Sjögren's Syndrome Foundation
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The Moisture Seekers
30 Years
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Q Should I Treat My Sjögren's Different If I Have Primary vs Secondary Sjögren's? & A

The terms "Primary and "Secondary" were first used in the 1960s and were devised by researchers who wanted to distinguish between those Sjögren's patients whose disease was not "complicated" by other major rheumatic or autoimmune disorders. When carrying out research, the investigators wanted to make sure they were looking at purely Sjögren's patients and not looking at outcomes for patients who had, for example, both Sjögren's and rheumatoid arthritis (RA). They thought that could confuse clinical trials looking at how well a specific therapy worked. As such things usually happen, though, the

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An Inside Look at Sjögren's and Gluten Free Diets

by Keith Wilkinson, NMD, Naturopathic Doctor

What, if any, are the benefits of going on a gluten free diet because of my Sjögren's?

This is a question I get frequently. Going gluten free can have its benefit in some patients. However, gluten is found in many foods and it can be a challenge to eliminate from the diet. Before I recommend going gluten free, I typically go through a process with my patients. This article is some background on gluten and my thoughts on when I decide to recommend a gluten free diet.

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terms began to carry over to general clinical diagnosis and medical discussions and thought patterns, and that's where everything became complicated and not helpful for patients and not even helpful for the clinicians treating them. It didn't always make a major difference for the research, either.

So, first, what do the terms mean? "Primary" has been defined as a Sjögren's patient who does not have another major rheumatic and/or autoimmune disease and "Secondary" as a Sjögren's patient who does. But as you can imagine, it's not always simple or easily apparent. If a patient has another major rheumatic, autoimmune disease such as lupus, RA, scleroderma or the autoimmune disease multiple sclerosis, they would have traditionally been categorized as have "Secondary Sjögren's." The term "Secondary" has not been applied to the prevalent autoimmune thyroid diseases, however, which are common in Sjögren's, and so the terms are somewhat tricky.

Also, investigators have confronted a dilemma when a patient has had Sjögren's for many years and been labeled as "Primary" and then is diagnosed with another major rheumatic and/or autoimmune disease and automatically being re-labeled as "Secondary Sjögren's." And to complicate matters more, some clinicians have now started saying their patient has "Primary Sjögren's" and "Secondary lupus"(for example) while others undiagnosed the patient from having "Primary Sjögren's" and changed the diagnosis to "Secondary Sjögren's." How confusing!

Does it really matter? NO - It certainly doesn't matter to the patient or the clinician treating a patient. It doesn't alter treatment, since treatment for these diseases is based largely on the clinical manifestations and symptoms. All patients should be treated on a case-by-case basis.

Does the label mean your disease is more or less severe? ABSOLUTELY NOT. If someone has labeled you as having "Secondary Sjögren's," it does not mean that your Sjögren's is less severe or secondary in importance to the other condition. It also doesn't mean that symptoms that were labeled as Sjögren's symptoms previously are now symptoms of the other disease. Autoimmune diseases often overlap, and sometimes it's difficult to tell if a symptom is Sjögren's or, say, lupus. In fact, Sjögren's is the most frequent disorder that occurs in conjunction with other autoimmune and rheumatic diseases, so, again, your signs and symptoms must guide the treatment.

Does the label make a difference as to whether patients are monitored for specific complications or not? NO. Again, your management and treatment should depend on your manifestations of autoimmune disease. You might be labeled as having lupus AND Sjögren's or rheumatoid arthritis AND Sjögren's, and then your symptoms and diseases should be managed according to your specific case and with complications specific to each in mind.

Traditionally, it has mattered to an investigator running clinical trials, but even that is now being called into question. First, diagnosis and pigeon-holing these diseases is not always easy or an exact science. Second, investigators didn't mind if patients with RA or lupus who entered clinical trials also had Sjögren's and thought it did not muddy the results of trying a new therapeutic. Why? Because, again, like clinical treatment, the trials were primarily targeted toward clinical manifestations

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I used artificial tears often, like when at lunch with friends.

So I saw my doctor—after all, these are my eyes.

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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 the use.

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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
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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.

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You Stood Up!

Keep Shopping – You're making a BIG difference!

Last year, the SSF asked members to consider giving back in a different way by using iGive, a shopping website that gives a percentage of what you purchase back to the SSF.

