

# The Moisture Seekers



www.sjogrens.org

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## National Patient Conference Award Winners

Every year we recognize our most dedicated volunteers through awards that are announced at the Awards Banquet held during our National Patient Conference. We could not accomplish all that we do without the hard work and dedication of volunteers like these awardees.

### Healthcare Professional Leadership Award – Gary Foulks, MD

Dr. Foulks first began volunteering for the Sjögren's Syndrome Foundation in 2001. Recognized internationally as a leader in dry eye, the

Foundation asked Dr. Foulks to serve on its National

Board of Directors, on which he has generously contributed his time and expertise for the past 8 years. Dr. Foulks has served as Treasurer, Chairperson-Elect and most recently as Chairperson



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## Sjögren's Syndrome Foundation Resources Available To You

If you received this newsletter in your mailbox then most likely you are a member of the Sjögren's Syndrome Foundation. As a member, in addition to this newsletter, the SSF makes numerous resources available to you.

One of the main benefits of being a member of the Foundation is adding your voice to the cause. We have an active group of members – made up of patients, their friends and family – acting as one voice together to raise awareness about how debilitating and serious of an illness Sjögren's is.

However, there are other resources members are able to take advantage of on a daily basis. Some members have been a part of the SSF for decades and others just joined last month. We wanted to make sure

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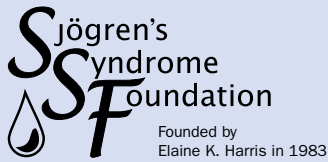
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for the Board. Under Dr. Foulks' leadership, the SSF expanded its research and awareness initiatives including the launching of an annual awareness campaign. Dr. Foulks has spoken at numerous patient and professional conferences on behalf of the SSF, most notably being the first ophthalmologist invited to present on dry eye and Sjögren's at the American College of Rheumatology Annual Meeting. Dr. Foulks continues his commitment to Sjögren's patients by serving as Co-Chair of the Ocular Working Group for the SSF's newest initiative - Clinical Practice Guidelines in Sjögren's.

Dr. Foulks' longstanding career in dry eye and ophthalmology includes a lifetime filled with accomplishments. He currently serves as Editor of *The Ocular Surface*, a journal linking science and clinical issues in dry eye, and just this year retired as Director of Cornea Service and Arthur and Virginia Keeney Professor of Ophthalmology at the University Of Louisville. Dr. Foulks, throughout his career, has demonstrated a commitment to Sjögren's patients that has no boundaries, and no matter where his career has taken him, he has always remains devoted to the SSF and its mission!

### Volunteer Leadership Award – Estrella Bibbey



Estrella Bibbey first was introduced to the Sjögren's Syndrome Foundation in 2005 when she volunteered to serve as a Host at our National Patient Conference in San Francisco. From that one volunteer opportunity, Estrella has continued to give of herself, her time and her talents to help expand awareness for Sjögren's as well as help raise crucial funds for Sjögren's research.

Today, Estrella serves on the National Board of Directors for the Sjögren's Syndrome Foundation where she works on various task forces and committees. Estrella also has served as an awareness volunteer and Sjögren's spokesperson for the past few years and in 2010, volunteered her time to serve as one of three patients whose stories were highlighted on the first-ever Sjögren's educational DVD.

In 2010, Estrella once again set the example for Sjögren's patients when she decided to make a difference in her local community of Santa Cruz. Estrella developed a localized version of Team Sjögren's, the SSF's marathon training program. Estrella took Team Sjögren's one step further by recruiting friends to join her in training for a six mile race while also raising crucial funds for Sjögren's research. Estrella organized weekly training sessions as well as promoted the program through the local media. Estrella was successful at getting Team Sjögren's into her local media and was proud that 16 friends joined her in July 2010 as they ran the 6

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mile race, proudly displaying Team Sjögren's shirts and raising awareness. Not only was awareness increased in her local community, but collectively, her team was able to raise nearly \$15,000 for the SSF.

