



2019 SSF National Patient Conference Highlights

On April 5th and 6th, over 500 patients and family members came together in Woburn, Massachusetts for “Conquering the Complexities of Sjögren’s” at the first-ever sold out SSF’s National Patient Conference. This annual Conference provides an opportunity for attendees to share with each other, while learning about new products from exhibitors and talking to leading experts.

SSF Conferences are designed to help patients take control of their health and gain a better understanding of Sjögren’s. The SSF Education Committee works to ensure that the program caters to both newly diagnosed patients and longtime Foundation members by continuously introducing new topics in order to cover the disease’s complexity. Thanks to the excellent agenda, this year’s Conference had our largest attendee turnout,

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Summer Sun Safety

by Mona Z. Mofid, MD, FAAD



Ultraviolet (UV) radiation emitted from the sun and other light sources (such as some fluorescent lights) can alter immune function and lead to an autoimmune response in the body and in the skin. Skin rashes and disease flares in Sjögren’s patients can result as well as ocular sensitivity and pain. In Sjögren’s, sun sensitivity is associated with the autoantibody SSA/or Ro. To avoid reactions to UV light, try the following tips:

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being sold-out for the first-time in the history of the SSF’s National Patient Conference!

During the two-day educational program, the audience enjoyed eleven informative lectures by expert speakers from around the country. This year’s presentation topics included:

- The Complexities of Sjögren’s: An Overview
- Oral Manifestations of Sjögren’s
- The State of Sjögren’s: Transforming the Future
- Product Showcase
- Fatigue and Sjögren’s
- Understanding Blood Changes and Lab Results
- Living with Sjögren’s: A Patient Panel
- Ocular Manifestations of Sjögren’s
- Nutrition, Wellness and Autoimmune Disease
- Sjögren’s Clinical Trials Update
- How Sjögren’s Can Impact the Central Nervous System

One of the many highlights of this year’s Conference was our Friday evening’s SSF Banquet Awards Dinner, honoring volunteers who have helped to further the Foundation’s mission by stepping up for all patients.

Following the awards ceremony, the 2019 Keynote Address was given by Brad Lemack. Brad is a Los Angeles-based talent manager, public relations consultant, educator and author. He established his agency, Lemack & Company Talent Management/Public Relations in 1982, after serving as a publicity executive for pioneering producer Norman Lear’s television and film production company, where he worked on such now-classic television series as “The Jeffersons” and the original “One Day at a Time,” among many others. Brad, who is also a Sjögren’s patient, spoke about finding your voice when living with a chronic illness. His lighthearted and insightful talk closed this inspirational evening. Learn more about our National Award recipients on page 3.

Day two of the Conference was packed with seven informative presentations and attendees took a mid-day break to participate in our Walk for Sjögren’s— *Celebrating our Strength!* This family-fun event was held right outside the Conference Hotel, where participants joined with others in the Boston community for a brisk walk, while also raising funds to benefit Sjögren’s educational and

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research programs. Using our new walk theme, *Celebrating our Strength*, patients had the opportunity to thank their friends and family who help them each day live their fullest life possible, despite their Sjögren's. These people are what we call a patients' "Circle of Strength."

Thank you to all of our speakers who volunteered their time, and everyone who attended this year's Conference and committed themselves to helping each other learn and expand their knowledge of Sjögren's. In addition, a special thanks to our sponsors, exhibitors and SSF Education Committee. Without their support, the SSF would not be able to provide such an outstanding Conference!

The Foundation understands not everyone was able to attend this year's National Patient Conference, which is why we are offering the most popular talks in a downloadable audio format or on CDs with the follow-along PowerPoint presentation printouts. Learn how to order your copies today on page 14.

National Patient Conference Volunteer Awards Banquet

Every year, the Foundation recognizes our most dedicated volunteers through awards that are announced at our Awards Banquet held during the first evening of the Conference. We could not accomplish all that we do without the hard work and dedication of volunteers like these awardees. Thank you to these recipients who show how an individual can make a big difference just by getting involved.



(L to R) Kathy Hammitt, SSF Vice President of Medical & Scientific Affairs; Alan Baer, MD; Janet Church, SSF Board of Directors Chair; and Steven Taylor, SSF CEO.

Healthcare Professional Leadership Award Alan Baer, MD

"Successful is the person who leaves the world better than they found it."



