The Moisture Seekers

Sjögren's Syndrome Foundation

www.sjogrens.org

Volume 29, Issue 2 February 2011

# Update on the International Sjögren's Syndrome Registry


*by Troy Daniels, DDS, MS with contributions from John Greenspan, BDS, PhD, Caroline Shiboski, DDS, PhD and Lindsey Criswell, MD, MPH*

Much is happening as we enter year eight of the 10-year NIH-supported registry called the Sjögren's International Collaborative Clinical Alliance (SICCA). We have had a very smooth transition in leadership: Troy Daniels, DDS, MS, and John Greenspan, BDS, PhD, founded SICCA and have co-directed the NIDCR contract since 2003 and remain actively involved as investigators. Caroline Shiboski, DDS, PhD, and Lindsey Criswell, MD, MPH, who have been involved with SICCA since its onset, Shiboski as lead Epidemiologist, and Criswell, a rheumatologist, as lead Geneticist, are the new co-directors of SICCA since July 2010. Since beginning participant enrollment in 2004, over 2200 individuals have completed baseline enrollments and almost 600 have completed two-year follow-up enrollments. These enrollments have been occurring at nine collaborating SICCA research groups located in Argentina, China, Denmark, India, Japan, the United Kingdom and the United States, directed from the SICCA Coordinating Center at the University of California, San Francisco.

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*The Moisture Seekers* is happy to bring to you a new installment of "Your Story," an opportunity for Sjögren's patients to tell their story and share with the rest of the Foundation members how they have learned to cope with their disease. This installment is an interview with Jeanne Dale, a Sjögren's patient, from Winnetka, Illinois, and her perspective on Sjögren's and how it impacts her life.


## *How long ago were you diagnosed with Sjögren's and by whom?*

I was diagnosed in December 2005. I was initially screened for ANA and RA factor by my internist and when the results came back extremely high, I was referred to a rheumatologist who then diagnosed me as having Sjögren's syndrome. I was fortunate that the diagnostic process took a relatively short period of time.

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## In This Issue

"SICCA" continued from page 1 ▼

One goal of the SICCA project is to develop new classification criteria. The way patients with SS have been diagnosed or classified has evolved over the years with 11 diagnostic or classification criteria published since 1965. It is important to keep in mind the difference between diagnostic criteria, which are based on an individual clinician's knowledge and experience applied to an individual patient, and classification criteria, which are based on an established disease definition and defined objective tests applied to groups of patients who will participate in clinical trials or other research studies. The current classification criteria for SS have been in use for eight years but can create heterogeneous patient groups. They also have not been approved by the usual professional groups that oversee classification criteria, such as the American College of Rheumatology, and need updating.

Many new drugs are becoming available for treating other autoimmune connective tissue diseases, such as rheumatoid arthritis (RA) and lupus. Some of these drugs, or newer related drugs, may eventually be useful for treating SS, but trials of new drugs, or new applications of existing drugs, require rigorously defined groups of patients. Therefore, new SS classification criteria are needed now to best support future trials of powerful new drugs that may be effective in treating the disease. To accomplish this, SICCA is now analyzing the consistently recorded histories and examination and test results obtained from each of its participants to determine the occurrence, patterns and overlapping relationships of these results. These analyses have supported the development of new and simplified SS classification criteria that are currently under review by the American College of Rheumatology, from which we seek advice and approval.

Complex autoimmune diseases, such as RA and lupus, have long been suspected of having a genetic basis. Recently completed genome-wide association studies (GWAS) of patients with these diseases have found strong associations with genes that regulate the immune system. A genetic component of SS has been suspected based on the observed clustering of the disease and other autoimmune diseases within families and the rare occurrence in identical twins. GWAS and other comprehensive genetics studies of SS are needed to define the genetic contribution to SS, including the relationship to other autoimmune diseases such as RA and lupus. To support such future genetic research on SS, SICCA has been collecting DNA from all of its participants and, beginning this December, a GWAS will be performed by the NIH using SICCA DNA specimens. From analyses of the GWAS data, we will try to learn which regions of the genome may be significantly associated with objective components of SS. In addition to GWAS, other forms of genetic analyses, such as studies of epigenetic factors, are in progress. In such studies, the way in which some genes express themselves is examined as a possible contributor to disease

