

The Moisture Seekers



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SjogrensSyndromeFoundation

@MoistureSeekers



12 tips to make cooking fun again — *minus* the pain!

This article is a reprint from Health Monitor. "New York City chef Seamus Mullen follows this kitchen motto: Work smarter, not harder!" by Lori Murray

When you have arthritis, even the *thought* of cooking can be exhausting. All that chopping, slicing and stirring—not to mention lifting and bending—is enough to make you bolt from the kitchen and say, “Let’s get takeout!” But there’s no need to let pain and fatigue win out over a delicious home-cooked meal, says *The Next Iron Chef* star Seamus Mullen. If there’s anything he’s learned in the five years since his rheumatoid arthritis (RA) diagnosis, it’s this: With the right tools and planning, you can still enjoy making good-for-you food that *tastes* good, too. Here, the 37-year-old chef-owner of the Manhattan restaurant Tertulia dishes on how to bring joy back into the kitchen.

continued page 4 ▼

Seamus Mullen star of Food Network's The Next Iron Chef

Patients sharing with Patients What’s the best tip you ever received?

We asked online for people to tell us what was the best advice they were ever given as a Sjögren’s patient and here are a few of the responses:

Know your body. When you’re exhausted and weak, it’s time to take it easy and slow it down. — *Michelle*

Take sips of water instead of gulping it. — *Leigh*

Be thankful for every good day you have. — *Dawn*

Take a warm bath with lavender scented Epsom salts – this really relaxes me and calms stiffness in my muscles when I’m cold and ache all over. — *Robin*

Wear soft contact lenses as band aids over very dry eyes. I live in Arizona where it is dry all the time. — *Janet*

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"Patients Sharing with Patients" continued from page 1 ▼

Sleeping with a humidifier helped my dry eyes & dry mouth. – *Jill*

Exercise gently every day if possible. Helps reduce stiffness and soreness. – *Christina*

Sleep when your body tells you to and learn your limits! – *Tara*

Stress makes it much worse. Try not to do too much and rest. – *Joseph*

Aveeno hand cream. I put gloves on and let it soak in. – *Kathy*

Pace yourself and rest when needed. Find a specialist that knows about the different complications of Sjögren's and is a partner in your care. – *Donna*

Do what needs doing (schoolwork, housework, work to meet deadlines etc) when you feel healthy and able. Putting stuff off just leads to stress and ultimately flare ups. – *Debbie*

My best advice would be to take one day at a time and don't take the good days for granted. Live life in moderation, but live it to the fullest that you can— life is too short! Eat healthy and exercise. – *Nicole*

Keep my hands warm! (It's less painful that way.) – *Pearlie*

For swollen paratid gland, using a warm compress to massage the area helps— especially when eating. – *Peggy*

Deep breathing techniques and meditation have helped me. – *Brandi*

Make sure you surround yourself with supportive friends and family. Stay away from negativity as it will add to stress and bring on more symptoms. – *Laurie*

I use chamomile tea, left to cool, as an eye bath to wash my eyes in... Heaven! – *Cheryl*

I get some pain relief from going to an acupuncturist. I am learning to rest when I need to and not feel guilty about it. – *Dale*

Have your thyroid checked. – *Jeanine*

Extreme fatigue is NOT just in your head! – *Terry*

Rest when your body insists on it, but exercise, exercise, exercise!!! Even if it's only 5 minutes— walk, lift weights, or whatever you can do. Believe it or not, exercise helps ease pain and gives energy, but definitely follow your body's cue. Overdoing it will make you feel worse and could put you in a flare. – *Elizabeth* ■

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May

Breakthrough Bullet:



Michele Champigny

*Journeying
into Sjögren's:
A Professional
Perspective*

50%
in 5 years
Sjögren's
syndrome
FOUNDATION

Please allow me to introduce myself, I am Michele Champigny (pronounced: Sham-pi-nee) and I am thrilled to be your new Director of Professional Awareness. Not having much previous experience with Sjögren's, I am diving into learning about the disease like I imagine many of you did when you were newly diagnosed. I am reading as much as I can about Sjögren's and talking with my own healthcare providers and friends about the disease. While that may be the same as you, admittedly my goal is likely a bit different than yours was. I want to assess how much these people in my life know about the disease and I have quickly learned that it's not enough.