From the time this issue went to print, iGive donations to the SSF for 2014 had already increased by 8% over the entire 2013 calendar year! It's easy to think that shopping percentages are a small contribution but because of you stepping up collectively, they become significant and allow the SSF to provide more educational resources and patient services this year.

If you are not familiar with iGive, it is a free service to both shoppers and charities. Shoppers can generate donations by simply shopping at any of iGive's 1,500+ brand name stores. Once you have selected the SSF as your charity, an "iGive Cookie" is assigned to your browser. This tells the store, "Here is an iGive shopper" and the store reports back the amounts for the donation to the SSF, meaning iGive never have access to your payment information.

From holiday shopping to general purchases, by shopping with our partners and choosing the SSF as your charity of choice, you're making a big difference! To learn more about shopping for Sjögren's, visit www.sjogrens.org or call the SSF at (301) 530-4420. ■

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for example, joint pain, which can occur in several rheumatic diseases including Sjögren's. While a few manifestations might be distinctive of one disease versus another, such as the joint damage that occurs only in rheumatoid arthritis, the results still were based on the manifestation.

The Sjögren's Syndrome Foundation (SSF) is trying to move the medical and scientific community away from these terms, because they usually are NOT helpful or necessary. In fact, they are most often used out of habit, and while we recognize that habits can be hard to change and it can take a long time for a majority to start using different terminology, the SSF is on a mission to accomplish this. Simply put, someone either has Sjögren's or does not have Sjögren's. Having another identifiable disease doesn't change the fact that the patient has Sjögren's, and a somewhat arbitrary decision about which additional diseases and conditions might change a patient between "Primary" and "Secondary" no longer makes sense.

Katherine Hammitt, SSF Vice President of Research

Q *I keep reading about immunosuppressants as therapy for Sjögren's —- What is an immunosuppressant?*

A There isn't a universally accepted definition of an immunosuppressant medication. In general, I think most providers would agree that a medication that has been shown to potentially increase the risk for infections in long-term studies would be considered an immunosuppressant. It is important to note that many, if not most, patients with Sjögren's do not need or benefit from immunosuppression. For certain patients, however, they can be very helpful. The most common immunosuppressant medications used for Sjögren's include methotrexate, azathioprine (Imuran), mycophenolate (Cellcept), cyclophosphomide (Cytoxan), and biologic agents, such as rituximab (Rituxan). These are also used for many other related autoimmune diseases, and the effect of each medication on the immune system varies from blocking inflammation pathways to directly affecting white blood cells.

There is a common goal for all immunosuppressants: to put the disease into remission, or at the very least reduce the severity or frequency of symptoms and allow patients to avoid steroids. As with all medical treatments, the hope is that the benefits outweigh the risks. If not, then the dose is typically decreased or the medication is stopped completely. With the exception of certain cases, immunosuppressives are generally used to help provide symptomatic relief and not necessarily to prevent something bad from happening. So if an immunosuppressive is tried but doesn't help after an adequate amount of time, it is usually stopped.

Hydroxychloroquine (Plaquenil®), a medication often taken by Sjögren's patients, is not generally considered an "immunosuppressant." While it does change or "modulate" the immune system in various ways, it does not lead to an increased risk of infections and does not require lab monitoring.

Joseph Lutt, MD

Q *Is it safe or suggested for a Sjögren's patient to use medical marijuana to cope with symptoms?*

A In the United States, medical marijuana (MM) has now been legalized in 23 states and the District of Columbia. The clinical indications for the use of MM vary from state to state with severe or chronic pain included in all but one. It is indicated specifically for patients with Sjögren's (SS) only in Illinois. This is curious in light of the absence of any literature on the use of medical marijuana in patients with Sjögren's.

The most common symptoms in patients with Sjögren's are dry eyes, dry mouth, fatigue and musculoskeletal symptoms, including arthralgia (joint pain), myalgia (muscle pain), arthritis and fibromyalgia syndrome (FMS). Cannabinoids, the active agents in marijuana, have been shown to be helpful in reducing musculoskeletal pain in both patient reporting surveys and in 3 formal clinical trials, 2 in patients with FMS and 1 in patients with rheumatoid arthritis. Meta-analyses of controlled trials in non-cancer-related pain patients also suggest that MM is useful. The benefits observed in these studies must be weighed against the observed side effects of marijuana which include dry mouth, drowsiness, impaired motor function, altered perception and altered cognition (thinking). Inhaled cannabinoids are also reported to be associated with increased periodontal disease which has a heightened significance in patients with SS.