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# *I Stood Up...*

*Walkabout Friends and FamilyTeams Stand Up Throughout the Country*

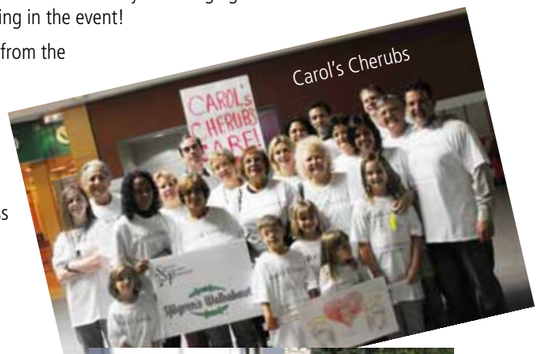

## *Let's hear it for our Friends and Family Walkabout Teams!*

Thanks to all of you who have taken the initiative and have built your own Walkabout Team by encouraging Friends and Family members to help you by joining your Team and participating in the event!

It is very exciting for all of us to see the outpouring of support at our events from the Walkabout Teams. It is great fun for Team members to wear their own Team T-shirts that they have created and/or to read the signs that they carry with their Team message! The Walkabout Teams make it fun for everyone, whether they are a part of the team or an event participant!

It is reassuring for all attending to see how we are making an impact on community members and to know that we all can and do increase awareness of Sjögren's!

Here are just a few of our Walkabout Teams and photos!











Soon we will be kicking off the spring *Walkabout* events. If you happen to have a Walkabout in a city near you, please plan to attend and be sure to invite everyone you know! Form your own Team — all you need to do is create a name and a sign or create a sticker to wear or decorate t-shirts for all to wear! The key is to make it FUN! Your friends and family will thank you for offering them a chance to help you make a difference!

Remember, your loved ones want to know how they can fight back, too!

How will you ***Stand Up***?

"Your Story" continued from page 1 ▼

### *What were the symptoms that led you to see a doctor?*

The initial complaint that I went to my internist with was a bothersome ankle that became painful, with swelling that occurred and disappeared with seemingly no reason. After x-rays, blood work was performed that then led to my diagnosis. After the diagnosis, I realized that some of the then minor annoyances, such as Raynaud's and peripheral neuropathy, were probably due to the Sjögren's. But it was the swollen joints that first led me to my physician.

### *What is your main everyday challenge with Sjögren's now?*

The daily challenges vary, again with seemingly no reason for the changes. However, there are two major problems that, for me, can be a daily challenge. The first and most frustrating is fatigue. I have learned how to manage it, for the most part, but can never eliminate it. I read either in one of your newsletters or heard at one of your conferences, a hint on managing fatigue that I use almost daily. Divide your day into three blocks of time and never fill more than two of those blocks with activities. If I am going out for the evening, I am resting either in the morning or afternoon. It can be frustrating because my spirit can't always grasp why my body is giving out. It took many years and many days of relentless fatigue before I finally learned how to adapt.

The second most difficult challenge is with my eyes…the dryness. When I was diagnosed, my eyes were a minor concern. I had stopped wearing contacts six months prior to my diagnosis because they were bothering me… I didn't realize then it was the beginning of my eye issues. I am a voracious reader and also spend several hours each day at my computer, so my eyes are always a problem and when I have to stop reading or working, it becomes frustrating and difficult to cope. Living in the North, the cold winters exacerbate many of my symptoms… dry eyes, neuropathy, etc., and the symptoms are always more severe in the coldest of months.