Estrella is a great example of a person who won't let her personal struggles with Sjögren's interfere with how she will make a difference in her world! The SSF is proud to recognize Estrella for standing up for Sjögren's!

#### **Awareness Award – Kathryn McCarren**



Kathy McCarren has volunteered for the Sjögren's Syndrome Foundation for the past 20 years. Diagnosed earlier than most Sjögren's patients, Kathy knew she needed to help increase awareness for the disease and started volunteering for the SSF right away. From serving as a local support group leader to volunteering as

an awareness ambassador, Kathy stepped into any role the SSF asked her to do.

In 2010, Kathy was asked to commit to a year-long awareness campaign on Dry Mouth and Sjögren's and immediately stepped up to the challenge. Over the past year, Kathy has spoken to various media outlets, conducted interviews and helped to increase awareness by telling her personal Sjögren's story. Most notably in 2010, Kathy was highlighted on Sirius Satellite Radio on a series on dryness and Sjögren's. In addition, Kathy also traveled to New York City to take part in a media round table discussion, where she presented her personal story with Sjögren's to a group of magazine and newspaper journalists to encourage them to write stories on Sjögren's.

In addition, Kathy has assisted with advocacy issues on Capitol Hill to benefit Sjögren's patients. She most recently spoke during a Congressional Briefing about the importance of Sjögren's research funded by the National Institutes of Health.

Looking back over the past 20 years of Kathy's many contributions to Sjögren's, it is only fitting that the SSF recognize Kathy for her outstanding leadership, service and commitment in the fight against Sjögren's.

#### **Development Award – Cheryl Levin**

Congratulations to Cheryl Levin, Fundraiser Extraordinaire, the Top Sjögren's Walkabout Fundraiser in the nation for 2010 who personally raised a record-breaking \$15,300 for the 2010 Chicago Area Walkabout.

Cheryl's story is much like that of many others... an otherwise healthy active woman, who, because of Sjögren's, has not been able to do the physical activities that she loves to do the most, often-times even daily routine activities seem impossible.



Cheryl did not let this stop her - Sjögren's may have taken a toll on her health, but not her spirit! Cheryl found the strength to fight back by deciding to participate in the Chicago area

walkabout and fundraise by sending request letters to friends and family while also setting up her own fundraising webpage that shared her personal story about Sjögren's and how it has affected her life. The outpouring of support was outstanding and Cheryl continued to fundraise all the way until the walk – setting a nationwide Walkabout record by individually raising over \$15,300!

Cheryl serves as an example of how the power of one voice can change the face of Sjögren's!

#### **Media Award – WJLA-ABC7 (Washington, DC)**



In 2010, the SSF partnered with Daiichi-Sankyo and WJLA TV, the ABC affiliate in Washington, DC, to develop a month-long awareness campaign on dryness and Sjögren's. The goal of the

campaign was to increase the knowledge of Washington DC residents about the connection between dryness symptoms and Sjögren's.

With the help of a New York City PR Firm, MSL, the SSF and WJLA launched a public service announcement and website banner ads promoting the Sjögren's Syndrome Foundation along with [www.livingwithdryness.com](http://www.livingwithdryness.com) – a comprehensive new website connecting dryness symptoms with Sjögren's. In addition to the promotional spots, WJLA also organized a 2-hour live phone bank where viewers of WJLA's evening news could call in and talk to Sjögren's volunteers about their dryness symptoms. Over 200 calls were received during the broadcast which also included interviews with our two spokespeople, Dr. Herbert Baraf, Washington, DC-area rheumatologist and Steven Taylor, CEO of the SSF. These interviews reached over 3.2 million viewers in the DC metro market.

Thank you to WJLA-TV for organizing this amazing awareness effort – a first in SSF history. ■



"SSF Resources" continued from page 1 ▼

everyone knew what resources are available and how to access them. So throughout this issue you will find various Foundation resources listed that are available to all members of the SSF.