My professional career has mainly been spent in two areas. I first spent 3 years in fundraising and community awareness for a national non-profit and secondly, I spent 11 years as the Director of Education for a community health system. This combination of experiences makes me keenly aware of how to approach spreading the word about a disease and how healthcare professionals go about acquiring their information. With these skills behind me and your needs in front of me, I have big plans!

As your Director of Professional Awareness, my focus is on building on the work of those who have come before me and to help the SSF achieve our *Breakthrough Goal* of shortening the time to diagnose Sjögren's by 50% in 5 years! I have several ideas of how I can help impact this, however these goals also have the potential to impact you- the millions of patients already living with this disease.

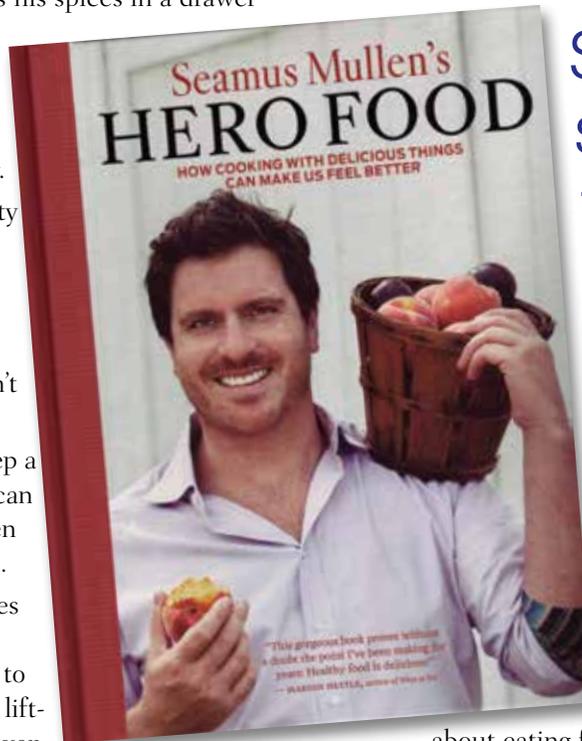
My main goal is to build relationships with healthcare professionals and professional organizations to bring overall awareness to Sjögren's. I plan to do this by:

- Speaking to any healthcare provider I can about the disease and its systemic effects so that when they

"12 Tips" continued from page 1 ▼

Beat fatigue with...

- **Leftovers!** Take advantage of your good days by doubling recipes for soups, stews and sauces. Then store half in the freezer for days when you're too pooped to make a meal from scratch.
- **Smart storage:** Cut down on bending and reaching by keeping frequently used items at waist level. For example, Seamus stores his spices in a drawer rather than a cupboard. Another tip? Keep your favorite pots, pans and appliances (like your blender or can opener) on the counter.
- **Easy cleanup:** Dodge crusty pots and pans by cooking one-pot meals like soups and stews. If you're roasting or baking, line the pan with foil or wax paper so you won't have to scrub it later.
- **A four-legged friend:** Keep a stool in the kitchen so you can give your joints a break when chopping or washing dishes.
- **A cake tester:** Seamus uses one to test the doneness of everything from croquettes to fish. The benefit? No more lifting pans in and out of the oven for just a look-see! Try a long tester (8 inches) with a rubber grip.



Seamus' secret to feel-good cooking (and eating!)

