2017 SSF National Patient Conference Highlights
This is Sjögren’s: An educational journey

On Friday, March 31, nearly 500 attendees traveled from 35 states and 3 countries to Cherry Hill, NJ for the 2017 Sjögren’s Syndrome Foundation’s (SSF) National Patient Conference, “This is Sjögren’s: An educational journey.” The Conference was a huge success thanks to the 10 exhibitors, 12 guest speakers, and all of our attendees who came ready to learn and share with others.

Over the years, SSF Conferences have helped thousands gain a better understanding of Sjögren’s while giving them an opportunity to meet fellow Sjögren’s patients. As part of the SSF’s mission to educate patients and their family members, the SSF takes planning this Conference very seriously. We recruit expert speakers from around the country to talk on the most pressing topics and each presentation also allows time for audience questions at the end.

Clinical Trials

by Herbert S. Baraf, MD, FACP MACR, Clinical Professor of Medicine, George Washington University; and Managing Partner, Arthritis & Rheumatism Associates, PC, Wheaton, Maryland

Understanding Clinical Trials

Clinical Research, Clinical Trials, Clinical Studies, Protocols – These are terms that describe the process by which we advance our understanding of disease and make medical progress in treatment.

Goals of Clinical Research –

- Identify causes of disease
- Evaluate treatment options with either new or existing medications or therapies
- Compare treatments

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Understanding Clinical Trials

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The SSF Education Committee works to ensure that the yearly program caters to both newly diagnosed patients and longtime Foundation members by continuously introducing new topics to cover the disease’s complexity. In one weekend it is impossible to cover every aspect of the disease, but this year the Foundation was very excited about new topics that were presented for the first time, including Pediatric Sjögren’s presented by Scott Lieberman, MD, and Men with Sjögren’s that was presented by Nancy Carteron, MD. The complete list of topics included:

- Sjögren’s Overview
- Pulmonary Issues and Sjögren’s
- Oral Manifestations of Sjögren’s
- Pediatric Sjögren’s
- Ocular Manifestations of Sjögren’s
- Men with Sjögren’s
- Social Security Disability for Sjögren’s
- Neurological Complications and Sjögren’s
- Are you Collecting Autoimmune Diseases?

Friday evening ended with the SSF Banquet Awards Dinner, honoring volunteers, groups, and organizations that have helped to further the Foundation’s mission by stepping up for all patients. Following the awards ceremony, the 2017 Keynote Address was given by Janet Church who closed the inspirational event by sharing with the audience her journey of how to re-invent yourself after a diagnosis - a necessity when living with an autoimmune disease.
The second day was full with 8 informative presentations and attendees took a mid-day break to participate in our Cherry Hill Sjögren’s Walkabout! This family-fun event was held right outside the Conference Center where participants took a brisk walk before lunch and afternoon speaker presentations, while also raising funds to benefit SSF programs.

Thank you to everyone who attended this year’s Conference and committed themselves to finding new friends, helping each other learn, and expand their knowledge of Sjögren’s. We understand that 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. See the ad on page 11 to learn how you can order them today!

In addition, a special thanks to our sponsors and exhibitors at this year’s SSF National Patient Conference. Without their support, the SSF would not be able to provide this educational Conference!

SSF National Patient Conference Volunteer Awards Dinner and Keynote Address

Each year, during our Awards Banquet, the Foundation recognizes volunteers or groups that have given their time and/or talents to helping the SSF reach our mission to:

- Educate patients and their families
- Increase public or professional awareness of Sjögren’s
- Support Sjögren’s research

This year’s award winners show how an individual can make a difference just by getting involved. We could not accomplish all that we do without the hard work and dedication of volunteers like these awardees. If you were not able to join us, here are a few highlights about the SSF Volunteer Award Winners and Keynote Speaker.

Leadership Awards

Healthcare Professional Leadership Award - Athena Papas, DMD, PhD

Dr. Athena Papas has long been a champion for Sjögren’s patients, devoting her career to helping patients and finding better ways to manage and treat their disease. She heads the Tufts School of Dental Medicine’s oral medicine division, engages in clinical research in Sjögren’s, and has worked tirelessly to encourage pharmaceutical companies to develop a systemic therapy for Sjögren’s. She has led numerous clinical trials in Sjögren’s to help find better answers for patients.

