

# The Moisture Seekers

Sjögren's Syndrome Foundation



www.sjogrens.org

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 SjogrensSyndromeFoundation

 @SjogrensOrg



## You've Probably Never Heard of My Disease

by Vicki Baldwin

*This article was first published by HealthyWomen.org with collaboration by the Sjögren's Syndrome Foundation. We encourage you to share this article with family and friends in your life.*

I'm outdoorsy, but I rarely go hiking anymore. I love live music, but I've had to skip many concerts. I enjoy my job, but I often find myself struggling to stay awake. I enjoy time with friends, but I frequently find myself needing to cancel plans.

I'm not lazy. I'm not an introvert. I'm not a pessimist. I have Sjögren's.

Chances are you've never heard of Sjögren's, and if you have heard of it, you probably don't understand it.

Sjögren's is an autoimmune disease affecting more than 4 million Americans—90 percent of whom are women.

*continued page 8 ▼*

## Ask the Experts: All About Dry Eye

The recent "Living with Sjögren's" patient survey, conducted by Harris Poll on behalf of the Sjögren's Syndrome Foundation, SSF, and published in April 2017, showed that 92% of Sjögren's patients suffer from dry eye. Chronic dry eye has two main causes: decreased secretion of tears by the lacrimal (tear-producing) glands and loss of tears due to excess evaporation. Both can lead to ocular surface discomfort, often described as feeling of dryness, burning, a sandy/gritting sensation, itchiness, visual fatigue, sensitivity to light and blurred vision.

In 2005, Congress officially declared July "Dry Eye Awareness Month" to help educate the public about symptoms and treatment options. In honor of this past Dry Eye Awareness Month, the Foundation is bringing you our most popular dry eye questions from leading experts aimed to promote dry eye education.

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### “Dry Eye Q&A” *continued from page 1* ▼

**Q** *Many eye drops claim to have disappearing preservatives. Are these the equal of preservative-free drops, or should they still be used like eye drops with standard preservatives?*

**A** The development of “disappearing preservatives” has allowed eye drops to be formulated in multiuse dropper bottles for convenience without the risk of surface damage that can occur with the more potent and persistent preservatives. The mechanism by which such new preservatives “disappear” is usually due to chemical changes in the preservative that occur upon exposure to air or the tear film. The most common such chemical reaction is oxidation of the preservative, turning it into an inactive molecule. It must be remembered, nevertheless, that the inactive molecule can be something to which sensitive patients may react. It is worthwhile, therefore, that the patient be alert to any intolerance of such medication, which can occur as irritation, discomfort or red eyes. The “disappearing preservative” eye drops can be used up to four times a day in most cases without difficulty and some patients can use them even more frequently than drops with regular preservatives. It should be remembered that other eye drops, particularly those used to treat glaucoma, could contain preservatives as well and, therefore, it is important for patients to keep track of how many drops are being instilled in the eye during the day.

Truly preservative-free eye drops contain no such preservative chemicals but, therefore, typically require special packaging that limits the amount of the solution in the dropper to usually only one or two drops. The challenges of the smaller packaging can be a nuisance, but if the patient is sensitive to even the “disappearing preservative” this nuisance can be worth the better tolerance to the lubricant.



Gary N. Foulks, MD

**Q** *My eyes are so dry after working on the computer. What should I do?*

**A** In society today, all of us increasingly use computers, smart phones and tablets on a daily basis. We may experience symptoms related to computer use called, computer vision syndrome. Symptoms after extensive viewing of technology can lead to eye discomfort, fatigue, blurred vision and headaches, dry eye and eyestrain. These symptoms may be exacerbated by poor lighting, glare, an improper workstation arrangement, uncorrected

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## Do your eyes need help making more of their own tears?

If so, you might have a type of Chronic Dry Eye caused by reduced tear production due to inflammation.

RESTASIS MultiDose™ (cyclosporine ophthalmic emulsion) 0.05% can help you make more of your own tears with continued use twice a day, every day, one drop at a time. **Ask your eye doctor for a Chronic Dry Eye exam today. Learn more at Restasis.com.**

### APPROVED USE

RESTASIS MultiDose™ Ophthalmic Emulsion helps increase your eyes' natural ability to produce tears, which may be reduced by inflammation due to Chronic Dry Eye. RESTASIS MultiDose™ did not increase tear production in patients using anti-inflammatory eye drops or tear duct plugs.

