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LETTER FROM SSF CEO STEVEN TAYLOR

his is the time of the year that we at the Sjögren's Syndrome Foundation look back and give thanks to all of you who have supported us throughout the year! Thanks to your generous support, the SSF has continued to soar to new heights as we strive to conquer Sjögren's.

Patient care continues to be a focus of the SSF. With the development of the SSF's Clinical Practice Guidelines for Sjögren's, patients will eventually see standardized care in how healthcare providers treat, manage and monitor their Sjögren's patients. This initiative marks the first time in the history of the disease that a roadmap for treating Sjögren's has been developed. The SSF is proud to be the lead organization to make this happen for all Sjögren's patients, and we couldn't do it without the support of hundreds of healthcare professionals who, along with the SSF staff, are researching the evidence, discussing the best

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How to Talk With Your Family about Sjögren's

here is a growing body of evidence that rich social support networks are important to overall health, immune function and healing. They improve quality of life and facilitate coping with chronic illness. Conversely, negative social interactions create a stress response that have the opposite effect. Support from family members and close friends can be one of the most important resources for you to draw on when dealing with Sjögren's. Skillful communication about your illness is key to nourishing the relationships that matter the most to you. This article only attempts to skim the surface of this complex topic.

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Special acknowledgment to Teri Rumpf, PhD and Julia Oleinik,

RN for their contributions to this article.



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"Update" continued from page 1 ▼

treatment options, and compiling recommendations. In 2015, watch for news releases and updates on these guidelines as they will be published in numerous professional journals for your healthcare providers to read.

In addition, as you will see in this issue, the SSF continues to take the lead on ensuring that patients and their families are aware of the latest Sjögren's research as well the many manifestations of the disease. Talking to your family and friends about Sjögren's is a challenge but so important to helping us increase awareness. If your family and friends don't know about it, how can we expect others to know? So keep distributing SSF materials to your physicians, follow us on Facebook and continue to share your story with family and friends. One by one we are moving the needle on the awareness barometer.

And I would be remiss if I didn't mention how excited the SSF is about the strides we have made in shortening the time to diagnose Sjögren's. Ten years ago when I joined the SSF, it took over ten years to get a diagnosis, and this past month, the SSF just announced that we have reduced the time to 3.9 years. As you know, our goal is to reduce this time to 2.5 years by 2017, so we have a way to go, but thanks to all of our volunteers, we are well on our way!

So, where do we go from here?

The SSF is already busy with plans for 2015.

Our Medical Advisors and staff are planning to expand our focus on working with pharmaceutical companies to convince them to develop new therapeutics for Sjögren's. Because the SSF is educating companies about the importance and severity of Sjögren's, the number of companies interested in our disease is starting to increase dramatically. The SSF also will be talking with the FDA about ways to facilitate getting new Sjögren's drugs to market. This will be extremely critical as we enter clinical trials for more treatments.

Equally important, the SSF will continue to work on clinical practice guidelines to answer the many more questions we all have about how to treat, monitor and manage the systemic manifestations of Sjögren's. The expansion will take us into such areas as lymphoma, brain fog and peripheral neuropathy.

And finally, the SSF is always working on educating healthcare providers about Sjögren's, its symptoms as well as its manifestations. Outreach to all specialists who treat Sjögren's is a huge undertaking but we hope with the help of our Awareness Ambassadors, we can continue to reach new providers and help them to understand the severity of the disease and how influential their specific specialty can be in helping treat and support Sjögren's patients.

And this is only a few of the items we plan to accomplish in 2015, but we need your help. We have come a long way, but there is much more to be done so every year-end donation will help us to ensure 2015 is another great success. You can visit our website at www.sjogrens.org to make a year-end donation or call our office at (800) 475-6473.

And as always, I want to thank all of you – our volunteers and donors, who continue to support the SSF. Together, we are making great strides and I know, with your support, 2015 will be another banner year! ■

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Could you have a type of Chronic Dry Eye disease?

If you use artificial tears often, ask your eye doctor to screen you for Chronic Dry Eye caused by reduced tear production due to inflammation.

Find out if you can

MAKE MORE OF YOUR OWN TEARS

with RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05%

For Chronic Dry Eye disease caused by reduced tear production due to inflammation, you can use artificial tears for temporary relief, but they cannot help you make more of your own tears. Only continued use of RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05% twice a day, every day, can help you make your own tears. Individual results may vary.

Approved Use

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 anti-inflammatory eye drops or tear duct plugs.

Important Safety Information

Do not use RESTASIS® Ophthalmic Emulsion if you are allergic to any of the ingredients. To help avoid eye injury and contamination, do not touch the vial tip to your eye or other surfaces.
RESTASIS® should not be used while wearing contact lenses. If contact lenses are worn, they should be removed prior to use of RESTASIS® and may be reinserted after 15 minutes.

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.

Please see next page for the Brief Summary of the full Product Information.

Call 1-866-271-6242 for more information.

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GO TO restasis.com.

Take the Dry Eye Quiz, and show the results to your eye doctor.

Available by prescription only.



Make more of your own tears



RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05%

BRIEF SUMMARY—PLEASE SEE THE RESTASIS® PACKAGE INSERT FOR

FULL PRESCRIBING INFORMATION.

