

Looking to the Future

A New Vision and Mission for the SSF

The Sjögren's Syndrome Foundation (SSF) began in 1983 in the home of Elaine Harris, a patient. For the past 35 years, the SSF has been honored to support all Sjögren's patient and the mantra of Elaine—“founded by a patient, for patients”—remains the center of what we do by ensuring that the patient voice is never lost in our efforts. Over the years, the work of the Foundation has grown and adapted to meet the needs of both current patients and future generations. As we continue to expand our reach and scope as the disease evolves, the SSF volunteer Board of Directors wanted to clearly communicate our vision and what we want to accomplish in the coming years.

Today, the SSF is proud to announce that after months of planning and the involvement of many volunteers, patients, researchers and physicians, we have set a new vision statement.

SSF Vision Statement

“To create a community where patients, healthcare professionals and researchers come together to conquer the complexities of Sjögren's.”

With a new vision, the Foundation decided to update our mission to better reflect our current and future goals and aspirations for the SSF.

SSF Mission Statement

- Support Sjögren's patients and their loved ones through education, resources and services
- Provide credible resources and education for healthcare professionals
- Serve as the voice for all Sjögren's patients through advocacy and awareness initiatives
- Lead, encourage and fund innovative research projects to better understand, diagnose and treat Sjögren's

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The new mission and vision statements underscore the SSF’s commitment to supporting patients, while acknowledging the truly complex nature of the disease. The core values from our previous mission statement that we had for 35 years remains the same: educate patients and their families about Sjögren’s, increase public and professional awareness of Sjögren’s, and research into new treatments and a cure. The updated mission encompasses those core values but includes our work in advocacy, professional educational resources and patient programs, to better portray what work needs to be done today in order to conquer this debilitating disease.

The accomplishments of the past 35 years have been incredible and the SSF has recently seen extraordinary results from our efforts. It was only a year ago that we announced surpassing our *5-Year Breakthrough Goal* to reduce the time of diagnosis by 50% in 5 years. Taking the average diagnosis time from over 6 years to 2.8 years. Back in 2012, when we established the goal, we were told by experts that it would be very hard to reach. But the SSF staff and volunteers knew that the Foundation couldn’t sit on the sidelines and let patients go years without having a proper diagnosis. We also knew, that by getting patients diagnosed quicker, patients could then get the appropriate treatment to hopefully prevent and/or be monitored for serious complications such as corneal scarring, loss of teeth, internal organ involvement, misdiagnosed neuropathy pain, profound fatigue, or chronic upper respiratory problems, to just name a few. Systemic issues could also be caught earlier and mitigated. With our new mission and vision, it is still our hope to have Sjögren’s at the top of physician’s minds when they hear a patient complaining of dry mouth, dry eye, fatigue, or joint pain, because no patient should have to suffer from the lack of a physician’s awareness and education. This is why our awareness efforts will surely continue.

Other recent achievements include: writing and publishing the first-ever clinical practice guidelines on how to treat and manage Sjögren’s patients with Phase 2 currently underway; our work in getting closer to developing a drug to treat all Sjögren’s symptoms; and efforts to increase awareness and educate healthcare professionals.

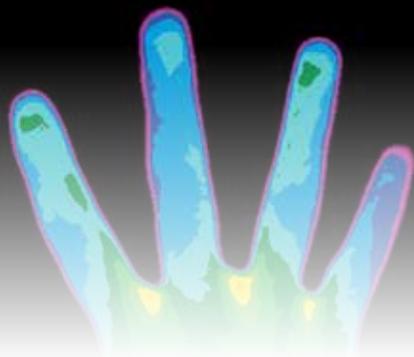
We know our work is far from over, but we have also seen what we are able to accomplish together! We are seeing the disease being taken more seriously in the medical community. The Foundation will continue building on our work to ensure Sjögren’s is

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Raynaud's and Sjögren's

by Ashley Beall, MD

Raynaud's (sometimes called Raynaud's syndrome or phenomenon) is defined as repeated episodes of color changes in the fingers and/or toes with exposure to cold temperatures or during episodes of emotional stress. The color changes are due to a spasm of the blood vessels that feed the fingers and toes. The digits typically turn very white, then can take on a bluish color with prolonged exposure to the cold, and finally can turn very red as blood flow resumes. Raynaud's occurs in approximately 15-30% of patients with Sjögren's.