### *What is the best tip you have learned along the way on coping with your Sjögren's that you would like to share with other Sjögren's patients?*

The tip about the fatigue that I mentioned earlier has certainly helped me the most. In addition, I would say to be open to integrative treatments. If possible, find a reputable integrative medical center, preferably attached to a university hospital or larger hospital and explore. Investigate and remain open to accupuncture, anti-inflammatory diet choices, energy work. There may be a treatment that can alleviate some complaint or moderate any pain. Again, remain open.

### *You attended the National Patient Conference in San Francisco last April 2010. What were your impressions of that conference?*

We have attended several of the patient conferences, both the national and the one-day regional conference. At all of them, I have learned from both the presenters and the fellow patients and their families. I believe that knowledge is power, and education is paramount in our medical care and the responsibility for our health and our care is ours in partnership with the medical community. To be informed is to be empowered.

Hearing some of the patients' stories has led me to a place of gratitude, and I remember some of these fellow Sjögren's patients when I have a difficult day and I realize perhaps my day isn't as difficult after all. I encourage all who have never attended a conference or seminar haven't done so recently, to try to do so. Science changes so rapidly that information can evolve within a short period of time.

### *We know your family is supportive of you as well as the Foundation. What suggestions would you give to others to help encourage family support and involvement?*

Again, education is critical. We must tell our families and close friends about Sjögren's and the symptoms we deal with on a daily basis. I learned about the importance of opening dialogue when our son, who is a cancer survivor, was diagnosed with leukemia as a 17-year-old high school senior. Friends, teachers, neighbors hesitated to ask about our son's illness and I

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"SICCA" continued from page 2 ▼

development. Results from those genetic studies are expected to be available in late 2011.

We have published two manuscripts: one describing the SICCA Project and some of its early results[1], and another describing our simplified method for assessing dry eyes (keratoconjunctivitis sicca - KCS).[2] Additional manuscripts are currently in review: one describes detailed associations of labial salivary gland biopsy microscopic results with the serological and ocular components of Sjögren's syndrome (SS); another manuscript describes the extraglandular diseases associated with SS among SICCA participants (e.g. thyroid, liver, kidney or lung disease or lymphoma). A future SICCA update in this publication will describe these results.

Earlier this year, SICCA began disseminating its specimens and data to scientific investigators. Five completed applications have been received: three have been approved by an external scientific review panel and two are in review. The application process is available on the SICCA website (http://sicca.ucsf.edu) including all necessary instructions and forms. It is important to note that the epigenetic study mentioned above is supported by a grant from the Sjögren's Syndrome Foundation.

In 2009, two new SICCA Research Groups opened in the United States. These are located at the University of Pennsylvania, Philadelphia and at Johns Hopkins Medicine in Baltimore, Maryland. There are now three US locations in which patients with diagnosed or suspected Sjögren's syndrome may inquire about or enroll in the SICCA registry. Their contacts are:

**University of Pennsylvania**, Philadelphia
Kristel Dow, SICCA Project Coordinator
kristel.dow@uphs.upenn.edu
(215) 615-4306

**Johns Hopkins Medicine**, Baltimore
Anthony Keyes, SICCA Project Coordinator
sicca@jhmi.edu
(410) 550-6259

**University of California**, San Francisco
Danielle Drury, SICCA Project Coordinator
danielle.drury@ucsf.edu
(415) 476-0535

## References:


1. Daniels TE, Criswell LA, Shiboski C, Shiboski S, Lanfranchi H, Yi D, et al. An early view of the International Sjögren's Syndrome Registry. *Arthritis Rheum* 2009; 61:711-714.

2. Whitcher JP, Shiboski CH, Shiboski SC, Heidenreich AM, Kitagawa K, Zhang S, et al. A simplified quantitative method for assessing keratoconjunctivitis sicca from the Sjögren's Syndrome International Registry. *Am J Ophthalmol* 2010; 149:405-415.


"Your Story" continued from page 4 ▼

realized it was up to me to inform them and let them know what we might need, and to tell them it was okay to ask how he and our family were managing. By doing so, we expanded our circle of support, made the entire experience easier, and earned new friends. I have followed that pattern with my Sjögren's. Again, education, education, education.

