

The Moisture Seekers

Sjögren's Syndrome Foundation



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SjogrensSyndromeFoundation

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50%
in 5 years
Sjögren's
syndrome
FOUNDATION

by Elizabeth Trocchio
SSF Senior Director
of Marketing



SSF 5-Year Breakthrough Goal Update: **WE DID IT!**

In January 2012 the SSF embarked on our 5-Year Breakthrough Goal: "To shorten the time to diagnose Sjögren's by 50% in five years!"

When the Sjögren's Syndrome Foundation (SSF) first launched our Goal, the average time it took for a patient to be accurately diagnosed with Sjögren's, from the time they started seeking a diagnosis, was nearly six years. This was too long, and meant that to achieve our Goal we would need to shorten the diagnosis time to less than three years.

Now, in this final SSF 5-Year Breakthrough Goal update, the Foundation is honored and excited to announce that we have not only reached our Goal but have surpassed it, by reporting that **the average diagnosis time is currently 2.8 years!**

When we first embarked on our Goal, we understood that changing the diagnosis time was an ambitious initiative and one that we might not succeed at, but we also knew it was an important initiative to help the millions of patients who were suffering from the symptoms and not yet diagnosed with the disease. We believed that our Goal would transform the disease because as physicians started seeing more Sjögren's patients in their practices, they would need to become more knowledgeable of the disease's different manifestations and the treatment options available.

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SSF at the 2017 American College of Rheumatology Annual Meeting



SSF Booth

The American College of Rheumatology (ACR) Annual Meeting was held November 4-8, 2017 in San Diego, CA. 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 staffers were available to help educate

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Diagnosing a patient quickly can be a challenge because often a patient will discuss tooth decay with their dentist, vaginal dryness with their gynecologist and fatigue or joint pain with their primary care doctor. While each symptom alone wouldn't indicate an underlining autoimmune disease, when coupled together they would suggest Sjögren's.

"We cannot sit on the sidelines and let undiagnosed patients suffer any longer. That is why the SSF Board of Directors is taking action to ensure we do everything we can to increase awareness and to help those patients yet to be diagnosed.

It will take an army to achieve our Goal, but just imagine if we all band together – how we could change the face of Sjögren's for all patients, present and future!"

Steven Taylor, SSF CEO, in January 2012.

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 continue to work on educating all specialties within the medical community, as well as encourage the general public to be their own health advocates by knowing the symptoms of Sjögren's.

An early diagnosis and proper treatment are important for preventing serious complications and greatly improve a patient's quality of life. Without appropriate treatment, patients may develop serious consequences such as corneal scarring, loss of teeth, internal organ involvement, misdiagnosed neuropathy pain, profound fatigue, or chronic upper respiratory problems. Systemic issues could also be caught earlier and mitigated. We know many SSF members could have benefited if a physician had only considered Sjögren's earlier on and helped them receive a proper diagnosis. And as difficult as the physical symptoms can be, we at the Foundation are aware of how devastating the emotional repercussions of having a misdiagnosed or undiagnosed disease can be. Over the years, patients would often tell us about their daily struggle with worrying about what was wrong with them before they were diagnosed and the validation they eventually felt when knowing there was an explanation for their symptoms.

Below, you will read more about the history of our Goal and the journey it took for us to reach this moment.

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“5-Year Breakthrough Goal” *continued from page 2* ▼

History of the 5-Year Breakthrough Goal

At first inception of our Goal, the Foundation began working with an outside marketing research company, Polaris, that surveyed newly diagnosed patients each year and analyzed the results to track the time it took for patients to receive a proper Sjögren’s diagnosis. The data discovered by them after the first survey in 2012 was used to set our benchmark.

The additional information gathered from Polaris was used by the SSF Breakthrough Goal Committee to develop three specific action items, with sub-goals, to help us achieve our ultimate Goal of shortening the diagnosis time. Every year, priorities were placed as sub-goals, under the three consistent action items, to help focus our combined efforts. Below are the three main action items that have remained consistent since 2012 and the sub-goals that were the focus in 2017.

Increase Public Awareness

- Strategically expand awareness efforts by utilizing volunteers across the country
- Expand fundraising efforts
- Optimize use of www.sjogrens.org as well as multiple social media outlets
- Continue to be the most credible resource for Sjögren’s information

Increasing involvement from our friends and partners

- Create a new approach to pharmaceutical relationships
- Expand our partnership with those outside the pharmaceutical market
- Continue to develop the SSF Clinical Trials Consortium
- Create relationships with marketing experts to further our outreach

Increase Education and Awareness in the Healthcare Professional Sector

- Increase education and awareness among rheumatologists
- Build strong relationships with the top professional areas that treat Sjögren’s patients
- Continue to develop Clinical Practice Guidelines and promote their use by clinicians

- Ensure that the Foundation is positioned as the go-to source for healthcare professionals for Sjögren’s information
- Ensure that our professional materials are meeting healthcare professional needs

Thank you for being our Army!

