

The Moisture Seekers



www.sjogrens.org

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 SjogrensSyndromeFoundation

 @MoistureSeekers

SSF 5-Year Breakthrough Goal: First Year Update

It is hard to believe that a year has gone by since the Sjögren's Syndrome Foundation announced the launch of our 5-Year Breakthrough Goal in the January 2012 issue of *The Moisture Seekers*. Our Goal:

"To shorten the time to diagnose Sjögren's by 50% in five years!"

That means by 2017 the SSF hopes to shorten the time it takes to be diagnosed with Sjögren's to less than 2.5 years from the time a person started seeking a diagnosis. From surveying patients who were diagnosed in 2011, the SSF worked with a marketing research company and determined that it currently takes an average 4.7 years to receive an accurate diagnosis. The SSF Board of Directors and Medical and Scientific Advisory Board believe that this is too long!

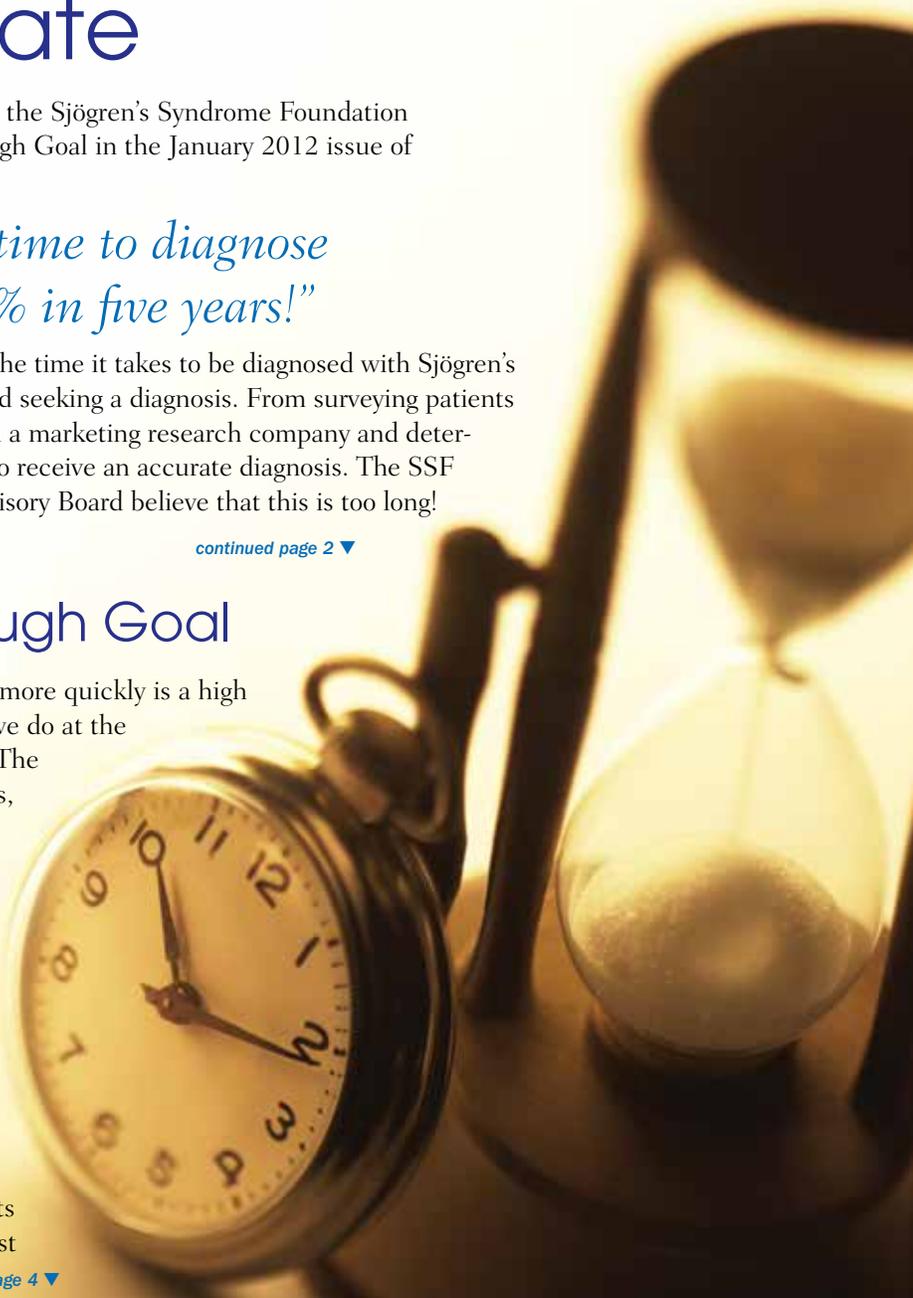
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Beyond the Breakthrough Goal