### *What is your hope for Sjögren's patients in the next ten years?*

My hope is that with the research being done on Sjögren's, its possible cause(s) and new medications, our prognosis will improve and our symptoms will become more manageable. I think we currently classify Sjögren's as an "orphan disease," and I hope that in ten years it will not remain in that category. ■

*Jeanne Dale*


## Q *What can I do to decrease the chronic fatigue I experience during Sjögren's flare-ups?*

**A** Fatigue is a common symptom of Sjögren's. The fatigue may be chronic. In other words, it is persistent or may be more intermittent and considered due to a "flare-up of disease." Many patients with Sjögren's syndrome also have fibromyalgia, and this condition is a common cause of fatigue.

Regular aerobic exercise that increases your heart rate and good sleep are essential to help with fatigue. Ideally patients should attempt to exercise 30 minutes per day for at least 4-5 days per week. It is important to get enough hours of sleep per night to feel rested or refreshed on awakening. Try not to exercise too close to bed time as this can aggravate sleep. If you snore or make other mouth noises at night such as smacking, snorting or chumping your teeth, be evaluated for sleep apnea. Pacing yourself, especially during "flares" can be helpful.

In terms of medication, Plaquenil often helps energy. I have also used a cousin of Plaquenil in my practice called quinicrine. Quinicrine is a prescription medication which is compounded. DHEA is an over-the-counter supplement or may be compounded with a prescription. I recommend my patients who take DHEA purchase from a compounding pharmacy or a reputable company. The one that I tend to use is out of Massachusetts called Pure Encapsulations. Other treatments that can be used for fatigue off label include antidepressants such as Prozac and Provigil. Talk to your physician about this option.

***Scott Zashin, MD***

## Q *When I'm out walking with my friends, I am always 'huffing and puffing' to keep up with them. My respiratory function tests are all in the normal range. Is this a common symptom of Sjögren's?*

**E** xertional breathlessness should be evaluated. Most primary care physicians should first check lab studies to exclude anemia and thyroid disorders. Then if those are normal, consider breathing function tests (simple spirometry), chest x-ray, oxygen saturation while walking and an ECG or echocardiogram to exclude a heart issue.

Depending upon those results, a referral to a pulmonologist for more specialized testing (hi-resolution CT scanning, complete pulmonary function testing and formal exercise testing), bronchoscopy or a specialized heart echo to exclude a shunt in the heart could be performed.

These tests are designed to exclude infection, malignancy, or Sjögren's-related interstitial lung disease or bronchiolitis. At our institution, we have an autoimmune lung center which performs these tests in consultation with our pulmonologists and rheumatologists. If necessary, more advanced diagnostic studies are done to yield an explanation before therapy is recommended, as often there is an underlying condition such as asthma or reflux-related lung injury which may be the cause.

A lung biopsy is usually not necessary unless the history or testing suggests another possible explanation such as an allergic environmental condition (hypersensitivity pneumonitis), sarcoidosis or we suspect a malignancy. Often mild lung inflammation responds well to well-tolerated and safe therapy.

***Richard T. Meehan, MD***

## Q *What are the effects of Sjögren's on an individual during pregnancy and post-pregnancy?*

**A** With the exception of the Ro/La antibody or phospholipid antibody issue in pregnancy, Sjögren's by itself does not usually present problems in pregnancy. In fact, some increased hormones, like cortisol, may decrease inflammation resulting in less joint pain and other symptoms. Certainly, if an individual is very dry, this is an ongoing discomfort during pregnancy.

When Sjögren's occurs with other autoimmune diseases like SLE (lupus), the lupus process can be associated with various increased risks in pregnancy. In contrast, individuals with rheumatoid arthritis (RA) usually have less joint pain during pregnancy when cortisol (a steroid) is elevated.

