

# The Moisture Seekers

Sjögren's Syndrome Foundation



www.sjogrens.org

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 SjogrensSyndromeFoundation

 @MoistureSeekers



 *How often should I get my blood tested with Sjögren's?*

**A** Since Sjögren's is a chronic autoimmune illness, there are two reasons as to why we would need to get blood work. First is to evaluate disease activity, then secondly, to monitor for medication toxicity if a patient is on an immunosuppressant or a disease-modifying antirheumatic drugs (DMARDs).

When we evaluate for Sjögren's disease activity, we obtain labs that are related to the organs involved or specific manifestations of their disease. Labs could be taken twice to three times a year for patients with stable disease, or more frequently for patients that start developing new or worsening symptoms. If a patient starts to develop other symptoms that may make the provider be concerned of an evolving process, then we also obtain certain antibodies to help us determine if the patient has now evolved into another condition (such as systemic lupus erythematosus or to rheumatoid arthritis).

For patients on immunosuppressants or DMARDs, the frequency of their laboratory monitoring is definitely more frequent. This usually involves obtaining their complete blood count, liver and kidney function tests, electrolyte levels, and at times, urine sample, depending on which organs are affected by Sjögren's. The purpose is to make sure that the patients are not developing any toxicity or adverse events from these medications. This may vary from every 6 weeks (usually when a new medication is being introduced) to every 3-4 months (once patients have been more stable). Your rheumatologist will notify you if certain changes in your blood work are concerning and may require a more frequent monitoring or a potential change in your medication regimen.

*Guada Respicio Duque, MD, MSc, FACP, FACR*

 *I have Sjögren's and I know autoimmune diseases can run in families. Should I be concerned that my children will get this?*

**A** The tendency to develop Sjögren's depends on a multitude of factors; both genetic and environmental. Hence, it is difficult to predict disease susceptibility within a family and there are no definitive tests to help determine whether your child will develop Sjögren's.

The majority of children born to a parent with Sjögren's will not inherit the disease. Studies have shown that Sjögren's was reported

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Elaine K. Harris in 1983

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in only an estimated 4% of first-degree relatives of patients with the disease. However, if you or a close family member has Sjögren's, there is a 30 - 35% chance of your children developing any variety of other autoimmune disorders.

In the absence of symptoms, laboratory evaluation and/or treatment is not warranted for your child. Your pediatrician can monitor your child for development of any signs or symptoms and pursue testing if necessary. However, if you are pregnant, your baby may be at risk for neonatal heart block and your baby may need further testing.

*Sukesh Sukumaran, MD, DPMR, FACP*



*I keep reading about the use of vitamin D with autoimmune diseases. How important is it for Sjögren's patients?*

**A** Vitamin D is important in bone and cartilage homeostasis. New evidence indicates that vitamin D may have extraskeletal benefits on several systems including the immune system. Autoimmune diseases such as systemic lupus erythematosus (SLE), and Sjögren's syndrome (SS) have been associated in a few studies with low vitamin D levels. However, the significance of low vitamin D levels in disease pathogenesis and prevention is unclear.

What are the sources of Vitamin D? Vitamin D has two precursors, Vitamin D2 (ergocalciferol) and Vitamin D3 (cholecalciferol). Vitamin D3 is synthesized mainly in the skin by the action of ultraviolet light. Vitamins D2 and D3 are found in very few dietary sources, such as fish oils or fortified dairy products, as well as supplements.

Recommendations regarding desirable levels are based upon evidence related to bone health. Some controversy exists, but experts such as the International Osteoporosis Foundation suggest that a minimum level of 30 ng/mL is necessary to decrease the risk of falls and fracture.

Vitamin D deficiency is very prevalent in the general population. In the National Health and Nutrition Examination Survey between 2005 and 2006, 41.6% of adult participants had vitamin D levels below 20 ng/mL. In the 2000 to 2004 survey, over 70% of participants had levels <32 ng/mL.

Some studies indicate a higher prevalence of vitamin D deficiency in certain autoimmune diseases. However, these studies have not been conclusive. As an example, in SLE patients, recent studies have indicated the prevalence of vitamin D deficiency to range between 38% and 96%. The wide variation can be attributed to many factors, such as the age of the patients recruited, geographic location, season at the time of the study, ethnicity, medications used and the accuracy of the vitamin D assay method used.

In Sjögren's, few small trials have been performed to assess the prevalence of low vitamin D levels and the association with disease severity. No conclusive data has been assembled to indicate that subjects with SS have lower vitamin D levels than healthy subjects, or to suggest a pathogenic relationship between lack of vitamin D and development of disease.

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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

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### Approved Use

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### 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.

