What can I expect from Sjögren’s in the future? Will the symptoms worsen with time?

In general, most Sjögren’s syndrome patients lead full and healthy lives. Although Sjögren’s is a chronic, systemic autoimmune disorder, in most cases symptoms are physically annoying but not serious. This is not to minimize the impact of the condition but to recognize that it is most often life-altering, not life-threatening.

Most Sjögren’s patients, although typically long-term, remain active and generally have a normal life span. In terms of life-threatening complications, Sjögren’s is rarer than other autoimmune diseases such as lupus and rheumatoid arthritis. However, the risk of lymphoma is higher among Sjögren’s patients than in the general population.

Virtually all patients have sicca symptoms (dry eyes, dry mouth and sometimes vaginal dryness, dry skin and dry cough) and many have fatigue. A minority of patients develop extra-glandular (non-sicca) symptoms or associated disorders which can involve the respiratory tract, gastrointestinal tract, kidneys, skin or neurological system. In most cases these are not dangerous although others, such as glomerulonephritis and certain neurological problems (severe peripheral neuropathy and, more rarely, severe central nervous system involvement), can be serious and require aggressive treatment. The extra-glandular manifestation that we are most concerned with is the occurrence of lymphoma. Although only a small percentage of Sjögren’s patients develop this complication, it occurs much more often than in the general population. All patients with Sjögren’s syndrome need to be observed carefully for any signs and symptoms of lymphoma. These include swollen lymph nodes or salivary glands, unexplained fever or weight loss and the development of hypogammaglobulinemia (low immunoglobulin levels) as Sjögren’s patients usually have hypergammaglobulinemia (high immunoglobulin levels).

Fortunately, researchers have recognized certain findings which are associated with an increased risk of developing lymphoma in Sjögren’s
syndrome, so these patients can be identified and monitored regularly.

The course of Sjögren’s syndrome is variable and unpredictable. There are few long-term studies, but those that exist suggest that often the disorder does not worsen markedly over time. However, every patient is unique. Some patients have stable symptoms, some improve and some worsen despite treatment, which at this time is, for the most part, symptomatic and not curative or disease-modifying. Research is being conducted looking at treatments for Sjögren’s syndrome that will be disease-modifying, and there is a great deal of hope that new and better treatments will be available in the near future. There is much that patients can do now to minimize the impact of Sjögren’s syndrome. The Sjögren’s Syndrome Foundation provides many tips on its website and much more detail can be found in the latest (fourth) edition of The Sjögren’s Book, available through the Foundation.

Neil I. Stahl, MD, FACR
Philip C. Fox, DDS

Lupus patients are told to avoid the sun. Lupus and Sjögren’s are similar. Should Sjögren’s patients also avoid the sun?

Although Sjögren’s and SLE may coexist and/or have some overlapping features, Sjögren’s patients as such need not avoid the sun as SLE patients are sometimes advised. In SLE, sun sensitivity is quite common and may precipitate a flare in the underlying disease. In Sjögren’s patients, sun sensitivity may occur independent of the disease process in the setting of a drug-related phenomenon or may occur when SLE patients have secondary Sjögren’s and the sun sensitivity is related to the primary disease process. In general, other than the above, Sjögren’s patients need not avoid the sun as a general rule.

In SLE patients, the cause of sun sensitivity is that, when exposed to UV A and UVB wavelengths of light, patients experience cell death of skin cells and the altered appearance of the cells may contribute to the inflammatory process seen in SLE patients after sun exposure. This again is not the case with Sjögren’s patients as such.

Stuart S. Kassan, MD, FACP

What is the truth about antibody levels and disease activity? I originally was told that there was not a correlation, but so many people have been told differently. Would you expect to see higher/increasing SSA/SSB antibodies with more disease activity and lower/decreasing levels with less activity or not necessarily?

"Q&A" continued from page 1 ▼

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In a patient who has Sjögren’s syndrome with SSA (Ro) and/or SSB (La) antibodies, the levels of these antibodies do not correlate with disease activity. In fact, these levels remain fairly constant in a given patient.