### IMPORTANT SAFETY INFORMATION

Do not use RESTASIS MultiDose™ Ophthalmic Emulsion if you are allergic to any of the ingredients. Be careful not to touch the bottle tip to your eye or other surfaces, to help avoid eye injury and contamination. RESTASIS MultiDose™ should not be used while wearing contact lenses. If contact lenses are worn, they should be removed prior to use of RESTASIS MultiDose™ and may be reinserted after 15 minutes.

The most common side effect is a temporary burning sensation. Other side effects include eye redness, discharge, watery eyes, eye pain, foreign body sensation, itching, stinging, and blurred vision.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

Please see next page for a Brief Summary of the Full Product Information.

Your Eyes. Your Tears.   
*(Cyclosporine Ophthalmic Emulsion) 0.05%*



**RESTASIS MULTIDOSE™ (Cyclosporine Ophthalmic Emulsion) 0.05%**  
**BRIEF SUMMARY—PLEASE SEE THE RESTASIS MULTIDOSE™ PACKAGE**  
**INSERT FOR FULL PRESCRIBING INFORMATION.**

**INDICATION AND USAGE**

**RESTASIS MULTIDOSE™** ophthalmic emulsion is indicated to increase tear production in patients whose tear production is presumed to be suppressed due to ocular inflammation associated with keratoconjunctivitis sicca. Increased tear production was not seen in patients currently taking topical anti-inflammatory drugs or using punctal plugs.

**CONTRAINDICATIONS**

**RESTASIS MULTIDOSE™** is contraindicated in patients with known or suspected hypersensitivity to any of the ingredients in the formulation.

**WARNINGS AND PRECAUTIONS**

**Potential for Eye Injury and Contamination**

Be careful not to touch the bottle tip to your eye or other surfaces to avoid potential for eye injury and contamination.

**Use with Contact Lenses**

**RESTASIS MULTIDOSE™** should not be administered while wearing contact lenses.

Patients with decreased tear production typically should not wear contact lenses. If contact lenses are worn, they should be removed prior to the administration of the emulsion. Lenses may be reinserted 15 minutes following administration of

**RESTASIS MULTIDOSE™** ophthalmic emulsion.

**ADVERSE REACTIONS**

The following serious adverse reactions are described elsewhere in the labeling: Potential for Eye Injury and Contamination

**Clinical Trials Experience**

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in practice.

In clinical trials, the most common adverse reaction following the use of cyclosporine ophthalmic emulsion, 0.05% was ocular burning (17%).

Other reactions reported in 1% to 5% of patients included conjunctival hyperemia, discharge, epiphora, eye pain, foreign body sensation, pruritus, stinging, and visual disturbance (most often blurring).

**Post-marketing Experience**

The following adverse reactions have been identified during post approval use of cyclosporine ophthalmic emulsion, 0.05%. Because these reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

Reported reactions have included: hypersensitivity (including eye swelling, urticaria, rare cases of severe angioedema, face swelling, tongue swelling, pharyngeal edema, and dyspnea); and superficial injury of the eye (from the bottle tip touching the eye during administration).

**USE IN SPECIFIC POPULATIONS**

**Pregnancy**

**Risk Summary**

Clinical administration of cyclosporine ophthalmic emulsion 0.05% is not detected systemically following topical ocular administration and maternal use is not expected to result in fetal exposure to the drug. Oral administration of cyclosporine to pregnant rats or rabbits did not produce teratogenicity at clinically relevant doses [see Data].