INDICATIONS AND USAGE

RESTASIS® ophthalmic emulsion is indicated to increase tear production in patients whose tear production is presumed to be suppressed due to ocular inflammation associated with keratoconjunctivitis sicca. Increased tear production was not seen in patients currently taking topical anti-inflammatory drugs or using punctal plugs.

CONTRAINDICATIONS

RESTASIS® is contraindicated in patients with known or suspected hypersensitivity to any of the ingredients in the formulation.

WARNINGS AND PRECAUTIONS

Potential for Eye Injury and Contamination

To avoid the potential for eye injury and contamination, be careful not to touch the vial tip to your eye or other surfaces.

Use with Contact Lenses

RESTASIS® should not be administered while wearing contact lenses. Patients with decreased tear production typically should not wear contact lenses. If contact lenses are worn, they should be removed prior to the administration of the emulsion. Lenses may be reinserted 15 minutes following administration of **RESTASIS®** ophthalmic emulsion.

ADVERSE REACTIONS

Clinical Trials Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in practice.

In clinical trials, the most common adverse reaction following the use of RESTASIS® was ocular burning (17%).

Other reactions reported in 1% to 5% of patients included conjunctival hyperemia, discharge, epiphora, eye pain, foreign body sensation, pruritus, stinging, and visual disturbance (most

Post-marketing Experience

The following adverse reactions have been identified during post approval use of **RESTASIS®**. Because these reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

Reported reactions have included: hypersensitivity (including eye swelling, urticaria, rare cases of severe angioedema, face swelling, tongue swelling, pharyngeal edema, and dyspnea); and superficial injury of the eye (from the vial tip touching the eye during administration).

USE IN SPECIFIC POPULATIONS

Pregnancy

Teratogenic Effects: Pregnancy Category C

Adverse effects were seen in reproduction studies in rats and rabbits only at dose levels toxic to dams. At toxic doses (rats at 30 mg/kg/day and rabbits at 100 mg/kg/day), cyclosporine oral solution, USP, was embryo- and fetotoxic as indicated by increased pre- and postnatal mortality and reduced fetal weight together with related skeletal retardations. These doses are 5,000 and 32,000 times greater (normalized to body surface area), respectively, than the daily human dose of one drop (approximately 28 mcL) of 0.05% **RESTASIS**® twice daily into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed. No evidence of embryofetal toxicity was observed in rats or rabbits receiving cyclosporine at oral doses up to 17 mg/kg/day or 30 mg/kg/day, respectively, during organogenesis. These doses in rats and rabbits are approximately 3,000 and 10,000 times greater (normalized to body surface area), respectively, than the daily human dose. Offspring of rats receiving a 45 mg/kg/day oral dose of cyclosporine from Day 15 of pregnancy until Day 21 postpartum, a maternally toxic level, exhibited an increase in postnatal mortality; this dose is 7,000 times greater than the daily human topical dose (0.001 mg/kg/day) normalized to body surface area assuming that the entire dose is absorbed. No adverse events were observed at oral doses up to 15 mg/kg/day (2,000 times greater than the daily human dose).

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

Nursing Mothers

Cyclosporine is known to be excreted in human milk following systemic administration, but excretion in human milk after topical treatment has not been investigated. Although blood concentrations are undetectable after topical administration of RESTASIS® ophthalmic emulsion, caution should be exercised when $\textbf{RESTASIS}^{\texttt{®}}$ is administered to a nursing woman.

Pediatric Use

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

Geriatric Use

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

NONCLINICAL TOXICOLOGY

Carcinogenesis, Mutagenesis, Impairment of Fertility

Carcinogenesis: Systemic carcinogenicity studies were carried out in male and female mice and rats. In the 78-week oral (diet) mouse study, at doses of 1, 4, and 16 mg/kg/day, evidence of a statistically significant trend was found for lymphocytic lymphomas in females, and the incidence of hepatocellular carcinomas in mid-dose males significantly exceeded the control value.

In the 24-month oral (diet) rat study, conducted at 0.5, 2, and 8 mg/kg/day, pancreatic islet cell adenomas significantly exceeded the control rate in the low dose level. The hepatocellular carcinomas and pancreatic islet cell adenomas were not dose related. The low doses in mice and rats are approximately 80 times greater (normalized to body surface area) than the daily human dose of one drop (approximately 28 mcL) of 0.05% **RESTASIS®** twice daily into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed.

Mutagenesis: Cyclosporine has not been found to be mutagenic/genotoxic in the Ames Test, the V79-HGPRT Test, the micronucleus test in mice and Chinese hamsters, the chromosome-aberration tests in Chinese hamster bone-marrow, the mouse dominant lethal assay, and the DNA-repair test in sperm from treated mice. A study analyzing sister chromatid exchange (SCE) induction by cyclosporine using human lymphocytes in vitro gave indication of a positive effect (i.e., induction of SCE).

Impairment of Fertility: No impairment in fertility was demonstrated in studies in male and female rats receiving oral doses of cyclosporine up to 15 mg/kg/day (approximately 2,000 times the human daily dose of 0.001 mg/kg/day normalized to body surface area) for 9 weeks (male) and 2 weeks (female) prior to mating.

PATIENT COUNSELING INFORMATION

Handling the Container

Advise patients to not allow the tip of the vial to touch the eye or any surface, as this may contaminate the emulsion. To avoid the potential for injury to the eye, advise patients to not touch the vial tip to their eye.