The presence or absence of SSA/SSB antibodies serves to define “seropositive” versus “seronegative” Sjögren’s syndrome. Seropositive Sjögren’s syndrome accounts for approximately 60-80% of all those affected. Many inflammatory manifestations in various organ systems (such as those involving the lungs, kidneys, skin, and blood) are more prevalent in those with seropositive Sjögren’s syndrome. Such manifestations are often included in physician assessments of “disease activity.” However, key symptoms of Sjögren’s syndrome which impair the quality of life, including fatigue, joint pain, and dryness of the eyes, mouth, skin and vagina, do not have an association with SSA/SSB antibodies and occur equally in both forms.

Finally, low levels of SSA/SSB antibodies have to be interpreted cautiously, since they may represent a false-positive test and, therefore, lead to an erroneous diagnosis of Sjögren’s syndrome. As a general rule, higher levels of these antibodies are better predictors of an underlying autoimmune disease (such as Sjögren’s syndrome or systemic lupus).

Alan Baer, MD

Fatigue seems to be a common symptom for many Sjögren’s patients and greatly affects our quality of life (QOL). Is there any research on fatigue? What treatment(s) do you suggest?

Fatigue is a major problem in most rheumatic disorders. Research on fatigue in Sjögren’s has consistently demonstrated strong links between fatigue, pain and depression. Fatigue and pain are strongly associated, but not everyone who is tired is in pain and, likewise, while depression is “always” associated with high levels of fatigue, most Sjögren’s patients with persistent fatigue are not severely depressed. Fatigue that is not attributable to some readily identifiable physical ailment seems to be the most prevalent problem, but in Sjögren’s, just as in other chronic illnesses in which fatigue plays a major role, pain and symptoms of mild depression seem to “cluster” together with fatigue. So the prevalence of fatigue may have more to do with the “stress” of dealing with a chronic illness as opposed to the specific underlying autoimmune condition. If you are feeling stressed out, chances are that fatigue is a major problem as well. In fact, comparative studies invariably show that the worst fatigue is experienced by people with primary fibromyalgia, a disorder characterized by poor sleep, fatigue, widespread pain and very high levels of stress without any associated inflammatory or autoimmune problem.

Fatigue is often the first sign of an acute infectious illness. The reason that fatigue so often persists in the absence of an acute inflammatory process is becoming less of a mystery. One or the other can predominate, but often physical and mental fatigue occur together. While more work needs to be done, research that included detailed cognitive tests has made it possible to break up the “brain fog” into components that reflect the activity of different neural pathways and brain regions. So, for example, the anterior cingulate gyrus part of the brain where emotional responses to pain are being processed, has a strong neural connection to brain regions involved in attention. In other words, our “brains are wired” to pay attention to pain and when we are busy ruminating on pain and the potential negative consequences of having pain, we “can’t” perform very well on tasks requiring concentration. In the future, novel quantitative imaging that reveals brain microstructure and functional imaging techniques that are used to examine brain processes in real time will reveal even more about the central causes of fatigue.

Recommended Dos and Don’ts:

Do learn to recognize those signs that your stress level is getting out of control and ask for professional help. Counseling and educational interventions designed to help people learn to manage their stress can be very helpful. Find the stress reducers that work best for you.

Do exercise regularly. Low-impact aerobic exercise (such as walking) three times a week with a gradually increased intensity can improve physical fitness, reduce depression and help to reduce physical fatigue.

Do discuss treatments for irritability, low mood and anxiety with your physician.

Don’t take mood-altering or any herbal or natural products without discussing the pros and cons with your physician.

Don’t rely on traditional sleeping pills or sedatives for correction of insomnia. Traditional hypnotic agents, while helpful in initiating and maintaining sleep, do not provide restorative sleep or reduce pain. Consider requesting referral to a sleep center if you are chronically not getting a good night’s rest.