### Brochures Available for You and Your Doctors

The SSF has created a set of brochure covering Sjögren's and its hallmark symptoms. These include:

- What is Sjögren's Syndrome?
- Dry Mouth
- Dry Eyes

These are a great resource for newly diagnosed patients, helping them to better understand a disease they are only starting to learn about.

These brochures are also available free-of-charge to medical professionals for them to display in their offices or distribute to other Sjögren's patients. Have your doctor contact our office to receive their own supply.

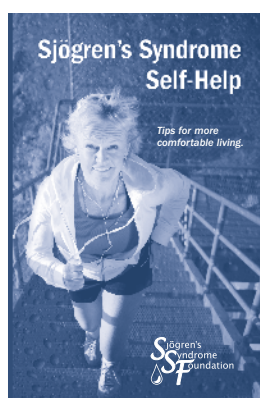


*My burning, hurting, numb feet and hands have bothered me for years but it was only recently that I received the diagnosis of peripheral neuropathy (PN). I have attended support group meetings and learned some things to help deal with the discomfort. I think my experiences and suggestions (listed below), may be of value to you. I am not saying all the pain disappears, but you may be able to be a bit more comfortable. Treating the underlying disease, Sjögren's syndrome, will often lessen the problem of peripheral neuropathy too.*

*The biggest change I made was my shoes. I found that with shoes that accommodated thick fluffy socks I felt a lot less pain. My personal favourite is SAS® brand, Free Time with Thorlos® walking socks. Wearing socks all the time was really a new concept for me too. I thought wearing even 100% cotton light-weight socks at night would make my feet hotter, but they didn't and even made me more comfortable. Some people get relief from wearing tight socks. Mild support knee highs might be worth a try and I found these the most helpful.*

*If my feet are really hurting, I first try soaking them for a while in really cool water. I then try to talk my husband into massaging them for a few minutes before I go to bed since this seems to be my worst time of day. Neutrogena® Foot Cream works well for massage and is really good for dry skin too. The massage often gives me several hours of relief. If anyone needs convincing, just read what the Mayo Clinic says, "A massage helps improve circulation, stimulates nerves and may temporarily relieve pain."*

### Booklets Available for Help Coping With Sjögren's



In addition to these basic brochures, we have a detailed booklet titled Sjögren's Syndrome Self-Help: Tips for a more comfortable living. This pamphlet is written by a long time volunteer and patient, Dona Frosio, and is a great resource for learning basic tips to help cope with all aspects of this disease. An excerpt from the Self-Help booklet is below. The full booklet is

available online at [www.sjogrens.org/selfhelp](http://www.sjogrens.org/selfhelp) or you can request a print copy by contact the Foundation office at 800-475-6473 or by email at [info@sjogrens.org](mailto:info@sjogrens.org).

**Excerpt from book.**

#### PERIPHERAL NEUROPATHY

Another booklet that many patients find to be helpful is our Product Directory. This is a listing of products, separate by the symptoms that they treat, that Sjögren's patients might find useful. Listings include products for:

- Dry Eye
- Dry Mouth
- Dry Nose
- Dry Skin
- Humidifiers
- Vaginal Dryness
- Footwear for Neuropathy Pain

The most updated Product Directory is available in the Member Community on our website (login information required) and print copies of the booklet are available from the Foundation office upon request. ■





For patients with Sjögren's syndrome

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

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

**Talk to your doctor to see if EVOXAC can help, or visit [DiscoverEVOXAC.com](http://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](http://www.FDA.gov/medwatch), or call 1-800-FDA-1088.

Please visit [www.EVOXAC.com](http://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](http://www.dsi.com/news/patientassistance.html).