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

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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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# April Advocacy Update

**O**n Monday, March 23 2015, the SSF represented Sjögren's patients at "The State of Autoimmune Disease: A National Summit" at the National Press Club in Washington, DC.

The summit was hosted by the American Autoimmune Related Diseases Association (AARDA) and the National Coalition of Autoimmune Patient Groups (NCAPG), which the Sjögren's Syndrome Foundation (SSF) is a member of. Serving on coalitions like this is priority for the SSF because of the valuable discussions that come from bringing together other autoimmune groups and the advocacy strength that it gives us.

During the summit, Steven Taylor, SSF CEO, moderated the panel discussion: Patient Perspective: Getting an Autoimmune Disease Diagnosis. The SSF is also excited that Beth Harkavy Axelrod, a Sjögren's patient and SSF volunteer, was able to be a part of the panel and represent the patient voice during the summit discussion.

A main highlight of the meeting was around the session, "Autoimmune Disease & Fatigue: What's the Connection?" For many of you who follow the SSF on social media or visit the "news" section on [www.sjogrens.org](http://www.sjogrens.org), you may remember us posting a survey announcement that would be used at this summit. This national survey was designed to further explore the link between autoimmune diseases and fatigue.

The survey results announced that profound and debilitating fatigue was found to be a major issue for autoimmune disease patients. Fatigue is often described as one of the most debilitating symptoms of Sjögren's and one of the diseases four primary symptoms, along with joint pain, dry eye and dry mouth.

## Breakthrough Bullet:

### The State of Autoimmune Disease: A National Summit



*Steven Taylor, CEO, Sjögren's Syndrome Foundation*

The SSF is happy that fatigue is being taken seriously as a symptom and we would like to thank everyone who helped and added his or her voice to this study by taking the survey.

The SSF would also like to thank Beth for being on the patient panel, and AARDA for giving us this opportunity to represent those who suffer from Sjögren's. ■

"Q&A" continued from page 2 ▼

Patients with Sjögren's can be prone to vitamin D deficiency. Photosensitivity, where exposure to ultraviolet light triggers a rash is prevented by avoiding exposure to sunlight, could contribute to lower levels of vitamin D. Furthermore, certain medications may aggravate vitamin D deficiency. Chronic corticosteroid and hydroxychloroquine use are suspected to affect Vitamin D concentration and activity respectively.

In summary, although there are no guidelines regarding optimal Vitamin D levels for extraskeletal and immune system health, it would be reasonable to recommend that patients be screened for vitamin D deficiency and treated with supplementation. The American College of Rheumatology recommends a daily intake of 800–1000 IU per day of vitamin D in patients on treatment with steroids.

Stamatina Danielides, MD



**What is Blepharitis and how do you treat it in Sjögren's patients?**

**A** Blepharitis is due to inflammation of the eyelids at the base of the eyelashes. Patient may experience symptoms of itchy eyelids, swollen eyelids, red eyes, burning sensation, foreign body sensation, tearing, and crusting around the eyelashes upon wakening. Many of these symptoms are similar to dry eye symptoms that Sjögren's patients experience. However, blepharitis symptoms most commonly occur in the morning while dry eye symptoms usually worsen later in the day.

There are two types of blepharitis: anterior and posterior blepharitis. Anterior blepharitis is caused by staphylococcal bacteria. Exotoxins from this bacteria cause a hypersensitivity reaction on the eyelids and leads to scales or crusty deposits on the base of the eyelashes. Posterior blepharitis is due to dysfunction of the oil glands in the posterior portion of the eyelids called meibomian glands. Bacteria alter the oil gland secretions making it thicker and cloudier. This causes the tear film to be unstable and results in the tears evaporating too quickly. Dry eyes can occur as a result of blepharitis. Although patients may have both types of blepharitis, studies show that Sjögren's patients most commonly have posterior blepharitis.

To treat blepharitis, in many cases, good eyelid hygiene and a regular cleaning routine can control blepharitis. This includes warm compresses to soak the eyelids and doing eyelid scrubs. Pre-packaged eyelid scrubs or over-the-counter eyelid foam cleansers typically work better than diluted baby shampoo remedies. In moderate to severe cases, various ophthalmic antibiotics and other medications may be prescribed along with eyelid hygiene. Because Sjögren's patients typically have more moderate to severe cases of dry eyes, it is important to rule out blepharitis as a contributing factor.

#### Directions for Warm Compress:

- Wash your hands thoroughly.
- Place dry uncooked rice in a ZipLock bag and heat in the microwave for 15 to 30 seconds.
- Wrap the bag in a cloth.
- Check the temperature of the compress against your hand or arm prior to applying to the eyelids to avoid burning the skin.
- Place compress for 5 minutes then massage eyelids.

