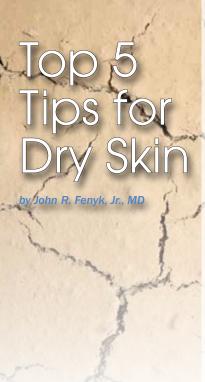
Volume 33, Issue 2

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f SjogrensSyndromeFoundation



@MoistureSeekers



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

Your dermatologist can be your best ally and may be able to give you samples of products to try, but here are some basic dry skin survival tips that may help:

- Use gloves when you are using strong soaps or chemicals to clean. One way to get in the habit is to keep a pair of gloves in several areas, i.e. kitchen, bathroom, garage.
- Terry robes will dry you gently. Or after the shower, let yourself dry naturally since the moisture from the water will be absorbed by your skin.
- Use warm, not hot, water for bathing and use soap sparingly (shampoo might also be drying to the rest of your body in the shower).
- After bathing, apply lotion as soon as possible to seal in moisture.
- Use a humidifier, especially if you have forced-heat, which is especially drying. For Sjögren's patients, an optimal range of humidity is between 55% and 60% regardless of ambient temperature.

Steven Taylor Elected to Serve on National Health Council's Board of Directors

by Kenneth Economou, Chairman of the SSF Board, and the SSF's Board of Directors



he Board of Directors for the Sjögren's Syndrome Foundation (SSF) is proud to announce that our CEO, Steven Taylor, has been appointed to the National Health Council's (NHC) Board of Directors. This appointment will allow Steven to represent over 4 mil-

lion Sjögren's patients and the Foundation at the NHC.

"I am honored to have been elected to serve once again on the Board of Directors for the National Health Council where I will represent the 4 million Americans suffering from Sjögren's and ensure that their voice is heard!"

Steven Taylor, SSF CEO

continued page 2 ▼



Founded by Elaine K. Harris in 1983

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e-mail: tms@sjogrens.org www.sjogrens.org

"Taylor elected to NHC" continued from page 1 ▼

Congratulations Steven on your work to continue to elevate the Foundation and give a voice to all of those suffering from Sjögren's.

About the National Health Council:

The NHC is the only organization that brings together all segments of the health community to provide a united voice for the over 133 million people with chronic diseases and disabilities and their family caregivers. Made up of more than 100 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient advocacy organizations, which control its governance. Other members include professional and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device, health insurance, and biotechnology companies.

The National Health Council's Priorities for 2015

- Encouraging the development of new treatments and diagnostic tools for people with chronic conditions through passage of the MODDERN Cures Act.
- Serving as the united patient voice before the bipartisan 21st Century Cures initiative, spearheaded by the House Energy and Commerce Committee, to ensure Congress addresses the unmet medical needs of patients, increases patient engagement in the drug development continuum, and improves data sharing to make knowledge gleaned at the point-of-care more available to researchers.
- Championing health insurance marketplace improvements, conducting a state-by-state analysis of how "patient friendly" the exchange requirements are, and educating people with chronic conditions about picking the right exchange plan. ■



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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.

CALL your optometrist or ophthalmologist to get screened.

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: sindicated to therease 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



Based on package insert 71876US17 ©2014 Allergan, Inc. Irvine, CA 92612, U.S.A. narks owned by Allergan, Inc. APC76HF14 Patented. See www.allergan.com/products/patent_notices Made in the U.S.A.



FILL A RESTASIS® (CYCLOSPORINE OPHTHALMIC EMULSION) 0.05% PRESCRIPTION

AND WE'LL SEND YOU A REBATE CHECK FOR \$20!*

IT'S EASY TO GET YOUR REBATE. JUST FILL OUT THIS INFORMATION AND MAIL.

Follow these 3 steps:

- 1. Have your prescription for RESTASIS® filled at your pharmacy.
- 2. Circle your out-of-pocket purchase price on the receipt.
- 3. Mail this certificate, along with your original pharmacy receipt (proof of purchase), to Allergan RESTASIS® Ophthalmic Emulsion \$20 Rebate Program, P.O. Box 6513, West Caldwell, NJ 07007.

Enroll me in the <i>My Tears, My Rewards</i> ® Program to save more
I am not a patient enrolled in Medicare, Medicaid, or any similar
federal or state healthcare program.