Barbara M. Segal, MD

Q Since my main issue is an extra-glandular problem (nerve pain), does this mean that I am more likely to develop other organ manifestations or lymphoma?

A There are different types of peripheral neuropathy in Sjögren’s syndrome. Some correlate strongly with the presence of other organ manifestations and the risk of lymphoma. Fortunately, these types of neuropathy are rare. A continued page 4 ▼
prominent example is vasculitic neuropathy, in which there is a lack of blood supply to larger nerves. In contrast, the most common type affects small sensory nerve fibers, causes burning pain, and does not correlate with the presence of other organ manifestations or an increased risk of lymphoma.

Alan Baer, MD

Cognitive function seems to be a concern for many individuals with Sjögren’s? Are we just a few steps away from Alzheimer’s disease?

A In a word, no. Admittedly, research regarding the long-term neurocognitive sequelae of Central Nervous Sjögren’s Syndrome (SS) is in its infancy and lags behind research regarding diagnosis and treatment of the physical symptoms. Research generally shows that the most common symptoms of cognitive impairment include poor attention and concentration, memory deficits and slowed processing speed, although a more recent study showed no cognitive impairments in visual processing speed, verbal working memory, delayed memory and immediate memory in a group of SS patients (Mataro et al., 2003; Norman, Maitz, Mandel, & Murphy-Eberenz, 2012). Other less common symptoms include impairment in abstract reasoning, response-inhibition, set-shifting abilities, general intellectual functioning, and impaired visuospatial skills. (Johnstone, Pepmueller, Vieth, and Komatireddy, 1996; Lafitte et al., 2001).

The severity of cognitive and neuropsychological impairments reported in patients with SS ranges from mild to severe, consistent with a recent study in which 72.8% of the subjects exhibited neuropsychological impairment, ranging from mild to moderate (Norman et. al, 2012). However, reported severity of symptoms between studies is inconsistent (Mataro et al., 2003). Most studies used small sample sizes, and have not examined factors that could impact one’s cognitive or neuropsychological deficits, such as pre-morbid education level, psychological distress and duration of illness. Moreover, when evident, the course of cognitive decline is unclear. In our practice, we have found that the patient’s cognitive functioning appears to improve if the illness is effectively treated.

Additionally, many individuals with SS present with co-morbid psychiatric conditions, including anxiety or depression (Cox & Hales, 1999). Between 33-75% of individuals with Primary SS experience depressive symptoms (Cox & Hales, 1999). Prior research suggested a correlation between cognitive impairment and depression effect (Murphy, Michael, Robbins, & Sahakian, 2003). However, it is unclear if anxiety and depression cause cognitive deficits or if cognitive deficits cause anxiety and depression.

Presently, there is no clear evidence to indicate that SS results in Alzheimer’s disease or any progressive non-reversible dementing illness. That said, our knowledge regarding the long-term neurocognitive implications of SS is very limited; there are no longitudinal studies that provide serial neuropsychological testing for patients with Sjögren’s syndrome or examination of the correlation with the overall course of the illness.

It is critical that physicians who treat patients with SS ask about any perceived changes in cognitive functioning, as these can result in impaired work or school performance and also can lead to significant secondary psychological problems (anxiety, depression, and decreased sense of self-confidence and self-esteem). In addition, friends and family members may become frustrated by the person’s inability to remember information, which can result in withdrawal and social isolation.

Overall, if a patient does complain of cognitive impairment, we recommend a consultation with a neurologist and a neuropsychologist for a formal evaluation of the patient’s overall neurologic and neurocognitive functioning. Very often the cognitive deficits can be treated with medication and cognitive rehabilitation therapy.

Jessica Norman, MS, MA
Edward A. Maitz, PhD
Steven Mandel, MD

Should alcohol be avoided with Sjögren’s? Could it make one’s symptoms worse?

A In general, alcohol in small quantities will not be a problem for a person with Sjögren’s syndrome except for certain situations:

Many of our Sjögren’s patients have motility disturbances that result in gastroesophageal reflux symptoms; these symptoms may be worsened by alcohol.

