

Pulmonary Complications with Sjögren's

Overview of the respiratory system and how Sjögren's can disturb it

Omar Zaki, MD, Research Trainee, Mayo Clinic Florida

Augustine Lee, MD, Chair, Division of Pulmonary, Allergy, and Sleep Medicine, Mayo Clinic Florida

Sjögren's has been associated with a multitude of respiratory conditions and can affect every "compartment" of the respiratory system. The fundamental function of the respiratory system is to allow absorption of oxygen from the atmosphere and to eliminate carbon dioxide, which is a waste product of metabolism. For this to happen, air must traverse the mouth and nose, down the main windpipe called the trachea, and then divide and branch over 20 times, down the bronchi (large and medium sized airways), the bronchioles (the small airways numbering around 30,000), then finally carry air to the alveoli ("air sacs" numbering over 450 million). The alveoli

[continued page 2 ▼](#)

Patients Sharing with Patients

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

The best advice often comes from patients and we want to thank you for your openness and willingness to share. Below are your "best tips" for living with Sjögren's.

Listen to your body and be aware of how it's feeling every day. – Vivian K.

Compression gloves! Pain has always been my most difficult symptom and I find my hands are where I have the most pain. More often than not, I find comfort when wearing the gloves. I often only wear them in the morning until my joints wake up. – Katherine D.

[continued page 6 ▼](#)





Founded by
Elaine K. Harris in 1983

Board of Directors

Chairman of the Board

Janet E. Church

Chairman-Elect

Kathy L. Sivils, PhD

Treasurer

Monica McGill, EdD

Secretary

Tricia Gooding

Immediate Past Chairman

Stephen Cohen, OD

Esen K. Akpek, MD

Susan Barajas

Patricia Hurley, MSc

Cathy Ingels

Chadwick Johr, MD

Theresa Lawrence Ford, MD

Scott Lieberman, MD

Cynthia Lopynski

Jonathan Morse, MSc

Jason Nichols, OD

Timothy Niewold, MD, FACP

Thomas D. Sutton

Donald E. Thomas, MD

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

Senior Director of Marketing/Editor

Elizabeth Trocchio

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

“Pulmonary” continued from page 1 ▼

are covered with a fine network of blood vessels (capillaries) that will pick up the oxygen, which is separated from the air by a very thin “interstitial” space where the gases must cross. The blood or vasculature system that courses through the lungs to deliver waste gas and pick up oxygen is referred to as the pulmonary arteries, which themselves branch into small fine vessels (capillaries) and is carried away by the pulmonary veins. Outside the lungs, there is a space called the pleural space which is the space between the lungs and the chest wall where the lungs can inflate and deflate with minimal resistance. The diaphragm muscles, situated below the lungs, are the main bellows that lead to this cyclical inflation and emptying of the lungs.

Sjögren's has been associated with disease in every compartment of the respiratory system described above. Starting again from above the windpipe, you can have easy collapsibility of the airways that can predispose you to obstructive sleep apnea, which appears to be more common in patients with Sjögren's. Treating this may lead to improvement in symptoms of excessive drowsiness and fatigue.

Next, the trachea and some of the larger bronchi coming from the mouth can be dried and inflamed, much like the dryness that can affect the mouth and eyes of patients with Sjögren's. This is referred to as xerotrachea and the primary symptom is a chronic nonproductive cough. There is no practical diagnostic test for this, rather it is a diagnosis of exclusion of other conditions; including non-respiratory causes such as gastroesophageal reflux disease, which is also more common in patients with Sjögren's. Agents to stimulate saliva or promote hydration of the airways are often tried with variable response. Cough suppressive medicines that reduce the cough nerve reflex (e.g. gabapentin) may be necessary in refractory debilitating cases.

Asthma and chronic obstructive pulmonary disease (COPD, typically seen as a consequence of smoking) also are considered airway disorders that appear to be more common in patients with Sjögren's. They are considered under the category of “obstructive lung diseases” that are easily confirmed by pulmonary function testing (PFT) that measures the flow of air in and out of your lungs and estimates your lung capacities. Treatment for this is like other patients with COPD and asthma, typically utilizing inhalers as first line therapies.

As the airways branch even further, the medium sized bronchi can get damaged, and a CT scan may reveal a condition called bronchi-

The Moisture Seekers® Newsletter is published by the Sjögren's Syndrome Foundation Inc.,
10701 Parkridge Boulevard, Suite 170, Reston, VA 20191.

Copyright ©2019 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.

ectasis, which literally means dilated airways. This is usually associated with a productive cough, and can lead to an increased risk of infections, including pneumonias. Treatment strategy employs “bronchial hygiene” measures to promote clearance of mucus and secretions that these damaged airways can no longer clear naturally. Other treatment options may include chronic antibiotics. Prevention strategies such as with immunizations are important.