Dr. Papas has been actively involved with the SSF for over 20 years. She serves as the medical advisor to the Boston Area SSF Support Group and as a member of the SSF Medical and Scientific Advisory Board. She also has contributed her expertise to many SSF initiatives including the development of SSF Clinical Practice Guidelines.

Dr. Papas’ passion to help Sjögren’s patients far exceeds most in her field. As she was recently quoted saying, “Once there’s an effective and approved therapy for Sjögren’s, I’ll be ready to retire.”

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June 2017 / The Moisture Seekers
**Service Awards**

**Development Service Award – Vincent and Yolanda Gales**

Yolanda never thought that Sjögren’s, a disease with a difficult name to pronounce, would have such an effect on her life when she was diagnosed in 2007. She had always loved running since her high school track days but doubted her ability to complete a Team Sjögren’s race because of her disease.

With her husband Vincent encouraging her and also stepping up to join the SSF running program, Yolanda decided to run as a way to raise awareness of Sjögren’s. With their daughter smiling from the first row and keeping the audience laughing, Yolanda and Vincent shared their journey of joining Team Sjögren’s, what they discovered when becoming more involved with the SSF, and why giving back to the Foundation is important to them.

**Volunteer Leadership Award – Mary McNeil**

Diagnosed in 2005, Mary McNeil immediately became her own best advocate! She joined the SSF and then attended her first National Patient Conference in 2007. Following that conference, Mary formed the Akron Ohio Area Support Group, which has now grown to represent all of Northeast Ohio. Today, the NE Ohio Support Group is one of our most active groups, encouraging all of its members to help educate their physicians and community about Sjögren’s!

In addition to her work of helping educate other patients and their families, Mary has also chaired the NE Ohio Sip for Sjögren’s events as well as the NE Ohio Sjögren’s Walkabouts. Mary and her volunteer committees have raised over $100,000 for the SSF! In 2010, the SSF asked Mary to serve on our National Board of Directors, where she served until 2016.

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Awareness Service Award – Sherry Mengle

The SSF was honored to recognize Sherry Mengle who shows how someone with passion can make a BIG difference! Sherry and her family have been dedicated to increasing awareness in their hometown located in Snyder County Pennsylvania by hosting an annual Comedy Fun Night! In addition to awareness, the annual family fun event also raises vital funds needed to support SSF patient and research programs. Sherry’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 – Daughters of Penelope

This award recognizes an individual or group that has significantly contributed to the mission of the SSF. Jan Spanos, the Daughters of Penelope’s Grand President, accepted the award on behalf of the organization. She spoke about the Daughters of Penelope’s longstanding tradition of generosity and praised the Foundation for our work in supporting all Sjögren’s patients, creating awareness and encouraging research to find a cure! The Daughter's of Penelope continue to support SSF events and also increase awareness within their own organization by telling the Sjögren’s story to their membership.

Keynote Speaker: Janet E. Church

Back by popular demand after last year’s National Patient Conference in Seattle, Janet Church gave the closing Keynote Address sharing her journey of having to deal with a chronic illness on a daily basis. Janet, who struggled for 8 years to receive a correct Sjögren’s diagnosis, talked about challenges she still faces when learning to constantly re-invent herself to cope with this complex and debilitating disease.

About Janet

Janet is an entrepreneur and tech-industry veteran and is currently Chair-elect of the SSF Board of Directors. As an early employee at Microsoft, Janet helped launch many of the products we work with today. Since then, Janet has founded several successful businesses including her own multi-million dollar tech marketing firm, a jazz record label, a consulting firm, and is a co-founder of an enterprise software company. Diagnosed with Sjögren’s in 2006, Janet always shares her perspective as a patient’s point-of-view.

“Whenever my Sjögren’s life changes on me, I want the opportunity to reinvent myself so I can feel like I’m living as well as I possibly can.” – Janet Church

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SSF in Action!

Sjögren’s in the News!

This April the Foundation reached our largest audience yet during Sjögren’s Awareness Month thanks to our #ThisIsSjögrens awareness campaign that focused on both traditional and social media stories.

When working with traditional media, our goal was to increase awareness among the public and healthcare professionals by promoting the results of our recent patient survey “Living with Sjögren’s.” The SSF used the survey results to demonstrate the physical and emotional burden of the disease.

