Sjögren's Syndrome Foundation
The Moisture Seekers
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Q&A

Q *I noticed that it takes me longer to get over colds and infections. Is this because of my Sjögren's? Do you recommend Sjögren's patients should get the flu vaccine in 2016?*

A People with Sjögren's often have significant dryness of their upper respiratory tract, and as a result, when infected with a cold virus, are more prone to develop bronchitis, sinusitis, and other respiratory complications related to viral infections. In addition, many patients are taking medications that may decrease their immune response to infection, such as immunosuppressive medications, Imuran, Cellcept, and Prednisone.

I recommend that all people with Sjögren's be vaccinated to protect against the flu each year. Flu vaccines cause antibodies to develop about two weeks after vaccination and these antibodies provide protection against the heat killed viruses that are in most commonly used vaccines. Previous studies of people with autoimmune diseases, including Sjögren's, showed that flu vaccination was effective in preventing the flu about 87% of the time. Newer vaccines that are currently available should even be better.

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An Inside Look at Keeping Your Eyes Healthy

by Melissa Barnett, OD, FAAO, FSLS

Q *My doctor mentioned something about meibomian glands and eyelid cleaning. What does that mean?*

A The meibomian glands are glands in the upper and lower eyelids that produce lipids and proteins. These lipids and proteins help maintain a healthy tear film. They reduce tear film evaporation, contributing to a healthy ocular surface. Meibomian gland dysfunction is the clogging of these glands, which significantly contributes to the chronic, incurable condition dry eye disease. The symptoms of dry eye disease include eye dryness, burning, itching, foreign-body sensation and excessive tearing.

Eyelid hygiene

Several ways to combat dry eye symptoms are to practice eyelid hygiene by using warm compresses on the eyelids and

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This year there are 5 vaccines that should be effective. The standard seasonal flu vaccine is made up with three flu viruses (trivalent): an influenza A (H1N1) virus, an influenza A (H3N2) virus, and an influenza B virus. There is also a quadrivalent flu vaccine with an additional Influenza B component. There are two vaccines that are more recommended for older people (over 65) or people that need a stronger immune response to the vaccine. These include a high dose trivalent flu vaccine that is U.S. Food and Drug Administration (FDA) approved for people over 65 and a trivalent flu vaccine made with an adjuvant (an ingredient that creates a stronger immune response). For people allergic to eggs, there is a recombinant trivalent vaccine that is egg-free. There is also a quadrivalent flu vaccine that contains an attenuated virus grown in cell culture (a virus that is modified to not cause a symptomatic infection) that is approved for people 4 years of age and older. If you are 65 or older, I recommend the high dose trivalent flu vaccine. If you have previously had a flu vaccine but developed the flu that season, your immune response may not have been adequate or the strain of flu virus that infected you may not have been one of the strains in the vaccine you received. You may want to ask for the quadrivalent flu vaccine, or the trivalent flu vaccine with adjuvent.

You may have heard about an inhaled flu vaccine that has previously been used for children and young adults. The Centers for Disease Control (CDC) has recommended that this vaccine not be used this year because the components are not the virus strains that are predicted to circulate. It is important to know that even if the vaccine is not a good match for the circulating flu this coming season, it still may provide some protection.

Over the course of every flu season, the CDC monitors which flu viruses are circulating to evaluate how close a match there has been between the vaccine recommended and the active flu diseases. In the event that you might get the flu there are three FDA approved influenza antiviral drugs recommended by CDC. The brand names for these are Tamiflu® (generic name oseltamivir), Relenza® (generic name zanamivir), and Rapivab® (generic name peramivir). Tamiflu® is available as a pill or liquid, and Relenza® is a powder that is inhaled (Relenza® is not for people with breathing problems like asthma or COPD, for example). Rapivab® is administered intravenously by a health care provider. Relying on these medications rather than getting a flu vaccination is not a good idea. Some studies have shown that if you administer Tamiflu® to patients infected with the flu it may cause nausea and vomiting and exacerbate the dehydration that can result from the fever of the flu. This might actually prolong the illness by causing more debilitation of the patient.

