

The Moisture Seekers

Sjögren's
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Editor's Note: The following is an excerpt from the book Sick and Tired of Feeling Sick and Tired, which offers hope and coping strategies to the thousands of people who suffer from invisible chronic illness (ICI).

Sick and Tired of Feeling Sick and Tired

Living with Invisible Chronic Illness

by Paul J. Donoghue, PhD and Mary E. Siegel, PhD

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Introduction to Invisible Chronic Illness

"I want to be well. I'm willing to fight, but..."

"But what?" Dr. Diamond asked. "But I must know what I'm fighting. I must have a name for this illness of mine." – Henrietta Aladjem

Recently, returning to Stamford, Connecticut, from a talk in New York, we turned off the highway behind a young man on a motorcycle. As we entered an intersection on a local street, the cyclist suddenly skidded and, in attempting to right his vehicle, spun out of control. We pulled over immediately and rushed to his still form. Within seconds, we were joined by other motorists who had pulled to the side. Some of us held his hands and murmured soothing words, others gathered his wallet, keys, and coins and carefully placed them in a pile next to him. Another person ran to a phone booth at a nearby gas station to call the police. In the space of a few minutes, all our efforts were employed unquestioningly to care for this young man. Later, we reflected on the fact that, faced with such evident disaster, we all re-

sponded, as if by instinct, to the needs of the young motorcyclist. Our own needs to get home to rest after a long day or to reach an appointment on time were temporarily suspended in favor of our concern for the cyclist.

The human potential to reach out in care seems to be tapped particularly when the need of the other is indisputably apparent. National disasters, such as the earthquake in Armenia in 1989, inspired an international outpouring of aid in the form of technological and medical assistance, despite the more typically felt restrictions of ideological differences between nations. The deep, instinctual, human capacity to act compassionately when confronted with disaster can overcome the powerful pull of skepticism, anger, or hate.

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What happens to this human reaction when the crisis of the person is not as patently clear as we witnessed in the fallen motorcyclist? When, for example, a man stumbles in front of us, we may start to wonder, "Is the person about to fall? Has he drunk too much? Is this just a momentary loss of balance?" Once we start to puzzle over the reason, we hesitate. "Does this person need my help? Did he do something that he shouldn't have that caused his stumble? Is he fine?" Unsure as to the cause of the stumble, we are less likely to move swiftly into action than if the person did, for instance, actually faint. And if we suspect that he has brought his problem on himself by doing something fool-hardy or inappropriate, we may become judgmental and refuse to provide help even if requested. In our hesitation, we may begin to feel self-protective, "Will I be rejected if I offer help? Will I risk being hurt physically? What if the person resents my offer of help and regards it as an insult?" Such reflection diminishes the immediate impulse to provide care for the other.

The dilemma described above is at the heart of the distress felt by millions of people who suffer from invisible chronic illnesses (ICI), that is, diseases that are characterized by chronicity and symptoms that are not externally manifested. Symptoms common to invisible illnesses are chronic fatigue, chronic pain, memory loss, transient vision disturbances, muscle weakness, bladder urgency, peculiar physical sensations (numbness, tingling, "pins and needles," hot flashes), skin irritation, intestinal distress, and cognitive difficulty. These symptoms do not show up in a way that makes it obvious to an observer that a person is suffering. Unlike a wound that bleeds or requires stitches, a mending limb that is encased in a cast, or malfunctioning legs that necessitate use of a wheelchair, the symptoms of invisible illnesses have no external evidence of suffering that elicit compassion. Instead, the patient often endures suspicion and withdrawal from others. And so, in addition to disturbing, even agonizing and disabling symptoms, the patient of invisible illness suffers, often deeply, from the negative reactions of others. Such reactions frequently lead the patient to confusion, loneliness, self-pity, and self-doubt.

A patient, Anna, who is suffering from fibromyalgia, a condition that causes chronic pain, related this incident to us:

I was standing on line at the passport agency. The room was very warm and the wait seemed interminable. I thought at one point that we had been standing for fifteen minutes without any turnover at the counter. The pain traveling across my shoulder and down my right arm was excruciating. Childishly, I wanted to lean head on the man in front of me. I wanted to cry or throw a tantrum and toss my papers on the floor. I considered approaching the agents to tell them that I needed special assistance. But I felt reluctant, wondering what I would tell them. If I said, "I'm in pain so hurry me through," you can imagine the look I would get. I even fantasized about going up and saying, "I have cancer and I'm dying. Can you speed up the process?"

In the middle of these thoughts, a man in a wheelchair entered the stuffy room looking lost. A passport agent went to his side and bent towards him.

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With the launch of the SSF 5-Year Breakthrough Goal, 50in5: “To shorten the time to diagnose Sjögren’s by 50% in 5 years” we are also hoping to change how Sjögren’s is understood.

The Foundation knows how isolating being diagnosed with an invisible illness can be, but you are not alone. There are an estimated 4 million Americans suffering from Sjögren’s, both men and women of different ages and ethnicities.

This is why we are launching a new awareness campaign for our website, www.sjogrens.org, called “Faces of Sjögren’s” where we want to share your stories!

As a way to help recently diagnosed patients, in addition to helping others find a diagnosis quicker, these stories will help others relate because no patient is alone. Whether you are a patient, doctor, loved one or family member, we want to know your own personal experience with Sjögren’s. With your help, we hope this project will help us reach our 5-Year Breakthrough Goal!

When submitting your story:

- Stay within 250 words
- Include aspects of how Sjögren’s has affected your life and ways you have been able to effectively cope with your symptoms
- Include a few personal words of inspiration
- At the beginning of your story, please complete the following phrase, “When I was diagnosed with Sjögren’s, my first thought was...”
- And don’t forget to include a picture of yourself!

Email your story to tms@sjogrens.org with the subject “Faces of Sjögren’s” or mail them to the SSF office. Together we will conquer Sjögren’s! ■

September Breakthrough Bullet



50%
in 5 years
Sjögren's
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"Sick and Tired" continued from page 2 ▼

They spoke for a few minutes. Then she brought him forms and completed them for him. She gathered their completed work up in her hands and took them with her and disappeared behind the counter. She returned shortly with papers in hand. They exchanged a few words again, he signed the papers, and then turned his wheelchair towards the exit, which the agent opened, and left.

I felt tears of frustration spill down my face. I had been standing in utter pain for thirty minutes and contemplated a possible twenty more. For the millionth time since I have had to deal with this condition, I "wished" that I bore some sign that revealed the suffering I am enduring and then maybe others would assist me as the passport agent had helped the man in the wheelchair.