Some things that you can do to control your Raynaud's include:

- When you know that you will be exposed to cold temperatures, wear layered clothing. This will keep your core body temperature warm and keep the vessels feeding the fingers and toes from spasm.
- Always carry a jacket with you on outings, as you may find yourself in an unexpectedly cool area.
- Wear a hat and cover your face and ears with a scarf in cold temperatures.
- Always wear hand coverings in cold temperatures. Mittens are best, as they will use the body heat generated by your fingers. However, a good pair of insulated gloves is also helpful.
- Wear heavy socks or layers of socks to keep feet warm at all times.
- Keep your home and office space comfortably warm (greater than 70 degrees is best).
- Avoid reaching into the freezer both at home and in the grocery store.
- Use insulated containers when handling cold drinks or food.
- Rinse food with warm water instead of cold water.
- Wear protective gloves when washing dishes.
- Use disposable heat packs as needed for your hands and feet. These are available at many sporting goods stores.
- Always let the water warm up before getting into the shower and keep the bathroom door closed while bathing or showering to hold in heat.
- When possible, have a loved one warm up your car before getting into it on a cold day.
- Moisturize your hands and feet every day to prevent your skin from cracking.
- When your hands or feet start to feel cold, wiggle your fingers and toes, move your arms and legs around to get blood flowing, or put your hands under your armpits to warm them up.
- If you have access to water when a flare starts, run warm water over your fingers and toes until skin color returns to normal.
- Do not smoke — this constricts the blood vessels that feed the hands and feet.

Talk to your doctor about your symptoms. Several medications can be used to help the vessels stay dilated, including a class of blood pressure medications called calcium channel blockers. Some medicines, such as beta blockers used for high blood pressure, may make Raynaud's worse. ■

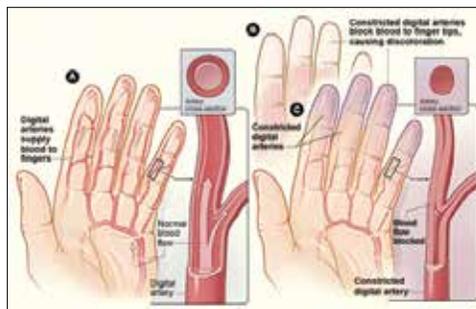


Figure A shows arteries in the fingers (digital arteries) with normal blood flow. The inset image shows a cross-section of a digital artery. Figure B shows fingertips that have turned white due to blocked blood flow. Figure C shows narrowed digital arteries, causing blocked blood flow and blue fingertips. The inset image shows a cross-section of a narrowed digital artery. Photo Credit: NIH: National Heart, Lung and Blood Institute.

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not forgotten in the research, pharmaceutical or physician communities. We are committed to accelerating the development of better diagnostic, management and therapeutics that will have the greatest potential impact on improving the quality of life for Sjögren’s patients.

The SSF Board of Directors and staff are humbled by your support and what we have been able to achieve together. From our patient volunteers to our professional educators and corporate partners, thank you to everyone who has helped us along our way and who are continuing to stand with us

as we look to the future. We encourage you to look for opportunities in this new year to become more involved with the Foundation and stand up for all patients, both current and future generations.

The updated mission and new vision of the Sjögren’s Syndrome Foundation will allow us to successfully forge ahead as we work to conquer the complexities of Sjögren’s.

