

The Moisture Seekers

Sjögren's Syndrome Foundation



www.sjogrens.org

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 SjogrensSyndromeFoundation

 @MoistureSeekers



My Journey, As My Body Attacks Itself

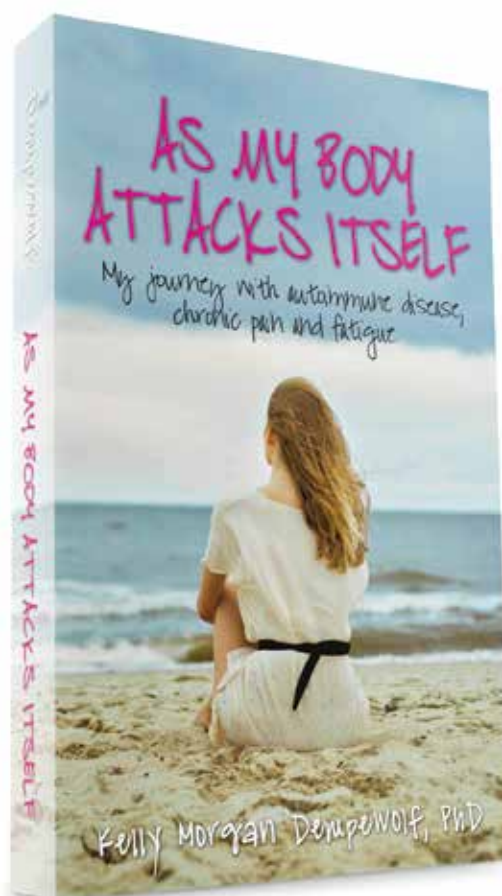
by Kelly Morgan Dempewolf, PhD, author of *As My Body Attacks Itself*

Many people that share stories of life-altering events can share the exact date and time. For health-related stories, many remember the date they noticed a symptom or found a lump for the first time or were given a diagnosis. I, however, can't do this. My life-altering event happened like Hemingway describes going bankrupt – “gradually and then suddenly.”

I know that I first complained to my primary care doctor in early 2008 of fatigue. I only know this because when I was sent to a rheumatologist in 2011, it triggered my memory of going to one year earlier, so I had my doctor pull the records from that first visit. In 2008, I was referred for fatigue and elevated proteins. The rheumatologist wrote in her report that those things are usually found in patients with inflammatory disease but since she had “no place to begin looking for one” and I had “no physical manifestations of one,” she wrote me off as just being tired from a full life and sent me on my way. This is why I don't remember those dates – because I was told they weren't worth remembering.

The only problem is that I'd been sent there with two physical manifestations – the fatigue and the elevated proteins. And had she thought to ask, I would have reported two more – dry mouth and eyes. How was I to know those were linked? I wouldn't know at that time – I had no idea what Sjögren's was or that I should be reporting these things along with the fatigue. But she should have asked. It should be asked of every patient being screened with unexplained fatigue by a rheumatologist!

I'm not sure when the dry eyes and mouth began so I can't use that as my important date. Again, “gradually and then suddenly.” I remember complaining to my optometrist about my contacts being uncomfortable in 2007. But if I was to the point of complaining in 2007 then it had been going on for a while. And I honestly can't even remember the last time I could take more than a bite or two without taking a drink to get it down.



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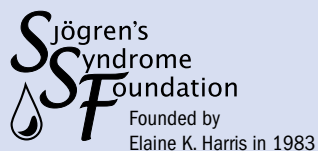
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I don't point to the date in 2011 when I was diagnosed with RA from an elevated sed rate and rheumatoid factor because that was a misdiagnosis. I don't use the date in the spring of 2013 when I first heard "Sjögren's Syndrome" (that was the first time a doctor asked if I had dry eyes and mouth!) and was told the RA probably wasn't correct, but I maybe had a possible overlap of RA and Lupus with the Sjögren's. And by the time I got a confirmation of the diagnosis of Sjögren's and had the RA/Lupus possible overlap dropped in the fall of 2013 (on my third rheumatologist by that point), by then it had clearly been going on far too long for that to be my "life-altering" date.

I'm one of the countless that have been brushed off, sent home, misdiagnosed, treated rudely by healthcare professionals, told that if I didn't think a treatment was working then I just quit taking it and come back in 4 months, and struggled as chronic invisible illness impacted literally every aspect of my life – personal care, social interactions, parenting, marriage, work, hobbies, and anything else I can think of. It has been overwhelming, invasive, pervasive and absolutely life-altering.

I struggled to verbalize what it was like to live with this and it was causing problems in relationships when others couldn't understand why I was closed off as I dealt with only the absolute necessities. I began writing a blog to share what was going on with me. It was easier than talking. I felt distanced from the feelings and therefore could get them "out" easier. It helped me process what I was actually feeling and thinking, and others could read it without me having to repeat it over and over.

Then I began to be contacted by others experiencing the same thing – and they shared with me that I was able to put it into words better than they'd been able to. They shared my writings with their friends and families to explain how they had been feeling. They felt validated while reading that they weren't alone and not imagining it and there are others like us.

And that's when the blog became a book. I processed everything I'd gone through, everything I was feeling and thinking, everything that was changing in my life as a result of this disease. This included the fact that I put off writing the end of the book because I was subconsciously waiting for the nice story arch that I felt should be there – woman gets final, clear cut diagnosis and treatment that if not highly successful at least has positive impact on symptoms, and most importantly comes to acceptance and the ability to live her life free of the emotional and mental burdens of chronic illness – until I realized that wasn't going to happen and finished it with a reflection on the lessons I'd learned so far (and the ones I was still working on).