While ensuring that people get diagnosed more quickly is a high priority, it is not the only facet of what we do at the Sjögren's Syndrome Foundation (SSF). The SSF has continued to expand our patient programs, initiatives and research program. We continue to fight for Sjögren's patients on Capitol Hill as well as through advocating for more treatments and increased research for Sjögren's. We add our voice to healthcare issues that matter to Sjögren's patients, and we continue to support Sjögren's patients and their families through education, materials and outreach.

One very important aspect of the SSF mission is to increase professional awareness of Sjögren's. This awareness not only will help speed up a diagnosis but also help physicians and dentists understand the severity of the disease and how best

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"50% in 5 Years" continued from page 1 ▼

As a patient-focused organization, it is our hope that by getting more patients diagnosed, all patients will benefit. As physicians start seeing more Sjögren's patients in their practice, they will need to become more knowledgeable about the different manifestations of Sjögren's and the treatment options, not to mention, those who get diagnosed will not need to struggle for as long as those who went before them. Many of our members waited for many years to receive a proper diagnosis and we know you join with us in not wanting any patient to suffer and wait that long.

As you may remember, the SSF plans to achieve our 5-Year Breakthrough Goal by 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

With an estimated four million people in America living with Sjögren's, the SSF is working toward making Sjögren's a household name. One way we are working to achieve this is by utilizing our Awareness Ambassadors, who volunteer their time to distribute Sjögren's educational information in their local communities. The theme for our 2011-2012 Awareness Ambassador Program was entitled *Defy the Dry*.™

Since last January, we recruited an additional 162 individuals from around the country who have stepped up and volunteered to become an Awareness Ambassador. This now gives us 374 Awareness Ambassadors – well on our way to our goal of having 500 by 2014! Together, our Ambassadors have distributed over 14,500 material kits about Sjögren's to over 1,700 healthcare professionals in their local communities to make sure their communities understand the importance of discussing their symptoms with their doctors. Additionally, the Ambassadors have sent over 5,800 emails to friends and family to raise Sjögren's awareness. Our Ambassadors' incredible effort has been a first step toward reaching our Breakthrough Goal.

The SSF has also started using social media to make Sjögren's information easily accessible to the general population. To date, the SSF has 6,807 Facebook followers (<http://www.facebook.com/SjogrensSyndromeFoundation>), 971 Twitter followers (@MoistureSeekers) and 6,118 Blog viewers (<http://info.sjogrens.org/conquering-sjogrens/>). While our presence on social media is a tool to get Sjögren's information out to the masses, we encourage everyone to use these online outlets as a way to connect with other patients and share their Sjögren's story.

Additionally, the SSF saw a huge increase in media attention around Sjögren's since Venus Williams (professional tennis player) and then Shannon Boxx (U.S. Olympic soccer player) announced they both had Sjögren's. Thousands of articles were written in 2012 and we continue to see Venus

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and Shannon sharing their story whenever interviewed by the media. The SSF is working with Shannon Boxx on various initiatives for 2012 and we are currently trying to find a partnership with Venus Williams that will fit her active lifestyle of professional tennis and launching her own fashion line called “EleVen.”

Increasing involvement from our friends and partners

This is another critical aspect to our Breakthrough Goal and the SSF is busy building partnerships with various companies and non-profit organizations to help further our goal.

First, the SSF is partnering with other autoimmune disease organizations to help co-brand our various diseases – especially those that regularly coincide with Sjögren’s. We appreciate the assistance of these other organizations and are proud to be in various coalitions with them to help advocate on Capitol Hill among other awareness activities.