In his new cookbook, *Hero Food: How Cooking with Delicious Things Can Make Us Feel Better*, Seamus reveals his simple formula for having fun in the kitchen: Focus on addition, not subtraction. "It's

about eating fresh food that tastes good—and is good for your body. When I was first diagnosed with RA, I tried elimination diets, focusing on what *not* to eat. But now I understand that rather than eliminate foods from my diet, it's much more helpful to add more of what I call 'hero food.'" Seamus likes to include these super-power ingredients—foods that can help ease inflammation, boost immunity and improve overall health—in nearly every dish he makes. Three of his favorites:

- **The push of a button:** It's worth investing in a food processor, says Seamus. "Prepping and chopping are probably the hardest kitchen tasks when you have RA." He uses a food processor to do everything from slicing, shredding and chopping to making smoothies. A cheaper, but less versatile, option is a mini-chopper.
- **Under-the-feet relief:** Put a rubber or gel-filled mat wherever you do lots of standing, like near the sink or stove. Seamus and other pro chefs (even those who don't have arthritis!) use a mat to relieve joint pressure and back pain caused by long bouts of standing.
- **A handheld blender:** "Because I have shoulder pain, whisking is a problem for me," notes Seamus.

- **Put your cookware on a diet!** Take the pressure off your joints by swapping heavy pans and glass or ceramic bowls with their lighter counterparts made from plastic and nonstick aluminum. Another tip: Distribute the weight by using cookware with two handles and baking pans with silicon grips.

- **Ramp up vitamin and mineral content with parsley:** "I try to have parsley juice or a green smoothie every day," says Seamus. He likes the underrated herb because it's cheap, easily available and high in nutrients like folate and vitamins A and C. It's a good source of iron and potassium, too. Seamus tosses a handful of parsley in a blender and adds lemon juice and apple slices to balance the herb's pungent flavor. Not into green drinks? Try sprinkling it over potatoes (mashed or baked) or other cooked veggies.

continued page 6 ▼

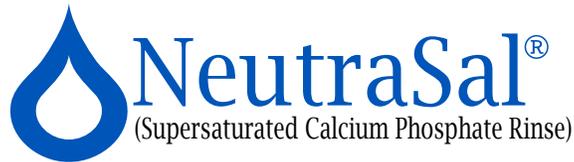
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"12 Tips" continued from page 4 ▼

- **Pack a flavor punch with mushrooms:** It wasn't until Seamus went to Japan to compete on *The Next Iron Chef* that he discovered why the local chefs revere these small flavor-enhancers: It's all about *umami*—loosely translated as "deliciousness." Mushrooms, especially dried ones, impart this special flavor due to their high glutamic acid content. The upshot? Adding grilled mushrooms (and even the juice!) is an easy way to turn blander dishes like rice, steamed veggies and salads into tasty sensations. And most varieties—including cheap, white button (cremini) mushrooms—are high in antioxidants and B vitamins. Plus, sun-dried mushrooms are a good source of hard-to-get vitamin D.
- **Swap fat villains for health-promoting almonds:** This workhorse ingredient does it all: Turn them into a snack, high-fiber flour, thickening

paste, puréed soup—you name it! Not only are almonds high in protein and good (monounsaturated) fat, they have more vitamin E and bone-building calcium than any other nut.

Editors Note

If you're interested in purchasing Seamus Mullen's cookbook on Amazon.com, *make sure to visit sjogrens.org first!* The SSF partners with other online retailers, including Amazon.com, who will donate a portion of the value of your purchase to the Foundation. Instead of going straight to Amazon's website, use the Amazon link on the Foundation's website and up to 8.5% of the value of your purchase is donated back to the Foundation because we referred you! Enter the following link to your browser to start shopping now: <http://www.sjogrens.org/home/get-connected/shop-for-sjogrens> and please keep this in mind for all your future Amazon.com purchase too! ■

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"Breakthrough Bullet" continued from page 3 ▼

- see patients with symptoms, Sjögren's comes to the front of their minds
- Coordinating speaking engagements at more professional conferences
- Working with leading professional organizations to have articles on Sjögren's placed in their journals
- Expanding the Healthcare Professionals portion of the SSF website
- Exploring options for creating programs for which healthcare providers receive professional credits for learning about Sjögren's

As I journey through my professional career here at the SSF, I am certain we will develop even more exciting and innovative ideas for keeping healthcare providers up to date on Sjögren's. I look forward to joining with the other SSF staff, our Board and our thousands of volunteers working toward the *Breakthrough Goal* and creating a nation of more informed healthcare professionals!