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

**Evoxac**<sup>®</sup>  
(cevimeline HCl) 30 mg  
Capsules



# 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 close 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 CYP3A/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 30 mg (tid) n=533	Placebo (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 30 mg (tid) n=533	Placebo (tid) n=164	Adverse Event	Cevimeline 30 mg (tid) n=533	Placebo (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, sialoadenitis, otitis media, erythematous rash, pneumonia, edema, salivary gland enlargement, allergy, gastroesophageal reflux, eye abnormality, migraine, tooth disorder, epistaxis, flatulence, toothache, ulcerative stomatitis, anemia, hypoesthesia, cystitis, leg cramps, abscess, eructation, 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 pain 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, thrombocythemia, thrombocytopenia, hypochromic anemia, eosinophilia, granulocytopenia, leucopenia, 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 oxaloacetic 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, hypoglycemia, hyperlipemia, 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, paresis, speech disorder, agitation, confusion, depersonalization, aggravated depression, abnormal dreaming, emotional lability, manic reaction, paroniria, 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 erythema, 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, strangury, 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 AST 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, intestinal 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, impotence, 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 overdose 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.

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# Team Sjögren's

## Raises Over \$70,000



Congratulations to our 2011 *Team Sjögren's* members who completed the Nashville Country Music Marathon and Half Marathon on April 30th.

This year's team was our biggest ever with 24 runners raising over \$70,000 for the fight against Sjögren's. The team included daughters, husbands, sons and friends of Sjögren's patients as well as a few patients themselves. They were victorious as they crossed the finish line after months of training. The team spanned in age from 18 to 67 and represented all parts of the country!

Many of our members signed up to be a part of *Team Sjögren's* as a way to give back and help fight this serious, chronic disease. Their journey leading up to the race was inspiring, challenging and rewarding, all at the same time. Seeing all of our runners make it across the finish line, and knowing everything they had been through in their training, it really was an amazing day!

This year's team had 10 runners in the full marathon (26.2 miles), including our very own CEO, Steven Taylor, and 14 others in the half marathon (13.1 miles). All 24 runners finished the event and the SSF is so proud to have had them represent us at this year's Nashville Country Music Marathon.

*continued page 8* ▼

# NASHVILLE 2012

Planning for the next marathon has already begun! We will once again be returning to the Nashville Country Music Marathon and Half-Marathon on April 28, 2012. If you or someone you know is interested in training for a marathon or half marathon to benefit Sjögren's patients, contact Cynthia Williamson at the SSF office at 800-475-6473, ext. 205 or [cwilliamson@sjogrens.org](mailto:cwilliamson@sjogrens.org).



"Nashville Marathon" continued from page 7 ▼

As difficult as the training and the race were, each runner knows the real challenge is living with Sjögren's. That is what motivated each *Team Sjögren's* member to step up to train while raising a minimum of \$2,600 for the SSF. All of our runners had a different story to tell, from being patients themselves or having a loved one with Sjögren's. In the days before the race as they gathered in Nashville, *Team Sjögren's* members enjoyed sharing their tales of the many training miles. And during the race they all were proud to answer the question they received from so many other runners: "What is *Team Sjögren's*?" Most



inspiring was knowing how debilitating this disease can be and yet seeing 10 patients themselves out there running among the competitors.

So when the sun set in Nashville on April 30th, there were 24 *Team Sjögren's* runners proud of accomplishing what they set out to do – officially being able to call themselves "marathoners" and, most importantly, having run and crossed the finish line as they represented Sjögren's patients worldwide! ■



## 2011 Team Sjögren's Marathoners

Penny Anderson  
 Juliann Bannon  
 Rob Bannon  
 Kirk Beckendorf  
 Gia Casale  
 Mabel Chan  
 Jane Clow  
 Julie Conquest  
 Nancy DeFurio  
 Ken Economou  
 Anne Economou  
 Kalla Ford  
 Lauren France  
 Dan Fuoco  
 Donna Gotshall  
 Kim Gross  
 Susan Hines  
 Stacey Mize  
 Anne Marie Pelletier  
 Eric Pratt  
 Steven Taylor  
 Cathy Taylor  
 Hannah Yu  
 Jay Do Yu





# *I Stood Up...*

## **SSF Support Group Leaders**



Every day Sjögren's Syndrome Foundation Support Group Leaders are Standing Up across the country.