As the airways branch further into the small airways, bronchiolitis with inflammation or scarring or plugging of these tiny microscopic airways may dramatically impede the ability of air to flow towards and away from the alveoli. In Sjögren’s, this may be specifically due to a condition called follicular bronchiolitis, where inflammation lining these small airways is similar to that seen in the salivary glands affected by Sjögren’s. Treatment is challenging, but corticosteroids and other immunomodulators are often tried.

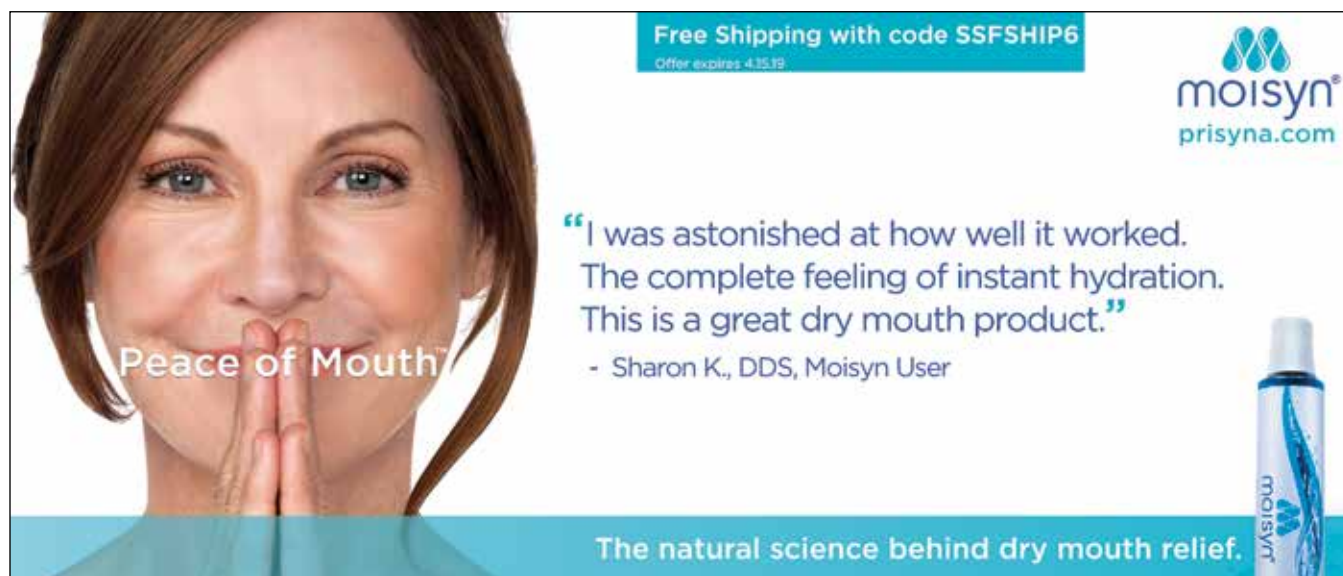
Once we are at the alveolar level, the most dreaded complication is probably interstitial lung disease (ILD), where the fine layer between the air and the blood vessel is thickened from scarring and/or inflammation. This typically limits the expansion of the lungs and is thus classified as among the causes of “restrictive lung diseases” as can be confirmed on pulmonary function testing. A high-resolution CT scan is necessary to confirm this, and a biopsy is sometimes necessary to identify the specific type if there remains uncertainty

on the diagnosis or on the management strategy. ILDs can result from many other conditions and not just Sjögren’s, and there are multiple patterns of damage that has been described. Examples include nonspecific interstitial pneumonia (NSIP), lymphocytic interstitial pneumonia (LIP), and usual interstitial pneumonia (UIP). Notably, idiopathic pulmonary fibrosis (IPF), which has a much worse prognosis, is not the same as having ILD related to Sjögren’s. Although there are now FDA-approved drugs for IPF, it is not yet known whether these new agents will help also in Sjögren’s-ILD. Currently, treatments for progressive or severe lung disease require steroids and/or immunomodulator therapies. An important understated therapy, and often to the patient’s resistance, is the role of oxygen therapy.

Also, at the alveolar level, multiple other processes may be seen including organizing pneumonia (noninfectious pneumonia that can respond to steroids), amyloidosis (deposition of abnormal proteins), cysts (holes in the lung), as well as lymphomas (a type of tumor) which fortunately is the most common variant called mucosa-associated lymphoid tissue (MALT), which tends to have a non-aggressive course.

At the blood vessel level, the main concern is for a condition called pulmonary arterial hypertension (PAH). Like systemic hypertension, there is an increase in the blood pressure, but here it’s an increase in blood pressure in the blood vessels in

continued page 4 ▼



Free Shipping with code SSFSHIP6
Offer expires 4.30.19

moisyn®
prisyna.com

Peace of Mouth™

“I was astonished at how well it worked. The complete feeling of instant hydration. This is a great dry mouth product.”
- Sharon K., DDS, Moisynt User

The natural science behind dry mouth relief.