As I wrote my story I was honest, open and scared to death that a lot of people were going to read these inner thoughts of mine. But I did it because I know that these stories need to be told. Because maybe it will help someone else, somewhere, someday, be able to pinpoint their specific date that their life-altering event happened – diagnosis of Sjögren's shortly after symptom onset by knowledgeable and empathetic healthcare professionals. ■

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Could you have a type of Chronic Dry Eye disease?

If you use artificial tears often, ask your eye doctor to screen you for Chronic Dry Eye caused by reduced tear production due to inflammation.

Find out if you can

MAKE MORE OF YOUR OWN TEARS

with RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05%

For Chronic Dry Eye disease caused by reduced tear production due to inflammation, you can use artificial tears for temporary relief, but they cannot help you make more of your own tears. Only continued use of RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05% twice a day, every day, can help you make your own tears. Individual results may vary.

Approved Use

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

Important Safety Information

Do not use RESTASIS® Ophthalmic Emulsion if you are allergic to any of the ingredients. To help avoid eye injury

and contamination, do not touch the vial tip to your eye or other surfaces. RESTASIS® should not be used while wearing contact lenses. If contact lenses are worn, they should be removed prior to use of RESTASIS® 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, or call 1-800-FDA-1088.

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

Call 1-866-271-6242 for more information.

CALL your optometrist or ophthalmologist to get screened.



GO TO **restasis.com**.

Take the Dry Eye Quiz, and show the results to your eye doctor.

Available by prescription only.

**Restasis**
(Cyclosporine Ophthalmic Emulsion) 0.05%

Make more of your own tears

RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05%

BRIEF SUMMARY—PLEASE SEE THE RESTASIS® PACKAGE INSERT FOR FULL PRESCRIBING INFORMATION.

INDICATIONS AND USAGE

RESTASIS® 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® 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

To avoid the potential for eye injury and contamination, be careful not to touch the vial tip to your eye or other surfaces.

Use with Contact Lenses

RESTASIS® 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® ophthalmic emulsion.

ADVERSE REACTIONS

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 RESTASIS® 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 RESTASIS®. 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 vial tip touching the eye during administration).

USE IN SPECIFIC POPULATIONS

Pregnancy

Teratogenic Effects: Pregnancy Category C

Adverse effects were seen in reproduction studies in rats and rabbits only at dose levels toxic to dams. At toxic doses (rats at 30 mg/kg/day and rabbits at 100 mg/kg/day), cyclosporine oral solution, USP, was embryo- and fetotoxic as indicated by increased pre- and postnatal mortality and reduced fetal weight together with related skeletal retardations. These doses are 5,000 and 32,000 times greater (normalized to body surface area), respectively, than the daily human dose of one drop (approximately 28 mcL) of 0.05% RESTASIS® 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 at oral doses up to 17 mg/kg/day or 30 mg/kg/day, respectively, during organogenesis. These doses in rats and rabbits are approximately 3,000 and 10,000 times greater (normalized to body surface area), respectively, than the daily human dose.

Offspring of rats receiving a 45 mg/kg/day oral dose of cyclosporine from Day 15 of pregnancy until Day 21 postpartum, a maternally toxic level, exhibited an increase in postnatal mortality; this dose is 7,000 times greater than the daily human topical dose (0.001 mg/kg/day) normalized to body surface area assuming that the entire dose is absorbed. No adverse events were observed at oral doses up to 15 mg/kg/day (2,000 times greater than the daily human dose).

There are no adequate and well-controlled studies of RESTASIS® in pregnant women. RESTASIS® should be administered to a pregnant woman only if clearly needed.

Nursing Mothers

Cyclosporine is known to be excreted in human milk following systemic administration, but excretion in human milk after topical treatment has not been investigated. Although blood concentrations are undetectable after topical administration of RESTASIS® ophthalmic emulsion, caution should be exercised when RESTASIS® is administered to a nursing woman.

Pediatric Use

The safety and efficacy of RESTASIS® ophthalmic emulsion 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 carried out 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 mcL) of 0.05% RESTASIS® 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 vial to touch the eye or any surface, as this may contaminate the emulsion. To avoid the potential for injury to the eye, advise patients to not touch the vial tip to their eye.

Use with Contact Lenses

RESTASIS® 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® ophthalmic emulsion.

Administration

Advise patients that the emulsion from one individual single-use vial is to be used immediately after opening for administration to one or both eyes, and the remaining contents should be discarded immediately after administration.

Rx Only



Based on package insert 71876US17

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Made in the U.S.A.

FILL A RESTASIS® (CYCLOSPORINE OPHTHALMIC EMULSION) 0.05% PRESCRIPTION AND WE'LL SEND YOU A REBATE CHECK FOR \$20!*

▶ IT'S EASY TO GET YOUR REBATE. JUST FILL OUT THIS INFORMATION AND MAIL.

Follow these 3 steps:

1. Have your prescription for RESTASIS® filled at your pharmacy.
2. Circle your out-of-pocket purchase price on the receipt.
3. Mail this certificate, along with your original pharmacy receipt (proof of purchase), to **Allergan RESTASIS® Ophthalmic Emulsion \$20 Rebate Program, P.O. Box 6513, West Caldwell, NJ 07007.**

- ☐ Enroll me in the *My Tears, My Rewards*® Program to save more!
- ☐ I am not a patient enrolled in Medicare, Medicaid, or any similar federal or state healthcare program.

Last Name	First	MI
Street Address		
City	State	ZIP

For more information, please visit our website, www.restasis.com.