At last month's National Patient Conference in April, it was great to meet so many of you and hear your stories about life with Sjögren's. I am excited about the opportunity in front of me and the impact I can have to improve the lives of all Sjögren's patients by educating the medical community about Sjögren's and its effects. ■

There's Still Time to Coordinate a **Bold Blue Day** for Sjögren's!

What is Bold Blue Day?

Imagine your colleagues or classmates trading in their tailored slacks or dresses for a day in **blue jeans** or **bold blue** to raise vital funds for Sjögren's research and awareness.

Ask your company or your school (even your kid's school) to consider doing a dress down day for the SSF.

How does it work?

Each person choosing to dress down would donate a suggested amount to the SSF as their fee for participating. Some companies suggest \$5 while others companies/schools let each person decide how much they want to donate.

What if your company doesn't ever allow jeans?

Then just have a BOLD BLUE DAY – where on a certain day everyone chooses to wear their favorite BOLD BLUE outfit! Then collect donations for the SSF that day as well.

To receive more information or have a "Bold Blue Day" kit sent to you, contact Steph Hilton at (800) 475-6473 ext. 227 or shilton@sjogrens.org to receive your "Bold Blue Day" kit.

Sjögren's
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I Stood Up...

Why am I Bold and Blue?



Blue Ridge Community Health Services (BRCHS) decided to go BOLD Blue for Sjögren's awareness to honor the memory of employee Ana Oviedo Medina. Although it wasn't until after Ana's passing that both her family and BRCHS became aware that she had been living with Sjögren's.

Ana died on March 4, 2013, after being hospitalized for 21 days with BOOP (bronchiolitis obliterans organizing pneumonia) at the age of 28. On the day of her passing, Ana's father was told by the pulmonologist that they had just diagnosed Ana with an autoimmune disease, which was affecting her lungs. Two weeks later, Ana's family met with the pulmonologist again and learned that the vaguely described autoimmune disease was Sjögren's.

Even though it would take Ana twice the amount of energy to complete a task as others and she had to rest frequently throughout the day, Ana's sister Amparo doesn't believe she knew that she had Sjögren's. "She would have told us and would have become involved with the Foundation, I'm sure," said Amparo.

Now a new member of the Foundation and an advocate for Sjögren's awareness, Amparo has become involved with the Foundation to learn more about the disease that affected her sister. The day after meeting with Ana's pulmonologist and hearing the name Sjögren's, Amparo contacted the Foundation to learn about Bold Blue Days. She then brought the idea of hosting a Bold Blue Day to BRCHS, who didn't hesitate at the opportunity to honor Ana's memory and raise awareness of an important health issue.

After BRCHS's Bold Blue Day, CEO Jennifer Henderson released the following the statement:

"Ana Oviedo was a beloved member of the Blue Ridge



Ana Oviedo Medina

I will Stand Up in 2013!



Community Health Services (BRHCS) team. Her recent passing, and Sjögren's syndrome diagnosis, increased our awareness of the issues and symptoms attached to the syndrome.

On April 5, BRCHS held their first ever Bold Blue Day to honor Ana and educate the BRCHS community about Sjögren's. We are proud to announce that \$500 was raised by BRCHS staff during our Bold Blue Day!"

The Sjögren's Syndrome Foundation is proud to honor Ana's memory and recognize Amparo and BRCHS's willingness to help with awareness. Thank you for stepping up for Ana and the four million Americans who suffer from Sjögren's. ■



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Patient Education Sheet

Raynaud's Syndrome

The SSF thanks Ashley Beall, MD for authoring this Patient Education Sheet. Dr. Beall is a Partner with Arthritis and Rheumatism Associates, Wheaton, Maryland.

Raynaud's Syndrome (sometimes called Raynaud's phenomenon) is defined as repeated episodes of color changes in the fingers and/or toes with exposure to cold temperatures or during episodes of emotional stress. The color changes are due to a spasm of the blood vessels that feed the fingers and toes. The digits typically turn very white, then can take on a bluish color with prolonged exposure to the cold, and finally can turn very red as blood flow resumes. Raynaud's Syndrome occurs in approximately 15-30% of patients with Sjögren's syndrome.