“Pulmonary” *continued from page 3 ▼*

the lungs. This can lead to hypoxia (low oxygen) and heart failure. This can be screened for by an echocardiogram (ultrasound of the heart), but a right heart catheterization (also called pulmonary artery catheterization) is required to definitively confirm its presence. Fortunately, there have been significant advances in therapy for this condition, as it occurs commonly with other rheumatologic conditions as well, but again, oxygen should not be underutilized as low oxygen levels can aggravate PAH. Other noteworthy vascular complications include a higher risk for development of venous blood clots in the legs and lungs that can cause more acute shortness of breath and chest pain. This is always considered life-threatening and should prompt immediate evaluation and treatment if confirmed.

As noted above, there are a variety of tests to evaluate your respiratory system. The PFT helps to measure your lung capacities and can sort out any abnormality as “obstructive” or “restrictive” in nature. As part of complete pulmonary function testing, diffusing capacity is also measured, which assesses how easily oxygen can be picked up by your circulation; as well as measurement of your oxygen levels using a pulse oximeter that should be checked both at rest and with exercise or activity. The lungs can be imaged in a variety of ways, but the best way is a high-resolution CT scan of the chest for most of the conditions that Sjögren’s has been associated with. Your doctor or the radiologist may want to do some additional maneuvers as part of the CT scan to tease out the different possibilities. For example, intravenous contrast may be needed, or imaging the lungs on your tummy (normally done on your back), or during complete exhalation or emptying of your lungs (normally done after a full breath in). An echocardiogram will be necessary when evaluating for and monitoring PAH, but as noted earlier,

a right heart catheterization is always necessary if treatment is to be considered.

Other, more invasive, procedures may be required occasionally. Bronchoscopy is a technique using an “endoscope” or a camera on a tube to go into your lungs through your mouth or nose. With this, your doctor can do a bronchoalveolar lavage (BAL) to evaluate for infection, hemorrhage (bleeding), or specific types of inflammation. A biopsy of both the lungs and the lymph nodes can also be performed using the bronchoscope,

sometimes with the aid of an ultrasound probe, but the samples are often too small to be fully confident on any abnormality that is being chased. Occasionally, a surgeon is required to go into the chest cavity, between the ribs, via a technique called video

assisted thoracoscopy (VAT), to get more substantial biopsies. These techniques are particularly important when concern for a tumor is present such as a lymphoma, but also sometimes are required to manage some of the other complications such as the ILDs.

In summary, Sjögren’s has been associated with multiple flavors of lung disease, affecting every aspect of the respiratory system. Depending on the reports, the most common manifestations include the ILDs and the airway disorders (bronchiectasis, bronchiolitis, small airways disease). Although 20-50% of patients with Sjögren’s will have respiratory symptoms (shortness of breath, cough), some patients at mild stages of disease may have no symptoms. Treatment is directed by the specific type of respiratory dysfunction identified, but rigorous scientific studies are lacking in terms of best management and treatment strategies. The management of respiratory complications of Sjögren’s thus requires a multi-disciplinary effort with close collaboration between the rheumatologist and the pulmonologist, and often also a chest radiologist and chest pathologist. ■

SSF Clinical Practice Guidelines: Pulmonary Complications & Sjögren’s

The Foundation is currently working on phase 2 of the SSF Rheumatology and Oral Clinical Practice Guidelines. These guidelines focus on pulmonary complications as well as dental caries, lymphoma, neuropathies and vasculitis.



You Stood Up!

We run for all Sjögren's patients

On December 14th, the Sjögren's Syndrome Foundation (SSF) lost a good friend and patient volunteer, Karen Caron from New Hampshire. Karen, 51, passed away at Massachusetts General Hospital in Boston, MA after a brief illness caused by pneumonia complicated from her Sjögren's.

Karen was an active SSF member who repeatedly stepped up to run as a part of the *Team Sjögren's* marathon training program with her daughter Sara. The mother-daughter duo ran in the *Team Sjögren's* Disney World®, *Team Sjögren's* Disneyland® and *Team Sjögren's* Nashville races. Raising thousands of dollars for the Foundation and educating her family and along the way, Karen accomplished all of this with a smile on her face.

Karen's bright life is one more reminder of why the SSF's work is vital to helping all patients living with this complex disease and why *Team Sjögren's* runs! Karen is survived by her husband Bob and their three children, Adam, Sara and Anna.

The Caron's are continuing Karen's legacy by supporting Sara in her fourth *Team Sjögren's* race, when she will be heading to New Orleans on February 10th. Sara will be joining with 24 other runners as she and the team are dedicating this run to her mother and all patients living with the disease.

If you would like to learn more about our *Team Sjögren's* New Orleans runners and why they run, please visit: www.firstgiving.com/event/SSF/TS-NOLA ■

"We Run in Honor of the 4 Million Americans with Sjögren's... We Are Team Sjögren's!"