Together we can make our vision a reality! ■

2018 By the Numbers

- Together we surpassed our *5-Year Breakthrough Goal* to reduce the time of diagnosis by 50% in 5 years. Current diagnosis time is 2.8 years.
- Awarded 7 Sjögren’s research grants.
- Managed 63 active support groups in the U.S.
- SSF served as a mentor to 25 international Sjögren’s Patient Groups.
- Over 700 volunteers donated their time to SSF programs and events.
- Designed first-ever online platform Sjögren’s Training and Education Platform (STEP) that will be used to train clinical trial investigators in Sjögren’s. Having all clinical trial clinicians complete the STEP training will help standardize how data is collected and trials completed.
- Exceeded 45,000 followers on Facebook.
- Educated over 250 rheumatologists about Sjögren’s through SSF educational programs and symposiums.
- Continued work on Phase 2 of the first-ever Sjögren’s clinical practice guidelines on how to treat and manage patients.
- Nearly 500 attendees traveled for the 2018 National Patient Conference in Colorado.
- Dramatically increased enthusiasm for the development of a systemic therapy for Sjögren’s by expanding our Clinical Trials Consortium (20 potential therapies currently being evaluated). ■

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* Oral Surg Oral Med Oral Pathol Radiol. 2017 Jan; 123(1):76-83

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SSF at the 2018 American College of Rheumatology Annual Meeting



The American College of Rheumatology (ACR) Annual Meeting was held October 21-24th in Chicago, IL. This is the premier conference in rheumatology, attended by over 15,000 rheumatologists from around the world. Our presence at this conference gives us important exposure to connect with clinicians and researchers who spend countless hours studying Sjögren's, as well as those who are new to rheumatology and/or are interested in learning how to best serve their patients living with Sjögren's.

The Sjögren's Syndrome Foundation (SSF) once again had an exhibit booth in a great location on the exhibit hall floor. Our corner location resulted in great exposure and traffic. The booth was stocked with materials for providers and SSF staff were available to help educate attendees about all we have to offer them. Visitors to the booth had the opportunity to subscribe to our medical newsletter, *Sjögren's Quarterly*, in order to keep them up-to-date on the latest clinical research and findings in Sjögren's for years to come.

This year, the SSF held a breakfast meeting rather than the normally scheduled lunch due to the number of Sjögren's programs being offered during the conference. This invite-only event included rheumatologists, researchers and industry partners

both from the U.S. and abroad, and was themed, "Patient Selection and Recruitment for Clinical Trials." This meeting was designed to spark conversation around key questions that needed to be considered for how we, as the Sjögren's community, can help enroll more patients in clinical trials while maintaining an effective trial design.

Theresa Lawrence Ford, MD, FACR, led the discussion by presenting each question and moderating the conversations that ensued. Some of the topics discussed on the day touched on demographics, whether to target the systemic disease or a defined subset of the disease and whether patients with various levels of disease activity should be considered for inclusion.

Additionally, during the breakfast, Steve Taylor, SSF CEO, provided a brief update on a variety of Foundation initiatives and Kathy Hammitt, SSF VP of Medical and Scientific Affairs, provided an update on STEP (Sjögren's Training and Education Platform).

As in past years, there were a variety of study groups that took place during the conference. These opportunities provide attendees the chance to hear from experts in the field, ask questions and further explore the concepts being discussed.

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This year, the SSF-coordinated study group took place on Tuesday, October 23, and was titled, “Multidisciplinary Teams for Clinical and Investigational Approaches to Sjögren’s.” Nancy Carterson, MD, moderated the discussion and was joined by Esen Akpek, MD, who provided an ophthalmologic perspective, Frederick Vivino, MD, who provided insight into the impact of a multidisciplinary team approach to guidelines development and patient care and Caroline Shiboski, DDS, MPH, PhD, who provided a perspective from oral medicine and dentistry.

Key takeaways from this study group included Dr. Akpek’s review of Sjögren’s-related dry eye and associated, potentially vision-threatening, problems to be aware of as well as the need for medical providers to be aware that dry eye may precede the formal diagnosis of Sjögren’s. Dr. Vivino reviewed the processes used for Phase 1 of the SSF Clinical Practice Guidelines initiative as well as the approach to Phase 2, which is currently underway. Highlights from this initiative so far are an increase in knowledge about Sjögren’s among professionals and societies and improved quality and consistency of care for patients in the U.S. Lastly, Dr. Shiboski reviewed ideas on the rheumatologist’s role in preventing oral complications of Sjögren’s, including caries, as well as a real-world model of integrated care for an effective multidisciplinary work-up of patients with suspected Sjögren’s.