Dr. Alan Baer is a quiet giant in the world of Sjögren's. He is a sought-after leader and rheumatologist who has had a profound influence on clinical practice as well as research in Sjögren's. In

“NPC Highlights” *continued from page 3* ▼

addition to directing the Johns Hopkins Sjögren’s Center, he also sees patients at the National Institutes of Health Sjögren’s Clinic.

Dr. Baer regularly steps up to volunteer for the SSF, whether as a speaker for our National Patient Conferences, writing for our newsletters and *The Sjögren’s Book*, or serving on the SSF Clinical Trials Consortium. In addition, Dr. Baer is leading the SSF team working to change the ICD diagnostic code. This change will expand physicians’ awareness and accurate documentation of Sjögren’s as a multi-organ/system disease.

Dr. Baer is a leader on the international stage in Sjögren’s, most recently having chaired the 2019 International Symposium on Sjögren’s Syndrome (ISSS).

Dr. Baer is truly deserving of this high award, and the SSF is honored to have such a giant whom we can claim as our own.



(L to R) Steven Taylor, SSF CEO; Kim and Charles Vaughn; Janet Church, SSF Board of Directors Chair.

Volunteer Leadership Award: *Kim and Charles Vaughn*

“Only a life lived for others, is worth living.”

Kim and Charles Vaughn’s commitment to the SSF has been steadfast and unwavering. From serving on our National Board of Directors, to helping increase awareness, to helping lead and host our annual fundraising event in Atlanta, Kim and Charles have shown what it is to be true volunteer leaders.

Charles and Kim, separately, have each served on the SSF’s National Board of Directors. Charles from 1997 – 2003 and Kim from 2003 – 2006. Their leadership on the board helped to make major changes to the SSF including a relocation

of the SSF national office in 2001 and the hiring of SSF CEO, Steven Taylor, in 2003.

As a former Mrs. Georgia America and Mrs. Georgia International, Kim has used her platform as a way to increase awareness of Sjögren’s. She has continued this work throughout her tenure with the SSF and continues to this day to be one of the best advocates and spokespeople for Sjögren’s.

In addition, Charles and Kim’s volunteer work on the SSF’s annual fundraising event in Atlanta has helped the SSF raise over \$300,000.



(L to R) Janet Church, SSF Board of Directors Chair; Allissa Latham; Steven Taylor, SSF CEO.

Awareness Service Award: Allissa Latham

“No one can do everything, but everyone can do something.”

As a fellow Sjögren’s patient, it is Allissa’s personal connection to the disease that makes her so passionate about helping others, especially pediatric patients, know that they are not alone in living with this complex disease.

Allissa’s involvement with the SSF began when she was crowned Miss Massachusetts USA 2018. Diagnosed with Sjögren’s as a teenager, she struggled with various complications for years, including what she describes as embarrassing swollen parotid glands.

Allissa made the Top 15 during the Miss USA pageant, which gave her the opportunity to create a short video that was aired during the telecast where she talked about her personal struggles with Sjögren’s. Although she did not win the Miss USA pageant, the awareness she garnered on national television was incredible and let everyone know that the disease is more than just dry eye and dry mouth.



(L to R) Steven Taylor, SSF CEO; Michele Champigny, SSF Senior Director of Awareness initiatives; Sharon Tiger; Grace Tiger; Jamie Dianni; and Janet Church, SSF Board of Directors Chair.

**Mission Service Award:
Sharon Tiger and Jamie Dianni**

“One of the greatest gifts you can give is your time.”

With great excitement, the SSF recognized our co-recipients, Jamie Dianni and Sharon Tiger with the Mission Service Award. Both Jamie and Sharon are long standing volunteers who became involved with the SSF after their children, AJ and Grace, were diagnosed with the disease.

Together, they have made an amazing dynamic duo raising awareness in their local communities and co-leading the pediatric Sjögren’s support group and online pediatric Facebook support group. In 2017, they joined the SSF in getting involved with the Childhood Arthritis Rheumatology Research Alliance (CARRA) organization. As part of CARRA, Jamie and Sharon work with a group of pediatric rheumatologists who help bring awareness to the fact that Sjögren’s does affect children!



(L to R) Steven Taylor, SSF CEO; Don and Mary Hammond; and Janet Church, SSF Board of Directors Chair.

