

The Sjögren's Syndrome Foundation Moisture Seekers



www.sjogrens.org

Volume 36, Issue 06 June 2018

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2018 SSF National Patient Conference Highlights

On April 13th, nearly 500 attendees traveled to Aurora, Colorado, for the 2018 Sjögren's Syndrome Foundation's (SSF) National Patient Conference themed, "Exploring Sjögren's." This annual Conference provides an opportunity for patients and their families to share with each other, while learning about new products from exhibitors and talking to leading experts.

Over the years, SSF Conferences have helped thousands of patients to take control of their health and gain a better understanding of Sjögren's. The SSF Education Committee works to ensure that the program caters to both newly diagnosed patients and longtime Foundation members by continuously introducing new topics in order cover the disease's complexity. During the two-day educational program, attendees enjoyed twelve informative lectures by expert speakers from around the country.

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Sjögren's Clinical Practice Guidelines: Phase 2 is Underway!

Phase 2 of the Sjögren's Syndrome Foundation (SSF) Clinical Practice Guidelines (CPGs) is now underway and will significantly increase the guidance offered on the management and treatment of Sjögren's. Excitingly, Phase 2 will include both a wide variety and number of specialists who have not traditionally been involved with Sjögren's or the SSF. Through this initiative, the SSF is covering a number of new topics beyond those covered in Phase 1, including five new topics under systemic disease, three new topics under oral manifestations in Sjögren's, updates to the ocular guidelines from Phase 1 and a new cross-cutting topic that will span rheumatology, oral and ocular medicine. Details on each are provided in this article.



Clinical Practice Guidelines – Phase 1

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This year’s presentation topics included:

- Sjögren’s Overview
- Joint Pain and Sjögren’s
- Oral Manifestations of Sjögren’s
- Lymphoma: Risk, Treatment and Prognosis
- Sjögren’s and Dry Eyes: What’s New?
- How Sjögren’s Can Impact the Central Nervous System
- Dermatological Issues and Sjögren’s

The first day ended with the SSF Awards Banquet Dinner, honoring volunteers who have helped to further the Foundation’s mission by stepping up for all patients. Following the awards ceremony, the 2018 keynote address was given by Darlene Cross, MS, LMFT, who spoke about coping with loss through chronic illness, a subject she knows well being a Sjögren’s patient herself. Her uplifting and fun-loving presentation focused on ways to deal with the diagnosis of a chronic illness and while Sjögren’s can change certain aspects of your life, it cannot define who you are or dictate your destiny.

The second day included seven informative presentations and attendees took a mid-day break to participate in our Walk for Sjögren’s– Celebrating our Strength! This family-fun event was held right outside the Conference Center, where participants joined with others from the Denver community for a brisk walk, while also raising funds to benefit Sjögren’s educational and research programs. Our new walk theme – “Celebrating our Strength” gave patients the opportunity to thank their friends and family who help them each day live their fullest life possible, despite their Sjögren’s. These people are what we call – a patient’s “Circle of Strength.”

Thank you to all of our speakers, who volunteered their time, and everyone who attended this year’s Conference and committed themselves to helping each other learn and expand their knowledge of Sjögren’s. In addition, a special thanks to our sponsors and exhibitors. Without their support, the SSF would not be able to provide this educational Conference!

The Foundation understands not everyone can travel to our annual National Patient Conference, which is why we are offering the most popular talks on audio CDs with the follow-along PowerPoint presentation printouts. Learn how to order your copies today on page 13.

SSF National Patient Conference Volunteer Awards Banquet

The SSF recognizes our most dedicated volunteers through awards that are announced at the Awards Banquet Dinner held during the Conference.

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

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“NPC 2018” *continued from page 2* ▼

These award winners show how an individual can make a big difference just by getting involved. We could not accomplish all that we do without the hard work and dedication of volunteers like these awardees.

2018 Leadership Awards

Healthcare Professional Leadership Award – Robert Fox, MD, PhD, FACP



Dr. Robert Fox has been a Sjögren’s advocate since early in his career, over 40 years ago. As a practicing rheumatologist at Scripps Memorial Hospital and the University of California, San Diego, Dr. Fox has treated thousands of Sjögren’s patients throughout his career, and he continues to be a leading voice for Sjögren’s on numerous topics

including classification criteria, Sjögren’s research as well as clinical trials.