Then I felt small and selfish for having those thoughts. God knows, I don't want to be disfigured or incapable of walking. And believe me, I didn't begrudge for a second the help that the man in the wheelchair had received. I was even impressed by and admiring of the agent who had, of her own accord, gone out of her way to make obtaining a passport as easy as possible for him. But, oh, how I resented this disease that makes me suffer so terribly and restricts my life, at the same time that no one can see the suffering and no one offers help.

Anna's experience at the passport agency typifies the stressful consequences of chronic invisible illnesses. Diseases such as chronic fatigue syndrome, irritable bowel syndrome, HIV infection, multiple sclerosis (MS), endometriosis, Crohn's disease, fibromyalgia, and lupus erythematosus, though vastly differently illnesses, share characteristics that encompass invisible illness. They are diseases that cause extraordinary pain, fatigue, and a multiplicity of other symptoms that result in great distress and disability. These symptoms may seem to be the kind that most of us feel from time to time. Pain, for example, is part of everyone's life. We feel it with a minor sunburn, a stubbed toe, a bruise, or a hangnail. We feel it more intensely from a broken limb, from a third degree burn, or after surgery. It is part of an inborn warning system that notifies us that something needs to be tended to, whether with rest, medication, or a band-aid. For the most part, when the cause of pain is removed or when a recuperative period is over, the pain lessens and eventually retreats completely.

For chronic pain sufferers, however, there is rarely sufficient relief from pain and always the threat of a lifetime of pain-- pain more intense than any caused by the bumps and bruises of a normal life. It may be as intense as that which is experienced after surgery but without any promise of relief. The quality of this pain is

so different from transient aches and pains that language is inadequate to the task of describing it.

Similarly, fatigue is a symptom of some of these illnesses. At some point in the day, we all feel tired. We feel tired when we work too hard, don't sleep at night, or exercise too vigorously. There are myriad reasons for feeling tired. Like pain, tiredness is ordinarily the body's means of telling us that it is time to rest. Fatigue for those with chronic illnesses, however, can actually be disabling. This fatigue is relentless. Overexercise or overwork does not cause it and bed rest frequently fails to relieve it. It appears regardless of activity or inactivity, happiness or sadness. It simply exists in and of itself, and no medication, positive thought, or rest can relieve it.

Nonmeasureable Symptoms

Symptoms of invisible chronic illnesses are not only non-observable, but also typically immeasurable. They are subjective experiences. Thus, if a person who is suffering from multiple sclerosis notes that his memory seems to be lacking, there are few measures to determine whether indeed his ability to remember is failing. If someone cannot remember his name, family, or occupation, we acknowledge a serious and evident condition of amnesia. But when the memory loss is subtle and transient, we must rely on the person's self-awareness and description of the impairment. The person's subjective experience, however, is one that the patient, his family, and health-care providers reluctantly trust. The patient may wonder, "Is this really happening or am I just tired?" The patient's wife may reflect, "He always forgets at the most inopportune times, like when he is supposed to pick up a few groceries." The doctor may muse, "This patient is under too much stress." Without proof of a deficiency, such as results of medical tests, everyone seems bent on disproving the possibility that there has indeed been memory loss—the patient because he is self-doubting, the family members because they are suspicious, frustrated, or frightened, and the doctor because he doesn't observe any perceptible problem.

James, who has "mild" multiple sclerosis, describes a typical experience of what it is like to have a problem that is experienced but cannot be proven:

I have been playing golf for fifteen years, and every Saturday in the past few years I have played with three buddies of mine. We wager on each hole. Lately, when we finish a hole and I try to count my strokes, I can't remember a thing. It's weird. No matter what I do, I just can't remember the strokes. At first, we all laughed—joked about getting older. But after a while my partner

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Numoisyn Liquid

Prescribing Information

Ingredients: Water, sorbitol, linseed (flaxseed) extract, *Chondrus crispus*, methylparaben, sodium benzoate, potassium sorbate, dipotassium phosphate, propylparaben.

How Supplied: 30 mL per bottle or 300 mL per bottle.

Therapeutic Group: Numoisyn Liquid is an oral solution formulated for the relief of chronic and temporary xerostomia (dry mouth), which may be a result of disease, medication, oncology therapy, stress, or aging.

Indications: Numoisyn Liquid is indicated for the treatment of symptoms of dry mouth. Numoisyn Liquid relieves the symptoms of dry mouth by enhancing swallowing, improving speech mechanics, and lubricating the oral cavity like natural saliva. Numoisyn Liquid may be used to replace natural saliva when salivary glands are damaged or not functioning. The viscosity is similar to that of natural saliva.

Contraindications: Numoisyn Liquid are contraindicated in patients with a known history of hypersensitivity to any of the ingredients.

Special Precautions for Use: As Numoisyn Liquid contains linseed (flaxseed) extract, patients with irritable bowel syndrome or diverticular disease or those on a high linseed diet may experience abdominal discomfort.

Warning: Federal law restricts Numoisyn Liquid to sale by, or on the order of, a physician or properly licensed practitioner.

Interactions: There are no known interactions between Numoisyn Liquid and any medicinal or other products.

Directions for Use: Shake bottle well. Take 2 mL (about 1/2 teaspoon) of Numoisyn Liquid and rinse around in the mouth before swallowing. Use as needed.

Side Effects: Patients may experience difficulty in swallowing, altered speech, and changes in taste. If side effects persist or become severe, patients should contact a physician.

Storage: Store at room temperature. Do not refrigerate. Use within 3 months of first opening. KEEP OUT OF REACH OF CHILDREN.

Please Note: Numoisyn Liquid is translucent and may contain some natural particles that do not affect the quality of the product.

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Numoisyn Lozenges

Prescribing Information

Ingredients: Sorbitol (0.3 g per lozenge), polyethylene glycol, malic acid, sodium citrate, calcium phosphate dibasic, hydrogenated cottonseed oil, citric acid, magnesium stearate, and silicon dioxide.

Pharmaceutical Form: Oral lozenge

Contents: 100 lozenges per bottle. Net weight of 40 g (0.4 g per lozenge).

Therapeutic Group: Numoisyn Lozenges are oral lozenges formulated to promote lubrication of oral mucosa that may be dry due to a variety of circumstances, including medication, chemotherapy or radiotherapy, Sjögren's syndrome, or oral inflammation.

Indications: Numoisyn Lozenges are indicated for the treatment of xerostomia (dry mouth). Numoisyn Lozenges provide temporary relief of dry mouth due to damaged salivary function. Numoisyn Lozenges are formulated to support the natural protection of teeth provided by saliva so that no damage occurs to teeth with repeated use of the lozenges.