In patients with balance and/or memory problems, alcohol ingestion will worsen these symptoms short term, and may exacerbate progressive deterioration.

Alcohol is a central nervous system depressant, so it could lower the seizure threshold in someone with a history of seizures.

Alcohol should be avoided if your physician has prescribed: Methotrexate and/or leflunomide (Arava); alcohol could increase the chance of liver fibrosis or inflammation that rarely occurs with these medications.

Medications that can affect the central nervous system: Anxiolytic agents (valium, xanax, ativan, librium, etc.), sleeping pills (sonata, ambien, restoril, etc.), and antidepressants (prozac, paxil, effexor, cymbalta, lexapro, zoloft, wellbutrin, trazadone, etc.).

Usually the pharmacist will mark on a medication bottle if it is unwise to take alcohol with the medication. Always read warning labels carefully.

Daniel Small, MD

continued page 8 ▼
I’m not shy about speaking my mind…

I was putting artificial tears in my eyes time after time, all day long

So I asked my doctor about RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05%

RESTASIS® helps increase your eyes’ natural ability to produce tears, which may be reduced by inflammation due to Chronic Dry Eye. RESTASIS® Ophthalmic Emulsion 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.

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Please see next page for important product information.

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RESTASIS® (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 reinserted 15 minutes following administration of RESTASIS® ophthalmic emulsion.

Carcinogenesis, Mutagenesis, and Impairment of Fertility
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 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 (28 µL) of 0.05% 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 V79-HGPT Test, the micronucleus test in mice and Chinese hamster, 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).

There is no impairment in fertility that 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 350 mg/kg/day during organogenesis. These doses in rats and rabbits are approximately 300,000 times greater than the daily human dose of one drop (28 µL) of 0.05% 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 embryo- and teratotoxic 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 (28 µL) of 0.05% 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, 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, pruritis, stinging, and visual disturbance (most often burning).

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q Enroll me in My Tears, My Rewards® Program to save more!
q I am not a patient enrolled in Medicare, Medicaid, any similar federal or state healthcare program, or a resident of Massachusetts.

*RESTASIS® Rebate Terms and Conditions: To receive a rebate for the amount of your prescription co-pay (up to $20), enclose this certificate and the ORIGINAL pharmacy receipt in an envelope and mail to Allergan RESTASIS® Ophthalmic Emulsion $20 Rebate Program, P.O. Box 6513, West Caldwell, NJ 07007. Please allow 8 weeks for receipt of rebate check. Receipts prior to August 31, 2012 will not be accepted. One rebate per consumer. Duplicates will not be accepted. See rebate certificate for expiration date. Eligibility: Other not valid for prescriptions reimbursed or paid under Medicare, Medicaid, or any similar federal or state healthcare program. Void in the following states: Void if any third-party payer reimburses you or pays for any part of the prescription price: Massachusetts. Offer void where prohibited by law, taxed, or restricted. Amount of rebate not to exceed $20 or co-pay, whichever is less. This certificate may not be reproduced and must accompany your request for a rebate. Offer good only for one prescription of RESTASIS® Ophthalmic Emulsion and only in the USA and Puerto Rico. Allergan, Inc. reserves the right to rescind, revoke, and amend this offer without notice. You are responsible for reporting receipt of a rebate to any private insurer that pays for, or reimburses you for, any part of the prescription filled, using this certificate.

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The Sjögren’s Syndrome Foundation’s 5-Year Breakthrough Goal is the largest initiative that the SSF has ever undertaken. This is why we are working with an outside marketing research firm to help us gather information needed to reach our goal, track our progress and tell us how long it currently is taking patients to be diagnosed with Sjögren’s.

This summer, the SSF and our marketing research firm surveyed newly diagnosed Sjögren’s patients from 2011, and of those patients surveyed, it was determined that it currently takes patients on average 4.7 years to be diagnosed with Sjögren’s. While 4.7 years is a great initial improvement from all past studies, we probably all can agree that it is still too long to wait for an accurate diagnosis!

