

The Sjögren's Syndrome Foundation Moisture Seekers



www.sjogrens.org

Volume 35, Issue 5 May 2017

 SjogrensSyndromeFoundation

 @SjogrensOrg



How to Qualify for Social Security Disability Benefits with Sjögren's

If you are unable to work or live your normal daily life due to Sjögren's, then disability benefits may be an answer. Social Security disability insurance (SSDI) was created by the government to help disabled Americans and their families receive monthly financial benefits. Continue below to see if SSDI may be a positive option for you.

Medical Requirements

Sjögren's has the potential to be a debilitating disorder. However, some people only experience few or treatable symptoms, making it difficult for the SSA (Social Security Administration) to provide benefits only using a diagnosis. In order to be eligible, applicants must prove that their disorders are both:

- a) severe enough to keep them from work and daily tasks on a regular basis, and
- b) expected to last more than 12 months or result in death.

To tell if an applicant's condition is severe enough, the SSA compares each applicant's case to its corresponding listing in the "Blue Book." This book contains all Social Security-approved disorders, as well as the requirements for each to be considered sufficiently disabling. To see if your case of Sjögren's is severe enough to qualify, we will look at its listing under Section 10.00: "Immune Disorders - Adult" in the Blue Book. This listing states that, in order

continued page 2 ▼

10 Reasons Not to Judge Me

by Marianna Paulson

The greatest risk factor for developing an autoimmune disorder is the existing presence of an autoimmune disease. Overlaps are common and often complex. According to the recent "Living with Sjögren's" patient survey, 21% of Sjögren's patients are also diagnosed with Rheumatoid Arthritis.

We all tend to pass judgment to varying degrees and in a variety of situations based upon what we see, hear, or experience. As we zoom to assume, there can be long-term repercussions that are hurtful and harmful. Share this list of 10 reasons not to judge those of us with rheumatoid arthritis (RA) with your family, friends, and colleagues to foster consideration and compassion about what it's like to live with RA.

continued page 6 ▼



In This Issue

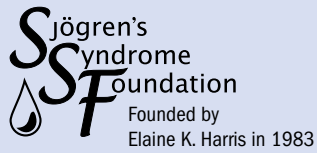
5 Clinicians Corner

7 You Stood Up

9 SSF in Action

10 In Memorial/Honor

15 Travel Tips



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

Herbert Baraf, MD, FACP, FACR

Nancy L. Carteron, MD, FACR

Jack Faricelli

Patricia Hurley, MSc

Cathy Ingels

Theresa Lawrence Ford, MD

Cynthia Lopynski

Monica McGill, PhD

Timothy Niewold, MD, FACR

Thomas D. Sutton

Michelle Wallace

Ava Wu, DDS

Medical & Scientific Advisory Board

Chairman

Nancy L. Carteron, MD, FACR

Esen Akpek, MD

Richard Brasington, MD, FACR

Michael T. Brennan, DDS, MHS

Steven E. Carsons, MD

Troy Daniels, DDS, MS

Denise Faustman, MD, PhD

H. Kenneth Fisher, MD, FACP, FCCP

Gary Foulks, MD, FACS

Theresa Lawrence Ford, MD

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, FACR

Jeffrey Wilson, MD, FACR

Chief Executive Officer

Steven Taylor

Director of Marketing/Editor

Elizabeth Trocchio

e-mail: tms@sjogrens.org

www.sjogrens.org

“Social Security” *continued from page 1* ▼

to qualify with Sjögren’s, the applicant must prove a diagnosis of the disorder, along with either:

Involvement of two or more organs/body systems, where one organ/body system is affected moderately and the applicant shows at least two of the constitutional signs of Sjögren’s (severe fatigue, fever, malaise, or involuntary weight loss).

OR

Repeated manifestations of Sjögren’s, where the applicant shows at least two of the constitutional signs of Sjögren’s (severe fatigue, fever, malaise, or involuntary weight loss) as well as a limitation of daily activities, a limitation in social functioning, or a limitation in concentration, persistence, or pace with normal tasks.

Because these descriptions are more subjective than some other entries, it is important for applicants to provide as much documentation of their symptoms as possible. Things like medical tests (specifically of affected organs), physician’s testimonies, therapy notes, medication lists, hospitalization history, or RFC forms (which measure your ability to perform normal functions) are all vital in helping you to qualify for benefits.