Ro/La antibodies can be associated with neonatal lupus and congenital heart block. An excellent review of this topic appeared in the Summer *Sjögren's Quarterly* by Jill Buyon, MD at New York University in NY City. Brief highlights include:

- 60% of Sjögren's patients have Ro and 40% have La, but only 2% experience neonatal lupus or congenital heart block
- 18% who experience congenital heart block will experience it with the next pregnancy

Phospholipid antibody can be seen in Sjögren's (~20%) but is more often looked for in lupus patients or in setting of recurrent miscarriage. This antibody can be associated with miscarriages in the second trimester or blood vessel clotting problems.

I recommend all patients with known Sjögren's know their SSA/B and phospholipid antibody status prior to conceiving

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"SICCA" continued from page 9 ▼

and visit their rheumatologist and consult a high-risk OB. An individual plan for follow-up during pregnancy is then developed. Staying well-hydrated and practicing balanced nutrition, exercise and stress reduction also make sense for mom and baby.

*Nancy L. Carteron, MD*

**Q** *My eye doctor feels I can reduce my Restasis use to once a day because my eyes are free of inflammation. Is that in compliance with the normally prescribed dose? Also, a person in my support group has been told by her doctor that she can use Restasis up to four (4) times a day. Is this safe?*

**A** These are excellent questions, and although there are not simple answers, there are many options available. When Restasis® received FDA approval late in 2002, the clinical studies were for six months. There was uncertainty as to how to prescribe Restasis® beyond that time period. For quite some time, an accepted standard of care was to use Restasis® twice-a-day for six months and then reduce it to once-a-day or twice every-other day. Recent studies have shown that Restasis® is safe and effective for long-term use, so many doctors now keep patients (especially those with conditions like Sjögren's) on a twice a day regimen, while other doctors still modify treatment after six months to a once-a-day plan. On an individual basis, your signs (what your doctor sees during an evaluation) and symptoms (what you feel) will help to determine the best ongoing course for you.

Current trends in dry eye treatment involve treating inflammation of the surface cells on the eye as well as the glands that help to produce part of the tears. As such, a long-term treatment plan is typically best. When someone stops using Restasis®, the benefits do continue for quite a while after cessation of treatment. However, over time, it is possible that inflammation may recur and symptoms may return. In light of its minimal side-effects, ongoing long-term treatment with Restasis® is safe and effective, particularly for Sjögren's patients.

While the recommended dosing is twice-a-day, some patients benefit from and tolerate more frequent dosing. As is true with many medications, other dosing and uses for the drug are found over time. These are referred to as "off label"use. Your doctor may find that alternative dosing is indicated or that Restasis® might be helpful for other conditions (such as some forms of allergic conjunctivitis). Restasis® has some anti-inflammatory characteristics, but since it is not a steroid, frequent and/or long-term use has been found to be effective for many patients. ■

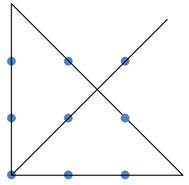
*Stephen Cohen, OD*



# Answers to Brain Excercises

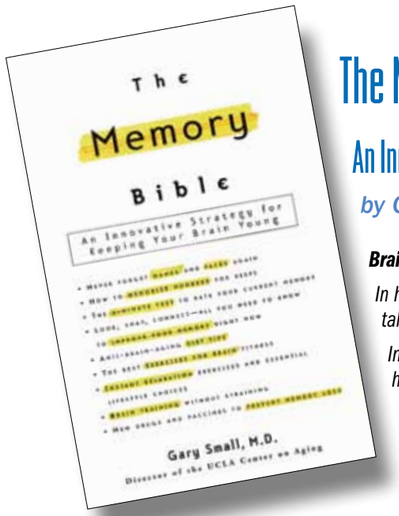
***Right Brain Answer:***

Letting go of our spatial mental assumptions allows us to "connect the dots."



***Left Brain Answer:***

'Braking' becomes 'Breaking' when you add the letter 'E.'