Use with Contact Lenses

RESTASIS® should not be administered while wearing contact lenses. Patients with decreased tear production typically should not wear contact lenses. Advise patients that if contact lenses are worn, they should be removed prior to the administration of the emulsion. Lenses may be reinserted 15 minutes following administration of RESTASIS® ophthalmic emulsion.

Administration

Advise patients that the emulsion from one individual single-use vial is to be used immediately after opening for administration to one or both eyes, and the remaining contents should be discarded immediately after administration.

Rx Only



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You Stood Up!

Patients Sharing with Patients, How to Beat the Winter Blues

eather can affect everyone differently and while many people prefer colder temperatures, when living with certain chronic illnesses, like Sjögren's, winter weather can have a negative effect on a person's symptoms. Winter weather can affect symptoms such as joint stiffness or dry skin, and also a person's mood.

Learning to live with Sjögren's is learning what your body's new normal is, which includes taking care of both your physical and emotional symptoms.

The best advice often comes from patients and we want to thank you for your willingness and openness to share. Below are your tips that the Foundation has received on how to beat the winter blues.

I make sure my clothing is warm, comfortable and wear fingerless mitts inside. I also try to be consistent about using over-the-counter (OTC) lubricants to keep my eyes, nose, mouth and skin from drying out.

- Cathy

Nasal spray or olive oil when the heat is blasting.

Valerie

I use Nivea A Kiss of Moisture essential lip care every other hour to coat dry winter lips. It doesn't have sunscreen, which dries out my lips.

- John

In the winter, I have found that getting outside to exercise makes a difference as it exposes me to sunlight. I live in New England so I just bundle up (put on several pairs of gloves) and go.

– Dale

Having a humidifier has helped with my chronic sore throat. It takes about an hour and a half each day to let the stiffness leave my body. I gave myself permission to have some "me time" during that time, which has drastically improved my mood. It also makes me more efficient when I do start my day.

- Heather

(SSF Tip, for Sjögren's patients, an optimal range of humidity is between 55% and 60% regardless of the ambient temperature.)

I open the shades and keep my house flooded with sunlight. And I have lots of tropical house plants to lift my spirits. Think spring!

– Sarah

When I'm cold and ache all over, I take a warm bath with scented Epsom salts.

- Robin

My worst symptoms are fatigue combined with muscle achiness. Sometimes I bring it on by doing too much. Especially around the holidays when I'm feeling good and staying out too late socializing, then I'm knocked back for a week. I'm learning that I run on adrenaline when I finally get to socialize, so I have to set a time limit on when I go home. Doing a stretching/yoga DVD every morning helps with the achiness.

- Mary

Physician tip!

Consider using an OTC emollient such as Ponaris[®] to cleanse the nose, particularly if large crusts and debris are present.

- Robert Lebovics, MD, FACS

Using Acupuncture and Chinese Medicine to Treat Sjögren's

by Iva Lim Peck, L.Ac., Dipl.Ac., RN, RMT, Integrated Center for Oriental Medicine

n conventional medicine, at the cellular level, Sjögren's is not any different from other autoimmune diseases like multiple sclerosis, rheumatoid arthritis, systemic lupus; chronic diseases like diabetes and heart disease; even mood disorders like depression, schizophrenia. They all share mitochondrial dysfunction, excessive inflammation, high cortisol levels, and other markers of broken biochemistry. For health to return, the chemistry must be reverted to normal and the communication between the cells must be restored.

Chinese medicine views a person as an energy system in which the body and mind are unified, each influencing and balancing the other. It is a holistic approach that treats the whole person. Conversely, Western medicine attempts to isolate and separate a disease from a person.

According to Chinese medical theory, autoimmune disorders occur when there is imbalance within the body. One of the basic theories of Chinese Medicine is that of Yin and Yang which represent the duality and interplay of all energies and phenomena. While Yin and Yang are oppositional, they are also interdependent, each always containing a bit of the other within and, together, they strive to be in a constant state of dynamic balance.

According to Chinese medical theory, illness arises when the cyclical flow of Vital Energy/ Life Force, "Qi" (pronounced "Chee") goes out of balance or becomes blocked, causing a disruption of the flow along the innate energy pathways, i.e. the Meridians.

Acupuncture promotes natural healing, restores balance, and improves function in treating the root of the disorder, while specifically addressing the symptoms unique to each individual. A person's entire physiology is taken into consideration.

Chinese medical diagnosis is based upon a thorough examination and consultation. The examination includes the assessment of the pulse and tongue diagnosis. Once a diagnosis is made the most appropriate acupuncture points will be chosen for treatment.

Acupuncture points are areas of designated electrical sensitivity. The points are located along the meridians that connect all of our major organs

By inserting sterilized, stainless-steel needles (as fine as a human hair) at specific points located near or on the surface of the skin, various biochemical and physiological conditions are altered. The stimulation of various sensory receptors in turn stimulate nerves that transmit impulses to the hypothalamic-pituitary-adrenal (HPA axis). The HPA axis is responsible for releasing neurotransmitters and endorphins, the natural pain-killing hormones. As a result, acupuncture not only relaxes the whole body, but also regulates serotonin in the brain, which is why depression can be treated with acupuncture.