Contraindications: Numoisyn Lozenges are contraindicated in patients with fructose intolerance or a known history of hypersensitivity to any of the ingredients.

Warning: Federal law restricts Numoisyn Lozenges to sale by, or on the order of, a physician or properly licensed practitioner.

Interactions: There are no known interactions between Numoisyn Lozenges and any medicinal or other products.

Directions for Use: Let one Numoisyn Lozenge dissolve slowly in the mouth when needed. To obtain optimal effect, move the lozenge around in the mouth. Repeat as necessary. Do not exceed 16 lozenges in 24 hours.

Side Effects: Excessive consumption can cause minor digestive problems.

Storage: Store at room temperature. KEEP OUT OF REACH OF CHILDREN.

Overdose: No overdoses have been reported to date.

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was getting pissed off. My forgetting was interfering with our game. Once we gave up a hole because I just couldn't be sure about a stroke. We've figured out a way to keep count, but it's embarrassing and it isn't funny anymore. It is strangely happening at other times too. Like I'll watch a news program and my wife will ask about a news item that I've just seen and I'll be completely blank. I can't remember a sequence of information. I can remember the last part—strange.

I have this sickening sensation in my stomach as I strain to remember. I try to remember rather than just admit to myself that I can't and then relax.

I was so disturbed that I went to the neurologist. He asked me to describe my memory problems and when I was finished he chuckled a bit and said, "You know, Jim, we are all getting older—you probably have to start keeping lists." When I told him that I had done some reading about multiple sclerosis and memory loss as a common symptom, he said "So they say, so they say. But I don't think so. The researchers keep debating the issue. You just have to make sure that you are getting enough rest. Who knows, it may be that your limp so distracts you when you are playing that you lose some of your concentration." I felt foolish when I felt the office. I felt like I would have to argue with him to get him to understand that I really had a problem. But I figured it wasn't worth the bother since there wasn't anything he could do for me anyway.

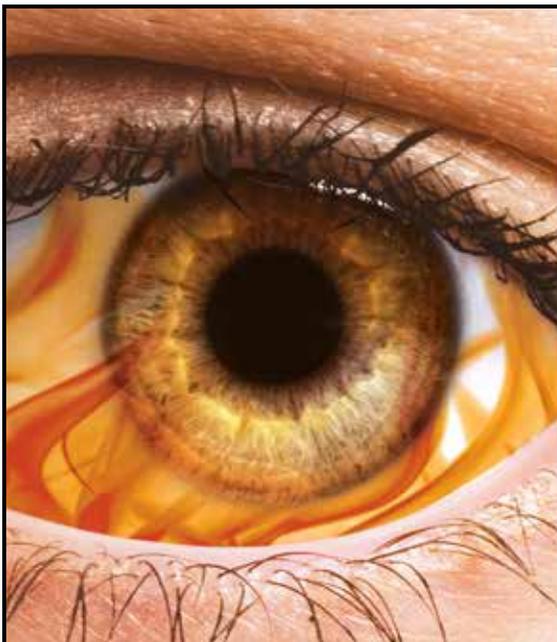
But I would have liked to have been able to tell my wife, "The neurologist confirmed that something is wrong with my memory." She wants to understand, but she thinks I've always been absentminded and now I'm even

more so. I'm not sure why I need anyone else to acknowledge what is happening to me. I feel furious when it happens. I guess I want to prove that it's really happening.

Diagnostic Dilemma

Jim's frustration with the immeasurability of his memory loss illustrates another integral aspect of the phenomenon of chronic invisible illnesses. Invisible diseases are so difficult to diagnose that they tend to be identified by the process of eliminating other disease possibilities. Patients become aware of vague, sometimes transient symptoms. Multiple sclerosis, for example, may appear initially as numbness in the limbs. The patient may dismiss the symptom as a result of excessive exercise; when he changes his exercise routine and the numbness passes, he is convinced that the new regimen relieved the problem. Then a new symptom occurs, such as intense fatigue, and the patient may feel compelled to see a physician.

Once the patient visits the physician, both he and the physician are confronted with the task of identifying the underlying cause of the symptom. Identifying the source is complicated by the type of symptoms that are described—numbness, fatigue, vision disturbance, pain. These symptoms defy medical measurement. They appear to be vague and unrelated. A persistent patient and a responsible doctor face the challenging prospect of determining the causes of the symptoms through the process of eliminating one possibility after another. The process is anxiety-provoking, uncomfortable, time-consuming, and costly. Doctor and patient struggle with the suspicion that the symptoms are psychosomatic or



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that the patient suffers from a mental disturbance. With each visit to the doctor and each test, the patient becomes hopeful that, at last, he will have an answer. Fear and dread of having a serious illness are surpassed by the driving need to know “What is making me so miserable?” This need to know is associated with the belief that “Once I know what I have, then I can handle it and receive treatment that will make me feel better, and I’ll know that I’m not crazy.”

Unfortunately, for patients with ICI, the diagnosis brings short-lived relief. The fear that the disease will attack vital organs, as, for example, in lupus or multiple sclerosis, replaces the relief felt on hearing the diagnosis. The diagnosis of post-polio syndrome triggers terrifying reminders of illness. For patients who are diagnosed with chronic fatigue syndrome, irritable bowel syndrome, or fibromyalgia, there is the disturbing fear that the disease has not been accurately identified. One patient cried, “How can I feel this awful and have something as vague and untreatable as irritable bowel syndrome? I am so afraid that someday they’ll find that I have cancer, but then it will be too late.”

Ellen’s experience is typical of a diagnosis built upon a bewildering process of elimination:

A year and a half ago, I started feeling this pain in my hand and somewhat in my shoulder and arm. I was pretty sure that the pain was caused by this new weight-lifting program I was doing. So I stopped for a while, but it got worse anyway. They thought at first that I had something called carpal tunnel syndrome. One doctor wanted to operate right away, but another advised me to wait. Now they are sure that it isn’t carpal tunnel, but they aren’t sure what it is. This last year the pain has gotten worse all the time. It is mostly in my neck, shoulder, and left arm. It had gotten so bad that I had to quit my job. I can’t concentrate or complete anything. Sometimes I wish I could just die, I am so overwhelmed with the pain.

I think I’ve had every test you can think of: MRI, EKG, EEG, spinal tap, X-rays, blood test, and urine tests. I’ve tried so many medications that my bathroom shelves look like a pharmacy. I decided to stop taking some narcotic pain relievers because I was afraid of the side effects, but I went through horrible withdrawal that was almost as bad as the pain. I’ve tried physical therapy, hypnotherapy, homeopathy, and biofeedback. They helped a little. Some of the medications helped somewhat too. But I’m still in pain.

