Fibromyalgia in Sjögren’s Syndrome  Part 1

by Frederick B. Vivino, MD, FACR

Fibromyalgia refers to a syndrome of diffuse, whole body musculoskeletal pain associated with poor sleep, chronic fatigue, morning stiffness, and waxing and waning symptoms that vary with changing conditions (e.g., weather, sleep patterns). In simple form, try to think of fibromyalgia (commonly referred to as “fibro”) as muscle spasms related to not sleeping.

Symptoms of Fibromyalgia:

- Migratory “aching pain” often localized around the neck, back, hips, elbows and knees
- Chronic fatigue; no sleep
- Worse with bad weather, overexertion or during periods of emotional stress
- Sensation of swelling
- Funny sensations in the extremities (e.g., tingling)
- Weakness
- Cognitive dysfunction (“Fibro fog”)
- Sicca symptoms

Weather: The weather may play a big role in your fibro symptoms. For example, a lot of people tell us their pain is worse when the weather is cold and rainy. Or conversely, people may feel better when the weather is warm and sunny.

Lack of sleep: People usually notice their fibro symptoms are more severe when they do not sleep.

Stress and overexertion: Stress is a very big factor in fibro. Patients complain of worsening symptoms during periods of physical or emotional stress as well as overexertion. The mind-body connection plays a role in many rheumatic diseases, and this tells us that fibromyalgia is no exception.

Fibro can cause many symptoms in addition to the classic muscle and joint pain and fatigue. Patients frequently come to us with what we call a “sensation” of swelling. People will tell us that their joints are swollen, but upon examination we find that this is actually not the case. Many fibro patients also relate a variety of neurological symptoms. For example, some patients have odd sensations in the arms or legs and other extremities. This could lead to a patient undergoing an evaluation for neuropathies, nerve damage.

Fibromyalgia Symptoms

Most people describe the pain as “aching pain” that involves the muscles or joints. It often starts in one area and over time will spread, eventually involving the whole body. It is significant, disabling pain. And though it may be felt throughout the whole body, the most commonly affected areas are the neck, back, hips, elbows and knees. Even though fibro causes muscle problems, it can also affect the joints, and often fibromyalgia symptoms will be confused with arthritis. Many patients suffer from chronic fatigue and simply do not sleep.

Changing conditions seem to affect the levels of pain and fatigue.

continued page 2 ▼
or even multiple sclerosis (MS), but the tests come back normal. Fibro may cause patients to feel weak. And much like Sjögren’s, fibromyalgia can cause cognitive dysfunction, or “brain fog,” as a lot of Sjögren’s patients call it. Fibro can also cause sicca (dryness) symptoms.

Looking at these symptoms for fibro, you can see that many symptoms overlap significantly with those of Sjögren’s. As a result, it can be a challenge for doctors to tell the two disorders apart. Most rheumatologists have seen cases of patients who ended up having Sjögren’s and were initially misdiagnosed with having fibromyalgia as well as the reverse. And to make things more confusing, the two disorders can coexist in one patient.

Fibromyalgia often travels with other diseases. We don’t understand exactly why this is, but frequently fibro patients also suffer from:

- Depression (between 30-40% of patients have concurrent depression or anxiety).
- Jaw pain from TMJ (temporomandibular joint disorder).
- Non-cardiac chest pain (costochondritis).
- Irritable bowel syndrome (IBS) due to muscle spasms in the intestines.
- Migraine headaches.
- Irritable bladder syndrome or pelvic urethral syndrome.

Who Gets Fibro?
The typical patient is a woman, but both men and children can develop fibromyalgia as well. While the average fibro patient is younger than the average Sjögren’s patient, there is overlap among the age ranges of the two diseases.

Risk Factors for Fibro
Genetics: Fibromyalgia is thought of as being a genetic disorder just like Sjögren’s, so we are seeing fibro passed down through families.