These are the short-term effects and side effects of MM. The long-term effects of MM have yet to be determined. Withdrawal of cannabinoids after long-term use can lead to sleep difficulties and strange dreams.

Taking these observations together, MM may help the musculoskeletal symptoms in SS but may worsen dry mouth and fatigue as well as increase periodontal disease, and cause impaired motor function, and alter perception and cognition. In conclusion, the side effects of MM probably outweigh the potential pain-related benefits of medical marijuana in patients with Sjögren's.

For those interested in further information about MM, the following website provides a balanced view of the conflicting opinions on the use of this drug in medicine: http://medicalmarijuana.procon.org.

Neil I. Stahl, MD, FACR

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

Please see full Prescribing Information on next page.

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Q Can Sjögren's patients wear contact lenses?

A Whether or not you can wear contact lenses depends on how severe your dry eye is. If you have mild dry eye, then there is a high likelihood that you will be able to wear contact lenses. If you are currently wearing contact lenses and they are uncomfortable, I usually recommend taking a "contact lens holiday" and not wearing your contacts at all for 3-4 consecutive weeks. I also recommend trying to improve the dry eye as much as possible before attempting to re-start contact lens wear. Some Sjögren's patients will need punctal plugs or cautery to keep extra tears on the surface of their eyes in order to allow them to wear contact lenses. For patients with moderate-to-severe dry eye, I will try to maximize all of their dry eye treatments before trying to have them wear contact lenses.

I usually recommend daily disposable soft contact lenses that are specifically made for dry eye patients. There is some trial and error involved in finding the best brand for a particular patient, and also the best fitting contact lens. Having a properly fitting contact lens is critical as sometimes the discomfort with contact lens wear is due to a poorly fitting lens rather than dry eye.

When you are trying to re-start contact lens wear, I recommend starting slowly and building up gradually to find the amount of time you can wear the contacts comfortably without much irritation. I usually recommend starting with 1 hour/day for a few days, and then gradually increasing by an additional hour/day as tolerated. I also instruct patients to use preservative free artificial tears (avoid bottled contact lens rewetting drops or bottled tears as these contain preservatives) when wearing the contact lenses. Preservative free tears should be administered at least every 3-4 hours or more frequently to keep the eyes well lubricated while wearing the contact lenses. If you have any discomfort or redness when wearing the contacts, you should immediately remove them.

If you are unable to tolerate soft contact lenses, then you could also consider trying the mini-scleral lens, or the PROSE lens (prosthetic replacement of the ocular surface ecosystem).

Vatinee Bunya, MD

Q I have heard a lot about a new test for Sjögren's called "Sjö™ "? What is it and who is being tested with it?

A The SSF is excited that new diagnostics are continuously being developed to test for Sjögren's. The Sjö™ test that was recently launched by Nicox is one example of progress being made in detecting Sjögren's early and promptly.

Sjö™ is an advanced diagnostic blood test to help doctors determine whether or not you may have Sjögren's. The test incorporates new biomarkers to help detect Sjögren's in its early stages and to provide more accurate results than previous testing methods.

Currently, Sjö™ is being marketed to eye care providers to test all dry eye patients. Patients who receive a positive Sjögren's indication are then referred to a rheumatologist for further follow-up. This new test will help those suffering from symptoms of Sjögren's get a proper and prompt diagnosis of Sjögren's. The test is currently being used on un-diagnosed Sjögren's patients.

Michele Champigny, SSF Director of Professional Awareness

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Sjögren's Syndrome Foundation is partnering with Tupperware to kick start your holiday shopping!

From **October 22 to November 19**, you can purchase Tupperware through the SSF website and 50% of your order will be donated back to the Foundation! Stock up on great items knowing that your purchase is helping the Foundation's life-changing initiatives.

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Q *I know dental care is important with Sjögren's. How often should I brush my teeth and what type of tooth brush do you recommend?*

A Xerostomia or dry mouth is among the most common symptoms experienced by Sjögren's patients. Dental care is extremely important to those who experience dry mouth because a decrease in saliva flow has many negative effects on overall oral health.

Saliva not only serves a natural lubricant that keeps our mouth moist and comfortable, but it also plays an important role in the health of our teeth and gums. Minerals in saliva help to neutralize acid and assist in the enamel repair of our teeth. Saliva also acts as a natural rinsing agent reducing the amount of bacterial plaque buildup on our teeth and gums. Plaque is a film of bacteria and sugars that forms on our teeth and leads to tooth decay (cavities) and gum disease if not removed properly.