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Recommended by eye doctors, tranquileyes eye hydrating therapy soothe dry, puffy eyes. The included gel packs can be warmed in a microwave and placed inside the goggles to stimulate tear production and the release of beneficial oils from the eyes’ meibomian glands, increasing relative humidity and moisture to relieve dry eyes. Or, freeze gel packs to reduce swelling and eye puffiness. The goggle can also be used during sleep, comfortably sheltering the eyes from drafts and light while keeping moisture in.

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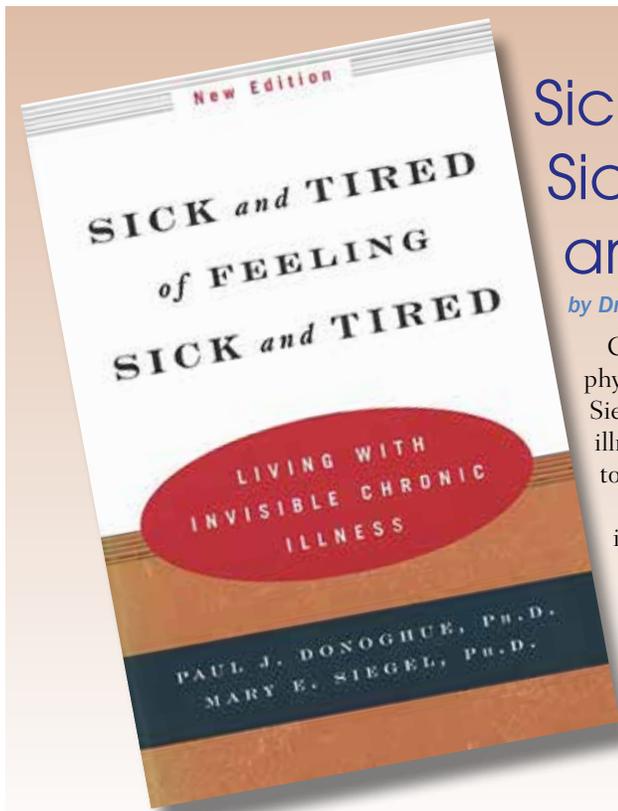


"Sick and Tired" continued from page 7 ▼

And—this is what is so unbelievable to me—I still don't know what I have. They have kind of reached a consensus that it is fibromyalgia, but one doctor said he doesn't even believe that there is such a condition. He said it is just a "catch-all" term that is used when there is no other explanation.

When Ellen first told us her "story," she felt sure that

her experience was unique. She was startled but comforted by the realization that she was not alone in her quest to find a name for her illness and a means of coping with it. For those of you reading this book who recognize the experience of illness that we have described, we hope that the following chapters comfort you and inspire you to love with your illness in a way that gives you dignity, confidence, and hope. ■



Sick and Tired of Feeling Sick and Tired: Living with an Invisible Chronic Illness

by Dr. Paul J. Donoghue and Dr. Mary E. Siegel

Chronic illness is often misunderstood because it lacks obvious physical symptoms. In this updated edition, Drs. Donoghue and Siegel highlight key components for someone living with a chronic illness, such as communicating with loved ones, conveying symptoms to a doctor and other closely related ailments.

This easy read will help one understand, sympathize and gain insight into living with an invisible chronic illness.

About the authors:

Dr. Paul J. Donoghue and Dr. Mary E. Siegel are psychologists in private practice in Stamford, Connecticut. Their work has been featured on "The Today Show," CNBC, and "Good Day New York," and in the *New York Times*.

This book can be purchased using the order form below, online at www.sjogrens.org or by contacting the Sjögren's Syndrome Foundation office at 800-475-6473.

	Non-Member Price	Member Price	Qty	Amount
Sick and Tired of Feeling Sick and Tired by Drs. Paul J. Donoghue and Mary E. Siegel	\$15.00	\$12.00		
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For patients with Sjögren's syndrome

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

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

Please see important information about EVOXAC below.



Important Safety Information

What is EVOXAC?

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

Who Should Not Take EVOXAC?

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

What should I tell my Healthcare Provider?

• Tell your healthcare provider if you have any of the following conditions:

- History of heart disease;
- Controlled asthma;
- Chronic bronchitis;
- Chronic obstructive pulmonary disease (COPD);
- History of kidney stones;
- History of gallbladder stones

• Tell your healthcare provider if you are trying to become pregnant, are already pregnant, or are breastfeeding.

• Tell your healthcare provider about all medications that you are taking, including those you take without a prescription. It is particularly important to tell your healthcare provider if you are taking any heart medications especially "beta-blockers".

• If you are older than 65, your healthcare provider may want to monitor you more closely.

General Precautions with EVOXAC

• When taking EVOXAC use caution when driving at night or performing other hazardous activities in reduced lighting because EVOXAC may cause blurred vision or changes in depth perception.

• If you sweat excessively while taking EVOXAC drink extra water and tell your health care provider, as dehydration may develop.

• The safety and effectiveness of EVOXAC in patients under 18 years of age have not been established.

What are some possible side effects of EVOXAC?

• In clinical trials, the most commonly reported side effects were excessive sweating, headache, nausea, sinus infection, upper respiratory infections, runny nose, and diarrhea.

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

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

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

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(cevimeline HCl) 30 mg
Capsules

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

Brief Summary – See package insert for full Prescribing Information.

EVOXAC® Capsules (cevimeline hydrochloride)

INDICATIONS AND USAGE

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

CONTRAINDICATIONS

Cevimeline is contraindicated in patients with uncontrolled asthma. Known hypersensitivity to cevimeline, and when miosis is undesirable, e.g., in acute iritis and in narrow-angle (angle-closure) glaucoma.

WARNINGS

Cardiovascular Disease:

Cevimeline can potentially alter cardiac conduction and/or heart rate. Patients with significant cardiovascular disease may potentially be unable to compensate for transient changes in hemodynamics or rhythm induced by EVOXAC®. EVOXAC® should be used with caution and under close medical supervision in patients with a history of cardiovascular disease evidenced by angina pectoris or myocardial infarction.

Pulmonary Disease:

Cevimeline can potentially increase airway resistance, bronchial smooth muscle tone, and bronchial secretions. Cevimeline should be administered with caution and with dose medical supervision to patients with controlled asthma, chronic bronchitis, or chronic obstructive pulmonary disease.