Fibromyalgia-associated diseases: You also are at an increased risk if you already have a fibromyalgia-associated disease like TMJ or migraines.

Lack of sleep: People who do not get enough sleep have a higher risk of developing fibro. A lot of research has been done on this topic, which I will touch on later.

Autoimmune rheumatic diseases: Although the numbers tend to vary from study to study, patients who already have an autoimmune rheumatic disease have an increased chance of developing fibro. In some studies, as many as 25% of rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE) patients also had fibro. And interestingly, in some studies, as many as half of Sjogren’s patients also had fibro.

What Causes Fibromyalgia?
The real answer is that we do not know, but we have a lot of good theories.
Once-daily,* preservative-free LACRISERT®
Extends tear life for all-day lubrication and protection

- Unlike artificial tears, LACRISERT® works continuously to stabilize and thicken tears for all-day relief.
- LACRISERT® begins to gently dissolve and lubricate within minutes.

69% of Sjögren’s syndrome patients in a clinical study preferred LACRISERT® over artificial tears due to increased comfort†

Most adverse reactions were mild and transient and included transient blurring of vision, ocular discomfort or irritation, matting or stickiness of eyelashes, photophobia, hypersensitivity, edema of the eyelids, and hyperemia. LACRISERT® is contraindicated in patients who are hypersensitive to hydroxypropyl cellulose. If improperly placed, LACRISERT® may result in corneal abrasion.

*Some patients may require the flexibility of twice-daily dosing for optimal results.
†In a 2-phase study of patients with dry eye: phase 1 was a 6-month, comparative, randomized, crossover study in 40 patients (37 with Sjögren’s syndrome); phase 2 was an open-label, follow-up study in 37 patients for 2 months to 18 months.


For more information, visit www.LACRISERT.com or call 1-877-ATON-549.
Please see brief summary of Prescribing Information on adjacent page.
LACRISERT® (hydroxypropyl cellulose) OPHTHALMIC INSERT

DESCRIPTION
LACRISERT® Ophthalmic Insert is a sterile, translucent, rod-shaped, water soluble, ophthalmic insert made of hydroxypropyl cellulose, for administration into the inferior cul-de-sac of the eye. Each LACRISERT is 5 mg of hydroxypropyl cellulose. LACRISERT contains no preservatives or other ingredients. It is about 1.27 mm in diameter by about 3.5 mm long. LACRISERT is supplied in packages of 60 units, together with illustrated instructions and a special applicator for removing LACRISERT from the unit dose blister and inserting it into the eye.

INDICATIONS AND USAGE
LACRISERT is indicated in patients with moderate to severe dry eye syndromes, including keratoconjunctivitis sicca. LACRISERT is indicated especially in patients who remain symptomatic after an adequate trial of therapy with artificial tear solutions. LACRISERT is also indicated for patients with exposure keratitis, decreased corneal sensitivity, and recurrent corneal erosions.

CONTRAINDICATIONS
LACRISERT is contraindicated in patients who are hypersensitive to hydroxypropyl cellulose.

WARNINGS
Instructions for inserting and removing LACRISERT should be carefully followed.

PRECAUTIONS
General
If improperly placed, LACRISERT may result in corneal abrasion.

Information for Patients
Patients should be advised to follow the instructions for using LACRISERT which accompany the package. Because this product may produce transient blurring of vision, patients should be instructed to exercise caution when operating hazardous machinery or driving a motor vehicle.

Carcinogenesis, Mutagenesis, Impairment of Fertility
Feeding of hydroxypropyl cellulose to rats at levels up to 5% of their diet produced no gross or histopathologic changes or other deleterious effects.

Pediatric Use
Safety and effectiveness in pediatric patients have not been established.

Geriatric Use
No overall differences in safety or effectiveness have been observed between elderly and younger patients.

ADVERSE REACTIONS
The following adverse reactions have been reported in patients treated with LACRISERT, but were in most instances mild and transient: transient blurring of vision, ocular discomfort or irritation, matting or stickiness of eyelashes, photophobia, hypersensitivity, edema of the eyelids, and hyperemia.