#### Directions for Eyelid Massage:

After doing the warm compress, apply light pressure with your index finger. Roll the finger upward on the lower lid while looking up, and then roll the finger downward on the upper lid while looking down.

#### Directions for Pre-Packaged Eyelid Scrub:

- Wash hands with soap and rinse well.
- Remove pad from packet.
- Close the eye and gently cleanse lids using side-to-side strokes for 30 seconds.
- Rinse lids with warm water.
- Avoid touching the eye directly.

#### Directions for Eyelid Foam Cleansers:

- Wash hands with soap and rinse well.
- Pump desired amount of Eyelid Foam Cleanser onto a clean, lint-free cloth, or fingertip. If you have long fingernails, use the lint-free cloth method.
- Close the eye and gently cleanse lids using lateral side-to-side strokes for 30 seconds.
- Rinse lids with warm water.
- Avoid touching the eye directly.

Margie Recalde, OD



**I have extreme fatigue and my doctor recommended a sleep study. What are the benefits of having one done and what will the results tell me?**

**A** Fatigue can be one of the most burdensome problems in Sjögren's. It can range in intensity from mild to disabling and is often multifactorial. It can be directly from the autoimmune process itself or it can be indirect from disrupted sleep due to movement, dryness or increased fluid consumption during the day.

Another possibility is from an underlying sleep disorder such as obstructive sleep apnea, which is quite prevalent in

continued page 8 ▼

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"Q&A" continued from page 6 ▼

the population whether or not someone has Sjögren's. The point of a sleep study is to check for poor sleep due to an airway obstruction or non-restful sleep. Some people experience repetitive episodes of apnea (pauses in breathing) or reduced airflow. While someone may continue to sleep, that sleep would not be restful.

Diagnostic evaluation of suspected OSA, titration of positive airway pressure therapy, and assessment of the effectiveness of therapy are the most common indications for PSG.

Polysomnography, or sleep study, is the most common test performed to check for the quality of sleep. It is usually performed in a sleep laboratory where a patient is connected to several monitoring devices that record electroencephalograph (EEG) activity, eye movements, muscle tone and airflow among other variables while he/she sleeps. Portable home monitoring can also be done, though the results are more variable.

A history is taken to elucidate environmental factors such as temperature, sleep times, noise and other related sleep hygiene measures. You will need to provide your medications and the lab may ask you to modify other variables such as caffeine and alcohol. Some of the important results of the study are the amount of sleep, how restful that sleep is, how long you are in each sleep stage, the amount of air flow that is going in, how often you wake up, snore etc.

Based on the information collected, the doctor is able to deduce your sleep architecture, the frequency of abnormal events (eg, apneas) during sleep, and various diagnostic measures.

Non-restful sleep can cause fatigue. If the results show that there is obstructive sleep apnea, assisted devices can be used to improve oxygen flow, sleep aids can be considered as can other medications or lifestyle measures. It would be important to discover if a poor sleep cycle is a contributor to fatigue as treatment can help symptoms.

*Neha Bhanusali, MD*

**Q** *I see a lot of sleep medications available, is there one that you recommend for someone with Sjögren's and extreme fatigue?*

**A** Effective, restorative sleep is very important to good health for all individuals, but absolutely imperative to those with fatigue associated with Sjögren's.

Before starting on any sleep medications, speak with your physician as there may be other reasons for your fatigue such as sleep apnea, or low thyroid, to name a few. However, if it comes down to simply non-restorative sleep, taking a sleep medication can enable you to wake up feeling more refreshed.

Sleep medication options vary from old-fashioned anti-depressants to mild over-the-counter choices to sedatives. The choice for someone with Sjögren's needs to be tempered by the potential of increasing dryness.

For those with mild difficulties getting to sleep, on an intermittent basis, over-the-counter melatonin is very helpful for short periods of time (< 3 months). Unfortunately when used on a regular basis its effectiveness starts to fade. Another over-the-counter choice is diphenhydramine (Benadryl) which is found in many sleep aids. This is an anti-histamine, and thus has a high likelihood of increasing dryness. However, when used for short periods of time both can help reset your sleep cycle.

Similar to melatonin, ramelteon (Rozerem), is a prescription sleep aid which stimulates the melatonin receptors. It is rarely drying, and mild, with a low chance of addiction. However, it may decrease testosterone levels or cause women difficulty getting pregnant. Best if you are past the child-bearing years.

For more persistent sleep problems, the class of low-dose anti-depressants, called Tricyclic Anti-depressants, can be helpful. These include amitriptyline (Elavil), nortriptyline (Pamelor), doxepin (Sinequan), and desyrel (Trazadone). Of these, desyrel appears to be the least drying. These medications are very gentle and can be slowly increased to find the right dose to ensure an effective night's sleep without causing morning grogginess. Amitriptyline and nortriptyline can also treat neuropathy or myalgias.