Additionally, the SSF recognized three young investigators during the presentation of this year’s SSF Outstanding Abstract Awards, that you will read more about on page 10.

The pediatric Sjögren’s study group returned for its third year and was moderated by Matthew Basiaga, DO, MSCE, (University of Washington) and Scott Lieberman, MD, PhD (University of Iowa). This year’s presentation discussed the continued momentum in their collection of clinical data from participants around the world in their retrospective database. This data will provide a baseline for the characterization of Sjögren’s in children with plans to develop a preliminary diagnostic workup and criteria. The group talked about opportunities that may exist to expand their efforts in the retro-

spective database study to begin to more deeply analyze the data for trends and commonalities among pediatric patients. To better understand the course of Sjögren’s in children, they discussed beginning to focus on the development of a prospective registry including children diagnosed with Sjögren’s as well as children who have manifestations that may suggest Sjögren’s but who have not been formally diagnosed (such as children with recurrent parotid gland swelling who have negative antibodies). The group also discussed the promising use of salivary gland ultrasound in pediatric Sjögren’s patients as a minimally invasive way to monitor for deterioration of the glands over time. Through their efforts the group is hoping to set the stage for future studies aimed at intervening early to prevent progression of disease manifestations in children diagnosed with Sjögren’s.

This year’s conference featured a variety of clinical programs on Sjögren’s, which are always a great way for rheumatologists to gain greater insight into the disease. Once again, Fred Vivino, MD, FACR, presented *Controversies in Sjögren’s* as part of ACR’s Meet the Professor series. These programs are designed to promote conversation and consultation among participants using cases and discussion. Dr. Vivino offered two sessions during the conference.

Sjögren’s left a large footprint on this year’s meeting during a standing-room only session, moderated by Drs. Frederick Vivino and Sara S. McCoy entitled, “Sjögren’s Syndrome: Beyond Dryness: A Comprehensive Approach to Diagnosis and Management.” Here, Dr. Alan Baer provided updates to the challenges in diagnosing Sjögren’s, including a review of the requisite components of a diagnostic evaluation for Sjögren’s as well as an overview of relevant and novel tests and the role, interpretation and utility of salivary gland biopsy and monitoring. Following Dr. Baer’s presentation, Dr. Arthur Bookman provided updates and challenges to treating Sjögren’s, which included a summary of the use of hydroxychloroquine in Sjögren’s, the utility of immunosuppressives, including biologics, for treating Sjögren’s and a review of specific treatments for extra-glandular manifestations.

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SSF in Action!

Our Partnership with the NHC



The Sjögren's Syndrome Foundation is proud to be a member and actively involved with the National Health Council (NHC). The NHC's membership is comprised of the nation's leading patient advocacy organizations as well as other professional and membership associations, non-profits with an interest in health and representatives from the pharmaceutical, health insurance, device and biotechnology industries.

The NHC's mission is to provide a united voice for people with chronic diseases and disabilities and their family and caregivers and envision a society in which all people have access to quality health care that respects personal goals and aspirations and is designed around the patient experience to promote their best possible health outcomes.

The Foundation's involvement with this important organization helps to further bring recognition to Sjögren's while elevating our voice and ensuring we have a seat at the proverbial table to participate in important discussions and decisions.

Many of the Foundation's staff collaborate and connect with staff at the NHC throughout the year. SSF staff participated in a variety of meetings, trainings and advocacy opportunities in 2018, such as:

- Healthcare Quality Training for patient advocates, including how to ensure the patient voice is heard in discussions on quality.
- Chief Medical and Scientific Officers Conference, where leaders across sectors and an

array of attendees discussed ideas and best practices for engaging patients for clinical research, using and sharing data and more.

- Advocacy & Government Relations Conference to discuss the NHC's advocacy and legislative focus for 2019.
- Joined with NHC and other patient advocacy organizations in signing letters and advocating to key legislators and government officials such as numerous Congressman and Senators as well as the Secretary of Health & Human Services and the FDA Commissioner. These letters included topics such as step therapy policy, pre-existing conditions, essential health benefits, prescription drug costs, transparency of drug pricing and the use of biosimilars.

