

The Sjögren's Syndrome Foundation Moisture Seekers



www.sjogrens.org

Volume 35, Issue 10 November/December 2017

SjogrensSyndromeFoundation

@SjogrensOrg



Theresa Lawrence Ford,
MD, FACP

SSF Advancing Forward: Promoting Clinical Trial Development

by Theresa Lawrence Ford, MD, FACP

Chair, SSF Clinical Trials Consortium; Chair, SSF Medical and Scientific Advisory Board; and CEO and Medical Director, North Georgia Rheumatology Group, PC, Lawrenceville, Georgia

What a journey this has been. It hardly seems possible that three years ago we began directing efforts promoting the development and availability of clinical trials for patients suffering from Sjögren's disease. We are very proud of the progress made by the Sjögren's Syndrome Foundation (SSF) Clinical Trials Consortium (CTC), which first convened in May of 2014. I serve as the Chair of the SSF CTC, an international initiative whose mission is to increase the availability and the accessibility of therapies for treating Sjögren's. We started with a small international steering committee. However, we have expanded to include many members who are leaders in the Sjögren's community. Three major goals were developed to accomplish our mission:

- To support and promote objectives that facilitates the design of clinical trials
- To increase industry partnerships with the SSF
- To engage in dialogue with government agencies that oversee therapy approval (i.e. FDA, EMA).

[continued page 2 ▼](#)

Letter From Your CEO, Steven Taylor

As any patient will tell you, Sjögren's can be extremely overwhelming. Experiencing so many symptoms and having to alter your life, commitments and responsibilities because of your Sjögren's, can truly be devastating but know that there is hope.

The Sjögren's Syndrome Foundation (SSF) strives every day to provide hope to patients and their families through our many initiatives that are transforming the future Sjögren's. As 2017 comes to a close and I look to the year ahead, I have never been more proud of our accomplishments and the promising future that our work is creating.

Especially during this time of year, I want to give thanks to all of those who have helped the SSF and believed in our mission of increasing awareness and education about the disease, while also supporting research into new treatment options and a cure. You will read about new research your support is funding in this issue with the announcement of the newest SSF Research Grantees. In addition to their



[continued page 8 ▼](#)

In This Issue

5 Research Update

9 You Stood Up

15 Clinician's Corner

17 In Memory/In Honor



Board of Directors

Chairman of the Board

Stephen Cohen, OD

Chairman-Elect

Janet E. Church

Treasurer

Kathy L. Sivils, PhD

Secretary

Tricia Gooding

Immediate Past Chairman

Ken Economou

Esen K. Akpek, MD

Jack Faricelli

Patricia Hurley, MSc

Cathy Ingels

Chadwick Johr, MD

Scott Lieberman, MD

Jason Nichols, OD

Theresa Lawrence Ford, MD

Cynthia Lopynski

Monica McGill, PhD

Timothy Niewold, MD, FACP

Thomas D. Sutton

Michelle Wallace

Ava Wu, DDS

Medical & Scientific Advisory Board

Chairman

Theresa Lawrence Ford, MD

Esen Akpek, MD

Richard Brasington, MD, FACP

Michael T. Brennan, DDS, MHS

Steven E. Carsons, MD

Nancy L. Carteron, MD, FACP

Troy Daniels, DDS, MS

Denise Faustman, MD, PhD

H. Kenneth Fisher, MD, FACP, FCCP

Gary Foulks, MD, FACS

S. Lance Forstot, MD

Philip C. Fox, DDS

Robert I. Fox, MD, PhD, FACP

Tara Mardigan, MS, MPH, RD

Austin Mircheff, PhD

John Daniel Nelson, MD, FACS

Kelly Nichols, OD

Athena Papas, DMD, PhD

Ann Parke, MD

Andres Pinto, DMD

Nelson Rhodus, DMD, MPH

Vidya Sankar, DMD, MHS

Daniel Small, MD, FACP

Neil Stahl, MD

Frederick B. Vivino, MD, FACP

Jeffrey Wilson, MD, FACP

Chief Executive Officer

Steven Taylor

Director of Marketing/Editor

Elizabeth Trocchio

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

“SSF Advancing...” *continued from page 1* ▼

The latest initiatives of the SSF CTC are currently underway. The SSF is excited to be launching the first-ever online platform to train clinical trial investigators and, eventually, educate clinicians from multiple specialties who manage and treat Sjögren's patients. Called STEP, or “Sjögren's Training and Education Platform,” this unique program will lead to more clinical trials in Sjögren's and higher quality trials. Ultimately, this new program will lead to greater interest in developing new therapies in Sjögren's on the part of pharmaceutical companies, because internationally-accepted training and models for trial execution will be easily available and accessible.

Currently, pharmaceutical companies must develop their own training programs for investigators leading their clinical trials. This approach takes a great deal of time and money and most often does not lead to the best and most consistent training. With STEP, clinical trial investigators will share the same training. The STEP program will offer an online portal for clinical trial investigators to take an online course to learn how to collect data for clinical trials.

The design of this online platform will ultimately help speed the training of investigators and ensure that all investigators, no matter which clinical trial they are working on, will be collecting data in the same manner. Consistencies in the way clinical trials are executed from one center to another and even from one trial to another is critical for determining if a therapy really works. Better methods for training was clearly identified by our corporate members and the SSF Clinical Trials Consortium.

STEP Initiatives Move Forward

Under STEP, we plan to:



- 1) *Develop an online training program for current Sjögren's-specific outcome measures*

STEP participants will be trained to use the leading international model for objective measurements in Sjögren's (ESSDAI) and its counterpart for patient reported measurements (ESSPRI) that were recently developed specially for Sjögren's. These measures are now the most frequently used indexes to gauge the effectiveness of therapies for Sjögren's.

Once the basic platform is developed, the SSF will partner with pharmaceutical companies to develop personalized platforms for each company and its clinical trials. Investigators will take the online qualifying test to ensure that they meet the requirements for rating disease activity in Sjögren's patients according to standard testing devised by our SSF key opinion leaders and, in addition, according to requirements for a company's specific trial.

continued page 6 ▼

The Moisture Seekers® Newsletter is published by the Sjögren's Syndrome Foundation Inc.,
 6707 Democracy Blvd., Ste 325; Bethesda, MD 20817.

Copyright ©2017 Sjögren's Syndrome Foundation Inc. ISSN 0899-637.

DISCLAIMER: The Sjögren's Syndrome Foundation Inc. in no way endorses any of the medications, treatments, or products mentioned in advertisements or articles. This newsletter is for informational purposes only. Readers are advised to discuss any research news, drugs, treatments or products mentioned herein with their healthcare providers.



Searching for more of your own tears?

