Volume 34, Issue 6 June 2016

SjogrensSyndromeFoundation



# "The Sjögren's Journey" 2016 SSF National Patient Conference Highlights

n April 8th, attendees traveled from 38 states and three countries to Seattle, Washington for this year's annual Sjögren's Syndrome Foundation's (SSF) National Patient Conference. With over 400 attendees, 14 exhibitors and 11 presenters, the National Patient Conference, "The Sjögren's Journey" was a huge success!

Every year the SSF Education Committee works to ensure that our annual Conference caters to both newly diagnosed patients and longtime Foundation members by continuously introducing new topics to cover the disease's complexity. We recruit the best speakers from around the country, talking on the most pressing and important topics. Having only two days, we can't hit every aspect of the disease, but try to mix up our topics each year. This year's presentations included:

- Sjögren's Overview
- Oral & Ocular Manifestations of Sjögren's
- Tips for Your Sjögren's Journey
- An Inside Look at Sjögren's and Gluten-Free Diets
- Dry Skin & Dermatological Issues
- Examining Sjögren's Case by Case
- Gynecological Issues with Sjögren's
- Sjögren's Where are we in Drug Development?





# Carrie Ann Inaba Stands Up for Sjögren's!

he SSF is honored to announce that Carrie Ann Inaba from ABC's "Dancing with the Stars" has agreed to serve as our National Awareness Ambassador and Spokesperson. We applaud Carrie Ann's courage for sharing her Sjögren's journey and joining with all Sjögren's patients to help increase awareness of this devastating disease.

Carrie Ann helped promote the SSF This is Sjögren's April Awareness Campaign and shared her best tip as a Sjögren's patient:

"Living with Sjögren's means you have to become your own best advocate! Finding what works for you and your unique journey is of the utmost importance! Be your own best advocate."

Stay on the lookout in the upcoming months to see how Carrie Ann is using her voice to help raise awareness of Sjögren's! ■



#### **Board of Directors**

#### **Chairman of the Board**

Ken Economou

#### Chairman-Elect

Stephen Cohen, OD

#### Treasurer

Vidya Sankar, DMD, MHS

#### Secretary

Janet E. Church

#### **Immediate Past Chairman**

S. Lance Forstot, MD

Esen K. Akpek, MD
Herbert Baraf, MD, FACP, MACR
Nancy L. Carteron, MD, FACR
Jack Faricelli
Tricia Gooding
Patricia Hurley, MSc
Cathy Ingels
Theresa Lawrence Ford, MD
Cynthia Lopynski
Mary McNeil
Timothy Niewold, MD, FACR
Kathy L. Sivils, PhD
Thomas D. Sutton
Michelle Wallace

#### Medical & Scientific Advisory Board

#### Chairman

Nancy L. Carteron, MD, FACR

Esen Akpek, MD Richard Brasington, MD, FACR Michael Brennan, DDS, MHS Steven E. Carsons, MD Troy Daniels, DDS, MS Denise Faustman, MD, PhD H Kenneth Fisher MD FACP FCCP Gary Foulks, MD, FACS Theresa Lawrence Ford, MD S. Lance Forstot, MD Philip C. Fox. DDS Robert I. Fox, MD, PhD. FACP Tara Mardigan, MS, MPH, RD Austin Mircheff, PhD John Daniel Nelson, MD, FACS Kelly Nichols, OD Athena Papas, DMD, PhD Ann Parke, MD Andres Pinto, DMD Nelson Rhodus, DMD, MPH Vidya Sankar, DMD. MHS Daniel Small, MD, FACP Neil Stahl, MD Frederick B. Vivino, MD, FACR leffrey Wilson MD FACR

#### **Chief Executive Officer**

Steven Taylor

#### **Director of Marketing/Editor**

Elizabeth Trocchio

e-mail: tms@sjogrens.org www.sjogrens.org

## "The Sjögren's Journey" continued from page 1 ▼

Starting early in the afternoon, participants gathered at the registration and exhibit area to kick off our two-day Conference. Here attendees were able to learn about new products, receive free samples and talk with other patients, speakers, exhibit representatives, SSF Staff and the Foundation's Board of Directors. With over 80% attending their first SSF Conference, it was exciting to feel the positive energy of over 400 people connecting and sharing with others who are going through a similar health journey.