Dr. Fox began his involvement with the SSF soon after it was founded in 1983. Currently, Dr. Fox serves on the SSF Medical and Scientific Advisory Board, the SSF Research Review Committee, and the SSF Clinical Trials Consortium Steering Committee and leads the SSF Clinical Practice Guidelines for Peripheral Nervous System involvement in Sjögren’s.

As a clinician, a clinical researcher, and a basic scientist, Dr. Fox brings a unique and rich perspective

to the many contributions he has made over the years. That is why the SSF is honored to recognize him for his 40 years of outstanding service to Sjögren’s patients!

Volunteer Leadership Award – Susan Barajas



Steven Taylor, SSF CEO, Susan Barajas, OD and Chair of the SSF Board of Directors, and Stephen Cohen, OD and Chair of the SSF Board of Directors

Susan Barajas has not stopped “stepping up” for the SSF since she joined the SSF in 2015. After becoming familiar with her disease and all the SSF has to offer, Susan inquired about joining our Denver Team Sjögren’s Marathon Training Program in 2016! Since then, Susan has become a Team Sjögren’s champion, she ran with us at the Denver Rock ‘n’ Roll Half-Marathon and in Las Vegas in 2017 and she has now raised nearly \$5,000 between the two events.

Susan’s dedication to her fellow Sjögren’s patients continued as Susan “stepped up” once again to serve as Support Group Leader for the Inland Empire Support Group in California. Her group is a thriving success thanks to Susan’s perseverance to recruit

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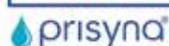
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* Oral Surg Oral Med Oral Pathol Radiol. 2017 Jan; 123(1):76-83

SSF in Action!

30 Faces for Sjögren's Awareness Month



Post: April 1, 2018

Melissa F., 42, (diagnosed at 36), Stay at home mom (Former RN)



I wish people knew that Sjögren's is more than dry eyes and dry mouth. It has affected every organ in my body. The skin being the biggest one, and the heart being the most important one.

This year's SSF April Campaign, "30 Faces for Sjögren's Awareness Month," was created to help others visualize the vast impact of this debilitating disease and how it affects those living with it by sharing your stories.

Every day in April, the Foundation used our website and one or more of our social media channels to feature a patient's photo and fact about their Sjögren's journey. While each daily post gave one small glimpse into the complexity of Sjögren's, at the end of April, we believe the collection of all 30 posts demonstrated the various physical and emotional burdens that can be associated with the disease.

Thank you to everyone who shared their story as part of this campaign and everyone who used April as an opportunity to talk about Sjögren's with the people in your life. By allowing us to represent your voice, you helped this campaign become one of the most viewed awareness projects in the history of the Foundation!

To learn more about this campaign, please visit www.sjogrens.org or email tms@sjogrens.org. Together, we will make Sjögren's a household name.

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Post: April 2, 2018

Ellen B., 26 (diagnosed at 25), Critical Care RN



During my most severe Sjögren's flare, when I was diagnosed, I had life-threatening swelling in my face, lips, and throat with a red rash all over my body. I was unable to walk at times because of weakness and joint pain. Sjögren's can be extremely severe, scary, and at times life-threatening. To protect my health, I've had to learn to say no and set boundaries.

Post: April 3, 2018

Joann C., 65 (diagnosed at 54), Counselor



I try to live each day to my fullest because I am not defined by my disease. Help others understand what to expect by talking about your Sjögren's and don't be afraid to talk to medical professionals about the disease.

“NPC 2018” *continued from page 4* ▼

speakers and raise awareness of Sjögren’s throughout her region, where she also serves as an active SSF Awareness Ambassador.

Susan’s positive attitude and desire to help people led her to give back to the SSF and her fellow Sjögren’s patients, which is why the Foundation is honored to present Susan with this year’s Volunteer Leadership Award!

Service Awards

Development Service Award – Jessica Levy



Steven Taylor, SSF CEO and Jessica Levy

The Foundation is excited to recognize Jessica, who first became involved with the Foundation 15 years ago when the SSF launched its first Walk for Sjögren’s in Denver, Colorado. Jessica has continued to serve on every Denver Walk Committee and has been the top fundraiser in Denver for all 15 events! Over the years, Jessica has personally raised nearly \$20,000 for the SSF Denver Walk and continues to raise Sjögren’s awareness in her community.