If your eyes feel dry, you might have a type of Chronic Dry Eye caused by reduced tear production due to inflammation. *RESTASIS MultiDose*[®] can help you make more of your own tears, with continued use, twice a day, every day, one drop at a time. *RESTASIS MultiDose*[®] is the same formulation as *RESTASIS*[®] (cyclosporine ophthalmic emulsion) 0.05%, which has been prescribed to 6.4 million patients since 2003*. Talk to your doctor to see if *RESTASIS MultiDose*[®] is a treatment option you may be searching for. **Your Eyes. Your Tears.**

APPROVED USE

RESTASIS MultiDose[®] and *RESTASIS*[®] Ophthalmic Emulsion help increase your eyes' natural ability to produce tears, which may be reduced by inflammation due to Chronic Dry Eye. *RESTASIS MultiDose*[®] and *RESTASIS*[®] did not increase tear production in patients using anti-inflammatory eye drops or tear duct plugs.

IMPORTANT SAFETY INFORMATION

Do not use *RESTASIS MultiDose*[®] and *RESTASIS*[®] Ophthalmic Emulsion if you are allergic to any of the ingredients. Be careful not to touch the container tip to your eye or other surfaces, to help avoid eye injury and contamination. *RESTASIS MultiDose*[®] and *RESTASIS*[®] should not be used while wearing contact lenses. If contact lenses are worn, they should be removed prior to use of *RESTASIS MultiDose*[®] and *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 a Brief Summary of the Full Product Information.

Plan ahead with *RESTASIS MultiDose*[®] before insurance deductibles reset in the new year.

With a Savings Card, pay as little as \$0[†] for 3 bottles of *RESTASIS MultiDose*[®]. Fill a prescription now so you are ready for the new year. **See if you are eligible at restasis.com**



*RESTASIS[®] (single-use vials): Projected Patient Counts SOW 2016-04

[†]Up to a \$250 savings on three 5.5 mL bottles or a 90-day supply of single-dose vials. Patients whose prescriptions will be paid for in part or in whole by Medicare, Medicaid, or any similar federal or state healthcare program are not eligible for savings or rebates according to federal and state law.

The actual savings on your out-of-pocket costs for *RESTASIS MultiDose*[®] will vary according to refill quantity and personal healthcare insurance coverage. Please review the *My Tears, My Rewards*[®] Program guidelines to learn more.



Available by prescription only

RESTASIS® and RESTASIS MULTIDOSE™ (Cyclosporine Ophthalmic Emulsion) 0.05%

BRIEF SUMMARY – PLEASE SEE THE RESTASIS® AND RESTASIS MULTIDOSE™ PACKAGE INSERTS FOR FULL PRESCRIBING INFORMATION.

INDICATION AND USAGE

RESTASIS® and **RESTASIS MULTIDOSE™** ophthalmic emulsion are 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® and **RESTASIS MULTIDOSE™** are 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

Be careful not to touch the container tip to your eye or other surfaces to avoid potential for eye injury and contamination.

Use with Contact Lenses

RESTASIS® and **RESTASIS MULTIDOSE™** 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®** and **RESTASIS MULTIDOSE™** 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 cyclosporine ophthalmic emulsion 0.05% 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 cyclosporine ophthalmic emulsion 0.05%. 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 container tip touching the eye during administration).

USE IN SPECIFIC POPULATIONS

Pregnancy

Risk Summary: Clinical administration of cyclosporine ophthalmic emulsion 0.05% is not detected systemically following topical ocular administration [see *Clinical Pharmacology* (12.3)], and maternal use is not expected to result in fetal exposure to the drug. Oral administration of cyclosporine to pregnant rats or rabbits did not produce teratogenicity at clinically relevant doses [see *Data*].

Data

Animal Data: At maternally toxic doses (30 mg/kg/day in rats and 100 mg/kg/day in rabbits), cyclosporine oral solution (USP) was teratogenic as indicated by increased pre- and postnatal mortality, reduced fetal weight and skeletal retardations. These doses (normalized to body surface area) are 5,000 and 32,000 times greater, respectively, than the daily recommended human dose of one drop (approximately 28 mL) of cyclosporine ophthalmic emulsion 0.05% 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 during organogenesis at oral doses up to 17 mg/kg/day or 30 mg/kg/day, respectively. These doses in rats and rabbits are approximately 3,000 and 10,000 times greater, respectively, than the daily recommended human dose.

An oral dose of 45 mg/kg/day cyclosporine administered to rats from Day 15 of pregnancy until Day 21 postpartum produced maternal toxicity and an increase in postnatal mortality in offspring. This dose is 7,000 times greater than the daily recommended human dose. No adverse effects in dams or offspring were observed at oral doses up to 15 mg/kg/day (2,000 times greater than the daily recommended human dose).

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

Lactation

Risk Summary

Cyclosporine is known to appear in human milk following systemic administration, but its presence in human milk following topical treatment has not been investigated. Although blood concentrations are undetectable following topical administration of cyclosporine ophthalmic emulsion 0.05% [see *Clinical Pharmacology* (12.3)], caution should be exercised when **RESTASIS®** and **RESTASIS MULTIDOSE™** are administered to a nursing woman. The developmental and health benefits of breastfeeding should be considered along with the mother's clinical need for **RESTASIS®** and **RESTASIS MULTIDOSE™** and any potential adverse effects on the breast-fed child from cyclosporine.

Pediatric Use

Safety and efficacy 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 mL) of 0.05% **RESTASIS®** and **RESTASIS MULTIDOSE™** 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 container to touch the eye or any surface, as this may contaminate the emulsion. Advise patients to not touch the container to their eye to avoid the potential for injury to the eye.

Use with Contact Lenses

RESTASIS® and **RESTASIS MULTIDOSE™** 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®** and **RESTASIS MULTIDOSE™** 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.

Advise patients to read the Instructions for Use for detailed first-time use instructions for the multidose bottle.

Rx Only



Based on package inserts 71876US18 and 72843US12
© 2017 Allergan. All rights reserved.
All trademarks are the property of their respective owners.
RES103567 3/17
Patented. See www.allergan.com/products/patent_notices
Made in the U.S.A.



Research Update

SSF Awards 2017-2018 Research Grants

Introduction

The Sjögren's Syndrome Foundation is excited to announce that the 2017-2018 research grant recipients have been selected. For 2017, the research review committee sought grants that focused on biomarker development for Sjögren's and how to monitor disease risk and prognosis, though all high-caliber, innovative projects were considered.

After careful consideration of this year's outstanding pool of applications, the research review committee awarded three new research grants and renewed three excellent research grants from the 2016-2017 awardees.

