

The Sjögren's Syndrome Foundation Moisture Seekers



www.sjogrens.org

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f SjogrensSyndromeFoundation

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Three Year Update

by Steven Taylor, SSF CEO, and Elizabeth Trocchio, SSF Director of Marketing

50%
in 5 years
Sjögren's
syndrome
FOUNDATION

As we end the third year of our *5-Year Breakthrough Goal*, “to shorten the time to diagnose Sjögren’s by 50% in 5 Years,” we are honored and excited to announce that we have seen another decrease in the average diagnosis time! **It is now 3.9 YEARS!**

Three years ago, in January 2012, when the SSF announced our *5-Year Breakthrough Goal*, research showed that the average Sjögren’s patient waited over five years to receive an accurate diagnosis. The Sjögren’s Syndrome Foundation (SSF) Board of Directors understood it would take a huge initiative to change the diagnosis time but knew it was important to help those 2.5 million American’s not yet diagnosed but suffering from the symptoms. And that is why we created our *5-Year Breakthrough Goal*:

“To shorten the time to diagnose Sjögren’s by 50% in five years!”

Since then, the SSF has worked with a marketing research company to survey newly diagnosed patients to seek the time it took them to receive a proper diagnosis of Sjögren’s. This data, along with other important questions we ask, is then used to set our new benchmark and develop awareness-increasing programs.

The SSF knows that having patients spend an average of 3.9 years searching for answers without receiving treatment is still too long but this decrease reflects the major progress being made in the awareness of Sjögren’s. We know that having patients diagnosed faster will also benefit all Sjögren’s sufferers because as physicians start seeing more patients in their practice with Sjögren’s, they will need to become more knowledgeable about the different manifestations of Sjögren’s and the treatment options available.

As many SSF members know, to achieve our *5-Year Breakthrough Goal* and shorten the time it takes to be

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diagnosed to less than 2.5 years by 2017, we are focusing on three specific action items:

- Increasing public awareness
- Increasing involvement from our friends and partners
- Increasing education and awareness among healthcare professionals

Increasing public awareness

Sjögren's can often be overlooked or misdiagnosed because a patient's symptoms can manifest in various ways and the disease can affect every body system. We know that 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. This is why our awareness efforts work on educating all specialties within the medical community, as well as encourage the general public to be their own health advocate by knowing the symptoms of Sjögren's!

Since the launch of our Breakthrough Goal, SSF Awareness Ambassadors have been on the front lines of increasing public awareness by helping distribute Sjögren's educational information throughout their local communities. Taking the torch from our Awareness Ambassador Chairperson, Venus Williams (Olympian and Pro-Tennis Player), we now have over 525 Awareness Ambassadors educating their communities about the disease. These volunteers have stepped up to be a part of our Carroll Petrie Foundation Sjögren's Awareness Ambassador Program and have distributed information on various themes to specific businesses or medical professionals this past year. In 2014, our Awareness Ambassadors (AA) volunteered their time to focus on three specific campaigns:

- Theme 1 – "SSF Patient Resource Sheets" This campaign focused on our AA distributing information about the 20+ Sjögren's Patient Resource Sheets that are available for download on our website, www.sjogrens.org. These sheets are available for rheumatologists to print out and distribute to their patients to help them with their various manifestations and complications with Sjögren's.
- Theme 2 – "Dry Mouth Issues" This theme was our focus on making sure that dentists and primary care physicians knew that increased tooth decay could be a sign of a systemic issue, such as Sjögren's. In addition, we asked our AAs to distribute this information on dry mouth and tooth decay to local community health centers.
- Theme 3 – "Fatigue & Sjögren's" Our final theme was our first foray into educating physicians about the connection between fatigue and Sjögren's, a huge issue for many of our patients and an area that we know physicians

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Rx Only



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IMPORTANT SAFETY INFORMATION

CONTRAINDICATIONS: Aquoral is contraindicated for any patient with a known history of hypersensitivity to any of its ingredients.

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To report a serious adverse event or obtain product information call **(800) 531-3333**.

References: 1. Aquoral [package insert]. San Antonio:TX. Mission Pharmacal Company; 2013. 2. Mouly SJ et al. Efficacy of a new oral lubricant solution in the management of psychotropic drug-induced xerostomia: a randomized, controlled trial. *J Clin Psychopharmacol*. 2007;27(5):437-443. 3. Mouly SJ et al. Management of xerostomia in older patients: a randomised controlled trial evaluating the efficacy of a new oral lubricant solution. *Drugs Aging*. 2007;24(1):957-965. 4. Data on file.