*Karen Caron (center)
November 21, 1967 –
December 14, 2018*



Sjögren's Syndrome Foundation Vision:

Creating a community where patients, healthcare professionals and researchers come together to conquer the complexities of Sjögren's

"Patients Sharing" continued from page 1 ▼

It can be difficult to wear any makeup with dry eye, but it helps to apply mascara from the tips rather than the roots of the lashes. – Sarah M.

Be an advocate for yourself! – Kelly I.

Educate close friends and family about Sjögren's and tell them how you're doing on bad days and what you need. It's ok to feel down but you have to pick yourself back up. – Myla H.

I recommend starting and maintaining a mild/ moderate exercise program. I began one six months ago and am feeling much better as a result. – Richard E.

Stay hydrated and informed! My doctors and I couldn't figure out why I kept producing kidney stones until I read the Sjögren's Handbook. – Kathy M.

["Sjögren's patients who have kidney involvement may present with symptoms of muscle weakness as a result of an electrolyte imbalance known as hypokalemia (low potassium). This electrolyte imbalance may also lead to the development of kidney stones, which often present with symptoms of renal colic. Renal colic is a recurrent, sharp back pain in the area of the kidney." – Sjögren's Handbook]

Playing puzzles and word games help me with stress and brain fog. – JoAnn W.

Learn to be in acceptance of your condition and know your limits. Trying to do too much can cause a disease flare. – Joe B.

For dry eye, I use EyeEco wrap around glasses. Air and wind, which is irritating, is virtually not a problem anymore. – Marilyn K.

Be kind and forgiving to yourself. It's ok to say no. – Diana C.

I struggle with burning tongue and extreme dry mouth. I used to choke when swallowing food but found that drinking 1% milk with each food bite helps. It works better than water. – Nancy B.

Get to know others with Sjögren's. It's nice to have reinforcement that we are not alone. – Kathy M.

Join Our Online Patient Community

The SSF and Smart Patients have partnered to create an online Sjögren's community. Patients and their caregivers can join the community for free to share, interact and learn from each other in a safe, supportive environment.

We encourage you to learn more about the SSF Smart Patients Sjögren's community by visiting: www.smartpatients.com/partners/ssf. ■

SSF in Action!



Interagency Pain Research
Coordinating Committee



"This is an exciting time to be involved at the forefront of discussions on pain. I attended my first in-person IPRCC meeting in November and was deeply impressed with the incredibly dynamic administrative team and committee membership that has delved into a complicated and burdensome issue to come up with potential strategies that hopefully will make a profound difference in the way pain is managed and treated."



Kathy Hammitt

*SSF Vice President
of Medical and
Scientific Affairs*

The Sjögren's Syndrome Foundation (SSF) has joined with a special government-led interagency consortium to tackle the growing issue of chronic pain in our country. Sjögren's patients cited pain as a prominent and debilitating symptom in the SSF National Patient Survey executed in 2016 by Harris Poll, so when SSF Vice President of Medical and Scientific Affairs, Kathy Hammitt, was invited to join a nationwide initiative whose charge is to address the problem of chronic pain, she jumped at the opportunity to represent Sjögren's patients. Her 3-year term on the Interagency Pain Research Coordinating Committee (IPRCC) began in late 2018, with Hammitt contributing both as a Sjögren's patient as well as a representative of those who suffer from pain brought on by their Sjögren's.

The SSF understands the need for answers to chronic pain! For Sjögren's patients, pain can occur as part of musculoskeletal inflammation; peripheral nervous system involvement (peripheral neuropathies); oral pain from mucosal ulceration, infection, and dental decay; pain that results from dryness anywhere in the body, whether in the mouth, larynx and throat, eyes, sinuses and nasal cavity, skin, or genitals; and, less frequently, central nervous system involvement that can lead to headache pain.

Pain is a concept that is broad-reaching and encompasses many causes and manifestations, making it a complex topic to address. The IPRCC has developed a multi-angled approach, including

SSF EVENT CALENDAR

FEBRUARY

Team Sjögren's New Orleans

Sunday, February 10, 2019

Phoenix Walk for Sjögren's

Saturday, February 23, 2019

Paradise Valley Mall



APRIL

2019 SSF National Patient Conference

April 5–6, 2019

Hilton Boston/Woburn

Boston Walk for Sjögren's at the 2019 SSF National Patient Conference

Saturday, April 6, 2019

Hilton Boston/Woburn

Tastefully Georgia

Sunday, April 28, 2019

Nelson Mullins – Atlantic Station

NPC 2019



MAY

Philadelphia Walk for Sjögren's

Saturday, May 4, 2019

Philadelphia Zoo

JUNE

Denver Walk for Sjögren's

Saturday, June 8, 2019

Hudson Gardens



To learn more about SSF events, please visit www.sjogrens.org or contact Jessica Levy at (301) 530-4420 ext. 218 or email jlevy@sjogrens.org.



Why I Walk

by Susan Barajas, Sjögren's patient

Are you looking for an opportunity to be more involved in the Sjögren's community?