**Data**

*Animal Data*

At maternally toxic doses (30 mg/kg/day in rats and 100 mg/kg/day in rabbits), cyclosporine oral solution (USP) was teratogenic as indicated by increased pre- and postnatal mortality, reduced fetal weight and skeletal retardations. These doses (normalized to body surface area) are 5,000 and 32,000 times greater, respectively, than the daily recommended human dose of one drop (approximately 28 mL) of cyclosporine ophthalmic emulsion 0.05% twice daily into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed. No evidence of embryofetal toxicity was observed in rats or rabbits receiving cyclosporine during organogenesis at oral doses up to 17 mg/kg/day or 30 mg/kg/day, respectively. These doses in rats and rabbits are approximately 3,000 and 10,000 times greater, respectively, than the daily recommended human dose. An oral dose of 45 mg/kg/day cyclosporine administered to rats from Day 15 of pregnancy until Day 21 postpartum produced maternal toxicity and an increase in postnatal mortality in offspring. This dose is 7,000 times greater than the daily recommended human dose. No adverse effects in dams or offspring were observed at oral doses up to 15 mg/kg/day (2,000 times greater than the daily recommended human dose).

**Lactation**

**Risk Summary**

Cyclosporine is known to appear in human milk following systemic administration, but its presence in human milk following topical treatment has not been investigated. Although blood concentrations are undetectable following topical administration of cyclosporine ophthalmic emulsion 0.05%, caution should be exercised when **RESTASIS MULTIDOSE™** is administered to a nursing woman. The developmental and health benefits of breastfeeding should be considered along with the mother's clinical need for **RESTASIS MULTIDOSE™** and any potential adverse effects on the breast-fed child from cyclosporine.

**Pediatric Use**

Safety and efficacy have not been established in pediatric patients below the age of 16.

**Geriatric Use**

No overall difference in safety or effectiveness has been observed between elderly and younger patients.

**NONCLINICAL TOXICOLOGY**

**Carcinogenesis, Mutagenesis, Impairment of Fertility**

**Carcinogenesis:** Systemic carcinogenicity studies were conducted in male and female mice and rats. In the 78-week oral (diet) mouse study, at doses of 1, 4, and 16 mg/kg/day, evidence of a statistically significant trend was found for lymphocytic lymphomas in females, and the incidence of hepatocellular carcinomas in mid-dose males significantly exceeded the control value.

In the 24-month oral (diet) rat study, conducted at 0.5, 2, and 8 mg/kg/day, pancreatic islet cell adenomas significantly exceeded the control rate in the low-dose level. The hepatocellular carcinomas and pancreatic islet cell adenomas were not dose related. The low doses in mice and rats are approximately 80 times greater (normalized to body surface area) than the daily human dose of one drop (approximately 28 mL) of cyclosporine ophthalmic emulsion, 0.05% twice daily into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed.

**Mutagenesis:** Cyclosporine has not been found to be mutagenic/genotoxic in the Ames Test, the V79-HGPRT Test, the micronucleus test in mice and Chinese hamsters, the chromosome-aberration tests in Chinese hamster bone-marrow, the mouse dominant lethal assay, and the DNA-repair test in sperm from treated mice. A study analyzing sister chromatid exchange (SCE) induction by cyclosporine using human lymphocytes *in vitro* gave indication of a positive effect (i.e., induction of SCE).

**Impairment of Fertility:** No impairment in fertility was demonstrated in studies in male and female rats receiving oral doses of cyclosporine up to 15 mg/kg/day (approximately 2,000 times the human daily dose of 0.001 mg/kg/day normalized to body surface area) for 9 weeks (male) and 2 weeks (female) prior to mating.

**PATIENT COUNSELING INFORMATION**

**Handling the Container**

Advise patients to not allow the tip of the bottle to touch the eye or any surface, as this may contaminate the emulsion. Advise patients to not touch the bottle tip to their eye to avoid the potential for injury to the eye.

**Use with Contact Lenses**

**RESTASIS MULTIDOSE™** should not be administered while wearing contact lenses.

Patients with decreased tear production typically should not wear contact lenses.

Advise patients that if contact lenses are worn, they should be removed prior to the administration of the emulsion. Lenses may be reinserted 15 minutes following administration of **RESTASIS MULTIDOSE™** ophthalmic emulsion.

**Administration**

Advise patients to read the "Instructions for Use" for detailed first-time use instructions.