Sedative medications have advantage of being effective without being too drying. These include zolpidem (Ambien), both short and long-acting, eszopiclone (Lunesta), and zaleplon (Sonata). All have the potential of being addictive, although the risk is low. Eszopiclone, and zaleplon are very gentle and lead to few side-effects. Zolpidem can be very affective, but there is a risk of sleep walking. All can lead to memory changes or odd behaviors.

Finally, there are the class of medications called benzodiazepines. They are primarily known for their anti-anxiety affects and ability to decrease time of onset to sleep. Those benzodiazepines which are short-acting such as alprazolam (Xanax) or temazepam (Restoril) are recommended over longer acting choices such as diazepam (Valium) which may result in daytime fatigue. These agents are not drying, but there is a risk of addiction. If anxiety is part of the reason for sleep disturbance, using these in very low doses may be helpful.

There is no one perfect medication for improving sleep efficacy, but the goal is always to wake up feeling refreshed. I usually start with melatonin and then try desyrel or doxepin, and if these are not effective, move to eszopiclone or temazepam.

*Kathryn Wildy, MD*

**Q** *I have heard a lot about some Sjögren's patients finding relief from Serum Tears. What are they, how are they made and will it help me with my dry eye?*

**A** Topical autologous serum used to treat ocular surface damage from dry eye disease is usually reserved for the most severe cases that have not responded to other treatments, particularly intensive lubricant and anti-inflammatory therapy. Autologous describes the fact that it is taken from the patient themselves; serum describes the component of the blood that is used to prepare the drop. It was first reported to improve dry eye symptoms and signs in 1984, but there are now a number of reports supporting its beneficial effect in Sjögren's disease. Most often prepared as a 20% topical solution, autologous serum must be prepared by removing blood from the patient's vein and spinning down the clotted cells to isolate the liquid serum which is then diluted in artificial tears solution into small vials. It is not specifically approved by the FDA. Autologous serum contains fibronectin, vitamin A, cytokines, and growth factors, as well as

anti-inflammatory substances, such as interleukin receptor antagonists and inhibitors of matrix metalloproteinases. It is not clear which of these components is most helpful, but significant improvement in symptoms, tear break up time, and surface staining have been reported.

The disadvantages of the use of autologous serum include the issue that it must be prepared by the eye care practitioner under well controlled conditions or by a compounding pharmacy, as well as the need to refrigerate the drops. There is a potential risk of infection if contamination of the solution occurs. The stability of frozen autologous serum has been verified for up to 3 months.

Typically, the serum is applied topically four times daily, and this can be done in conjunction with other therapy including topical lubricants, topical cyclosporine, or oral tear stimulants. The serum does not work well with contact lens wear.

This option may not work for every Sjögren's patient and thus one will need to find an ophthalmologist or optometrist that is familiar with Serum Tears to accurately gauge the benefits.

Gary Foulks, MD, FACS

continued page 14 ▼

<h1 style="margin: 0;">NEW</h1>	 <h2 style="margin: 0;">NeutraSal®</h2> <p style="margin: 0;">(Supersaturated Calcium Phosphate Rinse)</p>	<h1 style="margin: 0;">NEW</h1>
<h3 style="margin: 0;">NeutraSal® Sjögren's Syndrome Support Kit</h3> <p style="margin: 10px 0;"><b>Containing:</b></p> <ul style="list-style-type: none"> <li>• Eye Vitamin and Mineral Supplement for Dry Eye Comfort*</li> <li>• Sugar Free Dry Mouth Gum with Xylitol</li> </ul> <p style="font-size: small; margin-top: 10px;">* This statement has not been evaluated by the FDA. This product is not intended to diagnose, treat, cure or prevent any disease.</p>	<p><b>What is NeutraSal®</b></p> <p>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.</p> <ul style="list-style-type: none"> <li>◊ Clinically proven to relieve the symptoms of dry mouth in Sjögren's Syndrome patients with no reported side effects or drug to drug interactions</li> <li>◊ 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</li> <li>◊ Sodium bicarbonate ions reduce the acidity of the saliva in the mouth and break up accumulating mucus</li> <li>◊ The pH of NeutraSal® is similar to normal saliva which may protect the mouth against potential opportunistic fungal (oral thrush) and bacterial infections</li> </ul>	<h3 style="margin: 0;">NeutraSal® Burning Mouth Syndrome Support Kit</h3> <p style="margin: 10px 0;"><b>Containing:</b></p> <ul style="list-style-type: none"> <li>• Alpha Lipoic Acid for Burning Mouth Comfort†</li> <li>• Sugar Free Dry Mouth Gum with Xylitol</li> </ul> <p style="font-size: small; margin-top: 10px;">† 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.</p>
<p><b>NeutraSal® is a prescription item. For additional information on NeutraSal® or the Direct Access Program, please visit <a href="http://www.neutrasal.com">www.neutrasal.com</a> or call 866-963-8881 ext #1.</b></p>	<p><b>DIRECT ACCESS PROGRAM</b> 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).</p>	<p>Proud Sponsor</p>  <p style="font-size: small; margin-top: 10px;"> <b>INVADO</b> PHARMACEUTICALS                  2014 Invado Pharmaceuticals, Pomona, New York             </p>