Do you want to help educate your family and friends about Sjögren's, while raising crucial funds for the Sjögren's Syndrome Foundation (SSF)?

If you're like me, then a walk for Sjögren's may be just the thing you are looking for!

My own involvement with the Foundation began when I was diagnosed with Sjögren's in 2015. In my search for more information about the disease, I found an organization staffed with amazing people dedicated to patients, their families, and friends. I quickly knew that I wanted to be a part of this Sjögren's community. I now volunteer whenever I have the chance.

One opportunity came last summer when the SSF hosted its first Los Angeles Area Walk for Sjögren's. I volunteered to chair the event and worked closely with local volunteers and SSF staff. The walk was a success! We had over 100 people in attendance and raised over \$11,000.

Walk for Sjögren's are wonderful events with music, vendors, prizes and "Ask the Expert" sessions, where attendees can interact with doctors. I think one of the greatest benefits is the opportunity to meet others living with the disease because it's easy to feel isolated as a Sjögren's patient. Having friends and family there to honor and thank for their support is a special moment as well. It is truly a positive and uplifting event.

If this appeals to you, please consider volunteering at a walk in your area or consider starting a walk yourself! You can help a little or help a lot –

it's your choice. Some of the things the committee does is make phone calls, distribute flyers, find local sponsors and recruit family and friends to participate on walk day.

By participating in a walk, I guarantee you will get more in return than you give – meeting new people, sharing the experience with those important to you, and a chance to give back to both the SSF and the Sjögren's community. Plus, you get the satisfaction of helping raise the crucial funds needed for the SSF to continue its important work.

To learn more about Walk for Sjögren's events, please contact Jessica Levy at (301) 530-4420 ext. 218 or email jlevy@sjogrens.org. ■



“SSF in Action” *continued from page 7 ▼*

information-gathering on kinds and causes of pain, understanding how acute pain becomes chronic pain, determining priorities for future research, and ensuring funding from federal agencies is available for research studies that aim to better understand and address pain. Developing better screening tools and methods to measure pain are also part of the IPRCC mission. Pain is usually measured subjectively, which is not always consistent or accurate. Measurements that are reliable and validated are needed in order to conduct clinical trials for better therapies and other modes of intervention.

So far, the IPRCC has engaged in data-gathering, strategy development and priority setting. For example, the committee established a searchable

interagency pain research portfolio. It encourages collaboration among government institutions and the private and public sectors to ensure information is shared and that everyone joins forces together to tackle a massive and debilitating problem.

Chaired by Walter Koroshetz, MD, Director of the National Institute of Neurological Disorders and Stroke, National Institutes of Health (NIH), members include federal agency representatives; leading scientists whose research has focused on pain; and the public, the category for which Hammitt contributes to the committee on behalf of the SSF. As the committee moves forward, the SSF will keep its members updated. More information on the committee can be found at www.iprcc.nih.gov/. ■

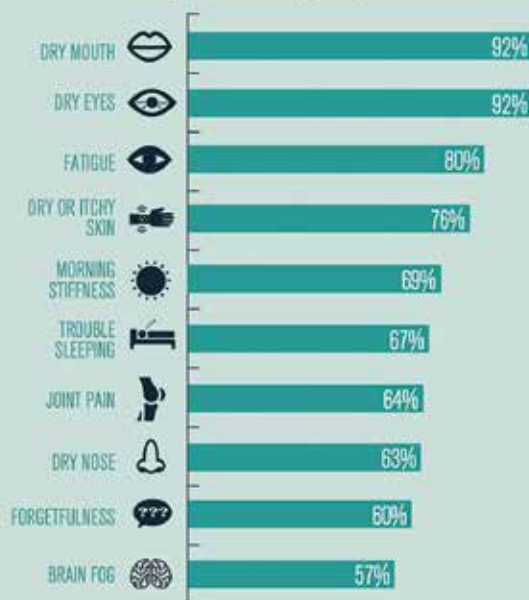
Most Common Symptoms Experienced

The vast majority of Sjögren's patients reported having experienced dry eyes (97%), dry mouth (97%), fatigue (94%), dry or itchy skin (93%), trouble sleeping (91%) and forgetfulness (90%) over the last year. Most said that their dry mouth (92%), dry eyes (92%), and fatigue (80%) symptoms occurred almost weekly or more frequently.

Patients 60 years of age and under said they were more likely than patients over age 60 to experience brain fog (i.e., confusion, forgetfulness, and lack of focus and mental clarity) (66% vs. 53%) and joint pain (67% vs. 62%) almost weekly or more frequently. Patients over 60 years of age reported that they were more likely than patients 60 years of age and under to experience dry nose (65% vs. 59%) and photosensitivity (sunlight) (64% vs. 56%) almost weekly or more frequently.

Half of Sjögren's patients with severe dryness (53%) also have severe fatigue.