Last Name	First	MI	
Luot Humo	11130		
Street Address			_
City	State	7IP	

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. Prescriptions dated more than 60 days prior to the postmark date of your submission 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.

Interstitial Cystitis or Bladder Pain Syndrome

by the Interstitial Cystitis Association (ICA)

nterstitial cystitis (also known as IC) is a chronic bladder condition that usually consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region, urinary frequency (needing to go often) and urgency (feeling a strong need to go). IC also may be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). The exact cause is unknown, but researchers have identified different factors that may contribute to the development of the condition.

About 25% of IC patients have a definite or probable diagnosis of Sjögren's, and as many as 14% of Sjögren's patients are estimated to have IC.

Some things you can do to control your IC include:

- Avoid or limit foods and beverages that may irritate the bladder, including coffee, tea, soda, alcohol, citrus juices, and cranberry juice. For some, spicy foods may be a problem as well as foods and beverages containing artificial sweeteners.
- Apply heat or cold over the bladder or between the legs to alleviate some pain.
- Modify or stop Kegel exercises which may make pelvic floor muscles even tighter.
- Avoid tight clothing to prevent further irritation and restricted blood flow to the pelvic region.
- Treat constipation. It can add pressure to the pelvic area and increase pain and discomfort.
- Develop healthy sleep habits as sleep is crucial for pain control.
- Adjust fluid intake. Increase or decrease depending on your situation.
- Retrain your bladder by learning to urinate on a set schedule and not when your bladder tells you.
- Find healthy ways to manage your stress since it may make IC symptoms worse.
- Find, in advance, the location of restrooms along your route when traveling.
- Get active! The health of your bladder depends on good blood flow to the area and on having flexible



and strong muscles around your bladder and other pelvic organs to protect and support them.

- Quit smoking. Cigarettes may irritate the bladder and worsen pelvic and bladder pain.
- Take a trial and error approach to treatment as no one treatment works for everyone. A combination of treatments is often necessary to get your IC under control.
- Track how your symptoms change with treatment and speak with your healthcare provider if you think a therapy is not working.

Visit the Interstitial Cystitis Association website, www. ichelp.org, for the most up-to-date and accurate information about IC and to find knowledgeable healthcare providers.



Ask the Clinician: Stephen Cohen, OD

Dr. Cohen will be speaking at the 2015 SSF National Patient Conference in Tampa, Florida





Why do dry eyes feel awful in the morning when I first wake up, especially if I don't use an eye lubricant at night?

There are certain conditions that can get worse during the night with the eye in a closed state. For example, if you have blepharitis, which is caused by a common skin bacteria called "staph epidermidis," the waste products of the staph are very irritating. But with your eye closed that staph toxin is lying there all night. If I have a patient who wakes up with really irritated eyes, one of the first things I want to look at is untreated blepharitis.

Another possible cause is called "recurrent corneal erosion." Think about pulling a scab off all the time. It starts to heal and you pull the scab off. If the surface of the eye gets irritated through dryness and adherence to the back of the lid, or through an injury, that tissue needs to heal. The good news is it heals very quickly. The bad news is it hurts a lot, as I'm sure you've found. So it heals quickly but it doesn't necessarily anchor itself. That thin, outer layer of the cornea doesn't anchor itself to the eye very fast, so you run the risk of re- irritating your eye even after you are feeling better. And when you do that over-and-over, it is called "recurrent corneal erosion." You are basically tearing off the outer layer of the front of your eye. A classic sign is you wake up, you open your eyes and it hurts. Using ointments at night helps. Using an antibiotic ointment would help if you have blepharitis as well because it would treat that and give your eye a little more coating.

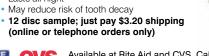
Dry Eye Tip!

If you have severe dry eyes and trouble opening your eyes in the morning because your lid is sticking, try to keep your eyes closed when you wake up and use the heels of your hands to gently massage your lids. What this will do is break any of those adhesions that may be there and it stimulates a little tear production so that you can actually open up your eye safely. But if you wake up and open up your eyes right away, you run the risk of – ouch – pulling that adhesion off, again, like pulling a scab off of a wound.