Ocular:

Ophthalmic formulations of muscarinic agonists have been reported to cause visual blurring which may result in decreased visual acuity, especially at night and in patients with central lens changes, and to cause impairment of depth perception. Caution should be advised while driving at night or performing hazardous activities in reduced lighting.

PRECAUTIONS

General:

Cevimeline toxicity is characterized by an exaggeration of its parasympathomimetic effects. These may include: headache, visual disturbance, lacrimation, sweating, respiratory distress, gastrointestinal spasm, nausea, vomiting, diarrhea, atrioventricular block, tachycardia, bradycardia, hypotension, hypertension, shock, mental confusion, cardiac arrhythmia, and tremors.

Cevimeline should be administered with caution to patients with a history of nephrolithiasis or cholelithiasis. Contractions of the gallbladder or biliary smooth muscle could precipitate complications such as cholecystitis, cholangitis and biliary obstruction. An increase in the ureteral smooth muscle tone could theoretically precipitate renal colic or ureteral reflux in patients with nephrolithiasis.

Information for Patients: Patients should be informed that cevimeline may cause visual disturbances, especially at night, that could impair their ability to drive safely.

If a patient sweats excessively while taking cevimeline, dehydration may develop. The patient should drink extra water and consult a health care provider.

Drug Interactions:

Cevimeline should be administered with caution to patients taking beta adrenergic antagonists, because of the possibility of conduction disturbances. Drugs with parasympathomimetic effects administered concurrently with cevimeline can be expected to have additive effects. Cevimeline might interfere with desirable antimuscarinic effects of drugs used concomitantly.

Drugs which inhibit CYP2D6 and CYP3A3/4 also inhibit the metabolism of cevimeline. Cevimeline should be used with caution in individuals known or suspected to be deficient in CYP2D6 activity, based on previous experience, as they may be at a higher risk of adverse events. In an *in vitro* study, cytochrome P450 isozymes 1A2, 2A6, 2C9, 2C19, 2D6, 2E1, and 3A4 were not inhibited by exposure to cevimeline.

Carcinogenesis, Mutagenesis and Impairment of Fertility:

Lifetime carcinogenicity studies were conducted in CD-1 mice and F-344 rats. A statistically significant increase in the incidence of adenocarcinomas of the uterus was observed in female rats that received cevimeline at a dosage of 100 mg/kg/day (approximately 8 times the maximum human exposure based on comparison of AUC data). No other significant differences in tumor incidence were observed in either mice or rats.

Cevimeline exhibited no evidence of mutagenicity or clastogenicity in a battery of assays that included an Ames test, an *in vitro* chromosomal aberration study in mammalian cells, a mouse lymphoma study in L5178Y cells, or a micronucleus assay conducted *in vivo* in ICR mice.

Cevimeline did not adversely affect the reproductive performance or fertility of male Sprague-Dawley rats when administered for 63 days prior to mating and throughout the period of mating at dosages up to 45 mg/kg/day (approximately 5 times the maximum recommended dose for a 60 kg human following normalization of the data on the basis of body surface area estimates). Females that were treated with cevimeline at dosages up to 45 mg/kg/day from 14 days prior to mating through day seven of gestation exhibited a statistically significantly smaller number of implantations than did control animals.

Pregnancy:

Pregnancy Category C.

Cevimeline was associated with a reduction in the mean number of implantations when given to pregnant Sprague-Dawley rats from 14 days prior to mating through day seven of gestation at a dosage of 45 mg/kg/day (approximately 5 times the maximum recommended dose for a 60 kg human when compared on the basis of body surface area estimates). This effect may have been secondary to maternal toxicity. There are no adequate and well-controlled studies in pregnant women. Cevimeline should be used during pregnancy only if the potential benefit justifies the potential risk to the fetus.

Nursing Mothers:

It is not known whether this drug is secreted in human milk. Because many drugs are excreted in human milk, and because of the potential for serious adverse reactions in nursing infants from EVOXAC®, a decision should be made whether to discontinue nursing or discontinue the drug, taking into account the importance of the drug to the mother.

Pediatric Use:

Safety and effectiveness in pediatric patients have not been established.

Geriatric Use:

Although clinical studies of cevimeline included subjects over the age of 65, the numbers were not sufficient to determine whether they respond differently from younger subjects. Special care should be exercised when cevimeline treatment is initiated in an elderly patient, considering the greater frequency of decreased hepatic, renal, or cardiac function, and of concomitant disease or other drug therapy in the elderly.

ADVERSE REACTIONS

Cevimeline was administered to 1777 patients during clinical trials worldwide, including Sjögren's patients and patients with other conditions. In placebo-controlled Sjögren's studies in the U.S., 320 patients received cevimeline doses ranging from 15 mg tid to 60 mg tid, of whom 93% were women and 7% were men. Demographic distribution was 90% Caucasian, 5% Hispanic, 3% Black and 2% of other origin. In these studies, 14.6% of patients discontinued treatment with cevimeline due to adverse events.

The following adverse events associated with muscarinic agonism were observed in the clinical trials of cevimeline in Sjögren's syndrome patients:

Adverse Event	Cevimeline	Placebo
	30 mg (tid) n=533	(tid) n=164
Excessive Sweating	18.7%	2.4%
Nausea	13.8%	7.9%
Rhinitis	11.2%	5.4%
Diarrhea	10.3%	10.3%
Excessive Salivation	2.2%	0.6%
Urinary Frequency	0.9%	1.8%
Asthenia	0.5%	0.0%
Flushing	0.3%	0.6%
Polyuria	0.1%	0.6%

*n is the total number of patients exposed to the dose at any time during the study.

In addition, the following adverse events (≥3% incidence) were reported in the Sjögren's clinical trials:

Adverse Event	Cevimeline	Placebo	Adverse Event	Cevimeline	Placebo
	30 mg (tid) n=533	(tid) n=164		30 mg (tid) n=533	(tid) n=164
Headache	14.4%	20.1%	Conjunctivitis	4.3%	3.6%
Sinusitis	12.3%	10.9%	Dizziness	4.1%	7.3%
Upper Respiratory Tract Infection	11.4%	9.1%	Bronchitis	4.1%	1.2%
Dyspepsia	7.8%	8.5%	Arthralgia	3.7%	1.8%
Abdominal Pain	7.6%	6.7%	Surgical Intervention	3.3%	3.0%
Urinary Tract Infection	6.1%	3.0%	Fatigue	3.3%	1.2%
Coughing	6.1%	3.0%	Pain	3.3%	3.0%
Pharyngitis	5.2%	5.4%	Skeletal Pain	2.8%	1.8%
Vomiting	4.6%	2.4%	Insomnia	2.4%	1.2%
Injury	4.5%	2.4%	Hot Flashes	2.4%	0.0%
Back Pain	4.5%	4.2%	Rigors	1.3%	1.2%
Rash	4.3%	6.0%	Anxiety	1.3%	1.2%

*n is the total number of patients exposed to the dose at any time during the study.