With the 2018 SSF National Patient Conference being held in her home state, the SSF is honored to present Jessica with our 2018 Development Service Award.

Awareness Service Award – Vicki Baldwin

Vicki first volunteered with the SSF in 2012, when she learned that Team Sjögren’s was coming to her area with a team of runners for the Nashville Country Music Marathon! Here, Vicki helped cheer all of our runners to the finish line and made sure no one could miss her by wearing a blue wig and holding pom poms! Since then, Vicki has stepped up to serve as a SSF Support Group Leader for the Nashville area group and is an active SSF Awareness Ambassador.

Vicki continues to be an advocate for all patients and shared her story for the SSF 2017 April Aware-



Steven Taylor, SSF CEO, Vicki Baldwin, and Sheriese DeFruscio, SSF Vice President of Marketing and Corporate Relations

ness Campaign. Her article, entitled, “You’ve Probably Never Heard of my Disease” was featured on HealthyWomen.org, an online women’s magazine, and was seen by tens of thousands.

Vicki’s ongoing commitment to helping Sjögren’s patients and the Foundation makes her the perfect recipient of this year’s Awareness Service Award.

Mission Service Award – Casey Hogan, OD



Steven Taylor, SSF CEO, Casey Hogan, OD and Michele Champigny, SSF Director of Professional Awareness

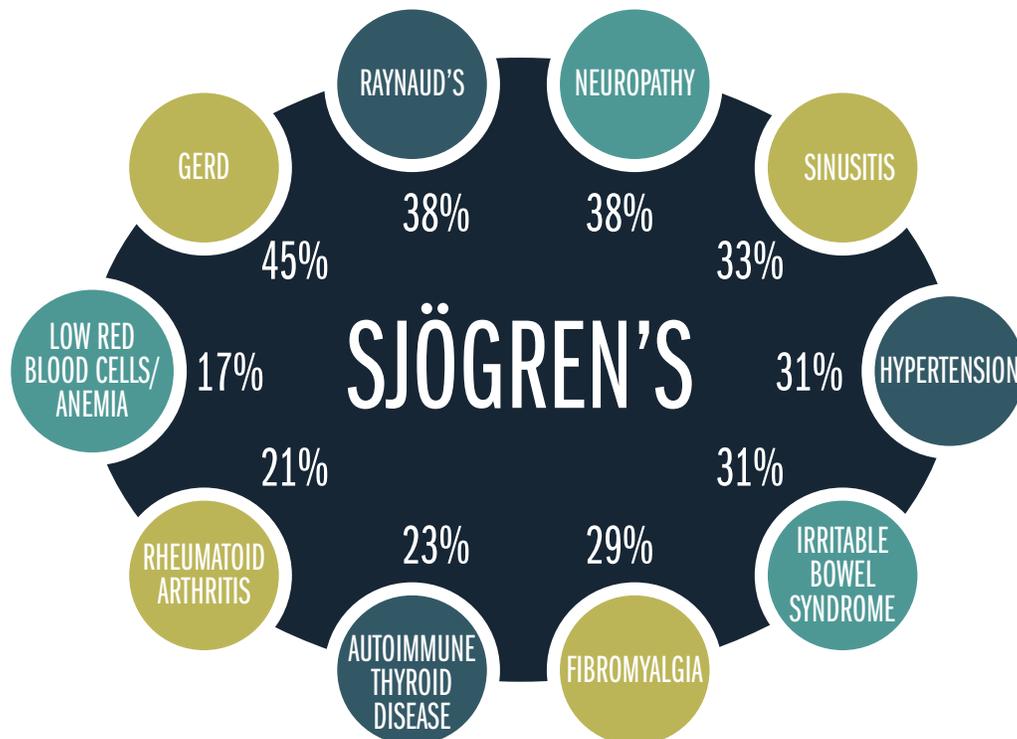
As a fellow Sjögren’s patient, it is Dr. Casey Hogan’s personal connection to the disease that has made her passionate about helping those with dry eye and Sjögren’s. Dr. Hogan was diagnosed with the disease at the age of 24 during her 3rd year of Optometry school. After her diagnosis, she has been active in helping to bring the patient voice to her fellow optometrists and dedicated to increasing professional awareness.