DOSAGE AND ADMINISTRATION
One LACRISERT ophthalmic insert in each eye once daily is usually sufficient to relieve the symptoms associated with moderate to severe dry eye syndromes. Individual patients may require more flexibility in the use of LACRISERT; some patients may require twice daily use for optimal results.

Clinical experience with LACRISERT indicates that in some patients several weeks may be required before satisfactory improvement of symptoms is achieved.

Issued June 2007
Q I have heard some patients have started IVIG therapy for their Sjögren’s. What is this?

A Intravenous immune globulin (IVIG) is an immunosuppressant agent, a type of antibody preparation made from purified serum of normal blood donors. It currently is FDA-approved for treatment of many different disorders including Kawasaki disease, common variable immunodeficiency syndrome, B-cell chronic lymphocytic leukemia, and idiopathic thrombocytopenic purpura. It also is used in bone marrow transplant recipients to prevent certain complications. Additionally, it appears to be useful for treatment of many other immune-mediated diseases, including Sjögren’s syndrome. In Sjögren’s patients, IVIG most often is used to treat painful peripheral neuropathy (nerve damage in the legs due to inflammation). IVIG therapy typically is administered over 3-4 days once monthly for several months and usually is well tolerated. However, as with any treatment, side effects may occur and include headaches, flushing, dizziness, joint or muscle pain, allergic reactions and, in rare cases, kidney failure. Patients with deficiency of an antibody called IgA (can be tested with blood) are particularly susceptible to side effects.

– Frederick B. Vivino, MD, FACR

Q What are some tips for dealing with the dry skin from my Sjögren’s?

A Dry skin often is overlooked as a major symptom of Sjögren’s syndrome but deserves greater recognition as a frequent issue for patients. Dry skin may occur as the result of immune dysfunction and destruction of the structures which moisturize and lubricate the skin – a process similar to that which causes dry mouth and dry eye in Sjögren’s. These skin structures include the hair and oil glands as well as sweat glands. Once destroyed, these oil and sweat glands cannot be restored. Although most common in fall, winter and early spring, dry skin occurs throughout the year. Areas most often affected are legs, arms and abdomen (especially the beltline/waist).

Major features of dry skin are:
- Scaling
- Redness
- Itching
- Cracking of the skin

Tips for dealing with dry skin:
- Take short, warm baths or showers. They do not remove skin oils as completely as hot water.
- Use gentle bars (Dove®, Basis®, Cetaphil® or the low/no residue glycerin bars such as Neutrogena®) instead of harsh true “soaps.” Detergents are not the same as...

continued page 6 ▼
“Fibromyalgia” continued from page 2

Genetics: As I alluded to above, it is now thought that many people may be genetically predisposed to fibro. However, not everybody that carries associated genes ends up with the disease. This leads some to theorize that environmental triggers might set off the whole process. At my practice, we often hear stories such as the following: Someone has been in a car accident and has residual neck pain. Then three or four months later, that patient comes down with whole-body pain and is diagnosed with fibro. Or, someone has had a serious infection such as mono, gets better and then gets worse once again, and eventually develops whole-body pain leading to a diagnosis of fibromyalgia.

Hormones: Some people have blamed fibro on problems with the hypothalamus and the pituitary glands (Hypothalamic-pituitary dysfunction). This may affect as many as 10-15% of fibromyalgia patients. It has been shown that there is a decreased excretion of cortisol in the urine and a decreased excretion of another hormone called “Insulin-like growth factor-1” (IGF-1). In some people, this could be an important cause of fibromyalgia.

Autonomic nervous system dysfunction: The autonomic nervous control essential body functions (e.g. heart rate, blood pressure, temperature regulation). Some of our patients with fibromyalgia will report that they have problems with orthostatic hypotension, meaning the blood pressure does not adjust fast enough when they stand up, so they get dizzy. Some patients may have problems with hot or cold intolerance (“vasomotor instability”). And other fibro patients may have visceral dysfunction (i.e. bowel or bladder dysfunction) that is thought to be due to problems with the autonomic nervous system.