2017-2018 Research Award Recipients:

Daniela Cihakova, MD, PhD



Associate Professor of Immunology; Associate Director of Immunology Laboratory; Director of WHO Collaborating Center, Dept. of Pathology, Johns Hopkins University, Baltimore, Maryland

Research Project

Epithelial Cells and Innate Lymphoid Cells Collaborative Role in

the Pathogenesis of Primary Sjögren's Syndrome

Description

The immunopathogenesis of Sjögren's and the active role of the glandular epithelium is not entirely understood thus limiting therapeutic approaches. We found for the first time, in human and mouse salivary glands, that ductal epithelial cells overexpress the prostanoid receptor CRTH2 during Sjögren's autoimmunity. Importantly, CRTH2 blockade is a promising therapeutic strategy in asthma. Also, we found that innate lymphoid cells (ILCs), a subset of epithelium-associated leukocytes, infiltrate salivary glands and show pro-inflammatory properties in Sjögren's and its murine model (autoimmune regulator knock-out). We hypothesize that ductal epithelial cell activation via CRTH2 ligation leads to ILC activation and recruitment, thus perpetuating the inflammatory response. This translational project aims to investigate the pathogenic features of salivary epithelial cells and ILCs on Sjögren's in humans and murine models and might potentially lead to new therapeutic/diagnostic approaches.

SSF Research Grant Reviewers concluded that "understanding the epithelial cell/immune cell interface is highly important in further understanding Sjögren's pathogenesis. [There is a] high probability that significant findings will come from this project."

Danielle Marie Robertson, BS, OD, PhD



Associate Professor, University of Texas Southwestern Medical Center, Department of Ophthalmology Dallas, Texas

Research Project

Comparative Structural and Molecular Analysis of Tear and Salivary Derived Exosomes in Sjögren's Syndrome

Description

The major problem facing Sjögren's patients and clinicians today remains the absence of effective biomarkers to allow for early detection and treatment of the disease. Based upon available data, we propose to test a hypothesis that saliva and tear derived from exosomes will contain biomarkers unique to patients with primary Sjögren's. We will test this hypothesis by characterizing the ultrastructural biology and molecular signature of saliva and tear derived exosomes from women with primary Sjögren's compared to age-matched healthy controls using cryo-electron microscopy and next generation RNA-sequencing. The identification and characterization of the exosomal structure and molecular profile is the first step in the identification of novel, early biomarkers for Sjögren's.

“SSF Advancing...” *continued from page 2* ▼

- 2) *Develop online training programs for additional outcome measures that can be used in Sjögren’s trials*

Future plans to expand our offerings through the STEP platform include training on multiple outcome measures that might be used in clinical trials in Sjögren’s. For example, outcome measures already exist for specific symptoms in Sjögren’s, such as fatigue and cognitive function (or “brain fog”), and our hope is to add these to our online training either as they currently are or changed slightly to better fit Sjögren’s. This will greatly expand our educational offerings to companies and clinical trial investigators to ensure successful clinical trial design.

- 3) *Offer educational videos demonstrating how to perform Sjögren’s-specific tests that can be used for clinical assessment of patients in a clinician’s office and/or for use in clinical trials*

Gaining knowledge and consistency in conducting

Sjögren’s-specific tests is critical for healthcare professionals. Properly and consistently performing tests such as a lip biopsy (and reading these biopsies), the Schirmer’s test to measure dry eye, unstimulated and stimulated salivary flow measures, and skin biopsies for small fiber neuropathy will help medical providers in their diagnosis and treatment of Sjögren’s.

Conclusion

To accomplish our goals, the CTC has engaged in regular discussions to assess barriers to clinical trials in Sjögren’s and strategies to tear down those barriers. Many barriers exist in getting new therapies to market, but tremendous progress has been made. We now have internationally accepted classification criteria and outcomes measures that are being utilized with ongoing updates and improvements. The development of biomarkers and novel diagnostics are also in the pipeline and a priority for SSF awarded research grants.

This journey has been both challenging and rewarding. Through the efforts of many, we are actively moving forward getting closer to our goals! I thank each one of you for your support in our continuing efforts. ■

Sjögren’s Clinical Trials – Get Involved!



Everyday research is being conducted to unveil new medications, therapies and diagnostic tools for Sjögren’s and its symptoms. By participating in a clinical trial, you will be helping to potentially uncover breakthroughs that will help Sjögren’s patients worldwide, including the next generation.

Clinical trials are designed to add to medical knowledge and most importantly, the results of these trials can make a difference in the care and treatment of Sjögren’s patients.

Clinical trials in Sjögren’s are starting to actively recruit patients. The SSF hosts a listing of studies on our website and with over 40 clinical trial sites currently recruiting patients, we encourage you to learn more about what’s involved in a clinical trial and review the listing on www.sjogrens.org.

NEUTRASAL® RELIEVES DRY MOUTH SYMPTOMS, SO

SING ON

90% OF PATIENTS REPORTED
IMPROVEMENT IN
TALKING*

A prescription rinse that provides proven dry mouth relief

- Patients in a clinical study who used NeutraSal® for 28 days reported **improvements in talking, eating, drinking, and swallowing**
- Natural formulation—no sugars, artificial flavors, or colors added
- Ask your doctor or dentist if NeutraSal® is right for you

INDICATIONS

NeutraSal® is indicated for dryness of the mouth (hyposalivation, xerostomia) and dryness of the oral mucosa due to drugs that suppress salivary secretion.

IMPORTANT SAFETY INFORMATION

- Not intended to prevent xerostomia or oral mucositis
- Patients should avoid eating or drinking for at least 15 minutes after use
- Solution should not be swallowed but be spit out
- Not intended for systemic use to treat any diseases of the throat or upper gastrointestinal tract
- Not intended for use as an antacid
- No adverse events anticipated if swallowed accidentally
- Contains sodium; if you are on a low sodium diet consult with your doctor
- No known interactions with medicinal or other products

Please see Instructions for Use at NeutraSal.com/Sjogrens

*In a clinical study patients with varying degrees of xerostomic symptoms (n=30), reported improvement at 28 days

NeutraSal is a trademark of Valeant Pharmaceuticals International, Inc. or its affiliates.
©2017 Valeant Pharmaceuticals North America LLC NSL.0048.USA.17

\$0 COPAY FOR ELIGIBLE
PATIENTS

Visit NeutraSal.com/Sjogrens for details.



 **NeutraSal®**
(Supersaturated Calcium Phosphate Rinse)

“Letter from CEO” *continued from page 1* ▼

innovating research, I wanted to share with you the top 5 SSF programs and the reasons that I am thankful for all of you and hopeful for the future ahead:

Finding new therapeutics for Sjögren’s

The SSF is working with nine companies that are developing therapies for systemic symptoms and complications of Sjögren’s; together, these companies are currently investigating 12 different therapies that are either classified as biologics or small molecule drugs. One (or more) of these therapies could lead to the very first therapeutic available to directly target Sjögren’s.

**“There is no medicine like hope,
no incentive so great, and no
tonic so powerful as expectation
of something tomorrow.”**
~ Orison Swett Marden

Creating support for all patients

The SSF launched Smart Patients, a new online community for Sjögren’s patients to share with one another about living with Sjögren’s.