Back in 2012, we knew it would take an army to achieve our Goal and that is why we asked for your help. We knew, it would take hundreds of patients to help educate the medical community as a whole so that they would start taking Sjögren’s more seriously.

Today, 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!

The 2017 SSF Army by the numbers:

- Over 700 volunteers and 250 awareness ambassadors throughout the US gave their time to the SSF
- The SSF awarded 6 Sjögren’s research grants
- Volunteers stepped up and there are 65 active SSF support groups in the United States
- The Foundation served as international mentor to 25 international Sjögren’s patient groups
- SSF leadership with volunteer physicians started phase 2 on Rheumatology and Oral Clinical Practice Guidelines
- The Foundation launched “Smart Patients,” a new online discussion forum for Sjögren’s patients that now has 2,000 members
- Over 40,000 people “Like” the SSF Facebook page
- The SSF hosted our largest April awareness campaign for Sjögren’s Awareness Month
- Developed the first-ever online platform (STEP) to train clinical trial investigators in Sjögren’s
- SSF staff and volunteers attended numerous professional conferences and health fairs to represent the voice of all Sjögren’s patients
- Nearly 500 patients attended our 2017 National Patient Conference in Philadelphia
- **And we all decreased the time to diagnose Sjögren’s to 2.8 years!**

We knew it wouldn’t be easy to achieve our 5-Year Breakthrough Goal and our accomplishment is remarkable! The momentum our volunteers have created is

Meet Our Scientific Team

Kathy Hammitt

SSF Vice President of Medical and Scientific Affairs



As a long-time Sjögren's patient and one who has always enjoyed tackling challenges (and, yes, we all know that many challenges loom in the world of Sjögren's!), I feel passionately about working for changes that benefit Sjögren's patients and their caregivers. We must find better ways to deal with its symptoms and reduce patients' frustration with this disease, including the lack of knowledge and the dearth of treatments.

I'm a journalist by training and was a television news producer and writer in Washington, D.C. before becoming extremely ill after my daughter was born. It took another year and a half to get a diagnosis of Sjögren's (and tentative diagnosis of lymphoma that can come with Sjögren's, the first of several), which set me on a new life journey and followed 17 years of struggling with many seemingly disconnected symptoms and doctors perplexed by my complaints.

The physician who diagnosed me with Sjögren's offered to bicycle home and share his notes from medical school – all of two sentences! I immediately used my journalism skills on Sjögren's (pre internet) to learn as much as I could. I had the good fortune of meeting SSF founder Elaine Harris when I participated in a clinical trial for dry eye soon after my diagnosis and who provided me with an opportunity for action. I have been involved ever since. I now call myself a "Sjögren's Survivor" with more than 30 years of living with Sjögren's under my belt!

I started by covering Congress and the medical and scientific agencies it funds. Ensuring that the National Institutes of Health (NIH) added Sjögren's to its programs and grants and had the funding to execute these were a top priority. Millions of dollars were spent at the time on other diseases and conditions, but Sjögren's was near the bottom of the list. We needed our voices heard! We launched an NIH Autoimmune Diseases Coordinating Committee to bring different institutes together and focus on cross-cutting issues in autoimmune disease.

When SSF CEO Steven Taylor came on board in 2003, he brought a vision for accomplishing everything from greater awareness and education to patient

support and increased research. He hired a professional staff to get it done, and, as part of this vision, he brought me on to focus full-time on increasing research. I love to tackle the "big picture," figure out what needs to be accomplished, and strategize about how to get there and bring the right people together to create change and make progress. Working with our Medical and Scientific Advisory Board, we drafted a long list!

To increase research, we expanded our research grants program, developed and deepened relationships at key medical and dental centers and federal agencies, and held scientific workshops to bring different specialists together to focus on issues in Sjögren's. The worlds of science and medicine so often exist in silos, and bringing people together from different fields sparked collaborations that never would have happened otherwise and interactions that we continue to nurture. Likewise, we launched a newsletter for healthcare professionals that would bring information on all aspects of Sjögren's to a wide spectrum of those in clinical care and research.

We brainstormed together and realized that many healthcare providers sadly did not want to take care of Sjögren's patients because they didn't know what to do with them. In addition, no standards of care existed, so patients were treated very differently around the country (and the world), and healthcare training in Sjögren's was often non-existent and even detrimental as medical schools characterized Sjögren's as a nuisance rather than a severe and devastating systemic disease. As a result, we launched a major initiative – probably one of the biggest the SSF has ever launched – to develop the first Clinical Practice Guidelines in Sjögren's. Over the last two years,

“5-Year Breakthrough Goal” *continued from page 4* ▼

propelling us into 2018. With the help of many, the dream of making Sjögren’s a household name is within our grasp.