Our toothbrush serves as the most important tool to remove bacterial plaque from the tooth surface. Brushing at least twice a day for 2 minutes will help to remove sticky plaque from the teeth, reducing the risk of developing cavities. Sonic toothbrushes are an excellent option for patients with Sjögren's. These brushes are shown to remove more plaque than manual toothbrushes because of the high intensity vibrations that they generate. Sonic toothbrushes create an average of 30,000 brush-strokes per minute as compared to an average of 300 with a manual toothbrush. The vibration created by the sonic toothbrush also drives fluid between the teeth and along the gum line. This can aid in stimulating the gum tissue and which can sometimes become sensitive with a chronically dry mouth. Using a soft or extra soft bristled toothbrush is also recommended since lack of saliva can cause the mouth to be more susceptible to cuts and sores.

In addition to brushing, it is important to floss daily to help remove the plaque in between the teeth and under the gum line. If not cleaned effectively, plaque that is allowed to accumulate around the gums can lead to gum disease.

A dry mouth also makes it easier for bacteria to stick to the tongue. This can lead to bad breath and impaired taste. It is recommended to brush your tongue daily with your toothbrush to loosen bacteria from the surface. You can also use a tongue scraper to gently remove bacteria from the tongue.

Because saliva plays such a significant role in the health of our teeth and gums, patients who experience dry mouth are at an increased risk for tooth decay and gum disease. Excellent oral hygiene and regular visits to an understanding and Sjögren's-knowledgeable dentist and dental hygienists can help reduce the negative effects of dry mouth and keep the patient happy and healthy.

Erin LaChapelle, RDH, BSDH

Q *I have joint pain because of Sjögren's, are there any holistic treatment options that you can recommend?*

A Many patients with Sjögren's experience joint symptoms. Most commonly, patients will complain of joint aching that is often worse in the morning. Joint swelling may also sometimes occur. Tart cherries are a delicious nutrient and anti-oxidant rich fruit with potential health benefits. In fact, the red color of cherries are due to powerful anti-oxidants, called anthocyanins. Red tart cherries have been considered a folk remedy to help joint symptoms for many years. Studies conducted at the University of Michigan concluded that a cherry enriched diet lowered inflammation in animals by 50%. Clinical studies conducted with human subjects using commercially available cherry products have also shown benefit in osteoarthritis, the most common type of arthritis. One study was conducted at Lenox Hill Hospital in New York and the University of Pennsylvania used a brand of cherry juice called Cheribundi. In addition to some benefit with joint pain, there was also some improvement in sleep as tart cherries contain natural melatonin.

In addition to eating the fruit or drinking cherry juice, another common way to get the benefits of cherries is through supplements. CherryFlex is a popular brand that a number of my patients have tried over the years. It was developed by a cherry farmer in Michigan. Each gel cap contains both the skin and the pulp of the Montmorency tart cherry. A word of caution regarding cherries, in any form, is that some people may develop loose stools as a side effect.

Other natural supplements which may also be helpful for joint symptoms include turmeric, boswellia, and SAMe (S-adenosylmethionine). If muscle discomfort is an issue, magnesium supplementation may be of help.

I recommend patients discuss the use of any supplement with their physician and consider periodic blood monitoring for unusual side effects that can occur with any product, even natural ones. While there are no studies available looking at these "holistic" treatments for Sjögren's, information gained from other common arthritic conditions indicate that these products could be helpful for the joint health of Sjögren's patients.

Scott Zashin, MD

October

Breakthrough Bullet:

Time it takes to diagnose Sjögren's is shorted to 3.9 years

Thank you for joining us on the journey to reach our 5-*Year Breakthrough Goal* and help Sjögren's patients receive better care from knowledgeable physicians by shortening the time it takes to be diagnosed with Sjögren's. As many of you know, the SSF is tracking our progress by working with a marketing research company and surveying newly diagnosed patients.

When our Goal was launched in 2012, the average time it took for a patient to be accurately diagnosed with Sjögren's from the time they started seeking a diagnosis was over 5 years- an amount of time that we all agreed was grossly too long! And in 2013, we were happy to announce that the average time had decreased to 4.7 years.

It is with great pride that we can reveal the initial results from this year's survey, which shows that it currently takes an average 3.9 years to receive a diagnosis from the time a patient started seeking a diagnosis for their symptoms! There is a lot more work to be done for us to reach our Goal by 2017 and shortening the time it takes to be diagnosed to less than 2.5 years, but all of the hard work is paying off.