Second, the SSF is proud of our partnerships with various pharmaceutical companies who help the SSF increase awareness in many ways. First, some companies assist us in underwriting educational and/or awareness campaigns. Without their support, some of these campaigns would not be cost effective and we truly appreciate their support. In 2012, the SSF asked many of our partnering pharmaceutical companies to utilize their staff to help us educate physicians and/or dentists with which they are building new relationships. We gave them SSF materials to leave with physicians and dentists in the hope that they would display our information for their patients. This program helped increase our presence in many physicians’ and dentists’ offices in 2012.

Finally, we have asked our contacts, friends and families to help us spread the word. Our Sjögren’s *Walkabouts*, *Sip for Sjögren’s* and our *Team Sjögren’s* events had record turnouts as we focused on increasing awareness while raising funds for Sjögren’s. We saw an increase of individuals willing to share their story with family and friends. As Steven Taylor, CEO of the Sjögren’s Syndrome Foundation, said, “every time Sjögren’s patients share their story, they are helping another person to understand the disease and, in return, they may be able to help someone else in their life who is suffering from Sjögren’s but doesn’t know it.” The SSF continues to receive stories from patients who were diagnosed with Sjögren’s because a friend or family member heard about the disease and was able to explain to the patients and thus prompted them to go see a doctor!

Increasing education and awareness among healthcare professionals

Having healthcare professionals fully understand Sjögren’s is something that all patients know is urgently needed. That is why the SSF continues to make professional education a top priority among this group. This fall, the SSF was once again able to serve as an exhibitor at the 2012 American College of Rheumatology Conference. This annual conference and scientific meeting was attended by 16,000 rheumatologists and healthcare professionals who work in rheumatology. This year, Sjögren’s received more attention than ever before.

First, the SSF met with hundreds of interested physicians who wanted SSF brochures for their offices. Sjögren’s was highlighted in four specialized Sjögren’s breakout sessions including a new session called “Curbside Consult,” where physicians attend to discuss difficult-to-diagnose cases and their final diagnosis. The SSF was also invited by the ACR Planning Committee to give an hour-long presentation on our Clinical Practice Guidelines. We are proud to say that over 600 rheumatologists attended this presentation given by Dr. Fred Vivino, Dr. Ann Parke and Dr. Steven Carsons. Additionally, the SSF was able to host three very important private meetings to discuss various issues surrounding Sjögren’s including one on Novel Diagnostics for Sjögren’s. As part of the SSF’s goal, we hope to work with companies and researchers who are looking at novel diagnostics for Sjögren’s. We hope with the right focus and energy that a better diagnostic tool than what is currently available can be found. That alone would help to speed up a Sjögren’s diagnosis.

In addition to ACR, the SSF was invited to attend and present at the California Dental Association Conference, the Florida Dental Association Conference and the American Optometric Association Conference. Cumulatively at these three conferences, the SSF was able to present to over 1,000 medical and dental professionals about Sjögren’s, its diagnosis and its management. A big highlight came at the California Dental Association’s Sjögren’s presentation where over 400 dental professionals filled the room and even more people crowded around the doorway in order to see our presentation and receive an SSF informational packet. In addition to these great presentations, another 1,526 new physicians/dentists signed up to receive the SSF’s *Sjögren’s Quarterly* newsletter that is tailored to medical professionals. Look in this issue of *TMS* for more information about how patients can subscribe to this newsletter.

"Beyond the Breakthrough Goal" continued from page 1 ▼

to treat Sjögren's patients. That is why nearly three years ago the SSF embarked on our largest initiative ever – to develop clinical practice guidelines for Sjögren's. These guidelines will give physicians and dentists a roadmap of how to treat, monitor and manage their Sjögren's patients. They will be the first guidelines ever written for Sjögren's and we are proud that the SSF has taken the lead to develop them. We are also excited that the SSF has the blessing of such major professional entities as the American College of Rheumatology and American Dental Association for these guidelines.

The guidelines also would not be possible without the support of an amazing group of physicians and dentists who have given their time freely to engage in a rigorous process to develop evidence- and consensus-based guidelines. We are still finalizing these guidelines with a tentative launch of mid-2013. As you can imagine, to receive the endorsement of leading national professional organizations, we need to ensure that our recommendations result from the best evidence and processes available, and thus it takes extensive time, work and commitment from a wide range of experts to ensure our recommendations are broadly accepted and put into use.