Some things that you can do to control your Raynaud's Syndrome include:

- When you know that you will be exposed to cold temperatures, wear layered clothing. This will keep your core body temperature warm and keep the vessels feeding the fingers and toes from spasm.
- Always carry a jacket with you on outings, as you may find yourself in an unexpectedly cool area.
- Wear a hat and cover your face and ears with a scarf in cold temperatures.
- Always wear hand coverings in cold temperatures. Mittens are best, as they will use the body heat generated by your fingers. However, a good pair of insulated gloves is also helpful.
- Wear heavy socks or layers of socks to keep feet warm at all times.
- Keep your home and office space comfortably warm (greater than 70 degrees is best).
- Avoid reaching into the freezer both at home and in the grocery store.
- Use insulated containers when handling cold drinks or food.
- Rinse food with warm water instead of cold water.
- Wear protective gloves when washing dishes.
- Use disposable heat packs as needed for your hands and feet. These are available at many sporting goods stores.
- Always let the water warm up before getting into the shower, and keep the bathroom door closed while bathing or showering to hold in heat.
- When possible, have a loved one warm up your car before getting into it on a cold day.
- Moisturize your hands and feet every day to prevent your skin from cracking.
- When your hands or feet start to feel cold, wiggle your fingers and toes, move your arms and legs around to get blood flowing, or put your hands under your armpits to warm them up.
- If you have access to water when a flare starts, run warm water over your fingers and toes until skin color returns to normal.
- Do not smoke — this constricts the blood vessels that feed the hands and feet.
- Talk to your doctor about your symptoms. Several medications can be used to help the vessels stay dilated, including a class of blood pressure medications called calcium channel blockers. Some medicines, such as beta blockers used for high blood pressure, may make Raynaud's worse.

For more information on Sjögren's syndrome contact the Sjögren's Syndrome Foundation at:
6707 Democracy Blvd, Suite 325, Bethesda, MD 20817 • 800-475-6473 • www.sjogrens.org • ssf@sjogrens.org

Clinicians: Please make multiple copies of this Patient Education Sheet and distribute to your patients.



in memoriam

- In Memory of Betty Nordeen Stoffel**
Robin & Craig Schoenfeld
- In Memory of Ellen Hurd**
Richard Hurd
- In Memory of Frances Dobb**
Judy & Peter Salzer
- In Memory of Karen Lynn Cordell**
Roger Ownbey
Melissa, Amy and Deborah Scharer
Cooper Ridge Home Owners Association, Inc.
Keith & Marilyn Spitznogle
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Andrew Andreeko
- In Memory of Norma Deem**
Bev Deem
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Bill & Lynn Hollick
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in honor

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- In Honor of Joshua Pearl**
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- In Honor of Linda Lehrman**
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Carol Baney
- In Honor of Yvette Gontkovsky's Birthday**
Von Lee



Remember
your loved ones and
special occasions with
a donation to the SSF
in their name.

Awareness Never Looked So Good

Awareness comes in many forms and it's been wonderful seeing so many of you wearing Sjögren's merchandise at recent events!

The Sjögren's Syndrome Foundation was founded by a patient, and it is because of volunteers that we have grown to be the field's leading organization and are able to drive important research and advocate on behalf all patients.

SSF members around the country have been sharing their stories with others, going BOLD Blue, stepping up as community Awareness Ambassadors, running as a part of *Team Sjögren's* and hosting fundraising events. Sporting Sjögren's gear is another way to increase awareness and many of you have asked us where you can purchase more Sjögren's items.

The SSF currently partners with Café Press to provide a selection of awareness merchandise and have recently added more items that you've requested! Items including:

Beach bags

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Bold Blue Butterfly items

And much more!

So now you can be seen at the gym in your *Team Sjögren's* sweat-shirt, on vacation with a Sjögren's beach bag or at your next doctor's appointment in a Sjögren's T-shirt. With millions of Sjögren's patients around the world, be prepared for someone to ask you about the Sjögren's item you're wearing and tell you their story with the disease.