Common Symptoms Experienced Almost Weekly or More Frequently



Graphic from the SSF Living with Sjögren's survey. The survey administered in the United States by Harris Poll on behalf of the Sjögren's Syndrome Foundation between May 11 and July 11, 2016, was conducted among 2,962 adults aged 18+.



in memoriam

In Memory of Karen Caron

The Sweeney Family
Sue and Rich Wetherbee
Nicole, Steven and Hannah White
Angela Lavinski and Family
Debbie and Ed Sinamark
Paltrow-McCole Family
Whitcomb Family and Gloria
Missy and Kendal Joyce
Robert and Elaine Gingerella
Mark and Stephanie Summers
Paul and Beverly Demoorjian
Craig B Corson
Maurice and Manon Archambault
Paul Hebert
Ray M Cleland Memorial Fund
Edward and Jo Marie Lammy
The Flints, Windles and Grotes
Greg and Heather Proulx
David and Lina Fecteau

The Justic Family
Michele Champigny
The Rutherford Family
MLS PLC Team
Vicki and Joe Matheny

In Memory of My Mom, Nancy
Pam "Little Voice" Detrich
In Memory of Allen Rosa
Joanne Rosa
In Memory of Barbara Reilly
Executive Officers of MandT Bank in Villanova

In Memory of Carol W. McClain

Dave and Pat Stanton
In Memory of Gunnel Crummy

Solveig Sandell
Gun Landwehr

In Memory of Jan Gordon

Kevin McCaffrey

In Memory of Kim Sturm

Patricia Clark

In Memory of LaRue Horst

Carol Watson

In Memory of Lesley Schneider

Lisa and Steven Soontupe and Family

In Memory of Marie Vella

Luisa Scarselli

In Memory of Marlene Rhea Rideout

Isaac Eagan

Rosanna and Don Wellman

Sarah Caviness and Lil Galphin

In Memory of Pat

Living Trust of Laurence and Ann Brown

In Memory of Phyllis M "Sue" Smith

Monica Smith

In Memory of Rosaria "Sadie" Forte

Auntie Anna's Children and Families

Dennis Tzickas



in honor

In Honor of Nancy Poole

Ryan and Lisa Reeser

In Honor of Kim Wilkins

Jacobs Levy Equity Management

In Honor of Margaret Rothman

Gale and Bruce Stockman

In Honor of Linda and Dennis Howard

Martha Costa

In Honor of Annette Melucci

Dr. Elliot Rosenstein

In Honor of Paula Markowitz

Lee Markowitz

In Honor of Carol Hirashiki

Jennie Handy

In Honor of Pamela Burkart

Pauline Shinn

In Honor of Jeannie Bassman

Exclusive Events, Inc.

In Honor of Ken Sabotta

FlexPro Group LLC

In Honor of Sonja Ferry

April Ferry

In Honor of Nancy Visocki

Gail Berkoff

In Honor of Lari Lopp

Steve and Isabelle des Fontaines

In Honor of Joyce Granger

Mike and Ruthie Granger

In Honor of Mary Kendall

Your Daughter Kim Kendall

In Honor of Cathy Creedy

Alan "Papa" Creedy

In Honor of Jessica Levy

Peggy Beck

In Honor of Stefanie Campbell

Ellen "Mom" Campbell

In Honor of Catharine Claiborne

Kerry "Your Favorite Niece" Moore

In Honor of Nutritional Concepts

Paula Josephson

In Honor of Susan Paul-Souza

Rita Paul

In Honor of Andrew and Yvette Gontkovsky

Anita, Colette and Raymond Gontkovsky

In Honor of Kathryn Donnelly

Elvira "Vivie" Albert

In Honor of Elizabeth DiFilippo

Roseann Cordelli

In Honor of Stephen Cohen and Marcy Edwards

Steven Crystal

Karla Reynolds

In Honor of Bonnie Meyer

Joseph Meyer

In Honor of Jane Nelson

Ann Franke

In Honor of Sara Caron

The Rutherford Family

In Honor of Carolyn Kennedy

Marion Kennedy

In Honor of Margaret Voshell

Marcia Wood

In Honor of Gretchen Reeks

Mimi Skala

In Honor of Judy McDowell

Jocelyn M

In Honor of Lisa Stege

Terri Bass

In Honor of Connie Steen

Your Friends at NPP

In Honor of Laura Mancuso

Art and Marjorie Knapp

In Honor of Leah Economos

Heather Coker

In Honor of Xiomara Arango

Omaira Arango

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		
Drying My Tears: One Family's Journey with Autoimmunity by Liz Wilkey.	\$15	\$12		
Awareness Wristbands with the wording, "Conquering Sjögren's - www.sjogrens.org." Pack of 10	\$18	\$15		
SSF New/ Renewal Membership Includes 10 current issues of <i>The Moisture Seekers</i> newsletter and more benefits.	\$36	\$32		
<i>The Moisture Seekers</i> newsletter Volume 35, 2018 (10 issues) as originally published.	\$50	\$20		
<i>The Moisture Seekers</i> newsletter Volume 33, 2017 (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		
Shipping and Handling: US Mail: \$5 for first item + \$3 for each additional item Canada: \$25 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 _____