This year's program began with opening remarks from Steven Taylor, SSF CEO, and Ken Economou, SSF Chairman of the Board. Next, Timothy B. Niewold, MD, gave the first presentation, "Sjögren's Overview." Dr. Niewold presented a comprehensive explanation of the range of symptoms that Sjögren's patients experience, causes, and practical management tips. The afternoon continued with three more talks and as is tradition, our first day ended with our annual Banquet Awards Dinner, honoring volunteers, groups and organizations that have helped to further the Foundation's mission by stepping up for all Sjögren's patients.

The inspirational evening closed with the Conference's Keynote Speaker, Janet E. Church, an entrepreneur and tech-industry veteran, who shared her 8-year struggle to get a correct Sjögren's diagnosis as well as the struggle to re-invent herself — a necessity when living with an autoimmune disease.

The next day was full with 7 informative talks! The first session, "Examining Sjögren's- Case-by-Case," was given by Nancy Carteron, MD, who received the SSF Healthcare Professional Leadership award at the previous night's banquet dinner. Dr. Carteron reviewed a few unique cases and discussed how she helped them reach their optimum level of wellness.

Later attendees took a break from the day's lectures to participate in our Seattle Sjögren's Walkabout! This family-fun event took place right outside the Conference Center Lobby where participants soaked up some sunshine during their walk and raised over \$23,000 to benefit SSF programs! The Walkabout was a great way to stand up for Sjögren's with others in the Seattle community, while taking a mid-day stroll before the afternoon speaker presentations.

Thank you to everyone who attended this year's Conference and committed themselves to helping each other learn, find new friends and expand their knowledge of Sjögren's. We understand that not everyone can travel to our annual National Patient Conference, which is why we are offering the most popular talks on audio CDs with the follow-along PowerPoint presentation printouts. See the ad on page 14 to learn how you can order them today!

The Moisture Seekers® Newsletter is published by the Sjögren's Syndrome Foundation Inc., 6707 Democracy Blvd., Ste 325; Bethesda, MD 20817.

Copyright ©2016 Sjögren's Syndrome Foundation Inc. ISSN 0899-637.

DISCLAIMER: The Sjögren's Syndrome Foundation Inc. in no way endorses any of the medications, treatments, or products mentioned in advertisements or articles. This newsletter is for informational purposes only. Readers are advised to discuss any research news, drugs, treatments or products mentioned herein with their health care providers.

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

# SSF National Patient Conference Awards Winners

Every year The Foundation recognizes our most dedicated volunteers through the awards that are announced at the Awards Banquet Dinner held at our National Patient Conference. These award winners show how an individual can make a difference just by getting involved. We could not accomplish all that we do without the hard work and dedication of volunteers like these awardees.

For members who were not able to join us this year, here are a few highlights about the SSF Volunteer Award Winners. Congratulations again to our 2016 National Award Winners!



Healthcare Professional Leadership Award -Nancy Carteron, MD

Dr. Nancy Carteron has long been a champion for Sjögren's patients. Not only is Dr. Carteron a dedicated rheumatologist in the San Francisco area, but she is also the founder of her own Sjögren's blog/website Sjögren's Forum, as well as co-author of one the best-selling patient books on Sjögren's, "A Body Out Of Balance," with a patient, Ruth Fremes.

Dr. Carteron's commitment to Sjögren's patients has continued with her service on the SSF's National Board of Directors for the past seven years. In 2012, Dr. Carteron stepped up to serve on the SSF's Clinical Practice Guidelines Committee as well as our Clinical Trials Consortium Committee. In 2015, she was also

named as the SSF's Medical & Scientific Advisory Board Chairperson. The SSF expresses its deepest appreciation to Dr. Carteron for her dedication to Sjögren's patients and the Foundation.



Volunteer Leadership Award – Sarah Schafer, MD

Dr. Sarah Schafer's dedication to helping her fellow Sjögren's patients makes her the perfect recipient for the Foundation's Volunteer Leadership Award. Although Sjögren's has seriously affected Dr. Schafer's life and changed the trajectory of her career as a physician, she has not let it stop her from helping Sjögren's patients.