Fostering clinical research

The SSF is excited to be launching the first-ever on-line platform to train clinical trial investigators and, eventually, educate clinicians from multiple specialties who manage and treat Sjögren’s patients. The STEP (Sjögren’s Training and Educational Platform) program will lead to higher quality and more effective clinical trials in

Sjögren’s. The educational part of this platform will help the SSF expand our education to healthcare professionals that so desperately need to know more about Sjögren’s.

Furthering Sjögren’s Clinical Practice Guidelines

The SSF has started phase two of the Rheumatology and Oral Clinical Practice Guidelines. The guidelines will focus on dental caries restoration as well as lymphoma, pulmonary complications, neuropathies and vasculitis.

Encouraging knowledge for medial professionals

The SSF just launched an online communication forum for rheumatologists to engage with one another, share case studies and answer each others questions about how to treat their Sjögren’s patients.

Hope moves us forward and helps transport us to a more promising place. A place where Sjögren’s becomes a household name, where physicians and healthcare providers know about Sjögren’s and where there are treatments available for this devastating disease.

I am very proud to be your CEO and on behalf of the SSF staff and our volunteer Board of Directors, I thank each of you for carrying the Sjögren’s torch, sharing your story, being a member of the Foundation, donating and supporting our work. Together, we can continue these initiatives into 2018 and continue to give all patients hope.

Wishing you and your family a happy and healthy holiday season.

Steen Taylor
Chief Executive Officer

Dry Mouth Can Damage Your Teeth

Now there is a mouth watering sugar free soft chew that coats teeth with Saliva Mimicking Technology

b a s i c B I T E S[®]

Clinically Shown to Help Maintain Enamel Health

Order Today at basicbites.com or call 800-863-9943





You Stood Up!

Thank You to Everyone Who Joined Team Sjögren's Goes Turkey!

Sjögren's Syndrome Foundation friends from around the country joined together to raise awareness in their communities by participating in local Turkey Trots wearing a Team Sjögren's Turkey T-shirt!

We hope everyone had a great race or walk, while also raising awareness and funds for Sjögren's! Thank you again to everyone who joined Team Sjögren's Goes Turkey and stepping up for Sjögren's!

Remember to send us pictures of you at your Turkey Trot by emailing them to tms@sjogrens.org. ■



Top Stories

- 9 SSF Outstanding Abstract Awards at ACR
- 10 TFS Overview and Innovations Showcases
- 11 TFS Highlights: Microbiome & Neuropathic Pain
- 19 Patient Education: Swallowing Medications

Vol. 12, Issue 1 - Winter 2017 The Professionals' Resource on Sjögren's

SSF Medical and Scientific Advisory Board

Chair: Nancy L. Catzman, MD, FACP

Members: Dan Aycock, MD; Michael S. Baier, MD, MSCR; Richard Buggage, MD, FACS; Michael Brennan, DDS, MEd; Steven E. Catzman, MD; Ted Daniels, DDS, MEd; Denise L. Frazier, MD; H. Kenneth Fisher, MD, FACS; Guy Fadden, MD; Thomas Lammi-Pelt, MD; S. Lorne Pearce, MD; Philip C. Pao, DDS; Sara Peterson, MD, MPH, PhD; Robert L. Fox, MD, PhD, FRCR; Anna Mitchell, PhD; John S. Nelson, MD, FACS; Arlyn Nelson, MD; Allan Pappas, DMD, PhD; Alan Parke, DMD; Andrew Pines, DMD; Nelson Phillips, DMD, MPH; Vikas Sharma, DMD, MEd; David Scharf, MD, FACP; Neil Sattil, MD; Frederick S. Stone, MD, FACS; Jeffrey Wilson, MD, FACS

Associate Editors: Steven J. Eisen, PhD, FRCP; James A. Craven, MD; Richard Johnson, MD, PhD; Richard Johnson, MD, PhD; Richard Johnson, MD, PhD; Michael Lento, MD; James M. Macintosh, MD; Marshall Spector, MD, PhD; James J. Sordani, DMD, PhD; Hans Spronk, MD; Les Swadlow, DDS, MD, PhD; Alessandro C. Tassioli, MD; Ina A. Uebel, MD; Charles W. Day, MD; Daniel J. Wallace, MD; Peter Wallace, MD, DSc; "Consultant" 

6707 Democracy Blvd., Ste 325 Bethesda, MD 20817 (301) 530-4420 www.sjogrens.org ©2017 Sjögren's Syndrome Foundation

The Difficulties of Diagnosing Sjögren's: Examples of Ro/SSA-Negative Patients and Previous Erroneous Diagnoses of Patients with Sjca

by Astrid Rosenbaum, MD, PhD, Antibody and Clinical Immunology, *Mayo Medical Research Foundation, Rochester, NY, USA*

Key Messages

- The diagnosis of Sjögren's is difficult and often preceded by diagnoses of other autoimmune disorders.
- A subset of patients with Sjögren's present with objective salivary and lacrimal dysfunction with focal lymphocytic sialadenitis but without anti-Ro/SSA antibodies.
- Rheumatoid factor and/or ANA increase the risk of misdiagnosing Sjögren's as rheumatoid arthritis or lupus.
- Advances in biomarker and pathophysiology discovery should result in more sensitive and specific tests for Sjögren's.

Introduction

Sjögren's is characterized by exocrine gland damage and dysfunction mediated by autoantibodies and lymphocytic infiltrates, resulting in xerostomia and keratoconjunctivitis sicca. A significant proportion of patients with Sjögren's have systemic manifestations including arthritis, fatigue, hemetological abnormalities, pulmonary, renal and peripheral nervous system involvement, and an increased risk for lymphoma.



Increased Tear Catepsin S in Sjögren's Illustrates Fundamental Changes in Rab Protein Function in Lacrimal Gland Acinar Cells

by James C. Johnson, Zhou Meng, and Joseph S. Stamm-Albanese, Department of Ophthalmology, USC, Beck Eye Institute and Department of Pharmacology and Pharmaceutical Sciences, University of Southern California

Introduction

In Sjögren's, the salivary and lacrimal glands are infiltrated by lymphocytes. The foci of lymphocytes are found in between the tear- or saliva-producing acinar cells and are often localized along the major efferent ducts. Another hallmark of Sjögren's is the reduction of tear and salivary production from the acinar cells, a reduction that often is greater than what can be explained by the loss of acinar cell



Urological

Health is considered an important physical and mental health; it is associated with general well-being and satisfaction of life. It can be affected by the physiological sequelae of autoimmune diseases such as pain, fatigue, stiffness, depression, reduced libido, and hormonal imbalance as side effects from treatments.

By Van Nimwegen and Arends et al., demonstrated that women with Sjögren's have significantly more sexual dysfunction.