According to clinical research, acupuncture is shown to induce physical responses in nerve cells, the pituitary gland, and parts of the brain. These responses regulate the release of appropriate proteins, hormones, and brain chemicals that control many body functions.¹

Some of the physiological effects observed throughout the body include increased circulation, decreased inflammation and pain, reduced muscle spasms and increased T-cell count that stimulates the immune system. Through these actions, acupuncture can affect blood pressure, body temperature and the immune system. Therefore, acupuncture is effective in restoring hormonal imbalance, regulating energy, improving emotions and sleep disorders. ²

Alternative medicine definitely provides different options. A standard model of simply fixing the guts, stabilizing the blood sugar level, balancing the hormones, taking enough essential fatty acids and anti-inflammatory protocols, etc is essential, but nevertheless insufficient. They are effective, however, they are not any different than treating any type of autoimmune disorders. We need to go further.

The major deficiency is actually how to actively identify the autoimmune mechanism. In order to figure out the autoimmune mechanism one must dissect the person's cytokine production and T cells and B Cells break down to figure out what's going on with the immune pattern.

In addition to various acupuncture protocols, an Integrated Chinese medical practitioner might incorporate

other treatments to treat Sjögren's. These could include, but are not limited to: Acupuncture for pain and stress management; Allergy Elimination and Desensitization to address foods, chemicals and environmental sensitivities; Neuro-Emotional Technique to address domino effects of emotional complexes; Enzyme and Nutritional recommendations for digestive disorders; Herbs and Supplements to support the overall excess or deficiencies; Homeopathy to address the totality of each person's individual make up, in an attempt to communicate with the psychological and spiritual components as well as the physical essence of the person; last but not least, Tai Chi Chuan and Qi Gong for the overall stress reduction, energy regulation, improvement and prevention of the physical pain and stiffness that most Sjögren's patients suffer from.

With the variety of symptoms that encompass Sjögren's, it is very important to have a plan with a practitioner who works with full oversight and a set of complimentary skills under one roof. Having support and sharing information — and having a positive attitude — contribute to positive outcomes.

References

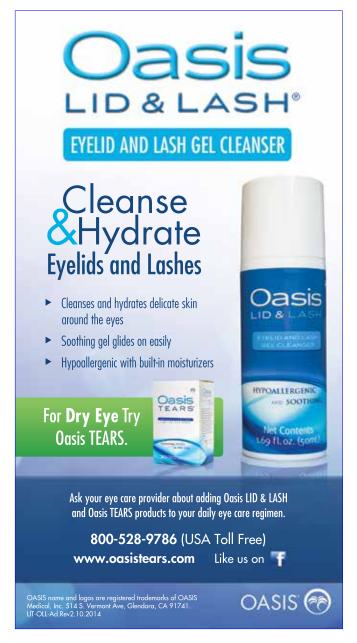
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"Talking to Your Family" continued from page 1 ▼

Three characteristics of Sjögren's create particular communication challenges.

1. Untimely: Sjögren's is typically diagnosed in the prime of life (40s and 50s), when family responsibilities and careers are in full swing.

While some are lucky enough to have mild symptoms, the majority of patients experience flu-like fatigue, pain and brain fog that demand a new, strict energy budget. Jobs may be lost or hours cut. Frequent medical and dental visits and costly products such as artificial tears strain both schedules and finances. Family dynamics are rearranged by the illness, causing stress, especially if there is little support or strong disagreement about how



to meet the new challenge. Single people who become ill may feel particularly vulnerable and alone, wondering how will they ever manage.

2. Uncertain: Early on, many patients have a hard time accepting that this disease will be a lifelong challenge. The sense of loss and fear of long term illness can be profound for both patients and loved ones.

Symptoms may wax and wane for no obvious reason, although they rarely disappear. This can add to confusion and denial. The initial focus of patients and family members is often "how can we fix this?" Denial can make adjustment to a new normal even more protracted. Sometimes denial persists for years, until it becomes clear that medications and other interventions cannot bring back "life as usual."

3. Invisible: Sjögren's patients tend to look well most of the time, even when feeling quite ill.

The outward appearance of normalcy can make it hard for others to appreciate the severity of your illness. This is made worse when doctors don't address symptoms such as fatigue and pain that make it a struggle to get through the day. Even though Sjögren's is quite common, most doctors are not trained to recognize even typical systemic symptoms, and tend to focus on dryness. Some medical websites reinforce this incorrect notion that Sjögren's is mostly about dryness, rather than a serious systemic disease. When presented with this inaccurate portrayal of the disease, family members and patients become understandably confused. Healthcare providers frequently minimize life-changing symptoms or even become dismissive, leaving the patient feeling powerless or invisible. When family members also fail to understand the devastating impact that Sjögren's can have, the emotional turmoil can be overwhelming.

As a result of widespread misinformation, patients find themselves needing to become "experts" in their disease. Backed with up-to-date knowledge, it is possible to advocate for care and educate health care providers when needed. An excellent, reliable source of information can be found at the Sjögren's Syndrome Foundation website, www.sjogrens.org. Be sure to read –or reread- the "About Sjögren's" section, especially the FAQ. Encourage family members to read it too. It's really good. It might seem overwhelming and a bit disheartening that you need to learn so much about Sjögren's, especially early after diagnosis. However, educating yourself will provide essential tools for communication with family, friends and doctors.

Communication with family members

Spouses/partners and other family members suffer grief and loss too. It is important to acknowledge this.