Technical Requirements

Qualifying for disability benefits also requires certain technical aspects to be met. This often involves looking at work history and income to ensure that applicants are in need of financial assistance. For SSDI specifically, applicants must have contributed a certain number of “credits” in order to qualify for benefits.

Credits are earned by contributing taxes to Social Security each year. For every \$1,260 a person makes in taxable income each year, they earn a credit. These can be earned up to four times per year. The amount of credits a person needs to qualify for SSDI depends on their age. For example, a 44-year-old would need 22 credits (5.5 full work years) in order to qualify for benefits, while a 58-year-old would require 36 credits (9 full work years) in order to qualify.

Applicants who qualify for SSDI receive Medicare coverage as well as monthly financial benefits. The amount of these benefits depends on the average income of the applicant during their working years, not on the amount of credits they have obtained. Typical SSDI recipients receive around \$1100/month, but it is possible to receive as much as \$1700/month.

If you are unsure whether or not you qualify for SSDI, you can consult the SSA’s credit chart online or speak with a representative at your local Social Security office.

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.

NEW! *Restasis*
MultiDose™
(Cyclosporine Ophthalmic Emulsion) 0.05%

Restasis
(Cyclosporine Ophthalmic Emulsion) 0.05%

**DO YOUR EYES NEED HELP MAKING
MORE OF THEIR OWN TEARS?
IF SO, YOU COULD HAVE A TYPE
OF CHRONIC DRY EYE.**

Talk to your doctor
about **RESTASIS®**
(Cyclosporine Ophthalmic Emulsion) 0.05%



**THE ONE AND ONLY
PRESCRIPTION MEDICATION
FDA-APPROVED TO HELP YOU MAKE
MORE OF YOUR OWN TEARS**

PRESCRIBED FOR **6.4** MILLION PATIENTS SINCE 2003



Ask for **NEW RESTASIS MultiDose™** —
Same **RESTASIS®** formulation now in a bottle.



Most commercially insured patients pay \$0[†] for every 90-day prescription with the My Tears, My Rewards® Savings Card. Get your Card today at restasis.com/savings

RESTASIS® is the one and only prescription medication that is FDA approved to help increase your eyes' natural ability to produce tears, which may be reduced by inflammation due to Chronic Dry Eye disease.

Approved Use

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

Important Safety Information

Do not use RESTASIS® and *RESTASIS MultiDose™* 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® and *RESTASIS MultiDose™* should not be used while wearing contact lenses. If contact lenses are worn, they should be removed prior to use of RESTASIS® and *RESTASIS MultiDose™* 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 for RESTASIS® and RESTASIS MultiDose™.

[†]RESTASIS® Projected Patient Counts, SOW 2016-04

[†]Up to a \$250 savings. The actual savings on your out-of-pocket costs for RESTASIS® and *RESTASIS MultiDose™* will vary according to refill quantity, personal healthcare insurance coverage, and adherence to FDA dosing guidelines. Please review the *My Tears, My Rewards®* Program guidelines to learn more.

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 mcL) 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 mcL) 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.

Clinicians Corner

by Daniel Small, M.D.



The recent "Living with Sjögren's" patient survey reported that the four major treatments/medications being used are: anti-inflammatory agents (81%), disease-modifying anti-rheumatic drugs (DMARDs) (67%), OTC or prescription fluoride (67%), corticosteroids (62%).

As a newly diagnosed patient, what are these four treatment types and what should I be aware of before talking to my doctor about these options?



Daniel Small, MD

Treatments and Medications Used

Today, there is no cure for Sjögren's, so patients must resort to using a multitude of treatments to help them cope with various symptoms. On average, Sjögren's patients said they use nearly nine (8.8 mean) medications and treatments to help with their Sjögren's symptoms, with an average of over four prescription medications or treatments. Patients living with Sjögren's for a longer period of time (5-9 years) reported using slightly more treatments than patients living with Sjögren's for a shorter period of time (0-4 years) (8.7 vs. 8.2 mean).

Virtually all patients (97%) reported using eye drops, artificial tears, or non-prescription eye ointments for treatment at some time, while a majority said they have used ibuprofen or other anti-inflammatory agents (81%), disease-modifying anti-rheumatic drugs (DMARDs) (67%) and OTC or prescription fluoride (67%), or corticosteroids (62%) for treatment. Younger patients (60 and under) were significantly more likely than patients over 60 to have used health food supplements/remedies (90% vs. 87%), exercise (88% vs. 83%), and alternative therapies (70% vs. 58%) to treat their Sjögren's.