Background

Women with Sjögren's have an increased risk of cardiovascular disease. Dr. Carlam at the FDA tried to have the remaining COX-2 selective inhibitor, Celebrex[®] recalled as well. Our academic physicians advised the use of traditional NSAIDs (ibuprofen, naproxen, diclofenac, etc.) with the addition of a PPI. Over the years we found an association of PPIs with worsening osteoporosis (perhaps helped with

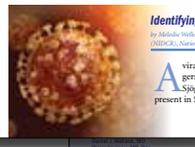
Background

that might relate to dementia. The report of an association of proton pump inhibitor (PPI) use with an increased risk of dementia will be alarming.^{1,2} For our patients, we need to remind them that the study found this association in an older age group (>75 yrs). Before we throw away the PPIs, we need to consider their clinical indications and remember a little history.

Identifying Viral-Mediated Triggers of Sjögren's

by Melissa Wilton, PhD, National Institute of Dental and Craniofacial Research (NIDCR), National Institutes of Health (NIH), Bethesda, Maryland

A viral infection is thought to be one of the triggers in the development and/or progression of Sjögren's. Prior studies have identified viruses present in Sjögren's patients, including Epstein Barr



Stay informed. Stay aware. Be your own best medical advocate!

To increase professional awareness about Sjögren's, the SSF has launched *Sjögren's Quarterly* – a professional resource geared toward medical and dental professionals, clinicians, researchers, and anyone interested in the latest in Sjögren's research findings and treatments.

Although the content is primarily written for a professional audience, *Sjögren's Quarterly* is not just for doctors and researchers. Patients may benefit from the information, too.

If you are interested in subscribing to *Sjögren's Quarterly*, we are offering a special introductory rate of just \$20 for SSF members. Take charge of your healthcare by keeping on top of all the best medical information available.

Subscribe to *Sjögren's Quarterly* today, and you might just teach your doctor a thing or two about Sjögren's.

4 issues for just \$20 for SSF members!

	Non-Member Price	Member Price	Qty	Amount
A one-year subscription to the <i>Sjögren's Quarterly</i>	\$50.00	\$20.00		
Total Amount				

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

Name _____
Address _____
City _____ State _____ Zip _____
Telephone _____ E-Mail _____

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

MasterCard VISA Discover AmEx Card Number _____

Exp. Date _____ Security Code _____ Signature _____



“Research Grantees” *continued from page 5* ▼

Upon review, an SSF Research Grant Reviewer felt that “this study has the potential of elucidating new biomarkers for Sjögren’s,” which could prove a very important advancement to the field. Additionally, this project involves a “newly formed Center of Excellence for Sjögren’s Clinical Care and Research that is multi-disciplinary and involves an excellent team and infrastructure.”

Anat Galor, BS, BA, MD, MSPH



Associate Professor of Clinical Ophthalmology, Bascom Palmer Eye Institute, University of Miami, Miami, Florida

Research Project

Fecal Microbiota Transplant (FMT) in Sjögren’s Syndrome

Description

The purpose of this research is to study the feasibility and efficacy of Fecal Microbiota Transplant (FMT) in Sjögren’s patients. Given the immune destruction of exocrine glands seen in Sjögren’s, severe immune modulators have been evaluated as treatments but none have consistently improved gland function and/or clinical metrics of disease. Individuals with Sjögren’s have been found to have gut dysbiosis less diverse gut microbiome with a greater abundance of pathologic organisms and a lower abundance of healthy ones. In fact, the severity of ocular and systemic disease in Sjögren’s inversely correlated with microbial diversity. Furthermore, mice that spontaneously develop Sjögren’s and dry eye were also found to have gut dysbiosis. Dry eye in these mice worsened when given antibiotics and improved when fed feces from a healthy animal. This brings into question whether Fecal Microbiota Transplant (FMT) can improve the dry eye phenotype in patients with Sjögren’s.

An SSF Research Grant Reviewer believes that Dr. Galor’s project “has the potential to revolutionize the treatment of Sjögren’s.”

continued page 12 ▼

The search
for dry skin
solutions
is over!



All Sjogren’s Syndrome patients
& their family may enjoy
20% off!

Use coupon code: SSF
www.PEAK10SKIN.com

*Here’s what your fellow Sjogren’s patients
are saying about PEAK 10 SKIN:*

“LOVE, LOVE, LOVE the HYDRO 1000 and LIPID DEFENSE serums, plus the Black Diamond moisture repair cream. So glad I found something that works for my Sjogren’s ravaged skin.”

~Sandy B.

“I love all these products and they really are making an amazing difference in my skin.”

~Victoria D.

*PEAK10SKIN was a sponsor for the SSF patient conference in Seattle.



PEAK10SKIN.com

Stay connected...   

© Breck Edge, LLC 2016

“Research Grantees” continued from page 11 ▼

Renewed 2016-2017 Research Awards

Stergios Katsiogiannis, PhD

Assistant Project Scientist, Center for Oral/Head & Neck Oncology Research, UCLA School of Dentistry

Research Project

System Analysis of Mouse Models for Sjögren’s Syndrome Pathogenesis

Description

This work promises to define molecular targets for initiation and pathogenesis of Sjögren’s, which can be tested in predictive mouse models of the disease. These results could lead to novel treatment approaches for humans that are based on animal models.

Nancy McNamara, OD, PhD and Jes Kristen Klarlund, PhD

Associate Professor, School of Optometry, The Regents of the University of California, Berkeley

Research Project

A New Generation of Eye Drops to Treat the Ocular Manifestations of Sjögren’s Syndrome

Description

This study proposes a new method to produce eye drops that allow proteins to remain at the surface of the eye for up to 16 hours and consequently have time to act. This versatile technology will allow using therapeutic proteins to address other eye-related problems in Sjögren’s, such as corneal haze, pain, and insufficient secretion of tears.

Xaralabos Varelas, PhD

Assistant Professor, Department of Biochemistry, Boston University School of Medicine

Research Project

Defining Epithelial Cues Contributing to Sjögren’s Syndrome

Description

This study aims to define the molecular events accompanying the structural changes that occur in the organs of Sjögren’s patients, and to test whether promoting such defects in animal models will lead to similar disease symptoms. This will help define biomarkers of disease progression and offer new targets for therapeutic development.

For a full description of renewed research awards, please view the abstracts on the SSF website at www.sjogrens.org/home/research-programs/research-grants/current-recipients. ■

**Rated Most Effective by Dentists
Clinicians Report® March 2016***

OraCoat  **XyliMelts®** All-natural 
for dry mouth

Adhering discs for use while sleeping and daytime!

XyliMelts long lasting adhering discs temporarily relieve dry mouth[†] day and night, even while sleeping when dry mouth is worst.

