I love when someone asks about the tattoos and I hear one of my daughters or my husband tell our story about scleroderma and the Scleroderma Foundation!

I hope that our story inspires other patients to keep moving forward and trying to live their lives.

I also hope this serves as an example to caregivers, family members and friends of patients.

Love and support mean so much!

KELLY HOMEN
Escalon, California

What IS Scleroderma?

Scleroderma is a chronic connective tissue disease. It is not contagious, infectious, cancerous or malignant. Symptoms of scleroderma vary greatly and the effects of scleroderma can range from very mild to life threatening.

The seriousness will depend on the parts of the body affected and the extent to which they are affected.

The diagnostic process may require consultation with rheumatologists (arthritis specialists), and/or dermatologists (skin specialists) and require blood studies and other specialized tests depending upon which organs are affected.

It is estimated that about 300,000 Americans have scleroderma.

VIRTUAL SUPPORT GROUP

The Northern California Chapter is pleased to announce our first Virtual Support Group meeting.

The virtual meeting will be in addition to our existing support group meetings. We hope this meeting will be helpful for people who are unable to attend regular meetings due to logistics or mobility issues.

All are welcome to join us on Wednesday, February 19th at 7:00 p.m.
The call-in number will be 1-530-881-1300, the participant access code will be 370184.
Please announce your name and then mute your phone when not speaking to eliminate background noise.

If you have any questions about this service please call our NCC chapter number 1-916-832-1102

Who’s in YOUR corner?

Connections welcomes stories or suggestions for stories about special people who help individuals with scleroderma cope, adjust, adapt and persevere.
Send stories or suggestions to Connections editor Paul Merkoski: pmerkoski@gmail.com

VOLUNTEERS WELCOME

The Northern California Chapter needs YOU.
If you have a few hours a month to spare, we can use your time, your talents, your help.
Contact Julie Reid at 530-906-3519 or jujuannr@att.net,
or Mary Huckabee at 209-852-2870 or maryhuckabee_sd@yahoo.com

STAY CONNECTED

The Northern California Chapter of the Scleroderma Foundation can be reached by phone at 916-832-1102 by mail at P.O. Box 601313, Sacramento CA 95860 or by email at nocachapter@scleroderma.org
To find out more about our chapter and events, please visit us online at scleroderma.org/norcal
SclerodermaNorCal is also on Facebook. Our Facebook page provides great information, contacts and resources.
INSPIRE.COM is another terrific on-line resource that allows you to share questions and insights about scleroderma and other health and wellness issues.
NORTHERN CALIFORNIA CHAPTER OFFICERS

JULIE REID, president
I do not have scleroderma, but Mary Huckabee does. She is a support group leader and the V.P. of the Nor Cal Chapter.
She is also my sister, best friend, my hero, my confidant, my rock to name a few. She has helped many others who suffer from this disease and I wanted to do anything I could to help the foundation.
I started out attending the walks, then helping at events, became a board member and now have the honor of being the chapter president.
I do this for selfish reasons: to help find a cure for Mary and the 300,000 + who suffer from this disease.

MARY HUCKABEE, vice president
I live in the beautiful Sierra Foothills not far from Yosemite Valley. I was diagnosed in 2001 with systemic sclerosis.
I became a support group leader in 2010 and now volunteer for the northern California Chapter of the Scleroderma Foundation.
I live the best life possible despite the limitations imposed upon me by my disease, and share this message of hope as well as bring awareness about scleroderma whenever I can.

STEVE PORTER, secretary
I am an attorney and arbitrator in San Francisco. I am a partner of Whitehead & Porter LLP and have practiced commercial litigation and business law since 1976.
I have served on the El Cerrito City Council and its Planning Commission, Parks and Recreation Commission and Tree Commission; the board of the San Francisco Independent Living Resource Center; as president and board member of the Contra Costa Civic Theatre; as president and board member of the Eskaton-Hazel Shirley Manor senior housing project; as president and board member of the Grizzly Peak Fly Fishers; and as a coach in the El Cerrito Youth Soccer League and Albany-Berkeley Girl’s Softball League.
My mother died from scleroderma in 1984, before there were patient resources like the Scleroderma Foundation.