# 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 ext. 218, or [mlee@sjogrens.org](mailto:mlee@sjogrens.org) to receive your Bold Blue Day kit!

**Win a  
Lifetime  
Membership**





# You Stood Up!

## Kids Helping Dr. Carole

When piano teacher, Patricia Goldman, heard that her friend Dr. Carole was diagnosed with Sjögren’s, she felt compelled to help in the only way she knew how- with her music!

Patricia, along with help from her family, friends and piano students, creates CDs to help raise awareness and funds for various causes. And as Patricia watched the progression of her friend’s disease, she decided to create her most recent CD, “Kids Helping Dr. Carole,” to honor her friend and everyone affected by Sjögren’s.

The CD consists of 29 tracks that are played by Patricia and children of various ages. Even Dr. Carole’s son, Ben, participated and was featured on a song entitled, “Wishing Carole Well.”

These CDs not only helped raise awareness of Sjögren’s, but the sales raised \$1,000 for the SSF! The production of “Kids Helping Dr. Carole” was a team effort that required a lot of hard work, dedication and desire to help those who suffer from Sjögren’s!

The SSF would like to thank Patricia, Dr. Carole, and all those who helped make this CD possible!

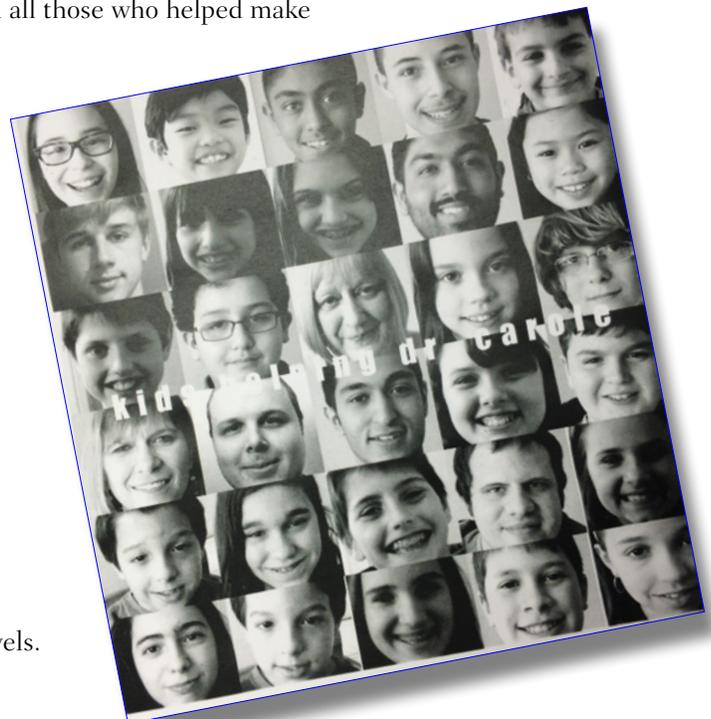
Thank you to all those who are featured on the CD:

- |                    |                     |
|--------------------|---------------------|
| Branden Chi        | Ian Klatzco         |
| Donna Contreras    | Ben Prete           |
| Alexander Dallas   | Mauricio Proano     |
| Abigail Dizon      | Bella Reza          |
| Malina Gataric     | Alex Reza           |
| Niki Gataric       | Cristian Rivera     |
| Tijana Gataric     | Ares Stavropoulos   |
| Patricia Goldman   | Thanos Stavropoulos |
| Anjam Gulati       | Melina Stavropoulos |
| Kivaun Jahad       | Ileana Stavropoulos |
| Natalija Jevdoscic | Elysa Stavropoulos  |
| Ivana Jevdoscic    | Katya Stillman      |
| Danijela Jevdoscic | Isaac Stillman      |

With production help from Jonathan Sill & Miles Revels.

