

Back to School, Back to Sjögren's Basics

This fall, as students around the country begin to head back to school and get ready for a new year, the Sjögren's Syndrome Foundation thought to use this time to write about "back to basics" in terms of managing your Sjögren's health. In this issue, we have focused on the fundamentals that can often be forgotten in the busy day-to-day life.

Your Medical Team:

As you most know, rheumatologists have the primary responsibility for managing Sjögren's and usually are the lead of your "medical team."

That is why, when seeing a new physician or any of your many specialists, it is important to establish clear guidelines regarding your medical management, which means clarifying what things that doctor will be managing versus what your rheumatologists and/or primary care physician will oversee.

All of these healthcare providers make up your "medical team." However, it is crucial that your lead physician has all of the information regarding your diagnoses, treatment plans and prescriptions that your entire medical team is providing. This will help the lead physician better manage your case.

How to find a knowledgeable doctor in your area:

It is important to find a doctor who is both a good partner in treating your disease, as well as a good listener. While we know this

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How I Found a New & Happier Life with Sjögren's

My sense of humor is dry, and so is everything else! I've always had a dry sense of humor coupled with an optimistic personality. But I must admit, when I was diagnosed with Sjögren's, it took me quite a bit of time to go through the grieving process and create a bold life with my sense of humor intact.

I love those stories about people who are able to accept the diagnosis and immediately say, "Sjögren's, I may have you but you will not have me." That was not my experience. In fact, I found that the more I challenged my Sjögren's, the more it did have me!

Like all of you, I now can look back and pinpoint when I was presenting early Sjögren's symptoms. My early symptoms began in 1997 as ongoing sinusitis and exhaustion. For a decade, symptoms escalated until I was hospitalized for two weeks. Nine months after my hospitalization I was finally diagnosed with Sjögren's in January 2007.

I was relieved to have the diagnosis and excited to look Sjögren's in the face and tell it, "You will not have me! I am a fighter, an optimist, a model patient and I will knock you down."

Although it turns out a fighting attitude was not what I needed and it took

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can be very difficult, it is needed to make sure you are getting the attention your disease requires.

While the Foundation cannot keep a list of physicians due to liability, we encourage our Volunteer Support Group Leaders and Volunteer Phone Contacts to keep a personal referral list of physicians that other patients in their area have been to and found knowledgeable. Even if you cannot go to a recommended doctor, try calling that doctor's office to discover if they know of any other knowledgeable rheumatologists in your area that they could refer. You can see a list of SSF Support Group Leaders with their contact information on our website www.sjogrens.org or by contacting the Foundation at (301) 530-4420 or info@sjogrens.org.

We are glad that medical professionals are becoming more aware and educated about Sjögren's, but we want every treating physician to understand the complexity and seriousness of Sjögren's. You can help by asking your physician to connect to the SSF! At your next appointment, bring a copy of *The Moisture Seeker* newsletter and mention to your doctor or the office receptionist that if they call the SSF, we will mail them free brochures. In addition, we will subscribe their physician to receive our medical newsletter, the *Sjögren's Quarterly*, that contains the latest information on how to treat patients as well as updates on research and new treatment options.

What to take to a doctor's appointment:

You should be prepared for a new doctor's appointment and know your specific objectives for that visit. If this is your first visit to a doctor, it is essential to give them a copy of all your medical records. They will not have time to read it over there during your appointment, but they can keep it on file to review after your first visit.

It is also key to show your physician that you want to be an active participant in your care. Make sure to tell them about all of your daily care. Bringing with you a typed list of medications with dosage (including over-the-counter products and supplements) can be helpful.

In addition, keeping a symptoms journal or diet journal can be beneficial to recognize new or worsening symptoms along with foods that can trigger a flare. See our "Tracking Your Sjögren's Symptoms" worksheet on page 7.