Image from the "Living with Sjögren's: Summary of Major Findings" <http://livingwithsjogrens.org>

Sjögren's is a complex disease with a wide range of signs and symptoms. The Sjögren's Syndrome Foundation (SSF) has been instrumental in educating both patients and physicians about the pathogenesis, diagnosis, and treatment of this disease. Through initiatives from the Foundation, there has been substantial progress in making clinical practice guidelines for the diagnosis and treatment of Sjögren's and there has been significant stimulation of the pharmaceutical industry to invest in clinical trials of new agents for this disease.

The current options available to providers includes symptomatic therapies such as cevimeline or pilocarpine to stimulate saliva flow to help oral dryness and prevent complications of dry mouth such as dental decay and oral infections, and systemic therapies to try to delay the progression of the disease. Although there is a general lack of literature support for medications to delay the progression of the disease, many physicians who treat patients with Sjögren's are convinced that aggressive management leads to a reduction in symptoms and improvement in overall well being as well as a decrease in disease progression. The disease modifying anti-rheumatic agents (DMARDs) are often used to help some of the systemic manifestations of Sjögren's such as inflammatory arthritis, interstitial lung disease, progressive neuropathy, central nervous system involvement, rashes, lymph node, salivary gland

continued page 11 ▼

“Social Security” *continued from page 2* ▼

Starting the Application

SSDI applications are most easily accessible online on the SSA's main website, www.ssa.gov. This website also contains FAQs, income calculators, and helpful tips to guide you through the application process if you need help. Applications can also be filled out in-person at your local Social Security office by calling to schedule an appointment.

This article was written by the Outreach Team at Disability Benefits Help. They provide information about disability benefits and the application process. To learn more, please visit their website at <http://www.disabilitybenefitscenter.org> or by contacting them at help@ssd-help.org. ■

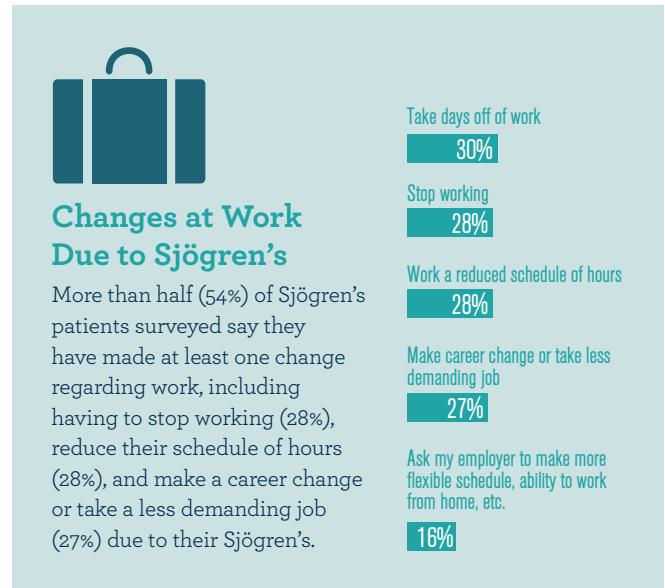


Image from the “Living with Sjögren's: Summary of Major Findings” <http://livingwithsjogrens.org>

“10 Reasons” *continued from page 1* ▼

Before you judge, you should know:

1. I am making the best decisions I know how to make in my treatment choices. In a perfect world, I wouldn't have to take medications to manage my disease. There's a good chance that I have explored all sorts of treatment options, natural remedies, and am practicing self-care techniques that are right for me.
2. I may not move too quickly because I am in pain. I may be having a flare-up, which results in stiffness, swollen joints, and tight muscles. It doesn't stop there, though. RA also affects ligaments and tendons. RA is temperamental and my mobility may change throughout the day, sometimes from hour to hour.
3. When I appear clumsy, it's not because of lack of care. I may have lost my manual dexterity due to swelling and pain. My joints may have dislocated, making it difficult to use my hands properly. And yes, that hurts. A lot.
4. If I'm irritable, I may be in a tremendous amount of pain, have had a series of bad nights, or am struggling with one of the many aspects of what living with rheumatoid arthritis means. RA has far-reaching consequences that can erode finances and the ability to work. It can even limit engagement in activities and experiences that we with RA

Other Diagnosed Health Conditions for Sjögren's Patients

There are many known comorbidities or manifestations of Sjögren's that can occur in conjunction with the disease. Survey respondents reported having been diagnosed by a health care provider with an average of five other health conditions, including Gastroesophageal Reflux Disease (GERD) (45%), Raynaud's (38%), Neuropathy (38%), Sinusitis (33%), Hypertension (31%), and Irritable Bowel Syndrome (31%).