In addition to our guidelines, the SSF is actively working with three pharmaceutical companies that are developing and launching clinical trials this coming year in the United States and Europe for new Sjögren's treatments and with two additional companies that have either just completed initial trials or are in ongoing trials. These trials are a major breakthrough for our disease and something that the SSF has been advocating for over eight years. In the coming years, we will need your support to make these trials successful, so please watch *The Moisture Seekers* for more information in the future. We are proud of our work with these companies as they now better understand the need and the market for new treatments, and we applaud their pursuit of various compounds that have shown potential in treating Sjögren's.

Finally, the SSF continues to offer educational materials to patients and their families to help them understand the breadth of Sjögren's. We offer our website which includes downloadable fact sheets, brochures and information about Sjögren's. We host an online blog as well as actively participate in social media to keep patients and their families informed about the latest research and information on Sjögren's.

The SSF is continuously expanding and enhancing our offerings for patients by presenting additional information online as well as continuing to produce an informative and educational patient newsletter. We are

thankful to our patients who are involved with us on our Board and on volunteer committees as well as healthcare professionals who also volunteer their time to ensure that our patient materials are as accurate as possible.

As many of you know, the SSF was founded by a patient for patients, and the SSF will always put Sjögren's patients first! We will continue to listen to your ideas and implement new programs and initiatives that will help patients as we strive to push the bar higher and higher to get Sjögren's recognized and appreciated by the general public as well as the healthcare community. ■

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Sjögren's
SSF
Syndrome
Foundation

Call us today for more information.

800-475-6473

"50% in 5 Years" continued from page 3 ▼

As you can see, the SSF has been busy this past year as we launched our 5-Year Breakthrough Goal. We knew it wouldn't be easy to achieve but the success we have made in our first year is remarkable. The momentum our volunteers and patients have created is propelling us into 2013, but we still need more hands to make it possible! The dream of making Sjögren's a household name is only possible if everyone will do something to help. Read later in this issue about how you can stand up to help – but for now share your story and tell others about the SSF. This alone will make people realize how common Sjögren's really is, and together we can conquer Sjögren's! ■



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The symptoms of Sjögren's Syndrome can have devastating effects. Oral dryness can result in severe and chronic dental decay, fissures, infections, and difficulty in speaking and swallowing.

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What is NeutraSal[®]

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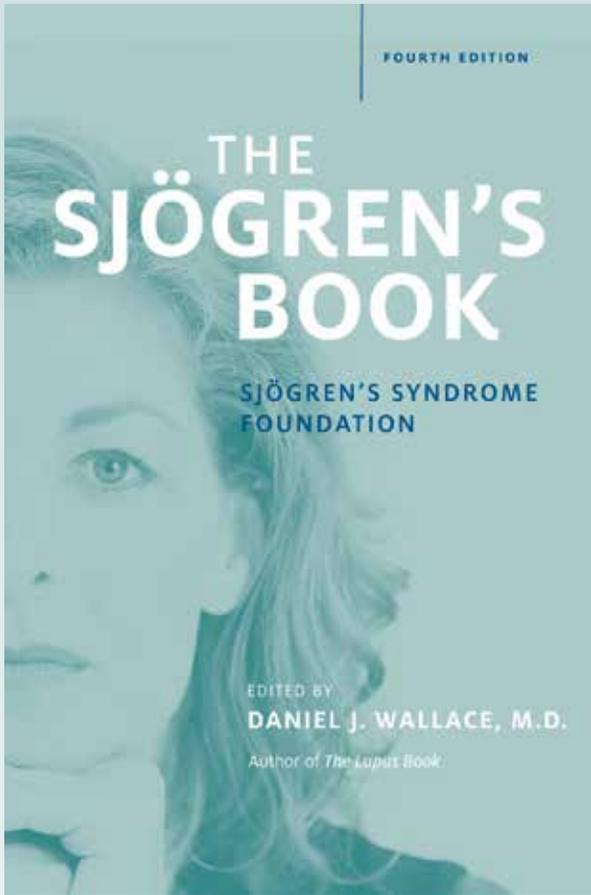
- Calcium and phosphate ions have been shown to aid in the the prevention of dental caries (cavities) and promote the remineralization of the teeth in normal saliva
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The Sjögren's Book – Fourth Edition

Edited by Daniel J. Wallace, MD

This edition of the Sjögren's handbook was completely revised and expanded in 2011 with **ALL NEW** chapters and the latest information on Sjögren's!