This sampling of events and conferences only shows part of the diverse work the NHC is doing and how the SSF is involved with the organization. These events also provide a wealth of knowledge and serve as great learning opportunities for our staff. In addition, another major benefit for the SSF is that we are able to build relationships and partner with staff from other non-profit organizations who are doing similar work. Being able to both learn from their experiences, share and discuss ideas and collaborate on projects helps strengthen the SSF's ability to support and advance the mission of the Sjögren's community.

Excitingly, the Foundation's voice will remain prominent in the NHC, as Steven Taylor, CEO of the Sjögren's Syndrome Foundation, will serve as Chair of the NHC Board for 2019, a position he held previously in 2013.

Learn more about Steven Taylor's role as Chair of the NHC Board of Directors on page 12. ■



“ACR” *continued from page 6* ▼

As in past years, there were many abstracts submitted for presentation at this conference on a wide variety of topics, including Sjögren’s. These abstract sessions provide a forum for attendees to hear about the latest developments across rheumatologic interests. This year, more than 50 Sjögren’s-related abstracts were accepted and presented throughout the conference, including a dedicated poster-session on Sjögren’s, which took place Monday, October 22, in the poster hall.

While the ACR Annual Meeting is always a great forum for learning and promoting awareness about Sjögren’s, it is also a wonderful opportunity to connect with others interested in focusing their work on the disease. The SSF staff met with numerous companies who are developing new therapies in Sjögren’s, as well as other professional organizations who are interested in partnering on projects and sharing knowledge. We left the meeting with many new connections and much excitement about what is ahead in the world of Sjögren’s. ■



Do we have your e-mail address?

If you want to receive all the latest updates from the Sjögren’s Syndrome Foundation, then you should make sure we have your most up-to-date e-mail address! The SSF is starting to share more information via e-mail, from news about the SSF and Sjögren’s, to information about the latest treatments and medicines, to local Support Group updates and more. So contact us at ssf@sjogrens.org to be certain we have your latest e-mail address in our database, and then keep an eye out in your Inbox for Sjögren’s news.

Just like all information you give the Foundation, your e-mail address will remain private and will never be given or sold to an outside organization.

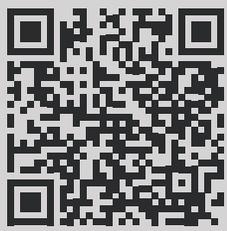


Learn more about Clinical Trials in Sjögren’s!

The SSF now has a section on its website devoted to clinical trials in Sjögren’s. Visit <http://www.sjogrens.org/home/about-sjogrens/clinical-trials-whatsinvolved>.

Links on this page take you to:

- An article by Theresa Lawrence Ford, MD, the SSF Medical and Scientific Advisory Board Chair and Chair of the SSF Clinical Trials Consortium
- A list of clinical trials in Sjögren’s that are currently recruiting Sjögren’s patients





Research News

Restructuring the SSF Research Program

The Sjögren's Syndrome Foundation (SSF) is excited to announce that we've revamped our research grants program, with changes being implemented in hopes of having an even greater impact on the Sjögren's community. This program has, and will continue, to place a high priority on both clinical and basic scientific research into the cause, prevention, detection, treatment and cure of Sjögren's.

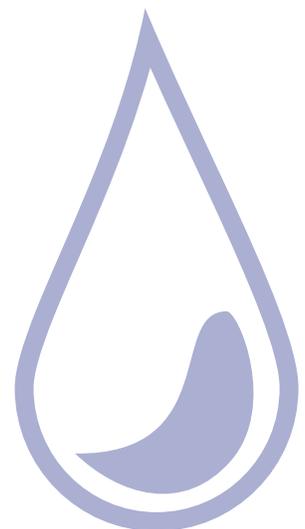
The biggest change to the program will be the addition of a new funding opportunity, the SSF High Impact Research Grant, which will be offered at up to \$75,000. This is a significant increase in funding for a single grant from the Foundation, which we hope will attract a wider range of experience levels, including more senior investigators. We, at the Foundation, understand how costly research projects can be and wanted to provide greater incentive for researchers to focus on Sjögren's. Applicants for this grant are expected to have more fully developed research proposals, with the majority of the necessary preliminary data and methodology already in place.