# The Memory Bible:

## An Innovative Strategy for Keeping Your Brain Young

*by Gary Small, MD*

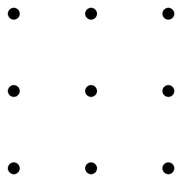
***Brain Exercise***

*In his book,* The Memory Bible, *Dr. Gary Small recommends we practice a form of "mental aerobics" as a way to stimulate our brains without stressing them.*

*In the book there are several pages of varying levels of mental aerobic exercises that help stimulate either the left or right side of your brain or both sides.*

*The left side of your brain tends to handle more of the logical analysis as well as mathematics, reading, writing and speech. The right side of your brain handles more spatial relationships (e.g. reading maps or doing puzzles) and other more artistic abilities.*

*Below are two examples of intermediate exercises, one for the left side of your brain and the other for the right side. (Answers can be found on page 10.)*



***Right Brain Exercise:***
*Look at the dots on the left. Without lifting your pencil, draw four straight connected lines through all nine dots, only going through each dot once.*

***Left Brain Exercise***
*Can you think of a word that begins with the letters 'BR,' and when you add the letter 'E' after those letters, it creates a new word that sounds the same as the original?*

These books can be purchased using the order form below, online at www.sjogrens.org or by contacting the Sjögren's Syndrome Foundation office at (800) 475-6473.

| | Non-Member Price | Member Price | Qty | Amount |
|---|---|---|---|---|
| The Memory Bible: An Innovative Strategy for Keeping Your Brain Young | $16.00 | $13.00 | | |
| *Maryland Residents add 5% sales tax* | | | | |
| **Shipping and Handling:** U.S. Mail: $5 for first item + $2 for each additional item<br>Canada: $8 for first item + $2 for each additional item<br>Overseas: $18 for first item + $2.50 for each additional item | | | | |
| **Total Amount** | | | | |

Mail to SSF, BB&T Bank · PO Box 890612 · Charlotte, NC 28289-0612 or Fax to: 301-530-4415

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____ E-Mail _____

❑ Enclosed is a check or money order (in U.S. funds only, drawn on a US bank, net of all bank charges) payable to SSF.

❑ MasterCard ❑ VISA ❑ Discover ❑ AmEx Card Number _____ Exp. Date _____

Signature _____ CC Security Code _____



## in memoriam

**In Memory of Billie Margaret Wagner**
John & Beth Morrison

**In Memory of Carol Friess**
Kenneth & Joni Lahmann

**In Memory of Diane Weiner**
Evan & Leslie Langbein

**In Memory of Gladys Beach**
Charlotte Beach Hankins

**In Memory of Isabel "Babe" Daldos**
Shari Robertson

**In Memory of Joan Elizabeth**
Andy Burish & The Burish Group

**In Memory of Joan Pientka**
Jim & Susan Hill
Dora & Ari Zuniga

**In Memory of Josh Hansen**
Sandy Lapin

**In Memory of Kathleen Koski**
Nancy Menefee

**In Memory of Mary Case**
James & Sondra Foy
Rose Meise
Sandy Coleman
Betty Johnston
Mr. & Mrs. Baxter Breaux
Doris Fischer

**In Memory of Tillie Zaid**
Sandy & Bob Leon

## in honor

**In Honor of Barbara Hyler**
Jo Ludwig

**In Honor of Betsy Hixon**
Andrew Hixon

**In Honor of Louise Hillery**
The Family of Tom Spofford

**In Honor of Our Mom - Catharine Claiborne**
Jaka, Yvie & Kaizer Claiborne

**In Honor of The 71st Birthday of Jackie Hill**
Michael Hill

**In Honor of The Birthday of Dr. Steven Carsons**
Lynn-Anne & Stuart Spitzer

sip for Sjögren's
a fine water tasting event

Host an event in your area... *We'll help.*

If you are interested in organizing a *Sip for Sjögren's* event in your area, please contact Pat Spolyar, Director of Awareness, at 800-475-6473, ext. 221 or pspolyar@sjogrens.org.


Sjögren's Syndrome Foundation
Legacy of Hope

If you would like to receive information on how you can *Leave a Legacy* to support the Sjögren's Syndrome Foundation's critical research initiatives or to support one of our many other programs, please contact Steven Taylor at 800-475-6473.

