The Moisture Seekers

Sjögren's Syndrome Foundation
www.sjogrens.org

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National Patient Conference 2013 Highlights

On April 12th and 13th, 418 patients, family members and physicians traveled to Bethesda, Maryland to "Discover the Possibilities" at the 2013 SSF National Patient Conference.

With over 60% diagnosed within the last two or three years and attending their first National Patient Conference, it was a great way to learn the latest Sjögren's information from leading experts and connect to others who are going through a similar health journey. The SSF staff and Board of Directors always love meeting attendees, seeing patients discovering new products from the 18 conference exhibitors while also feeling the excitement and energy of 400 people uniting to fight Sjögren's by participating at the conference's awareness *Walkabout*.

The conference saw a wide range of speakers and topics such as "Neurological Complications of Sjögren's," "What Does Your Blood Work Mean?" as well as "Sex and Sjögren's." These talks along with others were given by wonderful medical experts from around the United States. Our keynote speaker on Saturday evening, Ann Fry, gave an inspirational talk about finding yourself among the chaos of a chronic disease.

The SSF wants to thank everyone who attended and made this educational conference possible. From our sponsors to patients and their family members, everyone committed themselves to helping each other learn and network to find new friends and supporters. The SSF's Education Committee always works hard to ensure that we have wonderful speakers and a great conference that attracted attendees from 31 states and two countries!

We know not everyone can travel to our National Patient Conference and we would like to make the information available to everyone, which is why we are offering five of the most popular talks on audio CDs with the follow-along PowerPoint presentation printouts. See the ad in this issue to learn how you can order them today.

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"NPC 2013" continued from page 1 ▼

Each year at our annual conference, the SSF recognizes volunteers with the awarding of our National Volunteer Awards. This year's award winners show how anyone can make a difference just by getting involved! This year's award winners were:

Conference Award Winners

Healthcare Professional Leadership Award – Dr. Steven Carsons

Dr. Steven Carsons has had a 30-year-plus career in Sjögren's. That includes treating patients, conducting research, organizing clinical trials as well as volunteering for the SSF. His compassion for patients is unparalleled and that is why he was chosen for this year's award.

Since the beginning of the SSF, Dr. Carsons has played an active volunteer role, including serving on the SSF Medical & Scientific Advisory Board and Board of Directors, as well as lead editor of the first two editions of *The Sjögren's Syndrome Handbook* as well as current Medical and Scientific Editor for the *Sjögren's Quarterly*. Currently, Dr. Carsons serves as Co-Chair for the Rheumatology/Systemic Manifestations Group of the SSF Clinical Practice Guidelines initiative.

Volunteer Leadership Award – Anne Rose

Anne Rose from Birmingham, Alabama exemplifies a volunteer leader.

Anne began volunteering for the SSF just a couple of years ago but since then has been a force to be reckoned with. From starting a successful support group to raising awareness in the Birmingham area to organizing our first-ever Birmingham *Walkabout*, Anne has been a champion for Sjögren's patients. With over 100 walkers in attendance, the event was a great success with hopes for an even larger event in 2013.

Anne was also officially the first volunteer to sign up as a Sjögren's Awareness Ambassador when the SSF announced the program in 2011. Through her dedication and persistence, Anne has personally distributed thousands of

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"NPC 2013" continued from page 2 ▼

"What is Sjögren's" brochures to healthcare professionals throughout Alabama.

Anne is a great example of one woman, with a passion, who will not let up until Sjögren's is officially a household name! As she said during her acceptance speech, "don't sit silent waiting on others. Join the Sjögren's army, and for heaven's sake, don't wait until you feel like it."

Development Award – The Casale Family

The Casale Family exudes energy, enthusiasm and love. When you couple that with their dedication and commitment to changing Sjögren's, they are unstoppable.