The SSF has over 60 active Support Groups. Each group is led by a volunteer, usually a Sjögren's patient, who is well versed in the disease. They donate their time to run several meetings a year – sometimes a "Meet and Greet" for patients to get together, and other times bringing in an expert to talk about an aspect of Sjögren's.

Support Group Leaders also act as advocates for the Foundation, welcoming the newly diagnosed and talking with other patients over the phone and at the meetings they organize. Most importantly, Support Group Leaders are an extension of the Foundation that lets others with Sjögren's know that they are not alone.

Some of our Leaders have been at the helm of their group for many years. Our longest running Support Group Leader is Rhoda Dennison, volunteering her time in charge of the Los Angeles group for over 20 years!

We thank each of our Support Group Leaders for all of the time and dedication they have given us as they Stand Up for Sjögren's!

To see if there is a Support Group in your local area visit [www.sjogrens.org/supportgroups](http://www.sjogrens.org/supportgroups) or contact the Foundation office at 800-475-6473.

## ***Donate Your Old Vehicle***

*Call us today for more information.*

# **800-475-6473**





## 2011 SSF National Patient Conference Audio CDs are Now Available!



Five of our most popular talks from the 2011 National Patient Conference held in Reston, Virginia are available for purchase as audio CDs. Each talk is 30-40 minutes long and each CD comes enclosed with the handouts and visual aids used by the presenter. Buy just the talks you want to hear or purchase the whole set! Whether you attended the conference or not, these audio CDs are an excellent way to have a permanent resource with some of the most vital information available to Sjögren's patients.

The CDs may be purchased using the order form below, online at the SSF Store, or by calling the SSF office at 800-475-6473.

**Overview of Sjögren's Syndrome – Herbert Baraf, MD** presents a comprehensive explanation of the range of symptoms that Sjögren's patients experience, explain their causes, and offer practical tips for managing them. Dr. Baraf is a senior member and Managing Partner of Arthritis and Rheumatism Associates, one of the largest private rheumatology groups in the country. He is also a Clinical Professor of Medicine at The George Washington University School of Medicine.

**Aching Joints, Fatigue and Sjögren's – Theresa Lawrence Ford, MD** discusses the symptoms of extreme fatigue and joint pain and offers tips to help you cope, manage and treat these issues. Dr. Lawrence Ford is the Medical Director of North Georgia Rheumatology Group and an Active Staff member at Gwinnett Medical Center Hospitals. She practices in a single specialty group with her sister, who is also a rheumatologist, in Gwinnett County, GA and has done research in the fields of lupus and rheumatoid arthritis.

**Management of Accelerating Dental Caries – Michael Brennan, DDS, MHS** provides insight into how Sjögren's impacts oral health as well as information and tips to share with your own dentist. Dr. Brennan is Associate Chairman and Oral Medicine Residency Director at the Department of Oral Medicine at the Carolinas Medical Center in Charlotte, NC. There he is also the director of the Sjögren's Syndrome and Salivary Disorders Center.

**Overlapping Major Connective Tissue Diseases – Lee Shapiro, MD** discusses the importance for individuals with Sjögren's to be aware of the symptoms that might indicate the development of "overlap" features with other connective tissue diseases. Dr. Shapiro is a rheumatologist and a member of The Center for Rheumatology, LLP, in Albany, NY. He is an active participant in the teaching program of Albany Medical College and former Chief of Rheumatology at St. Peter's Hospital. He is the author of numerous peer-reviewed journals and also has written several self-help patient guides.

**Neurological Manifestations of Sjögren's – Steven Mandel, MD** understands the challenges that may afflict patients with neurological complications of Sjögren's and shares insights and coping strategies in this discussion. Dr. Mandel is the Professor of Neurology and Anesthesiology at Jefferson Medical College in Philadelphia, PA, and Adjunct Clinical Professor of Psychology at The School of Human Service Professions of Widener University. He has published over 100 articles, co-authored three books and numerous chapters for textbooks.