**Rx Only**



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**in memoriam**

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Bonnie and Ronald Schneider

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Elaine Levin

**In Honor of Gene Stuckey**  
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Bobette Morgan

**In Honor of Jackie Coffin, on her 25<sup>th</sup> birthday**  
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**In Honor of Jessica Levy**  
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**In Honor of John and Geri Rowlinson, on their 50<sup>th</sup> Wedding Anniversary**

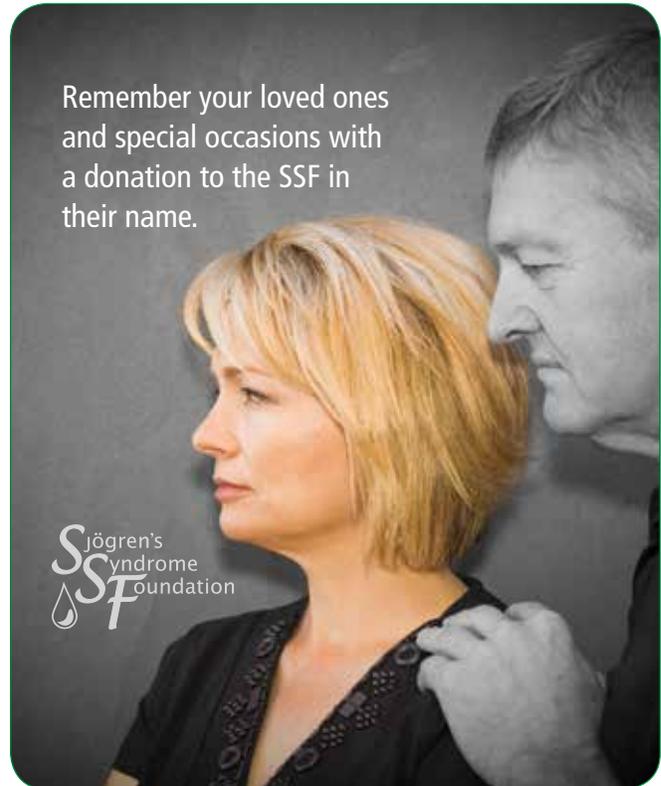
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**In Honor of Stephanie Manson**  
Valerie Manson

**In Honor of Vicki Deem, on the occasion of her birthday**  
Mark and Sara Deem





# SSF in Action!

## SSF Attends Congressional Briefing for Dry Eye Awareness Month

### Congressional Briefing Speakers:

*Paul Karpecki, OD*

*Susan Vitali, PhD, MHS, NEI, NIH*

*Janine Austin-Clayton, MD, ORWH Director, NIH*

*David Sullivan, MS, PhD, TFOS Founder*



**K**atherine Hammitt, SSF Vice President of Medical and Scientific Affairs, recently attended the Congressional Briefing entitled, “Dry Eye: An Updated Definition, A Greater Impact on Vision Health,” on July 12<sup>th</sup>. The Briefing was co-hosted by the Tear Film and Ocular Surface Society (TFOS) and the Alliance for Eye and Vision Research (AEVR).

The Foundation is dedicated to being a part of the vision community and continuing to make Congressional education about dry eye a priority as it impacts healthcare policy and federal research funding from the National Institutes of Health (NIH), including its National Eye Institute (NEI), which is used to study dry eye causes and develop treatments.

Following the Congressional Briefing, TFOS released their *Major Study of the Disease Final Report*, which is currently available on the Foundation’s website ([www.sjogrens.org](http://www.sjogrens.org)). The report will cover every aspect of dry eye including, epidemiology, definition, clinical management, treatment, and clinical trial guidelines. The SSF is proud to have contributors of this report include: Katherine Hammitt, SSF Vice President of Medical and Scientific Affairs who Chaired the TFOS Public Awareness and Education

Subcommittee, Dr. Stephen Cohen, Chair of the SSF Board of Directors, Dr. Esen Akpek, SSF Board Member, and Dr. Jason Nichols, SSF Board Member.