- 1/2 gram of Xylitol coats, moisturizes and lubricates[†]
- Discreetly sticks to gums or teeth
- Lasts all night
- Reduces plaque and new cavities[†]
- Stimulates saliva[†]
- **12 disc sample; just pay \$3.20 shipping (online or telephone orders)**



 CVS pharmacy

 RITE AID

 amazon.com

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

 facebook.com/OraCoat

* Survey of 1168 dentists, March 2016 Clinicians Report®, an independent, non-profit, dental education and product testing foundation. Full report available at oracoat.com

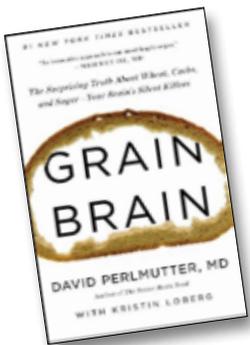
[†] These statements have not been evaluated by the Food and Drug Administration. This product is not intended to diagnose, treat, cure, or prevent any disease.





Holiday Recipe Box

Holiday Soft Diet Dessert Recipe: Chocolate Coconut Mousse



This recipe is from, “Grain Brain: The Surprising Truth about Wheat, Carbs, and Sugar – Your Brain’s Silent Killers” by David Perlmutter, MD (author) and Kristin Loberg (contributor).

Looking for a dessert in minutes? Keep a can of coconut milk in the refrigerator so it’s ready to go when you feel like indulging in a decadent treat.

Serves 2

- 1 can of full-fat coconut milk
- 3 Tablespoons cocoa powder
- 1-2 teaspoons stevia (depending on how sweet you want it)
- Optional: shredded coconut, almond butter, cinnamon

Chill the unopened can of coconut milk in the refrigerator for several hours or overnight.

Scoop out the solidified cream into a mixing bowl and beat vigorously with a whisk or electric mixer until softened (it shouldn’t be liquified). Add the cocoa powder and stevia and continue to beat until the mousse is light and fluffy. Top with shredded coconut, and a dollop of almond butter, or cinnamon, and serve.

Resource Order Form

	Non-Member	Member	Qty	Amount
Healing Arthritis: Your 3-Step Guide to Conquering Arthritis Naturally by Susan S. Blum, MD, MPH (Author), Mark Hyman (Foreword).	\$24	\$20		
The Sjögren's Book, Fourth Edition edited by Daniel J. Wallace, MD. The 2011 edition of the Sjögren's handbook has been completely revised and expanded with all new chapters and the latest information on Sjögren's.	\$32	\$28		
The Sjögren's Syndrome Survival Guide by Teri P. Rumpf, PhD, and Kathy Hammitt. A complete resource, providing medical information, research results, and treatment methods as well as the most effective and practical self-help strategies.	\$20	\$17		
Tales From the Dry Side by Christine Molloy. Thirteen personal stories behind the autoimmune illness. Sjögren's tales from courageous men and women who share their journey with Sjögren's.	\$16	\$13		
SHOWgrins – Women Who Walk on Water by Betty Collier. The author has written an inspirational book that brings into the limelight the cases of five women who open their hearts and share their Sjögren's stories to help increase awareness and expedite new diagnoses and treatment options.	\$16	\$13		
Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop by Norman Latov, MD, PhD. Peripheral neuropathy is a widespread disease, yet many people do not even realize they have it.	\$19	\$16		
You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life by Mims Cushing and Norman Latov, MD. A compendium of tips, techniques, and life-task shortcuts that will help everyone who lives with this painful condition.	\$19	\$16		
A Body Out of Balance by Ruth Fremes, MA, and Nancy Carteron, MD, FACR. A Sjögren's patient and a doctor offer their authoritative insight into one of the most common yet most misunderstood autoimmune disorders.	\$16	\$13		
Vulvodynia Survival Guide: How to Overcome Painful Vaginal Symptoms & Enjoy an Active Lifestyle by Howard I. Glazer, PhD and Gae Rodke, MD, FACOG. A great resource for anyone experiencing vulvodynia symptoms. This book will help readers identify triggers, reduce symptoms, find medical help, reduce pain, and renew their enjoyment of life.	\$18	\$15		
The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease by Susan Blum, MD, MPH. This book shares Dr. Blum's four-step program to help autoimmune patients reverse their symptoms, heal their immune systems and prevent future illness.	\$25	\$22		
The Memory Bible: An Innovative Strategy for Keeping Your Brain Young by Gary Small, MD. This program has helped thousands of people improve their ability to remember everyday issues like where their car is parked as well as more important abilities to think fast and maintain a healthy brain.	\$16	\$13		
As My Body Attacks Itself: My Journey with Autoimmune Disease, Chronic Pain & Fatigue by Kelly Morgan Dempewolf, PhD. This book is an honest, raw look at the thoughts, concerns, fears and struggles, as Kelly deal with Sjögren's.	\$15	\$11		
Grain Brain: The Surprising Truth about Wheat, Carbs, and Sugar – Your Brain's Silent Killers by David Perlmutter, MD (author) and Kristin Loberg (contributor) A #1 New York Times bestseller – the devastating truth about the effects of wheat, sugar, and carbs on the brain, with a 4-week plan to achieve optimum health.	\$25	\$20		
How to Live Well with Chronic Pain and Illness – A Mindful Guide by Toni Bernhard. The book addresses challenges created from chronic illness to help readers make peace with a life turned upside down.	\$17	\$14		
Awareness Wristbands by purchasing these awareness wristbands, you are helping the SSF to achieve our 5-Year Breakthrough Goal. With the wording, "Conquering Sjögren's - www.sjogrens.org." Pack of 10	\$18	\$15		
<i>The Moisture Seekers</i> newsletter Volume 33, 2015 (10 issues) as originally published.	\$50	\$20		
<i>The Moisture Seekers</i> newsletter Volume 34, 2016 (10 issues) as originally published.	\$50	\$20		
<i>Sjögren's Quarterly</i> newsletter subscription (4 issues) a leading edge medical and scientific newsletter aimed at educating professionals about the latest information on Sjögren's research, treatments and products.	\$50	\$20		
Maryland Residents add 6% sales tax				
Shipping and Handling: US 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				
Please consider an additional contribution: <input type="checkbox"/> \$25 <input type="checkbox"/> \$50 <input type="checkbox"/> \$75 <input type="checkbox"/> \$100 <input type="checkbox"/> \$250 <input type="checkbox"/> \$500 <input type="checkbox"/> Other: _____				

Total Amount Due: _____

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

Name _____
Address _____
City _____ State _____ Zip _____
Telephone _____ E-Mail _____



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

MasterCard VISA Discover AmEx Card Number _____

Exp. Date _____ Security Code _____ Signature _____



Nancy L. Carteron,
MD, FACR

Senior Consultant,
Rheumatology Immunology
Autoimmune Disease;
Volunteer Associate Clinical
Professor, University of
California San Francisco; Tips
based on Urogynecologist,
Rita Melkonian, MD,
FACOG, Corte Madera CA
presentation at ACR 2016
Luncheon Program and
Sjögren's Quarterly Article
Vol 11(3) 2016.