Although our job is far from done, the SSF has seen our years of hard work and perseverance paying off. Please enjoy this milestone celebration with us because it wouldn’t be possible without your support as an SSF

member! And know that the Foundation will continue fighting for you and ensuring that the patient voice is heard. 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.

Together we will conquer Sjögren’s and transform the future of the disease, giving hope to all patients! ■

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attendees about all we have to offer them. Visitors to the booth had the opportunity to subscribe to our medical newsletter, *Sjögren’s Quarterly*, which will keep them up to date on the latest clinical research and findings in Sjögren’s for years to come. *The Clinical Practice Guidelines*, patient materials and the *Living with Sjögren’s* survey results were all well distributed and met with great enthusiasm.



SSF Luncheon at ACR

The annual SSF luncheon meeting is an invitation-only gathering of rheumatologists and researchers from around the globe with a special interest in Sjögren’s. This year’s theme was Collaboration: Moving Sjögren’s Forward. Attendees enjoyed presentations from Theresa Lawrence Ford, MD, Chair of the SSF Medical and Scientific Advisory Board, and Kathy Hammitt, SSF Vice President of Medical and Scientific Affairs, who discussed the results of the SSF’s *Living with Sjögren’s* survey and international collaborations that are enhancing knowledge in Sjögren’s in areas such as genetics and biomarkers and data-pooling on symptoms, diagnostics and natural history as well as clinical trials in Sjögren’s. Also discussed at the meeting was the international research initiative HARMONICSS, led by Athanasios Tzioufas, MD, of the University of Athens, Athens, Greece. The collab-



Luncheon speakers

oration and analysis of regional, national and international cohorts on Sjögren’s will help move us towards improved stratification, treatment and health policy around Sjögren’s. Alan Baer, MD from Johns Hopkins University, Baltimore, MD, invited attendees to come to the 14th International Symposium on Sjögren’s Syndrome. This international conference, held every 2-3 years specifically for clinicians and researchers with a special interest in Sjögren’s, will take place in April 2018 in Washington, DC. To conclude, Steven Taylor, CEO of the SSF, wrapped up the luncheon with an inspiring view of how the Foundation is working with industry, providers, researchers, and patients to move Sjögren’s forward. The SSF would like to thank Theresa Lawrence Ford, MD for chairing this year’s event!

During the SSF Clinical Trials Consortium meeting that followed the luncheon, Dr. Ford covered the newly created Sjögren’s Training and Education Platform (STEP) that will be used as a tool for clinicians who are participating in Sjögren’s trials. Having all clinical trial clinicians complete the STEP training, can help standardize how data is collected and trials completed. This strengthens the overall results of multiple studies encouraging cooperation and collaborative comparisons across trials. In addition, Xavier Mariette, MD (Paris,

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France) discussed an international initiative to develop better outcome measures for clinical trials, and Valérie Devauchelle-Pensec (Brest, France) discussed the latest evidence on the usefulness of salivary ultrasound for diagnosing and monitoring Sjögren's patients during clinical trials. As Chair of the SSF Clinical Trials Consortium, Dr. Ford moderated the session.

Study groups are great opportunities for individuals interested in a particular area, such as Sjögren's, to come together and learn. During these sessions attendees often hear a presentation and then participate in large group discussions about the topic, asking questions and sharing ideas with their colleagues from around the world.

The annual Sjögren's Study Group was highly attended this year with more than 175 participants in the room. This year's theme was, "From Improved Patient Stratification, Towards Treatment," which was moderated by Athanasios Tzioufas, MD & Kathy Sivils, PhD. Three speakers presented during the session: Alan Baer, MD, Johns Hopkins University, Baltimore, MD, Francesca Barone, MD, PhD, University of Birmingham, Birmingham, United Kingdom, and Jacques-Olivier Pers, DDS, PhD, Université de Bretagne Occidentale, Brest, France. Together, these presenters spoke on the ability to separate patients according to risk factors for particular complications, which will greatly enhance the ability to monitor and manage patients as well as help physicians and companies identify which potential therapies will work for specific groups of patients.

The study group began with the the SSF presenting their annual Outstanding Abstract Award to two

individuals, Drs. Jessica Tarn and Katrine Norheim. Dr. Tarn was presented the award for her abstract entitled, "The Effect of Non-Invasive Vagus Nerve Stimulation on Fatigue and Immune Responses in Patients with Primary Sjögren's Syndrome." Dr. Norheim was presented the award for her abstract entitled, "Genetic Determinants of Fatigue in Primary Sjögren's Syndrome – a Genome Wide Association Study."