Since Gia Casale was diagnosed in her late teens with Sjögren's, she instinctively knew that her life was about to change. So in 2010, when Gia heard that the SSF had a marathon training program, she immediately stepped up and joined *Team Sjögren's* to run in the Nashville Country Music Marathon. From that moment, her amazing parents and supportive brothers began helping to raise funds and awareness of Sjögren's. Through their local businesses, they asked vendors to support Gia, placed signs outside their business to increase awareness and they even joined Gia in Nashville to cheer on all of our runners.

Since then, the Casale Family has continued to support the SSF's initiatives. Each year, they sponsor our local fundraising events in the Albany, New York area and also Gia has now run in three *Team Sjögren's* marathons raising over $10,000 for the SSF.

Mission Award – Patricia Hurley, MSc

This year, the SSF is honored to recognize Patricia Hurley, a Sjögren's patient who has volunteered her methodology expertise to steer the SSF Clinical Practice Guidelines initiative in its methodology for developing the first-ever guidelines for managing and treating Sjögren's patients.

Patricia has devoted countless hours to our cause-ensuring that physicians across the country will have evidence, and expert-based guidance to assist them in the best care for patients.

Patricia has been essential in helping the SSF navigate through the rigorous process of developing our guidelines and certainly has not stopped fighting to ensure that our guidelines are comprehensive, non-biased and useable for all healthcare professionals.

Awareness Award – In loving Memory of Cynthia Williamson

Cynthia Williamson, SSF Director of Field Services and dear friend to all who knew her, passed away suddenly this past August. Cynthia was a critical part of the SSF and, as many of you know, our small staff works like a family and thus this loss was felt immeasurably.

For those who met or worked with Cynthia, you wouldn't forget her. She was loving, caring and full of life. Her commitment was evident in her leadership of our 65 support groups, her outreach to community groups to involve them in our various *Walkabouts* and her dedication to running our Bold Blue Day campaign. Cynthia didn't only talk the talk, but she walked the walk as was evident when she showed up the Nashville Country Music Marathon wearing blue pants, blue sneakers and with a blue wig to cheer on *Team Sjögren's*! Cynthia was all in for awareness and was always drawing attention to our cause.

In her five years at the SSF, we were honored to grow with her professionally as well as personally as she expanded her family and introduced her son, Sean-Carlos to her two amazing daughters, Nyla and Calistah.

The absence of her light, energy and enthusiasm is felt each day, but we now have a Sjögren's Awareness Angel watching over us! ■

Missed the 2013 National Patient Conference?

Get all the vital information you need on an audio CD by going online to sjogrens.org or by calling the SSF office at 800-475-6473 today!

Five of our most popular talks from the 2013 National Patient Conference held in Bethesda, Maryland, are available for purchase as audio CDs. Each talk is 30-40 minutes long and each CD comes enclosed with the handouts used by the presenter. Buy just the talks you want to hear or purchase the whole set! Whether you attended the conference or not, these audio CDs are an excellent way to have a permanent resource with some of the most vital information available to Sjögren's patients.

5

- Overview of Sjögren's Syndrome — *Dr. Frederick Vivino*
- Dry Eye and Sjögren's — *Dr. Mina Massaro-Giordano*
- Sex and Living with Sjögren's — *Dr. Anne Burke*
- What Do the Numbers Mean? Understanding Blood Changes and Test Results — *Dr. Guada Respicio*
- Neurological Complications and Sjögren's — *Dr. Julius Birnbaum*