So, with all these choices, what should a patient with Sjögren's do? Most importantly get a flu vaccine because any immunity to the flu virus is going to be better than not getting vaccinated. People with Sjögren's are more at risk for complications from flu infection. Have family and friends

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TO GET DRY EYE ANSWERS,

BE YOUR OWN ADVOCATE

Call your eye doctor and ask to get screened for Chronic Dry Eye disease caused by reduced tear production due to inflammation.

Ask about RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05%.

RESTASIS® is the only prescription treatment for this type of Chronic Dry Eye disease. You can use artificial tears for temporary relief, but they cannot help you make more of your own tears. Only continued use of RESTASIS® twice a day, every day, can help you make more tears. Individual results may vary.

Approved Use

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

Important Safety Information

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

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

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

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

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

Make your eyes your priority—call your optometrist or ophthalmologist, ask to get screened, and see if RESTASIS® is right for you.

- Are you using artificial tears often?
- Could you have a disease called Chronic Dry Eye, caused by reduced tear production due to inflammation?
- Have you called your optometrist or ophthalmologist, asked to get screened, and seen if RESTASIS® is right for you?

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Restasis®

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Make more of your own tears.

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RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05%

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

INDICATION AND USAGE

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

CONTRAINDICATIONS

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

WARNINGS AND PRECAUTIONS

Potential for Eye Injury and Contamination

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

Use with Contact Lenses

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

ADVERSE REACTIONS

Clinical Trials Experience

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

In clinical trials, the most common adverse reaction following the use of **RESTASIS®** was ocular burning (17%).

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

Post-marketing Experience

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

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

USE IN SPECIFIC POPULATIONS

Pregnancy

Teratogenic Effects: Pregnancy Category C

Adverse effects were seen in reproduction studies in rats and rabbits only at dose levels toxic to dams. At toxic doses (rats at 30 mg/kg/day and rabbits at 100 mg/kg/day), cyclosporine oral solution, USP, was embryo- and fetotoxic as indicated by increased pre- and postnatal mortality and reduced fetal weight together with related skeletal retardations. These doses are 5,000 and 32,000 times greater (normalized to body surface area), respectively, than the daily human dose of one drop (approximately 28 mcL) of 0.05% **RESTASIS®** twice daily into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed. No evidence of embryofetal toxicity was observed in rats or rabbits receiving cyclosporine at oral doses up to 17 mg/kg/day or 30 mg/kg/day, respectively, during organogenesis. These doses in rats and rabbits are approximately 3,000 and 10,000 times greater (normalized to body surface area), respectively, than the daily human dose.

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

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

Nursing Mothers

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

Pediatric Use

The safety and efficacy of **RESTASIS®** ophthalmic emulsion have not been established in pediatric patients below the age of 16.

Geriatric Use

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

NONCLINICAL TOXICOLOGY

Carcinogenesis, Mutagenesis, Impairment of Fertility

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

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

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

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

PATIENT COUNSELING INFORMATION

Handling the Container

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

Use with Contact Lenses

RESTASIS® should not be administered while wearing contact lenses. Patients with decreased tear production typically should not wear contact lenses. Advise patients that if contact lenses are worn, they should be removed prior to the administration of the emulsion. Lenses may be reinserted 15 minutes following administration of **RESTASIS®** ophthalmic emulsion.

Administration

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

Rx Only

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 Please allow 8 weeks for delivery of your rebate check. APC84HR14 Certificate expires 12/31/2015

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eyelid scrubs to keep the glands open. Warm compresses, with either warm cloths or a variety of commercial products, provide heat, which loosens plugged meibomian glands in the eyelids. Apply warm compresses to closed eyelids for 10 minutes daily. In addition, commercial product use ranges from five to 10 minutes daily. Afterward, gently move a cotton swab across the eyelid margins five to 10 times. This gentle scrubbing removes all debris that may be blocking the meibomian glands.

Eyelid hygiene products are used to kill any microorganisms and bacteria and prevent biofilm formation in addition to clearing potentially clogged meibomian glands. I have my patients use the product each night prior to bed, making it part of their bedtime routine. Similar to dental hygiene, think of it as flossing for your eyelids. You don't have to clean your meibomian glands, just the ones you want to keep.