The study group with a focus on Childhood Sjögren's returned for its second year. Moderated by Scott Lieberman, MD, PhD (University of Iowa) this year's presentation, "Looking Toward the Development of Child-specific Diagnostic Criteria," discussed the initial look at data collected on children being treated for Sjögren's as part of an effort to develop better, more child-specific, criteria. Data suggests children present with Sjögren's a bit differently than adults, and since there are fewer children diagnosed with the disease, it is important for clinicians to begin collaboratively looking at children in greater numbers to find common threads and themes, leading to greater understanding.

Clinical programs on Sjögren's are always a great way for rheumatologists to learn more and gain greater insight into the disease. Once again, Fred Vivino, MD, FACR (University of Pennsylvania) 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, both of which filled the room.

Abstract sessions are a forum for providers to receive the latest developments on the most relevant

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topics in rheumatology. Every year the number of abstracts focusing on Sjögren's increases, which is an exciting thing for the disease. Researchers are gaining more and more interest in Sjögren's and others are interested in finding out how the field is progressing. More than 80 abstracts with a focus on Sjögren's were presented at this year's conference. These abstracts can be presented in one of two ways, either by poster or oral presentation. For poster sessions, researchers have a poster of their work and attendees visit during specific times where the researcher is available to discuss their work and answer questions. Two dedicated poster sessions on Sjögren's were a part of this year's conference. The first focused on translational research and the second on clinical research. During oral presentation sessions, several researchers present their work in a lecture format to the attending group. There

were two oral presentations focusing on Sjögren's this year, Sjögren's Syndrome I: Clinical Assessment and Trial Outcomes and Sjögren's Syndrome II: Pathogenesis, Autoantibodies and T-Cells.

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 with the SSF. This conference also allowed for us to pull together our Clinical Trials Consortium to talk about clinical trials available for both providers and patients to get involved in. Interested in finding out about clinical trials in Sjögren's? To learn more, please visit: <http://info.sjogrens.org/clinical-trials> ■

“Meet Our Scientific Team” continued from page 5 ▼

we published guidelines in prestigious journals for management and treatment of oral health/caries prevention, ocular manifestations, and three topics under rheumatology/systemic areas of Sjögren's (fatigue, inflammatory musculoskeletal pain, and use of biologics).

We are now tackling a very ambitious number of guidelines topics that include pulmonary involvement; the peripheral nervous system (including autonomic symptoms); the central nervous system (ranging from MS-like symptoms to cognitive dysfunction, anxiety and depression, and sleep problems); vasculitis; and lymphoma and other blood cancers. Under oral guidelines, we're working on caries management and restoration; mucosal management and treatment; and use of secretagogues. In addition, we're covering parotid and lacrimal gland swelling and updating the ocular guidelines. The most exciting part of this second phase of the guidelines is that we're bringing different specialists together to accomplish this. For example, in addition to rheumatologists, we are bringing neurologists, neuropsychologists, psychiatrists, sleep specialists, oncologists, and pulmonologists into Sjögren's to talk about the disease and share their expertise. We also are partnering with these specialists' professional organizations, so that, ultimately, we reach out to even more practitioners beyond those traditionally involved with Sjögren's.

We also brought international key opinion leaders and pharma together to brainstorm about why no one was working on a new systemic therapy for Sjögren's. This led to launching the SSF Clinical Trials Con-

sortium (CTC) which serves to identify barriers to increasing pharma interest in Sjögren's and their successful execution of clinical trials. We have pursued a dialogue with companies, and we now have at least nine companies that have launched clinical trials or are in pre-trial planning for new potential therapies. We continue to discuss issues they confront in their pursuit of clinical trials in Sjögren's and strategize about overarching issues with the CTC, and we work closely with these companies on clinical trial site selection, finding investigators who are experienced and knowledgeable about Sjögren's, and patient recruitment. There is much work to be done in this area, but it's exciting to see the changes and activity to-date that bring so much hope and promise to patients.

I enjoy serving on multiple national and international coalitions, committees and boards and use these to learn from others and ensure the voice of Sjögren's is heard by the broader community. My current service includes the 14th International Sjögren's Syndrome Symposium International Scientific Committee, the Tear Film & Ocular Society (TFOS) Steering Committee for the international Dry Eye Workshop (DEWS) II, and the American Association for Dental Research Board of Directors.

My daughter and son are grown now, and I have two grandchildren who bring me and my husband incredible joy. They have grown up with Sjögren's and are keenly aware of the problems this disease brings

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Stephen Cohen, OD

Chairman of the SSF Board

Q “I recently heard about a corneal bandage for dry eye. How does this work? Is this a treatment option for me since I have Sjögren’s? Can I still use my eye drops?”