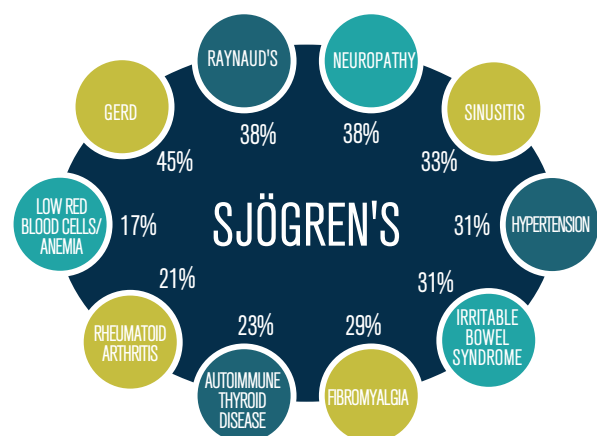


Image from the “Living with Sjögren's: Summary of Major Findings” <http://livingwithsjogrens.org>



You Stood Up!

This is Sjögren's Photo Booth

During the 2017 SSF National Patient Conference, the Foundation hosted a fun photo booth to kick off our *This is Sjögren's!* April Awareness campaign.

This is Sjögren's! was created to help others visualize the disease because Sjögren's is commonly referred to as an invisible disease. While many patients experience debilitating symptoms, people cannot physically see them, which can create a misunderstanding about the seriousness of the disease.

The SSF photo booth was one way to help bring our campaign to life and help others better understand the reality of living with the disease. At the booth, patients could pick from one of seven signs that resonated the best with them. Each sign included one of the following messages:

- 4 million Americans suffer from Sjögren's #ThisIsSjögrens
- I wake up everyday hoping a treatment is developed #ThisIsSjögrens
- You can't see the profound fatigue #ThisIsSjögrens
- My body is attacking itself #ThisIsSjögrens
- #ThisIsSjögrens
- I support all Sjögren's patients
- This is Sjögren's

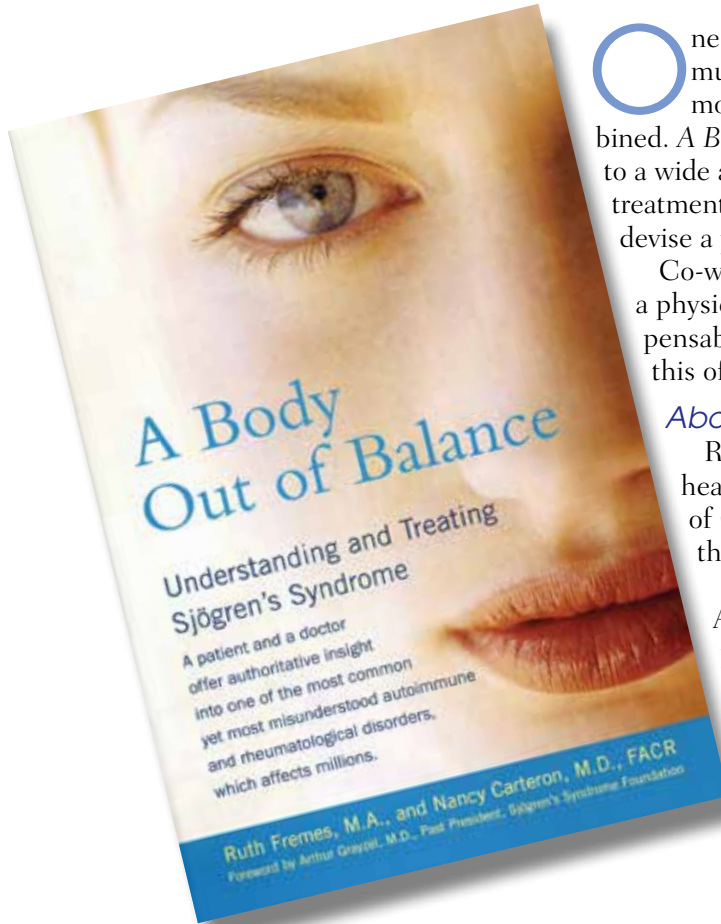
Thank you to everyone who participated in our photo booth for standing up and sharing your story. We hope these pictures inspire you, like they inspired us. Learn more about this campaign by visiting www.sjogrens.org.

