

# Conquering the Complexities of Sjögren's

April 5 – 6, 2019

Hilton  
Boston / Woburn

2019 National Patient Conference





# Conquering Sjögren's Conference Schedule

Friday, April 5, 2019

**12:30pm Registration and Exhibit Area Opens**

**2:00pm Welcome and Opening Remarks**

Janet E. Church, SSF Chair of the Board

**2:20pm 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.

**3:20pm 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.

**4:00pm 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.

**4:40pm 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.

**5:00pm BREAK AND EXHIBITS**

**6:30pm 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, 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 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.

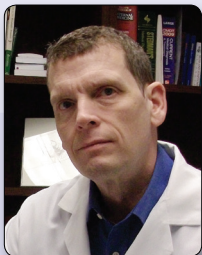


# Saturday, April 6, 2019

**8:30am Registration and Exhibit Area Opens**

**9:00am Opening Remarks**

**9:10am 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.

**9:50am 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.

**10:30am 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.

**11:10am WALK FOR SJÖGREN'S**



Participants are encouraged to join us for our national Walk for Sjögren's event – where patients and family members come together to celebrate their "Circle of Strength." You can walk, support, or cheer on your fellow friends as we take a stroll outside the hotel.

**12:15pm LUNCH AND EXHIBITS**

**1:15pm 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.

## Exhibit Area Hours

*Please visit our "Exhibit Area" and find new products and receive free samples!*

**Friday, April 5<sup>th</sup>**

Exhibits open from 12:30pm – 6:30pm

**Saturday, April 6<sup>th</sup>**

Exhibits open from 8:30am – 2:00pm



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### 1:55pm **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.

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### 2:35pm **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.

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### 3:15pm **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.

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### 3:55pm **Conference Recap and Closing Remarks**

Janet E. Church, SSF Chair of the Board  
Steven Taylor, SSF Chief Executive Officer

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### 4:15pm **Conference Adjourns**

## Please Join Us!

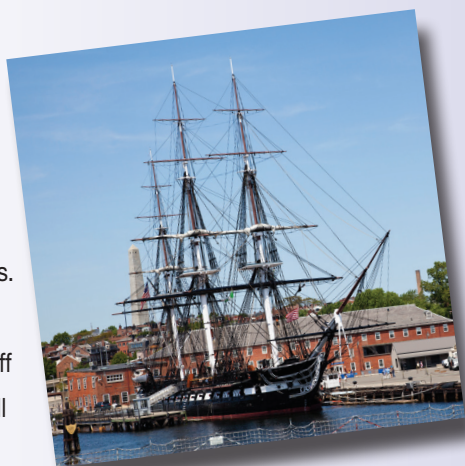
**T**his spring we invite you to join with fellow Sjögren's patients, their families, medical experts, and product exhibitors and attend our 2019 National Patient Conference, "Conquering the Complexities of Sjögren's."

Attending the SSF National Patient Conference is one way you can gain information from many different sources while also meeting fellow patients.

This year's Conference will include opportunities to:

- Learn from national Sjögren's experts, researchers and SSF staff
- Find new products and receive free samples in our exhibitor hall
- Share with your fellow patients
- Browse Sjögren's resources at the SSF Book Table

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.





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 11<sup>th</sup> and before

\$170 per person

\$190 per person

March 12<sup>th</sup> 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 11<sup>th</sup> 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](http://www.sjogrens.org)