XyliMelts long lasting adhering discs temporarily relieve dry mouth* day and night, even while sleeping when dry mouth

- 500 mg of Xylitol coats, moisturizes and lubricates · Discretely sticks to gums or teeth
- · Lasts all night
- (online or telephone orders only)





Available at Rite Aid and CVS. Call 877-672-6541 for telephone orders or visit www.oracoat.com

These statements have not been evaluated by the Food and Drug or prevent any disease.



Aquoral® is approved for dry mouth due to Sjögren's Syndrome

BEING SERVEI

- 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: Aguoral 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

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

> Visit aquoral.com Download the valuable savings card for your doctor's visit today

Most People Pay No More Than

\$25

For a 6-8 Week Supply

(go artificial saliva PROTECTIVE ORAL SPRAY

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

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

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.



The Sjögren's Syndrome Foundation and Nicox Recognized for Awareness Campaign



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.



AQU-14002

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icox's and Dudnyk's unbranded "Drying Sunflowers" campaign that was created in partnership with the Sjögren's Syndrome Foundation, emphasizes the urgent need to look for Sjögren's as a possible diagnosis in the many dry eye patients that eye care professionals see. Recently, Nicox and Dudnyk were highlighted in *PM*360's "Greatest Creators" annual magazine issue for its educational campaign about Sjögren's. *PM*360 is one of the nation's leading trade publications in healthcare marketing and advertising.

Nicox, who bought the rights for promoting a novel diagnostic test for Sjögren's, the Sjö test from Immco Diagnostics, Inc., has been reaching out to ophthalmologists and optometrists to ensure that they are aware of Sjögren's, help patients get diagnosed as soon as possible, and send those patients to knowledgeable rheumatologists to coordinate overall care and help establish a full healthcare team.

The Sjögren's Syndrome Foundation applauds Nicox for the novel and far-reaching campaign that will significantly increase awareness of Sjögren's as well as provide the opportunity for patients to obtain an earlier diagnosis.

An investigative team led by Dr. Julian Ambrus at the University of Buffalo identified three proteins as early biomarkers in Sjögren's that appear earlier than Ro or La. These biomarkers provide the basis for the new Sjö™ diagnostic panel. ■



s many of you may remember, this past fall the Sjögren's Syndrome Foundation (SSF) emailed out a survey to help us identify "Sjögren's friendly" health care providers, as well as those in medical fields that may need more education.

Thank you to the over 2,000 respondents who shared this valuable information with us! Many questions were asked but one question that is already helping us shape our professional awareness activities for 2015 was, "What type of specialist(s) do you feel is/are the least knowledgeable about Sjögren's and needs more awareness and education?"

Your responses, shown in the chart on right, indicated on the "primary care/internal medicine providers" was the top field identified as needing more education about Sjögren's.

February

Breakthrough Bullet:

Identifying "Sjögren's Friendly" Health Care Providers

Answer	# Times Mentioned	% Contribution
Primary Care / IM	921	31%
OB/GYN	628	21%
Dentist	576	20%
Eye Doctor	318	11%
Other	259	9%
Rheumatologist	225	8%
	2,927	100%

From the answers you provided, the first SSF Awareness Ambassador campaign of 2015 is focusing on distributing materials to primary care/internal medicine providers. In

continued page 10 ▼



NeutraSal® Sjögren's Syndrome Support Kit

Containing:

- Eye Vitamin and Mineral Supplement for Dry Eye Comfort*
- Sugar Free Dry Mouth Gum with Xylitol
- *This statement has not been evaluated by the FDA. This product is not intended to diagnose, treat, cure or prevent any disease.

NeutraSal® is a prescription item. For additional information on NeutraSal® or the Direct Access Program, please visit www.neutrasal.com or call 866-963-8881 ext #1.



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.

- Clinically proven to relieve the symptoms of dry mouth in Sjögren's Syndrome patients with no reported side effects or drug to drug interactions
- 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

DIRECT ACCESS PROGRAM The Direct Access Program is designed to provide access to NeutraSal® treatment for all patients regardless of their insurance coverage or financial condition. The program includes no out- of-pocket costs (co-pay) for most patients and free trial medication for patients without coverage. The NeutraSal® Direct Access Program and Support Kits are only available through the NeutraSal® Specialty Pharmacy Network. (Not valid for local retail pharmacies).