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"3-Year Update" continued from page 1 ▼

need to be educated about. This information was distributed specifically to primary care physicians, rheumatologists and OB/GYNs.

We hope that in 2015, more of you will step up and serve as an Awareness Ambassador. We encourage you to visit our website at www.sjogrens.org to sign up and get more information.

In addition to our strong Awareness Ambassador program, the SSF has also used our online presence and social media outlets to get Sjögren's information out to the masses. The SSF blog, "Conquering Sjögren's: Follow us on our journey to change the face of Sjögren's," launched simultaneously with our Breakthrough Goal as a way to educate and increase awareness for both diagnosed and

undiagnosed patients. The blog alone has over 3,000 subscribers and over 500,000 views! Coupled with our strong online presence on Facebook and Twitter, it is our hope that information shared will encourage undiagnosed patients to talk to their doctor about the possibility of a Sjögren's diagnosis.

The most recent survey results also showed that a significant number of newly diagnosed patients were referred by another physician to a rheumatologist to be tested for Sjögren's. Most impressive, however, was that many of the newly diagnosed patients went on their own and were not referred by another physician, which shows that our specific strategy of increasing general awareness and driving potential patients to our website to learn more about Sjögren's is working!

Increasing involvement from our friends and partners

Increasing involvement from our friends and partners is a critical aspect to achieving our Breakthrough Goal. The SSF strongly values our partnerships with other autoimmune disease organizations, especially those that regularly coincide with Sjögren's. The SSF staff serves on various coalitions to advocate on Capitol Hill and ensure Sjögren's patients are not forgotten in the healthcare debate.

Most recently this past December, Steven Taylor, SSF CEO, went with Virginia Ladd, president of Autoimmune and Autoimmune Related Diseases (AARDA), and three other patient organizations to meet with Health & Human Services (HHS) and further the conversation about the healthcare coverage needed for autoimmune patients, specifically those suffering from Sjögren's. Joining together has helped make the SSF effective in changing the way Sjögren's is viewed within the healthcare policy community, on Capitol Hill as well as among our elected officials.

As you have seen in past issues of *The Moisture Seekers*, we continually ask our contacts, friends and their families to help us spread the word by participating in awareness events and other activities. Our *Sjögren's Walkabouts*, *Sip for Sjögren's* and our *Team Sjögren's* events allow patients to connect in a casual and fun environment that also increases awareness in their community and raises funds for Sjögren's. We encourage you to check this issue to see a calendar of upcoming SSF events this spring and summer. If you don't see an event near you – we hope you'll contact the SSF about organizing one in your area.

And finally, the SSF has worked hard at creating partnerships with corporations and private foundations

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INGREDIENTS: Oxidized glycerol triesters (TGO), silicon dioxide, aspartame, and artificial flavoring.

ACTIONS: Aquaoral® is a lipid-based solution resembling human saliva designed to moisten and lubricate the oral cavity, including the oral mucosa of the mouth, tongue and throat, by formation of a lipid film which limits loss of water and restores the viscoelasticity of the oral mucosa. Aquaoral also provides protective action against further inflammation of the oral mucosa. Xerostomia (dry mouth) has harmful effects on the oral cavity and quality of life; consequently, management of dry mouth is primarily based on relief of symptoms.

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CONTRAINDICATIONS: Aquaoral is contraindicated for any patient with a known history of hypersensitivity to any of its ingredients.

PRECAUTIONS: Read package insert carefully before using this spray. Avoid contact with eyes. Flush eyes with water if accidental introduction into eyes should occur.

INTERACTIONS: There are no known interactions with medicinal or other products.

DIRECTIONS FOR USE: Shake gently. One dose (2 sprays) into the mouth 3 to 4 times a day. Spread product on to inflamed and/or dry areas of the mouth with the tongue. Pump may require priming for initial use.