Disorder of sensory processing in the central nervous system: In other words, although the symptoms may be felt in the muscle, the actual problem may be in the brain. We do not know why this is, but a lot of people with fibro are incredibly sensitive – they cannot be touched or tolerate other stimuli (heat or cold). And for some reason, people with fibro tend to have a lower threshold for perceiving these stimuli as noxious. (i.e. stimuli that a non-fibro patient would normally be able to ignore in their daily life can be a major problem for fibro patients.) In four separate clinical studies of cerebrospinal fluid in people with fibro, researchers tested a neurotransmitter for pain called “Substance P.” In fibro patients, the Substance P levels were significantly higher than in the control patients. Whether this is a cause of fibro or an effect, we just do not know. But these results have given rise to the theory that fibro is a result of a disorder with pain processing.

Sleep disorders: Sleep studies in fibro patients have shown that 75-80% of patients have abnormal “sleep architecture.” This means that if you measure the brain waves of fibro patients, you will find abnormalities (“alpha wave intrusion”) in a particular stage of sleep called “stage-4 non-REM sleep.” This is one of the deeper stages of sleep that everyone must achieve in order to feel renewed and refreshed in the morning. Furthermore, in other studies in which healthy volunteers were deprived of sleep, researchers were able to reproduce the signs and symptoms of fibromyalgia. Clearly, sleep is a very important factor in the cause of fibromyalgia. And as most of you know too well, Sjögren’s patients frequently suffer from poor sleep or a lack of sleep.

The second part of this informative article will be continued in the June issue of The Moisture Seekers.

“Information” continued from page 5

- Apply moisture frequently. In reality, there are relatively few ways of maintaining or adding to your skin’s moisture content. These are:
  - Trap moisture in the skin immediately after bathing or showering while your skin is still damp or showering while your skin is still damp or while your skin is still damp or wet. (e.g. bowels or bladder dysfunction) that is thought to be due to problems with the autonomic nervous system.
  - Repair the skin’s protective function by retaining or trapping the skin’s natural moisture with a relatively new group of products based on naturally occurring chemicals called ceramides (CeraVe®).
  - Avoid fabric softeners in the washer and dryer.
  - Drink plenty of water and remain well-hydrated.
  - Use a humidifier, especially if you have forced-air heat which is especially drying.
  - After swimming, make certain that you shower and then immediately use a moisturizer.

---

— John R. Fenyk, Jr., MD
RESTASIS® Ophthalmic Emulsion helps increase your eyes’ natural ability to produce tears, which may be reduced by inflammation due to Chronic Dry Eye. RESTASIS® did not increase tear production in patients using topical steroid drops or tear duct plugs.

**Important Safety Information:**
RESTASIS® Ophthalmic Emulsion should not be used by patients with active eye infections and has not been studied in patients with a history of herpes viral infections of the eye. The most common side effect is a temporary burning sensation. Other side effects include eye redness, discharge, watery eyes, eye pain, foreign body sensation, itching, stinging, and blurred vision.

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

**Find out more about a $20 rebate offer!**
**See next page for details.**

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

**Important Safety Information:**
RESTASIS® Ophthalmic Emulsion should not be used by patients with active eye infections and has not been studied in patients with a history of herpes viral infections of the eye. The most common side effect is a temporary burning sensation. Other side effects include eye redness, discharge, watery eyes, eye pain, foreign body sensation, itching, stinging, and blurred vision.

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

**Go to www.restasis29.com, or call 1-866-311-2412 for a free information kit.**

Please see next page for important product information.
TERATOGENIC EFFECTS: No evidence of teratogenicity was observed in rats or rabbits receiving oral doses of cyclosporine up to 300 mg/kg/day during organogenesis. These doses in rats and rabbits are approximately 300,000 times greater than the daily human dose of one drop (28 µL) of 0.05% RESTASIS® BID into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed.