All of these audio CDs can be purchased using the order form below, online at [www.sjogrens.org](http://www.sjogrens.org) or by contacting the Sjögren's Syndrome Foundation office at 800-475-6473.

	Non-Member Price	Member Price	Qty	Amount
<b>Overview of Sjögren's Syndrome – Herbert Baraf, MD</b>	\$30	\$12		
<b>Aching Joints, Fatigue and Sjögren's – Theresa Lawrence Ford, MD</b>	\$30	\$12		
<b>Management of Accelerating Dental Caries – Michael Brennan, DDS, MHS</b>	\$30	\$12		
<b>Overlapping Major Connective Tissue Diseases – Lee Shapiro, MD</b>	\$30	\$12		
<b>Neurological Manifestations of Sjögren's – Steven Mandel, MD</b>	\$30	\$12		
<i>Maryland Residents add 6% sales tax</i>				
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<b>Total Amount</b>				

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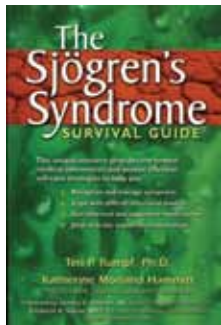


# Make Sure You Have Each of These Best Sellers!

The Sjögren's Syndrome Foundation sells a wide variety of books to make sure all of our members can educate themselves on their disease to be their own best advocates. Below are three of our best-selling books that we have been told by Sjögren's patients are excellent resources and a must for every patient's collection.

## The Sjögren's Syndrome Survival Guide

by Teri P. Rumpf, PhD and Katherine Morland Hammitt

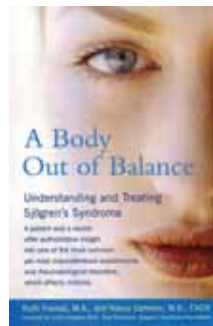


Written together by two Sjögren's patients – one a clinical psychologist and the other a longtime staff member of the Sjögren's Syndrome Foundation – the *Survival Guide* is a complete resource providing vital medical information, research results, and treatment methods, as well as the most effective and practical self-help strategies. The *Survival Guide* is a wonderful resource in a highly readable format addressing all aspects of Sjögren's. It includes clear and practical advice to allow people to take control of this disease and enjoy enormous improvements in their quality of life.

**Member Price: \$13**

## A Body Out of Balance: Understanding and Treating Sjögren's Syndrome

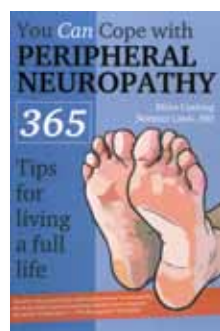
by Ruth Fremes, MA and Nancy Carteron, MD, FACR



Co-written by a woman living with the disease and by a physician who has treated Sjögren's patients, *A Body Out of Balance* provides a comprehensive guide to a wide array of symptoms, traditional and complementary treatments, and invaluable coping methods, so patients may devise a personal treatment plan.

This indispensable resource will enhance awareness and demystify this often misunderstood disorder.

**Member Price: \$10**



## You Can Cope with Peripheral Neuropathy: 365 tips for living a full life

by Mims Cushing and Norman Latov, MD

Peripheral neuropathy is one of the most common, as well as one of the most debilitating and mysterious symptoms of Sjögren's. Written by both a patient-expert and a doctor, this book is a welcome addition to the information on peripheral neuropathy. The book covers such diverse topics as:

- What to ask at the doctor appointments
- Where to find a support group
- Advice for traveling
- Making the house easier to navigate with neuropathy
- Using vitamins and herbs for treatment

*You Can Cope With Peripheral Neuropathy* is a compendium of tips, techniques, and life-task shortcuts that will help everyone who lives with this painful condition.