***RESTASIS® Rebate Terms and Conditions:** To receive a rebate for the amount of your prescription co-pay (up to \$20), enclose this certificate and the ORIGINAL pharmacy receipt in an envelope and mail to Allergan RESTASIS® Ophthalmic Emulsion \$20 Rebate Program, P.O. Box 6513, West Caldwell, NJ 07007. Please allow 8 weeks for receipt of rebate check. Prescriptions dated more than 60 days prior to the postmark date of your submission will not be accepted. One rebate per consumer. Duplicates will not be accepted. See rebate certificate for expiration date. **Eligibility: Offer not valid for prescriptions reimbursed or paid under Medicare, Medicaid, or any similar federal or state healthcare program including any state medical or pharmaceutical assistance programs. Offer void where prohibited by law, taxed, or restricted. Amount of rebate not to exceed \$20 or co-pay, whichever is less.** This certificate may not be reproduced and must accompany your request for a rebate. Offer good only for one prescription of RESTASIS® Ophthalmic Emulsion and only in the USA and Puerto Rico. Allergan, Inc. reserves the right to rescind, revoke, and amend this offer without notice. You are responsible for reporting receipt of a rebate to any private insurer that pays for, or reimburses you for, any part of the prescription filled, using this certificate.



March

Breakthrough Bullet:

Working to Provide Clinicians
with "Pre-research" Information

While many of you know that the Sjögren's Syndrome Foundation provides funding for research grants, the Foundation also supports various pre-research projects and initiatives that are designed to provide clinicians and researchers with information that shows the need for future Sjögren's research.

As part of our *5-Year Breakthrough Goal*, "To shorten the time to diagnose Sjögren's by 50% in 5 years," these research projects and initiatives are a vital part of increasing education and awareness around Sjögren's, as a way to help healthcare professionals recognize the many facets of the disease.

Recently, the SSF chose to partner with the International Foundation for Autoimmune Arthritis and other expert associations on the project, "Early Symptoms of Autoimmune Arthritis: A Patient-Centered Research Study."

The purpose of this study was to establish a more complete and cohesive Early Symptom Patient Model

(ESPM) to promote earlier detection, referrals, diagnosis, and treatment of the diseases included in the study.

This study was important to the SSF because even though Sjögren's is one of the most prevalent autoimmune diseases, it is often overlooked or misdiagnosed since its outward symptoms can mimic other conditions and diseases.

Initial results of this ESPM study found that autoimmune arthritis patients should be monitored for Sjögren's, which is a wonderful step forward to help speed up the diagnosis for Sjögren's patients!

As you all know, it currently takes nearly 3.9 years to receive a Sjögren's diagnosis, which is too long! This is the reason the SSF created our *5-Year Breakthrough Goal* and why we are proactive in ensuring that Sjögren's is included in studies like these, so our patients and those who are suffering from Sjögren's symptoms are heard. ■



As My Body Attacks Itself

My journey with autoimmune disease,
chronic pain & fatigue

by Kelly Morgan Dempewolf, PhD

50 million Americans suffer with an autoimmune disease and countless more deal with chronic pain, fatigue and illness. These diseases are often invisible yet they touch every part of a person's life and of the lives of the people they love.

This book is an honest, raw look at the thoughts, concerns, fears and struggles, as Kelly deals with Sjögren's (the second most common rheumatic autoimmune disease). The story isn't just about Sjögren's, or even just autoimmune disease. It's for everyone impacted by chronic disease of any kind.

Kelly's hope is that patients will find solace and validation; friends and family will gain understanding and the abilities to empathize, communicate and support loved ones; and medical professionals will gain understanding and the ability to empathize - impacting the way they interact with patients.

**Call 800-475-6473 and order your copy today at the special
SSF member's price of \$11 \$15 non-member price plus shipping and handling**



Learning to Thrive with Sjögren's



Ask the Clinician: Julius Birnbaum, MD

*Dr. Birnbaum will be speaking at the
2015 SSF National Patient Conference in Tampa, Florida*

Peripheral Neuropathy & Sjögren's

There are many different types of neuropathies in Sjögren's. These neuropathies can have different causes and may require different diagnostic techniques and different therapeutic strategies. Unlike other autoimmune disorders, in which the neuropathies predominantly cause weakness, the neuropathies in Sjögren's primarily affect sensation and also can cause severe pain. Recognition of unique patterns and causes of neuropathies in Sjögren's is important in arriving at appropriate therapies.

Here are some facts to help you better understand neuropathies in Sjögren's:

- Initial and predominant neuropathies in Sjögren's can occur anywhere – in the feet, thighs, hands, arms, torso and/or face.
- Neuropathic pain can be alleviated and assuaged, although there may initially be a “trial-and-error” process with different and perhaps multiple agents.

- Many different symptomatic therapies for neuropathic pain are available. Both physician and patient awareness of potential benefits and side effects can help tailor an appropriate approach.
- While the class of tricyclic anti-depressants (TCAs) often constitute a first-line tier of therapy in other neuropathy syndromes, the TCAs can increase mouth and eye dryness and therefore are not routinely used as front-line therapies in most Sjögren's patients.
- A relatively rare neuropathy can cause significant weakness in Sjögren's patients. In contrast to other neuropathies, which develop slowly, this neuropathy can present with very abrupt-onset of weakness. This so-called “mononeuritis multiplex” occurs because the blood flow through vessels which nourishes nerves is suddenly compromised.
- Sjögren's patients frequently wonder whether pain associated with a neuropathy means they are at an increased risk for more severe motor weakness. While there are exceptions, if weakness is not present at onset, it most likely will not occur.
- Recognize that neuropathic pain is a chronic disease. Just as most causes of neuropathies and neuropathic pain in Sjögren's do not come on suddenly, reduction of neuropathic pain can take a while. ■



OraCoat XyliMelts[®]
for dry mouth

Adhering discs for use while sleeping and daytime!