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

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

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

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

Pediatric Use: The safety and efficacy of RESTASIS® opthalmic emulsion have not been established in pediatric patients below the age of 16.

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

ADVERSE REACTIONS: The most common adverse event following the use of RESTASIS® was ocular burning (17%). Other events reported in 1% to 5% of patients included conjunctival hyperemia, discharge, epiphora, eye pain, foreign body sensation, pruritus, stinging, and visual disturbance (most often burning).

No Reactions: Based on package insert 71876US1OU Revised January 2008 ©2009 Allergan, Inc. Irvine, CA 92612, U.S.A. ® marks owned by Allergan, Inc. APC44MN09 US PAT 4,649,047; 4,839,342; 5,474,979.

Follow these 3 steps:

1. Have your prescription for RESTASIS® filled at your pharmacy.

2. Circle your out-of-pocket purchase price on the receipt.

3. Mail this certificate, along with your original pharmacy receipt (proof of purchase), to Allergan RESTASIS® Ophthalmic Emulsion $20 Rebate Program, P.O. Box 6513, West Caldwell, NJ 07007.

For more information, please visit our Web site, www.restasis29.com.

RESTASIS® Rebate Terms and Conditions: To receive a rebate for the amount of your prescription co-pay (up to $20), enclose this certificate and the ORIGINAL pharmacy receipt in an envelope and mail to Allergan RESTASIS® Ophthalmic Emulsion $20 Rebate Program, P.O. Box 6513, West Caldwell, NJ 07007. Please allow 8 weeks for receipt of rebate check. Receipts prior to March 1, 2009 will not be accepted. One rebate per consumer. Duplicate will not be accepted. See rebate certificate for expiration date. Eligibility: Offer not valid for prescriptions reimbursed or paid under Medicare, Medicaid, or any similar federal or state healthcare program including any state medical or pharmaceutical assistance programs. Void in the following states if any third-party payer reimburses you or pays for any part of the prescription price: Massachusetts. Offer valid where prohibited by law, tax, or restricted. Amount of rebate not to exceed $20 or co-pay, whichever is less. This certificate may not be reproduced and must accompany your request for a rebate. Offer good only for one prescription of RESTASIS® Ophthalmic Emulsion and only in the USA and Puerto Rico. Allergan, Inc. reserves the right to rescind, revoke, and amend this offer without notice. You are responsible for reporting receipt of a rebate to any private insurer that pays for, or reimburses you for, any part of the prescription filled, using this certificate.

© 2009 Allergan, Inc., Irvine, CA 92612, U.S.A. ® marks owned by Allergan, Inc. Please allow 8 weeks for delivery of your rebate check.

APC71SD09 Certificate expires 12/31/2009
Chronic pain is defined as “persistent pain” and is a common complaint in Sjögren's syndrome. For example, Sjögren’s patients often complain of muscle aches, joint pain, oral and eye pain, and pain from neuropathies and vasculitis. Not only does pain interfere with everyday life functions, it contributes to “brain fog,” fatigue, and a general lack of mental well-being. Some tips for dealing with chronic pain:

**Continue caring for the condition causing your pain.**
- The underlying medical condition needs to be attended to on a continuing basis.

**Pay attention to any new pain problems.**
- Your pain may be caused by other conditions not related to your underlying chronic pain condition or disease. These conditions need to be investigated aggressively.

**Don’t be a couch potato.**
- A common cause of chronic pain is de-conditioning or getting badly out of shape. An intelligent and consistent exercise program with your doctor’s approval may be extremely helpful.

**If you are overweight, shed those pounds.**
- As a general rule, do your best to maintain a healthy weight by pursuing a healthy diet as well as initiating an exercise program if okayed by your physician.