Keep an eye out for more information from the 2017 SSF National Patient Conference in upcoming issues of *The Moisture Seekers*. ■



A Body Out of Balance: Understanding and Treating Sjögren's Syndrome

by Ruth Fremes, MA and Nancy Carteron, MD, FACR



One of the most common yet under recognized autoimmune and rheumatological disorders, Sjögren's, affects more people than rheumatoid arthritis and lupus combined. *A Body Out of Balance* provides a comprehensive guide to a wide array of symptoms, traditional and complementary treatments, and invaluable coping methods, so patients may devise a personal treatment plan.

Co-written by a woman living with the disease and by a physician who has treated Sjögren's patients, this indispensable resource will enhance awareness and demystify this often-misunderstood disorder.

About the Authors

Ruth Fremes, MS is the author of nine books on health and nutrition, has consulted for the University of California, the American Dietetic Association, and the National Cancer Institute.

Nancy Carteron, MD, FACR is a fellow of the American College of Rheumatology and maintains a private practice in rheumatology and autoimmune disease at the California Pacific Medical Center in San Francisco. Her extensive research on autoimmunity has appeared in numerous medical journals and publications.

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

	Non-Member Price	Member Price	Qty	Amount
A Body Out of Balance by Ruth Fremes, MA, and Nancy Carteron, MD, FACR	\$16.00	\$13.00		
<i>Maryland Residents add 6% sales tax</i>				
Shipping and Handling:	U.S. Mail: \$5 for first item + \$3 for each additional item Canada: \$14 for first item + \$3 for each additional item Overseas: \$22 for first item + \$3 for each additional item			
Total Amount				

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 US bank, net of all bank charges) payable to SSF.

MasterCard VISA Discover AmEx Card Number _____ Exp. Date _____

Signature _____ CC Security Code _____



SSF in Action!

National Autoimmunity Summit:
Yesterday, Today and Tomorrow

Steven Taylor, SSF CEO, spoke at the Autoimmune Related Diseases Association (AARDA) and the National Coalition of Autoimmune Patient Groups (NCAPG) National Autoimmunity Summit, “Yesterday, Today and Tomorrow,” at the National Press Club in Washington, DC on March 28.

The summit brought together leading experts in research, environment, advocacy, and patient issues to explore the most current trends in autoimmune disease diagnosis, treatments and therapies.

Topics covered at the summit included:

- Barriers to Access
- The Affordable Care Act and Autoimmune Patients
- Coming to Market: The Current and Future Autoimmune Pipeline
- Epidemiology of Autoimmune Diseases
- ARNet: Patient-Powered Research
- Autoimmunity: The Next 25 Years
- The Frontiers of Autoimmune Research

The Foundations knows that by working together, we have a greater impact to promote increased education, awareness, and research into all aspects of autoimmune diseases. Know that we are always fighting for you to ensure that the patient voice is heard. ■




in memoriam
In Memory of Anna Marie Martire

Stamford Cross Road Residence

In Memory of Barbara "Bobbi" Melfi

Mary Azzolini

In Memory of Harriet Russomano

Dave, Pat, Gene, John, Dan, Jeff and Floyd

Mary and Tom James

Lady Lake Historical Society, Inc.