**Member Price: \$16**

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

	Non-Member Price	Member Price	Qty	Amount
<b>The Sjögren's Syndrome Survival Guide</b> by Teri P. Rumpf, PhD and Katherine Morland Hammitt	\$15.00	\$13.00		
<b>A Body Out of Balance</b> by Ruth Fremes, MA and Nancy Carteron, MD, FACR	\$13.00	\$10.00		
<b>You Can Cope with Peripheral Neuropathy</b> by Mims Cushing and Norman Latov, MD	\$19.00	\$16.00		
<i>Maryland Residents add 6% sales tax</i>				
<b>Shipping and Handling:</b> US Mail: \$5 for first item + \$2 for each additional item				
Canada: \$8 for first item + \$2 for each additional item				
Overseas: \$18 for first item + \$2.50 for each additional item				
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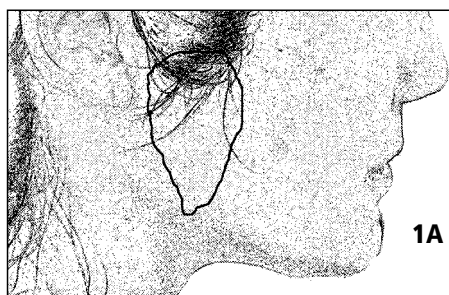


# How to Massage Salivary Glands

by Ava J. Wu, DDS

Dr. Wu is a Clinical Professor and Co-Director of the Salivary Gland Dysfunction Clinic, School of Dentistry, University of California, San Francisco.

If a sharp and stabbing pain occurs in one of your salivary glands right before or while eating or drinking, the cause might be an obstruction (a stone or mucous plug). In rare cases, associated gland swelling can accompany the discomfort. Here are some tips for massaging or “milking” the gland that might help:



**Figure 1A:**

The parotid glands are located bilaterally in the cheek area in front of your ear and have a “tail” area that can extend over the lower jaw.



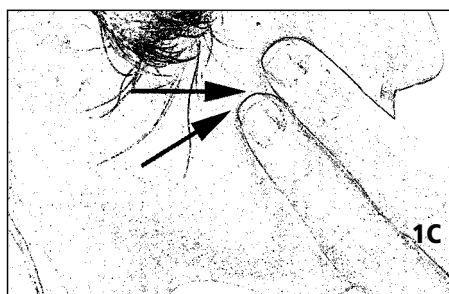
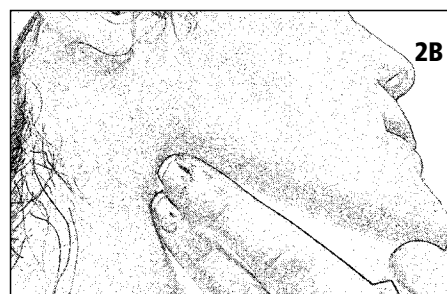
**Figure 2A:**

The submandibular and sublingual glands are located bilaterally under your jaw and tongue with the sublingual gland closer to the chin.



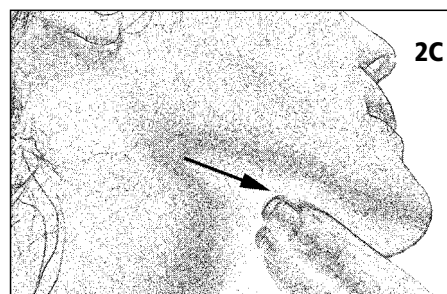
**Figures 1B and 2B:**

Place two fingers on the body or tail area of the parotid or under the jaw for the submandibular/sublingual glands.



**Figures 1C and 2C:**

Sweep fingers forward with gentle pressure as indicated by the black arrows. This will encourage movement of saliva past a possible obstruction or constriction and into the oral cavity.