Q *Do you have any recommendations for makeup? How should I remove makeup at night?*

A Many of my patients like to wear makeup, especially around the eyes and are concerned about the type of makeup to purchase and how to remove makeup. In a study published in 2015 from the Univeristy of Waterloo, people who apply eyeliner on the inner eyelid run the risk of contaminating the eye and causing vision problems. The researchers noticed that the makeup migration happened quicker and was greater when eyeliner was put on the inner lid margin. Within five minutes, more particles (15-30%) moved into the eye's tear film when subjects applied eyeliner to the inside of the lash line, compared to outside the lash line. The makeup also moved more quickly into the eye when eyeliner was applied inside the lash line.

Makeup in the tear film may cause discomfort for those with sensitive or dry eyes due to waxes and oils in the eyeliner. It is also important for people who wear contact lens to apply eyeliner on the outside, not inside of the eyelid margin. It is also important to apply makeup after contact lens insertion.

For my patients who wear makeup, I recommend the nightly removal of eye makeup via safe, commercially available products. Removing eye makeup accelerates clean eyelids in order to create a healthy tear film. Apply the product to a cotton pad or use pre-moistened pads, I recommend gently rubbing them back and forth along the eyelids for five and 10 times.

**Please refer to the SSF Product Directory for suggested eyelid hygiene products*

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

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

What to do:

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

Q *My eyes are always dry. Do you have any other recommendations?*

A Treatments for dry eyes include over the counter artificial tears, punctal plugs (small plastic pieces that close the ducts that drain tears out of the eyes), eyelid hygiene, dietary supplementation, such as omega-3 supplementation, specifically containing GLA (gamma linolenic

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get flu vaccination too, because the fewer people with the flu that you are exposed to, the less chance you have of being infected with the flu. Flu vaccination should take place as soon as the vaccines are available, but they may be offered throughout the flu season. Most seasonal influenza outbreaks can happen as early as October with peaks of activity into the winter months.

Your primary care physician office, other physician offices, local health departments, pharmacies, and some businesses offer flu vaccination. As a rheumatologist, I recommend and offer flu vaccination for ALL of my patients.

by Dan Small, MD, Rheumatologist, Sarasota, FL

Q How do I know if my joint pain is associated with my Sjögren's or my rheumatoid arthritis?

A Sjögren's and rheumatoid arthritis (RA) are both associated with joint symptoms. Patients with rheumatoid arthritis commonly experience painful and swollen joints. The hands, feet, knees, elbows, and shoulders are often affected. Early diagnosis and treatment of RA can help prevent damage, deformity and disability. Sjögren's patients may also have joint symptoms but are more likely to describe achiness and are less likely to experience joint swelling. The joints that are involved with Sjögren's can be similar to that of RA, so when swelling exists, it may be difficult to distinguish the arthritis of Sjögren's from the arthritis of RA. In addition, it is not uncommon for patients with Sjögren's to have a positive Rheumatoid Factor in the blood, which is an antibody that is often found in RA. On the other hand, the presence of an Anti CCP antibody is characteristically diagnostic of RA, especially when found at high levels and can help distinguish whether or not the arthritis is due to Sjögren's or RA. In addition, the arthritis of Sjögren's is typically not associated with joint deformity or damage. As a result, if there is evidence of joint damage on examination, or on radiographs (x-ray) the cause is typically from RA and not Sjögren's.

Treatment of the joint symptoms may include an anti-inflammatory diet, natural anti-inflammatories such as tart cherries or Tumeric, analgesics such as Tylenol or anti-inflammatories such as over the counter or prescription strength NSAIDS (ibuprofen, naproxen), low dose corticosteroids (eg, prednisone) or DMARDs (disease modifying drugs such as Plaquenil, Methotrexate or Arava) and in some cases off label use of biological DMARDs such as TNF blockers or Orencia.

Finally, there can be an association between gluten sensitivity and Sjögren's. Some patients may find that they can get relief of their joint symptoms by avoiding gluten and this benefit may become apparent as soon as one week after the diet change.

by Scott Zashin MD, Rheumatologist, Dallas, TX

Q What type of birth control would you recommend for Sjögren's patient?