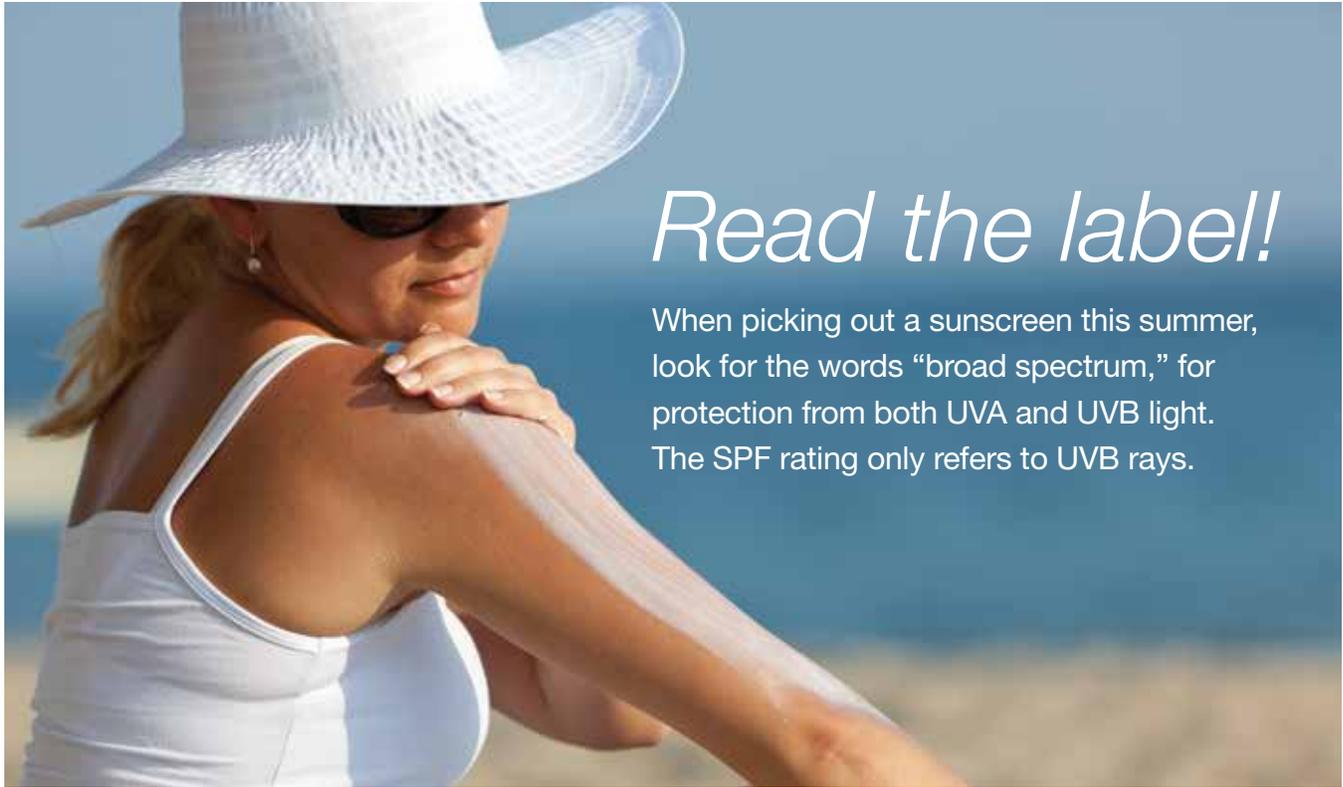
Vision Award: Mary and Don Hammond

“You make a living by what you get. You make a life by what you give.”

This award recognizes an individual or group that has contributed in a substantial way to the vision of the Foundation. This year we had the privilege of recognizing Mary and Don Hammond who have generously given a major gift to the SSF for the last 18 years.

Their long-standing gifts have been instrumental in supporting various SSF initiatives that have helped us lead the charge in transforming the future of Sjögren’s for all patients. Mary and Don own Hammond Lumber, the largest lumber company in the state of Maine.

While they are not ones who like a lot of attention around their support, it is our distinct honor to celebrate what they have done to help shape the vision of the SSF to conquer the complexities of Sjögren’s. ■



Read the label!

When picking out a sunscreen this summer, look for the words “broad spectrum,” for protection from both UVA and UVB light. The SPF rating only refers to UVB rays.

