After dryness, fatigue may be the most common symptom in Sjögren’s syndrome. The definition of fatigue has always been hard to pin down. Estimates of the frequency of fatigue problems in Sjögren’s have varied from 50-80% depending on how fatigue was defined and what questionnaire was used to elicit the diagnosis. Fatigue is often thought of as mental and/or physical exhaustion, extreme tiredness or weariness. However, the sense of fatigue a healthy person has after exercise or hard mental work can be a pleasant sensation, while fatigue that may be felt from Sjögren’s syndrome not only will leave one unable to respond to physical or mental tasks or stimuli but also at times will leave one depressed, despondent and isolated. ‘Lethargy’ implies fatigue as a state of physical slowing down or mental dullness due to tiredness, disease or medications and may be closer to what is described in Sjögren’s. Alternatively, ‘malaise’ that implies more a feeling of illness without specific diagnosis may be closer still.

Fatigue researchers describe fatigue as the final common pathway to which a multiplicity of predisposing or etiologic factors contribute. Fatigue

Do-It-Yourself Nasal Irrigation Solutions
by Susan F. Rudy, MSN, CRNP, CORLN

Nasal irrigation (also known as nasal hygiene, nasal flushing, or nasal douche) has become a mainstay of therapy for nasal allergies and chronic sinus infections and has long been the primary treatment for dry nose problems. In these challenging times many people are seeking ways to cut their costs across the board. While over-the-counter nasal saline and nasal hygiene products are not among the most costly therapies, there are some cost savings in making your own nasal saline, if needed. Read on to learn how.
Fatigue also may be defined as a persistent and subjective sense of tiredness that interferes with ability to function normally. The emphasis that Sjögren’s fatigue can result in tiredness at rest and rapidly can progress to fatigue with exertion resulting in the inability to maintain prior levels of performance is key to appreciating how much can be lost to fatigue.

To summarize, using the Mitchell and Berger definition, fatigue is described as a multifaceted condition characterized by diminished energy and increased need for rest disproportionate to any recent change in activity level and accompanied by general weakness, insomnia or hypersomnia and emotional reactivity.

My goal is to first discuss where the energy that is so rapidly depleted with fatigue comes from and how it is regulated. Secondly, I will elucidate when fatigue is normal and expected to occur. Thirdly, I will review more specifically the causes of fatigue in Sjögren’s syndrome. Lastly, I will offer some suggestions on the approach to treatment of fatigue.

Energy at a cellular level is made by organelles called mitochondria that produce ATP used to power the cell. If you have a mitochondrial mutation as seen in many muscle disorders, or if mitochondria are adversely affected as can happen with chemotherapy or occasionally with the use of statin drugs, your body will experience fatigue. Exercise builds muscle but also increases mitochondrial size and numbers and that increases energy production. In contrast, illness or disease may result in premature mitochondrial apoptosis (cell death), decreased mitochondrial numbers, function or even mitochondrial mutation.

Regulation of the energy produced by our body is also important. Nerve regulation of energy is done by ergoreceptors that respond to metabolites such as lactate, calcium and hydrogen products released by muscle during exercise. Excess metabolites from muscle overuse result in a signal from the ergoreceptors to the brain that causes you to feel tired and to slow down. Additional stimulation of similar receptors called nociceptors will give us pain, but this occurs only with much higher concentrations of the same metabolites. Therefore, we all feel fatigue before we are completely out of energy or in pain, the brain having left us a small energy reserve. A variety of small protein messengers in the body that are released in Sjögren’s syndrome, including TNF alpha, IL6 and other cytokines, also can stimulate these ergoreceptors, causing us to feel fatigue.

The AMPK system (AMP activated protein kinase system) is our energy charge sensor and acts as a central control gauge for metabolic homeostasis and cellular energy regulation. It controls processes that will provide glucose and ATP for energy. In special types of mice called knockout mice that lack a functioning AMPK system, fatigue occurs much earlier with any given task than in normal mice.

The mitochondria, ergoreceptors and AMPK system are the very basic regulatory systems for energy. However, a variety of...
Why aren’t artificial tears enough for me?

They provide temporary relief. If your type of Chronic Dry Eye causes inflammation which decreases your ability to make tears, use RESTASIS®. I do.

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:
RESTASIS® Ophthalmic Emulsion should not be used by patients with active eye infections and has not been studied in patients with a history of herpes viral infections of the eye. RESTASIS® should not be used while wearing contact lenses. If contact lenses are worn, they should be removed prior to use. 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 important product information.

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Find out more about a $20 rebate offer! See next page for details.

Dr Tendler is an actual patient and is compensated for appearing in this advertisement.
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.

