

# 2020

National Patient  
CONFERENCE

## *“Coming Together to Conquer Sjögren’s”*

**April 3 – April 4, 2020**

Hyatt Regency Phoenix  
Phoenix, Arizona



# “Coming Together to Conquer Sjögren’s”

**Friday, April 3, 2020**

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

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

**Janet Church**

*Sjögren’s Foundation Chair of the Board*

**2:05pm Transforming the Future of Sjögren’s**



**Steven Taylor**

*Sjögren’s Foundation Chief Executive Officer*

The Sjögren’s Foundation continues to launch new patient, healthcare and research focused initiatives that are changing the direction of Sjögren’s! Join Steve as he shares updated information about clinical trials, clinical practice guidelines, international collaborations and much more.

**2:40pm Sjögren’s: An Overview**



Nancy Carteron, MD, is a San Francisco area rheumatologist with a long-standing interest in Sjögren’s, beginning with co-authoring a book, *A Body Out of Balance*, with a Sjögren’s patient. Recently, Dr. Carteron has joined the University of California, Berkeley, School of Optometry, to collaborate with dry eye and oral medicine specialists to advise Sjögren’s patients. Additionally, she is the

medical and scientific editor for *Sjögren’s Quarterly* and Rheumatology Chair for the Sjögren’s Foundation Clinical Practice Guidelines initiative. Dr. Carteron will present a comprehensive explanation of the range of symptoms that Sjögren’s patients experience, explain their causes, and offer treatment options and practical tips for managing them.

**3:40pm Sjögren’s and Dry Eyes: What’s New?**



Stephen Cohen, OD, a private practice optometrist in Scottsdale, Arizona, will describe the latest dry eye therapeutic treatments, covering the extensive range of options for managing your ocular complications of Sjögren’s. Dr. Cohen is the Immediate Past Chair of the Sjögren’s Foundation Board of Directors and Past-President of

the Arizona Optometric Association. Additionally, he has been a principal investigator on a number of FDA clinical studies and is one of 100 doctors worldwide to work on the “DEWS II” program to update the diagnosis and treatment of ocular surface disease.

**4:20pm Oral Manifestations of Sjögren’s**



Ava J. Wu, DDS, is a Clinical Professor at the Department of Orofacial Sciences, School of Dentistry, University of California, San Francisco, where she is Director of the Sjögren’s Syndrome Clinic. Dr. Wu’s presentation will provide insights into how Sjögren’s impacts your oral health as well as information to help manage and minimize the effects of

issues related to dry mouth. After seeing thousands of patients in her career, Dr. Wu will deliver the answers that you have been waiting to hear.

**5:00pm BREAK AND EXHIBITS**

**6:30pm BANQUET AWARDS DINNER**

**Keynote Address by Joy H. Selak, PhD**



Joy Hubbard Selak is a published author and experienced public speaker. In the mid-1990’s, while living on San Juan Island, Washington, Joy was diagnosed with several overlapping chronic illnesses and had to leave her career in finance. As she slowly regained her health, Joy, with her physician, wrote her first book *You Don’t LOOK Sick! Living Well with Invisible*

*Chronic Illness*, a guide to help others build meaningful lives that contain long-term illness.

We are delighted to have Joy Hubbard Selak as our 2020 Keynote Speaker – you won’t want to miss this insightful, warmhearted and inspirational presentation!

In addition, join us as we present our national awards to volunteers, groups, and organizations that have helped to further the mission of the Sjögren’s Foundation.





## Saturday, April 4, 2020

8:30am Registration and Exhibit Area Opens

9:00am Opening Remarks

9:10am Integrative Medicine: A Role for Treatment in Sjögren's



William Mitchell, ND, is a naturopathic physician specializing in rheumatology and works with patients with various autoimmune diseases. Dr. Mitchell is a proponent of "integrative medicine" and works alongside rheumatology specialists in Gilbert and Scottsdale, Arizona. His special interests include systemic lupus erythematosus, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and fibromyalgia. We know you won't want to miss this presentation as you will learn about alternative treatment approaches coupled with information on traditional therapies.

9:50am Pediatric Sjögren's



Scott M. Lieberman, MD, PhD, is a pediatric rheumatologist with the University of Iowa Stead Family Children's Hospital and Associate Professor of Pediatrics (with tenure), Carver College of Medicine, University of Iowa. Dr. Lieberman's research lab studies the role of T lymphocytes in the initiation of lacrimal and salivary gland autoimmunity in the context of Sjögren's. He is also heavily involved in an international effort to better define childhood Sjögren's. Dr. Lieberman will discuss aspects of childhood Sjögren's to highlight clinical manifestations, diagnosis, and the need for greater awareness that children get Sjögren's, too.

10:30am "Ask the Doctor" Panel

Moderated by: **Steven Taylor**

Sjögren's Foundation Chief Executive Officer

Join us for this esteemed panel of Sjögren's experts, who will be answering your questions and offering suggestions on fatigue, joint pain, internal organ issues, and lymphoma. This informative session will be a conference highlight. Start thinking of your questions for the doctors now!

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 take part in the many fun-filled festivities and educational activities, create your Circle of Strength chain, and show your best pose at the photo booth – all of which will take place right inside the hotel!

12:15pm LUNCH AND EXHIBITS

1:15pm New Look! New Logo! Same Foundation!



**Janet Church,**  
*Sjögren's Foundation Chair of the Board*

**Ken Economou,**  
*Past Sjögren's Foundation Chair of the Board*

**Steven Taylor,**  
*Sjögren's Foundation Chief Executive Officer*

Join us for this special presentation where Steven Taylor and two lead volunteers, Janet Church and Ken Economou, will explain the future of the Foundation and exciting changes happening in 2020. They will share how dropping "syndrome" from the Foundation's name is the first step in changing how the disease is appreciated, treated, and researched. Same Foundation - with a renewed purpose of getting Sjögren's the respect it deserves!

1:55pm International Sjögren's Research Update



Kathy L. Sivils, PhD, is Director of the Oklahoma Sjögren's Center of Research Translation in Oklahoma City. She is Chair-Elect of the Foundation Board of Directors and serves on the Foundation's Clinical Trials Consortium. Dr. Sivils is engaged in basic and clinical research aimed at understanding the causes of Sjögren's. She is founder and director of the Sjögren's Genetics Network, where investigators from over 20 research sites around the world have come together to perform large-scale genetics projects that are shedding new light on the complex causes of Sjögren's. Dr. Sivils also holds leadership positions in other major international research projects and will provide an update into the exciting progress of Sjögren's research.

## Exhibit Area Hours

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

**Friday, April 3<sup>rd</sup>**

Exhibits open from 12:30pm – 6:30pm

**Saturday, April 4<sup>th</sup>**

Exhibits open from 8:30am – 2:00pm

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### 2:30pm    **How Coaching Can Help You Live Your Best Life**



Janet Church, Chair of the Sjögren's Foundation Board of Directors is also a Certified Professional Coach and Certified Yoga Instructor. As a Sjögren's patient, Janet has been on a 10-year journey to discover how chronically ill patients

can live their best life and achieve their goals while managing their disease. Coaching is a solution-focused practice that helps you break through what holds you back from getting all you want in life — and a Sjögren's diagnosis can certainly derail your life plans! In this session, Janet will present what coaching is (and isn't) to help you learn if a professional life coach can support you to thrive in your "new normal."

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### 3:10pm    **Autonomic Nervous System Involvement and POTS**



Brent P. Goodman, MD, is a neurologist at the Mayo Clinic in Arizona where he is the Founding Director of the Autonomic Laboratories and Clinic. His clinical and research interests include neurophysiology, clinical phenotypes of autonomic dysfunction, dysautonomia in

Sjögren's, and autonomic neuropathies. Dr. Goodman will discuss the autonomic nervous system (ANS) which controls and regulates vital bodily functions that we don't have to think about - such as blood pressure, heart and breathing rates, and digestion. Additionally, he will explain how postural orthostatic tachycardia syndrome (POTS) impacts the autonomic nervous system.

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### 3:50pm    **Conference Recap and Closing Remarks**

#### **Janet Church**

*Sjögren's Foundation Chair of the Board*

#### **Steven Taylor**

*Sjögren's Foundation Chief Executive Officer*

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### 4:10pm    **Conference Adjourns**



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## ***Please Join Us!***

This spring we invite you to join with fellow Sjögren's patients, their families, medical experts, and product exhibitors and attend our 2020 National Patient Conference, "Coming Together to Conquer Sjögren's."

Sjögren's is not the same for every person diagnosed, which is why educating yourself on the most up-to-date information and treatment options is so important. Attending the Sjögren's Foundation 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 Sjögren's Foundation staff
- Find new products and receive free samples in our exhibitor hall
- Share with your fellow patients
- Browse Sjögren's resources at the Sjögren's Foundation 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 lunch, conference materials from speakers and entrance to exhibit area on both days.



## 2020 *"Coming Together to Conquer Sjögren's"*

National Patient CONFERENCE

**April 3 – April 4, 2020**

**Hyatt Regency Phoenix**  
122 North Second Street,  
Phoenix, Arizona

### 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 10, 2020)

	March 10 <sup>th</sup> and before	March 11 <sup>th</sup> and after
Sjögren's Foundation Members & Guests	<b>\$170 per person</b>	<b>\$190 per person</b>
Non-Members	<b>\$190 per person</b>	<b>\$210 per person</b>
<b>TOTAL:</b>		

### 3 PAYMENT – Mail to Sjögren's Foundation, 10701 Parkridge Blvd., Suite 170, Reston, VA 20191

☐ 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 Sjögren's Foundation.

☐ 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 10th will receive a 75% refund. After that time, we are sorry that no refunds can be made.
- Dietary Requests: We can accommodate vegetarian or gluten-free dietary requests. Unfortunately, we cannot accommodate all special dietary requirements.

☐ 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 Hyatt Regency Phoenix (122 North Second Street, Phoenix, Arizona 85004) at the Foundation rate of \$169 per night plus tax if reservations are made by March 10, 2020. To make room reservations, call the hotel's toll-free central reservations number at (877) 803-7534 or the Hyatt Regency Phoenix directly at (602) 252-1234 and refer to the group name "Sjögren's Foundation" for the discounted rate.
- The Hyatt Regency Phoenix is approximately 5 miles from Phoenix Sky Harbor International Airport.

**QUESTIONS? Call 800-475-6473 or visit [www.sjogrens.org](http://www.sjogrens.org)**