NEW

NeutraSal® Burning Mouth Syndrome Support Kit

Containing:

- Alpha Lopic Acid for Burning Mouth Comfort[†]
- Sugar Free Dry Mouth Gum with Xylitol
- [†] This statement has not been evaluated by the FDA. This product (alpha lipoic acid) is not intended to diagnose, treat, cure or prevent any disease.

Proud Sponsor





2014 Invado Pharmaceuticals, Pomona, New York

"Breakthrough Bulllet" continued from page 9 ▼

addition to the work of our Awareness Ambassadors, the SSF is also planning to work with professional organizations that provide materials and hold conferences for these physicians — creating a relationship that will help us distribute Sjögren's information to these groups.

If you are interested in learning more about becoming an SSF Awareness Ambassador, please visit www.sjogrens.org. ■





Health Insurance & Your 2014 Tax Filing

Learn about what's new for individuals and families in health care law with the new IRS document: 5187

This new IRS document explains how to report your health insurance coverage in 2014 and claim a premium tax credit. The publication covers some of the tax provisions of the Affordable Care Act (ACA). It also includes a glossary to help taxpayers understand new terms related to ACA. We hope you find this information helpful when filing your taxes in the upcoming months. Please visit www.irs.gov to learn more.



Saliva plays a major role in oral health.

Dry mouth can impact the health of your teeth. If you have reduced salivary flow, it is critical to support the healthy pH on your tooth surfaces.

Now there is a delicious breakthrough oral care innovation that can help dry mouth sufferers keep teeth in a healthy pH zone.

New
BasicBites™
sugar free
chocolate soft chews

A Healthy oral pH matters...
Your teeth need
BasicBites

Revolutionary soft chew with vital saliva based nutrients

Nourishes the enamel and good bacteria on tooth surfaces

As an added benefit, an excellent source of calcium



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Congratulations Team Sjögren's Disney 2015

n behalf of the entire SSF family, we would like to give a BIG thank you and congratulations to our *Team Sjögren's* runners and walkers who recently participated in various events during the Walt Disney World Marathon weekend, January 9 – 11th!

Our 42 runners all chose a different distance to run – some ran the 10K race (6.2 miles), others the half-marathon (13.1) and one runner took on the full marathon (26.2 miles). These 42 runners collectively covered over 543 miles in one weekend, increased awareness in their communities and raised over \$99,000 for the SSF!

Team Sjögren's, the SSF marathon training program, helps raise funds to help support the life-changing initiatives of the SSF. Our most recent team that ran at Disney World was the largest team in the history of the Team Sjögren's program, and also raised more money than any previous SSF event!

After months of conference calls with the *Team Sjögren*'s nutritionist and trainer, along with individually training and fundraising efforts, the runners traveled from all around the country to Disney World with SSF CEO, Steven Taylor, leading the charge.

Team Sjögren's runs in honor of all Sjögren's patients, but each member had their own personal reason for joining the program. At the breakfast, one member talked about running being a part of her life before she was diagnosed with Sjögren's and wanted to bring it back into her life. Her story was easily relatable to the 20 other runners with Sjögren's. Others ran in honor of a family member or friend who's living with the disease, like the Holden family who had four runners participate in honor of their grandmother.

Congratulations and thank you again to our 2015 *Team Sjögren's* Disney runners! Keep an eye out in *The Moisture Seekers* to see where *Team Sjögren's* next race will be and how you can get involved.



"What an absolute amazing time we had! Thank you so much for all your hard work! Definitely the most organized group I have been a part of! Loved every minute of it all!" — Samantha, Team Sjögren's Disney Runner



"Thank you so much for all the planning, support and CARE you gave the team. All I can say is thank you from the bottom of my heart. Sign me up for next year! I'm hooked."
-Danita, Team Sjögren's Disney Runner

"memoriam

In Memory of Alfred and Annie Webster

Janette Webster

In Memory of Alice Kavcic

Denise and John Reape Diana Manheim Mary Canavan The Hahn Family Vince and Cathy Cainkar

In Memory of Annette A. Nix Robert Nix

In Memory of Barbara McBride Robin Lorton

In Memory of Bonnie Litton

Dawn and David Hill Diane Kaplan James and Joann Nasby Lenny and Susie Segal and Family Linda Phillips