Sjögren's Gynecology and Urology Tips

Sjögren's is an autoimmune inflammatory disease targeting exocrine glands, including the vestibular glands (vulva). Lymphocytic perivascular infiltration of predominately CD4+ T-helper cells can result in gland destruction and decrease in lubrication by glairy fluid. Vaginal dryness and itching, painful intercourse (dyspareunia) and frequent yeast infections contribute to decrease in quality of life, including sexual dysfunction.

In addition to vaginal dryness (common), the following occur in Sjögren's:

- Lichen planus and Lichen sclerosis
- Vaginal yeast infections
- Cervical dysplasia and cancer, especially in setting of HPV (human papilloma virus)
- Interstitial cystitis (~10%) | pelvic pain relieved by voiding; urgency, and frequency
- Endometriosis (4-fold increase) | pelvic pain around menses, excessive bleeding, back pain, painful urination
- Primary ovarian failure (20%) | premature menopause, infertility

Treatment Tips

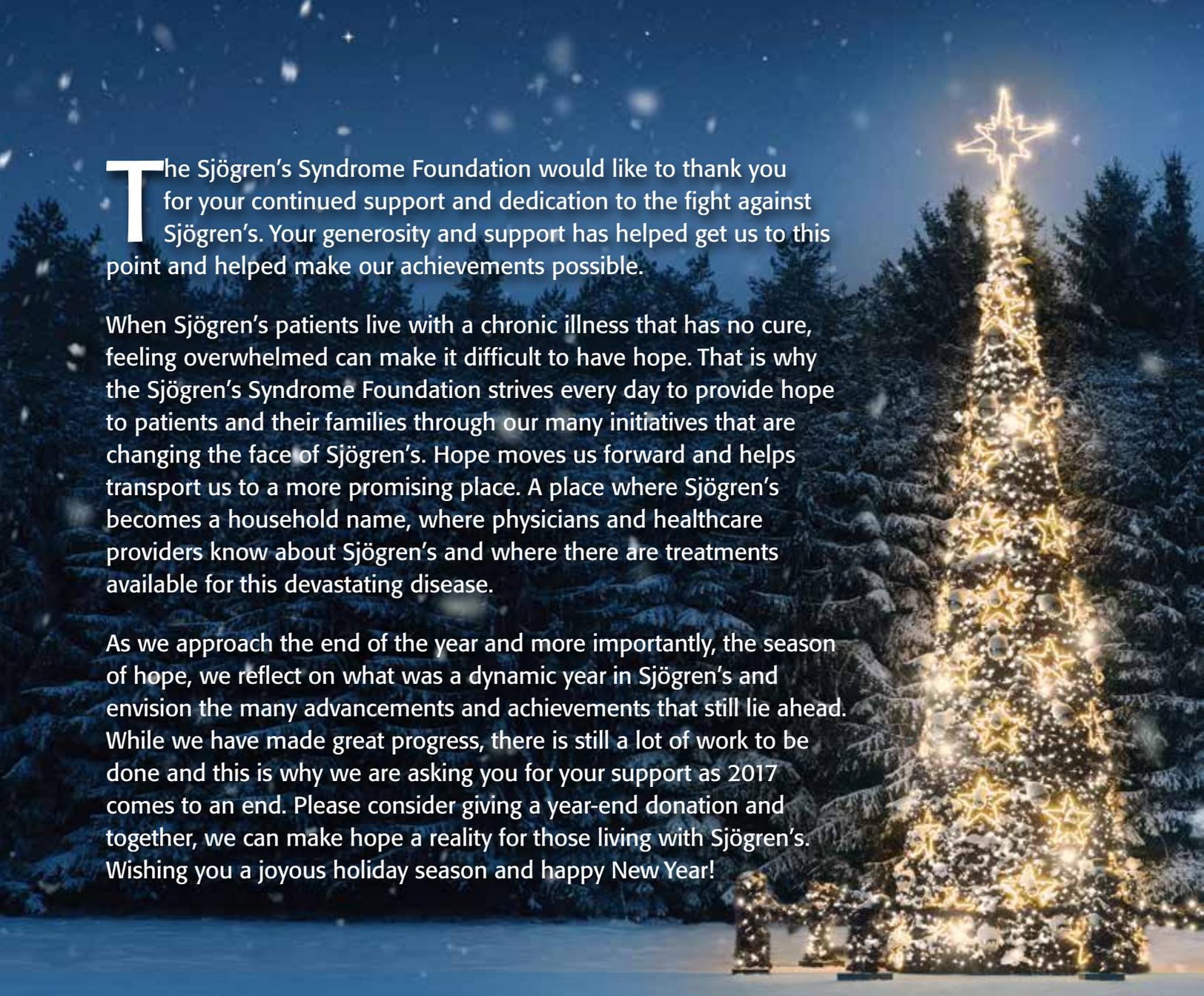
- Topical estrogen products (vaginal cream, pill, ring) or systemic Hormone Replacement Therapy (HRT)
- Topical lubricants for dryness (see SSF Product Directory for a list of vaginal moisturizers)
- PAP or visual inspection (if prior hysterectomy) every 1-2 years; PAP yearly and colposcopy for high risk patients
- Lichen planus or sclerosis may warrant topical steroids
- Antifungals (topical or oral) for frequent or severe vaginal yeast infections
- Refer to Urogynecologist for interstitial cystitis and pelvic pain symptoms ■



Do we have your e-mail address?

If you want to receive all the latest updates from the Sjögren's Syndrome Foundation, then you should make sure we have your most up-to-date e-mail address! The SSF is sharing more information via e-mail, from news about the SSF and Sjögren's, to information about the latest treatments and medicines, to local Support Group updates and more. So contact us at ssf@sjogrens.org to be certain we have your latest e-mail address in our database, and then keep an eye out in your Inbox for Sjögren's news.

Just like all information you give the Foundation, your e-mail address will remain private and will never be given or sold to an outside organization.



The Sjögren's Syndrome Foundation would like to thank you for your continued support and dedication to the fight against Sjögren's. Your generosity and support has helped get us to this point and helped make our achievements possible.

When Sjögren's patients live with a chronic illness that has no cure, feeling overwhelmed can make it difficult to have hope. That is why the Sjögren's Syndrome Foundation strives every day to provide hope to patients and their families through our many initiatives that are changing the face of Sjögren's. Hope moves us forward and helps transport us to a more promising place. A place where Sjögren's becomes a household name, where physicians and healthcare providers know about Sjögren's and where there are treatments available for this devastating disease.