A Inflammation can cause damage to our organ systems and chronic inflammation can cause long-term damage. Ocular inflammation can cause symptoms such as pain, redness, blur, dryness, fluctuating vision, itching, burning, photophobia (sensitivity to bright lights), and ocular fatigue, and prolonged and recurrent inflammation can make healing more difficult. Each day, the inflammatory cycle causes irritation to the surface of our eyes, particularly the “conjunctiva (the clearing coating over the white part of our eyes)” and the “cornea (the clear cap over the colored part of our eyes).” With Sjögren’s, irritation to the cornea can progress throughout the day, and, while some healing might occur when we sleep at night, the cycle continues and can worsen over time.

Certain contact lenses have been used as a corneal “bandage” to protect the surface of the eyes. More recently, however, the use of “amniotic tissue (obtained from a strictly regulated tissue bank from planned C-sections)” has been used not only for wound healing, but also to reduce inflammation and to promote healing of the corneal surface for people with chronic dry eyes. Studies have shown

that with this FDA-cleared, in-office 4-5 day treatment (one eye at a time), benefits can be sustained for several months. Patients have reported less pain, irritation, better and more consistent clarity of vision, and less need for lubricating drops. The treatment can be repeated as needed. While during the treatment period vision in the treated eye will be blurry, and there can be some awareness of the device in the eye, patients can maintain their normal activities. Patients who are using eye drops (lubricating, topical medications) can continue to do so while the tissue is on the eye. Two of the main products on the market are “Prokera (whose process maintains full biologic activity)” and “Bio D (which uses a dehydrated form of the tissue).”

I have had the opportunity to use this treatment for quite a few Sjögren’s patients, many of whom have since returned for repeat treatment. Since there is notable healing of the corneal surface, we have found that the interval between repeat treatments has increased as patients are experiencing sustained benefits for longer periods of time.

This is an exciting newer option to help our Sjögren’s and other dry eye patients see better and feel better. You can check with your eye care professional to see if this might be an option for you, and with your insurance carrier about possible coverage for the treatment. ■

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

“Meet Our Scientific Team” continued from page 8 ▼

for both patient and family. I come from a family of educators, and hence my drive to ensure that healthcare professionals understand this disease, appreciate its seriousness, and know how to manage and treat it. And, with both of my grandfathers having been physicians (and one also a pharmacist), a great-grandfather as a physician, and an uncle and cousins in medicine, I must have inherited a love of looking at the state of the science, what can be done to offer the best medical management, how we might come up with better solutions, and, ultimately, what we can do to ensure a better future for patients.

My areas of focus have increased significantly since I first started working for the SSF, and new ideas that should be pursued for continual progress always emerge, so I was very excited when CEO Steven Taylor raised the funds to hire Matt Makara as Director of Research and Scientific Affairs. With Matt joining me as a critical part of the scientific team, he is taking over some of the initiatives I’ve long handled, will tackle new projects that will change the face of Sjögren’s, and in a short time has already proven to be a major asset in driving our accomplishments and reaching for heights we never before thought possible!

Matt Makara

SSF Director of Research & Scientific Affairs



I’ve always been interested in health and the medical field, so I saw joining the SSF as part of the research and scientific team was a great opportunity. Since coming on board in September I’ve learned quite a bit and gained a healthy appreciation for Sjögren’s and the associated challenges for the

millions of patients living with the disease.

My education and professional background is in public health and communications. I’ve worked on a variety of nationwide, far-reaching, campaigns for prominent non-profit organizations as well as multiple agencies within the federal government. These efforts were focused on reaching and educating audiences on important health issues and advances. Through these experiences I’ve learned the importance of, and gained the skills for, conducting targeted campaigns and ensuring that the appropriate information and resources are accessible to those who need them most. I feel this is very important with Sjögren’s. As I’ve learned in my short time with the Foundation, there are many questions that remain unanswered and confusion around

certain aspects of the disease.

One way the SSF helps address such questions and disseminates important information related to Sjögren’s to key audiences is by publishing the *Sjögren’s Quarterly*, a medical newsletter with an increasingly growing subscribership of healthcare professionals. Here, the Foundation provides current news from relevant medical fields, including rheumatology, ocular and oral medicine, and more. Industry and foundation news are also included, as well as major occurrences in Sjögren’s and related fields. This publication also includes guest contributions from experts in the field, which provides clinicians and researchers the opportunity to share research and provide their perspectives on a variety of topics, both of which have made for important, thought-provoking, contributions over the years. In my new role with the SSF I serve as the associate editor for the *Sjögren’s Quarterly*. This role has proven a great learning experience as it has forced me to delve into research and current events relevant to the field and become acquainted with the various facets of the disease.

Also, as part of my new position, I oversee the SSF Research Grants Program. These grants are critically important to providing investigators with the means to study this complex disease. By providing these funds, we’re ensuring that opportunities for Sjögren’s research continues and stays top-of-mind for interested investigators. Excitingly, our current grant recipients are investigating a variety of important topics, many on the cutting edge of the field, including the microbiome and Sjögren’s and novel treatments for the various manifestations of the disease.