In Memory of Diane Litchfield Mello

Ann Tyeryar Eileen Tyeryar Kenny and Pauline Souther

In Memory of Douglas West

Susan L West Fran-Man Foundation

In Memory of Jeff Spreckman Elaine and Larry Levin

In Memory of Jerry Wolk

Fred Fernandez and Irma Rodriguez Sherree Meyers

In Memory of Jill Walker

Pat Stanley Susan and Jeff Ray Wolters Kluwers Pharmacists In Memory of Julia Gay Jessica Taylor

In Memory of Linda Lehrman

Allan Lewis and Ralph Lutrin Bob Horton Carole Becker Chris and Carla Sloan Cindy and Mark Soloway

Debby and Jerry Schwartz

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> Jeff and Pam Stenback Joan and Stan Worton

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Mary Rose Kaplan Merle R. Saferstein

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Rebecca and Michael Glinsky Ronnie Pertnoy

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Weiss Serota Helfman Cole Berman and Popok, P.L. Kathy Devereux and Kenton Robertson

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Richard Miller

In Memory of Lois Aulis

Elizabeth Wilcox Peggy Kew

In Memory of Mamie Jewell Bartley Loving Grandchildren

In Memory of Marilyn Lesser

A.J. Fort Cleo Pierce

Thanh Vu, Minh Vien, Nu Vu

In Memory of Mary Louise McCarthy

DC Construction Associates, Inc. In Memory of Mathew Piconer

Geraldine Vobis

In Memory of Norma Deem Vicki Deem

In Memory of Norma Werner

Lois Pohlmann

Noland and Denise Peacock

In Memory of Patricia Evans

Thomas Norris David Sheerman

In Memory of Robert Kenney

Jim, Sharon, Katie Zerwekh, Joanne, Brian Lynn, Linda Meier, Sandy Quinn

> In Memory of Sheldon Schacter Elaine and Larry Levin

In Memory of Sylvia Rodman Rick and Sharon Keller

In Memory of Vicky Thorp The Hansen Family

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In Honor of Al, Debbie, and Jill Herman Ken and Edie McPherson

In Honor of Andy and Yvette Gontkovsky

Colette, Anita, and Raymond Von Lee

In Honor of Angela Tysdal Roxanne Venn

In Honor of Anne Economou Jim, Kathleen and Max Vincent and Kathleen Azzaro

In Honor of Anne Leibold Taras Skibicky

In Honor of Anne Meibohm Allison McCool

In Honor of Ashley Gottfried - Quam Mom and Michael

> In Honor of Barbara Honig Daniel Honig

> In Honor of Carol Hirashiki Jennie Handy

In Honor of Catharine Claiborne The Moore Family

In Honor of Chris, Teri, and Dakota Dave, Ann, Ethan, and Sara

In Honor of Christine Molloy Jeanne Mollov

In Honor of Connie Cooper Rita Becchetti Sallie Elmore

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In Honor of Dennis and Linda Howard Martha Costa

In Honor of Dr. Janet Schwartzenberg Jan Stanford

In Honor of Elizabeth DiFilippo Roseann Cordelli

In Honor of Emily Adney Bill, Lori, Jamie and Josh, Jen and Julie

> In Honor of Florence Fox The Fox-Corns

In Honor of Harry Spiera, M.D. Laura Figueiredo

In Honor of Heather, wife and mother Husband, Kids and Gus

> In Honor of Jackie Hill Michael Hill

In Honor of Jane F. Nelson Ann Franke

In Honor of Janelle Barnette Kelly Dixon

In Honor of Janet Church Mom and Dad

In Honor of John and Jean Scott Harold Scott

In Honor of Kathleen Tomick Jonathan Tomick

In Honor of Kathryn Donnelly Elvira Albert

In Honor of Linda Howard Ms. Jane Webb

In Honor of Livija Von Lolhoffel Egon Von Lolhoffel

In Honor of LoriAnn Giangr&e Frank and Kathy Giangrande

In Honor of Margaret Blessing Voshell Marcia Wood

In Honor of Margaret Rothman Gale and Bruce

In Honor of Margaret Scott & Nelson Hubbel Harold Scott

In Honor of Mary F. Kendall Kimberly Knazik

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In Honor of Richard and Sue Scott Harold Scott