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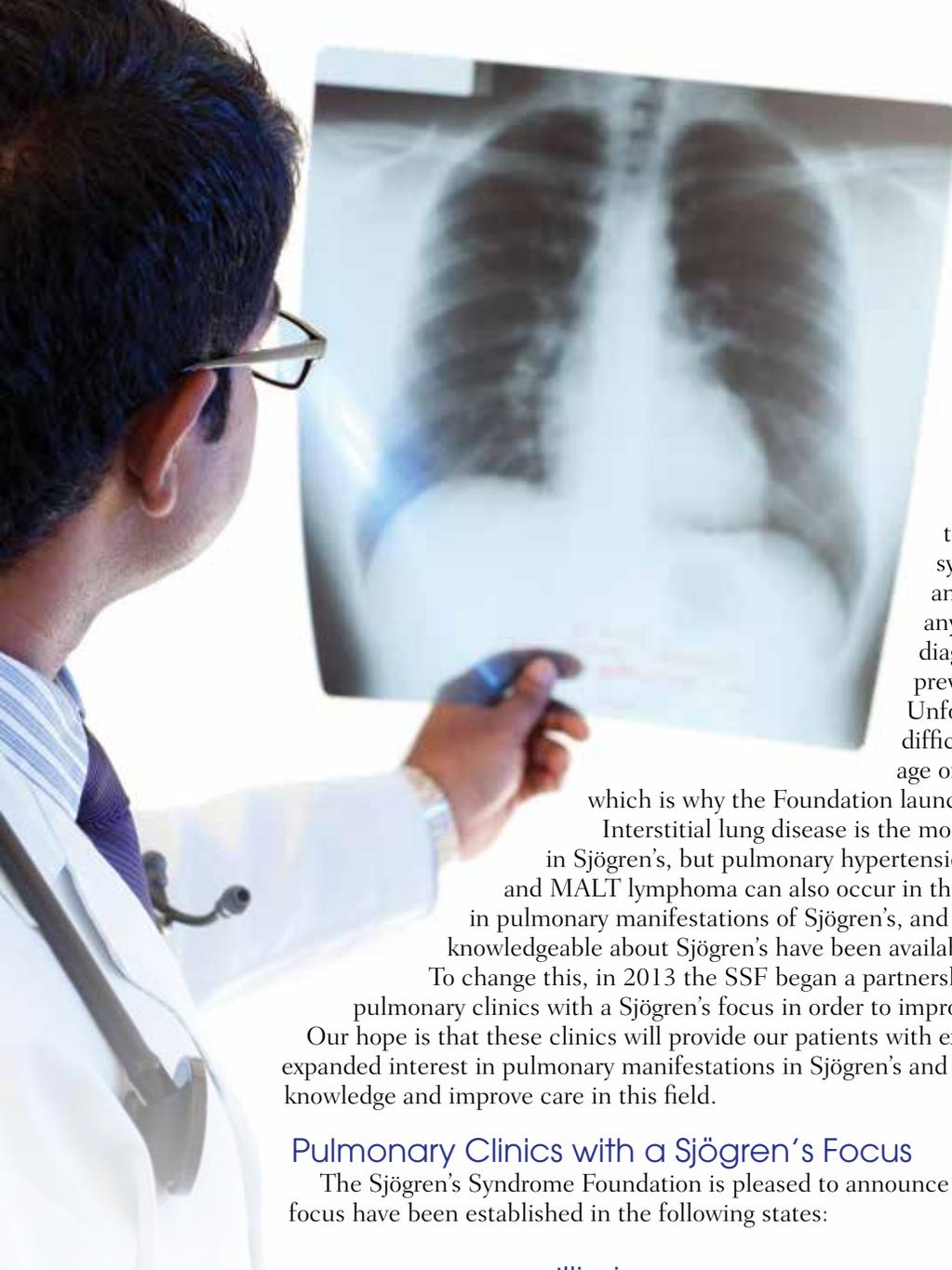
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Pulmonary Manifestations of Sjögren's

Sjögren's is a systemic disease in which the body's immune system mistakenly attacks its own moisture producing glands. The hallmark symptoms are dry eye, dry mouth, fatigue and joint pain, but Sjögren's can affect any body organ or system. While an early diagnosis and treatment are important for preventing complications with Sjögren's. Unfortunately, reaching a diagnosis is often difficult and has been found to take an average of 3.9 years from the onset of symptoms,

which is why the Foundation launched our *5-Year Breakthrough Goal*.

Interstitial lung disease is the most common pulmonary manifestation in Sjögren's, but pulmonary hypertension, amyloidosis, cystic lung disease and MALT lymphoma can also occur in the lungs. Few studies have been done in pulmonary manifestations of Sjögren's, and few pulmonary experts who are also knowledgeable about Sjögren's have been available to patients.

To change this, in 2013 the SSF began a partnership with The LAM Foundation to create pulmonary clinics with a Sjögren's focus in order to improve the care and treatment of patients.

Our hope is that these clinics will provide our patients with expert specialized care and lead to an expanded interest in pulmonary manifestations in Sjögren's and create future studies that will increase knowledge and improve care in this field.