Check the box that applies if:

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RESTATEIS® (cyclosporine ophthalmic emulsion) 0.05%
Sterile, Preservative-Free

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 active ocular infections and in patients with known or suspected hypersensitivity to any of the ingredients in the formulation.

WARNING
RESTASIS® ophthalmic emulsion has not been studied in patients with a history of herpes keratitis.

PRECAUTIONS
General: For ophthalmic use only.

Information for Patients
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.

Do not allow the tip of the vial to touch the eye or any surface, as this may contaminate the emulsion.

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 reininserted 15 minutes following administration of RESTASIS® ophthalmic emulsion.

Carcinogenesis, Mutagenesis, and Impairment of Fertility
Systemic carcinogenicity studies were conducted in male and female mice and rats. In the 78-week oral (diet) mouse study, at doses of 1, 4, and 16 mg/kg/day, evidence of a statistically significant trend was found for lymphoid 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 1000 and 500 times greater, respectively, than the daily human dose of one drop (26 µL) 0.5% RESTASIS® BID into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed.

Cyclosporine has not been found mutagenic/teratogenic in the Ames Test, the 997-HGPT Test, the micronucleus test in mice and Chinese hamsters, the chromosomal 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).

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 15,000 times the human daily dose of 0.001 mg/kg/day) for 9 weeks (male) and 2 weeks (female) prior to mating.

Pregnancy–Teratogenic Effects
Pregnancy category C.

Teratogenic Effects: No evidence of teratogenicity was observed in rats or rabbits receiving oral doses of cyclosporine up to 360 mg/kg/day during organogenesis. These doses in rats and rabbits are approximately 350,000 times greater than the daily human dose of one drop (26 µL) 0.5% RESTASIS® BID into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed.

Non-Teratogenic Effects: 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 embryotoxic and fetotoxic as indicated by increased pre- and postnatal mortality and reduced fetal weight together with related skeletal retardations. These doses are 30,000 and 100,000 times greater, respectively than the daily human dose of one drop (26 µL) of 0.5% RESTASIS® BID 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 17,000 and 30,000 times greater, 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 post partum, a maternally toxic level, exhibited an increase in postnatal mortality; this dose is 45,000 times greater than the daily human topical dose of 0.001 mg/kg/day, assuming that the entire dose is absorbed. No adverse events were observed at oral doses up to 15 mg/kg/day (15,000 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.

ADVERSE REACTIONS
The most common adverse event following the use of RESTASIS® was ocular burning (17%).

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

Rx Only

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For more information, please visit our Web site, www.restasis29.com.
We all know that having Sjögren’s can be a family affair and those sometimes affected most are the children and grandchildren of Sjögren’s patients.

Each year at the Foundation we are inspired to hear stories of kids and how they stood up to make a difference for Sjögren’s. This Spring, we heard three great stories.

Sara Jaskot, a 7th grader at Agnes Irwin School, an all-girls school in Pennsylvania, decided to Stand Up for Sjögren’s in support of her Aunt Lizz who has Sjögren’s. Sara increased awareness by creating and presenting a PowerPoint presentation about Sjögren’s at her school. Sara also, along with her advisory group, held a bake sale for Sjögren’s and was able to raise over $120 for the Foundation and, most importantly, raise awareness among her fellow classmates and school faculty. Sara was quoted as saying, “Sjögren’s has greatly impacted my family. I hope one day soon we can find a cure for this autoimmune disease.”

Michael Wischmeyer, another 7th grader, from St. Rita Catholic School in Dallas, Texas, took it upon himself to write a research paper on Sjogren’s for his English class. Michael’s mother, Monica, is a Sjögren’s patient. Michael knew how much the disease had affected their family and wanted to educate others about Sjögren’s. He asked to interview the Sjögren’s Syndrome Foundation CEO, Steven Taylor, as well as Sjögren’s patients along with his mother. “Michael’s questions were insightful and inquisitive. You can surely see that he is greatly concerned for his mother and her struggle with Sjögren’s. Michael knows a lot about Sjögren’s,” said Steven Taylor after he was interviewed.

Jack Taylor, a 6th grader at Riverbend Middle School in Sterling, Virginia, convinced his Student Activities Club (SAC) and school principal to hold a “Bold Blue Day” for Sjögren’s in honor of his grandmother, Cathy, who has Sjögren’s. Jack and his twin brother, Owen, saw the school hold a Passionately Pink Day for breast cancer last October and thought that they should do something for Sjögren’s, since it affects as many women. So Jack wrote a letter to the SAC and the principal, and on April 28th the school all wore Bold Blue for Sjögren’s. Not only was there a competition amongst the grades to see who wore more “blue” that day, but it was also a great way to educate over 200 faculty and staff about Sjögren’s! As Jack said, “my goal is to have everyone know about Sjögren’s.” Not surprising coming from Jack, who sees his dad work tirelessly for Sjögren’s patients. Jack’s dad is the SSF’s CEO!