XyliMelts long lasting adhering discs temporarily relieve dry mouth* day and night, even while sleeping when dry mouth is worst.

- 500 mg of Xylitol coats, moisturizes and lubricates*
- Discreetly sticks to gums or teeth
- Lasts all night
- May reduce risk of tooth decay
- **12 disc sample; just pay \$3.20 shipping (online or telephone orders only)**



RITE AID **CVS pharmacy** Available at Rite Aid and CVS. Call **877-672-6541** for telephone orders or visit **www.oracoat.com**

* These statements have not been evaluated by the Food and Drug Administration. This product is not intended to diagnose, treat, cure or prevent any disease.

Rx Only



DRY MOUTH RELIEF NOW BEING SERVED

Aquoral® is approved for dry mouth due to Sjögren's Syndrome¹

- Coats, lubricates, and protects
- Reduces mouth dryness^{2,3}
- Improves ability to chew and swallow^{2,3}
- One application lasts up to 4 hrs^{2,3}
- Easy to afford with patient savings card
- Gluten free⁴

INDICATIONS: Aquoral is intended to provide relief from chronic and temporary xerostomia (dry mouth), which may be a result of disease such as Sjögren's Syndrome, oral inflammation, medication, chemo or radiotherapy, stress or aging. Aquoral relieves symptoms of dry mouth such as difficulties in swallowing, speech, and changes in taste.

IMPORTANT SAFETY INFORMATION

CONTRAINDICATIONS: Aquoral is contraindicated for any patient with a known history of hypersensitivity to any of its ingredients.

PRECAUTIONS: Read package insert carefully before using this spray. Avoid contact with eyes. Flush eyes with water if accidental introduction into eyes should occur.

INTERACTIONS: There are no known interactions with medicinal or other products.

Please see full Prescribing Information provided.

To report a serious adverse event or obtain product information call **(800) 531-3333**.

References: 1. Aquoral [package insert]. San Antonio, TX: Mission Pharmacal Company; 2013. 2. Mouly SJ et al. Efficacy of a new oral lubricant solution in the management of psychotropic drug-induced xerostomia: a randomized, controlled trial. *J Clin Psychopharmacol*. 2007;27(5):437-443. 3. Mouly SJ et al. Management of xerostomia in older patients: a randomized controlled trial evaluating the efficacy of a new oral lubricant solution. *Drugs Aging*. 2007;24(1):957-965. 4. Data on file.

Please see full Prescribing Information on next page.



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For
Sjögren's Syndrome
Patients suffering from
"COTTON-MOUTH"



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People Pay
No More Than

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For a 6-8 Week
Supply

aquoral
artificial saliva
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today for more
information.



800-475-6473



Rx Only—Prescription Medical Device

INGREDIENTS: Oxidized glycerol triesters (TGO), silicon dioxide, aspartame, and artificial flavoring.

ACTIONS: Aquaoral® is a lipid-based solution resembling human saliva designed to moisten and lubricate the oral cavity, including the oral mucosa of the mouth, tongue and throat, by formation of a lipid film which limits loss of water and restores the viscoelasticity of the oral mucosa. Aquaoral also provides protective action against further inflammation of the oral mucosa. Xerostomia (dry mouth) has harmful effects on the oral cavity and quality of life; consequently, management of dry mouth is primarily based on relief of symptoms.

INDICATIONS: Aquaoral is intended to provide relief from chronic and temporary xerostomia (dry mouth), which may be a result of disease such as Sjögren's Syndrome, oral inflammation, medication, chemo or radiotherapy, stress or aging. Aquaoral relieves symptoms of dry mouth such as difficulties in swallowing, speech, and changes in taste.

CONTRAINDICATIONS: Aquaoral is contraindicated for any patient with a known history of hypersensitivity to any of its ingredients.

PRECAUTIONS: Read package insert carefully before using this spray. Avoid contact with eyes. Flush eyes with water if accidental introduction into eyes should occur.

INTERACTIONS: There are no known interactions with medicinal or other products.

DIRECTIONS FOR USE: Shake gently. One dose (2 sprays) into the mouth 3 to 4 times a day. Spread product on to inflamed and/or dry areas of the mouth with the tongue. Pump may require priming for initial use.

To report a serious adverse event or obtain product information call (800) 531-3333.

HOW SUPPLIED: Aluminum canister with 0.1 ml spray pump containing 40 ml (1.4 fl. oz.) (net content) of solution which corresponds to 400 sprays of Aquaoral (NHRIC 0178-0420-40).

KEEP OUT OF REACH OF CHILDREN.

U.S. Patent: 8,367,650



Manufactured for:
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San Antonio, TX USA 78230 1355
MADE IN FRANCE

Aquaoral® artificial saliva is a medical device registered with the United States Food and Drug Administration.



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AQU-14002

C01 Rev 005130



Remembering Your Mother or Another Fabulous Lady on Mother's Day

Make a donation in honor or in memory of your mother or a mother that you know! Your honoree or family member will receive a personalized Mother's Day acknowledgement before May 10th from the Sjögren's Syndrome Foundation. The Foundation will also acknowledge your gift in an upcoming issue of *The Moisture Seekers* newsletter and with a special Mother's Day card.

Please complete form on page 9.

Mother's Day Form

Mail to: Sjögren's Syndrome Foundation, 6707 Democracy Blvd., Suite 325,
Bethesda, MD 20817 or Fax to: 301-530-4415

Please choose a donation amount: ☐ \$25 ☐ \$50 ☐ \$100 ☐ other _____

Name of person this donation is in honor of _____

Name of person this donation is in memory of _____

Who would you like the acknowledgment sent to?