Pulmonary Clinics with a Sjögren's Focus

The Sjögren's Syndrome Foundation is pleased to announce that pulmonary clinics with a Sjögren's focus have been established in the following states:

Alabama

Birmingham, University of Alabama at Birmingham

Arizona

Scottsdale, Mayo Clinic- Scottsdale

California

San Francisco, University of California
Los Angeles, UCLA Clinic- Los Angeles
San Jose, Stanford University Medical Center
La Jolla, University of California

Colorado

Denver, National Jewish Health

Florida

Jacksonville, Mayo Clinic- Jacksonville
Miami, University of Miami

Georgia

Atlanta, Emory University School of Medicine

Illinois

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Minnesota

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Portland, Oregon Health and Science University

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Charleston, Medical University of South Carolina

Tennessee

Nashville, Vanderbilt University Medical Center

Texas

Dallas, University of Texas Southwestern Medical Center
Houston, UTHealth Pulmonary Clinic

Washington

Seattle, Swedish Medical Center

For additional information about these clinics, please visit www.sjogrens.org.

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to create awareness programs for Sjögren's. One of these new partners includes Nicox, the makers of the "Sjo" test, which is a new diagnostic tool that is being used to help us speed up the diagnosis time for Sjögren's. Nicox, partnered this past year on a large awareness initiative to eye care providers as well as worked with the SSF on a national awareness campaign for Sjögren's. This is just one example of many companies that are starting to help the SSF increase awareness.

Increasing education and awareness among healthcare professionals

Increasing professional awareness is a vital aspect of the SSF's mission and overall strategy to achieving our Breakthrough Goal. A comprehensive understanding of Sjögren's by healthcare professionals is something that all patients know is urgently needed, which is why professional education is a top priority. The SSF continues to work on increasing our visibility at healthcare professional conferences, especially those specialties that see symptoms long before patients are diagnosed. You can read more about the most recently attended medical conference by the SSF in this issue's "Breakthrough Bullet" on page 10.

Professional education will also help physicians understand the severity of the disease and how best to treat Sjögren's patients. That is why the SSF's recent work to develop Sjögren's clinical practice guidelines is a critical facet in achieving our Breakthrough Goal. These guidelines will help standardize patient care by giving

physicians a roadmap of how to treat, monitor and manage their Sjögren's patients. Working documents of these guidelines are currently being reviewed and continue to get praise from the American College of Rheumatology, the American Dental Association and the American Academy of Ophthalmology.

In addition, the SSF Clinical Trials Consortium has built up tremendous strength this past year in encouraging the availability and development of more therapies for Sjögren's. This group continues to engage in dialogue with government agencies that oversee therapy development and approval. Our goal is that by building relationships and learning the approval system, we can help speed the process for the development and approval of new therapies for Sjögren's! The SSF is also thrilled to announce that there are currently 16 compounds or molecules under review for clinical trials for Sjögren's. The SSF is working with each of these companies that have a molecule or compound and helping them understand Sjögren's, our patient community are encouraging them to continue their fight to develop a treatment for our disease. We encourage you to watch future newsletters for more information about clinical trials and the progress that is being made.

Summary

As you can see, the momentum to reach our 5-Year Breakthrough Goal grows stronger every year. Thank you to everyone who has helped us along our way! From our patient volunteers to our professional educators and corporate partners- the SSF Board of Directors and the staff are humbled by your support.

We feel our dream of making Sjögren's a household name is within our grasp but we still need your help. We need your support by volunteering, donating and continuing to spread the word about Sjögren's. We encourage you to look for opportunities in this and future issues of *The Moisture Seekers* newsletter for ways to connect with the SSF!

Remember that one person at a time, one community at a time and one physician at a time is what it will take to reach our goal of conquering Sjögren's! ■



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50%
in 5 years
Sjögren's
syndrome
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Sjögren's-Related Lung Disease

by Teng Moua, MD with the Mayo Clinic, Division of Pulmonary/Critical Care Medicine in Rochester, Minnesota

One feature defining Sjögren's is the inappropriate infiltration of certain white blood cells into glandular tissues known as 'exocrine' glands. This infiltration contributes to reduced tear and saliva production, causing the classic symptoms of dry eyes and dry mouth associated with Sjögren's. Because the airway and lungs are lined with exocrine glands, the lung is commonly involved in Sjögren's, with respiratory symptoms occurring in up to two thirds or more of patients.