## Additional Tips:

- Stay well hydrated to encourage the flow of saliva through the gland.
- Temporarily avoid foods and beverages that cause the pain and possible swelling.
- Apply warm compresses to the area to increase comfort.
- Ibuprofen may be taken temporarily to decrease pain and inflammation.
- Talk to your doctor about use of a mucolytic agent for 5-10 days to thin the saliva and allow it to easily pass through the salivary ducts.

*In all cases of salivary gland swelling and associated pain a medical professional should be consulted as soon as possible to determine the cause.*

Additional Patient Fact Sheets like this one are available online at [www.sjogrens.org/brochures](http://www.sjogrens.org/brochures)





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Martin R. Abroms

Ed & Jane Hall

Susan Irons

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Thompson Station United Methodist Church

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### In Honor of Linda J. Harris' Birthday

Elaine & Herb Harris

### In Honor of Maryanne Boshko

Michael Boshko

### In Honor of Ruthanne Palmer's 70th Birthday

The Graff Family



## Keep Working, Women, Work, and Autoimmune Disease

by Rosalind Joffe and Joan Friedlander

*Women, Work, and Autoimmune Disease* is a book for women who live with chronic illness, encouraging them to stay employed to preserve their independence and sense of self.

The authors take a hard, yet inspirational look at what it takes to be successful in a job while managing a chronic illness, including developing strategies and tactics, evaluating communication skills, building a support team, and analyzing options for self-employment.

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# Live, Learn & Share



*T*his October, come to Chicago and take control of your health by learning the most up-to-date information from the brightest minds in Sjögren's syndrome.

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

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

## CHICAGO PATIENT SEMINAR SATURDAY, OCTOBER 15, 2011

**FEES** – Note: Early Bird Deadline is September 20, 2011

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September 20th and before  
\$65 per person  
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September 21st and after  
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- A fee of \$25 will be charged for all seminar registration cancellations. Refund requests must be made by September 20, 2011. After that date, we are sorry but no refunds will be made.
- Dietary Requests: We can accommodate vegetarian or gluten-free dietary requests. If you require a vegetarian or gluten-free meal option, please contact Stephanie Bonner at the SSF office (800-475-6473 ext. 210) by October 6th.
- A limited number of rooms are available at the Sheraton Gateway Suites Chicago O'Hare hotel, 6501 North Mannheim Road, Rosemont, Illinois 60018, at the SSF rate of \$99 per night plus tax if reservations are made by September 21, 2011. To make reservations, call the toll-free Central Reservations number at 888-627-8117 (or call the hotel directly at 847-699-6300) and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.

**Call Today**  
to reserve your place.  
**800-475-6473**

**QUESTIONS?** Call 800-475-6473 or visit [www.sjogrens.org](http://www.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

# ***Don't Forget... Shop for Sjögren's***

## **Shop to benefit the Sjögren's Syndrome Foundation**

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

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

- ◆ **Amazon.com** is one of the most popular online stores in the world, offering a wide variety of products. Up to 8% of the value of your purchase is donated back to the Foundation.
- ◆ **DentalPlans.com** offers you a discounted dental plan to use along with your dental insurance, or as an alternative to dental insurance. Even if you already have dental insurance, the discounts offered through DentalPlans.com may be used along with your dental insurance for even more savings on your dental care. Just visit [www.dentalplans.com/ssf](http://www.dentalplans.com/ssf), find a discount dental plan that works for you, and when purchasing use the coupon code SSF10 to receive a 10% discount from the published price. Additionally, 10% of your purchase will be contributed to the Foundation!
- ◆ **Drugstore.com** is a leading online provider of health, beauty, vision, and pharmacy products. The website allows you to shop as if you were at your local drug store, and you can get instant savings while 10% of your purchase benefits the SSF.
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- ◆ **iGive.com** offers exclusive deals with over 700 brand name stores you know and love, with a specified percentage of each purchase coming back to the SSF. Be sure to select "Sjögren's Syndrome Foundation" as your charity of choice. Whenever you return to iGive.com and log in, any shopping you do will benefit the SSF! It's that simple.

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