The SSF worked with an outside consulting agency to create media-specific materials for this campaign, including the “Living with Sjögren’s: Summary of Major Findings” infographic, and a host of press materials, including press releases, and informational fact sheets on Sjögren’s and the Sjögren’s Syndrome Foundation. Utilizing the new materials, the Foundation focused outreach to Health/Lifestyle and Medical Professional media sources and organized both national and local interviews having doctors explain the disease and patients share their stories.

Thanks to the combined effort of our volunteers who spoke to the media, we were able to receive more coverage for Sjögren’s Awareness Month than ever before! Below are only a few highlights of the media stories that featured Sjögren’s this April.
Media Highlights:

- **U.S. News & World Report**
  “Sjögren’s Syndrome: Most common autoimmune condition you’ve never heard of”

- **Fox29 TV Philadelphia**
  “How to identify what is Sjögren’s”

- **Philly Inquirer/ Philly.com**
  “Sjögren’s, a disease you probably can’t see or pronounce, wreaks havoc on women”

- **The Rheumatologist**
  “Sjögren’s Awareness Month: Educate Patients, Families, Caregivers”

- **Registered Dental Hygienist**
  “Sjögren’s Awareness Month: During April Hygienists held screenings for xerostomia”

- **Sirius XM Radio**
  Rehabilitative Medicine Doctor Radio Live Show with Host Dr. Jonathan Whiteson “Overview of Sjögren’s”

- **Dentistry Today**
  “Sjögren’s Syndrome Is About Much More Than a Dry Mouth”

- **Healthy Women**
  “You’ve Probably Never Heard of my Disease”

- **Men’s Health Network**
  “Sjögren’s Awareness Month”

- **Healio Primary Care Optometry News**
  “First OD Chairman for Sjögren’s Foundation”

- **eNewsRheum**
  (American College of Rheumatology) “Sjögren’s Awareness Month”

- **Professional Eye Care Associates of America (PECAA)**
  “Sjögren’s Awareness Month Living with Sjögren’s”

- **Healio Rheumatology**
  “Patients with Sjögren’s reported visiting almost five health professionals per year”

- **Vision Monday**
  “Sjögren’s Awareness Month”

- **OptometryWeb**
  “SSF Releases Results of Living with Sjögren’s Survey”

- **Dentistry Today**
  “April is Sjögren’s Awareness Month”

- **DentistryIQ**
  “Sjögren’s Survey Reveals Deep Impact on both health and lifestyles”
Phases of Drug Development

Before being tested in humans, new treatments are usually evaluated in animals to evaluate basic measures of therapeutic effect and safety. Once certain safety criteria are met and the nature of the effect a drug has in animals is understood, the drug may move on to testing in human volunteers. This testing occurs in four phases:

Phase 1
- The first testing of a drug in humans
- Conducted with a small number of volunteers (20–100 participants)
- Purpose is to determine how the body handles a drug; how it is metabolized and eliminated
- Screen for adverse effects

Phase 2
- Small scale program in up to a few hundred patients with the targeted disease
- Purpose is to evaluate efficacy and side effects and to determine ideal dosing
- About 33% of drugs studied in phase 2 go on to the next phase

Phase 3
- Larger number of patients with disease studied (from 200 to >3,000) Primary concern is effectiveness and safety
- About 25–30% of new treatments are eventually approved

Phase 4
- These studies are usually performed after a drug has been approved
- Studies often mandated by the FDA and agreed to by the sponsor (drug company) as a condition of drug approval

Will I always get the new drug if I participate?
- Earlier phase trials usually dispense the new medication to all patients.
- Later phase trials usually involve randomly receiving a placebo or the medication being tested in one or more doses. This is called a placebo–controlled Randomized Clinical Trial (RCT) and

“Clinical Trials” continued from page 1 ▼

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“Clinical Trials” continued from page 1 ▼
Carteron Delivers Sjögren’s Audio Lectures

Medical and Scientific Advisory Board Chair and Member, SSF Board of Directors, Nancy Carteron, MD, FACR, delivered two lectures on Sjögren’s for HSTalks. Henry Stewart Talks Ltd (HSTalks) is a leading provider of specially prepared, animated, online, audio-visual lectures, seminar-style talks and case studies for medical schools, in over 60 countries around the world. Carteron’s lectures (Sjögren’s disease – symptoms, clinical signs and treatment & Sjögren’s disease – epidemiology, etiology, pathogenesis) are available online at www.hstalks.com.