Some fast facts:

- Parts of the lung that may be involved in Sjögren's include the upper and lower airways, the small or microscopic airways, and the lung tissue or air sacs and their supportive structures.
- The most common respiratory symptom is a dry cough or airway irritation referred to as "xerotrachea" or "dry airway."
- Other symptoms include cough productive of sputum, wheezing, and shortness of breath both at rest and with exertion.
- Doctors may perform breathing tests (pulmonary function tests (PFT)) to assess for abnormalities and order chest x-ray and special radiologic testing such as computed tomography (CT) to help characterize the extent of lung involvement.
- Findings on radiology may include patchy infiltrates or locally consolidated lung suggesting inflammation or infection. Cysts or small thin-walled air pockets in the lung and thickened or elongated airways are other findings seen in Sjögren's.
- Other dryness symptoms and blood inflammatory markers for Sjögren's often do not correlate with the likelihood or severity of respiratory symptoms.
- Occasionally, Sjögren's may be associated with an-

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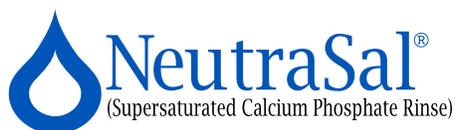
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What is NeutraSal®

NeutraSal® is an advanced electrolyte solution indicated in the treatment of dry mouth (xerostomia) in patients with Sjögren's Syndrome. NeutraSal® consists of single use packets of dissolving powders that when mixed with water creates an oral rinse supersaturated with calcium, phosphate and bicarbonate ions.

- ◊ Clinically proven to relieve the symptoms of dry mouth in Sjögren's Syndrome patients with no reported side effects or drug to drug interactions
- ◊ Calcium and phosphate ions have been shown to aid in the prevention of dental caries (cavities) and promote the remineralization of the teeth in normal saliva
- ◊ Sodium bicarbonate ions reduce the acidity of the saliva in the mouth and break up accumulating mucus
- ◊ The pH of NeutraSal® is similar to normal saliva which may protect the mouth against potential opportunistic fungal (oral thrush) and bacterial infections

NEW

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† This statement has not been evaluated by the FDA. This product (alpha lipoic acid) is not intended to diagnose, treat, cure or prevent any disease.

NeutraSal® is a prescription item. For additional information on NeutraSal® or the Direct Access Program, please visit www.neutrasal.com or call 866-963-8881 ext #1.

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It Takes an Army!

"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

We knew it would take an army to reach our 5-Year Breakthrough Goal and you have not let us down. More of you continue to join our Sjögren's army and we thank you for your help in getting the new diagnosis time down to 3.9 years! In 2014:

- 403 patients attended our National Patient Conference with 18 conference exhibitors
- 2,000 walkers attended our Sjögren's Walkabouts
- 51 runners/walkers participated in *Team Sjögren's Goes Turkey*
- 520 individuals stepped up to become SSF Sjögren's Awareness Ambassadors
- 51,285 minutes were spent by volunteers and SSF staff on conference calls to plan events, projects, conferences, advocacy and initiatives
- 64 healthcare providers contributed to *The Moisture Seekers* or *Sjögren's Quarterly*
- Over 23,400 friends followed us on Facebook
- 18 companies went BOLD Blue for Sjögren's Awareness
- 684.2 miles were run in races by *Team Sjögren's* participants
- Over 150 healthcare professionals volunteered their time to create or review our Sjögren's Clinical Practice Guidelines
- 968 fundraising web pages were established to raise funds for the SSF
- Almost one million people went to www.sjogrens.org during Sjögren's awareness month in April
- Over 35 businesses in the United States partnered with us to host local awareness and fundraising events, including Ben & Jerry's of Rockville, Brenda-wood Financial & Union Brew House Golf Tournaments, Corvino Performance Thanksgiving Workout, and the Dodds brothers "Cycle for Sjögren's"



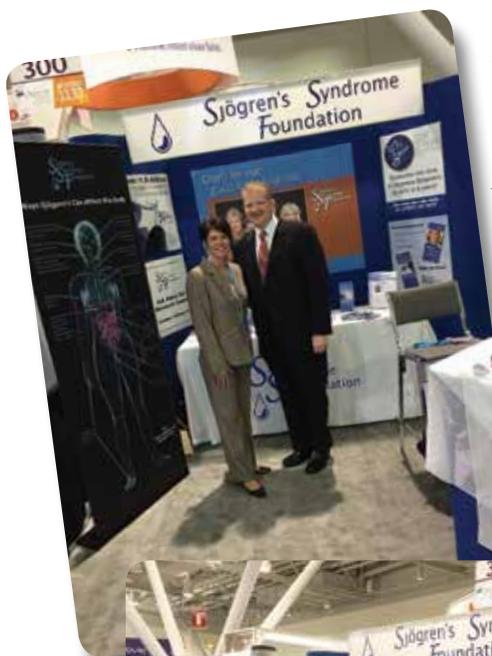
Thank you for joining our Army and helping the 2.5 million patients who are still suffering without a diagnosis!