We hope these stories inspire you to Step Up for Sjögren’s. No matter what your age – you can make a difference by doing something! As the saying goes, “You can be a spectator or a participant in life.” We hope you will choose to participate and help us as we expand awareness for Sjögren’s and make a difference for all patients!
hormones such as testosterone, organ systems including the lungs that provide oxygen for metabolic processes, the heart and vasculature that circulates glucose and oxygen, the brain that may override and control any system, the muscles that provide the functioning component for much of the energy produced, and the kidney that eliminates the unwanted metabolites that can cause fatigue are all intimately involved in what level of energy we will have. Even the quality of the food we eat, the amount of water we drink and the amount of sleep we get all may contribute to the final amount of energy we have available.

When should you expect fatigue normally? Sadly, aging causes fatigue. Starting in the fourth to fifth decade of life a process of sarcopenia occurs in muscle with remodeling of the motor unit that results in loss of strength. Exercise may delay this overall weakening, but as seen when you compare Olympic records to senior Olympic records, despite the senior Olympics having not just dedicated athletes but often the same athletes but at an older age, the senior Olympic records are never as good.

Fatigue also normally occurs from overwork, even over-exercise. Work shift disorder is well described as a cause of fatigue, as is jet lag, trauma or post-traumatic stress syndrome. At higher altitudes fatigue comes more easily as it does with weight gain, dialysis, fighting infection, poor diet, severe environmental allergies, pregnancy, post-pregnancy and with lung disease and undiagnosed heart disease. Many diseases such as AIDS, Lyme disease, cancer, Parkinson’s disease, celiac disease, post-polio syndrome, depression and diabetes have fatigue as a big part of their symptom complex.

People often are unaware that too much coffee may have the opposite effect and cause fatigue as can too much food (after Thanksgiving) or taking any of a large number of legal and illegal medications. Additionally, I find that we often underestimate the fatigue that can come from one or certainly more surgeries in one year, even if they go well. Studies show prolonged sleep disturbances, non-restorative sleep patterns and generalized weakness can occur from deconditioning but also from the stress of the surgeries. In fact, any extreme stress, whether a death in the family, divorce or job loss often will be followed by fatigue. Menopause in women or andropause in men is associated with fatigue as is too much alcohol, chronic infections of any sort, chronic liver or kidney disease or COPD.

The most common causes of fatigue in Sjögren’s syndrome cited in a variety of recent reports include non-restorative sleep patterns, autoimmune thyroid disease and overlapping fibromyalgia. Non-restorative sleep patterns are often the result of dryness resulting in frequent nocturnal awakening due to a need for water or eye drops. Obstructive sleep apnea is well described as are the EEG pattern with alpha wave intrusion into delta wave sleep seen with fibromyalgia. Sjögren’s often results in the inability to concentrate urine (isosthenuria). This can result in waking frequently to use the bathroom and that alone can disrupt sleep as can restless leg syndrome.

Hypothyroidism is seen in 20% of Sjögren’s syndrome patients. Secondary Sjögren’s syndrome often has fatigue as a component of the associated disease, whether it is rheumatoid arthritis, systemic lupus erythematosus, poly or dermatomyositis or primary biliary cirrhosis. Prior use of corticosteroids can result in adrenal insufficiency and that causes fatigue. Medications such as corticosteroids, azathioprine, methotrexate, leflunomide, etc. also can cause fatigue. Rarely, lymphomas are a cause of fatigue as is overlapping vasculitis. Deconditioning is often present especially when concomitant illness or musculoskeletal pain cause inactivity. Pain of any sort often goes hand-in-hand with fatigue. Anemia in Sjögren’s syndrome along with less common findings of heart, lung and renal problems can cause fatigue. Psychological problems such as depression related to disease also can cause fatigue, and results of studies on neurologic complications of Sjögren’s suggest overlapping neurologic disease can result in profound fatigue.

The approach to the treatment of fatigue in Sjögren’s syndrome first involves the investigation of the underlying causes. Special emphasis should be given to sleep problems, thyroid, fibromyalgia, secondary disorders and medications. A sleep study may be indicated, especially if there is a history of snoring, daytime sleepiness, obesity, large neck circumference, irritability, morning headaches, decreased libido, trouble with concentration or short-term memory loss. Depending on the diagnosis, treatment may involve a CPAP machine, wedge pillow, oral appliance and review of appropriate sleep hygiene. Problems with dryness during the night may be helped with a humidifier using distilled water and appropriate nighttime drops for eyes and products for the mouth. Nutritional counseling can help with fatigue as can stress reduction techniques, proper exercise programs and in certain cases biofeedback and self-hypnosis techniques.