### kids helping dr. carole

1. A Song For Donna: by Donna Contreras (piano & guitar)
2. Greg’s Math: by Patricia Goldman & Donna Contreras
3. Dancing With Alexis: by Katya Stillman, age 14
4. A Garden for Violet: by Natalija Jevdoscic, age 8
5. Checkers for Charles: by Alexander Dallas, age 8
6. Maxine’s T.V. Set: by Mauricio Proano, age 12
7. Debbie’s Song: by Malina Gataric, age 9
8. Reading with Esther: by Abigail Dizon, age 9
9. Our Father’s House: by Ivana Jevdoscic, age 11
10. Hank’s Internet: by Ares Stavropoulos, age 9
11. Manuel, Leo, Arthur and Rick’s Hockey Team: by Thanos Stavropoulos, age 9
12. Running & Jumping with Maddy, Molly & Grace: by Milan Gataric, age 10
13. Two Peter’s Tale: by Niki Gataric, age 12
14. A Parade for Two Patricks: by Isaac Stillman, age 12
15. A Gift for Casey: by Melina Stavropoulos, age 10
16. Sam & Helen’s Family Portrait: by Ileana Stavropoulos, age 13
17. Block Party with David & Josie: by Bella Reza, age 12
18. Jackie’s Wings: by Danijela Jevdoscic, age 13
19. Israel’s Prize: by Alex Reza, age 16
20. Wishing Carole Well: by Ben Prete, age 12
21. A Love Song for Bob & Terry: by Patricia Goldman
22. An Etude for Isaiah: by Cristian Rivera, age 13
23. A Journey with Gary, Dennis & Norbert: by Elysa Stavropoulos, age 9
24. Farewell to Elizabeth: by Tijana Gataric, age 14
25. Having Fun with Lindsey & Family: by Branden Chi, age 9
26. Gifts of Love & Second Look: by Kivaun Jahad, age 12
27. A Place of Peace with Randi & her Dog Gabriella: Ian Klatzco, age 17
28. A Song for Peace a Second Look: by Anjam, Saheb & Anmol Gulati, ages 20, 24 & 14
29. A Promise & a Song for Abraham, Stephen & Kris: by Patricia Goldman




**in memoriam**

**In Memory of Bonnie Litton**  
Dr. Karee Lehrman

**In Memory of Caroline Pasqualone Oldani**  
Greg Volpone  
Janis Valpone Crowell  
Margaret & Michael D'Amico  
Sara Wasserman

**In Memory of Elizabeth Garrison**  
Dorothy & Richard Carney  
Jim & Nona Henderson  
John & Marilyn Riley

**In Memory of Etienne Mary Bowen**  
Linda King

**In Memory of Grace Shanley**  
William Shanley

**In Memory of Helen Conner**  
Gloria Joann Moulton

**In Memory of Jill Francis Walker**  
Steve & Nancy Rudolph  
William & Mary Susan Vanburen

**In Memory of Kay Teegarden-Amberg**  
Betty Ballard  
Dennis & Tracy Teegarden  
Doris Clark  
Janet Johnson  
Larry & Mary Ellen Mitchell  
Ruth Gill  
Sandy Plank & Don Nemeth

**In Memory of Margene Oswald**  
About Time Clockmaking  
AnceL & Mary Peckham  
Timesavers

**In Memory of Marjorie Ramsdell**  
Mary Anne & Victor Babin  
Mimi Feldman  
Sheryl Nussbaum

**In Memory of Mary Louise McCarthy**  
Donna & David Pavcek

**In Memory of Pauline Moris Rankin**  
Joicy Sutherland

**In Memory of Ralph Mason**  
Bonnie Mason

**In Memory of Stephen Logsdon**  
Connie Cooper

**In Memory of Toby Douglas Wilt**  
Steve & Jackie Stuckey


**in honor**

**In Honor of Anne & Wilson Barnes**  
Maura Barnes

**In Honor of Beth Harkavy**  
Andy and Lauren Epstein

**In Honor of Charlotte Eglick**  
Peter Eglick

**In Honor of Lina Galvao**  
Sara and Yaniv

**In Honor of Mrs. Pauline McCaffrey**  
Estelle Ruderman

**In Honor of Samantha Whitman**  
Blanche Whitman

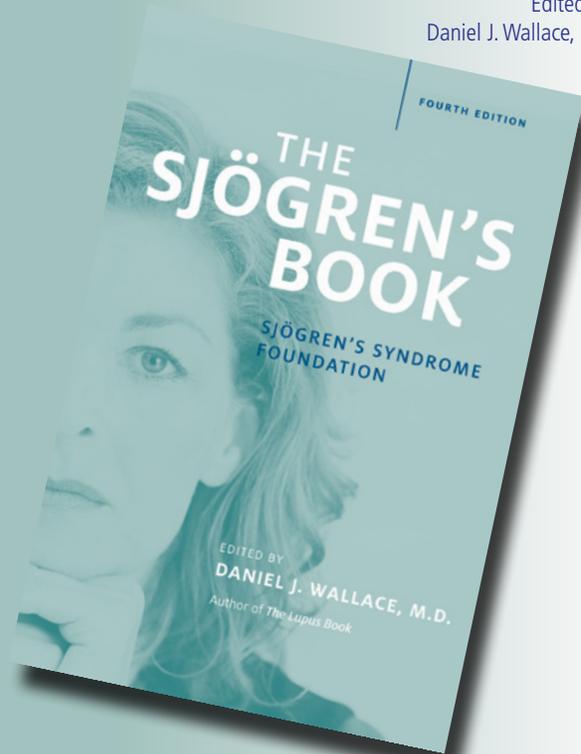
**In Honor of Sharon Adley**  
Lyle & Sue