By focusing on educating the general public and physicians, who were missing the diagnosis, it is clear to see that awareness of Sjögren's is on the rise! The SSF knew we couldn't do it alone and it is because of you and your efforts that we can share this exciting news. As always, the SSF will give a full update on the 5-*Year Breakthrough Goal* and this year's survey results in the January issue of *The Moisture Seekers*. ■

In Memory of Alice A. Fieger
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Louise Dombroski
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Roberta Kahn
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Kathy Lawrence and Georgia Petros

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Olivia Kurtz
The Apple Creek Banking Co.

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Madeline and Pete Forsyth
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Marjorie Gene Owen
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Dwayne Hershberger and Cindy Sellers
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Cass Witkowski
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The Faculty and Staff of
Abington Senior High School
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In Memory of Michael Kermit Walker
Betty Hundley

In Memory of Mildred Tolson
Jessie Drake
John and Barb Straley

In Honor of Ken Economou
Dr. Stephen Cohen

In Honor of Jennifer Unger
Mom and Dad

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Linda Fifield

In Honor of Abby Swanson
Juliette & Andreas Johnson

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Gabor & Terez Kalman

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Jeff McCall

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In Honor of Sarah Schafer
Nicole Noran

In Honor of Myron Levin
Barbara & Alan Levin

IT'S TIME

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. (CFC #10603)

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(c)(3) organization and qualify for most payroll deduction campaigns. If they need more information, please contact the Foundation at 800-475-6473 and ask for Elizabeth Trocchio.

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:

BEST IN AMERICA
INDEPENDENT CHARITIES OF AMERICA

NATIONAL HEALTH COUNCIL
Standards of Excellence

Team Sjögren's is once again going to Disney World to participate in the 2015 Disney World Half-Marathon and 10K Race weekend in January 2015.

This year, the SSF is looking for runners/walkers that want to train to participate in either a Disney World half marathon (13.1 miles) or the Disney World 10K (6.2 miles). Both events happen the same weekend and each runner/walker will be a part of the Team Sjögren's training program- where we help you train and get ready for the race!

The Walt Disney World course will take you through Walt Disney World Theme Parks including Epcot and the Magic Kingdom before a picture worthy finish back at Epcot, where you'll receive your Mickey Mouse finisher medal!

As a team member, you will receive world-class training along with mentorship from past runners and Foundation staff. Our team trainer and nutritionist will be there to help guide you and ensure you're ready to complete the 6.2 or 13.1 miles. If you're unable to run or walk in a race, consider recruiting someone you know to run or walk in your honor.

Limited spaces are available for both the half-marathon and the 10K. Please contact Steven Taylor, CEO of the SSF, at staylor@sjogrens.org as quickly as possible to learn more about our great program.

We hope you will join us at the most magical place on earth- Disney World!

Team Sjögren's

"Gluten-Free" continued from page 1 ▼

What is gluten?

Gluten is an umbrella term for many different proteins found in gluten containing grains. The two most common gluten proteins are gliadin and glutenin, however there are many more. The most common gluten containing grains are wheat, rye, and barley. Gluten can also be found as an additive in many processed foods.

How do people react to gluten?

The effects of ingested gluten can range from no reaction at all to the most serious reaction called celiac disease (CD). Celiac disease is triggered by an interaction between gluten and one's intestinal cells. This interaction modifies the cells enough to trigger an autoimmune reaction and destruction of the intestinal villi by the immune system. On the other end of the spectrum are people that have no autoimmune reaction to gluten and therefore no positive labwork or gastrointestinal damage, but nevertheless feel better when they go gluten free. This is called Non-Celiac Gluten Sensitivity (NCGS).

What are the symptoms of a gluten reaction?

Symptoms of gluten sensitivity, whether CD or NCGS, are not limited to the GI tract. They include conditions such as arthritis, brain fog, ataxia, fatigue, myalgias, plus many more. All of these symptoms can be seen in people with Sjögren's.

How do I know if I react to gluten?