In Honor of Rochelle Schndeiderman Lynda Sohl

In Honor of Sallianne Thorpe Diane and Fred Scott Voelkel

In Honor of Sharon Adley Lyle and Sue

In Honor of Stefanie Campbell Mom and Dad

In Honor of Susan Needles Nancy Visocki

In Honor of Teresa and Rick Steinberg

Jerry Steinberg



Speakers and Topic of Discussion – NPC 2015

Systemic, Ocular and Oral Manifestations of Sjögren's: A Panel Discussion & Overview

Join us for this kickoff session where Dr. Frederick Vivino, Dr. Stephen Cohen, and Dr. Vidya Sankar, three world-renowned experts, will share with us an overview of Sjögren's, its manifestations and treatment options.

Frederick B. Vivino, MD, MS, Chief, Division of Rheumatology, Penn Presbyterian Medical Center, and Director of the Penn Sjögren's Center, Philadelphia, Pennsylvania, will present a comprehensive explanation of the range of symptoms that Sjögren's patients experience, explain their causes, and offer practical tips for managing them. In his role as the Immediate Past Chairman of the SSF's Medical and Scientific Advisory Board, Dr. Vivino implemented and developed the idea to create clinical practice guidelines for how to treat, manage and monitor Sjögren's. This initiative has now become one of the largest initiatives ever undertaken by the SSF and will change the face of Sjögren's in the clinical setting.

Stephen Cohen, OD, a private practice optometrist in Scottsdale, Arizona, since 1985, will describe the latest dry eye therapeutic treatments, covering the extensive range of options - from artificial tears to silicone plugs to systemic drugs that are available for managing the ocular complications of Sjögren's. Dr. Cohen is a founding board member of the Arizona Optometric Charitable Foundation and a past recipient of the "Arizona Optometrist of the Year Award." Dr. Cohen serves as the current Chairman-Elect of the SSF Board of Directors and has also been a principal investigator on a number of FDA clinical studies involving ocular surface disease and dry eye.

Vidya Sankar, DMD, MHS, Director of the Tertiary Care Oral Medicine Clinic and Associate Professor at the University of Texas Dental School in San Antonio, will provide insights into how Sjögren's impacts your oral health including tooth decay as well as share with us information to help manage and minimize the effects of dry mouth. Dr. Sankar is the current Treasurer of the SSF Board of Directors and has served on numerous professional committees to help increase awareness for Sjögren's, most recently presenting at the American Dental Association's annual scientific meeting.

Neurological Complications and Sjögren's

Julius Birnbaum, MD, MHS, Assistant Professor, Division of Rheumatology, and Assistant Professor, Department of Neurology, Johns Hopkins University School of Medicine, Baltimore, Maryland, will share his insights and vast knowledge of the challenges that may afflict patients with neurological manifestations of Sjögren's. Dr. Birnbaum, who also serves as an Associate Director at the Johns Hopkins Jerome L. Greene Sjögren's Syndrome Center, is committed to improving the diagnosis and treatment of neurological complications due to Sjögren's and you won't be disappointed with his passion and knowledge!

How To Be A Proactive Patient

Katherine M. Hammitt, SSF VP of Research Ken Economou, SSF Chairman of the Board Anne Economou, Sjögren's Patient and Volunteer

Taking your diagnosis and learning how to be your own best advocate is an art form! During this session, our presenters will share with you some tips they have learned along the way. As you will hear, they have learned not to let their diagnosis define them but instead use their diagnosis to help make a difference.

First, we will hear from Katherine M. Hammitt, Vice President of Research of the Sjögren's Syndrome Foundation, co-author of *The Sjögren's Syndrome Survival Guide* and a Sjögren's patient herself. She will share with us "*Tips for Being Your Own Patient Advocate*." Additionally, she will provide us with some practical tips for coping with the day-to-day symptoms of Sjögren's as well as advise us how to maximize the time spent with healthcare professionals to ensure the best quality of care.

Ken and Anne Economou will then moderate a session involving National Patient Conference attendees that have stood up for Sjögren's. During this session, "We Stood Up – Come Join Us," Ken and Anne will share how you can make a difference with your diagnosis by stepping up for Sjögren's and finding something you are passionate about. You will be inspired by the patients that have not let a Sjögren's diagnosis define who they are!