The following events were reported in Sjögren's patients at incidences of <3% and ≥1%: constipation, tremor, abnormal vision, hypertonia, peripheral edema, chest pain, myalgia, fever, anorexia, eye pain, earache, dry mouth, vertigo, salivary gland pain, pruritus, influenza-like symptoms, eye infection, post-operative pain, vaginitis, skin disorder, depression, hiccup, hyporeflexia, infection, fungal infection, sialadenitis, otitis media, erythematous rash, neurodermatitis, edema, salivary gland enlargement, allergy, gastroesophageal reflux, eye abnormality, migraine, tooth disorder, epistaxis, flatulence, toothache, ulcerative stomatitis, anemia, hypoesthesia, cystitis, leg cramps, abscess, eruption, moniliasis, palpitation, increased amylase, xerophthalmia, allergic reaction.

The following events were reported rarely in treated Sjögren's patients (<1%): Causal relation is unknown:

Body as a Whole Disorders: aggravated allergy, precordial chest pain, abnormal crying, hematoma, leg pain, edema, periorbital edema, activated part trauma, pallor, changed sensation temperature, weight decrease, weight increase, choking, mouth edema, syncope, malaise, face edema, substernal chest pain

Cardiovascular Disorders: abnormal ECG, heart disorder, heart murmur, aggravated hypertension, hypotension, arrhythmia, extrasystoles, t wave inversion, tachycardia, supraventricular tachycardia, angina pectoris, myocardial infarction, pericarditis, pulmonary embolism, peripheral ischemia, superficial phlebitis, purpura, deep thrombophlebitis, vascular disorder, vasculitis, hypertension

Digestive Disorders: appendicitis, increased appetite, ulcerative colitis, diverticulitis, duodenitis, dysphagia, enterocolitis, gastric ulcer, gastritis, gastroenteritis, gastrointestinal hemorrhage, gingivitis, glossitis, rectum hemorrhage, hemorrhoids, ileus, irritable bowel syndrome, melena, mucositis, esophageal stricture, esophagitis, oral hemorrhage, peptic ulcer, periodontal destruction, rectal disorder, stomatitis, tenesmus, tongue discoloration, tongue disorder, geographic tongue, tongue ulceration, dental caries

Endocrine Disorders: increased glucocorticoids, goiter, hypothyroidism

Hematologic Disorders: thrombocytopenic purpura, thrombocytopenia, thrombocytopenia, hypochromic anemia, eosinophilia, granulocytopenia, leukopenia, leukocytosis, cervical lymphadenopathy, lymphadenopathy

Liver and Biliary System Disorders: cholelithiasis, increased gamma-glutamyl transferase, increased hepatic enzymes, abnormal hepatic function, viral hepatitis, increased serum glutamate oxaloacetate transaminase (SGOT) (also called AST-aspartate aminotransferase), increased serum glutamate pyruvate transaminase (SGPT) (also called ALT-alanine aminotransferase)

Metabolic and Nutritional Disorders: dehydration, diabetes mellitus, hypercalcemia, hypercholesterolemia, hyperglycemia, hyperlipidemia, hypertriglyceridemia, hyperuricemia, hypoglycemia, hypokalemia, hyponatremia, thirst

Musculoskeletal Disorders: arthritis, aggravated arthritis, arthropathy, femoral head avascular necrosis, bone disorder, bursitis, costochondritis, plantar fasciitis, muscle weakness, osteomyelitis, osteoporosis, synovitis, tendinitis, tenosynovitis

Neoplasms: basal cell carcinoma, squamous carcinoma

Nervous Disorders: carpal tunnel syndrome, coma, abnormal coordination, dysesthesia, dyskinesia, dysphonia, aggravated multiple sclerosis, involuntary muscle contractions, neuralgia, neuropathy, paresthesia, speech disorder, agitation, confusion, depersonalization, aggravated depression, abnormal dreaming, emotional lability, manic reaction, paranoia, somnolence, abnormal thinking, hyperkinesia, hallucination

Miscellaneous Disorders: fall, food poisoning, heat stroke, joint dislocation, post-operative hemorrhage

Resistance Mechanism Disorders: cellulitis, herpes simplex, herpes zoster, bacterial infection, viral infection, genital moniliasis, sepsis

Respiratory Disorders: asthma, bronchospasm, chronic obstructive airway disease, dyspnea, hemoptysis, laryngitis, nasal ulcer, pleural effusion, pleurisy, pulmonary congestion, pulmonary fibrosis, respiratory disorder

Rheumatologic Disorders: aggravated rheumatoid arthritis, lupus erythematosus rash, lupus erythematosus syndrome

Skin and Appendages Disorders: acne, alopecia, burn, dermatitis, contact dermatitis, lichenoid dermatitis, eczema, furunculosis, hyperkeratosis, lichen planus, nail discoloration, nail disorder, onychia, onychomycosis, paronychia, photosensitivity reaction, rosacea, scleroderma, seborrhea, skin discoloration, dry skin, skin exfoliation, skin hypertrophy, skin ulceration, urticaria, verruca, bullous eruption, cold clammy skin

Special Senses Disorders: deafness, decreased hearing, motion sickness, parosmia, taste perversion, blepharitis, cataract, corneal opacity, corneal ulceration, diplopia, glaucoma, anterior chamber eye hemorrhage, keratitis, keratoconjunctivitis, mydriasis, myopia, photopsia, retinal deposits, retinal disorder, scleritis, vitreous detachment, tinnitus

Urogenital Disorders: epididymitis, prostatic disorder, abnormal sexual function, amenorrhea, female breast neoplasm, malignant female breast neoplasm, female breast pain, positive cervical smear test, dysmenorrhea, endometrial disorder, intermenstrual bleeding, leukorrhea, menorrhagia, menstrual disorder, ovarian cyst, ovarian disorder, genital pruritus, uterine hemorrhage, vaginal hemorrhage, atrophic vaginitis, albuminuria, bladder discomfort, increased blood urea nitrogen, dysuria, hematuria, micturition disorder, nephrosis, nocturia, increased nonprotein nitrogen, pyelonephritis, renal calculus, abnormal renal function, renal pain, stranguary, urethral disorder, abnormal urine, urinary incontinence, decreased urine flow, pyuria

In one subject with lupus erythematosus receiving concomitant multiple drug therapy, a highly elevated ALT level was noted after the fourth week of cevimeline therapy. In two other subjects receiving cevimeline in the clinical trials, very high ALT levels were noted. The significance of these findings is unknown.