In 2011, when the SSF launched our Awareness Ambassador program, Dr. Schafer immediately volunteered and has continued to give 100% to all general awareness initiatives and has since expanded her role by reaching out to medical schools, residency programs and hospitals to personally educate physicians and researchers about Sjögren's.

Dr. Schafer also authored an article, "Under the radar: A physician patient's experience with Sjögren's Syndrome," that appeared in the November 2013 issue of The Rheumatologist. And more recently, she designed a grand rounds presentation on Sjögren's for Primary Care that she delivered to internal medicine doctors in the San Francisco Bay area.

# Development Service Award -The Dodds Family

After Paula Dodds was diagnosed with Sjögren's in 2014, her 14-year old twin sons, Justin and Brandon Dodds decided to host a charity bike ride in her honor

"The Sjögren's Journey" continued from page 3 ▼



and to support Sjögren's research and awareness.

Their race was a huge success with nearly 100 riders showing up to participate, both serious and amateur riders alike. In addition to those individuals that participated, there were numerous volunteers as well as family, friends and community members that came simply to support the brothers and Sjögren's.

Thrilled with the outcome of the charity ride, Justin and Brandon have made it an annual event and are currently planning their third race for this fall!



Awareness Service Award -Bradley University: Game Design Program

The Bradley University Game Design Program was the perfect recipient for the Awareness Service Award. As part of a year-long class project, undergraduate students in the game design program at Bradley University created the puzzle game App "Wake Up, Koala!" that is not only fun to play but also promotes Sjögren's awareness.

The students decided to have the App benefit the SSF in honor of their Professor, Monica McGill, whose daughter was diagnosed with the disease.

The Foundation would like to thank all of the students from Bradley University's Game Design Program and Professor McGill for creating a new medium to raise Sjögren's awareness! To learn more about this App, please visit koala.sjogrens.org.



Vision Service Award -Charlie and Marie Kireker

The SSF is honored to recognize Charlie and Marie Kireker who show how someone can make a big difference by seizing an opportunity. Charlie and Marie were in a position to help when they learned about funding being needed to support the SSF's vision for advancing Sjögren's research and bringing a Sjögren's therapy to the market. Without hesitation, they stepped up!

Their gift was used to support a specific project that will help the SSF advocate for new therapeutics to treat Sjögren's. Thank you Charlie and Marie for allowing the SSF to explore where we can make the best impact for all Sjögren's patients!







# can Damage your Teeth

**Now** you can help **preserve your enamel health** with delicious mouth-watering sugar free chews

BasicBites

chocolate soft chews

Coats teeth and fuels your mouth's natural defenses

just like healthy saliva

- maintain healthy tooth structure
- neutralize harmful plaque acids
- support a normal oral pH

Sugar Free

BasicBites are here to help.

Revolutionary technology developed at Stony Brook University School of Dental Medicine. *A vital blend of nutrients mimics the profound protective benefits of healthy saliva.* 

Available exclusively online

basicbites.com

Just two a day - only 20 calories each. Enjoy BasicBites as a soft chew or let melt in mouth.

\$39.95 120 ct. 2 mo. supply Free Shipping



# Relapse to Reinvention — Navigating the Changing Stages of Living with an Autoimmune Disease



was honored to deliver the keynote speech at this year's National Patient Conference. My focus was to share some key things I've learned about how I manage my disease, how I navigate from one emotional stage to the next, and how I reinvent myself so I can live a fulfilling life. This article is a brief recap of the speech to share with my fellow *The Moisture Seekers* readers.

# Stages of Autoimmune Grief and Life

After my diagnosis in 2006 I found myself going through the Kübler-Ross grieving process (Anger, Bargaining, Denial, Depression, Acceptance), as many of us do. However, several years after diagnosis, I was still challenged with defining other emotional stages that I was experiencing. I knew that understanding what I was experiencing was key to determining how I was going to have a better life, so I decided to clarify these other stages.