Supporting the July 2017 Dry Eye Awareness Month educational activities and the Congressional Briefing included:

- Alliance for Eye and Vision Research American Academy of Ophthalmology
- American Academy of Optometry
- American Optometric Association
- Association for Research in Vision and Ophthalmology
- HealthyWomen
- Prevent Blindness
- Research to Prevent Blindness
- Sjögren’s Syndrome Foundation
- Tear Film and Ocular Surface Society
- University of Alabama at Birmingham School of Optometry
- Women’s Eye Health
- Women in Ophthalmology

NEUTRASAL® RELIEVES DRY MOUTH SYMPTOMS, SO

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**90%** OF PATIENTS REPORTED  
IMPROVEMENT IN  
TALKING\*

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- Patients in a clinical study who used NeutraSal® for 28 days reported **improvements in talking, eating, drinking, and swallowing**
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### INDICATIONS

NeutraSal® is indicated for dryness of the mouth (hyposalivation, xerostomia) and dryness of the oral mucosa due to drugs that suppress salivary secretion.

### IMPORTANT SAFETY INFORMATION

- Not intended to prevent xerostomia or oral mucositis
- Patients should avoid eating or drinking for at least 15 minutes after use
- Solution should not be swallowed but be spit out
- Not intended for systemic use to treat any diseases of the throat or upper gastrointestinal tract
- Not intended for use as an antacid
- No adverse events anticipated if swallowed accidentally
- Contains sodium; if you are on a low sodium diet consult with your doctor
- No known interactions with medicinal or other products

Please see Instructions for Use at [NeutraSal.com/Sjogrens](http://NeutraSal.com/Sjogrens)

\*In a clinical study patients with varying degrees of xerostomic symptoms (n=30), reported improvement at 28 days

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 **NeutraSal®**  
(Supersaturated Calcium Phosphate Rinse)

**“You’ve Probably...”** *continued from page 1* ▼

Sjögren’s causes the body to attack moisture-producing glands—most commonly the eyes and mouth—and presents symptoms of fatigue and joint pain. It can also cause dysfunction of other organs, affect the kidneys, gastrointestinal system, blood vessels, lungs, liver, pancreas and nervous system.

I’ve been living with a Sjögren’s diagnosis for nearly seven years, but I’ve had it much longer. When I first saw my health care provider about my original symptoms—dry eyes and severe fatigue—they were brushed off. The dry eyes were attributed to Lasik surgery I had, and the fatigue was thought to be thyroid related. After having a thyroidectomy—surgery to remove my entire thyroid gland—my fatigue became worse.

It took four long years to receive my Sjögren’s diagnosis.

Once I received my diagnosis, I was relieved, but I also knew life would not go back to being normal—ever. Yes, I received treatment, which helped, but fatigue and pain are a constant. I deal with them daily.

I didn’t just watch my life slip away, though. I made adjustments. I live a wonderful life, despite Sjögren’s, by:

- Working from home, which allows me to rest as needed.
- Educating people about my disease. I carry pamphlets with me wherever I go. If Sjögren’s comes up, I hand them a pamphlet. This includes educating health care professionals, many of whom aren’t fully aware of this disease!
- Carefully planning my schedule. If I plan to go to a concert on a Friday, I know I will need the entire weekend to recover and rest.
- Having a therapy dog. Being at home alone can become isolating, so having a companion helps. I also bring my dog to visit people in nursing homes, which gets me out of the house and brings joy to others.
- Joining and creating support groups. I’m not alone, and it helps to know there are other people living with Sjögren’s. I’ve formed very close friendships with several people from Facebook pages that provide support to people living with Sjögren’s, and I even created a local support group in my town.

You can find information about SSF support groups on the Foundation’s website, [www.sjogrens.org](http://www.sjogrens.org), and learn more about Vicki’s journey in her “You Stood Up” feature on page 9. ■

**“Dry Eye Q&A”** *continued from page 2* ▼

refractive error (vision problems), or a combination of these factors but there are ways to help.

**What to do:**

- Start with a comprehensive eye examination. An eye examination will ensure that vision is corrected enabling you to see clearly and comfortably at all distances and detect conditions that may contribute to eyestrain. If needed, glasses, contact lenses or vision therapy (eye exercises) can provide clear and comfortable vision for computer use.
- Check the height and arrangement of the computer. A computer screen should be 15 to 20 degrees below eye level (about 4 or 5 inches) as measured from the center of the screen and held 20 to 28 inches away from the eyes.
- Check for glare on the computer screen. Windows or other light sources should not be directly visible when sitting in front of the monitor. If needed, adjust the desk or computer to prevent glare on the screen. A lower-wattage light can be substituted for a bright overhead light or a dimmer switch may be installed to give flexible control of room lighting.
- Take a break and keep blinking. A 20 second break every 20 minutes will reduce the development of eye focusing problems and eye irritation. In order to minimize the chances of developing dry eye when using a computer or digital device, make an effort to blink frequently. Blinking keeps the front surface of the eye moist. Additionally, non-preservative lubricant artificial tears or prescription eye drops may be beneficial to alleviate computer vision syndrome.