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Aquoral[®] is approved for dry mouth due to Sjögren's Syndrome¹

- · Coats, lubricates, and protects
- Reduces mouth dryness^{2,3}
- Improves ability to chew and swallow^{2,3}
- One application lasts up to 4 hrs^{2,3}
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- Gluten free⁴

INDICATIONS: Aguoral is intended to provide relief from chronic and Sjögren's Syndrome, oral inflammation, medication, chemo or radiotherapy, stress or aging. Aquoral relieves symptoms of dry mouth such as difficulties in

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CONTRAINDICATIONS: Aguoral is contraindicated for any patient with a known history

PRECAUTIONS: Read package insert carefully before using this spray. Avoid contact with

INTERACTIONS: There are no known interactions with medicinal or other products.

To report a serious adverse event or obtain product information call (800)531-3333.

References: 1. Aquoral [package insert]. San Antonio: TX. Mission Pharmacal Company; 2013. 2. Mouly SJ et al. Efficacy of a new oral lubricant solution in the management

Please see full Prescribing Information on next page.

of hypersensitivity to any of its ingredients.

Please see full Prescribing Information provided.



"Talking to Your Family" continued from page 8

Open the discussion early. Ask about their fears regarding the impact of your illness and the uncertainly it creates. Be prepared to revisit this conversation several times. Both you and your significant others will go through loss and grief, although the timing and process is different for each individual.

In spite of your best efforts toward clear, empathic communication with your family, some people may respond with judgment and blame. This often comes as a painful surprise, especially at a time when support feels most needed. Relationship upheaval is typical for people with serious illness. It is important not to blame yourself for the illness, but to develop good self-care with an at-



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ACTIONS: Aquoral® is a lipid-based solution resembling human saliva designed to moisten and lubricate the oral cavity, including the oral mucosa of the mouth, tongue and throat, by formation of a lipid film which limits loss of water and restores the viscoelasticity of the oral mucosa. Aquoral also provides protective action against further inflammation of the oral mucosa. Xerostomia (dry mouth) has harmful effects on the oral cavity and quality of life; consequently, management of dry mouth is primarily based on relief of symptoms.

INDICATIONS: Aquoral is intended to provide relief from chronic and temporary xerostomia (dry mouth), which may be a result of disease such as Sjögren's Syndrome, oral inflammation, medication, chemo or radiotherapy, stress or aging. Aquoral relieves symptoms of dry mouth such as difficulties in swallowing, speech, and changes in taste.

CONTRAINDICATIONS: Aquoral is contraindicated for any patient with a known history of hypersensitivity to any of its ingredients.

PRECAUTIONS: Read package insert carefully before using this spray. Avoid contact with eyes. Flush eyes with water if accidental introduction into eyes should occur.

INTERACTIONS: There are no known interactions with medicinal or other products.

DIRECTIONS FOR USE: Shake gently. One dose (2 sprays) into the mouth 3 to 4 times a day. Spread product on to inflamed and/or dry areas of the mouth with the tongue. Pump may require priming for initial use.

To report a serious adverse event or obtain product information call (800) 531-3333.

HOW SUPPLIED: Aluminum canister with 0.1 ml spray pump containing 40 ml (1.4 fl. oz.) (net content) of solution which corresponds to 400 sprays of Aquoral (**NHRIC** 0178-0420-40).

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U.S. Patent: 8,367,650



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A0H-14002

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Rev 005130

titude of deep kindness toward yourself. Attempt to keep lines of positive communication open, but set boundaries to protect yourself from negativity.

While unsupportive family members may eventually shift their stance, the approach of trying to educate them repeatedly after several unsuccessful attempts will only result in unnecessary pain. Just having one or two people in your life who truly "get it" can be enough. Recognize that some people may be good at practical support, but unavailable emotionally. The reverse may also occur.

Practical support tips

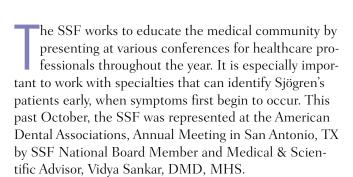
Practical support, especially from family members, can go a long way in helping you manage your health. Most Sjögren's patients can participate in a number of activities, especially when family members take over tasks that are particularly challenging for you to do. It takes some trial and error to learn what you can do without compromising your health. Being a good observer of your unique patterns will help you plan the types of activities and pacing that works for you. Even with careful planning, the unpredictable nature of Sjögren's will sometimes knock you down when you don't expect it. It is always good to have a backup plan ready- and soup in your freezer!

Many people are happy to help, but might not ask or could assume you are doing fine if you have a partner or other adults in the home. It can be difficult to ask for help, especially if you are the "can do" type of person. It is good to remember that providing support can be beneficial to both givers and recipients. Sometimes support arrives from people you don't expect to come through, while those you think of as close friends or family may not provide support.