Unfortunately, there is no free energy. Medications such as modafinil, DHEA, testosterone and various es-
The salt water recipe

There are many recipes published or espoused by some doctors and nurses (Rudy, 2004, p.109) that are not correct as to the amounts of salt and water to be mixed. For dry noses, an “isotonic” mixture, or one that mimics the amount of salt in the normal bloodstream, is best. The basic contents are un-iodized salt (e.g., kosher or canning salt), baking soda, and water. The recipe in various volumes, as confirmed by a chemist (Rudy, 2004, pp.111-113 & 205), is shown in Table 1.

While the list in Table 1 shows the correct mixtures, you will notice the impractical measures of sixths or thirds of a teaspoon of salt. It is easier to mix 3 cups of salt water and discard any unused portion for a single episode, or to mix larger amounts (6 cups or 9 cups) for canning and preserving. Adding baking soda raises the acid-base level of the mixture toward the “basic” side, which is thought to improve mucus flow (Talbot et al., 1997).

I do not advise the use of tap water as the base for homemade nasal irrigation mixtures due to its variable content of germs, salt, and chlorine (USEPA, 2011), which may disturb the nose’s lining and lead to infection. Filtered tap water may be OK to use if the filter is changed often, the filter is a type that removes the contents of concern from tap water, and does not add salt as ion exchange filters do.

Benjamin Franklin once said, “Fatigue is the best pillow.” Franklin did not have the fatigue of Sjögren’s syndrome. Fatigue can leave people old before their time, mentally cloudy, depressed, separated from friends and family and feeling like a turtle in a world of rabbits. All efforts should be made to find the cause or, more likely, causes of fatigue, be they normal or abnormal, and either eradicate or alleviate them.

Table 1: Accurate Homemade Saline Recipes by Batch Size

<table>
<thead>
<tr>
<th>Batch Size</th>
<th>0.9% Isotonic Saline</th>
<th>0.9% Isotonic Buffered Saline</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 oz. (½ cup or 120mL)</td>
<td>½ tsp. salt</td>
<td>½ tsp. salt + 1 tiny pinch baking soda†</td>
</tr>
<tr>
<td>8 oz. (1 cup or 240 mL)</td>
<td>¼ tsp. salt</td>
<td>¼ tsp. salt + 1 tiny pinch baking soda†</td>
</tr>
<tr>
<td>16 oz. (2 cups or 480 mL)</td>
<td>⅜ tsp. salt</td>
<td>⅜ tsp. salt + 1 tiny pinch baking soda†</td>
</tr>
<tr>
<td>24 oz. (3 cups or 720 mL)</td>
<td>1 tsp. salt</td>
<td>1 tsp. salt + 1 tiny pinch baking soda†</td>
</tr>
<tr>
<td>32 oz. (4 cups or 960 mL)</td>
<td>1½ tsp. salt</td>
<td>1½ tsp. salt + 1 pinch baking soda†</td>
</tr>
<tr>
<td>48 oz. (6 cups or 1440 mL)</td>
<td>2 tsp. salt</td>
<td>2 tsp. salt + 1 pinch baking soda†</td>
</tr>
<tr>
<td>128 oz. (16 cups or 3840 mL)</td>
<td>5½ tsp. salt</td>
<td>5½ tsp. salt + ¼ tsp. baking soda†</td>
</tr>
</tbody>
</table>

† pH = 8.0-8.3

How to make your own sterile water or sterile salt water

It is beyond the scope of this piece to give a step-by-step guide on how to do home canning. Instead, please see the excellent and reliable information sources in the reference list (Andress, 2007; Monson, 1988; NCHFP, n.d.; USDA, 2009). Also, your local cooperative extension service, usually run by your state’s university system, can guide you in the process or direct you to local sources of high-quality information. The canner you need is the same as that used to preserve food, which some people already own and use. For others, there would be an investment of time and money to buy and learn to use the canner. Please be aware that there are right and wrong ways, safe and unsafe ways, to make homemade sterile water or sterile salt water using home canners. Before you begin this.
task, please do your homework, paying attention to:

• your equipment – boiling water canners or pressure canners, jars and seals can be bought at department stores or online.
• the right temperature, pressure, and time for the canning process, given your height above sea level, in order to assure that all germs in the water are killed by the process.
• your own safety in doing the task.

What NOT to do
You may be tempted to sniffle nasal saline from the palm of your hand, in order to avoid the cost of buying your first, or a replacement nasal hygiene device (e.g., bulb syringe, neti pot, squeeze bottle, or other gravity or powered nasal irrigator). Because palm sniffing can carry bad germs from your hands to your nose and sinuses, this method is not advised (Johannssen et al., 1996). I am not aware that the method has been studied among people who practice good hand washing first.