All of these audio CDs 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
Overview of Sjögren's Syndrome by Dr. Frederick Vivino	$30	$16		
Dry Eye and Sjögren's by Dr. Mina Massaro-Giordano	$30	$16		
Sex and Living with Sjögren's by Dr. Anne Burke	$30	$16		
What Do the Numbers Mean? Understanding Blood Changes and Test Results by Dr. Guada Respicio	$30	$16		
Neurological Complications and Sjögren's by Dr. Julius Birnbaum	$30	$16		
			Maryland Residents add 6% sales tax	
Shipping and Handling: US Mail: $5 for first item + $1 for each additional item Canada: $14 for first item + $2 for each additional item Overseas: $22 for first item + $2.50 for each additional item				
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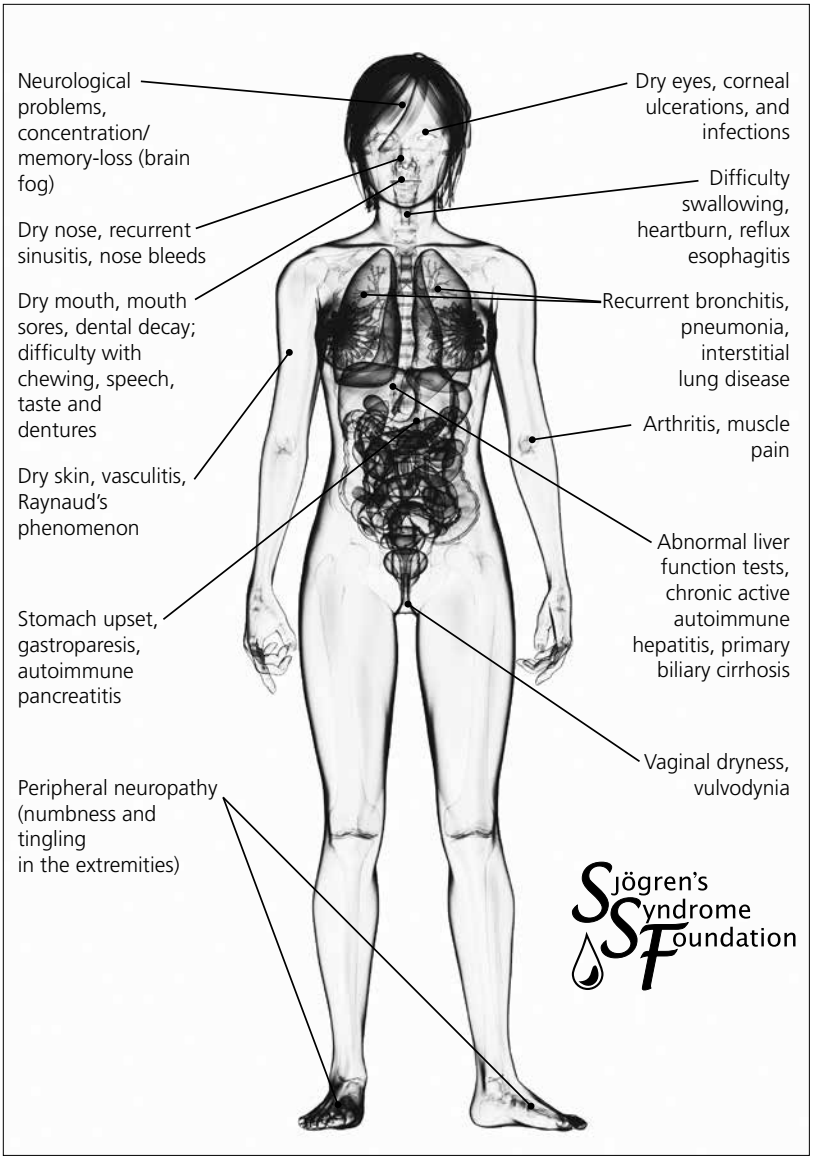
Tracking Your Sjögren's Symptoms

Work Sheet

Date: _____



Additional notes about daily activities/results:

Sleeping Notes

_____

_____

_____

_____

Bed Time: _____

Hours of Sleep: _____

Times Getting up for Medication: _____

Activity Notes

_____

_____

_____

_____

_____

_____

_____

_____

Symptom	Morning	Afternoon	Evening
Fatigue Level			
Joint Pain			
Dry Eyes			
Dry Mouth			

Key: **N**= None, **S**= Slight, **M**= Moderate, **SE**= Severe, **I**= Intense

NEW

NeutraSal® Sjögren's Syndrome Support Kit

Containing:

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- Sugar Free Dry Mouth Gum with Xylitol

* Compare to the ingredients in Ocuvite™ (Bausch and Lomb).