January Breakthrough Bullet:

The SSF puts Sjögren's in the spotlight at American College of Rheumatology's Annual Meeting



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



The American College of Rheumatology's (ACR) annual meeting is the premier scientific meeting for practicing rheumatologists. As you read in this issue's cover story, educating medical professionals about the complexity and severity of Sjögren's is a strategic priority for achieving our 5-Year Breakthrough Goal. The Foundation's presence at medical conferences, specifically ACR's annual meeting, is one of the most direct ways that we accomplish this.

As the SSF's relationship with ACR continues to grow, we increase our opportunities at ACR to educate rheumatologists and encourage research into Sjögren's. At this year's meeting, held in Boston, MA in November, the SSF saw many sessions on Sjögren's. Including:

- ACR Review Course Session: Management of Salivary Gland Involvement in Sjögren's
- Meet the Professor Course: Controversies in Sjögren's by Fredrick Vivino, MD
- Clinical Challenges in Sjögren's Syndrome: Neurological Complications and Lymphoma Risk
- Abstract Session: Sjögren's - Pathophysiology, Presentation and Treatment

In addition to these sessions, the SSF had an exhibit booth to educate physicians about the seriousness of Sjögren's and resources available for both them and their patients. This year, 125 new rheumatologists signed up for the *Sjögren's Quarterly* – the SSF's newsletter for medical professionals.

While this meeting helps to increase education and awareness of the disease among rheumatologists, it also allows the Foundation to bring together key opinion leaders who specialize in Sjögren's during our annual luncheon. This year, over 90 rheumatologists attended the SSF's luncheon that was centered on the theme, "Treating Sjögren's –The Future."

Another highlight from this year's meeting was the Research Study Group session, "Sjögren's Around the World," moderated by Hal Scofield, MD, with over 100 rheumatologists in attendance. In this session, researchers/clinicians from the United States, India, Columbia and England presented on the similarities and differences of Sjögren's patient populations from their countries. While each country saw many similarities among each other, one interesting disparity was in the average age of onset in Sjögren's. For example, the average age of Sjögren's patients in India was 10 years younger than in the United States, which furthers the suspicion that

"Lung Disease" continued from page 7 ▼

other autoimmune or inflammatory disease that can affect the lung. In this case, lung disease may be worse in terms of severity and progress more rapidly over time.

- Many medications used to treat Sjögren's may cause unintended side effects that injure the lung. A careful review is warranted, particularly if symptoms develop after starting a new medication.
- Medications that suppress the immune system may also increase the likelihood of lung infection. A careful assessment for possible infection is often the first step in managing new respiratory symptoms.
- Finally, if infection and medication side effects are ruled out, therapy directed at treating the underlying Sjögren's may need to be adjusted in an attempt to treat respiratory symptoms.
- Supportive treatments such as inhalers or oxygen in severe disease can be helpful for managing symptoms.

We encourage you to share this article with your rheumatologist and primary care physician to help educate them about Sjögren's and possible lung complications that patients should be monitored for. ■

"Breakthrough Bullet" continued from page 10 ▼

the age of onset we currently see could lower over time as more awareness is created and our time to diagnose is shortened!

This meeting is also a reminder to all of us that there are amazing rheumatologists throughout the world who have committed their entire careers to learning about, researching and treating Sjögren's. Unfortunately, the SSF knows that there are rheumatologists still who don't understand or appreciate the severity of the disease and that is why we encourage you to take it upon yourself to help educate them about the SSF and all of our resources. Together we can create a future where all healthcare professions are knowledgeable about Sjögren's! ■





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Laura Boycourt

In Memory of Bonnie LittonMichael and Christine Till
Robert and Marla Sorenson

Thomas Inglis

Abigail Wesley

Amy and Robert Brunner

Beautiful Smiles, P.A.