Conclusion
I hope this reading has broadened your knowledge of options for cutting costs in the practice of nasal hygiene.

Please discuss your plans for any change to your nasal hygiene self-care with an informed healthcare provider.

References
National Center for Home Food Preservation (NCHFP) (n.d.). How do I can? University of Georgia Cooperative Extension. Available from http://www.uga.edu/nchfp/index.html  Note: This site includes a wealth of information including a self-study online course

Naturally help relieve symptoms of Dry Eye.

The new tranquikeyes Moisture Release Eyewear (available in clear or sunglass lenses) were developed by a Board Certified Ophthalmologist and create a moisture rich environment while your eyes are open. Experience extended relief day and night.

For a limited time, friends of the Sjogren’s syndrome foundation receive a 15% discount off any purchase. An additional 15% of your purchase will be donated back to SSF in support of finding a cure.

For more information or to order, visit www.eyeeco.com. Use promotional code ‘SSF’ online to receive discount or call toll free 1-888-730-7999.
For patients with Sjögren’s syndrome

DRY-MOUTH SYMPTOMS DON’T HAVE TO BE SO DISTRACTING.

If you experience dry-mouth symptoms due to Sjögren’s syndrome, then you already know how distracting these can be to your daily life. It might be time to ask about EVOXAC® (cevimeline HCl), a prescription treatment that works by stimulating the production of your body’s own natural saliva.

Talk to your doctor to see if EVOXAC can help, or visit DiscoverEVOXAC.com.

Please see important information about EVOXAC below.

Important Safety Information

What is EVOXAC?
• EVOXAC (cevimeline HCl) is a prescription medicine used to treat symptoms of dry mouth in patients with Sjögren’s syndrome.

Who Should Not Take EVOXAC?
• You should not take EVOXAC if you have uncontrolled asthma, allergies to EVOXAC or a condition affecting the contraction of your pupil such as narrow-angle (angle-closure) glaucoma or inflammation of the iris.

What should I tell my Healthcare Provider?
• Tell your healthcare provider if you have any of the following conditions:
  • History of heart disease;
  • Controlled asthma;
  • Chronic bronchitis;
  • Chronic obstructive pulmonary disease (COPD);
  • History of kidney stones;
  • History of gallbladder stones
• Tell your healthcare provider if you are trying to become pregnant, are already pregnant, or are breastfeeding.
• Tell your healthcare provider about all medications that you are taking, including those you take without a prescription. It is particularly important to tell your healthcare provider if you are taking any heart medications especially “beta-blockers”.
• If you are older than 65, your healthcare provider may want to monitor you more closely.

General Precautions with EVOXAC
• When taking EVOXAC use caution when driving at night or performing other hazardous activities in reduced lighting because EVOXAC may cause blurred vision or changes in depth perception.
• If you sweat excessively while taking EVOXAC drink extra water and tell your health care provider, as dehydration may develop.
• The safety and effectiveness of EVOXAC in patients under 18 years of age have not been established.

What are some possible side effects of EVOXAC?
• In clinical trials, the most commonly reported side effects were excessive sweating, headache, nausea, sinus infection, upper respiratory infections, runny nose, and diarrhea.

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 visit www.EVOXAC.com for full Product Information for EVOXAC.

For patients having difficulty affording their Daiichi Sankyo medication, please call the Daiichi Sankyo Patient Assistance Program at 1-866-268-7327 for more information or visit www.dsi.com/news/patientassistance.html.

Please see a brief summary of Important Information for EVOXAC on the next page.
**EVOXAC® Capsules**

**(cevimeline hydrochloride)**

**INDICATIONS AND USAGE**

Cevimeline is indicated for the treatment of symptoms of dry mouth in patients with Sjögren's Syndrome.

**CONTRAINDICATIONS**

Cevimeline is contraindicated in patients with uncontrolled asthma, known hypersensitivity to cevimeline, and when use is uncertain, e.g., in acute sinusitis in narrow upper airway obstructions (e.g., nasopharynx).

**WARNINGS**

Cardiovascular Disease:

Cevimeline can cause or exacerbate coronary and/or heart rate. Patients with significant cardiovascular disease may potentially be in compensation for transient changes in hemodynamic or rhythm induced by EVOXAC®. Cevimeline should be used with caution in patients with cardiovascular disease, including those with coronary artery disease, or with a documented history of angina.

Pulmonary Disease:

Cevimeline has been shown to increase airway resistance, bronchial smooth muscle tone, and bronchial secretions. Cevimeline should be administered with caution and close medical supervision to patients with bronchial asthma, chronic bronchitis, or chronic obstructive pulmonary disease.