Additional adverse events (relationship unknown) which occurred in other clinical studies (patient population different from Sjögren's patients) are as follows:

cholinergic syndrome, blood pressure fluctuation, cardiomegaly, postural hypotension, aphasia, convulsions, abnormal gait, hyperesthesia, paralysis, abnormal sexual function, enlarged abdomen, change in bowel habits, gum hyperplasia, sensitivity obstruction, bundle branch block, increased creatine phosphokinase, electrolyte abnormality, glycosuria, gout, hyperkalemia, hyperproteinemia, increased lactic dehydrogenase (LDH), increased alkaline phosphatase, failure to thrive, abnormal platelets, aggressive reaction, amnesia, apathy, delirium, delusion, dementia, illusion, impotency, neurosis, paranoid reaction, personality disorder, hyperhemoglobinemia, apnea, atelectasis, yawning, oliguria, urinary retention, distended vein, lymphocytosis

The following adverse reaction has been identified during post-approval use of EVOXAC®. Because post-marketing adverse 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.

Post-Marketing Adverse Events: Liver and Biliary System Disorders: cholecystitis

MANAGEMENT OF OVERDOSE

Management of the signs and symptoms of acute overdosage should be handled in a manner consistent with that indicated for other muscarinic agonists: general supportive measures should be instituted. If medically indicated, atropine, an anti-cholinergic agent, may be of value as an antidote for emergency use in patients who have had an overdose of cevimeline. If medically indicated, epinephrine may also be of value in the presence of severe cardiovascular depression or bronchoconstriction. It is not known if cevimeline is dialyzable.

Rx Only

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For additional information
please call toll free:
1-877-437-7763

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I Stood Up... (in memory)

*Mourning the Loss of Our Friend,
SSF Staff Member – Cynthia Williamson*



It is with a heavy heart that the SSF announces that our friend and SSF Director of Field Services Cynthia Williamson passed away in a car accident on Saturday, August 18th at the young age of 27.

Cynthia's energy, dedication and persistence was the perfect example of a person who "stood up" for Sjögren's. Just look at her picture at the Nashville Marathon as she cheered on our Team Sjögren's runners! Cynthia always went the extra mile to ensure that our volunteers, donors and Sjögren's patients always knew how important they were to the SSF. She truly always stood up!

Cynthia joined the SSF in January 2008 and made incredible contributions during her tenure with the Foundation. Last year, Cynthia was promoted to Director of Field Services due to her commitment and leadership

qualities. For those who worked with Cynthia, you quickly saw her dedication in helping Sjögren's patients through her work with our 65 support groups, our Team Sjögren's Marathon Training Program, our National Patient Conferences, our Sjögren's Walkabouts as well as many other initiatives and events.

Cynthia will be missed by her friends and co-workers here at the SSF as well as by her family including her three beautiful children, her mother and step-father, and her dedicated and loving siblings.

As a way to remember Cynthia, we hope you will all take the time to hug your children and grandchildren – as Cynthia loved kids. Cynthia also believed that the SSF was her extended family and she was always working towards increasing awareness for Sjögren's patients. So in her honor, we hope you will step up and do something to change the face of Sjögren's! We know she would love to know that she inspired one person to go out and make a difference.

We will miss Cynthia, but together we can ensure her legacy continues on!



How will you Stand Up?

Friends Helping Friends



Congratulations! and Thank You for participating in the 2012 Friends Helping Friends Campaign!

Our Friends raised an outstanding \$17,825 for this year's campaign!

The following three names were drawn as the winners of the Friends Helping Friends Campaign:

Barbara of Chicago, IL Colleen of Ridgefield, WA Geraldine of Madison, CT

The winners have been awarded a Lifetime Membership to the Sjögren's Syndrome Foundation.

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.

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:



Standards of Excellence


in memoriam
In Memory of Barbara Hardin

Yolanda & Sara

In Memory of Betty StrochLinda & Larry Levin
Judy & Bernie Galtman**In Memory of Cecilia Hauck**Roger, Adeline & Teresa Rzonca
Sally Fernholz
Patricia & John Radabaugh**In Memory of Charlene Prybylski**

Pat Sand

In Memory of Dean Soliday

State of Connecticut Dept. of Transportation

In Memory of Debbie McGovney

Kim McHale

In Memory of Eileen Hardesty

Joan Hardesty

In Memory of Elaine DillbergerAnn Elizabeth Johnson
Lois Kiefer
Friends at Dell EqualLogic
Pauline Curtis
Phyllis Powder
Robert & Sharon Blackwell
Elaine & Charles Clark
Claire & Greg Smith & Family
Hampstead Circle of Lutheran
Church of Reconciliation
Shirley Galisdorfer**In Memory of Elizabeth Fields**

Kathleen Williams

In Memory of Eleanor JarrellsSusan Lindberg
Peggy Hedback
Karen & Mark Larson
Steven & Susan Carlson
Eris & Steven Cole-Hunter
Mary & Dale DeVries**In Memory of Elliot Weisenberg**

Elaine & Larry Levin

In Memory of Hope Gonzalez

The Castagno Family

In Memory of Jane Coffey

Maurice & Edith Eash

In Memory of Janice Polisner

Barbara & Steve Waxer

In Memory of Jay Feiner

Elaine & Larry Levin

In Memory of Jean BassoLinda Danek
Judith Batteen
Sally Beaudoin
Mary Ziegler
Lynette Houk**In Memory of Joan Swain**George Swain
Janelle Burnette**In Memory of LaRue Horst**

Dr. Roberta Kurtz & Mrs. Hazel Kurtz

In Memory of Mitchell Friedlaender, MD

Lynne & Lance Forstot

In Memory of Nancy GrayRita Gress
Lori & Joey Moore
Armond & Linda Leigh
Jacqueline Phillips**In Memory of Natanli Sterman, PhD**

Bonnie Schneider

In Memory of Patricia WardCharna Lefton
Anne Hickman
Jean Woods
Joan Chapel
Kathleen Presko
Dianne Cress**In Memory of Patricia Woodward**Patricia Massengill
Margaret Smith
Alan & Martha Nielson**In Memory of Ronnie Spilton**

ECC Discussion Group

In Memory of Sandra NagyThe Mustang Ladies
Kathleen Abrams**In Memory of Stan Rubin**