And finally, if you have questions for that healthcare provider, bring a list and hand it to them to review. This will help expedite their answers and make sure you get as many answers as possible in one appointment. The healthcare provider can sometimes quickly review a list of questions and tell you which ones are most important to be concerned about and which questions he/she can address at another appointment. Not only will you leave with more answers but your healthcare provider will appreciate your organization.

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

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

And she said I have a disease.

My eye doctor said I have reduced tear production caused by inflammation due to a disease called Chronic Dry Eye. That's a big deal.

She told me I can use artificial tears for temporary relief. But to make more of my own tears, she prescribed RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05% for continued use, twice a day in each eye, 12 hours apart, every day.

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 the use.

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.

Individual results may vary.

For a free information kit and long-term savings, go to **restasis.com** or call 1-866-271-6242.

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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 often blurring).

Post-marketing Experience

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

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

USE IN SPECIFIC POPULATIONS

Pregnancy

Teratogenic Effects: Pregnancy Category C

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

Offspring of rats receiving a 45 mg/kg/day oral dose of cyclosporine from Day 15 of pregnancy until Day 21 postpartum, a maternally toxic level, exhibited an increase in postnatal mortality; this dose is 7,000 times greater than the daily human topical dose (0.001 mg/kg/day) normalized to body surface area assuming that the entire dose is absorbed. No adverse events were observed at oral doses up to 15 mg/kg/day (2,000 times greater than the daily human dose).

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

Nursing Mothers

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

Pediatric Use

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

Geriatric Use

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

NONCLINICAL TOXICOLOGY

Carcinogenesis, Mutagenesis, Impairment of Fertility

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

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

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

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

PATIENT COUNSELING INFORMATION

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



Based on package insert 71876US15

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For more information, please visit our website, www.restasis.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 September 30, 2013 will not be accepted. One rebate per consumer. Duplicates 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. Offer void where prohibited by law, taxed, 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.



Patients sharing with Patients

*What's the best tip you
have ever received?*

We asked online for people to tell us what was the best advice they were ever given as a Sjögren's patient and here are a few of the responses:

No one grew up with plans to have a chronic disease. It just happens. Once it does, you have to do everything possible to live in the best way you can. – *The Sjögren's Syndrome Survival Guide*

A good team of doctors and do what they say. Rest when you need to, keep yourself moving as much as you can, and don't give up! – *Ryan*

Keep artificial tears drops EVERYWHERE. Bathroom, work, bedroom, purse, car, every jacket, family & friend's houses. To be caught without can be very debilitating! – *Sarah*

Not to push yourself when you're tired. If you have to think about having enough energy to do something, it means you do not! And if by chance you are having a good day don't push it to the limit because then you will pay for it for days! – *Stevie*

Vitamin D and rest when my body tells me to. It's not easy for others to understand the pain and tiredness, so I take it one day at a time. – *Renee*

Pace yourself, listen to your body, but keep moving. Yoga works best for me! – *Linda*

Soak in my soft tub (soft hot tub) daily and use Gold Bond foot lotion everywhere as it soaks into my skin and makes it feel smoooooth!! – *Cidney*

Learn to listen to your body when dealing with fatigue and joint pain- don't push yourself too much. I have days where I just overdo it because I'm feeling great and the next day I suffer. I also find a heating pad helps a lot. – *Tim*

Many things have helped lessen my symptoms such as juicing, low carb intake, flax seed (whole seeds, ground for juicing), low stress, low sun exposure, swimming for joints, naps, and the biggie- trying to be more positive! – *Cam*

Olive oil for the mouth before you go to sleep, I keep a container by the bed. – *Izabelle*

I find taking Flaxseed oil helps my eyes so much it improves the dryness, it's a source of Omega 3, I swear by it. – *Sonia* ■



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Questions to ask at a doctor's appointment

- How many patients have you treated with Sjögren's?
- Are you interested in receiving professional educational information regarding Sjögren's treatment, research and management from the SSF?
- Are there any lifestyle changes I can make to better control my _____ symptom?
- How should I expect my _____ symptom to progress over time?
- What type of treatment do you recommend for this symptom?
- With this type of treatment, how long until I should start to see results?
- What are the most common short and long-term side effects for this treatment?
- Do I need to see a specialist (or specialists) about my _____ symptom?
- If so, who would you recommend?
- How often should I follow-up with you?