Ocular:

Optometrists' formulation of mucin solutions are required to cause visual blurring which may impair the test and pulmonary function tests of the patient. Therefore, it is advisable to use a minimum of 2 drops of cevimeline daily to allow for an initial benefit in the patient with uncontrolled asthma.

**PRECAUTIONS**

Cevimeline is a weakly active agent with a minimal effect on platelet aggregation.

**Adverse Reactions**

Cevimeline is a weakly active agent with a minimal effect on platelet aggregation.

**Pharmacology**

Cevimeline is a weakly active agent with a minimal effect on platelet aggregation.

**DOSAGE AND ADMINISTRATION**

Cevimeline capsules should be used carefully in patients with cardiovascular disease.

**Injection**

Cevimeline should be avoided when taking with other medications that may interact with cevimeline.

**Storage**

Cevimeline should be avoided when taking with other medications that may interact with cevimeline.

**REFERENCES**

Cevimeline should be avoided when taking with other medications that may interact with cevimeline.

**PREGNANCY**

Cevimeline should be avoided when taking with other medications that may interact with cevimeline.

**NURSING MOTHERS**

Cevimeline should be avoided when taking with other medications that may interact with cevimeline.

**ADVERSE REACTIONS**

Cevimeline should be avoided when taking with other medications that may interact with cevimeline.

**OVERDOSAGE**

Cevimeline should be avoided when taking with other medications that may interact with cevimeline.

**INTERACTIONS**

Cevimeline should be avoided when taking with other medications that may interact with cevimeline.

**ADDITIONAL ADVERSE EVENTS**

In addition, the following adverse events (AEs) in a total of 80% of patients treated with EVOXAC® were reported in the Sjögren's Syndrome clinical trial:

<table>
<thead>
<tr>
<th>Event</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>14%</td>
</tr>
<tr>
<td>Nasal congestion</td>
<td>10%</td>
</tr>
<tr>
<td>Upper respiratory tract symptoms</td>
<td>9%</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>11%</td>
</tr>
<tr>
<td>Nausea</td>
<td>8%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>4%</td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td>3%</td>
</tr>
<tr>
<td>Constipation</td>
<td>2%</td>
</tr>
<tr>
<td>Pharyngitis</td>
<td>2%</td>
</tr>
<tr>
<td>Vomiting</td>
<td>2%</td>
</tr>
<tr>
<td>Dyspepsia</td>
<td>2%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>1%</td>
</tr>
<tr>
<td>Constipation</td>
<td>1%</td>
</tr>
</tbody>
</table>

*Since the total number of patients exposed to the drug at any time during the study.*

**ADVERSE EVENTS**

<table>
<thead>
<tr>
<th>Event</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>14%</td>
</tr>
<tr>
<td>Nasal congestion</td>
<td>10%</td>
</tr>
<tr>
<td>Upper respiratory tract symptoms</td>
<td>9%</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>11%</td>
</tr>
<tr>
<td>Nausea</td>
<td>8%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>4%</td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td>3%</td>
</tr>
<tr>
<td>Constipation</td>
<td>2%</td>
</tr>
<tr>
<td>Pharyngitis</td>
<td>2%</td>
</tr>
<tr>
<td>Vomiting</td>
<td>2%</td>
</tr>
<tr>
<td>Dyspepsia</td>
<td>2%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>1%</td>
</tr>
<tr>
<td>Constipation</td>
<td>1%</td>
</tr>
</tbody>
</table>

*Since the total number of patients exposed to the drug at any time during the study.*
Walking to raise awareness and understanding. Let’s all take a step toward a better tomorrow.

Contact the Sjögren’s Syndrome Foundation at 800-475-6473 and request information on hosting your own Walkabout.

In honor of “The Wedding of Diane Barrasso & Anurag Nigam”
The Carey Family of Long Valley

In honor of “The Birthday of Yvette (GG) Gontkovsky”
Kris, BJ, Miyah and Drew

In honor of “The Birthday of Dr. Robert Fox”
Lillyan Shelton

In honor of “The Birthday of Christine Froomer”
Connie Sellers

In honor of “Sandy Leon and her Support Group”
Eileen Maher

In honor of “Myra G. Hopkins, because we love you!”
The Smoot Family

In honor of Linh Pang, a dear friend
Thuy-Linh Bowman

In honor of Kathy Brauner
Patricia Richardson

In honor of Jennifer Bromberg
John & Beth Bromberg

In honor of “Irene Poppe, for courage in dealing with Sjögren’s syndrome”
Jeff & Linda Greenhagen

In honor of Dr. Harry Spiera
The Farishian Family

In honor of Dr. Frederick Vivino
Rona Lee Sands

In honor of Cheryl Levin
Elaine (mom) Levin

In Memory of Sara Buddington
Hannah Scher

In Memory of Natale “Tony” Umbro
The Clancy Family
Fred Homsy
Martin McGrann
Anna Blandino
The Mackenzie Family