In addition to the length of time to reach diagnosis, the SSF also was able to gather valuable data about the average age of those being diagnosed, which medical professionals are diagnosing Sjögren’s, which symptoms are causing patients to seek a diagnosis and what symptoms patients are currently experiencing. This new information will help the SSF in highlighting gaps in patients’ medical care as well as where we may be able to capture potential patients before they suffer for nearly 5 years. We then can direct our marketing efforts toward those symptoms and medical professionals.

So, now, the SSF can be proud that we have been able to decrease the time for diagnosis from nearly 8 years back in 2007 to now 4.7 years. This baseline will give us our starting point to reach our goal of shortening the time to diagnose Sjögren’s by 50% over the next 5 years. We hope that by 2017, we can say that it only takes a little over 2 years to obtain a proper diagnosis!

We can do this – but we still need more help! We thank those who have been participating in our awareness initiatives and coming out to fundraising events as well as those who support the SSF. However, there are more ways to get involved and we hope you will all step up and help us. Learn more about the SSF and how you can assist us by visiting www.sjogrens.org or calling the SSF office at 800-475-6473.

Help us break through. Call 800.475.6473 or visit us at www.sjogrens.org
"Q&A" continued from page 4 ▼

Q Is Postural Orthostatic Tachycardia Syndrome (POTS) associated with Sjögren’s?

A Sjögren’s patients have been shown to have subtle impairment of autonomic nervous system reflexes which may lead to difficulty in maintaining blood pressure. This is an uncommon condition but has recently received attention both in the United States and abroad. Full-blown POTS has not been well-documented in Sjögren’s.

Philip L. Cohen, MD

Q My mucous tends to be very thick and gets stuck in my throat and affects my voice. Sometimes I can dislodge the mucous plug by coughing. I do drink a lot of water. Any suggestions to thin the mucous?

A Thick mucous is one of the hallmark symptoms of Sjögren’s. There is less of the watery (serous) component of secretions and more of the mucous component making saliva and bronchial mucous more globular and less lubricating. The secretions in Sjögren’s tend to clump together instead of spreading out over the surface of the mouth, throat, nose or bronchial passages.

The primary intent of any form of treatment for the dryness of Sjögren’s is to provide more watery component of the lubricating secretions. Most people figure out that drinking more water all day long helps to remedy this discrepancy. Other ways to approach the problem are through the use of mucous thinning agents other than water.

One of the mucous thinning agents used in Sjögren’s is guaifenesin (active ingredient in Mucinex, Robitussin and most other medications labeled as “expectorants”). The research over 20 years ago using guaifenesin as a mucous thinner found that higher doses (600-1200mg every 12 hours) of the medicine were more effective than lower doses when combined with adequate water intake. The research also established guaifenesin as a very safe medicine with low toxicity even at very high dosage in children or adults. Various forms of guaifenesin are available including liquid (often compounded with an alcohol base which can be more problematic for the Sjögren’s patient), tablets (usually 200-400mg), and higher-dose sustained release tablets or sprinkles which are slowly dissolved in the GI tract and release the guaifenesin over a period of 8-12 hours.

I have found the sustained release high-dose formulation tablets to be more effective in treating the problem of thick globular mucous in Sjögren’s. The down side is that the tablets are large and hard to swallow for some people with a dry mouth/dry throat. Crushing them destroys the sustained release character of the tablet and is not recommended. I tell my patients to coat the large tablets with a tasty slippery food product like yogurt, honey, maple syrup, or corn syrup.

There is another less commonly used expectorant: potassium iodide (Pima Syrup) which should be used only after careful review with your doctor or pharmacist of the contraindications. This expectorant is taken in drops from a dropper bottle or as a syrup by the spoonful. It cannot be taken if you have thyroid disease or iodine allergy. It is highly effective in thinning mucous, but as a bothersome side effect, it can make your nose run profusely. Dosing is every 6 hours, which many find inconvenient. There is no long-acting formulation.