Richard Amant

Jim Eberle and Herb Bachmann

Diane Petrella

Lynn Payer

Bob and Lorraine Zona

Nicholas Novak

Matt, Rose and Madeline Aanensen

Elise and William Bossert

Raymond Russomano

Theodore and Gayle Aanensen

Jeff Labaton

In Memory of Janelle Theis

Jack and Margaret Henderson

In Memory of Janet Adams

Diane Roland

Jan Francis

Sally Whittaker

Mike and Karen Potty

Don and Karen Richer

Dylan Fox

In Memory of Katherine Estridge

Trinity Presbyterian Church

Susan Carlson

In Memory of Lenny W. Jensen

Mary and Joe Condon

Teri Merickel

Marcia Bourilier

Larry and Alan Stilling

James and Susan Frantz

Jerald and Mary Eiserman

In Memory of Louise T. Parker

Louise and Andrew Ten Eyck

Christopher Marston and Samantha Parker

In Memory of Nancy Cloman

Naomi Roberts

In Memory of Neala Kay Shager

Jerry and Pat Erickson

Nancy and Tom Austin

Phyllis Hopf

Mary Ostertag, DKG

William Gardner and Family

Merle and Val Landmark

Sharlene Jones

Jack and Judith Johnson

Leonard and Linda Sonterre

Vernon and Ruth Lunzer

Oren and Karen Quist

Staurt and Mary Ellen

Donna Spencer

Alan Gessner

Rev. Bruce and Norma Miller

Ralph and Marlys Swenson

Steve and Ann Wolff

Dolores and Amy Jacobson

Harold and Ruth Ziemann

Randall T. Jeans

Joan Sorensen

Robert and Lorraine Jacobson

Kathleen Brown

Charles and Rita Neslund

Nancy Krupa

Eldon and Penny Johnson

Marcia and Marvin Lindseth

In Memory of Norma Shull

Jo Renee Fine

In Memory of Patricia and Elfrieda Frank

Thomas and Diane Stadtmiller

In Memory of Toby Douglas

Steve and Jackie Stuckey


in honor
In Honor of Naomi Baresel

Daughters of Penelope Olympus Chapter 6

In Honor of Anita Freidenreich

Alicia Small

In Honor of Carie Ann

Hope Paige Design LLC

In Honor of Christina Deane

Leonard Deane Jr

William & Christine Albrecht

In Honor of Joann McPhail

Ralph & Barbara McKay

In Honor of Kim Giovannetti

Colleen Quigley

In Honor of Linda Zarzeczny

Stephen Barrington-Foote

In Honor of Yvette Gontkovsky

Yvonne Drum (Von Lee)

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


Sjögren's
SSF
syndrome
Foundation




SYLK® All-Natural Personal Lubricant

“Nothing Else Compares”

FDA Cleared - *safe and effective.*



30 Year Trusted Product
www.sylkusa.com



USE CODE “TMS” FOR 20% OFF!

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)



 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.

“Clinician’s Corner” continued from page 5 ▼

enlargement, or hematological problems. NSAIDs (non steroidal anti-inflammatory drugs) may be used for muscle and joint pain, but may exacerbate gastrointestinal symptoms such as gastritis or gastroesophageal reflux. Steroids may be used for the more severe complications, briefly due to their potential long-term side effects. Fluoride treatments may be used to help prevent dental decay.

My advice to patients is to be frank and open with your physician. Tell him or her your symptoms so that he or she may best be able to adjust your treatment. Make a list of questions ahead of time so as not to forget items that are of particular concern. Be aware that the source of information you use may be critical in terms of your understanding of your treatment. The SSF is an excellent source and there are many resources on its website www.sjogrens.org. The FDA no longer

helps us (as physicians) to treat patients and often demands that the pharmaceutical industry include data on advertisements or drug information sheets that can be very confusing for patients. For example, I was one of the principal investigators for the cevimeline trials. When my patients pick up cevimeline at the pharmacy, they get a long list of adverse events to watch for, including diarrhea. I point out to patients that 10.8% of the patients on cevimeline on the one year clinical trial had diarrhea. This may seem like a high number, but 10.8% of patients from the placebo group also had diarrhea. When I prescribe cevimeline I do not advise patients to watch for diarrhea, as it is not an adverse event from the drug, increased risk of sweatiness is. The best source of information about what to expect from the therapy that is being initiated, both benefits and risks, is the physician who is prescribing it for you and the resources available to you through the SSF. ■

“10 Reasons” *continued from page 6* ▼

enjoy.

5. I may not have the energy to listen/talk to you. I may seem unfriendly, but please understand that sometimes, I just don't have the energy to be fully engaged in conversation. In addition, my vocal cords may be affected by RA, and a study has shown that hearing loss can be a side-effect of some pain relievers.
6. If I seem forgetful, it could be from the side-effects of RA, and not necessarily due to lack of attention, or intention. The stress of living with RA can impact one's memory. Lack of sleep, chronic pain, and drug side-effects can erase what I store in my memory vault.
7. If my weight seems to have changed, either up or down, it could be because of the side effects of medications. For example, corticosteroids can increase hunger and result in belly fat, and a condition known as “moon face,” where the face becomes puffy. Please, as much as you'd like to comment on this (especially if it appears I've lost weight), refrain from commenting on my body. It's a good practice in general to be body sensitive and not comment on other people's body shapes, but in this case, it brings up painful reminders for me of my struggle with my weight around RA.
8. If my hair is thinning, or I seem to have hair growing in unusual places that could be related to the medication I am taking to manage my RA.
9. When I wear unfashionable shoes, it's not a matter of choice, but out of necessity. While I would love to wear the latest styles in footwear, the agony is not worth it. When I wear comfortable, supportive shoes, I can walk farther, possibly with less pain.
10. I'm doing the best I can while living with a chronic, debilitating disease. I may seem selfish, but I need to look after myself if I wish to travel the long road with this unwanted “companion.”