Stephen & Deirdre Perl-Strock

In Memory of Stu Satalof

Stephen & Deirdre Perl-Strock

In Memory of Terri SelfMarilyn Downs-Steward
Cathy Ingels**In Memory of Tete**

Delores Fritz


in honor
**In Honor of Bonnie & Marc Sosin's
25th Wedding Anniversary**

Alan & Fern Rosenberg

In Honor of Dr. Archibald Skemp

Sandi Karnowski

In Honor of Dr. Cheryl Levin

Elaine & Larry Levin

In Honor of Dr. Robert Fox & Office Assistants

Linda Zarzeczny

In Honor of Jennifer Unger's Birthday

Dad & Mom

In Honor of Leah Miller's Birthday

Laura Grigull

In Honor of Melissa Glazer's 30th Birthday

Carol Glazer

**In Honor of Mr. & Mrs. Mort Weisenfeld's
Birthday & Anniversary**

Bert Cohen

In Honor of Nancy & David Hargrove

Elizabeth Hargrove

In Honor of Phyll Walsh

Stacy Stoutenberg

In Honor of Sheila Syty

Redeye Dog

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



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 US and can range from a 1-mile fun run to a 5k race to even a 10k distance. 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 *Turkey Trots 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 – than 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*!



Viva Las Vegas!

Join Team Sjögren's in Las Vegas!



Take a gamble by signing up to join our *Team Sjögren's* Marathon Training Program for the Las Vegas marathon and half marathon. This program will take a walker or novice runner and prepare you to walk or run in the Las Vegas Marathon or Half Marathon!

Consider joining us for this December 2nd event where you will be able to enjoy the "Strip at Night" as we run a late afternoon marathon or half marathon with 25,000 other runners from all over the world! The marathon and half marathon course takes you up and down the Las Vegas Strip and is sure to be an amazing experience with bands along the route as well as cheerleaders to support us as we run or walk!

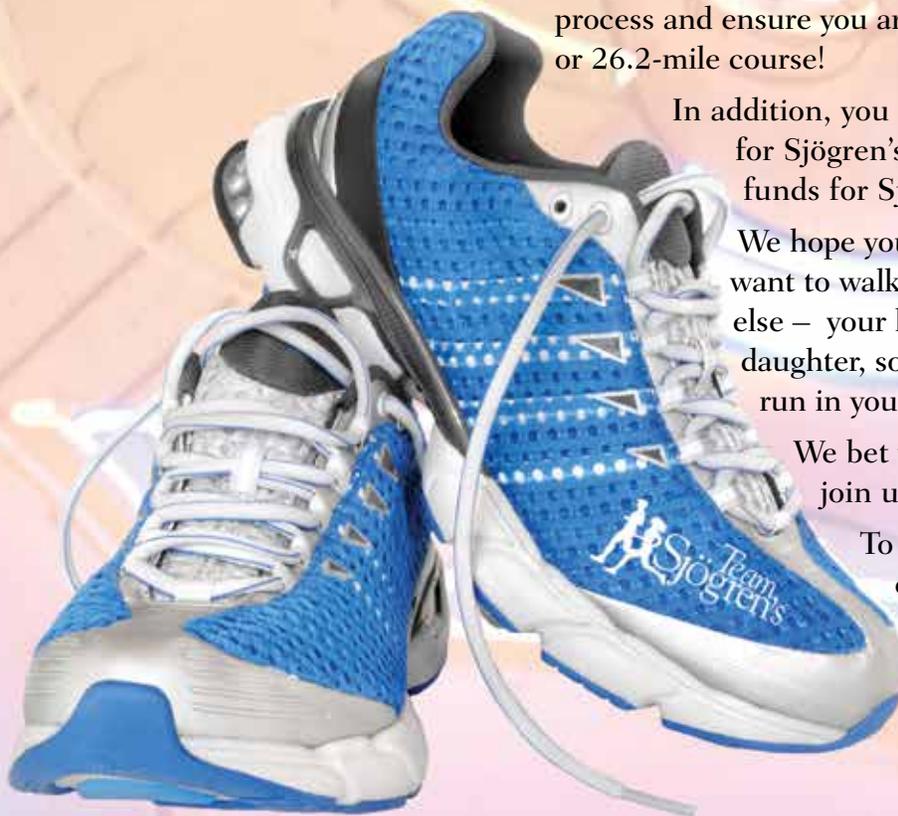
By signing up to join *Team Sjögren's*, you not only will receive world-class training but also leadership and mentorship from past runners and staff. You will receive coaching from our Team Trainer as well as our Team Nutritionist. The staff of the SSF will help guide you through the entire process and ensure you are ready to complete either the 13.1 or 26.2-mile course!

In addition, you not only will be raising awareness for Sjögren's but also helping raise crucial funds for Sjögren's research and education.

We hope you will join us! If you don't think you want to walk or run, help us recruit someone else – your husband, wife, sister, cousin, daughter, son or friend – and have them run in your honor.

We bet you can do it! Take a chance and join us. Viva Las Vegas!

To learn more about *Team Sjögren's*, contact Steven Taylor at 800-475-6473, ext. 211, or staylor@sjogrens.org



The Moisture Seekers

Sjögren's Syndrome Foundation Inc.
6707 Democracy Blvd., Ste 325
Bethesda, MD 20817

Phone: 800-475-6473

Fax: 301-530-4415

Join in the fun! 2012 SSF Special Event Calendar

The SSF is very excited for all of our events coming this Fall. Look at our special event calendar below to see if there is an event coming to your area.

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

October

- 13** **Capital Region Walkabout**
Colonie Center Mall
Albany, New York
Registration: 10:00am
Walkabout Step-Off: 11:15am
- 14** **Vermont Walkabout**
University Mall
South Burlington, Vermont
Registration: 10am
Walkabout Step-Off: 11am

November

- 15** **Dallas, Ft. Worth & Northern Texas Sip for Sjögren's**
Whole Foods
11700 Preston Road
Dallas, Texas
- 22** **Turkey Trots Across America**
Throughout the United States
Find your local run at www.active.com
Create a team by signing up on our Turkey Trots Across America page at www.firstgiving.com/ssf website

Help to Make a Difference in your Community!

We are currently recruiting committee members for all of our events.

Please call to see if there is an event in your area (800-475-6473).

December

- 2** **Team Sjögren's Las Vegas Rock n' Roll Marathon**
Las Vegas, Nevada

sip for
Sjögren's
a fine water
tasting event



Team Sjögren's

Sjögren's Walkabout