A Unfortunately, there are fewer specific recommendations for contraceptive options for women with Sjögren's than for those with other autoimmune conditions. Therefore, coexisting conditions need to be considered to guide choices of contraception. For women with or systemic lupus erythematosus (SLE) and positive antiphospholipid antibodies increasing the risk of clotting (deep venous thrombosis or pulmonary embolism), combined hormonal contraception including pills, patches and ring are contraindicated. Best options for these women are non-hormonal intrauterine contraception (copper IUD), barrier contraception or sterilization. Progestin only contraception may be used with caution in some patients.

For women who take immunosuppressive therapy for either Sjögren's or coexisting autoimmune conditions, the insertion of intrauterine contraception of either hormonal or non-hormonal type carries a small temporary risk of intrauterine infection and may warrant preventive antibiotic at insertion. The benefits of all other methods including combined hormonal contraception and progestin only contraception generally outweigh the risks.

For women with low platelet counts (thrombocytopenia), the initiation of copper IUD and contraceptive injection are relatively contraindicated due to risk of bleeding, whereas their benefits outweigh their risk with continued use. The latter is true for initial and continued use of all other contraceptive options in this group of women.

Given that some hormonal contraceptives worsen vaginal dryness, women experiencing Sjögren's related dryness or that associated with perimenopause, may need additional lubricants or vaginal moisturizers. Topical estrogen in the form of vaginal inserts or cream may also be prescribed.

Of note, there is no contraindication to the use of emergency contraception (morning after pill) in women with Sjögren's. Both over the counter and prescription pills are available for use up to 3 and 5 days post unprotected sex respectively, along with the insertion of a copper IUD up to 5 days post unprotected sex. The latter can be then used for ongoing contraception for up to 10

years and is the most effective emergency contraception method for women with higher Body Mass Index.

A woman with Sjögren's with or without coexisting diagnoses should seek individual recommendations from a health care provider taking into account the length of time, relative efficacy and convenience of each method, and what will work best for her individual needs and reproductive plans. She may need additional testing to determine risk of clotting and bleeding, and in some cases to determine menopausal status. All this information will help inform her ultimate contraceptive choice.

by Petra M. Casey, MD, Associate Professor OBGYN, Mayo Clinic Rochester, MN

Q What is Methotrexate and what is its benefit for a Sjögren's patient?

A Methotrexate is an extremely important therapy for Sjögren's and many other rheumatic and inflammatory diseases. Its predecessor, aminopterin was introduced in 1948 as a cancer treatment. By the early 1950's small studies of aminopterin in patients with rheumatoid arthritis (RA), psoriasis and psoriatic arthritis demonstrated efficacy but the drug was slow to capture the interest of rheumatologists, perhaps because of the landmark discovery of cortisone, also in 1948, one of the first "miracle drugs."

In 1962 methotrexate, a modified version of aminopterin, was introduced. Both inhibited the enzyme folic acid reductase, but methotrexate was easier to produce, making it easier to meet the growing demand for its use in cancer treatment. Small, successful clinical trials of methotrexate for RA, psoriasis and psoriatic arthritis followed its introduction and the case for its use in these disorders slowly built. By the 1970's methotrexate had become a mainstay in treatment of severe psoriasis and psoriatic arthritis treatment, and then in the 1980's it was adopted as standard management for RA after large-scale clinical trials demonstrated compelling efficacy and reasonably good safety.

Comprehensive guidelines for treatment of Sjögren's were recently published in Arthritis Care and Research. Methotrexate is prominently featured in these guidelines for the management of inflammatory musculoskeletal pain in Sjögren's patients. It should be noted that the arthritis in Sjögren's may be indistinguishable from that of RA and in some patients the overlap of these two disorders is considerable. Patients whose arthritis is poorly controlled with non-steroidal anti-inflammatory drugs (NSAIDs), low doses of steroids and Plaquenil (hydroxychloroquine) are often managed with methotrexate.

Methotrexate is usually taken just once a week in tablet form. Some patients take it as a weekly injection. The dose is usually steadily increased during the first two or three months of treatment until a maintenance dose is reached. Patients notice a gradual and meaningful reduction of joint swelling, pain and stiffness as the drug takes hold. Improvement may be noticed as early as 6 weeks; the full effect tends to be appreciated at three months. Systemic complaints such as fatigue, weakness and anemia may all improve on treatment.