Ford Talks Sjögren’s, Clinical Trials at Rheumatology Meetings

Theresa Lawrence Ford, MD, FACR, was invited to deliver a lecture on Sjögren’s at the Ohio Association of Rheumatology’s 11th annual meeting. She covered clinical presentation, classification criteria, and laboratory findings, the relationship between Sjögren’s and other autoimmune diseases, the risk for lymphoma, and current and future therapies.

Ford also presented an educational lecture on clinical trials and performing them for future investigators at the recent Association of Women in Rheumatology (AWIR) meeting. Dr. Ford of North Georgia Rheumatology Group, PC, serves on the AWIR Board of Directors as Treasurer, Chairs the SSF Clinical Trials Consortium, and serves on the SSF Board of Directors.

The SSF would like to thank Dr. Carteron and Dr. Ford for working to increase education of Sjögren’s and for standing up for all patients.
In Memory of Bryan Craig
Tim and Lori Gardner

In Memory of Bryan Lowe
Kenco Toyota Life

In Memory of Donna Grace Klein
Angel Garcia
Craig and Karen Purse
Bob Arroyo

In Memory of Eileen Legg Wilkinson
Dennis and Mary Jane Gallagher
Marie Wilkinson
Krietenstein American Legion Aux. 104

In Memory of Genevieve Shafer
Edward Shafer

In Memory of Gregory E. O’Neill
Ted and Kathy Michel

In Memory of Harriet Russomano
Joan B. Rahill

In Memory of Janet Adams
Cris Imle and Mother
Pentti Tofte
Michael and Janet Eagan
Barbara and Barry Bayon

In Memory of Josephine Petti
Gary and Valerie Basciano

In Memory of Lenny W. Jensen
Pat and Ann Wirtz
David and Pamela Oeffling
John W. Huff
George and Geraldine Bastear
Sally Johnson

In Memory of Marguerite Hocking
Joan and Cam McDonald

In Memory of Mary Sarro
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In Memory of Neala Kay Shager
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Terry Bloomsburgh

In Honor of Heidi Syndergaard
Colin Jost

In Honor of Katherine Elizabeth Moore
Lorrie A. Moore

In Honor of Lorna Simms-Carter
John Simms

In Honor of Noah Syndergaard
Isabelle DesFontaines
Colin Jost

In Honor of Paula Sosin
Rabbi Andy and Michelle Markowitz, LMSW

In Honor of Tim Lis
Heather and Ian Lis

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Eight of our most popular talks from the 2017 National Patient Conference held in Philadelphia/Cherry Hill, are available for purchase as audio CDs. Each talk is 30-40 minutes long and comes with the handouts used by the presenter.

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“Clinical Trials” continued from page 8 ▼

is considered the gold standard for determining whether a medication works or not. Neither the patient nor the clinician knows whether the patient is receiving a placebo or the drug.

- In some late phase trials, all patients will receive the active drug; the informed consent and the personnel conducting the study will make this clear at the outset of the trial.

Getting Involved

Clinical trials provide the means for evaluating a new or existing treatment in patients to see if the treatment, usually a drug, is safe and effective and at what dose. Clinical trials are necessary before a therapy can be approved and offered on the market. Before enrolling in a clinical trial, always discuss participation with your doctor.

Why Consider Participating in a Clinical Trial?

Patients participating in a trial will:

- Help ensure a new treatment is developed to control symptoms or overall outcome of their disease or disorder
- Gain access to a promising treatment that may provide unique benefit or meet unmet need
- Get access to care at no cost
- Help other patients
- Participate in helping to advance science/medicine

Am I Eligible to Participate in a Clinical Trial?

Clinical studies are performed according to a plan design called a protocol, which is unique to each project. Protocols define eligibility criteria of participants who can be enrolled. These criteria relate to such factors as age, gender, duration of illness, prior treatments and other medications you may be taking, etc.

Eligibility criteria fall into two categories:

- Inclusion criteria, which define the population of patients to be studied
- Exclusion criteria, which disqualify certain volunteers from participating due to age, other medical problems or other factors

Is it Safe to be in a Clinical Trial?

Before participating you will be provided with a document called an informed consent outlining the risks and benefits, the study design (features of the protocol such as length of the study and number of visits); after reviewing that document you may have some questions, all of which should be answered.