Conquering the Complexities of Sjögren's

April 5 – 6, 2019

Hilton

Boston / Woburn

2019 National Patient Conference



2019 NPC – Speakers and Topics

The Complexities of Sjögren's: An Overview

Theresa Lawrence Ford, MD, is a private practice rheumatologist at North Georgia Rheumatology Group in Lawrenceville, Georgia. Dr. Lawrence Ford has done research in the fields of lupus and rheumatoid arthritis and participates as an investigator in clinical trials for Sjögren's. She has been recognized in *Atlanta Magazine* annually as a Top Doctor in her field since 2005, and is a current SSF national board member where she serves as Chair of the Medical and Scientific Advisory Board, and Chair of the Clinical Trials Consortium. Dr. Lawrence Ford will present a comprehensive explanation of the range of symptoms and complications that Sjögren's patients experience, including internal organ involvement, dryness symptoms and treatment options.

Oral Manifestations of Sjögren's

Vidya Sankar, DMD, MHS, is Clinic Director of the Oral Medicine and Dentistry Clinic at Brigham and Women's Hospital and Co-Director of the Oral Medicine and Oncology Clinic at Dana Farber Cancer Institute in Boston, Massachusetts. She is also a current member of the SSF Medical and Scientific Advisory Board and past SSF national board member. Dr. Sankar will provide insights into how Sjögren's impacts your oral health including tooth decay as well as share with us information to help manage and minimize the effects of dry mouth issues.

The State of Sjögren's: Transforming the Future

Steven Taylor, SSF Chief Executive Officer

The Sjögren's Syndrome Foundation (SSF) has been continuously launching new patient and healthcare professional focused initiatives that are changing the direction of Sjögren's! Join with Steve as he shares updated information about Clinical Trials and Clinical Practice Guidelines as well as other projects on the horizon.

Fatigue and Sjögren's

Donald E. Thomas, Jr., MD, has a special interest in systemic autoimmune diseases, especially Sjögren's. He is in private practice in Maryland, but he also enjoys teaching health care providers about Sjögren's. He is a current national SSF board member and is passionate about empowering patients. Fatigue is one of the most prevalent and disabling symptoms of Sjögren's. Dr. Thomas will add to your understanding of the variety of causes and will offer tips to help you cope, manage and treat the problem.

Product Showcase

Sjögren's patients use a number of over-the-counter products to treat their various complications. This session will highlight the vast array of products that are available for Sjögren's patients.

Banquet Awards Dinner and Keynote Speaker

"Finding Your Voice"

Brad Lemack is a Los Angeles-based talent manager, public relations consultant, educator and author. He established his agency, Lemack & Company Talent Management/Public Relations, in 1982 after serving as a publicity executive for pioneering producer Norman Lear's television and film production company, where he worked on such now-classic television series as "The Jeffersons" and the original "One Day at a Time," among many others.

Brad is a strong advocate of lending one's talents and voice to move a greater agenda forward. His efforts and support over the decades have helped raise funds and awareness for many important movements. He is currently helping the Sjögren's Syndrome Foundation with the creation and production of a series of patient information and awareness videos for the Foundation.

In addition, join us for this inspirational evening as we present our National Awards to volunteers, groups and organizations that have helped to further the mission of the Sjögren's Syndrome Foundation.

Understanding Blood Changes and Lab Results

Alan N. Baer, MD, is Professor of Medicine and Director of the Jerome L. Greene Sjögren's Syndrome Center at Johns Hopkins University School of Medicine in Baltimore, Maryland. He is also an Associate Investigator in the Sjögren's Syndrome Clinic at the National Institutes of Health (NIH). Dr. Baer is engaged in clinical research studies in Sjögren's and takes part in the SSF's Clinical Trial Consortium. Dr. Baer will describe the blood changes typically associated with Sjögren's as well as help us understand the rationale and meaning of the tests ordered and procedures performed by physicians.

Living with Sjögren's: A Patient Panel

Join us as Janet E. Church, SSF Chair of the Board and a fellow Sjögren's patient, moderates an informative and lively patient panel about living with Sjögren's and its many manifestations and complications. Each of these individuals will share tips for living with Sjögren's and how to find your voice to help increase awareness. We know you will learn from the experiences and stories of each of our panelists.

Ocular Manifestations of Sjögren's

Michael H. Goldstein, MD, MM, is Co-Director, Cornea, External Disease and Cataract Service; Refractive Surgery Service; Uveitis & Immunology Service; and Assistant Professor, Tufts University School of Medicine. Additionally, Dr. Goldstein is the Co-Chair of the SSF's Ocular Clinical Practice Guidelines. Dr. Goldstein will describe the latest dry eye therapeutic treatments, covering the extensive range of options - from artificial tears to silicone plugs to systemic drugs that are available for managing the ocular complications of Sjögren's.