**In Honor of TEAM COOPER**  
Karen Truman

**In Honor of Yvette Gontkovsky**  
Von Lee

## The Sjögren's Book – 4<sup>th</sup> Edition

Edited by  
Daniel J. Wallace, MD



This book can be purchased online at  
**[www.sjogrens.org/ssfstore](http://www.sjogrens.org/ssfstore)**

or by contacting the Sjögren's Syndrome Foundation office at

**800-475-6473.**

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





## Do You Follow the SSF Blog?

With the launch of the Foundation’s 5-Year Breakthrough Goal, “To shorten the time to diagnose Sjögren’s by 50% in 5 years,” we knew more patients were going to be diagnosed with Sjögren’s and thus they would look for information about how to cope, treat and manage their disease.

That is why the SSF created a blog to help raise awareness of the disease, provide information for patients, and keep all patients informed as we work to reach our goal of increasing and educating patients and their families.

With two posts published every month, the SSF blog, “Conquering Sjögren’s: Follow us on our journey to change the face of Sjögren’s”, was created just for you!

**We encourage you to visit [www.sjogrens.org](http://www.sjogrens.org) to find the SSF blog!** With regular posts, the blog will help you stay even more updated about new resources, educational programs, coping information and much more! ■

Sjögren’s Syndrome Foundation

# *Legacy of Hope*



If you would like to receive information on how you can *Leave a Legacy* to support the Sjögren’s Syndrome Foundation’s critical research initiatives or to support one of our many other programs, please contact Steven Taylor at 800-475-6473.

*Leave A Legacy –  
Remember Us in Your Will*



**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\*
- Discretely sticks to gums or teeth
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- May reduce risk of tooth decay
- **12 disc sample; just pay \$3.20 shipping (online or telephone orders only)**



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\* 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.

"Q&A" continued from page 9 ▼

**Q** *I know as a patient with Sjögren's I am at a higher risk for Lymphoma, is there anything my dentist could be on the lookout for to help catch it early?*

**A** This is true; patients with Sjögren's have an increased risk for developing lymphoma. Most commonly, the lymphoma associated with Sjögren's is low-grade non-Hodgkin's B-cell in nature. Visiting a dentist regularly, at least twice a year, is essential, as early detection may affect treatment.

*What does lymphoma in the mouth look like?*

The tumors associated with non-Hodgkin's lymphoma usually present as non-tender, slow growing masses that may arise in several areas of the body including the neck or the oral cavity. In the mouth, lymphoma presents as a diffuse, non-tender swelling that may be described as boggy. Occurring with higher frequency in the gingiva, posterior (closer to the throat) hard palate and buccal vestibule (the area between the gums, teeth and cheek), these masses are often red or blue-purple in color.

*So what does this mean?*

As stated earlier, visiting a dentist regularly and routinely is extremely important for early detection. Additionally, when visiting your dentist, make sure to tell him/her of your history of Sjögren's. It is important that your dentist conducts a thorough and comprehensive head and neck examination, which includes palpating the cervical lymph nodes (lymph nodes in your neck) as well as lifting the tongue and assessing the lateral borders (teeth sides of the tongue), the hard palate, floor of the mouth, buccal vestibules, soft palate, gingiva and the remaining soft tissues in the oral cavity.

*Is there anything I can look out for?*

Yes. It is important to visit your physician if you notice a swelling in your neck that persists for more than two weeks. You should also visit your dentist if you notice a swelling in your mouth that remains for more than two weeks. As a rule of thumb, if you notice any lesions in your mouth that remain for more than two weeks, it is recommended that you visit your dentist.

*Lauren Levi, DMD, dental oncologist*

**Q** *I've heard of using enzymes to re-mineralize your teeth, would you recommend that for a Sjögren's patient?*

**A** Naturally occurring salivary enzymes work with minerals and proteins to maintain oral health. The idea of supplementing salivary enzymes for a Sjögren's patient is a good one, but at present the only way to increase salivary enzymes is to increase saliva output. Stimulated saliva is rich in minerals and enzymes to promote and maintain the health of hard and soft tissues.