Brian and Kim Liebo

Bruce Bartels

Burton and Sharon Schwartz

Carol Turbenson

Cathleen Taylor and James Osborne

David Mayer

Dawn and Daniel Jensen

Denise Schouweiler

Dr. Douglas and Marcia Jolstad

Dr. Martin and Carole Kaplan

Dr. Meyer

Dr. Stephen Robinson

Dr. Todd and Constance Tsychiya

Elliott Badzin

Jean and Clarence Lindley

Jeannie and Howard Schwartz

Jim and Fern Badzin and Family

Joan and Shelly Weinstein

Kent Krez

Kevin and Kristin Denis

Lee and Mary Jo Jess

Lorraine and Seymour Merrill

Lynn Petruzzi

Marcia and Larry Swartz Charitable Fund
at Schwab Charitable Fund

Marie and Matt Baudek

Marilyn Henken

Marty and Joann Virshek

Pat Spolyar

Paula and Michael Beugen

Stan and Jeanne Kagin

Stanley and Catharine Williamson

Steve Litton

In Memory of Connie Rodriquez

Fred R. Fernandez and Irma R. Rodriguez

In Memory of Deidra Paulnak

Nancy Finch

In Memory of Eva W. Stevens

JoAnne S. and Jeff Klein

Julia and Gene Wilson

In Memory of Gail Spence-Lennon

Maria Ellis

Michael and Maryellen Tenore

Mr. and Mrs. Joseph Ellis

In Memory of Joan Schuler

George and Helen Roth

Janet Evans

Maria Pietchke

Peg Bachmann

Robert and Karen Peterman

Roger Egleston

Shirley Davis

Susan and Wayne Martin

Walter and Diana Van Buren

In Memory of Marilyn Lesser

Beverly and Larry Fielden

In Memory of Mary Louise Whitt

Staff at Easter Seals Central Alabama

In Memory of Michael Price

Donna Richard

Jack Schluter

In Memory of Patricia Ausmus

Mr. and Mrs. L Hunsberger

In Memory of Shirley Landes

Mr. Landes


in honor
In Honor of Ann Keith

Susan Rawlston

In Honor of Bobette Morgan

Teri Rumpf

In Honor of Christine Carosella

Ace Prince

In Honor of Dennis & Jeanne Molloy

Christine Molloy

In Honor of Dr. Robert Fox

Linda Zarzeczny

In Honor of Ivan Knobler

Hyman & Trudy Applebaum

In Honor of Kathy Ivory

San Diego-Imperial Counties Chapter

In Honor of Lari Lopp

Steve & Isabelle des Fontaines

In Honor of Mary Winning

James Rae & Melinda Helman-Rae

In Honor of Maxine Simon

Alan & Barbara Levin

In Honor of Sam Swindle

Pam Shank

In Honor of the Staff at Elle Salon

Debbie & Jill Herman

In Honor of Trudy Applebaum

Laurie English



You Stood Up!

Robert cycles for Sjögren's and the memory of his wife Jenny

Robert, a retired physician, had been married to Jenny for over forty years when she died from Sjögren's complications on May 13, 2014. Jenny was always a Sjögren's advocate and even as she faced her final days, Robert promised her he would never stop telling people about Sjögren's.

Robert contacted the SSF with his idea to help spread Sjögren's awareness by cycling in Jenny's memory. Robert worked with the SSF to create his own *Team Sjögren's* cycling jersey with the wording, "Cycling in loving memory of Jennifer Garner 05/13/14 & the 4 million Americans suffering from Sjögren's." And as you can imagine, his jersey was a conversation starter wherever he rode!

Recently Robert passed the 1,000 mile mark riding in his *Team Sjögren's* jersey, increasing awareness for Sjögren's all while updating the SSF on his voyage. While cycling these past six months, numerous other cyclers and pedestrians asked him about Sjögren's. In addition, cars stopped to ask him about his Sjögren's jersey, including one newly diagnosed patient that wanted to know more about the SSF. Robert said that he and the patient had a 20 minute conversation about the disease and he advised her to find a specialist who knew about the disease because it seemed clear that her primary care physician was not well informed about the possible complications.

Of his completed 1,000 miles raising awareness of Sjögren's, Robert was saddened by how many people hadn't heard of the disease, and that ones who had thought it was only "manageable dry eyes and dry mouth." Unfortunately, that is something the SSF and Sjögren's patients often hear and the reason why the SSF works extremely hard to raise of awareness of this complex and debilitating disease.

Thank you Robert for continuing to raise awareness by riding in memory of Jenny and in honor of all Sjögren's patients. We know Jenny would be so proud that you

have kept her Awareness Ambassador torch going!