Nutrition, Wellness and Autoimmune Disease

Lauri Lang, RD, LDN, is a registered dietitian and licensed dietitian nutritionist based in Pittsburgh, Pennsylvania. She specializes in holistic nutrition and lifestyle strategies for health promotion and to help suppress inflammation in autoimmune conditions. In her private practice, Ms. Lang has counseled individuals of all ages and medical conditions who seek wellness through nutrition and lifestyle modifications. Ms. Lang will explain how different aspects of nutrition can impact your Sjögren's and share insights into making the best nutritional choices to maximize functioning and well-being.

Sjögren's Clinical Trials Update

Athena Papas, DMD, PhD, is the Erling Johansen Professor of Dental Research, and the Head of the Division of Oral Medicine at Tufts University School of Dental Medicine. Additionally, Dr. Papas is a member of the SSF Medical and Scientific Advisory Board and has led numerous clinical trials in Sjögren's. Dr. Papas has also worked tirelessly to encourage pharmaceutical companies to develop a systemic therapy for Sjögren's. Join us for Dr. Papas' informative presentation about how clinical trials add to our medical knowledge and, most importantly, how the result of these trials can make a difference in the care and treatment of Sjögren's patients.

How Sjögren's Can Impact the Central Nervous System

Edward A. Maitz, PhD, is a Diplomate in Clinical Neuropsychology and is also Board Certified in cognitive rehabilitation and biofeedback training. Dr. Maitz is in full time private practice in Pennsylvania and New Jersey. He has a special interest in Sjögren's and has published articles in the field, and is a member of the SSF Clinical Practice Guidelines Committee. Dr. Maitz understands the challenges that may impact patients with central nervous system complications and will share his vast knowledge, insights and strategies with you about the physical, cognitive ("brain fog"), and psychological manifestations of Sjögren's.

Conference Hours

Friday
12:30pm – 8:30pm

Saturday
8:30 am – 4:30pm

Space is limited. Please register early!

Registration Form

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



2019 NATIONAL PATIENT CONFERENCE

Hilton Boston/Woburn, Woburn, Massachusetts

April 5 – 6, 2019

1 ATTENDEE – complete for each registrant

Attendee Name(s) _____

Attendee Name(s) _____

Street Address _____

City _____ State _____ Zip _____

Telephone _____ E-mail _____

2 FEES – please circle appropriate fee(s) (Note: Early Bird Deadline is March 11, 2019)

SSF Members & Guests

Non-Members

March 11th and before

\$170 per person

\$190 per person

March 12th and after

\$190 per person

\$210 per person

TOTAL:

3 PAYMENT – Mail to SSF, c/o BB&T Bank • PO Box 890612 • Charlotte, NC 28289-0612 or Fax to: 301-530-4415

☐ 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 _____ CC Security Code _____

Signature _____

- Refund requests must be made in writing. Registrants whose written requests are received by March 11th will receive a 75% refund. After that time, we are sorry that no refunds can be made.
- Dietary Requests: Unfortunately, we cannot accommodate all special dietary requirements. We can accommodate vegetarian or gluten-free dietary requests.

☐ *I would like a vegetarian meal*
☐ *I would like a gluten-free meal*
- A limited number of rooms are available, on a first-come basis, at the Hilton Boston/Woburn hotel (2 Forbes Road, Woburn, Massachusetts 01801) at the SSF rate of \$129 per night plus tax if reservations are made by March 11, 2019. Call the Hilton Boston/Woburn hotel directly at (781) 932-0999 to make room reservations and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
(NOTE: The Hotel will require a deposit when you make your reservation. Please ask the Hotel about their cancellation policy.)
- The Hilton Boston/Woburn is approximately 12 miles from the Boston Logan International Airport.

QUESTIONS? Call 800-475-6473 or visit www.sjogrens.org

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



"Finding Your Voice"



National Patient Conference Keynote Speaker: Brad Lemack

The Sjögren's Syndrome Foundation is excited to welcome Brad Lemack as our 2019 National Patient Conference Keynote Speaker during the Banquet Awards Dinner.

Brad is a Los Angeles-based talent manager, public relations consultant, educator and author. He established his agency, Lemack & Company Talent Management/Public Relations, in 1982 after serving as a publicity executive for pioneering producer Norman Lear's television and film production company, where he worked on such now-classic television series as "The Jeffersons" and the original "One Day at a Time," among many others.

Brad, a Sjögren's patient, is a strong advocate of lending one's talents and voice to move a greater agenda forward. His efforts and support over the decades have helped raise funds and awareness for many important movements. He is currently helping the SSF with the creation and production of a series of patient information and awareness videos for the Foundation.

In addition to Brad's presentation, join us for this inspirational evening as we present our National Awards to volunteers, groups and organizations that have helped to further the mission of the Sjögren's Syndrome Foundation. ■