This book can be purchased using the order form below, online at www.sjogrens.org/ssfstore or by contacting the Sjögren's Syndrome Foundation office at 800-475-6473.

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Shipping and Handling: US Mail: \$5 for first item Canada: \$8 for first item Overseas: \$18 for first item				
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I Stood Up...



How Can You Stand Up?

The Sjögren's Syndrome Foundation is on a mission to increase awareness so those who are diagnosed with Sjögren's and those who are not yet diagnosed will receive the proper recognition and treatment! In order to do this, we need your help!

Here are some ideas on how you can make a difference, but remember – Sjögren's Awareness starts with You!

Consider the following:

- Become an official Sjögren's Ambassador! As an Ambassador, you will work on awareness projects within your community. You will use your voice to spread awareness, share your Sjögren's story and help us distribute information to your area's healthcare professionals.
- Organize a Sjögren's special event in your area, whether it is a *Walkabout*, *Sip for Sjögren's* or an event that you create yourself, the events give us a platform to talk about Sjögren's and increase awareness while also raising funds for Sjögren's.
- Offer your healthcare providers complimentary Sjögren's brochures for their offices plus a complimentary subscription to our healthcare professional newsletter, the *Sjögren's Quarterly*.
- Represent the Sjögren's Syndrome Foundation at a local community Health Fair.
- Generate Sjögren's Awareness by contacting your local health reporters and media outlets and asking them to help increase awareness in your community.

Remember – it takes many voices to help us increase awareness. In 2013, join us by *Standing Up For Sjögren's!*

Yes,

I am interested in learning more about:

- Becoming a Sjögren's Ambassador
- Organizing a special event in my area:
Sip for Sjögren's – Sjögren's Walkabout – other special event
- Contacting local Healthcare Provider(s)
- Participating in a local Health Fair(s)
- Contacting my local media

*I will Stand Up
in 2013!*

Name: _____

Address: _____ City: _____ State: _____

ZIP: _____ Email: _____

Phone: _____ (Home) _____ (Mobile)

Please complete and return to: Sjögren's Syndrome Foundation, Attn: *I Want to Stand Up*
6707 Democracy Blvd Suite 325 Bethesda, MD 20817



SSF Personal Support System

Listed below are SSF Support Group Leaders, individuals who volunteer to be sources of information for Sjögren's syndrome.

ALABAMA

Birmingham Anne Rose (205) 972-4261
sjobham@gmail.com

ARIZONA

Phoenix Area SSF Office (800) 475-6473

ARKANSAS

Little Rock Karen Fulton (501) 590-0171

CALIFORNIA

San Diego Suzanne Davies sfsuzannedavies@gmail.com
Dona Frosio (619) 303-9004
Nancy Crabbe (650) 593-9022
Lara Strom (650) 720-0912

San Francisco Bay Area
Santa Rosa

COLORADO

Denver/Englewood Maurine Daniels (303) 721-0241
Ft. Collins/Loveland Eunice Krivonak (970) 203-0147

CONNECTICUT

Farmington Mary Beth Walter (860) 569-6933

FLORIDA

Ft. Lauderdale Georgie Littlefield (954) 977-0775
Lady Lake Karen M. Marshall (Nov. 1 - April 30) (352) 259-1309
Orlando/Lakeland Joyce Tompkins (863) 701-0512
Tallahassee Kathleen Abrams (850) 668-3586

GEORGIA

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IDAHO

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ILLINOIS

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or (630) 853-6836

INDIANA

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Indianapolis Diana Altom (317) 356-2558

IOWA

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Dubuque Paula sigdbq@gmail.com

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Sjögren's Society of Canada
Sally Speers (778) 371-4664
sjogrensvancouver@hotmail.com

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Lee Durdon, President (888) 558-0950
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Montreal



Keep an Ear in the Sky

Shannon Boxx, World Cup soccer player and Olympic gold medalist, has been an inspiring Sjögren's advocate since she announced she has Sjögren's this past year. Shannon's willingness to help the Foundation has been greatly appreciated and she is now taking Sjögren's awareness to the sky!