What medications to ask your doctor about:

A Sjögren's patient's treatment path should be decided on a case-by-case basis after the potential benefits and side-effects are weighed by patients and their healthcare providers. Currently, a number of different medications are available that might be used to manage symptoms. However, at the present time there is no single medication that has been conclusively proven to slow the progression of Sjögren's or cure the disease.

Success in using disease-modifying agents to treat closely related disorders like systemic lupus and/or rheumatoid arthritis has led physicians to utilize some of these treatments in Sjögren's as well. The two most popular choices at present include Plaquenil and intravenous rituximab. The decision to prescribe these specific medications is made on a case-by-case basis after careful consideration of potential risks and benefits.

In addition, many patients also are prescribed corticosteroids as well as prescription products to treat their various symptoms including but not limited to dry eyes, dry mouth, gastrointestinal and joint pain symptoms.

The SSF is dedicated to research into studies that help us better understand the full benefit of these treatments as well as working with companies to help develop new

therapeutics that can treat the disease as a whole. The SSF is excited about the current pipeline for treatments that are being investigated by companies, and the SSF continues to be at the forefront at working with and encouraging these companies to move forward.

We hope you will support the SSF research program and innovative studies that we fund. Learn how to donate by visiting www.sjogrens.org or contacting the Foundation at (301) 530-4420 or info@sjogrens.org.

Find Support:

As a Sjögren's patient, you face the challenge every day of coping with this debilitating disease. Though there are an estimated four million Americans living with Sjögren's, being diagnosed with an invisible illness can be isolating, which is why it is important to find support and credible information.

Signing up to receive the SSF's *The Moisture Seekers* newsletter and becoming a member of the SSF was your first step! Please share the articles you find helpful with not only your physician, but family and friends to start a dialog about what you are going through.

Secondly, you should think about what works best for you in regards to how you can learn and gather information. For example, patients find different ways to learn how to live with Sjögren's and here is a listing of just a few:

- Attending a SSF annual National Patient Conference (NPC) that takes place each April
- Listening to audio talks from past NPC conferences. See a list of recent talks available with an order form on page 14
- Find a friend with Sjögren's by attending a local SSF event and/or group meeting
- Reading credible resources, including our three most popular books that are available by contacting the SSF ■



Tracking Your Sjögren's Symptoms

Work Sheet

Date: _____

Additional notes about daily activities/results:

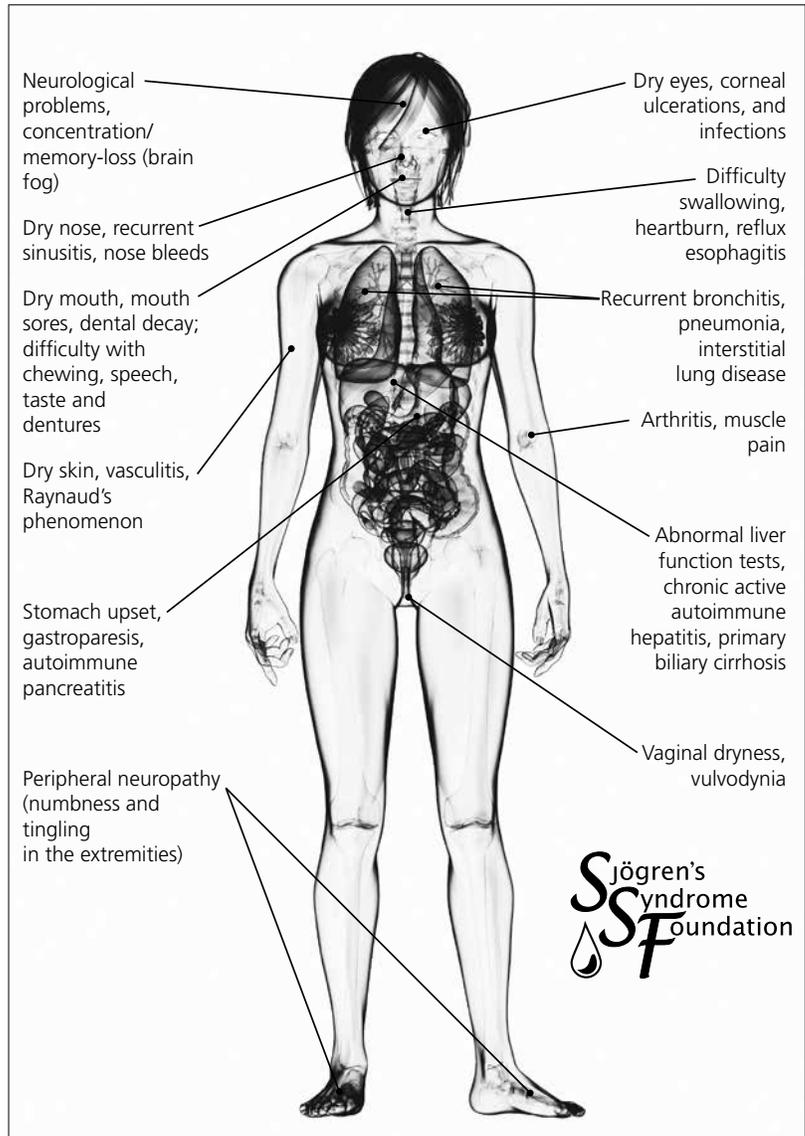
Sleeping Notes

Bed Time: _____

Hours of Sleep: _____

Times Getting up for Medication: _____

Activity Notes



| Symptom | Morning | Afternoon | Evening |
|---------------|---------|-----------|---------|
| Fatigue Level | | | |
| Joint Pain | | | |
| Dry Eyes | | | |
| Dry Mouth | | | |
| | | | |
| | | | |
| | | | |

Key: **N**= None, **S**= Slight, **M**= Moderate, **SE**= Severe, **I**= Intense


in memoriam

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In Honor of Vickie Baldwin
Andrea Loughry

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



Sjögren's
SSF
syndrome
foundation

"How I found..." continued from page 1 ▼

three years for me to find my way after my diagnosis. I was fighting Sjögren's to regain my "old self" and my previous life. What I needed was to love and embrace my Sjögren's in order to see my "whole self," accept my previous life as a point in time, and find my "new self." After all, I was young with a lot of life in front of me. It was time to explore new aspects and add to the journey.

Here are my big revelations about what worked for me. Perhaps you can find some tips for yourself or for a newly diagnosed friend.

I embraced my disease instead of fighting it

Instead of imagining an internal army kicking the sh** out of Sjögren's (as my friends who had successfully killed cancer had suggested), I found the imagery of embracing my Sjögren's to calm it down was what finally did the trick.

I think of my Sjögren's as a small girl who is tired and acting out (and yes, I recognize the "inner child" similarity here). I finally realized that I was already attacking myself and launching emotional attacks to combat Sjögren's was perhaps adding fuel to the fire. So I tried the tender ap-

proach. To me, this was different than the adage "be good to yourself" or "be kind to yourself." I imagined that the little girl dwelling inside of me was a separate person that I needed to care for. She is not mean or weak, she is in fact strong and confident, so she requires special attention.

If you are a person who tends to take care of everything and everyone around you, then this imagery might work for you too. After a few years of practicing this imagery, I now can take a short-cut and just "be good to myself."