Examples of useful responses and communication tools

- If you are unsure of a person's awareness or interest, you can ask: "I'm not sure how much you know about Sjögren's- do you want to know more about what's really going on with me?"
- When someone asks if they can help, try to be ready with a specific request such as stopping by with dinner, running errands, childcare, etc. If you are caught off guard, a good response might be: "Can I get back to you? I could really use help but I am feeling too overwhelmed to think about it right now."
- State your limitations and needs, clearly and without apology. If you are too tired to cook, shop

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Dr. Sankar and the SSF collaborated with several other autoimmune organizations for the presentation, "Disease Detective: Autoimmune in Dentistry." Using unique case studies, Dr. Sankar asked attendees to identify the autoimmune disease a patient was presenting with. The diseases covered were Behcet's, Lichen Planus, Lupus, Pemphigus, Pemphigoid and of course, Sjögren's. Once correctly identified, she discussed each disease and the way the dental community can help to quickly identify these patients, stressing the importance of early and correct diagnosis.

This is one of many presentations Dr. Sankar has given for the SSF on the severity of Sjögren's at dental conferences over the past few years. She is the perfect SSF representative to speak about the disease's complexity because not only is she a member of the SSF Board of Directors, but Dr. Sankar was the first SSF Student Fellowship Award Winner in 1995, when she first developed an interest in Sjögren's while in dental school.

Educating healthcare professionals about Sjögren's and encouraging young researchers to take an interest in perusing a career in Sjögren's, are two of the key strategies the SSF is using to reach our 5-Year Breakthrough Goal, "To shorten the time to diagnose Sjögren's by 50% in 5 years."

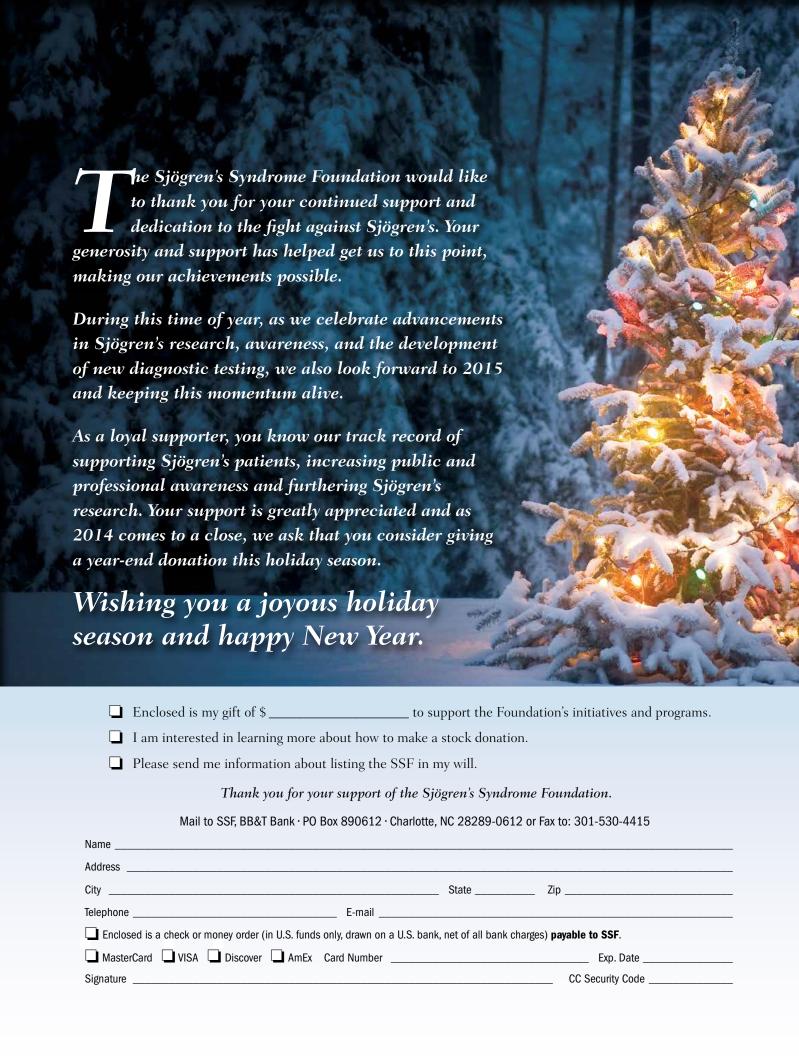
November/December Breakthrough Bullet:

Dr. Sankar presents on Sjögren's at the American Dental
Association's Annual Meeting





The SSF would like give a big thank you to Dr. Sankar for dedicating her career to helping Sjögren's patients and educating the dental community about this debilitating disease.





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The symptoms of Sjögren's Syndrome can have devastating effects. Oral dryness can result in severe and chronic dental decay, fissures, infections, and difficulty in speaking and swallowing.



What is NeutraSal®

NeutraSal® is an advanced electrolyte solution indicated in the treatment of dry mouth (xerostomia) in patients with Sjögren's Syndrome. NeutraSal® consists of single use packets of dissolving powders that when mixed with water creates an oral rinse supersaturated with calcium, phosphate and bicarbonate ions.

- Calcium and phosphate ions have been shown to aid in the the prevention of dental caries (cavities) and promote the remineralization of the teeth in normal saliva
- ♦ Sodium bicarbonate ions reduce the acidity of the saliva in the mouth and break up accumulating mucus
- The pH of NeutraSal[®] is similar to normal saliva which may protect the mouth against potential opportunistic fungal (oral thrush) and bacterial infections
- Clinically proven to relieve the symptoms of dry mouth in Sjögren's Syndrome patients with no reported side effects or drug to drug interactions

NO PATIENT LEFT BEHIND PROGRAM

The No Patient Left Behind Program is designed to provide access to NeutraSal® treatment for all patients regardless of their insurance coverage and includes no out-of-pocket costs for patients. NeutraSal® is a prescription only product. Ask your physician.