In Memory of Nancy E. Andreeko
Andrew Andreeko

In Memory of Nancy Cloman
Venetian Palace Domino Ladies

In Memory of Marilyn Schagel
Mary Barrett
R. Diana & Robert Bruton
Gloria Carpenter
Marjorie Helander
Roxanne Hodgson
Sean Keefe
Kelly Lee
Anne Maillette

In Memory of Ellen E. Arthur
Bishop & Mrs. Wesley Russ

In Memory of Colleen Commerford
Thomson & Zeldin & Julie

In Memory of Barbara Fisher Neet
Amanda Neet

In Memory of Ann Rowe
Rose Marie & David McFall

In Memory of Aleatha Iacolucci
Linda Osborne and Family

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In Memory of Aleatha Iacolucci
Linda Osborne and Family
Nuances of Nasal & Sinus Self-Help
by Susan F. Rudy, MSN, CS-FNP, CORLN
A world of help for the problem nose!

Do you
• Have nasal issues due to your Sjögren’s?
• Have frequent colds or sinusitis?
• Have a stuffy, runny or dry nose?
• Have repeated nosebleeds?
• Use nasal sprays?

Susan Rudy has put together a “nasal irrigation bible” bringing you the first reference to provide an objective and comprehensive review for all methods, devices and solutions available for nasal hygiene.

Susan F. Rudy is a family and otolaryngology nurse practitioner who has practiced ear, nose and throat nursing for over 20 years.
**Products For Dry Nose**

Excerpt from Sjögren's Product Directory

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**Moisturizers for Nasal Mucosal Tissue**

- **Afrin® Nasal Pump Mist**
  Schering-Plough HealthCare Products, Inc.
  P.O. Box 377
  Memphis, TN 38151-0001
  800/842-4090
  www.Afrin.com

- **Afrin® Pure Sea™ Hydrating Nasal Rinse**
  Schering-Plough HealthCare Products, Inc.
  P.O. Box 377
  Memphis, TN 38151-0001
  800/842-4090
  www.afrinpuresea.com

- **Ayr® Saline Nasal Gel**

- **Ayr® Saline Nasal Mist**
  B.F. Ascher & Co., Inc.
  15501 West 109th St.
  Lenexa, KS 66219-1308
  800/324-1880
  www.bfascher.com

- **Dristan® Nasal Spray**
  Pfizer Pharmaceuticals
  NARPQ
  P.O. Box 26609
  Richmond, VA 23261
  800/535-0026
  www.dristan.com

- **Na-Zone**
  Snuva, Inc.
  10323 Canterbury St.
  Westchester, IL 60154
  800/250-4258
  www.snuva.com

- **Xlear® Nasal Wash with Xylitol**
  Xlear Inc.
  P.O. Box 970911
  Orem, UT 84097
  877/599-5327
  www.xlear.com

- **NeilMed® NasalSpray™ Single-Use Saline Ampoules**

- **NeilMed® NasalFLO® Neti Pot**

- **NeilMed® NasalMist® Saline Spray**

- **NeilMed® NasoGEL® Gel Spray**

- **NeilMed® NasoGEL® Tube**

- **NeilMed® SinuFlo® Ready Rinse™**

- **NeilMed® Sinus Rinse™**
  NeilMed Pharmaceuticals, Inc.
  601 Aviation Blvd.
  Santa Rosa, CA 95403
  877/477-8633
  www.neilmed.com

- **Ocean Complete™ Sinus Irrigation**
  Fleming Pharmaceuticals
  1733 Gilson Lane
  St. Louis County, MO 63026
  800/343-9497
  www.ocean-complete.com
  www.flemingpharma.com

- **Ocean® Saline Nasal Spray**
  Fleming Pharmaceuticals
  1733 Gilson Lane
  St. Louis County, MO 63026
  800/343-9497
  www.flemingpharma.com

- **Ocean® Ultra Moisturizing Gel**
  Fleming Pharmaceuticals
  1733 Gilson Lane
  St. Louis County, MO 63026
  800/343-9497
  www.oceangel.com

- **Pretz® Moisturizing Nasal Spray**

- **Pretz® Nasal Irrigation and Sinus Rinse**
  Parnell Pharmaceuticals, Inc.
  1525 Francisco Blvd.
  San Rafael, CA 94901
  800/457-4276
  www.parnellpharm.com

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This October, come to Chicago and take control of your health by learning the most up-to-date information from the brightest minds in Sjögren’s.