If you'd like to learn more about purchasing *Team Sjögren's* or Sjögren's awareness merchandise, please contact Steph Hilton at shilton@sjogrens.org or (301) 530-4420 x227. ■



"It may seem crazy but riding in the jersey, it is as if she were riding with me." – Robert



Learning to Thrive with Sjögren's

2015 National Patient Conference

April 17-18, 2015

Grand Hyatt Tampa Bay

2900 Bayport Drive ■ Tampa, Florida

This April we invite you to join with fellow Sjögren's patients, their families, medical experts, the SSF staff and industry/ product exhibitors for our 2015 National Patient Conference, "Learning to Thrive with Sjögren's," at the Grand Hyatt Tampa Bay (Tampa, Florida).

Sjögren's is not the same for every person diagnosed, which is why educating yourself on the most up-to-date information and treatment options is so important. Attending the SSF National Patient Conference is one way you can gain information from many different sources while also meeting fellow patients.

This year's Conference will include opportunities to:

- Hear from national Sjögren's experts, researchers and SSF staff
- Find new products and receive free samples at our exhibitor hall
- Learn from your fellow patients
- Browse Sjögren's resources at the SSF Book Table
- Become inspired during the Conference's Awards Banquet Dinner

We encourage you to take this opportunity and learn how to thrive with Sjögren's. This educational journey will give you the tools to take control of your health and learn how to manage and understand your Sjögren's symptoms and complications.

Watch for your Conference brochure coming in January or visit www.sjogrens.org to see updated Conference information.

Presentation topics will include:

- Overview of Sjögren's
- Neurological Complications
- Dry Mouth & Sjögren's
- Dry Eye & Sjögren's
- Ear, Nose & Throat Involvement
- Gynecological Complications
- Major Organ System Involvement
- Financial Planning for Patients with Chronic Illness

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.



2015 NATIONAL PATIENT CONFERENCE TAMPA, FLORIDA — APRIL 17–18, 2015

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 20, 2015)

SSF Members & Guests
Non-Members

March 20th and before
\$170 per person
\$190 per person

March 21st 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 27th will receive a 75% refund. After that time, we are sorry that no refunds can be made.
- Dietary Requests: Unfortunately, we cannot accommodate all special dietary requirements. We can accommodate vegetarian or gluten-free dietary requests. If you require a vegetarian or gluten-free meal option, please contact Caroline Mullin at the SSF office (301) 530-4420, ext. 214 by April 3rd.
- A limited number of rooms are available at the Grand Hyatt Tampa Bay, 2900 Bayport Drive, Tampa, FL 33607, at the SSF rate of \$149 per night plus tax if reservations are made by March 24, 2015. Call the toll-free hotel Central Reservations number at (888) 421-1442 or call the Grand Hyatt Tampa Bay directly at (813) 874-1234 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
- The Grand Hyatt Tampa Bay is approximately one (1) mile from Tampa International Airport. The hotel offers a complimentary shuttle service to and from the airport. Alternate transportation suggestion: Taxi fare at a rate of \$18 (one way).

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

The Moisture Seekers

Sjögren's Syndrome Foundation Inc.
6707 Democracy Blvd., Ste 325
Bethesda, MD 20817

Phone: 800-475-6473
Fax: 301-530-4415

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

2015 SSF Special Event Calendar

SSF events are organized in an effort to increase Sjögren's awareness in local communities, while raising funds to support research & education. They are also an excellent opportunity to connect Sjögren's patients and their families to others living with the disease.

If there is already an event in your area and you would like to get involved, or learn about starting one, please visit www.sjogrens.org or contact us at (301) 530-4420 x227

February

- 21** **Phoenix Walkabout & Health Fair**
Paradise Valley Mall, Phoenix, Arizona

March

- 16** **New York City Sip for Sjögren's**
NYU Rosenthal Pavilion, New York, New York

April

- 17-18** **National Patient Conference**
Grand Hyatt - Tampa, Florida
- 18** **National Patient Conference Walkabout**
Tampa, Florida

May

- 2** **Philadelphia Walkabout & Health Fair**
Philadelphia Zoo - Philadelphia, Pennsylvania
- 16** **Dallas/Fort Worth Walkabout & Health Fair**
Vista Ridge Mall - Dallas, Texas
- 30** **Northeast Ohio Walkabout**
Brecksville Oak Grove Picnic Area - Brecksville, Ohio
- 31** **Atlanta Sip for Sjögren's**
Nelson Mullins at Atlantic Station - Atlanta, Georgia

June

- TBA** **Columbus Walkabout**
Columbus, Ohio
- 6** **Denver Walkabout & Health Fair**
Denver Zoo - Denver, Colorado
- 13** **Greater Washington Region Walkabout & Health Fair**
Bethesda, Maryland
- TBA** **Kansas City Walkabout & Run**
Parkville, Missouri