Name _____

Street Address _____

City _____ State _____ Zip _____

How would you like to be recognized on this letter?

Please provide your mailing address for donation receipt:

☐ Check this box if you would like to hand deliver the acknowledgment letter
and have it sent to you

Name _____

Street Address _____

City _____ State _____ Zip _____

Telephone _____

E-mail _____

Payment:

☐ Check (enclosed)

☐ VISA / MasterCard / Discover /
American Express (circle)

CC #: _____

Exp. Date: _____

CVV Code: _____

Name as appears on card: _____

Signature: _____

Date: _____

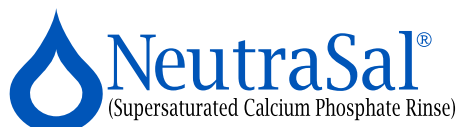
NEW

NeutraSal® Sjögren's Syndrome Support Kit

Containing:

- Eye Vitamin and Mineral Supplement for Dry Eye Comfort*
- Sugar Free Dry Mouth Gum with Xylitol

* This statement has not been evaluated by the FDA. This product is not intended to diagnose, treat, cure or prevent any disease.



What is NeutraSal®

NeutraSal® is an advanced electrolyte solution indicated in the treatment of dry mouth (xerostomia) in patients with Sjögren's Syndrome. NeutraSal® consists of single use packets of dissolving powders that when mixed with water creates an oral rinse supersaturated with calcium, phosphate and bicarbonate ions.

- Clinically proven to relieve the symptoms of dry mouth in Sjögren's Syndrome patients with no reported side effects or drug to drug interactions
- Calcium and phosphate ions have been shown to aid in the prevention of dental caries (cavities) and promote the remineralization of the teeth in normal saliva
- Sodium bicarbonate ions reduce the acidity of the saliva in the mouth and break up accumulating mucus
- The pH of NeutraSal® is similar to normal saliva which may protect the mouth against potential opportunistic fungal (oral thrush) and bacterial infections

NeutraSal® is a prescription item. For additional information on NeutraSal® or the Direct Access Program, please visit www.neutrasal.com or call 866-963-8881 ext #1.

DIRECT ACCESS PROGRAM The Direct Access Program is designed to provide access to NeutraSal® treatment for all patients regardless of their insurance coverage or financial condition. The program includes no out-of-pocket costs (co-pay) for most patients and free trial medication for patients without coverage. The NeutraSal® Direct Access Program and Support Kits are only available through the NeutraSal® Specialty Pharmacy Network. (Not valid for local retail pharmacies).

NEW

NeutraSal® Burning Mouth Syndrome Support Kit

Containing:

- Alpha Lipoic Acid for Burning Mouth Comfort†
- Sugar Free Dry Mouth Gum with Xylitol

† This statement has not been evaluated by the FDA. This product (alpha lipoic acid) is not intended to diagnose, treat, cure or prevent any disease.

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Spring into Spring: Light Anti-Inflammatory Recipe

Mediterranean Herb-Crusted Salmon *(makes 6 servings)*

As winter weather continues to linger over many states, it's hard to believe that spring really is just around the corner. Shake off the winter blues with this light and healthy, Mediterranean Herb-Crusted Salmon recipe from *"The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease,"* by Susan Blum, MD, MPH.

Wild Alaskan king salmon is one of the best sources of omega-3 fatty acids — an essential fat that is anti-inflammatory and benefits many health problems from heart disease to hormone imbalance. If you ask your fishmonger nicely, he or she will debone the fish, which saves you preparation time. The dill, mint, and parsley in this recipe make it full of flavor. The herbed breadcrumb mixture adds a great crunch on top, and the lemons are a nice touch in presentation and flavor.

2 lbs wild Alaskan king or sockeye salmon, boned
4 tbsp prepared mustard
½ cup parsley, finely chopped
½ cup mint, finely chopped
½ cup dill, finely chopped
¾ cup gluten-free breadcrumbs
4 tbsp extra-virgin olive oil
1 tsp salt
2 lemons, cut into 6-8 wedges each

Preheat the oven to 400 degrees

Place the salmon on a baking sheet lined with parchment paper and spread the mustard all over the salmon.

Mix the herbs, salt, olive oil, and breadcrumbs in a small bowl until well combined.

Cover the salmon with the herb mixture, and on the baking sheet line the lemon wedges around the fish snugly, to trap the juices.

Roast the fish for about 18 minutes or until cooked through. The time will vary depending on the thickness of the salmon. Garnish with the roasted lemon wedges. ■

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Saliva plays a major role in oral health.

Dry mouth can impact the health of your teeth. If you have reduced salivary flow, it is critical to support the healthy pH on your tooth surfaces.

Now there is a delicious **breakthrough oral care innovation that can help dry mouth sufferers keep teeth in a healthy pH zone.**

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**A Healthy
oral pH matters...
Your teeth need
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soft chew with
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**Nourishes the
enamel and
good bacteria on
tooth surfaces**

As an added
benefit, an excellent
source of
calcium



Order today with Free Shipping at **basicbites.com**



You Stood Up!

Anyone can help raise awareness for Sjögren's and this month we send a great big BRAVO to Michael Limbacher of Harrisburg, Pennsylvania



Michael is the fiancé of Ayu Jelita who is a staff member of the Sjögren's Syndrome Foundation. Over the past two years, Michael has heard the stories of Sjögren's patients from Ayu and witnessed first-hand the commitment of volunteers at SSF events he previously attended. That is why he asked Ayu how he could help – and she suggested that he hold a Bold Blue Day at his office.