There will be times when I will need to say “no” in order look after as many aspects of my health and wellness as possible. Please don't judge me when I do. Please ask me why, and we can talk about this chronic condition so we can learn more together about RA. ■

“10 Reasons Not to Judge Me” originally appeared on HealthCentral.com ©Remedy Health Media 2017

continued page 14 ▼

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 and supporters in our online community:

smartpatients.com/ssf





THIS IS SJÖGREN'S

As many as **4 MILLION AMERICANS** have Sjögren's with an estimated **2.5 MILLION PATIENTS** currently undiagnosed

9 OUT OF 10 Sjögren's patients ARE WOMEN



It now takes an average of **3 YEARS** to receive a SJÖGREN'S DIAGNOSIS



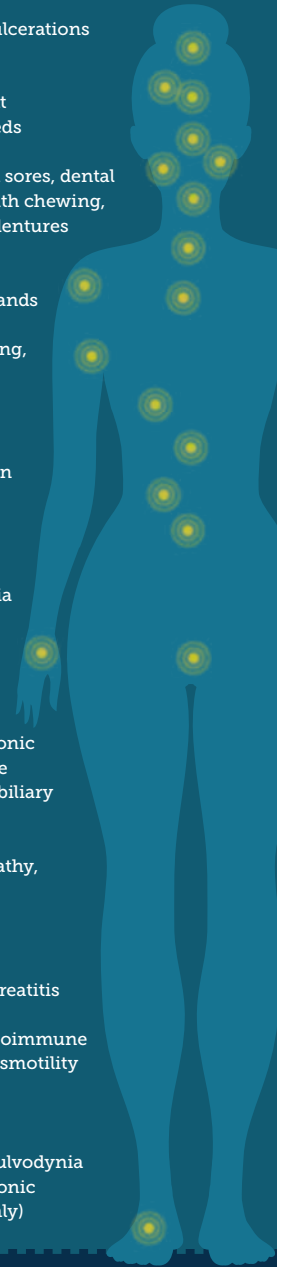
The average age of Sjögren's diagnosis is **40 YEARS** It can occur in all age groups



Frequency appears to INCREASE WITH AGE

Sjögren's ("SHOW-grins") is a systemic autoimmune disease that affects the entire body.

- Neurological problems, concentration/memory-loss, dysautonomia, headaches
- Dry eyes, corneal ulcerations and infections
- Dry nose, recurrent sinusitis, nose bleeds
- Dry mouth, mouth sores, dental decay, difficulty with chewing, speech, taste and dentures
- Swollen, painful parotid/salivary glands
- Difficulty swallowing, heartburn, reflux, esophagitis
- Fatigue, vasculitis, lymphoma, dry skin
- Recurrent bronchitis, interstitial lung disease, pneumonia
- Arthritis, muscle pain
- Abnormal liver function tests, chronic active autoimmune hepatitis, primary biliary cholangitis
- Peripheral neuropathy, Raynaud's
- Stomach upset, gastroparesis, autoimmune pancreatitis
- Irritable bowel, autoimmune gastrointestinal dysmotility
- Interstitial cystitis
- Vaginal dryness, vulvodynia (women only); chronic prostatitis (men only)



LEARN MORE sjogrens.org

“10 Reasons” continued from page 12 ▼



About the Author




Marianna Paulson, aka Auntie Stress, has had rheumatoid arthritis for 40 years. It has taken her on a journey of many career and health changes. Along the way, she has learned to adapt and adopt to a better way of living, much of which she shares on her two blogs, Auntie Stress Café (Healthline’s Best Stress Relief Blogs of 2017), and A Rheumful of Tips. She combines her education background with her life experiences when she works with clients to help them transform their stress. She is honored to work with clients of all ages (she’s had 5 to 87 year old clients), and enjoys cheering them on to feeling better emotionally, mentally, physically, and/or spiritually.

Missed the 2017 National Patient Conference?

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

Audio CDs of the most popular talks from our 2017 National Patient Conference in Philadelphia/Cherry Hill will be available soon.