Lastly, as part of my new role, I’ll have the opportunity to establish and maintain relationships with important partners, including NIH, FDA, and other organizations. Doing so will ensure that Sjögren’s is taken seriously and has a voice at the table, so-to-speak, in the important conversations that are taking place. I feel my prior experience working with similar agencies will help foster these relationships and continue the positive advancements that we’ve recently seen with Sjögren’s further into the future.

In my new position, I work closely with Kathy Hammitt, Vice President of Medical and Scientific Affairs at the SSF, who in my short time with the Foundation has been a great mentor and a wealth of knowledge on the disease. I’m encouraged by the progress that’s been made to this point and remain excited and optimistic about working with Kathy, the SSF staff, and the rest of the Sjögren’s community as we work together to advance the Foundation’s mission to educate patients, increase public and professional awareness, and encourage research into new treatments, and ultimately, a cure for Sjögren’s. ■

You Stood Up!

Thank you Noah Syndergaard and Gotham Magazine for shining the spotlight on Sjögren's

As *Gotham* magazine hosted a VIP reception celebrating their cover star Noah "Thor" Syndergaard, a baseball pitcher for the New York Mets, they also ensured that the event would help raise awareness of Sjögren's.

Noah has been an advocate for the disease since his mother, Heidi, was diagnosed. Heidi is a long-time volunteer with the Sjögren's Syndrome Foundation (SSF) and Noah is always looking for ways to support her. "She's a fighter," he commented to *Gotham* magazine. This is why it was not surprising that Heidi, Steven Taylor (SSF CEO) and Foundation staff were in attendance on Noah's big night.

The evening included a silent auction featuring official sports memorabilia from Noah and the NY Mets. Then, at the height of the event during the live auction, Noah tossed out official autographed baseballs, with all proceeds benefiting the SSF!

This is not the first time Noah has helped shine the spotlight on Sjögren's. He is often seen wearing his blue and white SSF Sjögren's Awareness Wristband, talking about the disease in media interviews, and has

previously auctioned off some of his gloves to raise money for the SSF and fight the disease.

Thank you Noah for stepping up to honor your mother and *Gotham* magazine for raising awareness of the disease by giving Sjögren's a platform! ■



Heidi, Noah Syndergaard and Steven Taylor

SSF Calendar Upcoming 2018 Events

Phoenix Walk for Sjögren's

Saturday, March 10, 2018
Paradise Valley Mall

2018 SSF National Patient Conference

April 13-14, 2018
Hyatt Regency Aurora- Denver Conference Center

Denver Walk for Sjögren's

Saturday, April 14, 2018
Hyatt Regency Aurora- Denver Conference Center

Philadelphia Tri-State Area Walk for Sjögren's

Saturday, May 5, 2018




in memoriam
In Memory of Evelyn Reisner

Elaine Cohen

In Memory of Heather C. McGlynn

Jacqueline Farrell
 Angela Scardinale
 Jane Marone
 Jennie Scardinale

In Memory of Jill Walker

Susan Sunderman

In Memory of Judith Bureau

Mary and George Mantak
 Sheldon Hausman

In Memory of Laura F. Lotkowitz

James Granger
 Vonnie Boitnott

In Memory of Shirley Dailey

The Quinn Family
 Timothy and Tina Dailey

In Memory of Leona H. Diamond

Shelly Homer

Ann and Stan Pruskowski

Catherine D. Siegl

Janet and James Roop

Sal and Kelly Sabatino

Airgas Friends

Judith W. Carmint

Elaine M. Bono

Sandy Kulesza

Marge Tepper and Judy Bigelow

In Memory of Linda Troutman

The Matsutani Family

In Memory of Martha Keeley

Chubb Charitable Foundation

In Memory of June M. Butteriss

Greta Somers

In Memory of Nancy Jane Vetare

Barbara J. Signore

Martin, DeCruze and Company

Mr. and Mrs. Daniel Pote

Peter Mazure

IHC

Cathy Toothill

Kaye May

Steve Bader

Elaine and Jim Matts

In Memory of Oma Lou Mushrush

Alys R. Veal

In Memory of Rita Macellaio

Joan C. Harmon

In Memory of Toby and Pearl

Jake and Shana Guerrero

In Memory of Vivian P. Sangil

Amy Semanscin


in honor
In Honor of Annie Palider

Alex McCrae

In Honor of Barb and Bob Deloian

Garrett and Kat Deloian

In Honor of Carol Hirashiki

Jennie Handy

In Honor of Darlene Sabinske

Kim and Chris Bowman

In Honor of Deborah Dudley

Mr. and Mrs. Joseph Eckenrode, Jr.