Michael then contacted his office supervisor to get approval and share SSF's Bold Blue Day materials and discuss the need to not only raise funds but also to get the word out about Sjögren's.

This past fall, Michael and his fellow co-workers at the Paychex corporate office in Pennsylvania held their first-ever Bold Blue Day! Not only did his co-workers sign up to wear blue and make a donation to the SSF, they also learned a few facts about Sjögren's!

So this Spring – consider who you know who may host a Bold Blue Day where they work. The SSF has all the materials they will need and we can walk them through step-by-step of what is involved! Please contact Michele Lee at 301-530-4420 to learn more and on behalf of all Sjögren's patients, thank you Michael for Standing up for Sjögren's! ■





in memoriam

In Memory of Alice Kavcic

Alice Vujtech
Carolyn and Mark Schumacher
Gerry and Donna Aguiar
Gerry and Mary Anne Chrabaszcz
Jean Alden

John and Loretta Norton
Linda and Anthony Maietta
Paula and John Ramirez and Family

In Memory of Anne Scotto

Diane Kay

In Memory of Baharawar Habashzada

Carle Place MS/HA Sunshine Club

In Memory of Bonnie Litton

Gary and Judy Goldetsky
Naomi and Neil Arnold

In Memory of Caroline Pasqualone Oldani

Kate Mahar
Reenie and Bill Lucker

In Memory of Chuck Johnson

Jan and Anthony Stanford

In Memory of Elizabeth Garrison

Candace Anderson
Fred and Gail Roberson
Michael and Tamey Craig
John and Debbie Morgan
Nancy Usifer
Rosalie Sheets

In Memory of Flora Feldman

Aileene Schottenfeld

In Memory of Jean Lenore Query

Robert and Jeanne Jacobs
Gay and Riggs Nelson, Roxi Nelson,
Kent and Monaca Nelson and Family

In Memory of Jeffrey Robert Miller

Agnes Wong
J&K VAB
Jackie Patterson
Lou Ann and Jeff Phillips
Robert and Laurie Charest
Susan Howell
Tanya Khatatba

In Memory of Jill Walker

Curt, Janne, Jacob and Knattan
Evan and Colleen Williams
Good Earth Montessori Day School
Howard and Marilyn Wood
Lois Krause
Marsha and Andy Kopral
Mr. and Mrs. Robert Francis
Ray and Diane Weber

In Memory of Kay Amberg

Cousins Bob, John and Ruth Stenstrom
and Jamie Ortiz
Jill and Bruce Brown
Joan Forslund
Joel and Kate Bowers
Mark and Angela Priebe
Mary Bowerman

In Memory of Mary Linda Abraham

Carolyn P. McDowell
Marilyn Carriere
Michael and Karen Blain
Tracie Garrett

In Memory of Mary Louise McCarthy

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Ken and Denise Johnson

Matt, Kari, Nathan and Marisa
Rose Loricchio
Rose Schmidt

Dave Gravelle and Cindy Giovani
Grayce and Peter Costantini
James and Linda Castle
Rosemarie Costantini

In Memory of Thelma Catherine Skinner

Bobette Morgan

In Memory of Vicky Thorp

Ronald Thorp and Family

In Memory of William A. Skahen

Frank Trippett

In Memory of Linda Lehrman

Association of Fundraising
Professionals Miami
Ernest and Ursula Elovic Family Fund
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Jane Meyers
Lydia Harrison
Mason-Glazier at Schwab Charitable Fund

In Memory of Lois Aulis

The Snay Group, Inc.
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Gene and Jackie Eisen

In Memory of Patricia Mertz

Darlene and Delbert Clark
Eric, Stacy, Zach, Annika and Ella Carlson
Janice and Phillip Montgomery
Section 1 SCPS

In Memory of Joann Hartwick

The Weekenders Quilting Group
Mike and Katrina Dennis

In Memory of Janis Rosenlund

Liane Leahy

In Memory of Gail Spence- Lennon

Mr. and Mrs. Carl Farris



in honor

In Honor of Ana and Joe Fraioli

Jennefer Witter

In Honor of Cathy Anderson

Nancy Mancuso

In Honor of Connie Cooper

Rita Becchetti

In Honor of Elaine Harris

The John M. and Sally B. Thornton Foundation

In Honor of Frances Rolader

Joanne Finnick

In Honor of Gloria Moses

Lauren A. Moses

In Honor of Mr. and Mrs. Smith- Skylar Marie Smith

Dorothy Pantton

In Honor of Nutritional Concepts

Paula Josephson

In Honor of Teresa and Rick Steinberg

Jerry Steinberg

2015 SSF Special Event Calendar

April

17-18

National Patient Conference

The Grand Hyatt Tampa Bay – Tampa, Florida

18

National Patient Conference Walkabout

Tampa, Florida

May

2

Philadelphia Walkabout & Health Fair

Philadelphia Zoo – Philadelphia, Pennsylvania

16

Dallas/Fort Worth Walkabout & Health Fair

Vista Ridge Mall – Dallas, Texas

30

Northeast Ohio Walkabout

Brecksville Oak Grove Picnic Area –
Brecksville, Ohio

31

Columbus Walkabout

Woodside Green Park – Gahanna, Ohio

31

Atlanta Sip for Sjögren's

Nelson Mullins at Atlantic Station –
Atlanta, Georgia

June

6

Denver Walkabout & Health Fair

Denver Zoo – Denver, Colorado

13

Greater Washington Region Walkabout & Health Fair


Bethesda, Maryland

TBA

Kansas City Walkabout & Run

Parkville, Missouri

If there is already an event in your area and you would like to get involved, or learn about starting one, please visit www.sjogrens.org or contact us at (301) 530-4420 x227



Learning to Thrive with Sjögren's

2015 National Patient Conference

April 17-18, 2015

Grand Hyatt Tampa Bay

2900 Bayport Drive ■ Tampa, Florida

This April we invite you to join with fellow Sjögren's patients, their families, medical experts, the SSF staff and industry/ product exhibitors for our 2015 National Patient Conference, "Learning to Thrive with Sjögren's," at the Grand Hyatt Tampa Bay (Tampa, Florida).