Systemic stimulation with Evoxac/Civimeline or Salagen/Pilocarpine will provide increased salivary output for 1-6 hours. Sugar-free products that stimulate saliva include gums, candies or sprays are best with Xylitol or preferably where Xylitol is in the top three ingredients. Chewing gum for 5-10 minutes increase saliva flow for up to 90 minutes.

Demineralization was first identified about 100 years ago as a process where bacteria colonize and produce acids that break down the chemical structure of exposed tooth surfaces. Remineralization is the rebuilding of the chemical structure of tooth surfaces. This can be accomplished in several ways:

1. Fluoride varnish to rebuild early stage cavities, provides the largest dose with the least fluoride ingested by the patient.
2. Mineral paste with or without fluoride provides building blocks to rebuild tooth surfaces, and neutralizes acids. The mineral paste maintains a neutral pH when used every four hours.
3. Mineral buffering products as rinses or gum. These supplement missing saliva components to improve oral health by maintaining a neutral pH (acid level).

Conventional prevention includes the use of a power toothbrush (less abrasion, more strokes per minutes); an oral irrigation device for up to 99% plaque removal; or fuzzy floss to avoid tissue trauma, fluoride in some form or Xylitol therapy, and more frequent dental hygiene visits. Brushing the insides of the cheeks and lips with a power toothbrush stimulates the slick component of saliva for about 90 minutes.

Newer therapies include pre- and pro-biotics to create an oral environment where healthy bacteria thrive and pathogens are inhibited; green tea anti-inflammatory gel, rinse or gum to promote healthier tissue and cleaner teeth; and a recently introduced arginine (an amino acid) with calcium carbonate as a tasty chewable supplement. Pathogens are converted from acid-producing microbes to alkaline-producing microbes for a neutral pH and healthier tooth surfaces. It is also available in a professional desensitizing polish. Zero-calorie Erythritol is the newest member of the sugar alcohol group and should be available in toothpaste in the near future. Currently it is found as an additive to some sugar-free drinks and as a powdered sugar replacement.

*JoAnn Snider, RDH*

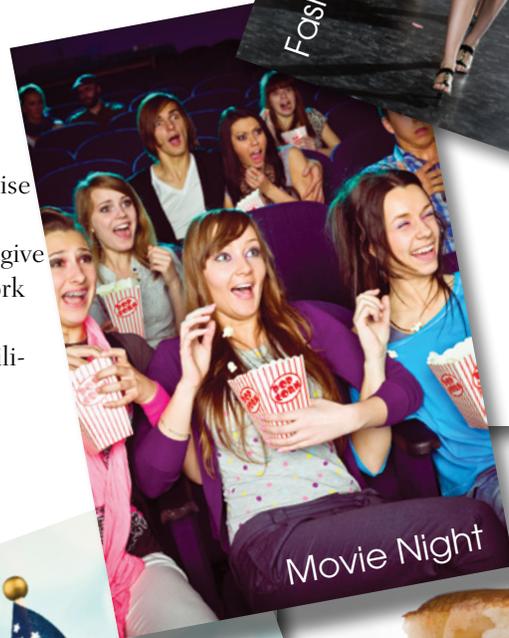
# Host Your Own SSF Event and Help Increase Awareness!

## EVENT IDEAS

Special event fundraisers can be a great way to raise money and many require spending little or no money. It is also a great way to get involved and give back while getting your friends, family, neighbors, work colleagues, etc., to help raise funds while increasing awareness for Sjögren's at the same time. The possibilities are endless. Have fun and use your imagination. Some examples:

- Bake Sale
- Restaurant "Night Out"
- Movie Night
- Dress Down Day
- Car Wash
- Pancake Breakfast
- Yard Sale
- Sports Tournament
- Dinner Party
- Bingo Night
- Fashion Show
- High Tea

Please contact Michele Lee, Special Projects Manager at the Foundation office with any additional questions at 301-530-4420 ext. 218 or [mlee@sjogrens.org](mailto:mlee@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

# Join in the fun! 2015 SSF Special Event Calendar

The SSF is very excited for all of our events coming this Spring. Look at our special event calendar below to see if there is a *Walkabout* or *Sip for Sjögren's* coming to your area.

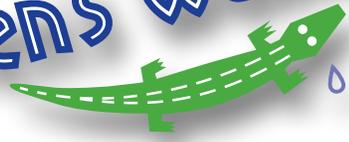
If there is already an event in your area and you would like to get involved, or learn about starting one, please visit [www.sjogrens.org](http://www.sjogrens.org) or contact us at (301) 530-4420 x227

## 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

  
**Sjögren's Walkabout**  


sip for  
**Sjögren's**  
a fine water  
tasting event