If you're flying US Airways or American Airlines this January, February or early March, tune into *Talk Business 360* to hear an interview of Shannon about her journey with Sjögren's and why raising awareness is so important to her. And while you're settling into your flight, take a minute to browse the flight's magazine, either *American Way Magazine* or *US Airways In-flight Magazine*, to see a mention of the interview and the Foundation's listing for people who want to find out more information about Sjögren's.

If you are not traveling on one of the 61,352 flights that will be broadcasting the interview, you can listen to it on the Foundation's website: www.sjogrens.org. Thanks, Shannon, for taking our message to new heights! ■



4 issues for just
\$18
 for SSF members!



Stay informed. Stay aware. Be your own best medical advocate.

The *Sjögren's Quarterly*, a medical and scientific newsletter, was launched in August 2006 and is aimed at increasing awareness and educating professionals about the latest information on Sjögren's research, treatments and products.

Although the content is primarily written for a professional audience, *Sjögren's Quarterly* is not just for doctors and researchers. Patients may benefit from the information, too.

If you are interested in subscribing to *Sjögren's Quarterly*, we offer the newsletter for the rate of just \$18 for SSF members. Take charge of your healthcare by keeping on top of all the best medical information available.

Subscribe to *Sjögren's Quarterly* today, and you might just teach your doctor a thing or two about Sjögren's.



	Non-Member Price	Member Price	Qty	Amount
A one-year subscription to The Sjögren's Quarterly	\$50.00	\$18.00		
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Faces of Sjögren's: Melaca's Journey

When I was finally diagnosed with Sjögren's, my first thought was... "how is this going to affect my life?" I was diagnosed in February 2011 and it felt like a whirlwind of events that led up to my diagnosis. I didn't have time to absorb what was happening to me or even try to grasp the concept that I might have a chronic illness. I was sick, depressed, angry, frustrated and, most of all, I didn't have one person who understood what I was going through! I had to deal with all of this myself and try to understand what was happening to me.

I went home confused and frustrated that I had nobody to help me and nobody to educate me on my new diagnosis. My thoughts were all over the place as to what my future would be like and how my health would deteriorate. I knew I would have to start telling people that I had Sjögren's to start educating them and help raise awareness. I decided to work with the Sjögren's Syndrome Foundation and start a support group in Hawaii. The Foundation was there to help educate me when I had no one, and I felt it was important to continue the Foundation's work in my community.

My life has changed since my diagnosis and every day is a challenge for me. I took charge of my life and decided to make changes to get healthy. I work out four to five times a week for an hour. I try to make healthy choices everyday when eating my meals. I have had to work hard to be more aware of what's going on with my body and make daily adjustments as needed in my life. I think I have been successful in finding a work/life balance because of my awareness of my body and disease.



Now I feel great and love my life! Sjögren's has helped me to meet many wonderful people and learn how to enjoy and appreciate life one day at a time.

-Melaca

View more stories on the Sjögren's Syndrome Foundation website: www.sjogrens.org.

50%
in 5 years
Sjögren's
syndrome
FOUNDATION

TEAM SJÖGREN'S... ON THE ROAD AGAIN!

*Join Team Sjögren's in Nashville,
the home of country music...
...and the Country Music Marathon and Half-Marathon*

Join *Team Sjögren's* and train to run or walk in the 2013 Country Music Marathon and Half-Marathon in Nashville on April 27, 2013.

We are looking for 30 inspired individuals to join us as we begin to train for this challenge. We understand that not all Sjögren's patients are able to run or walk in a marathon, so we hope you will help us recruit someone else – your husband, wife, sister, cousin, daughter, son or friend – and have them run in your honor!

By signing up to join *Team Sjögren's*, you not only will receive world-class training but also leadership and mentorship from past runners and staff. You will receive coaching from our Team Trainer as well as our Team Nutritionist. The staff of the SSF will help guide you through the entire process and ensure you are ready to complete either the 13.1- or 26.2-mile course!

In addition to raising awareness for Sjögren's, you also will be helping to raise crucial funds for Sjögren's research and education.

Just imagine the difference you will be making as you run or walk in honor of all Sjögren's patients!