**Avoid pain triggers.**
- Try to understand what causes the pain to get worse and avoid those triggers if possible.

**Don’t let stress compound your pain.**
- Stress is the result of the way you react to the world, and heightened stress equals heightened pain. Learn relaxation techniques or seek help in reducing your stress level.

**Get enough sleep.**
- Practice good sleep habits and get adequate sleep on a continuing basis.

**Don’t let depression persist.**
- Find out if depression is a problem for you, and discuss potential treatment with your physician.

**Remember your rights as a health consumer.**
- Try to gain as much information as possible from your health care providers. Become an active participant in treatment decisions and an informed consumer.

For more information on chronic pain, check out *Chronic Pain for Dummies*, written by Stuart Kassan, MD, Charles J. Vierck, Jr, PhD and Elizabeth Vierck, MS and available for purchase through the SSF. See the order form on page 16.
Are you a Man living with Sjögren’s?

You are not alone.

This Spring the SSF will host a teleconference to connect men living throughout the country with Sjögren’s syndrome. This will be an opportunity to interact and share your experiences, exchange helpful suggestions, and learn coping techniques from men just like you dealing day-to-day with Sjögren’s.

Contact the SSF at 800-475-6473 or send an e-mail to tms@sjogrens.org to learn how to participate in this teleconference.
For patients with Sjögren’s syndrome,

Dry mouth is no piece of cake.

Are you one of the 2-4 million patients with Sjögren’s syndrome? If you have experienced dry-mouth symptoms, then you know how difficult it can be to eat, chew and swallow food. But does your healthcare provider understand?

In the past, you may have tried to explain the uncomfortable feeling of your dry-mouth symptoms to your healthcare provider. Maybe it’s time to talk to him or her again.

Ask your healthcare provider about EVOXAC, a prescription treatment option for dry-mouth symptoms associated with Sjögren’s syndrome that works by stimulating the production of your body’s own natural saliva.

Visit DiscoverEVOXAC.com for a list of questions to take to your healthcare provider.

IMPORTANT SAFETY INFORMATION ABOUT EVOXAC (cevimeline HCl)

What is EVOXAC?
EVOXAC (cevimeline hydrochloride) 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
- 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 healthcare 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, running 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 see a brief summary of Important Information for EVOXAC on the next page.
Like so many others, I was diagnosed with Sjögren’s syndrome after years of pain, confusion, and an untold number of trips to doctors in multiple specialties. While there was some strange sense of relief to finally hear a diagnosis that had an actual name, there was also the sinking feeling of being very suddenly alone. Having grown up in a medical household, I’d heard the “Sjögren’s” name before, but I didn’t personally know a single soul who had the disorder. How was that possible?

So I set about trying to answer the most obvious questions for myself. What is this syndrome, and what does it mean for me? I began reading everything I could get my hands on including books on autoimmune disease processes and *The Sjögren’s Syndrome Survival Guide*. Searching online brought me across the Sjögren’s Syndrome Foundation website as well as various web-based discussion and support groups. The common thread in all that I read was that people, regardless of degree of the disease process and related struggle, were expressing that they were affected both physically and emotionally.

Since the range of effect is so great in patients with autoimmune diseases, it becomes impossible to come up with “one size fits all” answers to how best to go about living while we wait for a cure. While medications, artificial tears and saliva products, medical and self-help books, research foundations and support groups all have their beneficial and worthwhile places, I knew I needed more in order to live, not just continue to painfully exist. Having already employed

---

This little lozenge can make a big difference for Dry Mouth Sufferers!

Now there’s help for your Dry Mouth. Nuvora has introduced Salese, a revolutionary new soft lozenge that delivers moisture-retaining and bacteria-fighting ingredients for an hour or longer.

And there’s nothing else like it! The key to Salese’s long-lasting properties is our patented Sustained-Release Technology – SuRe™. This unique polymer combined with essential oils, Xylitol and a moisture-retaining ingredient helps dry mouth sufferers fight bacteria, normalize pH and freshen breath for an extended period of time.