NeutraSal® is a prescription strength oral rinse for dry mouth that has been proven to help improve a range of painful dry mouth symptoms, such as

- Difficulty eating, drinking, and swallowing
- Ability to speak
- Sore tongue and taste disorders
- Burning or stinging sensations in the throat
- Difficulty wearing dentures

Its supersaturated calcium phosphate formulation mimics your natural saliva to help repair and protect oral tissues, reduce bacteria levels to help prevent cavities, and help restore a healthy mouth.

NeutraSal® is easy to use 2 to 10 times a day, as needed, with single-use packets that dissolve in water. It has no added flavors, no anticipated side effects, and no known interactions with medicinal or other products.

For more information, visit www.neutrasal.com.

NeutraSal® is a registered trademark of Valeant Pharmaceuticals International, Inc., or its affiliates. ©OraPharma, Inc. 2016 OH/NSL/15/0026 1/16



Tips for Airline Travelers with Sjögren's

You should always know the latest travel rules before packing for your next airline trip!

As an invited member of the Transportation Safety Administration (TSA) Disability and Disease Coalition, the Sjögren's Syndrome Foundation has been fortunate to play an important role in educating officials about the special needs of Sjögren's patients. TSA policies apply to all domestic and international flights originating in the U.S.

TSA Guidelines and Tips for Travel

- You may place in a separate pouch all prescription and medically necessary OTC items to take with you on the plane.
 - Include all OTC items needed on your trip including eye drop; saline solutions; ointments; gels and lozenges to lubricate the eyes, mouth, nose or lips; gum; special toothpastes and sunscreen.
 - Medications in daily dosage containers are allowed.
 - While the TSA states that items do not need to be labeled, consider using original prescription bottles and packaging when possible to avoid questions.
 - You no longer need to have a doctor's note or prescription or information explaining why you need your items.
 - Pack medically necessary products in a clear bag separate from other carry-on items to make inspection easier and faster. X-rays will not damage medications.
 - The bag or pouch containing these items may be of any size.
 - Either place the bag to be X-rayed or request a visual inspection if you prefer.
 - In addition to a bag with medicines and medical products, you are allowed a single, one-quart, clear zip-lock bag with any liquid, gel or aerosol in containers marked three-ounces or smaller and placed separately on the conveyor belt for X-ray screening.
 - The TSA states that you may bring water or other liquid through security if your medical condition requires it. You must, however, declare the liquid to a Transportation Security Officer and be prepared to provide information from you or your physician about your condition and why you need it. Allow plenty of time for additional questioning and testing.
 - Wait to purchase water if at all possible after you've gone through security. Or, bring an empty water bottle, and when you board, ask the flight attendant to fill it or ask for a bottle of the airline's water.
 - Bring sugar-free candies, lozenges, gum and/or juicy fruit on board to stay moist. Foods in original containers are allowed through security and on the plane.
 - Use nasal saline a couple of days before flying and on the plane.
 - If you take Salagen® or Evoxac®, ask your doctor about taking it before boarding.
 - Carry a wet washcloth in a zip lock bag to place on your eyes or use special humidifying goggles such as Tranquileyes™ (an airline attendant can provide hot water). Bring moisture chamber glasses if you have them.
 - If taking an immunosuppressant, consider wearing a mask over your nose and mouth.
 - Always check out the latest information at www.tsa.gov, or call your airlines before traveling – especially if you are traveling internationally.
- The service, TSA Cares, is available specifically to help travelers with medical conditions and disabilities. Contact their office 72 hours ahead of your scheduled travel for answers to your questions. Call the TSA Cares Help Line at 855-787-2227, email TSA-ContactCenter@tsa.dhs.gov, or visit their site online at www.tsa.gov/travel/passenger-support. ■



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



2017 SSF Event Calendar

MAY

Saturday, May 20, 2017
 Northeast Ohio Walkabout, Parma, OH

Wednesday, May 24, 2017
 New York Sip for Sjögren's, NYC

JUNE

Saturday, June 3, 2017
 Dallas Walkabout

Saturday, June 3, 2017
 Denver Walkabout

Saturday, June 10, 2017
 Greater Washington Walkabout

Thursday, June 22, 2017
 Triangle Sips for Sjögren's, Raleigh, NC

If there is already an event in your area and you would like to get involved, or if there is not an event in your area and you would like to learn about starting one, please visit www.sjogrens.org or contact us at (301) 530-4420 x207



NEW Walk Prizes!



60" x 30" Towel

Sjögren's Walkabout T-shirt



Sjögren's Baseball Cap