Steam therapy using a small personal size table-top sauna mask is helpful for many at thinning and breaking up thick secretions. Singers have found this to be beneficial.

Use of a saline nasal irrigation (NeilMed, SinuCleanse, NetiPot) can be very helpful if the thick mucous tends to be from a post-nasal drip.

Finally, keep in mind that gastro-esophageal reflux disorder (GERD) can be a contributor to the sensation of thick mucous in the throat and on the vocal cords. Therefore, using OTC antacids, keeping the head elevated on a wedge while sleeping and avoiding late meals and snacks before bedtime are helpful. Sometimes prescription-strength meds may be needed from your doctor to control more severe reflux. Remember that most of yesterday’s prescription meds for GERD are now available OTC (Tagamet, Pepcid, Zantac, Prilosec, etc.), so there are many options to try before prescription meds.

David A. Bianchi, MD

Q I have lost nearly all my teeth due to Sjögren’s and I’m looking into the possibility of getting dental implants. Is this a good idea? Are there any drawbacks?

A There have been few careful studies of implants in Sjögren’s syndrome patients, so most of what is known is based on clinical experience and discussions among practitioners who have experience with implants. In general, Sjögren’s patients do well with dental implants. The implants appear to have the same success rate in Sjögren’s patients as in any individual, varying based on the amount of bone supporting the implant and the location in the mouth. The caveat is that this information is based on limited data.

This specific question is about implants that would support dentures, as opposed to single-tooth implants. Sjögren’s patients have difficulty keeping dentures in place because of the lack of saliva, particularly mandibular (lower jaw) full

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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.

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**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.

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Please see a brief summary of Important Information for EVOXAC on the next page.
On July 23rd, 2012, the Sjögren’s Syndrome Foundation joined with other Sjögren’s groups around the world to celebrate World Sjögren’s Day and received a BIG boost from Venus Williams, professional tennis player and Olympic Gold Medalist as well as fellow Sjögren’s patient.

A year after helping to increase awareness for Sjögren’s when she publicly announced her diagnosis, Venus once again stood up for Sjögren’s awareness when she carried the Olympic torch through the streets of London on a most appropriate day, World Sjögren’s Day (July 23rd).

Here is an excerpt from Venus’s Facebook page:

“Today was an amazing day. I carried the Olympic flame right through Wimbledon! I truly felt the Olympic spirit – participation, giving your best and bringing people together no matter what their background or differences. This Olympics is very special to me, having battled through an autoimmune disease in the last year. It was my dream come true to qualify for the Olympics. To carry the torch today on World Sjögren’s Day was so fitting. My run with the flame today represented triumph for everyone battling an autoimmune disease. I’m planning on enjoying every day at the Olympics — I won’t take even one for granted!”

As you know, World Sjögren’s Day commemorates the birthday of Henrik Sjögren, who first identified Sjögren’s in 1933. This past summer, we asked members and supporters to use World Sjögren’s Day as a reason to talk about Sjögren’s. Initially, sharing can be a scary thought, but you will never know what support is out there if you don’t. Awareness can be reached one person at a time, and we encourage everyone to find reasons in your own life to talk about Sjögren’s.

Venus went on to win the Women’s Doubles Olympic Tennis Gold Medal with her sister, Serena Williams. The Foundation wants to thank Venus not only for stepping up for Sjögren’s awareness but also for being an inspiration to all Sjögren’s patients.
dentures. The oral tissues also may be thinner and sore, making wearing a denture uncomfortable. Frequently, supporting bone of the alveolar ridge has been lost. Implant-based dentures can solve these problems, since they are fixed in position and are not constantly pressing down on the tissue. Implants may be a good alternative for Sjögren’s patients. There are many patients who have had successful outcomes. Of course, the major drawbacks are the expense and the necessity for surgical procedures to place the implants.

Philip C. Fox, DDS

Q

What does “disease modifying” mean when used regarding Plaquenil?