As we approach the end of the year and more importantly, the season of hope, we reflect on what was a dynamic year in Sjögren's and envision the many advancements and achievements that still lie ahead. While we have made great progress, there is still a lot of work to be done and this is why we are asking you for your support as 2017 comes to an end. Please consider giving a year-end donation and together, we can make hope a reality for those living with Sjögren's. Wishing you a joyous holiday season and happy New Year!

- Enclosed is my gift of \$ _____ to support the Foundation's initiatives and programs.
- I am interested in learning more about how to make a stock donation.
- Please send me information about listing the SSF in my will.

Thank you for your support of the Sjögren's Syndrome Foundation.

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

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____ E-mail _____

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

MasterCard VISA Discover AmEx Card Number _____ Exp. Date _____

Signature _____ CC Security Code _____


in memoriam
In Memory of Abby L. Swanson

Deborah Geraci
Chuck and Lana Tencate
Jane and Homer Collins

In Memory of Aleatha Iacolucci

Linda Osborne

In Memory of Emma Harris

Maggie Rothstein
Amy, Bob and Aliya Orenstein
Connie Rodriguez
Dr. Preethi Subramanian

In Memory of Fritzi Marsa

David and Denise Marsa

In Memory of Heather C. McGlynn

Brian Donahue and Heather Binder
David Breit and Maria Aslani-Breit
Rose Mary and David McNitt
Patrick and Wendy Donahue
Judith F. Lemoncelli
Pamela S. Wollam
Roberta and Robert Freitag
Jeanne and Thad Maxwell

In Memory of Helen MacLeod Steff

Pamm Swadley

**In Memory of Jack Wilder Beam,
infant son of Chad and Elizabeth Beam**

Grandma and Grandpa Collins

In Memory of Jean Bartlett

Peter and Janine Velardi
Mr. and Mrs. Frank Celli
Peter and Lee Velardi
Kim and Todd Barber
Jay and Iris Bartlett
Marie-Elena and Joe Crupi
Mark and Lisa Max
Harry and Donna Harran

In Memory of Joan M. Racana

Albany Medical Center Auxiliary
and Volunteer Office

In Memory of Marilyn Andrew

W.W. Grainger, Inc.

In Memory of Martha J. Keeley

Deborah Ramone

In Memory of Millie M. Hill

Michael L. Hill

In Memory of Phyllis Unger

Mollie and Harvey Goldberg

In Memory of Rebecca Klein

Marcy and Mark Adler

In Memory of Ruth Welch

Barbara Wiles
Teresa (Terrie) Hannam

In Memory of Sarah S. Reichert

Kay A. Finchum
David and Natalie Ross
Dave and Cynthia Shaffer
Lorie Ann Metheny
Evelyn L. Leiter
William Reichert
Julianne and Mike Harvey
David and Kathleen Monesmith
Kenneth and Margaret Stiles
Kimberly and Jeffrey Wanemacher
James C. and Ann E. Davis Trust
Peggy and Glen Evert
Mary Ellen Mitchell
Jill Jackson and Family

In Memory of Shirley Bartholomew

Andrea and George Zeiner

In Memory of Vincent J. McNeece, III

Carol Probeyahn
Larry and Rosemary Bernier
Robert W. Burns, Jr.


in honor
**In Honor of Ann and Bob Stanton,
on the occasion of their 50th Wedding Anniversary**

Ed and Maureen Coyle

In Honor of Gene Stuckey

Linda Stuckey

**In Honor of all
Team Sjögren's Runners**

Denise Pallatino

In Honor of Jane Donatich and Michael Fischer

Dave Leonard, Owner
JTD Productions, Inc.

In Honor of John Milnes, for his unwavering support

Your loving wife

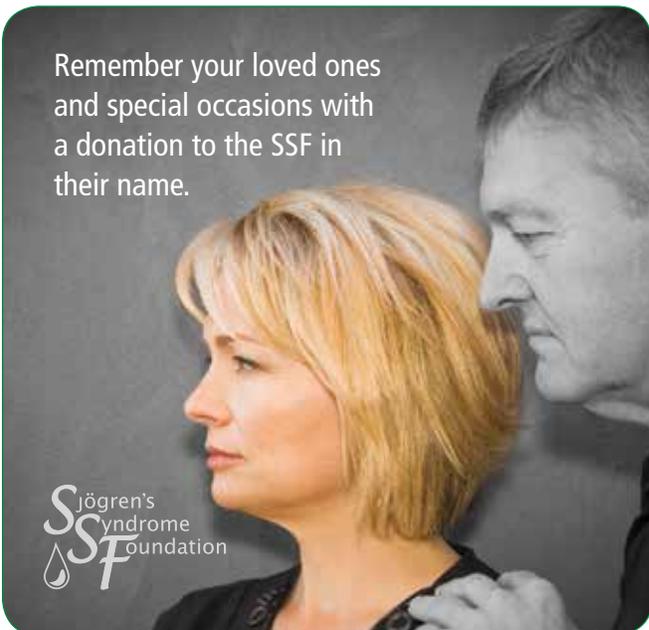
In Honor of Sheldon and Anne Harber, for your support

Linda and Harlan Harber

In Honor of Wendy Budd

Brenda Kahn (B.K.)

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



Sjögren's
SSF syndrome
Foundation

Smart Patients

Sjögren's Community
in partnership with the
Sjögren's Syndrome
Foundation

We're having honest conversations
about Sjögren's and our health. Join SSF
members in our online community:

smartpatients.com/ssf



Save the Date

2018 Sjögren's National Patient Conference

April 13-14, 2018

Hyatt Regency Aurora-
Denver Conference Center

13200 East 14th Place
Aurora, Colorado

This spring we invite you to join with fellow Sjögren's patients, their families, medical experts, and product exhibitors and attend our 2018 National Patient Conference at the Hyatt Regency Aurora-Denver Conference Center.



We encourage you to take this opportunity to gain an understanding of all the key aspects of Sjögren's. This two-day educational experience 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.



Presentation topics will include:

- Sjögren's Overview
- Joint Pain and Sjögren's
- Oral Manifestations of Sjögren's
- Lymphoma: Risk, Treatment and Prognosis
- Ocular Manifestations of Sjögren's
- The State of Sjögren's: Transforming the Future
- And More To Be Announced!



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

This Season Remember to Shop for Sjögren's

Shop for Sjögren's

Simplify your holiday shopping by having your gifts delivered directly to you, while also supporting the SSF!

Shop to benefit the Sjögren's Syndrome Foundation

The Sjögren's Syndrome Foundation has partnered with online retailers who will donate a portion 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. Once you select the "Sjögren's Syndrome Foundation" as your charity of choice, whenever you return to these retailers and log in, any shopping you do will benefit the SSF. It's that simple!

Some of our partners include:



Amazon is one of the most popular online stores in the world, offering a wide variety of products.



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.