In Honor of Dee Searle

Shanise Marshall

In Honor of Grace Tiger

Matthew and Elaina Roberts
 Jon Zeisler

In Honor of Heather and David Dungag

Paul T. and Martha E. Biker

In Honor of Jaynie Judaken

Betty H. Green

In Honor of Kathy Hammitt

Your friend, Ida

In Honor of Kayla Chen

Negda Jahanshahi

In Honor of Kim Wilkins

Jacobs Levy Equity Management

In Honor of LeeAnn Henn

Julie Schwartz

In Honor of Linda Bocell

Your Husband

In Honor of Lindsay Hatfield

Catherine D. Siegl

In Honor of Margaret Burkholder

Barbara and Joe Cudzik

In Honor of Margaret Rothman

Gale and Bruce Stockman

In Honor of Marie Regas Kaufman

Jennine Regas and Paul Regas

In Honor of Michiko Bowman

Kim and Chris Bowman

In Honor of Mrs. Dennis Howard

Jane Webb

In Honor of Nancy Crabbe

Jane Stone

Pete Giacobelli

In Honor of Nancy Poole

Lisa Reeser

In Honor of Nancy Visocki

Gail Berkoff

In Honor of Paula Sosin

Rosalyn Salzman

In Honor of Susan GonzalezWhitney Fields, *Stella and Dot***In Honor of Susan Paul-Souza**

Rita L. Paul

Lisa DiMarino

In Honor of Thalia Roderick

Andrew Roderick

In Honor of Valerie Usilton

Caneo Coleman

In Honor of Viktoria Schaub

Clemens Bruns Schaub

In Honor of Wanda Wannall

Will Wannall

A Note From Your CEO

Dear Friends,

I am excited to announce that the SSF National Office has moved just over 10 miles away to Reston, Virginia. Our phone number, (301) 530-4420, will stay the same but our new address is now:

10701 Parkridge Blvd., Suite 170 • Reston, VA 20191

Thank you for your support of the SSF as we move into this next chapter and continue to fight for all Sjögren's patients!



Sincerely,
 Steven Taylor, SSF CEO

Join Us
in Denver

2018
National Patient Conference

Exploring Sjögren's

April 13-14, 2018

Hyatt Regency Aurora-Denver Conference Center

13200 East 14th Place, Aurora, Colorado



Speakers and Topics of Discussion - NPC 2018

Sjögren's Overview

Chadwick R. Jöhr, MD, is an Assistant Professor of Clinical Medicine in the Division of Rheumatology at the University of Pennsylvania. He is also the Co-Director of the Penn Sjögren's Center and has a special interest in caring for patients with Sjögren's. Dr. Jöhr 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.

Ocular Manifestations of Sjögren's

Stephen Cohen, OD, a private practice optometrist in Scottsdale, Arizona, since 1985, 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. Dr. Cohen is a past-president of the Arizona Optometric Association and is the current Chairman of the SSF Board of Directors.

The State of Sjögren's: Transforming the Future

Steven Taylor, SSF Chief Executive Officer

The Sjögren's Syndrome Foundation (SSF) has been embarking on new initiatives that are realizing huge advancements for Sjögren's patients. From clinical trials for new therapies, to research to unlock the mystery of Sjögren's, Steven Taylor, CEO of the SSF, will share with us what is on the horizon for Sjögren's patients.

Following his talk, Mr. Taylor will lead a panel discussion with:

Janet Church, SSF Chairman-Elect

Stephen Cohen, OD, SSF Chairman of the Board

Ken Economou, SSF Immediate Past Chairman

The panelists will discuss the leadership of the SSF, talking about where we have been, where we are now, and where we plan to go in the future!

Product Showcase

Sjögren's patients use a number of over-the-counter products to treat their various complications. During this session, we will highlight the vast array of products that are available for Sjögren's patients. You won't want to miss this informative and helpful talk!

Banquet Awards Dinner and Keynote Speaker

Darlene F. Cross, MS, LMFT, is a Licensed Marriage and Family Therapist in Henderson, Nevada, with 20 years in private practice. Darlene is also the author of the Amazon Best Seller, *A New Normal: Learning to Live with Grief and Loss*. Additionally, she is the author of *Reinventing Normal: How Choice and Change Shape Our Lives*.

We are delighted to have Darlene Cross as our 2018 Keynote Speaker – who will speak as a clinician who works with people coping with an array of losses, including loss through chronic illness, a subject she knows well being a Sjögren's patient herself.

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.

How the Central Nervous System Can Impact Sjögren's

Edward 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, and has faculty appointments at Drexel University College and Widener University. 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 will share his vast knowledge about the physical, cognitive ("brain fog"), and psychological manifestations of Sjögren's.