*Dr. Melissa Barnett, OD, FAAO, FSLA*

**Q** *Why do dry eyes feel awful in the morning when I first wake up, especially if I don’t use an eye lubricant at night?*

**A** There are certain conditions that can get worse during the night with the eye in a closed state. For example, if you have blepharitis, which is caused by common skin



## You Stood Up!

### *Vicki's Journey to Cheering on the SSF!*

When I was diagnosed with Sjögren's in 2010, my doctor called and said, "I'm sorry, you have something called Sjögren's. I'll need to spell that for you." My first thought was to ask if any friends had heard of it. Were there others I could talk to? I found a friend of a friend with the disease and I was excited to talk with her. But the first e-mail said "your life as you know it is over." Wow... not what I needed to hear!

I'm very proactive, so I scoured the Internet for every website and discussion group. After a long search, I realized the Sjögren's Syndrome Foundation, SSF, was the most reliable source for information. I downloaded documents, fact sheets and became a member so I could access the newsletter archives and receive current copies of *The Moisture Seekers*. After learning more about Sjögren's, I looked for a support group and was disappointed there were none in Tennessee. I was sure there were patients and families near Nashville who would want a group, so I called the Foundation and they said, "We can help, you can start one." They sent me everything I needed to start the Nashville SSF Support Group. I now speak to many people referred by the Foundation, most of who are newly diagnosed.

The SSF Nashville Support Group had our first support group meeting in 2013. I cannot describe how amazing it was to finally meet people face-to-face who truly understood this journey and wanted to share that experience. Hearing others say, "Yes, I know what it's like," let me know I'm NOT alone! And I now had a new circle of supportive friends. When I attended the SSF National Patient Conference in 2014, I brought my new knowledge back to the group.

Since then, we have held two SSF Walkabouts in Nashville, set up information tables at several health fairs and twice organized cheerleaders for Team Sjögren's at the Nashville Rock 'N' Roll Marathon.

I'm part of the Sjögren's Facebook group and the new SSF SmartPatients online community. Here we ask questions and discuss medical issues, doctors, medicines, over-the-counter products, frustrations and victories! As a community, we share the Foundation's information and use social media to highlight April Sjögren's Awareness Month and World Sjögren's Day.

The more I talk about living with Sjögren's, I'm surprised how many people know someone who is affected by it.

If you're wondering how to get involved with Sjögren's awareness, start in your own community. Ask the Foundation, they will be happy to help you get started. ■



*Vicki cheering at the 2017 Team Sjögren's at the Nashville Rock 'N' Roll Marathon*

# CONGRATULATIONS TO TEAM SJÖGREN'S NASHVILLE 2017!



"We race in Honor of the 4 Million Americans with Sjögren's... We Are Team Sjögren's!"





The Sjögren's Syndrome Foundation, SSF, would like to congratulate the 25 Team Sjögren's Nashville walkers and runners who raised over \$35,000!

The Team Sjögren's program recently completed its 15<sup>th</sup> race at the Rock 'N' Roll Nashville Marathon event on April 28<sup>th</sup>. Among the team members was our very own SSF CEO, Steven

Taylor, who ran in his 15<sup>th</sup> Team Sjögren's Marathon event- participating in every race since the start of the program! Joining Steve, was an amazing group of walkers/runners that consist of:

- 15 Sjögren's Patients
- 1 Sister of a Sjögren's Patient
- 5 Children of Sjögren's Patients
- 3 Husbands of Sjögren's Patients
- 1 Friend of a Sjögren's Patient



SSF CEO, Steven Taylor, Celebrating his 15<sup>th</sup> Team Sjögren's Race!