Available at No Cost with Every NeutraSal® Prescription

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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
- 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

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For additional information, visit www.neutrasal.com or call 866-963-8881 ext #1

NEW

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Containing:

- Alpha Lopic Acid for Burning Mouth Comfort*
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Social Security Disability and Sjögren's

One of the main difficulties about Sjögren's is that it is not a "cookie cutter" disease and affects every patient differently. With Sjögren's, symptoms may plateau, worsen or uncommonly go into remission. While some people experience mild discomfort, others suffer debilitating symptoms that impair their functioning. If Sjögren's has made you unable to continue working, it is now easier for patients to qualify for disability by the Social Security Administration (SSA).

Your Disability Rights

After longtime advocacy by the Foundation, Sjögren's patients now have specific criteria for disability benefits for Sjögren's under the Guidelines for Revised Medical Criteria for Evaluation Immune System Disorder.

The SSA definition of Sjögren's syndrome (SS) discusses organ systems that might be involved, how Sjögren's can be associated with other autoimmune disorders, and how the agency will determine whether a patient's disease is disabling. Sjögren's is covered for adults under SSA listing 14.10 and for children under 114.10, but the guidelines are similar for all age groups.

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Demonstration of Disability

The SSA requests proof of disability based on the following:

Involvement of two or more organs/body systems that include both one of the organs/body systems involved to at least a moderate level of severity and at least two of the constitutional symptoms or signs (severe fatigue, fever, malaise or involuntary weight loss).

OR

Repeated manifestations of Sjögren's, with at least two of the constitutional symptoms or signs (severe fatigue, fever, malaise or involuntary weight loss) and one of the following at the marked level:

1) Limitation of activities of daily living

2) Limitations in maintaining social functioning

3) Limitations in completing tasks in a timely manner due to deficiencies in concentration, persistence or pace

Evaluation of Disability Criteria

All relevant information in a patient's record is considered when applying for disability, including persistent or even intermittent depression, fatigue, and/or pain that might interfere with the ability to concentrate, work as quickly as expected, or perform specific tasks.

In addition, the SSA guidelines also state that "Important factors we will consider when evaluating your functioning under these listings include, but are not limited to: your symptoms, the frequency and duration of manifestations of your immune system disorder, periods of exacerbation and remission, and the functional impact of your treatment, including the side effects of your medications."

Filing for disability doesn't mean you will never be able to work again. After being approved for disability

continued page 10 ▼

Inside the Sjögren's Syndrome Foundation's Advocacy History

The 2008 decision that recognized Sjögren's as a viable criteria for disability by the Social Security Administration (SSA) came after many years of advocacy from the Foundation and the SSF Medical and Scientific Advisory Board.

In 2003, the Foundation presented about the debilitating effects of Sjögren's at two policy conferences organized by the SSA. One presentation was given by Steven Taylor, the Foundation's CEO, and the other by Dr. Frederick Vivino, who chaired the SSF Medical and Scientific Advisory Board. The next year, Dr. Vivino gave another presentation in front of the National Organization of Social Security Claimants Representatives.

In addition, the Foundation submitted two sets of recommended changes to the SSA guidelines from Sjögren's experts including those who serve on the SSF Medical and Scientific Advisory Board, along with the expertise of patient Linda Charles, RN.

The Foundation continues to be dedicated to advocacy that will improve the lives of patients. In 2012, the Foundation was the only patient group represented at a hearing about the cost burden of over-the-counter (OTC) drugs and products patients depend on to treat Sjögren's. During the hearing, Taylor testified before the U.S. House Ways and Means Oversight Subcommittee on Capitol Hill.

Most recently, the Foundation represented Sjögren's patients at the Congressional Briefing, "Women and Autoimmune Disease – The Truth about Care, Access, and Treatment," sponsored by American Autoimmune Related Diseases Association and National Coalition of Autoimmune Patient Groups. Here Taylor was both the briefing monitor and presented on the "Difficulty of Diagnosis." The Foundation continues to speak on behalf of the millions of patients who suffer from Sjögren's. ■

Faces of Sjögren's: Joe's Journey

When I was diagnosed with Sjögren's, my first thought was… "I'm a man, I cannot have this." I represent one of the 10% of men who suffer from Sjögren's. I am 47 and was diagnosed with Sjögren's at 44. It took about 10 years from onset of dry eye symptoms in 1999 to get diagnosed. As a man with a predominately women's disease, I feel isolated and alone.