In 2017, Dr. Hogan generously covered the cost of an SSF exhibit booth at the American Academy of Optometry meeting to help advance professional awareness of the disease. Then this past year, Dr. Hogan hosted the First Annual Ocular Surface Disease Congress at



Why Your Rheumatologist Should be Monitoring for Overlapping Autoimmune Diseases

The greatest risk factor for developing an autoimmune disorder is the existing presence of an autoimmune disease. Overlaps are common and often complex. In the recent *Living with Sjögren's* survey*, Sjögren's respondents reported having been diagnosed with an average of five other health conditions.



**Living with Sjögren's*, 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+.



Daniel J. Wallace, MD

Sjögren's patients can have features of other autoimmune conditions such as rheumatoid arthritis, inflammatory myositis, biliary cirrhosis, scleroderma, Hashimoto's thyroiditis or lupus, while still being "mostly" Sjögren's. These features may warrant certain anti-inflammatory interventions. This would include corticosteroids for inflamed muscles, drugs that promote more oxygen to dilate the vessels of the hands for individuals with Raynaud's (often seen with scleroderma or lupus), approaches that halt the development of erosions (bone destruction) with rheumatoid arthritis (e.g., anti-TNFs), ursodiol for biliary cirrhosis, antimalarials for subacute cutaneous lupus rashes in anti-SSA positive patients or thyroid. Identification of a secondary autoimmune overlap can often explain symptoms that may be profound but are not a part of Sjögren's. ■

“CPG 2” continued from page 1 ▼

Systemic manifestations in Sjögren’s

Phase 2 will include five new topics on the systemic manifestations of Sjögren’s, including: pulmonary; peripheral nervous system; central nervous system; lymphoma and other blood cancers; and vasculitis. To date, three of these topics are underway.

Pulmonary

The Pulmonary Topic Review Group is comprised of both rheumatologists and pulmonologists and will be looking at a variety of potential pulmonary complications in Sjögren’s. Areas of pulmonary coverage include: screening and diagnosis; upper airway disease (xerostomia, dysphagia, laryngopharyngeal reflux, vocal cord and obstructive sleep apnea); lower airway disease (xerotrachea, bronchiectasis, bronchiolitis, obstructive lung diseases including COPD and asthma); interstitial lung disease; lymphoproliferative disease (including bronchus-associated lymphoid tissue lymphoma/non-Hodgkin lymphoma, amyloid and nodular lymphoid hyperplasia); vascular lung disease; lung transplant; and peri-operative and other non-medication management.

To date, and as part of the development process, this group has drafted 195 clinical questions and identified nearly 1,600 articles on relevant topics through a review of the literature.

Central Nervous System (CNS)

The Central Nervous System Topic Review Group is comprised of experts representing a variety of specialties, including rheumatologists, neurologists, neuro-ophthalmologists, neuropsychologists, psychiatrists and sleep specialists. Areas of CNS coverage are based upon the clinical syndromes involving encephalopathies, seizures, strokes and myelopathies and etiologies including demyelinating and vasculopathic pathology. Specific topics include: vasculitis; optic neuritis; vestibular/auditory, olfactory, taste; autoimmune encephalitis; myelitis or other demyelinating syndromes; psychiatric (anxiety, depression, psychosis); cognitive dysfunction; and impaired sleep. Nearly 160 clinical questions have been drafted related to the CNS and Sjögren’s.

Peripheral Nervous System (PNS)

The Peripheral Nervous System Topic Review Group is comprised of both rheumatologists and neurologists and

Round 1 of SSF Sjögren’s Clinical Practice Guidelines (CPG) Fast Facts

- 56 Recommendations were issued for oral, ocular and rheumatology/systemic management and treatment aspects for Sjögren’s patients
- 172 volunteers were involved in the CPG initiative
- 8 patients participated on the Expert Consensus Panels that voted on the Recommendations
- 42 experts led the effort for oral, ocular and rheumatology/systemic guidelines
- 129 experts participated in the Expert Consensus Panels that reviewed and voted on Oral and Rheumatology Recommendations
- 6 posters were presented at professional meetings on the guidelines
- 2,153 abstracts were reviewed for oral and rheumatology guidelines



will be looking at a variety of topics. Areas of PNS coverage are based on both the neuro-anatomic localization to the motor, sensory and autonomic nerves and the etiology involving demyelinating, axonal and antibody-based pathologies. Specific topics include: cranial neuropathies; axonal, sensory motor or sensory neuropathies; small fiber neuropathies (length dependent or non-length dependent); ataxic sensory neuropathies/large fiber ganglionopathies; mononeuritis multiplex/multiple mononeuropathies; and autonomic neuropathies.