In addition to this new grant, the Foundation will continue to award one project at an amount up to \$25,000 through what is now known as the SSF's Pilot Research Award. This award is designed to provide investigators with assistance in collecting necessary data and other preliminary needs so that they can then pursue larger forms of grant funding.

Currently, SSF grants are typically awarded for two years, whereas moving forward, all grants will be awarded for one year. All applications and subsequent awards will continue to undergo a rigorous review process involving a variety of experts as well as the SSF Board of Directors.

We're excited about these changes and look forward to sharing more about our researchers, their projects and the outcomes of their work in the future!

Learn more about our grants program by visiting our website at <https://www.sjogrens.org/home/research-programs/research-grants> ■



SSF Outstanding Abstract Awards at ACR



L to R: Theresa Lawrence Ford, MD;
Lauro Meneghel, MSc, PhD; Steven Taylor



L to R: Theresa Lawrence Ford, MD;
Saviana Gandolfo, MD; Steven Taylor



L to R: Theresa Lawrence Ford, MD;
Gaetane Nocturne, MD, PhD (accepting
the award on behalf of Elodie Rivière, MD);
Steven Taylor

The Sjögren's Syndrome Foundation (SSF) was delighted to recognize three young investigators at this year's Outstanding Abstract Award presentation during the 2018 American College of Rheumatology's (ACR) Annual Meeting in Chicago, IL. Lauro Meneghel, MSc, PhD, was announced as the winner and Saviana Gandolfo, MD, and Elodie Rivière, MD, were announced as honorable mentions. All three were recognized for their exceptional work during the Sjögren's Study Group on Tuesday, October 23, 2018.

Dr. Lauro Meneghel, Karolinska University Hospital, Stockholm, Sweden, received the award for his abstract entitled, "Clinical Correlations and Expression Pattern of Autoimmunity Susceptibility Factor DIOA-1 in Primary Sjögren's Syndrome." The findings from this study indicate a role for DIOA-1 in select B cell subsets and suggest that DIOA-1 potentially contributes to the inflammatory process and disease pathogenesis in Sjögren's through B cell involvement.

Dr. Saviana Gandolfo, University of Udine, Udine, Italy, received honorable mention for her abstract entitled, "Serum Levels of Thymic Stromal Lymphopoietin: A Possible Novel Biomarker in Primary Sjögren's Syndrome and Related Lymphoproliferation." This study found that thymic stromal lymphopoietin (TSLP) was significantly increased in Sjögren's, with further studies continuing, which involve Sjögren's cohorts belonging to the HarmonicSS consortium.

Dr. Elodie Rivière, Université Paris Sud - INSERM U1184, Le Kremlin-Bicêtre Cedex, France, received honorable mention for her abstract entitled, "RNA Sequencing Detection of Gene Dysregulation in B Cells Sorted from Salivary Gland Tissue and from Peripheral Blood Reveals New Pathways Involved in Primary Sjögren's Syndrome." Data from this study confirmed the B cell activation and differentiation through several markers, including CD40, CD22, CD48 and CD138 and highlighted the role of innate immunity with Toll-like receptors and key pathways including IFN and JAK signaling. The precise understanding of these dysregulations should offer development of new targeted therapeutic perspectives for patients.

The SSF Outstanding Abstract Award is designed to recognize exceptional research efforts in the field of Sjögren's and encourage new or early stage investigators to continue their focus on Sjögren's throughout their career. The winning abstracts were selected by a distinguished panel of scientists from 54 eligible applicants and are available online at <http://www.sjogrens.org/home/research-programs/outstanding-abstract>. ■