Sjögren's is not just a dry eyes and dry mouth disease, although I really wish it was. The fatigue, joint and nerve pain can be intense at times. I try not to complain but it is so difficult. I am currently on disability from work but hope I can get back to work.

I still do not have control of my Sjögren's, but I am not going to let this disease beat me. I am going to try to do my best at fighting this disease.

I am uncertain about my future and worry what it will bring, but worrying will just cause me stress and thus more flares. I need to take better care of myself so I can help my family in whatever capacity I can. I really would like to cry at times, but I cannot let my wife and kids see me this way. I am thankful that my family is healthy and that none of them have to go through this. However in a way, they are going through this as well because they are seeing what it is doing to me.

Sjögren's has taught me to value life and to appreciate what I have. There are so many others who are suffering worse than I am. I have learned that I will never be normal again because of this disease. I need to discover my new normal and get used to it.

I am going to be strong. — Joe

"Social Security" continued from page 8 ▼

benefits, the SSA has "work incentives" that allow patients to test their work ability.

Filing for Disability

The process of filing for disability can take months so patients should file for benefits as soon as they become disabled. Providing accurate and complete documentation is important when filing for disability. Types of information you should have available when filing are:

Medical records

- Names, addresses and phone numbers for any doctors, hospitals, medical facilities, treatment centers, or providers that may have information related to your disabling condition
- Your most recent federal tax return
- Names, addresses and phone numbers for recent employers and the dates worked for each employer
- Documentation of all physical and/or psychological symptoms that are preventing you from working

The SSF Patient Education Sheet has more tips to help when filing for disability. In addition, the "Tracking Your Sjögren's Symptoms" worksheet on page 6 is a great way to not only document your symptoms for your physician but to show the frequency, severity and duration of your symptoms when filing for disability.

Learn more about disability benefits and take advantage of the helpful Disability Starter Kit at www.socialsecurity.gov/disability/disability_starter_kits.htm or make an appointment at your local Social Security office by calling the toll-free number, 800-772-1213. ■

in memoriam

In Memory of Connie Rodriguez
Kathy Hammitt
Meri Cotney
Mark & Judy Johnson
Integrity Metals & Slitting
Jennifer & Steve Perry
Martin & Lisa Taylor
Eric & Barb Zarnikow
The Botsford Group
Al Toscano
Laurie Ulsh
Interstitial Cystitis Association Board of Directors and Staff
Sylvia, Scott & David Underhill
Irma Rodriguez & Fred Fernandez
Rusty Kennedy, OC Human Relations Commission
Biltmore Capital Advisors

In Memory of Kathy Kay Parsons
Rick Weinmann
Rob & Jane Dougan
Melissa Gutridge; Slagle-Kiser

In Memory of Karen Cordell
Tim & Lara Cordell

In Memory of Marie N. Meyer
Ronald Meyer

In Memory of Jackie Crone
Amanda Moore

In Memory of Holly Elliott
Jane Hendrix

In Memory of Barbara C. Heard
The Grosch Family

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Bill, Linda, Alex, Kait, Bob and Nicky

In Memory of Rhoda Dennison
Kathy Hammitt

In Memory of Sara Jane Evans
Gladys Hilling

In Memory of Patricia Ward
John, Susie & Chris Foley

In Memory of Ruth E. Allen
Carolyn & Tim Schroff

in honor

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Bob & Joyce Green

In Honor of Dr. Heather Block
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In Honor of Jesse Finkelstein
Liz Finkelstein

In Honor of Ruth Kemper
Barbara Plummer

In Honor of Dawn Jenkins
Matthew Jernigan

In Honor of Lari Loop's Birthday
Steve & Isabelle des Fontaines

In Honor of Barbara Melfi
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In Honor of Steve Taylor
Pat Spolyar

In Honor of Judy Naef
Stephen & Rae Atwood

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Sjögren's Syndrome Foundation

Patient Education Sheet

Tips on Obtaining Disability Benefits from the Social Security Administration (SSA)

The SSF thanks Linda Dorfner Charles, BSN, RN, for authoring this Patient Education Sheet. Charles assisted the Sjögren's Syndrome Foundation (SSF) in its long-time and successful advocacy for a specific federal disability listing for Sjögren's syndrome.