To date, this group has drafted 475 informational and clinical questions and identified more than 2,700 articles on relevant topics through a review of the literature.

The remaining two topics under systemic manifestations, lymphoma and other blood cancers and vasculitis, in Sjögren's have not started, but will get underway after the other systemic topics have been completed.

Oral Manifestations of Sjögren's

Phase 2 will include three new topics on the oral manifestations of Sjögren's, including: caries management and restoration; mucosal management and symptom relief; and the use of secretagogues. Currently, work has begun on the topics of mucosal management and symptom relief and the use of secretagogues. Guidelines for caries management and restoration, which will begin after substantial progress has been made on the first two topics, will build off of the guidelines on caries prevention developed in Phase 1.

Mucosal Management and Symptom Relief

The Mucosal Management and Symptom Relief Topic Review Group has drafted more than 50 clinical

questions and will be looking at a variety of areas covering symptoms of oral mucosal pain and/or inflammation in Sjögren's. Specific topics include: prevalence and identification of oral cancer; prevention and management of burning mouth; oral candidiasis; lichenoid reactions or hypersensitivity-induced mucositis; and oral trauma associated with oral dryness.

Use of Secretagogues

The Secretagogues Topic Review Group has drafted nearly 20 clinical questions and will be exploring a few topics related to sialogogues. Specific topics include the demonstration of improved salivary flow and composition; a reduction in the occurrence of candida, other oral infections and burning mouth; and a translation of better outcomes for the incidence of caries, periodontal disease, taste disturbance, hoarseness, chronic cough and subjective and objective dryness and discomfort.

Ocular Manifestations of Sjögren's

This group will focus on updating the ocular guidelines published during Phase 1 and building off of the findings of the Tear Film and Ocular Surface Society (TFOS) Dry Eye Workshop (DEWS) II report. Both of these documents are available online and can be found using the URLs below:

- Phase 1 Guidelines on Ocular Management in Sjögren's Patients:
www.sjogrens.org/files/research/OcularCPG.pdf
- TFOS DEWS II Report:
www.tfosdewsreport.org/report-tfos_dews_ii_report/36_36/en

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“CPG 2” continued from page 9 ▼

Cross-cutting Topics

Phase 2 will also include a cross-cutting guidance on parotid and lacrimal gland swelling, which spans rheumatology, oral and ocular medicine. More information on this topic will be available at a later date.

How are these guidelines created?

Creating reputable guidelines is an arduous and lengthy undertaking. In Phase 1, the SSF consulted with other professional organizations, including the American College of Rheumatology, American Dental Association, consultants from the American Society of Clinical Oncology and the Grading of Recommendations Assessment, Development and Evaluation (GRADE) methodology system to devise a transparent and rigorous guidelines development process. This process informed all aspects of guideline development, which includes drafting clinical questions, pre-selecting parameters for acceptable studies, literature searches and extracting data from selected studies and using a Delphi-type approach to gain consensus for recommendations. For consensus, the SSF creat-



Nancy Carteron, MD, FACR; Katherine Hammitt, MA; and Theresa Lawrence Ford, MD, FACR, during a scientific poster session at the 14th ISSS in Washington, DC

Recently, at the International Sjögren's Syndrome Symposium this past April, the SSF presented three scientific posters on Phase 2 of the Clinical Practice Guidelines. Though still in process, these posters brought awareness to the initiative and sparked important interest around this work.



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*Survey of 1168 dentists, March 2016 Clinicians Report[®], an independent, non-profit, dental education and product testing foundation. Citation available at oracoat.com

†These statements have not been evaluated by the Food and Drug Administration. This product is not intended to diagnose, treat, cure or prevent any disease.