Over time, I recognized a distinct pattern that I have placed in my "Autoimmune Grief and Life Stages" model. I use this model to help me understand what stage I'm truly at and then set out to meet my needs for that stage. The below illustration is how I have experienced the different stages of grieving the loss of "my old self" living daily with my autoimmune disease, and adjusting in order to reinvent for my "new normal." I have had to reinvent and adjust to my "new normal" several times.

It all starts with relief of finally receiving a diagnosis (and now I feel relief when I pull out of a relapse). You



will recognize the Kübler-Ross grief stages are included in my model, I have also added five others. After year's of living with Sjögren's and practicing this model, I find that it helps me stay out of the abyss.

Here are a few things that I have learned about these stages after a decade of practice:

 My disease level can dictate the time I may stay in a stage. Don't be fooled by thinking I am referring to only a bad disease level! Self-awareness at all times is an important practice with autoimmune disease (good and bad days).

- I may bounce between stages, but I am better at navigating them.
- I may get stuck on my challenging stages (such as denial), but I tend to recognize it more quickly than I used to.
- If I'm not mindful about what stage I'm in, or if I leave denial too long, then it can slap me across the face and set me back into a relapse (like it did last summer).
- I am not perfect at practicing this model, but the more I practice, the better I feel for longer periods of time.

# Where Am I, Honestly, with my Autoimmune Disease?

When I say, "Where am I, Honestly?" I'm not only checking in with my denial system, but I'm also attempting to fine-tune my understanding of my symptoms, emotions, and history. This is a process of fine-tuning my boundaries and limitations. The more detailed I am about how I really feel the better I manage my disease.

# Tips to Move through Autoimmune Stages

Self-care and rest are certainly key tips to managing my disease. However, I find my mental attitude is just as important. The slide Moving Through Stages, highlights my personal list of things I try and practice especially when I'm on the road to reinvention. My first item is **CHOOSE HAPPINESS!** 



I hope you've received an idea or two to help you on your Sjögren's journey and your own road to reinvention. The full speech with more tips and explanation of my grief and life model can be found on my blog Sjögren's Life at www.sjogrenslife.com.



All Sjogren's Syndrome patients & their family may enjoy 30% off!

Use coupon code: moistureseekers www.PEAK10SKIN.com

Here's what your fellow Sjogren's patients are saying about PEAK 10 SKIN:

"LOVE, LOVE, LOVE the HYDRO 1000 and LIPID DEFENSE serums, plus the Black Diamond moisture repair cream. So glad I found something that works for my Siogren's ravaged skin." ~Sandy B.

"I love all these products and they really are making an amazing difference in my skin." ~Victoria D.

\*PEAK10SKIN was a sponsor for the SSF patient conference in Seattle.





PEAK10SKIN.com Stay connected...

Facebook.com/peak10skin Instagram.com/peak10skin

© Breck Edge, LLC 2016



NeutraSal® is a prescription strength oral rinse for dry mouth that has been proven to help improve a range of painful dry mouth symptoms, such as

- Difficulty eating, drinking, and swallowing
- Ability to speak
- Sore tongue and taste disorders
- Burning or stinging sensations in the throat
- Difficulty wearing dentures

Its supersaturated calcium phosphate formulation mimics your natural saliva to help repair and protect oral tissues, reduce bacteria levels to help prevent cavities, and help restore a healthy mouth.

NeutraSal® is easy to use 2 to 10 times a day, as needed, with single-use packets that dissolve in water. It has no added flavors, no anticipated side effects, and no known interactions with medicinal or other products.

For more information, visit www.neutrasal.com.



NeutraSal® is a registered trademark of Valeant Pharmaceuticals International, Inc., or its affiliates. ©OraPharma, Inc. 2016 OH/NSL/15/0026 1/16







**Premier Sponsor** 



Friend Sponsors









# Official Exhibitors

Akorn

Alcon

**Biocosmetics Laboratories** 

Camellix

Eye Eco

Laclede

NeilMed Pharmaceuticals

OraHealth

OraPharma

Ortek Therapeutics

PEAK 10 SKIN

SalivaMAX

Soothee

"This is Sjögren's" Photo Booth

Wake Up Koala!