To learn more about *Team Sjögren's*, contact Steven Taylor at 800-475-6473, ext. 211, or staylor@sjogrens.org



Team
Sjögren's





in memoriam

In Memory of Annette Leak Davis

Mr. & Mrs. Kent Basson
BSA Troop 204
Carolyn Griffin
Rick & Xan

In Memory of Barbara Tschida

Jackie & John Tschida

In Memory of Della Lorraine Gray Tyson

Julie & Ron Matus

In Memory of Elvera Minnick

Rich & Kathleen Christensen
Paula Savino
Kerry Tritch
Matilde Yonkers

In Memory of Linda Peterson

Bonnie & Fred Richard

In Memory of Linda M. Pietroski

Robert Waters

In Memory of Marie Cooley

Michael & Mary Dillon
Diane, Ken, and Alex Heath
Northrop Grumman
Bill & Nancy Ratchford
Keith & Teresa Scott
Ulmstead Club Inc.
Eleanor Whelan

In Memory of Mary Butler

Kevin Butler

In Memory of Mary Hines

Jenny Gelman

In Memory of Nancy T. Aceto

Dr. Stuart Schneller & Office Staff

In Memory of Patricia Barber

M. Kathleen Barber & Family
Carl & Lorene Conklin
Ed & Bev Dauber
Paul & Shirley Fleener
Lola Jacobs
Gene & Ramona Jean Kile
Carolyn Morton
Oak Street Social Committee
Shirley Rice
John & Laverne Rosenberger
Ronald & Dorothy Sanders
Cora Belle Tebu
Shelby Waymire
Kenneth & Mary Jean West

In Memory of Rhoda Dennison

Delores Bachmura
Sharon Chelner
Elaine & Herbert Harris
Gene & Lois Ann Kirchner
Bonnie Litton
San Diego-Imperial Chapter

In Memory of Sandra Blust

Bill Kcenich



in honor

In Honor of Alyce Grillet, Happy Solstice

Noel Fulton

In Honor of Babs Kappe for Christmas

Sisty Ugler & Phil

In Honor of Barbara Honig

Danny & Crew

In Honor of Catharine Claiborne

The Girls

In Honor of Cheryl Levin

Sue, Kevin & Kids

In Honor of Christine Pyle

Matt Pyle

In Honor of Don & Diane Johnson

Patrick & Deborah Conner

In Honor of Dr. Audrey & Steve Honig/Swartz

Dan, Cindy, Sophie & Jenna

In Honor of Dr. Robert Fox

Linda Zarzeczny

In Honor of Elaine Haumann

Rowena Kather

In Honor of Emily Schetky

Priscilla Dalrymple

In Honor of Jamie Gaines for Christmas

Chris & Jennifer Gaines

In Honor of Lari Loop for Christmas

Steve & Isabelle des Fontaines

In Honor of Linda Howard for Christmas

Jane Webb

In Honor of Marcy Levine

Peter Joseph, MD

In Honor of Margaret Rothman

Gale & Bruce

In Honor of Mary Wasner for Christmas

Gin & Mark

In Honor of Maurine Daniels

Sharon O'Donnell

In Honor of Nancy Crabbe for Christmas

Pete & Aubrey Giacopelli

In Honor of Nancy Visocki

Gail Berkoff

In Honor of Nora McLean for Christmas

Janet & Lindsay

In Honor of Petrea Marvin

Lindsay & Philip

In Honor of Robert Pedrolie

Nancy Jenull

In Honor of Shannon Voelkel

Scott Voelkel

In Honor of Sharon Adley for Christmas

Lyle & Sue

In Honor of Shirley Hobde for Christmas

Lyndsay Hobde

In Honor of Susan Engelhart

Michael & Melissa Petty

In Honor of Susan Joyce

Scott & Louise Sternberg

In Honor of Tara Mardigan

Kathy Tower

In Honor of Tom Kort

Tish Armstrong

In Honor of Valerie Bowles for Christmas

Nancy Hubbell

In Honor of Virginia Kelly for Christmas

Susan Mactye

In Honor of Waltraud Schlanzky for Christmas

Paula Peterson

Register Now!