KATE HANNON, treasurer
My background is in finance. I have been diagnosed with both scleroderma and Sjögrens syndrome.
My biggest challenge is something doctors recognize as a symptom of Sjögrens called “brain fog.” It weaves in and out of my days and interferes with my ability to focus and concentrate. Raised in Southern California, I now live in Sacramento and enjoy golf, kayaking, birding and a good glass of wine or pint of ale.
My support system includes Hula, my 5-year old Havanese dog. She gets me through the rough patches. It takes just one look at Hula to remind me of how important the simple joys in life are. Thank you to the Hulas in this world! They are truly lifesavers!

HAVE YOU PAID YOUR DUES?
The $25 annual membership dues help support our educational meetings, along with awareness and research for scleroderma.
If you are a member of the Scleroderma Foundation and haven’t yet paid your annual dues, would like to give a gift membership or make a donation, you have two options:
1. Mail a check to:
Scleroderma Foundation Northern California Chapter
P.O. Box 601313
Sacramento, CA 95860
2. Go online to www.scleroderma.org and click the:
a. DONATE NOW button or
b. BECOME A MEMBER button.

SWIPE FOR S.H.A.R.E.S
You can help support the Scleroderma Foundation’s Northern California Chapter every time you shop at Save Mart, FoodMax and Lucky stores.
S.H.A.R.E.S is an acronym for Supporting Humanities, Arts, Recreation, Education & Sports in our community.
S.H.A.R.E.S Cards will be available at all support group meetings and at all Chapter events. You can also call the office at 916-832-1102 to have a card mailed to you.
Remember: You must swipe the special card BEFORE your order is finished being rung up. Up to 3% of your total spending goes to the NorCal Scleroderma Chapter.
Your support will help us raise funds to sustain our threefold mission of providing Patient Support Education Research.
No hassles, no paperwork, no information required.
Just swipe the card!
CONNECTIONS invites medical questions related to scleroderma from readers. This issue’s question is answered by Dr. Kari Connolly, a dermatologist and rheumatologist at the University of California San Francisco whose overall interest is in autoimmune skin diseases and the mechanisms by which tissue damage occurs. Dr. Connolly is involved with a variety of research studies involving scleroderma, lupus erythematosus, dermatomyositis and blistering diseases. Her laboratory processes several hundred skin specimens a year. She also participates in clinical trials looking at treatment in autoimmune diseases.

Question: “As a patient who has had more than a few digital ulcers in which some resolve themselves in time and heal on their own and others requiring more aggressive treatment such as topical dressings and antibiotics when is it time to seek a doctor?”

Answer: Management of digital ulcers (DU) in scleroderma patients can range from doing nothing to going into the hospital for multiple IV drug therapies. Most patients require something in between those two extremes. I think of them in terms of “internal” and “external” factor that can affect them.

Internal factors include the disease itself that may be making the skin very fibrotic in the area of the ulcer and hard to heal. Internal factors include Raynaud’s phenomenon that makes the tissue ischemic (lack of oxygen need to heal). Blood flow, clotting factors and platelets may also affect DUs.

External factors include trauma and pressure that may occur with even simple things like dish washing and housework can injure ulcers. Jobs requiring a lot of typing can be hard on the fingers. Outdoor work like gardening can be difficult.

Part of management includes managing and minimizing your Raynaud’s phenomenon attacks. This can be done by staying warm. In addition to keeping your fingers warm, it is important to heat your core (long underwear, vests) and head (warm hats and scarfs).