# Awareness Ambassadors

he Sjögren's Syndrome Foundation (SSF) Awareness Ambassadors have been standing up, all across the nation, since 2011. In the past 5 years, we have had over 500 members sign up to be part of the Awareness Ambassador program!

Our Ambassadors volunteer to participate in the SSF's designated campaigns in their communities. Three to Four campaigns are developed by the SSF each year, based on the Foundations goals and priorities. The focus of the work is on increasing awareness among healthcare professionals and inviting them to connect with the SSF. In addition, at least one campaign per year is dedicated to community awareness.

Here's a look at some of the campaigns our Ambassadors have done over the course of the year:

# Primary Care Providers (PCP) Campaign

These providers have a unique opportunity to put the pieces of the symptom puzzle together for patients and make referrals to rheumatologists. This campaign brought PCP's a specifically developed provider tip sheet for helping them quickly recognize symptoms of Sjögren's and make the connections for further testing. They also received an office display poster and brochures for distributing to their patients.

# Pharmacy Campaign

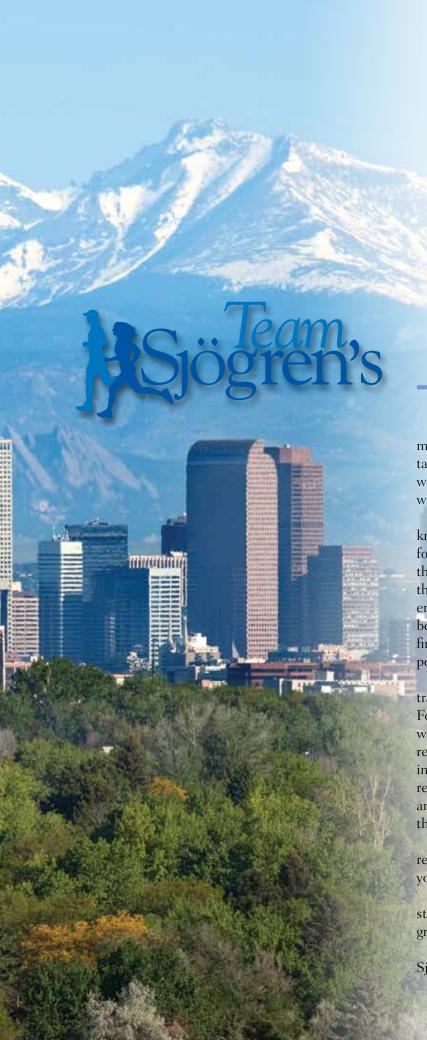
Ambassadors visited their community pharmacies and talked with the Pharmacists about Sjögren's. Armed with the SSF Product Directory, that was provided through the campaign, Pharmacists now have a tool to help patients who ask what other options there are for their symptoms. In addition, a tip sheet was developed with questions a Pharmacist can ask to help determine if patients should be further evaluated for Sjögren's. For instance, a patient looking for relief for their dry eyes could be asked if they have ever used eyes drops before, if they use them more than 3 times per day, do they have the sensation of sand in their eyes? Answers to these questions can be clues as to whether the Pharmacist can help lead the patient to a specialist for further testing.

# This is Sjögren's! Campaign

Back in March, our Ambassadors were the first to see our newest poster, showing Sjögren's symptoms and explaining how patients are affected by the disease. The new posters were shared with them back in March and have since been shared nationally! This campaign asked our Ambassadors to place the posters in areas all throughout their communities. They placed them in Provider's offices, pharmacies, health clubs, churches and schools, just to name a few-hundreds of posters were distributed all across the US! They shared the image on social media and they sent press releases and posters to their local news outlets. Several outlets picked up the news and reported on Sjögren's!

Interested in being part of this exciting group of volunteers? The SSF is always looking for individuals who are excited to get involved and help us as an Ambassador! Join us by signing up at www.sjogrens.org under the "Get Connected" tab!





Travel with us to Denver, Colorado for the Rock 'n' Roll Half Marathon and 10K October 16, 2016



he SSF is looking for runners/walkers that want to train to participate in the *Rock 'n' Roll Marathon Series* Half Marathon (13.1 Miles) or 10K (6.2 miles) in Denver, Colorado! These exciting events both take place on October 16th and each runner/walker will be a part of the Team Sjögren's training program, where we help you train and get ready for the race!