Lymphoma: Risk, Treatment and Prognosis

Richard F. Ambinder, MD, PhD, currently serves as the James B. Murphy Professor of Oncology and the Director of the Division of Hematologic Malignancies at the Johns Hopkins Kimmel Cancer Center. Dr. Ambinder is active in the treatment of lymphoma and is the Co-Leader of the SSF's Lymphoma Clinical Practice Guidelines group. Dr. Ambinder will clear away the confusion surrounding lymphoma and Sjögren's, defining the risks to Sjögren's patients and outlining the symptoms, treatment, and prognosis.

Tips for Comfortable Living

Do you have a tip for living with Sjögren's? Have you found a great way to cope with your Sjögren's? Bring your ideas to our conference and be ready to share them! We will be asking a few patients to join us on stage to share some practical tips for coping with the day-to-day symptoms of this chronic illness.

Joint Pain and Sjögren's

Donald E. Thomas, Jr., MD, has a special interest in systemic autoimmune diseases, especially Sjögren's and lupus. He is in private practice in Maryland, but he also enjoys teaching health care providers about Sjögren's. He is passionate about empowering patients, and he is the author of the patient education book, "The Lupus Encyclopedia: A Comprehensive Guide for Patients and Families." Dr. Thomas will add to your understanding of the many causes of joint pain and will offer tips to help you cope as well as treatment regimens.

Oral Manifestations of Sjögren's

Ava J. Wu, DDS, is Clinical Professor, 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 dry mouth issues. After seeing thousands of patients in her career, Dr. Wu will deliver the answers that you have been waiting to hear.

Clinical Trials Update

Every day research is being conducted to unveil new medications, therapies and diagnostic tools for Sjögren's. Join us for this informative presentation about how clinical trials add to our medical knowledge and, most importantly, the result of these trials can make a difference in the care and treatment of Sjögren's patients.

Dermatological Issues and Sjögren's

Natalie Wright, MD, is a board certified dermatologist practicing in Dallas, Texas, who specializes in the diagnosis and management of autoimmune conditions of the skin. She manages the skin manifestations of lupus, Sjögren's, dermatomyositis, systemic sclerosis, sarcoidosis, and psoriasis, in addition to skin cancer and general dermatologic conditions. She completed specialized training in these disorders at Harvard Medical School and Brigham and Women's Hospital in Boston. Sjögren's patients can present with a variety of skin disorders that Dr. Wright takes special interest in diagnosing and managing.

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.



2018 NATIONAL PATIENT CONFERENCE

Hyatt Regency Aurora-Denver Conference Center, Colorado

April 13 – 14, 2018

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 21, 2018)

SSF Members & Guests

Non-Members

March 21st and before

\$170 per person

\$190 per person

March 22nd 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 March 26th 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 Hyatt Regency Aurora-Denver Conference Center (13200 East 14th Place, Aurora, Colorado 80011) at the SSF rate of \$132 per night plus tax if reservations are made by March 22, 2018. Call the toll-free hotel Central Reservations number at 1-888-591-1234 or call the Hyatt Regency Aurora-Denver Conference Center directly at 1-303-365-1234 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
- The Hyatt Regency Aurora-Denver Conference Center is approximately 16 miles from the Denver International Airport.

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

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

SSF Outstanding Abstract Awards at ACR

The Sjögren's Syndrome Foundation (SSF) was delighted to select two winners for this year's Outstanding Abstract Award at the 2017 American College of Rheumatology's (ACR) Scientific Meeting in San Diego, CA. The recipients, Drs. Jessica Tarn and Katrine Brække Norheim, were recognized for their exceptional work during the Sjögren's Study Group on Sunday, November 5, 2017.

Dr. Jessica Tarn, Institute of Cellular Medicine, Newcastle University Medical School, Newcastle upon Tyne, United Kingdom received the award for her abstract entitled, "The Effect of Non-Invasive Vagus Nerve Stimulation on Fatigue and Immune Responses in Patients with Primary Sjögren's Syndrome." This study used the gammcore device to dissect the relationship between the vagus nerve, fatigue and immune response in Sjögren's and found that non-invasive vagus nerve stimulation may reduce clinical symptoms of fatigue, which could be underpinned by biological changes detectable in the whole blood.

Dr. Katrine Brække Norheim, Clinical Immunology Department, Stavanger University Hospital, Stavanger, Norway, received the award for her abstract entitled, "Genetic Determinants of Fatigue in Primary Sjögren's Syndrome – a Genome Wide Association Study." This study, the largest of its kind, examined fatigue in autoimmune disease and identified genetic variants in RTP4 that exceeded the study's level for association with fatigue. These findings provide additional evidence to a genetic regulation of fatigue.

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 eighty-four eligible applicants and are available online on the SSF website at <http://www.sjogrens.org/home/research-programs/outstanding-abstract>.



*Dr. Jessica Tarn
and SSF CEO
Steven Taylor*



*Dr. Katrine Brække Norheim
and SSF CEO Steven Taylor*