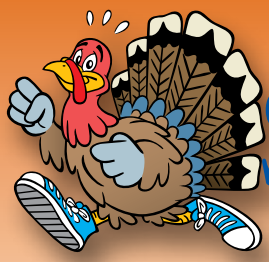
To test for CD the two most common blood based lab tests are Tissue-TransGlutaminase IgA and IgG and Deamidiated Gliadin IgA and IgG. If any of these are positive, it is an indication of an autoimmune reaction and gluten should be eliminated from the diet. Patients can also test for an allergy to wheat with a blood based test for Wheat, Gluten, and Gliadin IgA and IgG antibodies. Elevation in these indicates the immune system is making antibodies to gluten, but no autoimmune destruction of tissues. Gluten should be avoided in these patients, too. However, there are other patients that do not test positive for any of these tests.

What do you do if you do not have a positive lab test for a gluten reaction?

Before I recommend patients go gluten free I first assess the diet they are already consuming. If someone is consuming a diet high in processed foods, carbohydrates, and other "foods" that are low in nutrients, tremendous benefits can be made by just cleaning up their current diet. A health promoting diet is loaded with fresh vegetables, greens, healthy fats, clean sources of protein and therefore nutritionally dense foods. The vast majority of my patients that adhere to the whole foods way of eating that I recommend get significant health benefits. The concern I have with someone going "gluten-free" without addressing their overall diet first, is that it makes people think gluten is the primary concern without recognizing that for most people it is best to start by making sure they eat a diet of minimally processed fresh foods. Only after I have cleaned up their diet, but have not noticed significant improvement, would I then recommend patients go gluten free.

It is also important to know that "gluten-free" does not necessarily mean healthy. Many foods with a "gluten free" label are simply highly processed packaged foods with excess sugars and additives – ingredients that are pro-inflammatory.

In summary, yes, Sjögren's patients can benefit from going gluten free. However, given that most people can get significant benefit from making the simple changes of eating a whole foods diet, I recommend this as a starting point before I recommend the more challenging, but sometimes appropriate treatment of going gluten free. ■



Team Sjögren's

We hope this Thanksgiving 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.

Your Kit Includes:

- Awareness Bracelet
- Team Sjögren's T-shirt, with NEW Turkey Trot logo on the front!
- Certificate of Participation
- "What is Sjögren's Syndrome?" Brochures

Find Your Local Turkey Trot:

You can find a local Turkey Trot by visiting www.active.com. Then enter your state and type in "Turkey" under keyword search. You can also check with your local newspaper or search online.

If there's not a race near you, consider asking family and friends to join you for a morning walk on Thanksgiving in your neighborhood while wearing your Team Sjögren's T-shirts!

Price: $30 plus shipping and handling

Order your Team Sjögren's Goes Turkey Kit today by calling 800-475-6473 or online by visiting www.sjogrens.org.

NEW T-Shirt Design

		Qty.	Total
Team Sjögren's Turkey Trot Kit	$30 ea.		
Maryland Residents add 6% sales tax			
Shipping and Handling: U.S. Mail: $5 for first item + $3 for each additional item Canada: $14 for first item + $3 for each additional item Overseas: $22 for first item + $3 for each additional item			
		Total Amount Due	

Mail to SSF: BB&T Bank · PO Box 890612 · Charlotte, NC 28289-0612
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Sjögren's Syndrome Foundation

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

❑ MasterCard ❑ VISA ❑ Discover ❑ AmEx Card Number _____

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The Moisture Seekers
Sjögren's Syndrome Foundation Inc.
6707 Democracy Blvd., Ste 325
Bethesda, MD 20817
Phone: 800-475-6473
Fax: 301-530-4415

If you would like to receive this newsletter but are not currently an SSF Member, please contact us! 800-475-6473

Be Part of the SSF Breakthrough Goal Team!

Upcoming Special Events

Join in the fun and help increase Sjögren's awareness. The SSF is very excited for all of our events coming this year. Look at our special event calendar below to see if there is a event coming to your area.

Visit www.sjogrens.org or contact the SSF office to learn more about our events!

October

18 ***Harrisburg Walkabout***
Harrisburg Mall, Pennsylvania

November

8 ***Nashville Area Walkabout***
River Park in Brentwood, Tennessee

15 ***Capital Region Walkabout***
Colonie Center, Albany, New York

16 ***Boston Sip for Sjögren's***
The Athenaeum Building, Cambridge, Massachusetts

January 2015

9-10 ***Team Sjögren's Walt Disney World® Half-Marathon and 10K Race***
Orlando, Florida

April 2015

17-18 ***National Patient Conference***
The Grand Hyatt Tampa Bay, Tampa, Florida
(more details coming soon)