I didn't make my world too small

There have been times when I focused mostly on Sjögren's and what I could not do. I found that my world started shrinking and became quite small. That was not the life I wanted so I had to train myself to think of all the things I CAN do. Along the same lines, I started asking the question "Why Not?" instead of "Why." Try it, it's a good practice!

Beauty and nature matter

I moved to Sonoma, California wine country in order to have natural beauty surround me. Not everyone can pick up and move, but everyone can take a nature walk. Be still in nature and soak in what you find beautiful.

continued page 10 ▼

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I feel the same about the beauty and healing powers of music and art! I listen to new music and dance while making dinner almost every night.

Work and productivity

For years, I managed my work time and stress by consulting on a project basis. Two years ago I co-founded a software company and was concerned about the workload, but I have been fascinated at how well I feel! I don't work the crazy hours of my youth, and I don't see that as a shortcoming. I know my experience and wisdom (no longer sweating the small stuff) is more valuable to the company than extra hours. Even though I have periods of exhaustion, I'm actually feeling the best I have ever felt with Sjögren's.

Because I am challenged and doing something I believe I'm good at, I believe my Sjögren's is better controlled. I do have to manage stress and discipline myself to not "power through" things, which makes me feel worse. But this is all part of taking better care of myself and knowing the right work-life balance. You might find that managing your best work-life balance can help you too!

"No" is a complete sentence and it's ok!

If you are a person who has taken care of many people and many things, it's time to look at that. Sometimes it's a good thing and sometimes it crosses over into something else. Try letting go of the "something else." It's also time to let go of feeling bad about it!

Be a good friend

My friends have had my back when I was not doing very well. In fact, a couple of friends certainly gave more than they received for a few years. One day I asked myself "Would you want to be your friend?" I didn't like the answer so I vowed to be a good friend to those I love. In order to do that, I had to relinquish a relationship that took too much negative energy so that I had positive energy for those who lifted me up. I still make new friends, but I manage my energy and time well.

Give back to something

Find what is important to you and give some time to it. Although make sure you are using positive energy and that you're not pushing beyond your limits. I have several community things I support, but being on the Board of the Sjögren's Syndrome Foundation brings me great satisfaction. It combines three things for me. First, my desire to know more about the disease. Secondly, my desire to speed research for a cure. Finally, my desire to help others understand and deal positively with their Sjögren's.

I have been amazed at how much the SSF actually accomplishes on our behalf and I know we will accomplish our *5-Year Breakthrough Goal* of shortening the diagnosis time 50% in 5 years. I am proud to be part of making that happen for our community!

Sleep, Exercise, Food & Wine

Sleep is my best tool! I go to sleep when I'm tired and wake up when I'm ready. And exercise is something that always makes my joints feel better.

I love food and wine. I feel my best when I eat an organic diet of fruits, vegetables and proteins, exercise daily and steer clear of carbs and sugar (which includes wine). But I live in wine country for goodness sake so I'm going to drink wine. I do so many things "right" so that I can enjoy a glass of wine when I like (preferably a really good Pinot Noir, with really good friends).

Today, I have my Sjögren's in steady order by taking pretty good care of myself and making sure I balance all things in my life that define, for me, a bold life. Now I work smart and play smart. I do have daily symptoms that I stay on top of, but I simply accept them as part of my life now. Just like aging. And menopause. Good thing I've got my sense of humor back to deal with that!

PS: I lifted the first line of this article from fellow SSF board member Dr. Herb Baraf, who at our last Board of Directors meeting stated, "The SSF, even our sense of humor is dry." Funny man! ■



Sjögren's Syndrome Foundation Board Secretary, and Sjögren's patient – Janet E. Church

Rx Only



DRY MOUTH RELIEF NOW BEING SERVED

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}
- Easy to afford with patient savings card
- Gluten free⁴

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.

IMPORTANT SAFETY INFORMATION

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.

Please see full Prescribing Information provided.