A

There are a variety of arthritis medications called disease-modifying antirheumatic drugs, or DMARDs, that work by curbing the underlying processes that cause certain forms of inflammatory arthritis including rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis. They have been well-established to slow the progressive joint damage in these diseases. Plaquenil (hydroxychloroquine) has long been lumped in this group because of its beneficial effects not only for the arthritis but also for other manifestations in inflammatory diseases, such as rash and fatigue in systemic lupus and Sjögren’s. There are many articles in the medical literature supporting the use of Plaquenil in inflammatory rheumatic diseases. However, there are very few prospective studies demonstrating efficacy in Sjögren’s. In the mid-1990s, Robert Fox, MD, at Scripps Clinic, and I were asked by the manufacturer (Sanofi) to do a retrospective chart review of our patients with Sjögren’s who had been treated with Plaquenil. This review demonstrated that there was a beneficial effect on objective measures such as gamma globulin levels and sed rates and subjective improvement in fatigue, joint and muscle pain and decreased oral and ocular discomfort. In my experience, having thousands of interactions with patients with Sjögren’s over 35 years, the use of Plaquenil does appear to decrease the progression of the manifestations of Sjögren’s. Plaquenil rarely may cause retinal toxicity which can result in vision loss. It is a problem that can occur after years of taking Plaquenil. Therefore, it is important for people taking Plaquenil to have their eyes examined at least once yearly or more frequently if recommended to do so by their eye doctor. Make sure that your eye doctor knows that you are taking Plaquenil as special tests are necessary for monitoring for retinal toxicity.

Daniel Small, MD

“Q&A” continued from page 4 ▼

United Way • Combined Federal Campaign • State Payroll Deduction

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

If we are not listed on the contribution form, you usually may write in the Sjögren’s Syndrome Foundation. Tell your co-workers, friends, and family members how important it is to choose and write in the Sjögren’s Syndrome Foundation on their campaign form, too.

If your employers will not allow you to write in the Sjögren’s Syndrome Foundation, remind them that we are a national non-profit 501(C3) organization and qualify for most payroll deduction campaigns. If they need more information, please contact the Foundation at 800-475-6473 ext. 207 and ask for Ben Basloe.

Just think – every dollar counts.

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

Remember, the Foundation has received the:
In Memory of Cynthia Williamson
Marilyn Adams
Diana Altom
Robert & Constance Anders
Debbie Arnowitz
Richard Bliss
Stephanie Bonner & Shaneé Stephens
Mike Brennan
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Nancy Carter
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S. Lance Forstot
Margaret Goddard
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Annabel Hoffman
Patricia Huber
Linda Hughes
Kathy Ivory & Thelma Skinner
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Eunice Krivonak
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Carolyn Lee & the Greater Baton Rouge Sjögren’s Group
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In Memory of Debbie Reese Hebert
Booray Friends: Becky, Jim, Kitty, Bob, Carol P., Carol L., Steve, Martha, Ann, Rachel and Joanne Bigfifteen Too, Inc.
The UPS Store - Kel, Jason, Stephanie, Lauren, and Will

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Richard & Rebecca Hopkins

In Memory of Janice Polisner
Estelle & Sidney Freeman
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Muriel Levison
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Jennifer & Todd Mouton
Mr. & Mrs. Freeman Suttle
Eamy & Gary William

In Honor of Annemarie Labbate’s Birthday
Arlene Roode

In Honor of Marcy Levine’s Birthday
Nina Torcoletti

In Honor of Dr. Lance Forstot
Irmtraud Wettjen

Remember your loved ones and special occasions with a donation to the SSF in their name.
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<td>and expanded with new chapters and the latest information on Sjögren’s.</td>
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<td>A complete resource for Sjögren’s sufferers, providing medical</td>
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<td>A Sjögren’s patient and her doctor offer their authoritative</td>
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<td>insight into one of the most common yet most misunderstood</td>
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<td>A book for women who live with chronic illness, encouraging them to</td>
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<td>A dual memoir with a patient and her doctor that offers a powerful</td>
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<td>and inspirational testimony from either side of the examining table.</td>
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<td>Stop</td>
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<td>Peripheral neuropathy is a widespread disease, yet many people do</td>
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<td>not even realize they have it. If you experience pain, numbness,</td>
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<td>tingling in your feet or other extremities, this book is for you.</td>
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<td>A compendium of tips, techniques, and life-task shortcuts that will</td>
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<td>help everyone who lives with this painful condition.</td>
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<td>Vulvodynia Survival Guide: How to Overcome Painful Vaginal Symptoms</td>
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<td>&amp; Enjoy an Active Lifestyle</td>
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<td>A great resource for anyone experiencing vulvodynia symptoms. This</td>
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<td>book will help readers identify triggers, reduce symptoms, find</td>
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<td>The Woman’s Book of Sleep: A Complete Resource Guide</td>
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<td><em>(by Amy Wolfson, PhD)</em></td>
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<td>An overview of the latest findings pertinent to women’s sleep, and</td>
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<td>it distills their practical implications in a direct and straightforward</td>
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<td>The Memory Bible: An Innovative Strategy for Keeping Your Brain</td>
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<td>Young</td>
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<td>This program has helped thousands of people improve their ability</td>
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Team Sjögren’s –
Goes Turkey (again)!

Turkey Trots Across America was such a success last year that the SSF has decided to once again ask you to step up and join us this November!

We are hoping to have over 100 runners wearing Team Sjögren’s shirts on Thanksgiving Day as they run in their local hometown Turkey Trot races. Turkey Trot races happen all over the U.S. and can range from a 1-mile fun run to a 5K race to even a 10K distance. It doesn’t matter which one you do – it’s your choice – but this is a great way to increase awareness and help the SSF raise crucial funds for Sjögren’s research and education.

You can run yourself or organize a team to run with you – either way, you will be helping us to raise awareness.

So here is how it works:
Visit www.firstgiving.com/ssf and click on the Turkey Trot Across America page. On that page you will find all the information for how to set up your own personalized webpage, how to recruit a team and how to receive a Team Sjögren’s shirt to wear on race day!

Once you create your webpage, we will contact you to send you an informational pack with ideas for recruiting a team, fundraising and how to educate your local community.

We encourage you to recruit friends and family to join you at the Turkey Trot but if you can’t find anyone to join you, then run or walk yourself! What a great way to spend the day of “thanks” – Thanksgiving – by going out and raising awareness for Sjögren’s.

If you have any questions about Turkey Trots Across America or want help in setting up your webpage, contact Ben Basloe at the Sjögren’s Syndrome Foundation at 301-530-4420, ext. 207.

Thanks for standing up and going turkey with Team Sjögren’s!

Now You Can Breathe Easy
Because the best humidifier is on sale.

Properly humidified air can alleviate poor indoor air quality and many of the Sjögren’s disease symptoms, such as dry skin, dry nose and dry throat. At Venta, our German-engineered humidifiers are built for your comfort. What’s even more comforting is we’re having a sale, exclusively for Sjögren’s sufferers.

Buy today and also receive a FREE water treatment additive, FREE Venta cleaner and FREE shipping for a $50 savings. Just use the promotion code sjogrens during checkout or when you call and place your order.

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<td>LW44</td>
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Units available in charcoal gray and white.

888-333-8218 ventahumidifiers.com
This Holiday Season, Don’t Forget...  
Shop for Sjögren’s

Shop to benefit the Sjögren’s Syndrome Foundation

The Sjögren’s Syndrome Foundation has partnered with online retailers who will donate a portion of the value 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** is one of the most popular online stores in the world, offering a wide variety of products. Up to 8% of the value of your purchase is donated back to the Foundation.

- **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 10% of your purchase benefits the SSF.

- **Walmart.com** offers access to a wide assortment of products at their everyday low prices, with up to 4% of your purchases being donated to 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.

Just go to www.sjogrens.org/shopforsjogrens and start shopping!