The Team Sjögren's program was created to raise awareness and funds in honor of the 4 million Americans living with this disease, but each year the Foundation is impressed at how many patients join. As team members travel from around the country for each Team Sjögren's event, most meet in person for the first time at the SSF pre-race pasta dinner. Here, it is incredible to listen to everyone share why they decided to join the program. There is an overwhelming sense of pride that members have who joined for a loved one who they've seen fight for their health, and even more, it's the pride patients have who walk/run for themselves too.

If you have ever thought about joining Team Sjögren's in the past, make this the year you take that leap! Just imagine how it will feel to cross the finish line knowing that you met your personal goals while also helping to raise awareness and funds for Sjögren's research. And if you cannot walk/run, we encourage you to recruit a friend or family member to walk/run in your honor! For more information on Team Sjögren's next race and this amazing experience, please email us at [info@sjogrens.org](mailto:info@sjogrens.org).

Thank you to all of this year's walkers/runners and everyone who has been a part of Team Sjögren's 15 races!



Rock 'n' Roll  
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**“Dry Eye Q&A”** *continued from page 8* ▼

bacteria called “staph epidermidis,” the waste products of the staph are very irritating. But with your eye closed that staph toxin is lying there all night. If I have a patient who wakes up with really irritated eyes, one of the first things I want to look at is untreated blepharitis.

Another possible cause is called “recurrent corneal erosion.” Think about pulling a scab off all the time. It starts to heal and you pull the scab off. If the surface of the eye gets irritated through dryness and adherence to the back of the lid, or through an injury, that tissue needs to heal. The good news is it heals very quickly. The bad news is it hurts a lot as I’m sure you’ve found. So it heals quickly but it doesn’t necessarily anchor itself. That thin, outer layer of the cornea doesn’t anchor itself to the eye very fast, so you run the risk of re-irritating your eye even after you are feeling better. And when you do that over-and-over, it is called “recurrent corneal erosion.” You are basically tearing off the outer layer of the front of your eye. Classic sign is you wake up, you open your eyes and it hurts. Using ointments at night helps. Using an antibiotic ointment would help if you have blepharitis

as well because it would treat that and give your eye a little more coating.

### Dry Eye Tip!

If you have severe dry eyes and trouble opening your eyes in the morning because your lid is sticking, try to keep your eyes closed when you wake up and use the heels of your hands to gently massage your lids. What this will do is break any of those adhesions that may be there and it stimulates a little tear production so that you can actually open up your eye safely. But if you wake up and open up your eyes right away, you run the risk of – ouch – pulling that adhesion off, again, like pulling a scab off of a wound.



Stephen Cohen, OD,  
Chair of the SSF Board of Directors

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# Patients Sharing with Patients



*No one grew up with plans to have a chronic disease. It just happens. Once it does, you have to do everything possible to live in the best way you can.*  
– *The Sjögren’s Syndrome Survival Guide*

*This book is available on the SSF website*

**A**t the SSF National Patient Conference, we asked, “What is your best tip for living well everyday with Sjögren’s.” Here are a few of the responses:

- Stay active the best way you can and don’t try to do it all in one day. It’s okay to take your time and it’s ok to ask for help. –Kristine
- To help with brain fog, flip medicine bottles upside down after taking pills at night and flip them over in the morning so you remember if you took them. I also use a pill-organizing box for my weekly medications. –Randy
- For my desert dry, blistering, peeling lips, I discovered that extra strength vitamin E oil helps me. –Lianne
- Take advantage of services available, like using a special needs locker or locker room at your gym if they have it. You will enjoy the benefits of working out by having less stress and focusing on what you need to do instead of jamming things in a small space. –Mooda
- Get informed! Don’t assume doctors know more than you do and don’t settle for a doctor who doesn’t at least want to educate him/ herself. –Lisa
- Honesty with my family. I’ve got a young family and some days are harder than others. So being upfront and having grace makes each day easier. –Amber
- Make a playlist for your bad days with inspiring, calming or fun music to lift your spirits. –Katherine
- Stay confident and laugh a lot! –Connie
- Always take non-steroidal anti-inflammatory drugs (NSAIDs) with food or milk to avoid an upset stomach. –Donna
- Find a good team of doctors and do what they say. Rest when you need to, but keep yourself moving as much as you can. Don’t give up! –Ryan
- Learn to listen to your body and save up energy for what’s important to you. Don’t push yourself too much. I have days where I just overdo it because I’m feeling great and the next day I suffer. I also find a heating pad helps a lot. –Tim
- The one treatment that has helped me is water aerobics. Working out in the water and even doing it to music is restful but also improves coordination and is calming like yoga. –Susan
- Wake up everyday grateful for that day. Remember, others are also sharing the Sjögren’s journey with you! You are not alone. –Carolyn