Side effects of methotrexate are varied. It is a drug that must be monitored closely by a patient's physician. Common complaints consist of mouth sores, stomach upset, loss of appetite, fatigue or headache. Some patients notice mild hair loss, more of a thinning, usually more noticeable to the patient than to friends or family. Some patients develop a cough or low grade fever. Rarely, a pneumonia-like syndrome can complicate treatment.

Methotrexate can be irritating to the liver. Patients taking methotrexate should avoid drinking alcohol and need to have liver function tests performed by their physician on a regular basis. The bone marrow can be suppressed by methotrexate and blood counts need to be checked regularly as well. Use of the B vitamin folic acid is recommended for all patients taking methotrexate to reduce the risk of side effects.

Patients on methotrexate need to stay in close communication with their physician and should promptly inform their doctor about a cough, fever, mouth sores or loss of appetite.

Despite all of the concerns about side effects from methotrexate, this drug has been quite well tolerated by most patients. Most importantly, methotrexate is a very effective and life-altering therapy for many patients.

by Herbert S. B. Baraf, MD, FACP, MACR
Clinical Professor of Medicine, George Washington University

Q I've recently started experiencing frequent bladder infections, could this be associated with my Sjögren's?

A Sjögren's is an autoimmune disease that causes dryness in the body, including the vaginal area. Vaginal dryness may result in discomfort during sexual intercourse and an increase in the risk of bacterial and fungal vaginal infections. Painful urination, a common symptom of urinary tract infections (UTIs), also can occur with vaginal infections.

If you find that you are experiencing symptoms similar to those of a urinary tract infection — urinary frequency, urgency and pain — make sure that you ask

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acid to reduce inflammation), nighttime moisture goggles, daytime moisture release eyewear, or prescription eye drops such as Restasis (cyclosporine 0.05%) and recently FDA approved Xiidra (lifitegrast 5%).

Nighttime moisture goggles are advantageous to shelter eyes from drafts during sleep while keeping moisture in. Some types also include inserts that are moistened foam sponges for extra hydration. Daytime moisture release eyewear provide a custom seal to keep moist heat in which in turn increases relative humidity, providing a more stable and consistent tear film.

When speaking to my patients, I also recommend additional lifestyle modifications in order to reduce dry eye symptoms. These include redirecting the air vent in the car to aim at the feet instead of the eyes. Avoid using overhead ceiling fans, which dry out the eyes. Instead, add a humidifier, especially in the bedroom at night. Some of my patients benefit from using a humidifier during the day as well.

There are many oral medications that are drying to the ocular surface. When the systemic version needs to be taken, I recommend increasing hydration and topical eye drop use. Other times an oral product such as an oral antihistamine can be substituted with a topical and/or nasal formulation instead to prevent drying of the ocular surface.

If you suspect that your eyes may be dry, schedule an appointment with your eye doctor for evaluation, management and additional recommendations.

**For more information, please refer to the recently published SSF Clinical Practice Guidelines for Ocular Management in Sjögren's*

References

Ng A, Evans K, North RV, *et al*. Migration of Cosmetic Products into the Tear Film. *Eye Contact Lens* 2015 Sept;41(5):304-9.

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your doctor for a full urine culture. These urinary symptoms in the absence of bacteria, could point to Interstitial Cystitis (IC) and should be further investigated with the help of an urologist.

Research about the overlap of IC and Sjögren's is limited, however, case reports are beginning to pop up in the clinical literature. And, the Social Security Administration lists Sjögren's in the Social Security Disability Insurance guidelines and highlights IC as one of many overlapping conditions experienced by people with Sjögren's.

Although a universal cause for IC (such as a biomarker) has not been found, postulated causes include reoccurring bladder infections, pelvic dysfunction, and it being an autoimmune condition.

by Jennifer Zuzelski, Program Manager/Information Specialist, Interstitial Cystitis Association

Ask the Staff

Q *Should I subscribe to the Sjögren's Quarterly?*

A The *Sjögren's Quarterly* (SQ) is a medical and scientific newsletter that the Sjögren's Syndrome Foundation produces and distributes to thousands of healthcare providers in the fields of rheumatology, ophthalmology, optometry, dentistry as well as scientific researchers. The SQ is written and edited by the foremost experts in Sjögren's, and it helps keep medical professionals informed on the most cutting-edge advancements in Sjögren's so that they can provide all Sjögren's patients with better care.