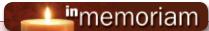
Just imagine how it will feel to cross that finish line knowing that you helped raise awareness and funds for Sjögren's research! Both scenic races will take you through beautiful downtown Denver. You'll experience the cities vibrant streets and be motivated by live music, entertainment and cheering spectators along the way before receiving the much coveted Rock 'n' Roll Denver finisher medal! Then, celebrate your success with the post-race headlining show at Civic Center Park!!

As a team member, you will receive world-class training along with mentorship from past runners and Foundation staff. Our team trainer and nutritionist will be there to help guide you and ensure you're ready to complete the 6.2 or 13.1 miles. By becoming a member of Team Sjögren's Denver you will also receive- travel reimbursement, a pre-race team dinner and hotel accommodations within walking distance of the start and finish line!

If you're unable to run or walk in a race, consider recruiting a friend or family member to run or walk in your honor!

Please contact Steven Taylor, SSF CEO at staylor@sjogrens.org to learn more about our great program!

We Run in Honor of the 4 Million Americans with Sjögren's... We Are Team Sjögren's!!!



## In Memory of Donna Jordon

Ann Spina Ann Van De Wal Anthony Jadhon Barbara and Gerald Countryman Barbara and Keith Folger Berkshire Hathaway Home Services CNY Realty Carl and Beth Ann Nora Dale and Eve Marie Van De Wal Denise Virkler Donald and Elizabeth Skermont Donna Kapes Elaine and Russ Blais Eugene Carcone Eva Pearlman Gina and Vincent Pristera Gordon and Kathleen Custodero James and Denise Giruzzi Kathryn Taylor Kevin and Ameena Copeland Linda Peters Louis and Linda Denato New Hartford Teachers Association

Regina Brown

Richard and Joanne Tehan

Roseanne Gerace

William and Janet Chanatry

In Memory of Herb Harris Kathy Hammitt

# In Memory of Barbara Patrone

Sharon Sheehan

#### In Memory of Jana Atkins

Music Library Association Texas Chapter

# In Memory of Joan Coleman

Bagliani's Food Market

## In Memory of Johnnie Batson

Brookline Cemetery Association

#### In Memory of Linda C. Zerby

Andy and Cindi Flanagan Audrey Farah Larry and Mary Ann Beattie Nationwide Insurance Property Claims Restoration Management Services, INC. Robert and Alice Young

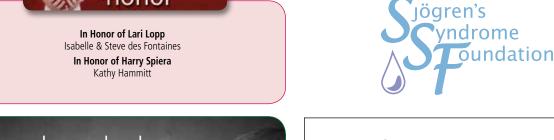
## In Memory of Margie Karp

Carol Hillsberg Flo and Bob

## In Memory of Sheila McLaughlin

Cornerstone Chemical CDS/Logistics Department InsureWise, LLC Katherine Degeneres Linda Willson Michelle Dyess Renee Rhodes and Family Roger and Pam Simmons

# •honor





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

Missed the 2016 National



Get all the vital information you need on an audio CD!

Audio CDs of the most popular talks from our 2016 National Patient Conference in Seattle, WA will be available soon.

Four of our most popular talks from the 2016 National Patient Conference held in Seattle, Washington, are available for purchase as audio CDs. Each talk is 30-40 minutes long and comes with the handouts used by the presenter.

In addition to the individual talks, you can purchase the conference kick-off session, a two-hour overview of Sjögren's, its manifestations and treatment options.

Buy just the talks you want to hear or purchase the whole set!