Our Live, Learn & Share seminars are the best one-day Sjögren’s patient seminars in the country. They have helped thousands gain a better understanding of Sjögren’s and will help you, too. Our panel of medical experts will address an array of Sjögren’s topics; plus, you’ll have the rare chance to meet and share tips with fellow Sjögren’s patients.

If you want to be your own best advocate by gaining a thorough understanding of all the key aspects of Sjögren’s, then this one-day seminar is for you.

Seminar Topics

Overview of Sjögren’s Syndrome — Daniel Small, MD, MMSc, FACP
Dr. Small has had a career-long interest in Sjögren’s. He established and is the Director of the Sjögren’s Center of Florida in Sarasota, Florida. Dr. Small has been practicing rheumatology since 1978 and has reported on a large series of patients with Sjögren’s at both national and international rheumatology meetings. Dr. Small will outline the many facets of Sjögren’s and provide a comprehensive explanation of the range of symptoms that Sjögren’s patients experience, explain their causes, and offer practical tips for managing them.

Dry Eye and Sjögren’s — Peter C. Donshik, MD
Dr. Donshik has practiced medical and surgical ophthalmology in the greater Hartford, Connecticut area since 1976. He sub-specializes in corneal and external diseases of the eye, laser vision correction, contact lenses and corneal transplant surgery. Dr. Donshik lectures nationally and internationally and is a widely published author with over 100 articles in both national and international journals. This esteemed eye care expert will discuss the latest dry eye therapeutic treatments, covering the extensive range of help available from artificial tears to silicone plugs to systemic drugs to help you manage and treat dry eye.

Sjögren’s Research Update — Steven Taylor, SSF Chief Executive Officer
Mr. Taylor will share an update on the Foundation’s Research Program and the goals for 2012. You will learn about how research holds future promise, greater understanding and hope for better therapies for all Sjögren’s patients.

Nutrition and Sjögren’s — Tara Mardigan, MPH, MS, RD, LD/N
Tara Mardigan is a Senior Clinical Nutritionist at the Dana-Farber Cancer Institute in Boston, Massachusetts, and Team Nutritionist for the Boston Red Sox. A very popular conference guest speaker, Ms. Mardigan will explain how different aspects of nutrition can impact Sjögren’s and share insights into making the best nutritional choices to maximize functioning and well-being.

Musculoskeletal Issues and Sjögren’s — Alan Baer, MD
Dr. Baer is Associate Professor of Medicine and Director of the Jerome L. Greene Sjögren’s Syndrome Clinic at Johns Hopkins University School of Medicine. He also serves as Chief of Rheumatology and Clinical Director of the Johns Hopkins University Rheumatology Practice at the Good Samaritan Hospital in Baltimore, Maryland. He was a faculty member at the University at Buffalo, State University of New York, from 1986 to 2007, and served there as Chief of the Section of Rheumatology and Fellowship Program Director. Dr. Baer has a long-standing interest in Sjögren’s syndrome and will enhance your understanding of Sjögren’s-related problems of the musculoskeletal system.
ATTENDEE – complete for each registrant

Attendee Name(s) ________________________________________________________________
Attendee Name(s) ________________________________________________________________
Street Address ___________________________________________________________________
City ___________________________ State ___________ Zip ________________
Telephone ___________________________ E-mail ________________________________

FEES – please circle appropriate fee(s) (Note: Early Bird Deadline is September 20, 2011)

SSF Members & Guests
Non-Members

September 20th and before $65 per person $90 (includes one-year membership)

September 21st and after $85 per person $110 (includes one-year membership)

TOTAL:

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 ☐ AmEx ☐ Discover Card Number _______________________________ Exp. Date ____________
Signature ___________________________________________________________ CC Security Code ____________

A fee of $25 will be charged for all seminar registration cancellations. Refund requests must be made by September 20, 2011. After that date, we are sorry but no refunds will be made.

Dietary Requests: We can accommodate vegetarian or gluten-free dietary requests. If you require a vegetarian or gluten-free meal option, please contact Stephanie Bonner at the SSF office (800-475-6473 ext. 210) by October 6th.

A limited number of rooms are available at the Sheraton Gateway Suites Chicago O’Hare Hotel, 6501 North Mannheim Road, Rosemont, Illinois 60018, at the SSF rate of $99 per night plus tax if reservations are made by September 21, 2011. To make reservations, call the toll-free Central Reservations number at 888-627-8117 (or call the hotel directly at 847-699-6300) and refer to the group name “Sjögren’s Syndrome Foundation” for the discounted rate.

QUESTIONS? Call 301-530-4420 or visit www.sjogrens.org
You can earn a penny for the SSF every time you search on the Internet! GoodSearch.com is a search engine that donates half its revenue to the charities its users designate.

Bookmark www.goodsearch.com as your new search engine and be sure to choose Sjögren’s Syndrome Foundation.