With a percentage of the proceeds being donated to the SSF, purchasing items from Café Press is an easy way to support the Foundation and help raise Sjögren's awareness. You can purchase items by typing the following link into your internet browser: www.cafepress.com/sjogrens-syndromefoundation.

Awareness never looked so good and we want to see pictures of everyone raising awareness in style! Please send us pictures of you wearing your Sjögren's merchandise to: tms@sjogrens.org or mail them to the SSF office: 6707 Democracy Blvd., STE 325; Bethesda, MD 20817.

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Could salivary biomarkers hold a key to novel diagnostics in Sjögren's?

Since David T. Wong, PhD, launched his renowned studies on salivary biomarkers in Sjögren's, he and other investigators have continued to focus on this promising area as a non-invasive means that might facilitate diagnosis and early detection as well as elucidate disease mechanisms that could provide targets for therapeutic intervention in Sjögren's. Of note, Dr. Wong authored a lead article for the Spring 2008 *Sjögren's Quarterly* (the SSF Medical Professional Newsletter) on the promise of salivary biomarkers in Sjögren's.

One of the latest studies in this area was published recently by Driss Zoukri, PhD, with the Department of General Dentistry, Tufts University School of Dental Medicine, Boston, Massachusetts: Zoukri D, Rawe I, Singh M, Brown A, Kublin CL, Dawson K, Haddon WF, White EL, Hanley KM, Tusé D, Malyj W, Papas A. Discovery of putative salivary biomarkers for Sjögren's syndrome using high resolution mass spectrometry and bioinformatics. *J Oral Sci.* 2012 Mar;54(1):61-70.

Abstract

The purpose of the current study was to determine if saliva contains biomarkers that can be used as diagnostic tools for Sjögren's syndrome (SjS). Twenty seven SjS patients and 27 age-matched healthy controls were recruited for these studies. Unstimulated glandular saliva was collected from the Wharton's duct using a suction device. Two μ l of saliva were processed for mass spectrometry analyses on a prOTOF 2000 matrix-assisted laser desorption/ionization orthogonal time of flight (MALDI O-TOF) mass spectrometer. Raw data were analyzed using bioinformatic tools to identify biomarkers. MALDI O-TOF MS analyses of saliva samples were highly reproducible and the mass spectra generated were very rich in peptides and peptide fragments in the 750-7,500 Da range.

Data analysis using bioinformatic tools resulted in several classification models being built and several biomarkers identified. One model based on 7 putative biomarkers yielded a sensitivity of 97.5%, specificity of 97.8% and an accuracy of 97.6%. One biomarker was present only in SjS samples and was identified as a

proteolytic peptide originating from human basic salivary proline-rich protein 3 precursor.

We conclude that salivary biomarkers detected by high-resolution mass spectrometry coupled with powerful bioinformatic tools offer the potential to serve as diagnostic/prognostic tools for SjS. ■

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The Moisture Seekers

Sjögren's Syndrome Foundation Inc.
6707 Democracy Blvd., Ste 325
Bethesda, MD 20817

Phone: 800-475-6473
Fax: 301-530-4415

If you would like to receive this newsletter but are not currently an SSF Member, please contact us! 800-475-6473

Join the Fun!

2013 SSF Special Event Calendar

Join in the fun and help increase Sjögren's awareness. The SSF is very excited for all of our events coming this year. Look at our special event calendar below to see if there is an event coming to your area. More events to come!

Visit www.sjogrens.org
or contact the SSF office to
learn more about our events!

June

- 1 **Northeast Ohio Walkabout**
Brecksville's Oak Grove Picnic Area, Brecksville, Ohio
- 2 **Sip for Sjögren's Atlanta**
Nelson Mullins - Atlantic Station, Atlanta, Georgia
- 8 **Kansas City Walkabout**
Independence Center, Independence, Missouri
- 15 **Denver Walkabout**
Denver Zoo, Denver, Colorado



July

- 28 **Team Sjögren's California - Six Miles for Sjögren's**
Santa Cruz, California