Non-

	Member	Member	Qty.	Total
Sjögren's Overview by Timothy B. Niewold, MD	\$30	<sup>\$</sup> 18		
Oral Manifestations of Sjögren's by Ava J. Wu, DDS	\$30	<sup>\$</sup> 18		
Dry Skin and Dermatological Issues by John R. Fenyk, Jr., MD	\$30	<sup>\$</sup> 18		
An Inside Look at Sjögren's and Gluten-Free Diets by Keith Wilkinson, NMD	\$30	<sup>\$</sup> 18		
Ocular Manifestations of Sjögren's by Majid Moshirfar, MD	\$30	<sup>\$</sup> 18		
Sjögren's - Where Are We in Drug Development? by Daniel J. Wallace, MD	\$30	<sup>\$</sup> 18		
Gynecological Issues with Sjögren's by Rita Melkonian, MD	\$30	<sup>\$</sup> 18		
Examining Sjögren's - Case by Case by Nancy Carteron, MD	\$30	<sup>\$</sup> 18		
Fatigue and Sjögren's by Donald E. Thomas, Jr., MD	\$30	<sup>\$</sup> 18		
Maryland Residents add 6% sales tax				

# **Shipping and Handling:**

U.S. Mail: \$5 for first item + \$3 for each additional item Canada: \$14 for first item + \$3 for each additional item Overseas: \$22 for first item + \$3 for each additional item

CD's will be available for delivery beginning July 1st.

Tota	l Amount	Due
------	----------	-----

## 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		

Cjög	ıren's
JC	<u>/nd</u> rome
$\wedge$	oundation

City		State	Zip				
Telephone	E-Mail _						
☐ Enclosed is a check	or money order (in U.S	S. funds only, drawn o	n a U.S. bank, net o	of all bank charges)	payable t	o SSF.	
☐ MasterCard ☐ VIS.	A 🔲 Discover 🖵 Am	Ex Card Number					
Exp. Date	_ Security Code	Signature					



SSF in Action!

Introducing SSF Director of Advocacy and Scientific Affairs, Sarah K. Martin, M.S., Ph.D.



"We are thrilled to be adding a new SSF Advocacy and Scientific Affairs position and welcome Sarah to the Foundation's team. With the addition of this Sarah, the SSF is working to expand our advocacy outreach, research and work in clinical trials." – Steven Taylor, SSF CEO

y name is Sarah K. Martin and I am delighted to be your new Director of Advocacy and Scientific Affairs. I earned my Master's degree in Animal Nutrition studying the effect of diet on Interstitial Cystitis and then continuing on, I earned my doctorate in Molecular and Cellular Biochemistry at the University of Kentucky. Since getting my PhD, I worked

as a science policy fellow with a national scientific society based near Washington, DC I am excited to put my scientific background and experience as an advocate to work for you!

As Director of Advocacy and Scientific Affairs, I will be managing the *Sjögren's Quarterly*, SSF's newsletter for medical professionals, and overseeing the Foundation's annual research grant program. I will also be keeping a watchful eye on the cutting-edge of scientific breakthroughs and looking for ways to leverage those advances to real-world therapies for Sjögren's patients.

As your Director of Advocacy and Scientific Affairs, I will be working closely with Steven Taylor, SSF CEO and Kathy Morland-Hammitt, Vice President of Medical and Scientific Affairs to strengthen the dialogue between policymakers, scientists, advocates and regulatory agencies. My goal is to bring your patient voice to the table in all policy discussions relevant to Sjögren's. I will strive to build working partnerships with the National Institutes of Health (NIH) and the Food and Drug Administration (FDA) as we seek to develop new therapeutics for Sjögren's.

One of my early missions is to help determine how pharmaceutical companies can design better clinical trials by incorporating measurements of patient-reported opinion. These measurements are collected using patient-reported outcome (PRO) instruments and I'll be working with the team here at the SSF to find the best possible PRO instrument to capture your Sjögren's experience in a quantifiable way.

I look forward to earnestly representing the SSF at Capitol Hill, NIH, FDA, scientific conferences, universities and hospitals, and with our coalition partners, researchers and medical professionals. Anytime I'm given the opportunity and sometimes even when I'm not, I'll be advocating for you!



*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

# July 23, 2016 is the 7th Annual World Sjögren's Day

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

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

Your support has allowed researchers to build on Dr. Sjögren's work, making the recent scientific breakthroughs in the field possible and on July 23, we will celebrate the man who has helped all patients find answers to their health questions.

Visit www.sjogrens.org to learn how you can join in the celebration of what would have been Dr. Henrik Sjögren's 117th birthday!



Dr. Henrik Sjögren