# Missed the 2017 National Patient Conference?



Get all the vital information you need on audio CD!

Audio CDs of the most popular talks from our 2017 National Patient Conference in Philadelphia/Cherry Hill are available.

Eight of our most popular talks from the 2017 National Patient Conference held in Philadelphia/Cherry Hill, are available for purchase as audio CDs. Each talk is 30-40 minutes long and comes with the handouts used by the presenter.

Buy just the talks you want to hear or purchase the whole set!

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Sjögren's Overview by Dr. Fred Vivino	\$30	\$18		
Pulmonary Issues and Sjögren's by Dr. Augustine Lee	\$30	\$18		
Oral Manifestations of Sjögren's by Dr. Domenick Zero	\$30	\$18		
Pediatric Sjögren's by Dr. Scott Lieberman	\$30	\$18		
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# IT'S TIME

## United Way • Combined Federal Campaign • State Payroll Deduction

Each fall your local United Way, Combined Federal Campaign, state employee, and private employer payroll deduction campaigns begin. We hope you will remember the Sjögren's Syndrome Foundation when choosing where to allocate your donation. (CFC #10603)

If we are not listed on the contribution form, you usually may write in the Sjögren's Syndrome Foundation.

Tell your co-workers, friends, and family members how important it is to choose and write in the Sjögren's Syndrome Foundation on their campaign form, too.

If your employers will not allow you to write in the Sjögren's Syndrome Foundation, remind them that we are a national non-profit 501(C3) organization and qualify for most payroll

deduction campaigns. If they need more information, please contact the Foundation at 800-475-6473 and ask for Elizabeth Trocchio.

**Just think – every dollar counts.**

Last year alone – thanks to those who chose to give through their employer's payroll campaign – the Sjögren's Syndrome Foundation was able to increase its Research and Awareness commitments.

Remember, the Foundation has received the:





*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*

# Viva Las Vegas!

**Walk or Run with Team Sjögren's in Las Vegas!**

Take a gamble and sign up to join our Team Sjögren's Training program for the Rock 'n' Roll series Las Vegas half marathon and 10K. Follow our program and we will prepare you to WALK or RUN in either the half marathon or 10K event on Sunday, November 12<sup>th</sup> in Las Vegas!

The SSF has only 25 reserved spots for the Las Vegas event and we hope you'll be one of them! By taking part, you will get to enjoy the "Strip at Night" as we participate alongside 20,000 other walkers/runners from all over the world! The half marathon and 10K courses take you up and down the Las Vegas Strip during an early evening race. You will be cheered on by bands along the route, as well as cheerleaders and spectators to support your effort.

As a Team Sjögren's member, you will not only receive world-class training from our team trainer, but also leadership and mentorship from past runners and staff. The SSF staff will help guide you through the entire process and ensure you are ready to complete either the 6.2 or 13.1 mile course. Our team is always full of walkers and runners – so don't fret if you aren't a runner – Team Sjögren's was designed for you! Our plan takes people from the couch to the starting line... so take a bet on yourself and join us!

In addition, you will be raising awareness for Sjögren's, as well as, helping raise crucial funds for Sjögren's research and education. So try your luck and plan to be with us on November 12<sup>th</sup>. If you don't feel you can walk or run in this event, do what so many other patients have done and recruit someone else – your husband, wife, sister, cousin, daughter, son or friend – and have them walk or run in your honor.

**We bet you can do it! Take a chance and join Team Sjögren's!**

To learn more about Team Sjögren's, contact Steven Taylor at 800-475-6473 or [staylor@sjogrens.org](mailto:staylor@sjogrens.org).