"Talking to Your Family" continued from page 1 ▼

- or clean, state that and request specific help from household members. For example: "I'm not well enough to do housework right now. Could you please vacuum and clean the bathrooms once a week?" as opposed to the more vague, "I need more help with the cleaning."
- Many people go into advice giving mode, offering instant remedies such as the latest diet, various medical regimens, healers etc. This may be motivated by a true desire to help, or it can be a way to distance themselves from your experience. Some possible responses: "Thanks for your concern, I am working closely with my doctor on this," or "I appreciate your concern. I need to do this in my own way and in my own time. It would be great if you could support my choices."
- Dealing with insensitive and judgmental comments, especially if repeated, is difficult. One strategy is to provide the speaker with an opportunity to consider the hurtfulness of their comments, by asking: "Let me understand. Are you saying (repeat hurtful comment)?" The person may back pedal or give their comment more thought. This does not always work. Here are examples of responses to real life comments:
 - "If you just stopped taking all those medications, you would be fine."
 - Response: "What I'm hearing you say is you think Sjögren's is not serious enough to require medication."

- "If you would exercise/lose weight/eat paleo etc. you would be fine."
- Response: "Do you think if I (fill in the blank) my Sjögren's will go away?"
- To a more subtle comment insinuating you are not trying hard enough: "I'm hearing you say that if I tried harder that I could do ______ (fill in activity) and still manage my Sjögren's symptoms."
- If responses like this do not work, set boundaries: "It hurts to hear you say this. I am doing my best. Please keep these comments to yourself."

It can be especially difficult when someone close to you clearly does not understand your illness or support your efforts to take care of yourself. Relationships that were difficult to begin with may become even more painful. Some relationships do not survive the stress of chronic illness. Family members have a limited capacity for emotional or practical support. If you don't feel supported by those closest to you, being creative about organizing your life, getting support from others, and setting excellent boundaries may be your best strategy. If you are dealing with a close relationship that seems to be faltering, it can be helpful to seek professional support from someone knowledgeable about chronic disease.

Most importantly, know that the news here is not all bad. Many people do step up to the plate, although they may need prompting. Be patient if they are trying to understand; it takes time to adjust and to learn about Sjögren's.





Clinicians Corner



Is depression common in Sjögren's?

Yes. Numerous studies over the years have shown that depression and anxiety are more common in Sjögren's. The study methods and populations vary, but depression appears to occur in 30-40 % of those with Sjögren's. Furthermore, even a higher number have anxiety (48%). In comparison, about 5-10 % of people without a chronic illness have depression. Cultural factors also affect these findings. We do not yet know if depression is more common (or not) in Sjögren's versus another chronic autoimmune illness, like Rheumatoid Arthritis or SLE (Lupus). But we do know that if there are multiple conditions, the rate of depression is higher (7 times) versus 2-3 times with one chronic condition. Given the number of body systems that can be affected in Sjögren's, it is likely that depression can be very common.

It is also possible that, in additional to the loss which accompanies chronic illness, that immune/inflammation mechanisms may be a co-factor in symptoms like depression, anxiety, fatigue, and neurocognitive changes. With the current focus on Neurosciences, we may gain further insights and treatment/management options for these additional challenges those with Sjögren's face. Sjögren's is not just an illness of "dryness."

-Nancy Carteron, MD, FACR Consultant, Rheumatology Immunology Autoimmune Disease Associate Clinical Professor University California San Francisco



NEW

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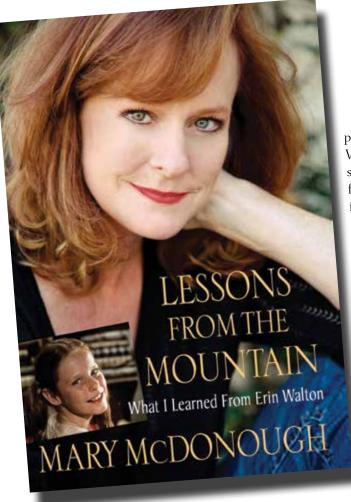
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Holiday Gift Idea

Lessons from the Mountain by Mary McDonough

Mary McDonough is not only a Sjögren's and Lupus patient, but she is also famous for having played Erin Walton on the ever popular series *The Waltons*. As a child star and through her life, she has learned that you have to find your voice, which is why she wrote her book "Lessons from the Mountain."

For nine seasons, Mary McDonough was part of one of the most beloved families in television history. Just ten years-old when she was cast as the pretty, wholesome middle child Erin, Mary grew up on the set of *The Waltons*, alternately embracing and rebelling against her good-girl onscreen persona. Now, as the first cast member to write about her experiences on the classic series, she candidly recounts the joys and challenges of growing up Walton – from her overnight transformation from a normal kid in a working class, Irish Catholic family, to a Hollywood child star, to the personal challenges that led her to take on a new role as an activist for women's body image issues.

Whether you are a Sjögren's patient or grew up watching Erin Walton on TV, this book gives everyone the opportunity to see the courageous woman behind the little girl on TV, making it the perfect holiday present!