2013 SSF National Patient Conference

“Discover the Possibilities”

April 12-13, 2013

Hyatt Regency Bethesda, Bethesda, Maryland

Presentation topics will include:

Overview of Sjögren's Syndrome

Sex and Living with Sjögren's

Biologic Therapies and Sjögren's

Understanding Blood Changes and Test Results

Caregiver/Patient Perspective on Sjögren's

Neurological Complications and Sjögren's

Dry Eye and Sjögren's

Dry Mouth and Sjögren's

Podiatry Issues and Sjögren's

Hope for the Future: Research Update

As a Sjögren's patient, it's easy to feel confused or overwhelmed by the abundance of information available about the illness and how it affects your body. But here is your opportunity to “Discover the Possibilities” for an educational journey to take control of your health and day-to-day living by learning from the best minds dealing with Sjögren's. This April, join fellow Sjögren's patients and their family members as well as healthcare professionals and other experts who specialize in Sjögren's at the 2013 SSF National Patient Conference in Bethesda, Maryland.

SSF programs are the best Sjögren's patient education opportunities in the country. They have helped thousands gain a better understanding of Sjögren's and will help you, too. This two-day event will feature an array of presentations from the country's leading Sjögren's experts – physicians, dentists, eye care providers, and researchers – who will help you understand how to manage all key aspects of your disease. So this April 12-13, we invite you to join with us and experience a weekend where you will “Discover the Possibilities” for heightening your understanding of Sjögren's at the 2013 National Patient Conference in Bethesda, Maryland!

Call **800-475-6473** or visit **www.sjogrens.org** today to receive the latest information.

Space is limited. Please register early!

Registration Form

Registration fees include: Lunch each day, snacks and beverages, Friday evening dinner, hand-out material from speakers and entrance to exhibit area on Friday and Saturday.



2013 NATIONAL PATIENT CONFERENCE BETHESDA, MARYLAND — APRIL 12-13, 2013

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 18, 2013)

	March 18th and before	March 19th and after
SSF Members & Guests	\$170 per person	\$190 per person
Non-Members	\$190 per person	\$210 per person

TOTAL:

3 PAYMENT – Mail to SSF, c/o BB&T Bank · PO Box 890612 · Charlotte, NC 28289-0612 or Fax to: 301-530-4415

Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) payable to SSF.
 MasterCard VISA Discover AmEx Card Number _____ Exp. Date _____
 Signature _____ CC Security Code _____

- Refund requests must be made in writing. Registrants whose written requests are received by March 22nd 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 Stephanie Bonner at the SSF office (301-530-4420, ext. 214) by April 2nd.
- A limited number of rooms are available at the Hyatt Regency Bethesda (One Bethesda Metro Center, Bethesda, MD 20814) at the SSF rate of \$129 per night plus tax if reservations are made by March 16, 2013. Call the toll-free hotel Central Reservations number at 888-421-1442 or call the Hyatt Regency Bethesda directly at 301-657-1234 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
- The Hyatt Regency Bethesda is approximately 18 miles from the Ronald Reagan Washington National Airport. The hotel **does not** provide a shuttle service. However, there is direct Metro subway access below the hotel to/from Reagan National Airport (Red Line/Bethesda Station). Alternate transportation suggestion: Taxi Fare / \$38 (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

Be Part of the SSF Breakthrough Goal Team – Join Us at One of Our Events!

2013 SSF Special Event Calendar

Join in the fun and help increase Sjögren's awareness. The SSF is very excited for all of our events coming this year. Look at our special event calendar below to see if there is an event coming to your area. More events to come!

Visit www.sjogrens.org

or contact the SSF office to
learn more about our events!

March

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

April

- 12-13** **National Patient Conference**
Bethesda Hyatt Regency, Bethesda, Maryland
- 13** **Bethesda NPC Walkabout**
Bethesda Hyatt Regency, Bethesda, Maryland
- 27** **Team Sjögren's Country Music Marathon**
Nashville, Tennessee

May

- 4** **Philadelphia Tri-State Walkabout & Health Fair**
Philadelphia Zoo, Philadelphia, Pennsylvania
- 5** **Long Island Walkabout & Health Fair**
Roosevelt Field Mall, Garden City, New York
- 11** **Dallas/Ft. Worth Walkabout & Health Fair**
Grapevine Mills Mall, Grapevine, Texas

June

- 1** **Northeast Ohio Walkabout**
Brecksville's Oak Grove Picnic Area, Brecksville, Ohio
- 15** **Denver Walkabout**
Denver Zoo, Denver, Colorado