‡In people with dry mouth who use 2 discs while sleeping and 4 more during the day.

ed Consensus Expert Panels, comprised of a least 30 professional experts and patients, who reviewed, voted and provided input on recommendations. A minimum of 75% consensus is needed in this step of the process.

The same process is being used in Phase 2. Notably, the SSF is working with new partners in this round, including the American Academy of Neurology, a group the Foundation had not previously worked with. By reaching out to these and other specialists, the SSF hopes to obtain an even broader acceptance and distribution of these guidelines, which will help to create awareness amongst the different specialty groups.

The SSF is excited about this important initiative and the potential impact it will have for ensuring that providers have access to the best information for managing and treating Sjögren's, which will facilitate patients receiving the appropriate and consistent care they need. ■

2018
National Patient Conference

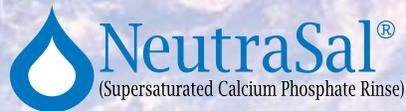
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30 Faces for Sjögren's Awareness: This is Sjögren's

Day 1



Day 30



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Sjögren's and Dry Eyes: What's New? by Stephen Cohen, OD	\$30	\$18		
How Sjögren's Can Impact the Central Nervous System by Edward A. Maitz, PhD	\$30	\$18		
Lymphoma: Risk, Treatment and Prognosis by Richard F. Ambinder, MD, PhD	\$30	\$18		
Joint Pain and Sjögren's by Donald E. Thomas, Jr., MD	\$30	\$18		
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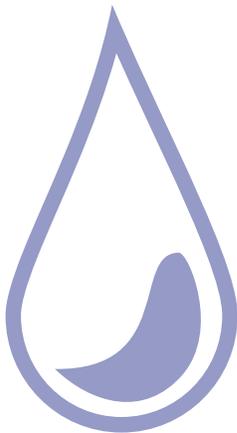
“NPC 2018” *continued from page 6* ▼

the Illinois School of Optometry and had a portion of the funds from the registration donated to the SSF as a charitable gift.

Dr. Hogan is a perfect example of someone helping the SSF advance our mission and we are honored to present her with the 2018 Mission Service Award! ■



Conference Moments



One Day Sjögren's Patient Conference

Saturday
June 30, 2018

Rosenthal Pavilion at
NYU Kimmel Center,
New York, New York

Registration required

If you have questions or are interested in volunteering, please contact Ben Basloe at the SSF at (301) 530-4420, ext. 207 or bbasloe@sjogrens.org.



in memoriam

In Memory of Camille G. Silliman

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Sherry Peña

Marathon County Friends of Camille

In Memory of Carol Geisler

Jeff and the team at CVS Regulatory

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In Memory of Michael E. Cromar

The Children of Shirley Peterson c/o Carol Vuceta

In Memory of Susie M. Smith (Phyllis)

Brenda Kiger and Sandy Smith



in honor

In Honor of Joyce Granger

Mike and Ruthie Granger

In Honor of Kim Vaughn

Mary Weinstein
Wade and Kelly Malone

In Honor of Kimberly Giovannetti

Christina Parkinson

In Honor of Lari Lopp

Isabelle and Steve des Fontaines

In Honor of Laura Mancuso

Marjorie and Art Knapp

In Honor of Mary Ladd Cope

Jennifer Howard



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

Get Ready to Celebrate!

World Sjögren's Day is July 23!



Dr. Henrik Sjögren

World Sjögren's Day commemorates the birthday of Henrik Sjögren, the Swedish ophthalmologist who first identified the disease in 1933. More importantly, this day is meant to put a face on the millions of people who live with this disease and help raise Sjögren's awareness.

World Sjögren's Day gives everyone touched by Sjögren's a vehicle to reach out and educate those close to them - family, friends, co-workers, neighbors, etc. – about the disease. It is the ideal opportunity for you to have your voice heard and share your story.

On July 23, we encourage you to join with the SSF and Sjögren's organizations around the world, to celebrate recent advancements made in Sjögren's and raise awareness. In helping to educate others, you are helping to form the message that Sjögren's is a serious disease.

Mark your calendars and visit www.sjogrens.org to learn how you can join in the celebration of what would have been Dr. Henrik Sjögren's 119th birthday!