Treatment of Major Organ System Involvement in Sjögren's

Daniel Small, MD, a practicing rheumatologist with the Sarasota Arthritis Center and a careerlong interest in Sjögren's, will present the major approaches to managing serious internal organ manifestations in Sjögren's including pulmonary involvement, renal disease, and serious gastrointestinal disease. Dr. Small practiced rheumatology in California and Texas before settling in Florida 22 years ago. Additionally, he has spoken at regional, national and international meetings on Sjögren's. Dr. Small also authored a chapter in "The Sjögren's Book" about treatment of major organ involvement, and he is a member of the SSF Medical and Scientific Advisory Board.

How To Put Your Financial House in Order When You Have a Chronic Disease

David P. Babinski is Advisor and President of Atlas Financial Solutions and Triad Financial Center, both located in The Villages, Florida. When you live with a chronic illness, you need to address both the day-to-day and long-term financial implications of that illness. Mr. Babinski will provide valuable information and suggestions to help you put together your financial plan.

Understanding the Otolaryngologic Manifestations of Sjögren's

Myron B. Jones, MD, is an otolaryngologist with the Robert A. Gadlage, MD, FACS and Associates practice, with offices in Duluth and Snellville, Georgia. His areas of special expertise and interest include: nasal and sinus medical and surgical disorders, sleep disorders including treatment of obstructive sleep, apnea salivary gland surgery, and thyroid surgery. Dr. Jones will enhance your understanding and provide a comprehensive explanation one of the most overlooked, yet frustrating, complications of Sjögren's – ear, nose and throat manifestations.

Vaginal Issues and Sjögren's

Colin MacNeill, MD, an Associate Professor and Vulvodynia and Vaginitis Clinic Director, Department of Obstetrics and Gynecology, Penn State Milton S. Hershey Medical Center, Hershey, Pennsylvania, will share his wealth of knowledge of gynecological issues including symptoms, diagnosis and treatment of vaginal discomfort and dryness concerns. With the increased risk for a variety of unique gynecological complications, including yeast infections, vaginal dryness, and burning/pain, Dr. MacNeill will help us understand this often misunderstood area of Sjögren's.



Space is limited. Please register early!

Registration Form

Registration fees include: Friday evening dinner, Saturday's lunch, hand-out material from speakers and entrance to exhibit area on Friday and Saturday.



2015 NATIONAL PATIENT CONFERENCE

TAMPA, FLORIDA — APRIL 17-18, 2015

State	
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• The Grand Hyatt Tampa Bay is approximately one (1) mile from Tampa International Airport. The hotel offers a complimentary shuttle

service to and from the airport. Alternate transportation suggestion: Taxi fare at a rate of \$18 (one way).

The Moisture Seekers

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

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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

2015 SSF Special Event Calendar

SSF events are organized in an effort to increase Sjögren's awareness in local communities, while raising funds to support research & education. They are also an excellent opportunity to connect Sjögren's patients and their families to others living with the disease.

If there is already an event in your area and you would like to get involved, or learn about starting one, please visit www.sjogrens.org or contact us at (301) 530-4420 x227

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February May 21 Phoenix Walkabout & Health Fair Philadelphia Walkabout & Health Fair Paradise Valley Mall, Phoenix, Arizona Philadelphia Zoo - Philadelphia, Pennsylvania 16 Dallas/Fort Worth Walkabout & Health Fair March Vista Ridge Mall - Dallas, Texas 16 New York City Sip for Sjögren's 30 Northeast Ohio Walkabout NYU Rosenthal Pavilion, New York, New York Brecksville Oak Grove Picnic Area - Brecksville, Ohio April **TBA** Columbus Walkabout 17-18 National Patient Conference Columbus, Ohio Grand Hyatt - Tampa, Florida 31 Atlanta Sip for Sjögren's 18 National Patient Conference Walkabout Nelson Mullins at Atlantic Station - Atlanta, Georgia Tampa, Florida June Denver Walkabout & Health Fair ogren's Walkabout Denver Zoo - Denver, Colorado 13 **Greater Washington Region Walkabout &** Health Fair Bethesda, Maryland Kansas City Walkabout & Run **TBA** Parkville, Missouri fine water tastina event giovedi

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