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 of psychotropic drug-induced xerostomia: a randomized, controlled trial. *J Clin Psychopharmacol*. 2007;27(5):437-443. 3. Mouly SJ et al. Management of xerostomia in older patients: a randomised controlled trial evaluating the efficacy of a new oral lubricant solution. *Drugs Aging*. 2007;24(1):957-965. 4. Data on file.

Please see full Prescribing Information on next page.



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For Sjögren's Syndrome Patients suffering from "COTTON-MOUTH"



Visit **aquoral.com**

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Most People Pay No More Than **\$25** For a 6-8 Week Supply

aquoral[®]
artificial saliva
PROTECTIVE ORAL SPRAY

September

Breakthrough Bullet:

Helping current patients with the
5-Year Breakthrough Goal



Rx Only—Prescription Medical Device

INGREDIENTS: Oxidized glycerol triesters (TGO), silicon dioxide, aspartame, and artificial flavoring.

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).

KEEP OUT OF REACH OF CHILDREN.

U.S. Patent: 8,367,650



Manufactured for:
MISSION PHARMACAL COMPANY
San Antonio, TX USA 78230 1355
MADE IN FRANCE

Aquoral® artificial saliva is a medical device registered with the United States Food and Drug Administration.



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AQU-14002

CO1 Rev 005130

The Sjögren's Syndrome Foundation launched our Goal, "To shorten the time to diagnose Sjögren's by 50% in 5 years," to create a future where Sjögren's is taken more seriously by the medical community, benefiting all patients.

The SSF strives to be the catalyst that creates the change in how Sjögren's is perceived. We accomplish this by working to educate physicians about the disease's symptoms and why it is not only important to think about a Sjögren's diagnosis when seeing a new patient, but also about what type of care is needed to help those currently diagnosed.

A common frustration of Sjögren's is that many medical professionals are neither aware of Sjögren's, nor fully aware of all the various ways it can manifest in the body. As more patients are being diagnosed, more physicians are starting to look to the SSF for information about how to treat the disease and that is why the development of the SSF's Clinical Practice Guidelines for Sjögren's is especially critical.

This labor intensive initiative was launched in 2008 under the leadership of Frederick Vivino, MD, FACR, Chief of Rheumatology at Presbyterian Medical Center, of the University of Pennsylvania, along with over 100 volunteer healthcare professionals. These guidelines will help standardize patient care by giving physicians a roadmap of how to treat, monitor and manage their patients with the disease.

The SSF's clinical practice guidelines initiative has working groups formed to concentrate on three major areas including:

- Rheumatologic/Systemic Manifestations
- Ocular Manifestations
- Oral Manifestations

The process of developing these guidelines is arduous but we are excited that recommendations for initial clinical questions are now either about to be published, or are in the final states of consensus. Additional clinical questions are being drafted as there are many facets of Sjögren's we must address.

It is our belief that as more patients begin to be diagnosed, physicians will be forced to become more knowledgeable about the disease and how to treat patients at their practice. We are excited about the significant impact that both our *5-Year Breakthrough Goal* and clinical practice guidelines will have on the quality of care that all patients receive. Thank you for your support of the SSF and our mission to help all patients! ■



We hope this Thanksgiving you will consider participating in your community Turkey Trot as a member of Team Sjögren's!

What a great way to start your day of giving thanks – by purchasing a Team Sjögren's Turkey Trot Kit and walking or running with others in your area, increasing awareness for Sjögren's and helping raise crucial funds for Sjögren's research.

Your Kit Includes:

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

Find Your Local Turkey Trot:

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

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

Price: \$30 plus shipping and handling

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



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

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

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

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

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

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





2014 SSF National Patient Conference

“Solving the Sjögren’s Puzzle”

Missed the Conference?

Get all the vital information you need on an audio CD!

Five of our most popular talks from the 2014 National Patient Conference held in Chicago, Illinois, are available for purchase as audio CDs. Each talk is 30-40 minutes long and comes with the handouts used by the presenter.