The SQ explores scientific and clinical innovations in every issue. In addition, scientific, clinical, regulatory and advocacy news stories are featured frequently. In the SQ, you can read updates about the scientific progress and career highlights of researchers who have received SSF Research Grants. Also, all of our Patient Education Sheets are originally debuted in the SQ. Because the SQ is written for medical professionals about clinical and scientific advancements in Sjögren's, the language will be more technical in nature but you will be able to understand most articles.

Sharing articles from the SQ or discussing topics about what you've read with your doctor can help you to become the most informed patient that you can be and in turn your own best patient advocate. I would definitely recommend that members subscribe to the SQ.

by Sarah Martin, MS, PhD, SSF Director of Advocacy and Scientific Affairs

Stay informed. Stay aware.

Be your own best medical advocate!

To increase professional awareness about Sjögren's, the SSF has launched *Sjögren's Quarterly* — a professional resource geared toward medical and dental professionals, clinicians, researchers, and anyone interested in the latest in Sjögren's research findings and treatments.

Although the content is primarily written for a professional audience, *Sjögren's Quarterly* is not just for doctors and researchers. Patients may benefit from the information, too.

If you are interested in subscribing to *Sjögren's Quarterly*, we are offering a special introductory rate of just $20 for SSF members. Take charge of your healthcare by keeping on top of all the best medical information available.

Subscribe to *Sjögren's Quarterly* today, and you might just teach your doctor a thing or two about Sjögren's.

	Non-Member Price	Member Price	Qty	Amount
A one-year subscription to The Sjögren's Quarterly	$50.00	$20.00		
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Sjögren's Syndrome Foundation

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You Stood Up!

Wake Up, Koala! is Now Available!

As you may remember from past issues of *The Moisture Seekers*, undergraduate students in the game design program at Bradley University worked with the Sjögren's Foundation to create Wake Up, Koala! as part of a yearlong class project.

Wake Up, Koala! is a puzzle game/App that's not only fun to play but also promotes Sjögren's awareness! The students wanted to feature Sjögren's within the game in honor of their professor, Monica McGill, whose daughter was diagnosed with the disease.

The game features a very sleepy Mama Koala who really needs to wake up. Help splash water drops on the sleepy Koala to wake her up, but the tricky part is how you get the water drops to her!

The Foundation would like to thank all of the students from Bradley University's Game Design Program as well as Professor Monica McGill for their commitment to creating this App and a new medium to raise Sjögren's awareness!

Wake Up, Koala! is now available for iOS and Android devices. To learn more and download the game, please visit wakeupkoala.com or koala.sjogrens.org.

2016 SSF Event Fall Calendar

OCTOBER

Sunday, October 23, 2016
Northern Virginia Sip for Sjögren's, Frying Pan Farm Park, Herndon, VA

NOVEMBER

Saturday, November 12, 2016
Houston Sjögren's Walkabout, Andrea & Bill White Promenade at Discovery Green, Houston, TX

Thursday, November 24, 2016
Team Sjögren's Goes Turkey

If there is already an event in your area and you would like to get involved, or learn about starting one, please visit www.sjogrens.org or contact us at (301) 530-4420 x207

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The SSF Partners with Yankee Candle

40%

of your purchase will be donated to the Sjögren's Syndrome Foundation

The Sjögren's Syndrome Foundation is partnering with Yankee Candle to kick-start your holiday shopping!

From November 1st through December 1st, you can purchase through the SSF website and 40% of your order will be donated back to the Foundation! Stock up on premium products from the world's #1 candle brand knowing that your purchase is helping the Foundation's life-changing initiatives.

Yankee Candle products are perfect for the upcoming fall holidays and special occasions: Thanksgiving, Christmas, birthdays, anniversaries, housewarming gifts, and teacher/coach gifts. Your purchase will be shipped directly to you.

Make sure to share the link with friends and family, because together we will transform the future of Sjögren's! Look for the link on www.sjogrens.org or email us at info@sjogrens.org to support the SSF today and start shopping for Sjögren's. If you have any questions, please contact the SSF at (301) 530-4420 or email Bess at batkinson@sjogrens.org.

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Steven Taylor, SSF CEO, represented the SSF at the BIO International Conference in San Diego, CA

SSF in Action!

Accelerating Research Around the Country

BIO International Convention

Steven Taylor, SSF CEO, represented the Foundation at the BIO International Conference in San Diego, CA. BIO brings together over 15,000 biotechnology and pharmaceutical leaders for intensive networking and to build partnerships in the fields of drug discovery, genomics, cell therapy and more.

Partners in Rheumatology Leadership Summit

Steven Taylor, SSF CEO, and Sarah Martin, MS, PhD, SSF Director of Advocacy and Scientific Affairs, joined representatives from the American College of Rheumatology, Association for Rheumatology Health Professionals, Alliance for Lupus Research, Arthritis Foundation, Scleroderma Foundation, National Psoriasis Foundation, the National Institutes of Health and others for the Partners in Rheumatology Leadership Summit in Atlanta, GA. The rheumatology community came together at the summit to collaborate and share information on how to optimize rheumatology research.

in memoriam

In Memory of Anastasia "Bonnie" Goldsmith
Rosalind Cozanitis

In Memory of Angelina DiFilippi
The Palladino Family
Maura Dalferro
Dr. Nicole Petzolt
April and Vazquez Family

In Memory of Catherine (Cass) Clarke
Jeanine, Diane and Marilyn Balsis
Ramona and Bob Hageman
Mark, Christina, Brittanie and Torrie Stellern
Rich and Jean Rittermann
Barbara Yamnicky

In Memory of Dorothy Huang
Kathi DeClerk and Dot's Wu Family
Paul and Barbara Petcan
Amy Gilrein

In Memory of Edna Rask Erickson
Jolana and Paul Bernhardt

In Memory of Georgianna Littlefield
Dan and Kathy Sullivan

In Memory of Geraldine Royse
Pamela K. Gibson

In Memory of Helen McManus
Charles L. McManus

In Memory of Helene Larkin
Eileen and Steve Garger

In Memory of Herb Harris
San Diego and Imperial Counties Chapter

In Memory of Hildegarde E. Clausen
Linden and Joy Clausen

In Memory of James Church
Lynn Espinoza

In Memory of Jana Corzine Atkins
Derek Corzine

In Memory of Janie Utzig Beerman
Pat Hackl (OLV Class of '62)

In Memory of Jean (Hansen) Murphy Gifford
Lesley Ochlis
Tina Proffitt

In Memory of Jeffrey M. Skinner
Bobette Morgan

In Memory of Jennifer Fariss
Ed Fariss

In Memory of Jean Gifford
Joseph P. Phelan III

In Memory of Judy Garland
Robert Telford Willis and Family

In Memory of Kum Hwa
Jim Ashburn

In Memory of Linda Zerby
Community Church of Pine Run

In Memory of Lorraine Chapman
Dohn and Clarice Kruschwitz

In Memory of Louise T. Parker
Louise P. Ten Eyck

In Memory of Mamie Lou McMillion
Clint, Andi, Phillip, Nicholas, BenjamIn and Leah Alday
Jack and Karen McMillion

In Memory of Mary Cornelissen
Amy Mackay and Noah
Rex and Barb Lenegir
John Francis and Connor Clayton

In Memory of Patricia E. Frisone
Carol Seibert

In Memory of Roberta Willis
Robert Telford Willis and Family

In Memory of Sylvia Jaffe
Laura, Liisa, and Linda Margosian
Phyllis Medoff
Sandra and Harold Miller-Jacobs

In Memory of Vermell M. Johnson Kelly
Susan Massey

in honor

In Honor of Abby Swanson
Juliette and Andreas

In Honor of Dr. Kashani
Marjan Nourai DDS

In Honor of Eileen Guldin
Christina Lea

In Honor of Julie Reeve
Nancy Ragonese
Julie Worrill

In Honor of Lauren Teukolsky
Roselyn Teukolsky

In Honor of Nancy Crabbe
Jane Mauldin
Dee and Carolyn

In Honor of Tim Lis
Heather and Ian Lis

In Honor of Gene Stuckey
Linda Stuckey

"Simplify your holiday shopping by using these links and having your gift delivered directly to you, while also supporting the SSF!"

Shop to benefit the Sjögren's Syndrome Foundation

The Sjögren's Syndrome Foundation has partnered with online retailers who will donate a portion of your purchase to the SSF, so shopping online is now an easy way to contribute to Sjögren's!