▸ Tips on Obtaining Disability Benefits from the Social Security Administration.

- **Know that documentation is key to winning your case!** Keep a journal of your symptoms and copies of all records from lab tests, doctors' visits and hospitalizations.
- **Review your medical records to ensure legibility and completeness.**
- **Submit documentation in order of occurrence.** Show disease progression and resulting limitations, including side effects of all current medications.
- **Have your doctor highlight the fact that Sjögren's symptoms can unpredictably wax and wane,** as SSA forms are not tailored to these features.
- **If applicable, state that during a flare-up, you are unable to perform specific activities.** Include basic self-care or activities of daily living (ADLs) such as eating, walking, bathing, lifting, shopping, cooking, reading, driving, working and household chores.
- **Document what it takes for you to get through every hour of a 24-hour day.** Include what you must do to alleviate symptoms, e.g. every time you use eye drops. State how each symptom affects you (frequency and duration), e.g. how often you are fatigued and what it prevents you from doing. Don't worry about sounding repetitive.
- **Cite the impact of your combined symptoms on your function and productivity,** including lost work days, job status, depression, and loss of relationships and social interactions. While one symptom alone might not be considered disabling, the combination of symptoms can be disabling.
- **Describe the overall impact of Sjögren's on you and your family's lives.** Don't forget loss of income and high treatment costs (drugs, OTC products, medical co-pays, frequent doctor visits, psychotherapy and physical therapy).
- **Explain the negative impact of the workplace on your physical well-being.** For example, dry air, fluorescent lighting and computers aggravate dry eye and travel and sleep deprivation worsen fatigue, joint pain, digestive symptoms and the ability to concentrate.
- **Use educational materials to help your case.** Visit the SSF Web site or contact the SSF for helpful materials.
- **Read SSA disability guidelines for Sjögren's syndrome.** The fact that the SSA now includes specific guidelines for Sjögren's will help your claim. Go to www.ssa.gov and enter "Immune System" in the Search feature to bring up the Immune System Disorders Guidelines.
- **Don't let rejection discourage you!** Applicants often are rejected for benefits the first time they apply.
- **Consider hiring an attorney who specializes in Social Security Disability** to help with documentation and to expedite your approval for disability.

For more information on Sjögren's syndrome, visit the SSF Web site at www.sjogrens.org, call 800-475-6473, email ssf@sjogrens.org or write to the Sjögren's Syndrome Foundation, 6707 Democracy Blvd, Suite 325, Bethesda, MD 20817.

June

Breakthrough Bullet:

Winners of the Awareness Challenge: Tell 5 or Tell 50

With awareness on a steady rise, it is vital that everyone starts sharing stories about Sjögren's with friends and family. This is so important because, as you know, the majority of people still do not have an accurate understanding of the disease. This is why the Foundation announced our first-ever Awareness Challenge, "Tell 5 or Tell 50," in the March newsletter.

Knowing how scary it can be to open up about your disease, the Foundation wanted to challenge members to inform either 5 or 50 people about Sjögren's. As returned forms started coming back to the office, we were both proud and stunned that most participants told 50!