in memoriam

In Memory of Aleatha Iacolucci

Linda Osborne

In Memory of Jean Field

The Staff at CPCO

In Memory of Jennifer Nordaby

Anonymous

In Memory of Karen Caron

Emily, Kristie and Mackenzie Amundsen

Kelan Tremblay

Coach Jay Brewster

Allison Smith and Family

The Luceys

Pepere Lenny

Rita and Gene Nelson

Stephanie Sandle

Gina and Chris D'Ambrosio

Lynne Lawrence and Nick Srmag

In Memory of Bonnie Buss

Mark and Sheridan Schoneman

Bruce Haupt

Linda Blevins

James and Joy Webster

Dawn and Robert Kennedy

In Memory of Lesley Schneider Allen

Carol Clothier and Lorraine Hahn

Fran, Cora and Martha Aronovitz

Susan and Don Kah

Sean and Chloe Kimmey

In Memory of Anthony Sodl

Kevin Reichel

In Memory of Jack Wilder Beam,

with the heart of a lion

Aunt Linda Haynes

In Memory of Marilyn Cooper

Elaine and Larry Levin

In Memory of Ralph Mason

Bonnie Mason

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in honor

In Honor of Cynthia Svezia

Donna Israel

In Honor of Andrea Nightingale

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In Honor of Annie Pallider

Alex McCrae "Nannie and Boomp"

In Honor of Athena Papas, DMD, PhD

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Steve and Jennifer Perry

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Phyllis Groat

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In Honor of Julie Reeve

Karen Swift

In Honor of Kim Vaughn

Kelly and Jeff Titus

In Honor of Kristi Alexander

Emma Cox

In Honor of Lindsey Hatfield

Catherine Siegl

In Honor of Margaret Mondlak

Doreen Mondlak

In Honor of Michiko Bowman

Kimberly Bowman

In Honor of Nancy Crabbe

Jane Stone

Pete Giacopelli

In Honor of Nancy Kirkpatrick

Noreen, David, Nick and Kirby Wolansky

In Honor of Nora McLean

John, Sarah, Grayson and Lachlan McLean

In Honor of Pamela Mackiewicz

Damien and Cynthia Graeff

In Honor of Paula Sosin

Rosalyn Salzman

In Honor of S. Lance Forstot

Michele, Darren and Liora Nadel

In Honor of Sarah Graham

Jean Graham

In Honor of Sasha Cashen

Celia Baldwin and Bruce Catania

In Honor of Suzanne Richey

Janet Hinkle



Ruth Strickland Price

Leaving a Legacy of Hope

If you would like to receive information on how you can *Leave a Legacy* to support the Sjögren's Syndrome Foundation's critical research initiatives or to support one of our many other programs, please contact Steven Taylor at 800-475-6473.

Leave A Legacy – Remember Us in Your Will

Sjögren's Syndrome Foundation
Legacy of Hope

Steven Taylor to Lead 2019 National Health Council Board of Directors



Steven Taylor, our CEO, was recently named Chair of the 2019 National Health Council (NHC) Board of Directors.

The NHC brings together all segments of the health community to provide a united voice for the more than 160 million people with chronic diseases and disabilities, and their family caregivers. Its members include 125 national health-related organizations, including the Arthritis Foundation, American Cancer Society, Lupus Foundation and the American Heart Association.

The SSF's involvement with the NHC helps to further Sjögren's recognition, while elevating our voice. With Steven Taylor leading the way, we are ensuring that Sjögren's has a seat at the proverbial table to participate in important discussions and decisions.

Look for more updates in 2019 about the Foundation's work with the NHC.

"As CEO of the SSF, I'm honored to lead the 2019 NHC Board of Directors and represent the voice of all."



NHC 2019 Executive Committee

Steven Taylor

Sjögren's Syndrome Foundation CEO

Ann Palmer

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Gary Reedy

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Conquering the Complexities of Sjögren's

April 5 – 6, 2019

Hilton
Boston / Woburn

2019 National Patient Conference

Sjögren's
SF
syndrome
foundation



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)

	March 11 th and before	March 12 th and after
SSF Members & Guests	\$170 per person	\$190 per person
Non-Members	\$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



The Moisture Seekers
 Sjögren's Syndrome Foundation Inc.
 10701 Parkridge Blvd., Suite 170
 Reston, VA 20191
 Phone: 301-530-4420
 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

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