Sjögren's is not the same for every person diagnosed, which is why educating yourself on the most up-to-date information and treatment options is so important. Attending the SSF National Patient Conference is one way you can gain information from many different sources while also meeting fellow patients.

This year's Conference will include opportunities to:

- Hear from national Sjögren's experts, researchers and SSF staff
- Find new products and receive free samples at our exhibitor hall
- Learn from your fellow patients
- Browse Sjögren's resources at the SSF Book Table
- Become inspired during the Conference's Awards Banquet Dinner

We encourage you to take this opportunity and learn how to thrive with Sjögren's. This educational journey will give you the tools to take control of your health and learn how to manage and understand your Sjögren's symptoms and complications.

Watch for your Conference brochure coming in January or visit www.sjogrens.org to see updated Conference information.

Presentation topics will include:

- Overview of Sjögren's
- Neurological Complications
- Dry Mouth & Sjögren's
- Dry Eye & Sjögren's
- Ear, Nose & Throat Involvement
- Gynecological Complications
- Major Organ System Involvement
- Financial Planning for Patients with Chronic Illness



**Announcing Keynote Speaker
Robbin Jorgensen, CPCC, ACC**

Speakers and Topic of Discussion – NPC 2015

Systemic, Ocular and Oral Manifestations of Sjögren's: A Panel Discussion & Overview

Join us for this kickoff session where Dr. Frederick Vivino, Dr. Stephen Cohen, and Dr. Vidya Sankar, three world-renowned experts, will share with us an overview of Sjögren's, its manifestations and treatment options.

Frederick B. Vivino, MD, MS, Chief, Division of Rheumatology, Penn Presbyterian Medical Center, and Director of the Penn Sjögren's Center, Philadelphia, Pennsylvania, will present a comprehensive explanation of the range of symptoms that Sjögren's patients experience, explain their causes, and offer practical tips for managing them. In his role as the Immediate Past Chairman of the SSF's Medical and Scientific Advisory Board, Dr. Vivino implemented and developed the idea to create clinical practice guidelines for how to treat, manage and monitor Sjögren's. This initiative has now become one of the largest initiatives ever undertaken by the SSF and will change the face of Sjögren's in the clinical setting.

Stephen Cohen, OD, a private practice optometrist in Scottsdale, Arizona, since 1985, will describe the latest dry eye therapeutic treatments, covering the extensive range of options - from artificial tears to silicone plugs to systemic drugs that are available for managing the ocular complications of Sjögren's. Dr. Cohen is a founding board member of the Arizona Optometric Charitable Foundation and a past recipient of the "Arizona Optometrist of the Year Award." Dr. Cohen serves as the current Chairman-Elect of the SSF Board of Directors and has also been a principal investigator on a number of FDA clinical studies involving ocular surface disease and dry eye.

Vidya Sankar, DMD, MHS, Director of the Tertiary Care Oral Medicine Clinic and Associate Professor at the University of Texas Dental School in San Antonio, will provide insights into how Sjögren's impacts your oral health including tooth decay as well as share with us information to help manage and minimize the effects of dry mouth. Dr. Sankar is the current Treasurer of the SSF Board of Directors and has served on numerous professional committees to help increase awareness for Sjögren's, most recently presenting at the American Dental Association's annual scientific meeting.

Neurological Complications and Sjögren's

Julius Birnbaum, MD, MHS, Assistant Professor, Division of Rheumatology, and Assistant Professor, Department of Neurology, Johns Hopkins University School of Medicine, Baltimore, Maryland, will share his insights and vast knowledge of the challenges that may afflict patients with neurological manifestations of Sjögren's. Dr. Birnbaum, who also serves as an Associate Director at the Johns Hopkins Jerome L. Greene Sjögren's Syndrome Center, is committed to improving the diagnosis and treatment of neurological complications due to Sjögren's and you won't be disappointed with his passion and knowledge!

How To Be A Proactive Patient

*Katherine M. Hammitt, SSFVP of Research
Ken Economou, SSF Chairman of the Board
Anne Economou, Sjögren's Patient and Volunteer*

Taking your diagnosis and learning how to be your own best advocate is an art form! During this session, our presenters will share with you some tips they have learned along the way. As you will hear, they have learned not to let their diagnosis define them but instead use their diagnosis to help make a difference.

First, we will hear from Katherine M. Hammitt, Vice President of Research of the Sjögren's Syndrome Foundation, co-author of *The Sjögren's Syndrome Survival Guide* and a Sjögren's patient herself. She will share with us "Tips for Being Your Own Patient Advocate." Additionally, she will provide us with some practical tips for coping with the day-to-day symptoms of Sjögren's as well as advise us how to maximize the time spent with healthcare professionals to ensure the best quality of care.

Ken and Anne Economou will then moderate a session involving National Patient Conference attendees that have stood up for Sjögren's. During this session, "We Stood Up – Come Join Us," Ken and Anne will share how you can make a difference with your diagnosis by stepping up for Sjögren's and finding something you are passionate about. You will be inspired by the patients that have not let a Sjögren's diagnosis define who they are!