Talking about Sjögren's and educating the general public is an important part of reaching our 5-Year Breakthrough Goal. As many of you read in the January issue of the newsletter, the Foundation is using a three-pronged approach to achieve our Goal:

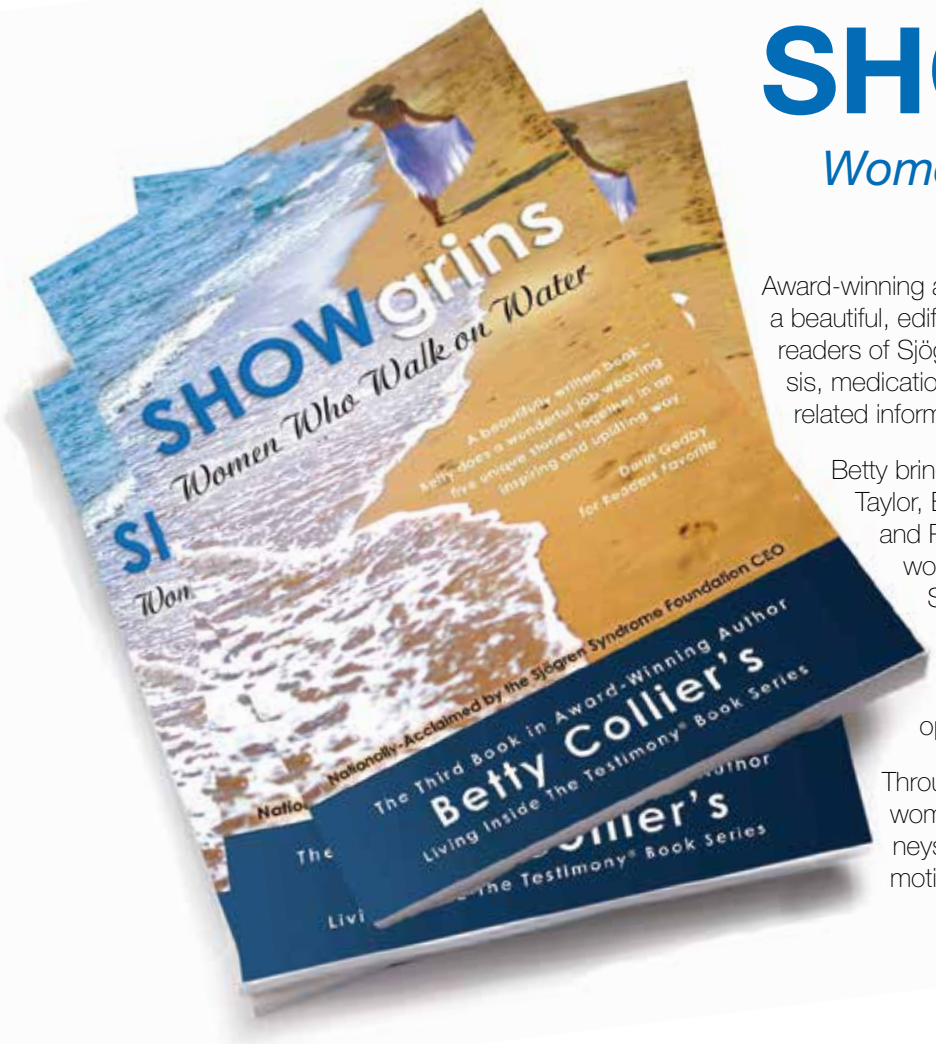
- Increasing public awareness
- Increasing involvement from our friends and partners
- Increasing education and awareness among healthcare professionals

We believe that combining these three key areas will not only help us reach our goal but will also change the face of Sjögren's and the quality of care that all patients receive.

Thank you to everyone who participated in this challenge and we want to congratulate our two winners, Kathy and Debora. They were both so excited when we contacted and informed them.

Please remember – one person at a time, one community at a time, one physician at a time – together we will make Sjögren's a household name.

50% in 5 years
Sjögren's syndrome FOUNDATION



SHOWgrins

Women Who Walk on Water

by Betty Collier

Award-winning author Betty Collier has intricately woven a beautiful, edifying and inspirational book that informs readers of Sjögren's – its signs and symptoms, diagnosis, medication and treatment, complications, and other related information.

Betty brings into the limelight the cases of Cathy Taylor, Estrella Bibbey, Judy Kang, Lynn Petruzzi, and Paula Beth Sosin. These five extraordinary women opened their hearts and shared their Sjögren's stories with the world for everyone to understand more about this chronic illness to help increase awareness and expedite new diagnoses and treatment options.