Just visit **www.sjogrens.org/shopforsjogrens** and click through the links provided so that your purchases will benefit the SSF. Some of our partners include:

- **Amazon.com** and **AmazonSmile** are two of the most popular online stores in the world, offering a wide variety of products.
- **Drugstore.com** is a leading online provider of health, beauty, vision, and pharmacy products. The website allows you to shop as if you were at your local drug store, and you can get instant savings while 8% of your purchase benefits the SSF.
- **iGive.com** offers exclusive deals with over 700 brand name stores you know and love, with a specified percentage of each purchase coming back to the SSF. Be sure to select "Sjögren's Syndrome Foundation" as your charity of choice. Whenever you return to iGive.com and log in, any shopping you do will benefit the SSF! It's that simple.

Save The Date

2017 NATIONAL PATIENT CONFERENCE

This spring we invite you to join with fellow Sjögren's patients, their families, medical experts, and product exhibitors and attend our 2017 National Patient Conference at the Crowne Plaza Philadelphia/Cherry Hill hotel.

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

This year's Conference will include opportunities to:

- Learn from national Sjögren's experts, researchers and SSF staff
- Find new products and receive free samples in our exhibitor hall
- Share with your fellow patients
- Browse Sjögren's resources at the SSF Book Table

We encourage you to take this opportunity to gain an understanding of all the key aspects of Sjögren's. This two-day educational experience will give you the tools to take control of your health and learn how to manage and understand your Sjögren's symptoms and complications.

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

2017
National Patient Conference
March 31 – April 1
Crowne Plaza
Philadelphia/Cherry Hill
2349 West Marlton Pike
Cherry Hill, New Jersey

Presentation topics will include:

- Sjögren's Overview
- Pulmonary Issues and Sjögren's
- Oral Manifestations of Sjögren's
- Pediatric Sjögren's
- Ocular Manifestations of Sjögren's
- Men with Sjögren's
- Social Security Disability for Sjögren's
- And More To Be Announced!

The Moisture Seekers
Sjögren's Syndrome Foundation Inc.
6707 Democracy Blvd., Ste 325
Bethesda, MD 20817
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If you would like to receive this newsletter but are not currently an SSF Member, please contact us! 800-475-6473

A Single Kit Includes: $30

- SSF Awareness Bracelet
- Team Sjögren's T-shirt, with Turkey Trot logo on the front!
- Certificate of Participation
- "What is Sjögren's?" Brochure
- SSF Reusable Shopping Bag

A Two-Person Kit Includes: $55

- 2 SSF Awareness Bracelets
- 2 Team Sjögren's T-shirts, with Turkey Trot logo on the front!
- 2 Certificates of Participation
- 2 "What is Sjögren's?" Brochures
- 2 SSF Reusable Shopping Bags
- 1 SSF Picnic/ Stadium Blanket

		Qty.	Size: S-2XL	Total
Single Team Sjögren's Turkey Trot Kit	$30 ea.			
Two-Person Team Sjögren's Turkey Trot Kit	$55 ea.			
Maryland Residents add 6% sales tax				
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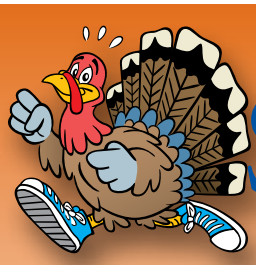

Team Sjögren's

Team Sjögren's Goes Turkey!

This Thanksgiving, we hope you will consider participating in your community Turkey Trot as a member of Team Sjögren's!

What a great way to start your day of giving thanks – by purchasing a Team Sjögren's Turkey Trot Kit and walking or running with others in your area, increasing awareness for Sjögren's and helping raise crucial funds for Sjögren's research.

We hope you consider creating your own Turkey Trot by asking family and friends to join you for a morning walk on Thanksgiving in your neighborhood while wearing your Team Sjögren's T-shirts! You can also find a local Turkey Trot by visiting www.active.com or in your local newspaper.

Order your Team Sjögren's Turkey TrotKit by calling 800-475-6473 or online at www.sjogrens.org. Additional T-shirts can be added to a Kit by calling the SSF office.