You have the right to withdraw from a study at any time and for any reason as is explained in all informed consent documents and by the personnel conducting the trial.

The overall clinical trials program is typically monitored by an independent institutional review board that approves the study design and the sites where the study is conducted.

Most trials of new medications performed at multiple sites across the country are monitored on an ongoing basis by a data safety monitoring board. The FDA has oversight for the clinical trials process and periodically conducts audits at sites where trials are being performed.

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.
Momentum and urgency in Sjögren’s clinical trials have seen a dramatic increase in the past year. Never in the history of the disease has there been so much interest in finding new treatment options and we are on the cusp of amazing discoveries! The most exciting aspect about these emerging therapeutics is that they could lead to the first Sjögren’s treatment for the entire disease, not just one symptom.

Clinical trials are designed to add to medical knowledge and most importantly, the results of these trials can make a difference in the care and treatment of patients. It’s important to be informed and understand what is involved in a trial. You can visit the SSF website, www.sjogrens.org, to learn more about clinical trials, what to expect, and view current trial locations.

Clinical trials in Sjögren’s are starting to actively recruit patients. Sites open all the time and you can view a listing of current trials on sjogrens.org. If there’s a trial in your area, we encourage you to contact the site directly to learn more about the study. You can ask as many questions as you want before deciding to enter a trial and even if you do not decide to participate, calling to learn more will show that there is a need for new and better treatment options.

Thank you for your interest in learning more and we hope you will visit our website to see if a clinical trial is right for you.

“Everyday research is being conducted to unveil new medications, therapies and diagnostic tools for Sjögren’s and its symptoms. By participating in a clinical trial, you will be helping to potentially uncover breakthroughs that will help Sjögren’s patients worldwide.”
– Steven Taylor, SSF CEO
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- Mission Pharmacal Company
- OraPharma
- Scleroderma Foundation
- Sjögren’s Book Table
- SSF Walkabout Registration
- “This is Sjögren’s” Photo Booth

*This program was made possible in part by a grant from Bausch + Lomb.*
Are you looking for a meaningful volunteer experience?

Interested in making a difference in the lives of other Sjögren’s patients?

Join us as a Patient Support Volunteer!

Patient Support Volunteers are seasoned Sjögren’s patients who are willing to receive calls from newly diagnosed Sjögren’s patients. You will provide them with support and Sjögren’s information, especially about day-to-day living, coping strategies and available resources. The SSF is looking for qualified volunteers throughout the country to be part of our growing network of support!

If you are someone who:
- Has been diagnosed with Sjögren’s for 1 year or more
- Has been a member of the SSF for at least 6 months
- Is knowledgeable about Sjögren’s and the resources available to newly diagnosed patients
- Is known for being a great listener and having a positive outlook

This could be the perfect volunteer opportunity for you!

If you are interested in becoming part of our team of volunteers and would like more information, sign up online at www.sjogrens.org under the “Get Connected” tab or contact Michele Champigny at mchampigny@sjogrens.org.
World Sjögren’s Day
July 23, 2017!

World Sjögren’s Day was created to commemorate the birthday of Dr. Henrik Sjögren, the Swedish ophthalmologist who discovered Sjögren’s.

In 1929, Dr. Sjögren met a patient who complained of dry eyes, dry mouth and joint pain. Each of these symptoms was already well known, but it was the combination of them that Dr. Sjögren noticed and decided to investigate. Dr. Sjögren could have been just an ophthalmologist who happened to meet a patient with dry eyes, but his open mind led him to the discovery of an unknown clinical entity that was later named after him.

Dr. Sjögren received international credit for his discovery and in 1970 he became an honorary member of the American Rheumatism Association. Later in 1976, he became a member of the Royal College of Physicians and Surgeons in Glasgow and that same year he was also appointed an honorary member of the Swedish Rheumatological Society. Henrik Sjögren retired in 1967 and died in 1986. He is buried beside his wife and her parents on Norra Begravningssplatsen in Solna, Stockholm.

On July 23, the SSF will join with other organizations around the world to celebrate recent advancements made in Sjögren’s this past year and honor the man who has helped all patients find answers to their health questions.

Visit www.sjogrens.org to learn how you can join in the celebration of what would have been Dr. Henrik Sjögren’s 118th birthday!