I like the hybrid mitten gloves you can get from the “Heat Factory” online that have heating packets you place right over the fingers. The next step in treatment is to use medications. Medications that have been shown to help include calcium channel blockers (like Norvasc and Nifedipine).

Additional medications can be added that help with blood flow like losartan, sildenafil and bosentan. It is important to monitor your blood pressure so it does not go too low when on these medications.

Another huge factor in DU management are dressings, which help facilitate healing. We have learned that drying out wounds is not really helpful and it is better to go with something that keeps it moist and clean. There are a variety of products out there that seem helpful.

One regimen I like is to place a topical antibiotic like metrogel at the base of the ulcer. Then cut out a small circle of thin duoderm a little bit larger than the ulcer and remove its adhesive backing and lay that over the ulcer. Then go over that with 1” paper tape wrapping around the finger three times to make sure it stays in place. Make sure it is snug but not too tight that it cuts off circulation or hurts. This dressing can be left on for several days to a week (in most cases the longer the better).

You have to be careful not to get it wet in the shower. If it does get wet, then remove it wait a day or two if it seems super soggy and then repeat. Care should be taken when you pull the dressing off that you don’t tear the skin or ulcer.

Several things should make you see a doctor: possible infection of the ulcer (a yellow discharge over the ulcer, a foul odor, more redness surrounding it or going up the finger or hand, or fever) or an unexplained increase in pain, size of the ulcer or numbers of ulcers.

Send Scleroderma-related medical questions for ASK A DOCTOR to Mary Huckabee, NorCal Chapter vice president: maryhuckabee_sd@yahoo.com
## NORTHERN CALIFORNIA SUPPORT GROUPS

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<tr>
<th>SUPPORT GROUP</th>
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<th>PHONE</th>
<th>EMAIL</th>
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<tbody>
<tr>
<td><strong>FRESNO SCLERODERMA SUPPORT GROUP</strong></td>
<td>Fig Garden Library, Fig Garden Meeting Room, 3071 West Bullard Ave., Fresno, CA 93711</td>
<td>Mary Huckabee</td>
<td>(209) 852-2870</td>
<td><a href="mailto:maryhuckabee_sd@yahoo.com">maryhuckabee_sd@yahoo.com</a></td>
</tr>
<tr>
<td><strong>SANTA ROSA SCLERODERMA SUPPORT GROUP</strong></td>
<td>Vintage Brush Creek (Vintage Senior Living), 4225B Wayvern Dr., Santa Rosa, CA</td>
<td>Cathy Eddy</td>
<td>(707) 538-9193</td>
<td><a href="mailto:eddyec@sbcglobal.net">eddyec@sbcglobal.net</a></td>
</tr>
<tr>
<td><strong>SACRAMENTO SCLERODERMA SUPPORT GROUP</strong></td>
<td>Consumes College (Jan.); Roseville thereafter</td>
<td>Julie Reid</td>
<td>(530) 906-3519</td>
<td><a href="mailto:jujuannr@att.net">jujuannr@att.net</a></td>
</tr>
<tr>
<td><strong>PALO ALTO SCLERODERMA SUPPORT GROUP</strong></td>
<td>Palo Alto Elks Lodge, Conference Room, 4249 El Camino Real, Palo Alto, CA 94306</td>
<td>Rachel Ho</td>
<td>(415) 606-5213</td>
<td><a href="mailto:rachelhosf@gmail.com">rachelhosf@gmail.com</a></td>
</tr>
<tr>
<td><strong>TURLOCK SCLERODERMA SUPPORT GROUP</strong></td>
<td>Raley’s Store, 2900 Geer Road, Turlock, CA</td>
<td>Mary Huckabee</td>
<td>(209) 852-2870</td>
<td><a href="mailto:maryhuckabee_sd@yahoo.com">maryhuckabee_sd@yahoo.com</a></td>
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## OUR PURPOSE

The PURPOSE of the chapter is to help patients make contact with each other through Support Groups, Newsletters, Website & 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 a cure;

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