Through the heartwarming stories of these five women and the intimate details of their journeys, millions will be inspired, encouraged, and motivated to face the crossroads in their lives.

Member Price: $10

This book 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
SHOWgrins – Women Who Walk on Water by Betty Collier	$13.00	$10.00		
Maryland Residents add 6% sales tax				
Shipping and Handling: US Mail: $5 for first item + $3 for each additional item Canada: $14 for first item + $2 for each additional item Overseas: $22 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

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❑ 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 _____

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I Stood Up...

Betty Collier

When Venus Williams pushed Sjögren's into the media spotlight by announcing her diagnosis and withdrawal from the 2011 U.S. Open tennis tournament, Betty Collier began reading about the disease and noticed that she had a lot of similar symptoms being described by the news– fatigue, joint pain and various areas of dryness.

It was the next day that Betty decided to start writing her new book, *SHOWgrins – Women Who Walk on Water,* and her journey into seeking a diagnosis for her symptoms. Along with her story, in the book Betty highlights five SSF members: Estrella Bibbey, Judy Kang, Lynn Petruzzi, Paula Beth Sosin and Cathy Taylor.

These courageous women opened their lives about Sjögren's to help people understand more about this debilitating disease that affects both sexes, all ages, ethnic groups and socioeconomic statuses. Betty, Estrella, Judy, Lynn, Paula and Cathy first introduced the book at the 2013 SSF National Patient Conference exhibit hall.

Although Betty discovered that she did not have Sjögren's, she said "my life is far better after meeting these awe-inspiring women who do!" In fact, Betty was so inspired by the women she met that she fundraised and ran her first half-marathon as a part of *Team Sjögren's* Nashville 2013.

"What better way to increase awareness of the disease I wrote about than to commit myself to train with *Team Sjögren's* and join them in one of the most memorable events of my entire lifetime," said Betty. Despite flooding rain conditions on race day, Betty completed her first half-marathon in honor of the four million Americans who suffer from Sjögren's. Learn more about Betty's story by visiting her website, SHOWgrins.com.

Thank you Betty for raising awareness, funds and helping us conquer Sjögren's for all sufferers! ■

From left to right: Lynn Petruzzi, Paula Beth Sosin, Estrella Bibbey, Cathy Taylor, Judy Kang, and Betty Collier.

Betty Collier at the Nashville Marathon

I will Stand Up in 2013!

The Moisture Seekers
Sjögren's Syndrome Foundation Inc.
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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

Team Sjögren's

On Saturday, April 27th, 14 runners took the Nashville Country Music Marathon and Half Marathon course in downtown Nashville as a part of *Team Sjögren's*. Nothing was going to stop the enthusiasm of our runners and walkers – not even down-pouring rain that didn't let up for the entire race. In fact, *Team Sjögren's* runners still went to the starting line with smiles on their faces and a quick hop in their step – knowing they were doing this for all Sjögren's patients.

Our team this year consisted of three runners taking on the challenge of completing the full marathon and its 26.2 miles, while the other 11 runners trained for the half marathon. Our team was made up of five patients, two sons and a daughter of patients, two husbands and three friends of patients. And for the second time, a rheumatologist joined our team! Special thanks to Dr. Theresa Lawrence-Ford from Atlanta, Georgia who has now completed two half marathons with *Team Sjögren's*!

Our runners were thrilled to cross the finish line. As one of them said, "crossing that finish line is so emotional and can't be explained – only experienced!" Another runner said that "getting a chance to experience the marathon with other Sjögren's patients while knowing that these ladies are also fighting to show that Sjögren's will not get them down was awe-inspiring."

If you want to learn more about *Team Sjögren's* and how you can run or walk in a local race in your area to support the SSF or participate in one of our nationally supported marathons, contact Steven Taylor, SSF CEO, at staylor@sjogrens.org or 301-530-4420, ext.211. He'll look forward to hearing from you.