So see how this little lozenge can make a big difference for you. Call today to order. Or visit our website.
playing and listening to music, writing, and visual arts, and still needing something to bring a greater relief, I decided to try ballroom dance. There was some initial reservation and concern on my part over whether I’d physically be able to participate in such an activity at any kind of meaningful level. I was in for the surprise of my life!

There were very certain immediate physical benefits – a much greater awareness of body position, posture, and how correct movement is achieved. Allowing the correct muscle groups to move the corresponding anatomy in physically appropriate ways is an acquired skill that, once learned, takes stress off joints and muscles and results in less pain. As body awareness grew, I began to learn to accept my body for all it was – the good, bad, weak, and strong. Learning to not take myself so seriously all of the time became its own mental vacation from stress. Learning to see the current limitations of my body as simply a beginning point from which progress could be made and measured rather than as a hindrance to be frustrated by was its own encouragement to continue trying to move. Learning to communicate my needs to others in social situations has been one of the most personally difficult things to do but one of the most rewarding. There was much less sense of aloneness as I began to realize that others accepted me “as is” – creaks, aches, limitations and all. Dancing has truly been one of the most humanizing experiences of my life.

As a lifelong musician and a professional music educator for more than a decade, I was thrilled to see the arts article in the February 2009 issue of The Moisture Seekers. (“More than a Feeling: How the Arts Affect Your Health.”) Prior to Sjögren’s, I’d have been drooling over an article like that! Making music had been my raison d’etre for thirty years, and I’d all but completely lost my connection to it due to Sjögren’s syndrome and all of the associated visual, neurological, and rheumatologic complications I was experiencing. The benefit of learning to dance, for me, went well beyond the expected social and physical gains. Learning to move in more mechanically correct ways gave me the ability to again approach my instruments with less pain and renewed passion. I was given back my soul. What an inestimable gift! As each of you navigates your own journey through Sjögren’s, whether as a patient, a partner, a caregiver, a doctor, an advocate, or volunteer, I hope you dance.
The Leader in Dry Mouth

☑️ #1 Dentist Recommended Dry Mouth brand
☑️ Proven to relieve Dry Mouth
☑️ Supplements saliva’s natural defenses

Toothpaste, Mouthwash, Gel, Spray, Gum and more
Chronic Pain for Dummies

by Stuart Kassan, MD
Associate Member of the SSF’s Medical and Scientific Advisory Board,
Clinical Professor of Medicine, University of Colorado Health Sciences Center

Charles J. Vierck, Jr, PhD
Professor Emeritus, University of Florida School of Medicine

Elizabeth Vierck, MS
Health Writer

This reassuring, practical guide helps you understand what causes pain and how to manage it with the newest pain-relieving techniques. You’ll see how to track pain triggers, weigh the benefits and risks of pain-reducing medications, improve your pain levels with diet and exercise, and determine whether surgery is right for you.

These books 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.

<table>
<thead>
<tr>
<th>Non-Member Price</th>
<th>Member Price</th>
<th>Qty</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Pain for Dummies</td>
<td>$18.00</td>
<td>$15.00</td>
<td></td>
</tr>
<tr>
<td>Maryland Residents add 6% sales tax</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shipping and Handling: US Mail:</td>
<td>$5 for first item + $2 for each additional item</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canada:</td>
<td>$8 for first item + $2 for each additional item</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overseas:</td>
<td>$18 for first item + $2.50 for each additional item</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Amount</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Mail to SSF, BB&T Bank • PO Box 890612 • Charlotte, NC 28289-0612 or Fax to: (301) 530-4415

Name ________________________________________________
Address _______________________________________________________________________________________
City ___________________________ State ________ Zip _______________________
Telephone ___________________________ E-Mail _____________________________________________________

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

☐ MasterCard ☐ VISA ☐ AmEx Card Number ___________________________ Exp. Date __________________

Signature ________________________________________________