Treatment of Major Organ System Involvement in Sjögren's

Daniel Small, MD, a practicing rheumatologist with the Sarasota Arthritis Center and a career-long interest in Sjögren's, will present the major approaches to managing serious internal organ manifestations in Sjögren's including pulmonary involvement, renal disease, and serious gastrointestinal disease. Dr. Small practiced rheumatology in California and Texas before settling in Florida 22 years ago. Additionally, he has spoken at regional, national and international meetings on Sjögren's. Dr. Small also authored a chapter in *"The Sjögren's Book"* about treatment of major organ involvement, and he is a member of the SSF Medical and Scientific Advisory Board.

How To Put Your Financial House in Order When You Have a Chronic Disease

David P. Babinski is Advisor and President of Atlas Financial Solutions and Triad Financial Center, both located in The Villages, Florida. When you live with a chronic illness, you need to address both the day-to-day and long-term financial implications of that illness. Mr. Babinski will provide valuable information and suggestions to help you put together your financial plan.

Understanding the Otolaryngologic Manifestations of Sjögren's

Myron B. Jones, MD, is an otolaryngologist with the Robert A. Gadlage, MD, FACS and Associates practice, with offices in Duluth and Snellville, Georgia. His areas of special expertise and interest include: nasal and sinus medical and surgical disorders, sleep disorders including treatment of obstructive sleep, apnea salivary gland surgery, and thyroid surgery. Dr. Jones will enhance your understanding and provide a comprehensive explanation one of the most overlooked, yet frustrating, complications of Sjögren's – ear, nose and throat manifestations.

Vaginal Issues and Sjögren's

Colin MacNeill, MD, an Associate Professor and Vulvodynia and Vaginitis Clinic Director, Department of Obstetrics and Gynecology, Penn State Milton S. Hershey Medical Center, Hershey, Pennsylvania, will share his wealth of knowledge of gynecological issues including symptoms, diagnosis and treatment of vaginal discomfort and dryness concerns. With the increased risk for a variety of unique gynecological complications, including yeast infections, vaginal dryness, and burning/pain, Dr. MacNeill will help us understand this often misunderstood area of Sjögren's.



Space is limited. Please register early!

Registration Form

Registration fees include: Friday evening dinner, Saturday's lunch, hand-out material from speakers and entrance to exhibit area on Friday and Saturday.



2015 NATIONAL PATIENT CONFERENCE TAMPA, FLORIDA — APRIL 17–18, 2015

1 ATTENDEE – complete for each registrant

Attendee Name(s) _____
Attendee Name(s) _____
Street Address _____
City _____ State _____ Zip _____
Telephone _____ E-mail _____

2 FEES – please circle appropriate fee(s) (Note: Early Bird Deadline is March 20, 2015)

SSF Members & Guests
Non-Members

March 20th and before

\$170 per person
\$190 per person

March 21st and after

\$190 per person
\$210 per person

TOTAL:

3 PAYMENT – Mail to SSF, c/o BB&T Bank · PO Box 890612 · Charlotte, NC 28289-0612 or Fax to: 301-530-4415

☐ Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) **payable to SSF.**

☐ MasterCard ☐ VISA ☐ Discover ☐ AmEx Card Number _____ Exp. Date _____

Signature _____ CC Security Code _____

- Refund requests must be made in writing. Registrants whose written requests are received by March 27th will receive a 75% refund. After that time, we are sorry that no refunds can be made.
- Dietary Requests: Unfortunately, we cannot accommodate all special dietary requirements. We can accommodate vegetarian or gluten-free dietary requests. If you require a vegetarian or gluten-free meal option, please contact the SSF office (301) 530-4420, by April 3rd.
- A limited number of rooms are available at the Grand Hyatt Tampa Bay, 2900 Bayport Drive, Tampa, FL 33607, at the SSF rate of \$149 per night plus tax if reservations are made by March 24, 2015. Call the toll-free hotel Central Reservations number at (888) 421-1442 or call the Grand Hyatt Tampa Bay directly at (813) 874-1234 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
- The Grand Hyatt Tampa Bay is approximately one (1) mile from Tampa International Airport. The hotel offers a complimentary shuttle service to and from the airport. Alternate transportation suggestion: Taxi fare at a rate of \$18 (one way).

QUESTIONS? Call 800-475-6473 or visit www.sjogrens.org

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

April is Sjögren's Awareness Month

Help raise awareness by coordinating a Bold Blue Day and be entered to win a LIFETIME MEMBERSHIP to the SSF!

By helping to recruit a company, school or small business to host a Bold Blue Day in your honor – you will be entered to win a SSF Lifetime Membership.

It is very simple. Contact the SSF to receive a Bold Blue Day Recruitment Kit. In this kit you will find information about how to recruit a coordinator to host a Bold Blue Day in your honor. Or you can host one yourself at your place of business!

Once you recruit a coordinator or commit to coordinating one yourself, you will send in a commitment form and then the SSF will send off a kit with all the materials they will need to host their Bold Blue Day. And if they host it by June 30th, you will be entered in a drawing to win a lifetime membership.

So, what is Bold Blue Day?

Imagine your colleagues or classmates trading in their tailored slacks or dresses for a day in blue jeans or blue to raise vital funds for Sjögren's research and awareness. Ask your company or a local company or school to consider hosting a dress down day for the SSF.

How does it work?

People who choose 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 the company doesn't ever allow jeans?

Then just have a Bold Blue Day – where on a certain day everyone chooses to wear his or her 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 Michele Lee at (800) 475-6473 or mlee@sjogrens.org to receive your Bold Blue Day kit!

**Win a
Lifetime
Membership**