*Leave A Legacy – Remember Us in Your Will*


# 2011 SSF National Patient Conference

## *"Your Passport To Learning"*

April 1-2, 2011
Hyatt Regency Reston
Reston, Virginia

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 Passport to Learning* 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 2011 SSF National Patient Conference in Reston, Virginia (just outside of Washington, DC).

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. Presentation topics will include:

**Overview of Sjögren's Syndrome**
**OB-GYN Issues and Sjögren's**
**Lung Complications**
**Dry Eye and Dry Mouth Issues**
**How to Find a Healthcare Professional**
**Neurological Manifestations**
**Vitamin D Deficiency in Autoimmune Disease**
**Sjögren's Survival: A Patient Perspective**
**Overlapping Major Connective Tissue Diseases**
**Research Update**
**Aching Joints, Fatigue and Sjögren's**

So this April 1-2, we invite you to pick up *Your Passport to Learning* and experience an amazing opportunity to heighten your understanding of Sjögren's at the 2011 National Patient Conference in Reston, Virginia!

***Call 1-800-475-6473 or visit www.sjogrens.org today to receive the latest information.***

*Space is limited. Please register early!*

# *Registration Form*

Sjögren's Syndrome Foundation

***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.*

## 2011 NATIONAL PATIENT CONFERENCE
## RESTON, VIRGINIA — APRIL 1–2, 2011

**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 7, 2011)

| | March 7th and before | March 8th and after |
|---|---|---|
| **SSF Members & Guests** | $165 per person | $185 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 ❑ AmEx Card Number _____ Exp. Date _____

Signature _____ CC Security Code _____

- Refund requests must be made in writing. Registrants whose written requests are received by March 18th 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 (800-475-6473 ext. 210) by March 23rd.
- A limited number of rooms are available at the Hyatt Regency Reston (1800 Presidents Street, Reston, Virginia 22090) at the SSF rate of $129 per night plus tax if reservations are made by March 8, 2011. Call the toll-free hotel reservation number at 888-421-1442 or call the Hyatt Regency Reston directly at 703-709-1234 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
- The Hyatt Regency Reston provides a complimentary shuttle service to/from the Dulles International Airport.

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*

# Spring 2011 Sjögren's Syndrome Foundation Special Event Calendar

The SSF is very excited for all of our events coming this Spring. Look at our special event calendar below to see if there is a *Walkabout* or *Sip for Sjögren's* coming to your area.

*Visit www.sjogrens.org or contact the SSF office to learn more about our events!*

## February

**12** ***Sarasota–Bradenton Walkabout***
DeSoto Square Mall, Bradenton, Florida

**13** ***Orlando Walkabout***
Waterford Lakes Town Center, Orlando, Florida

**26** ***Phoenix Walkabout***
Paradise Valley Mall, Phoenix, Arizona

## April

**1&2** ***National Patient Conference***
Hyatt Regency Reston, Reston, Virginia

**2** ***GWR Walkabout – Reston***
Reston Town Center at the Reston Hyatt, Reston, Virginia

**10** ***Sip for Sjögren's – Atlanta***
Nelson Mullins, Atlantic Station, Atlanta, Georgia

**30** ***Team Sjögren's – Nashville Country Music Marathon***
Nashville, Tennessee

## May

**7** ***Philadelphia Walkabout***
Philadelphia Zoo, Philadelphia, Pennsyvania

**10** ***Sip for Sjögren's – Harrisburg***
West Shore Country Club, Harrisburg, Pennsylvania

**18** ***Sip for Sjögren's – Akron***
Mustard Seed Market & Cafe, Akron, Ohio

## June

**11** ***Denver Area Walkabout***
Denver Zoo, Denver, Colorado

## To Be Announced

***Dallas Walkabout***

***Detroit Walkabout***

***Long Island Walkabout***

***San Antonio Walkabout***

***Sip for Sjögren's – San Diego***

Sjögren's Walkabout

sip for Sjögren's
a fine water tasting event