Purchase the talks you want to hear or purchase the whole set!

| | Non-Member | Member | Qty. | Total |
|---|------------|--------|------|-------|
| Overview of Sjögren’s Syndrome by Daniel Small, MD | \$30 | \$16 | | |
| Pulmonary Issues and Sjögren’s by Augustine S. Lee, MD | \$30 | \$16 | | |
| What is in the Clinical Trial Pipeline? by Theresa Lawrence Ford, MD | \$30 | \$16 | | |
| Nutrition, Wellness and Autoimmune Disease by Lauri Lang, RD, LDN, CWPC | \$30 | \$16 | | |
| Overlapping Major Connective Tissue Diseases by Lee S. Shapiro, MD | \$30 | \$16 | | |
| Maryland Residents add 6% sales tax | | | | |
| Shipping and Handling: | | | | |
| U.S. Mail: \$5 for first item + \$3 for each additional item | | | | |
| Canada: \$14 for first item + \$3 for each additional item | | | | |
| Overseas: \$22 for first item + \$3 for each additional item | | | | |
| Total Amount Due | | | | |

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I Stood Up!

The State of Alabama joins in the World Sjögren's Day Celebration!

Anne Rose, SSF Alabama Support Group Leader, decided that not only was she going to celebrate World Sjögren's Day on July 23rd, but that the whole state should celebrate with her! Determined to reach her goal, Anne gained the support of her local state representatives and had July 23rd officially declared Sjögren's Awareness Day in the State of Alabama.

World Sjögren's Day, which was created to commemorate the birthday of Dr. Henrik Sjögren who discovered Sjögren's in 1933, allows us to raise awareness of this serious yet lesser known disease and recognize advancements made over the past year like the development of Clinical Practice Guidelines for Sjögren's by the SSF that will help standardize patient care by giving physicians a roadmap of how to treat, monitor, and manage patients.

Anne is often seen utilizing every opportunity available to raise awareness on behalf of the millions affected by the debilitating disease and is also a part of Sjö Bham, the SSF Alabama Awareness Ambassadors. Sjö Bham works closely with the University of Alabama to spread the word about Sjögren's and its impact on patients, their families, and the state's medical system.

That is why Robert Bentley, Governor of Alabama, officially declared July 23rd, Sjögren's Awareness Day in the State of Alabama to honor Dr. Sjögren's birthday!

The SSF would like to thank Anne, Governor Robert Bentley, the State of Alabama, Sjö Bham, and the University of Alabama who helped us celebrate World Sjögren's Day 2014 in Alabama!

If you would like to learn more about becoming an SSF Awareness Ambassador, please email Kathy at kivory@sjogrens.org. ■



Dr. S Louis Bridges, Director of the Division of Clinical Immunology and Rheumatology at UAB, meets with Anne Rose



Proclamation Plaque from Robert Bentley, Governor of Alabama

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

IT'S TIME

United Way • Combined Federal Campaign • State Payroll Deduction

Each fall your local United Way, Combined Federal Campaign, state employee, and private employer payroll deduction campaigns begin. We hope you will remember the Sjögren's Syndrome Foundation when choosing where to allocate your donation. **(CFC #10603)**

If we are not listed on the contribution form, you usually may write in the Sjögren's Syndrome Foundation.

Tell your co-workers, friends, and family members how important it is to choose and write in the Sjögren's Syndrome Foundation on their campaign form, too.

If your employers will not allow you to write in the Sjögren's Syndrome Foundation, remind them that we are a national non-profit 501(C3) organization and qualify for most payroll deduction campaigns. If they need more information, please contact the Foundation at 800-475-6473 and ask for Elizabeth Trocchio.

Just think – every dollar counts.

Last year alone – thanks to those who chose to give through their employer's payroll campaign – the Sjögren's Syndrome Foundation was able to increase its Research and Awareness commitments.

Remember, the Foundation has received the:

