

2014 SSF National Patient Conference

“Solving the Sjögren’s Puzzle”

April 25-26, 2014

Hyatt Regency O’Hare

Chicago (Rosemont, Illinois)

Sjögren’s
Syndrome
SSF
Foundation

2014 SSF National Patient Conference Schedule

Friday, April 25, 2014

12:30pm

Registration and Exhibit Area Open

2:00pm

Welcome and Opening Remarks

Steven Taylor, SSF Chief Executive Officer

2:10pm

Overview of Sjögren's Syndrome



Daniel Small, MD, is a practicing rheumatologist with a career-long interest in Sjögren's. He practiced rheumatology in California and Texas before settling in Florida and joining the Sarasota Arthritis Center 21 years ago. During his career, Dr. Small has reported clinical research findings related to Sjögren's at regional, national, and international rheumatology meetings. He authored a chapter in *The Sjögren's Book* about treatment of major organ involvement, and he is a member of the SSF Medical and Scientific Advisory Board. Dr. Small will present a comprehensive explanation of the range of symptoms that Sjögren's patients experience, explain their causes, and offer practical tips for managing them.

3:00pm

Pulmonary Issues and Sjögren's



Augustine S. Lee, MD, is Assistant Professor of Medicine at Mayo Clinic College of Medicine; Director, Chronic Cough Clinic, Division of Pulmonary Medicine, Mayo Clinic; and Program Director, Pulmonary and Critical Care Medicine Fellowship, Mayo Graduate School of Medicine, Mayo Clinic College of Medicine, Jacksonville, Florida. Dr. Lee also is Consultant at both the Division of Pulmonary Medicine, Department of Internal Medicine and at the Department of Critical Care at the Mayo Clinic in Jacksonville. Lung complications are sometimes the most misunderstood and life-threatening manifestations of Sjögren's. Dr. Lee will add to your understanding of the various pulmonary complications and leave you with knowledge to share with your own physician.

3:40pm

Gastrointestinal Issues and Sjögren's



Matthew Nichols, MD, is a gastroenterologist and currently practices in Colorado with South Denver Gastroenterology, P.C. His areas of special interest include the management of chronic liver and inflammatory bowel diseases. Dr. Nichols is an active participant in the Rocky Mountain Chapter of the Crohn's and Colitis Foundation (CCFA). The manifestations of Sjögren's are multiple, and gastrointestinal involvement is common. Dr. Nichols will enhance your understanding of how the esophagus, stomach, liver, and intestines are affected by Sjögren's.

4:20pm

How I Stood Up For Sjögren's



Join us for a lively discussion as we hear from patients about how they stood up for Sjögren's through helping other patients, educating their communities or healthcare professionals, or by increasing awareness or raising funds for the fight against Sjögren's. Each of these inspiring individuals will also share their trials and tribulations with living with Sjögren's, give tips they have learned along the way while also sharing how their diagnosis made them determined that no one should suffer because of not receiving a prompt and proper diagnosis. We know you will learn from the experiences and stories of each of our panelists.

5:00pm

Break and Exhibits

6:30pm

Banquet Awards Dinner



Featuring Mary McDonough, Keynote Speaker
If the name Mary McDonough sounds familiar, it may be because she portrayed *Erin Walton*, the sensitive middle daughter, on the hit series *The Waltons* for a decade. Continuing her acting career into adulthood, Mary has appeared on numerous series including *ER*, *Picket Fences*, *Will and Grace*, *Boston Legal*, and *The New Adventures of Old Christine*.

We are delighted to have Mary McDonough, a fellow Sjögren's patient, as our 2014 Keynote Speaker - you won't want to miss this informative and moving presentation! (See "Insert" for more highlights about Mary McDonough.)

In addition, join us for an 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.



“Solving the Sjögren’s Puzzle”

Saturday, April 26, 2014

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

9:00am **Opening Remarks**

9:05am **Clinical Practice Guidelines Update:
A Panel Discussion**



Michael T. Brennan, DDS, MHS, is Professor and Oral Medicine Residency Director at the Department of Oral Medicine at the Carolinas Medical Center in Charlotte, North Carolina. He is also Director of the Sjögren’s Syndrome and Salivary Disorders Center at the Carolinas Medical Center. Additionally, Dr. Brennan is Co-Chair of the Oral Medicine Sub-Committee of the SSF Clinical Practice Guidelines Committee.



Gary N. Foulks, MD, is Emeritus Professor of Ophthalmology in the Department of Ophthalmology and Visual Sciences of the University of Louisville School of Medicine. Former Director of the Cornea and External Disease Service, he was also Assistant Dean for Clinical Trial Research at the University of Louisville School of Medicine. Dr. Foulks presently is Editor-in-Chief of *The Ocular Surface* and is on the editorial boards of *Cornea* and the *Eye and Contact Lenses*. Dr. Foulks is also Co-Chair of the Ocular Medicine Sub-Committee of the SSF Clinical Practice Guidelines Committee.



Ann Parke, MD, is Professor of Medicine, University of Connecticut Health Center at St. Francis Hospital and Medical Center in Hartford, Connecticut. She is an expert in Sjögren’s, rheumatoid arthritis, and systemic lupus erythematosus as well as pregnancy in patients with connective tissue diseases. Dr. Parke is also Co-Chair of the Rheumatology/Systemic Disease Sub-Committee of the SSF Clinical Practice Guidelines Committee.

This panel of esteemed Sjögren’s experts will discuss the Clinical Practice Guidelines for the management of Sjögren’s, a major initiative launched by the SSF several years ago. These guidelines will be the first of their kind for Sjögren’s and will establish a baseline for healthcare professionals to follow when treating Sjögren’s patients. The panel will review the guidelines process and status, covering the management and treatment of ocular, oral, and systemic manifestations of Sjögren’s.

11:15am



Sjögren’s Walkabout

Participants are encouraged to join us for our national Sjögren’s Walkabout – an event where patients and family members come together to stand up for Sjögren’s! You can walk, support, or cheer on your fellow friends.

12:45pm

Lunch and Exhibits

1:45pm



Hope for the Future: Foundation Update

Steven Taylor, CEO of the Sjögren’s Syndrome Foundation, will share an update on the Foundation’s Research Program and the goals for 2014. You will learn about how research holds future promise, greater understanding and hope for better therapies for all Sjögren’s patients.

2:10pm

**Overlapping Major Connective
Tissue Diseases**



Lee S. Shapiro, MD, is a rheumatologist and a partner at The Center for Rheumatology in Albany, New York. Dr. Shapiro also is Director of the Stefens Scleroderma Center in Saratoga Springs, New York, and Clinical Professor at Albany Medical College, and is a 20-year member of the medical advisory board of the Tri-State Chapter of the Scleroderma Foundation. Dr. Shapiro will discuss the importance for individuals with Sjögren’s to be aware of the symptoms that might indicate the development of “overlap” features with other connective tissue diseases.

Exhibit Area Hours

Please visit our exhibitors in our “Exhibit Area.”

Friday, April 25th

Exhibits open from 12:30pm– 6:30pm

Saturday, April 26th

Exhibits open from 8:30am – 11:15am

Exhibits open from 12:45pm – 2:15pm

2:50pm

Nutrition, Wellness and Autoimmune Disease



Lauri Lang, RD, LDN, CWPC, is a registered dietitian, licensed dietitian nutritionist, and certified wellness program coordinator based in Pittsburgh, Pennsylvania. She specializes in holistic nutrition, chronic disease prevention and improvement, and health promotion. She currently works for Cigna, Inc, as a Case Manager Specialist on the Integrated Personal Health Team. 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 an autoimmune disease like Sjögren's and share insights into making the best nutritional choices to maximize functioning and well-being.

3:30pm

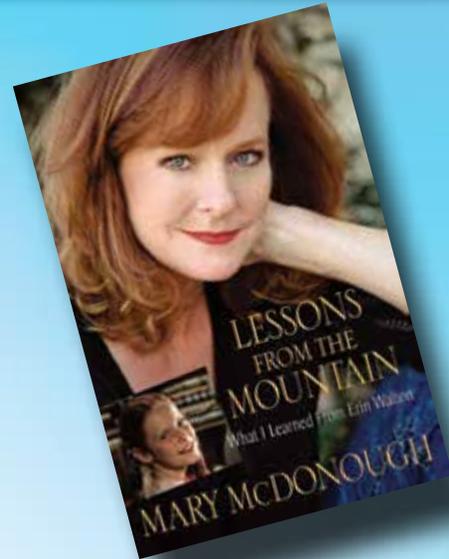
What is in the Clinical Trial Pipeline?



Theresa Lawrence Ford, MD, is the Medical Director of North Georgia Rheumatology Group and an Active Staff member at Gwinnett Medical Center Hospitals. She practices in a single specialty group in Gwinnett County, Georgia, with her sister who is also a rheumatologist. She has done research in the fields of lupus and rheumatoid arthritis and participates as an investigator in clinical trials. She has been recognized in *Atlanta Magazine* annually as a Top Doctor in her field since 2005. Dr. Lawrence Ford closes out the weekend by looking ahead to what the future holds for Sjögren's clinical trials.

4:30pm

Conference Recap and Closing Remarks



Friday Evening Keynote Speaker Mary McDonough

Join us on Friday evening as Mary McDonough shares lessons learned throughout her life as an actress, author, public speaker, life coach and patient. As an author, Mary chronicled her Walton family and life beyond the mountain in her strikingly honest book, *Lessons From The Mountain, What I Learned From Erin Walton*. In her book, Mary shares the story of her overnight transformation from a normal kid in a working class, Irish Catholic family, to a Hollywood child star. *Lessons from the Mountain* is the story of everything Mary McDonough learned on her journey over — and beyond — that famous mountain.

Perhaps the result of the many years she spent working in and successfully navigating her place in a difficult and highly visible industry, it seemed only natural for Mary to reach out to others. Thus, her work as a Life Coach began. A seasoned public speaker, she works with businesses and organizations of all sizes to help them attain their goals in a more harmonious and effective way. Most gratifying of all, however, is the one-on-one work she does with men and women to deal with and overcome the fear of anxiety associated with career transition, life balance, communication, and health issues so that they may experience the love, passion and success they so deeply desire.

An outspoken activist, Mary spent fifteen years lobbying Congress on behalf of women's health. After experiencing and overcoming her own health crisis, including being diagnosed with Sjögren's and Lupus, she began performing hands-on work to help others heal their health, spirits and lives. With "can-do" determination, she adheres to an indomitable "if life gives you lemons, make lemonade" philosophy. Utilizing solutions she created to solve issues affecting her own life, she was founding director of *Lupus LA*, and currently heads *In The Know*, an organization dedicated to educating women about their own health.

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.



2014 NATIONAL PATIENT CONFERENCE CHICAGO (ROSEMONT, ILLINOIS) — APRIL 25–26, 2014

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 31, 2014)

SSF Members & Guests
Non-Members

March 31st and before
\$170 per person
\$190 per person

April 1st 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 _____

Signature _____ CC Security Code _____

- Refund requests must be made in writing. Registrants whose written requests are received by April 3rd 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. If you require a vegetarian or gluten-free meal option, please contact Caroline Mullin at the SSF office (301-530-4420, ext. 214) by April 3rd.
- A limited number of rooms are available at the Hyatt Regency O'Hare (9300 Bryn Mawr Avenue, Rosemont, IL 60018) at the SSF rate of \$125 per night plus tax if reservations are made by April 1, 2014. Call the toll-free hotel Central Reservations number at 888-421-1442 or call the Hyatt Regency O'Hare directly at 847-696-1234 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
- The Hyatt Regency O'Hare is approximately one (1) mile from the O'Hare International Airport. The hotel offers a 24-hour complimentary shuttle service to and from the airport that runs every 15 minutes. Alternate transportation suggestion: Taxi Fare/\$10 (one way).

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