Non-

Mary McDonough was the Keynote Speaker at the 2014 SSF National Patient Conference

Member Price: \$14

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

Member Member Amount Price Price Qty Lessons From the Mountain: by Mary McDonough \$16.00 \$14.00 Maryland Residents add 6% sales tax Shipping and Handling: US Mail: \$5 for first item Canada: \$14 for first item Overseas: \$22 for first item **Total Amount**

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Raynaud's Syndrome

by Ashley Beall, MD

aynaud's Syndrome (sometimes called Raynaud's phenomenon) is defined as repeated episodes of color changes in the fingers and/or toes with exposure to cold temperatures or during episodes of emotional stress. The color changes are due to a spasm of the blood vessels that feed the fingers and toes. The digits typically turn very white, then can take on a bluish color with prolonged exposure to the cold, and finally can turn very red as blood flow resumes. Raynaud's Syndrome occurs in approximately 15-30% of patients with Sjögren's.

Some things that you can do to control your Raynaud's Syndrome include:

- When you know that you will be exposed to cold temperatures, wear layered clothing. This will keep your core body temperature warm and keep the vessels feeding the fingers and toes from spasm.
 - Always carry a jacket with you on outings, as you may find yourself in an unexpectedly cool area.
 - Wear a hat and cover your face and ears with a scarf in cold temperatures.
 - Always wear hand coverings in cold temperatures. Mittens are best, as they will use the body heat generated by your fingers. However, a good pair of insulated gloves is also helpful.
 - Wear heavy socks or layers of socks to keep feet warm at all times.
 - Keep your home and office space comfortably warm (greater than 70° is best).
 - Avoid reaching into the freezer both at home and in the grocery store.
- Use insulated containers when handling cold drinks or food
- Rinse food with warm water instead of cold water.
- Wear protective gloves when washing dishes.
- Use disposable heat packs as needed for your hands and feet. These are available at many sporting goods stores.
- Always let the water warm up before getting into the shower, and keep the bathroom door closed while bathing or showering to hold in heat.
- When possible, have a loved one warm up your car before getting into it on a cold day.
- Moisturize your hands and feet every day to prevent skin cracking.

- When your hands or feet start to feel cold, wiggle your fingers and toes, move your arms and legs around to get blood flowing, or put your hands in your armpits to warm them up.
- If you have access to water when a flare starts, run warm water over your fingers and toes until skin color returns to normal.
- Do not smoke—this constricts the blood vessels that feed the hands and feet.

Talk to your doctor about your symptoms. Several medications can be used to help the vessels stay dilated, including a class of blood pressure medications called calcium channel blockers. Some medicines, such as beta blockers used for high blood pressure, may make Raynaud's worse.

memoriam

In Memory of Alice Jaqueth

Matt and Kelly Betts

In Memory of Barbara Milligan

Kathy Heffernan Gotwals Family Lucette Shellenback

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Steve and Joan Nielsen

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Sue Matlof

Sue Snell

The Friday Morning Mah Jongg Group
The Magnuson's

Tracey and Mitch Galinson

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In Memory of Jean Collins

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Presentation topics will include:

- Overview of Sjögren's
- Neurological Complications
- Dry Mouth & Sjögren's
- Dry Eye & Sjögren's
- Ear, Nose & Throat Involvement
- Gynecological Complications
- Major Organ System Involvement
- Financial Planning for Patients with Chronic Illness

Save the Date

Learning to Thrive with Sjögren's

2015 National Patient Conference

April 17-18, 2015

The Grand Hyatt Tampa Bay 2900 Bayport Drive ■ Tampa, Florida

his April we invite you to join with fellow Sjögren's patients, their families, medical experts, the SSF staff and industry/ product exhibitors for our 2015 National Patient Conference, "Learning to Thrive with Sjögren's," at the Grand Hyatt Tampa Bay (Tampa, Florida).

Sjögren's is not the same for every person diagnosed, which is why educating yourself on the most up-to-date information and treatment options is so important. Attending the SSF National Patient Conference is one way you can gain information from many different sources while also meeting fellow patients.

This year's Conference will include opportunities to:

- Hear from national Sjögren's experts, researchers and SSF staff
- Find new products and receive free samples at our exhibitor hall
- Learn from your fellow patients
- Browse Sjögren's resources at the SSF Book Table
- Become inspired during the Conference's Awards Banquet Dinner

We encourage you to take this opportunity and learn how to thrive with Sjögren's. This educational journey will give you the tools to take control of your health and learn how to manage and understand your Sjögren's symptoms and complications.

Watch for your conference brochure coming in January or visit www.sjogrens.org to see updated conference information.

The Moisture Seekers

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

Phone: 800-475-6473 *Fax*: 301-530-4415

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



Shop to benefit the Sjögren's Syndrome Foundation

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

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

◆ Amazon.com is one of the most popular online stores in the world, offering a wide variety of products. 8.5% of the value of your purchase is donated back to the Foundation.

◆ **Drugstore.com** is a leading online provider of health, beauty, vision, and pharmacy products. The website allows you to shop as if you were at your local drug store, and you can get instant savings while 10% of your purchase benefits the SSF.

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

◆ iGive.com offers exclusive deals with over 700 brand name stores you know and love, with a specified percentage of each purchase coming back to the SSF. Be sure to select "Sjögren's Syndrome Foundation" as your charity of choice. Whenever you return to iGive.com and log in, any shopping you do will benefit the SSF! It's that simple.