“Summer Sun” continued from page 1 ▼

- Protect your skin and eyes through use of sunscreen, sunglasses, ultraviolet light-protective clothing, hats, and non-fluorescent lighting.
- Use sunscreen that protects against both UVA and UVB rays. Doctors now recognize the dangers of UVA light in addition to those of UVB.
- Look for the words “broad spectrum,” which often are used to mean protection from both UVA and UVB light. Note that SPF ratings refer only to UVB rays. In the U.S., a “star” rating on products is coming into increased use to help consumers figure out how much UVA protection is provided. A European rating referred to as “PFA” measures UVA protection.
- Use plenty of sunscreen! Most people only use about 1/3 the recommended amount of sunscreen. This reduces the benefit of the SPF rating.
- Use a higher number SPF sunscreen.
- Remember that water, humidity and sweating decrease sunscreen effectiveness and mean you must reapply your sunscreen.
- Wear sun-protective clothing. It is designed to protect your skin from UVA and UVB rays, is more reliable than sunscreen, does not wash off or need to be reapplied, can be washed and dried quickly, and, compared to sunscreen, is not known to cause skin reactions.
- Don’t forget to wear sunscreen on areas not covered by sun-protective clothing, such as the neck and ears. Consider purchasing UV-protective car and home window films (which come in clear) and tinting.
- Wear good UV-protective eye lenses and sunglasses.
- Seek the shade when outside.
- Investigate whether UV-protective clothing and eyewear, window shields, and sunscreens are eligible for reimbursement under your insurance plan or Flexible Health Care Spending Account. ■



Advocacy Update

Let My Doctor Decide

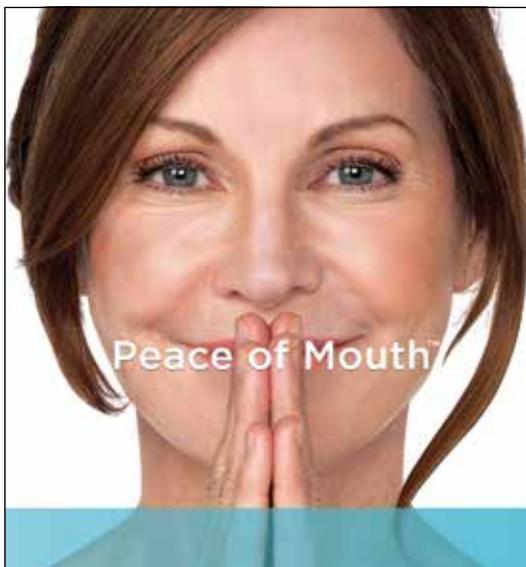


Let My Doctors Decide

The SSF is proud to have joined the *Let My Doctors Decide* task force focused on protecting patients against harmful “step therapy” practices imposed by insurance companies. When patients are forced into step therapy, they are required to try and fail on drugs before their insurance plans will cover the costs of doctor-prescribed medicines. This puts patient health at risk, interferes with doctor expertise and adds unnecessary financial waste to the rest of the healthcare system.

“When it comes to a condition like Sjögren’s, it’s particularly important to have doctors and patients making decisions involving medical treatments. The Foundation looks forward to working with Let My Doctors Decide and its partners on this critical initiative.” – Steven Taylor, SSF CEO.

Visit www.letmydoctorsdecide.org to learn more about the SSF’s involvement with the *Let My Doctors Decide* task force. ■



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SSF in Action!

Conquering the Complexities of Sjögren's
for April Awareness Month



This year's SSF April Campaign, *Conquering the Complexities of Sjögren's*, was created to help others visualize the vast impact of this debilitating disease and how it affects those living with it by sharing your stories.

Every day in April, the Foundation used our website and one or more of our social media channels to feature a patient's photo and fact about their Sjögren's journey. While each daily post gave one small glimpse into the complexity of Sjögren's, at the end of April, we believe the collection of all 30 posts demonstrated the various physical and emotional burdens that can be associated with the disease.

Thank you to everyone who shared their story as part of this campaign and everyone who used April as an opportunity to talk about Sjögren's with the people in your life. By allowing us to represent your voice, you helped this campaign become the most viewed awareness project in the history of the Foundation!

To learn more about this campaign and view all 30 daily posts, please visit www.sjogrens.org. Together, we will make Sjögren's a household name. ■



Candi B., 46
(diagnosed at 43)

"My most difficult Sjögren's symptoms is living with 49% lung function. I wish people knew how dangerous it is to call this only a "dry eye and dry mouth disease."

Jaeden, 9
(diagnosed at 6)

"My most difficult symptoms are body aches, dry mouth and muscle pain. The hardest part of living with this disease is that people don't understand when I need to take breaks."



Yvette Y., 42
(diagnosed at 28)

"Sjögren's means living with tooth decay, joint pain, fatigue and having to explain what your disease is to everyone. It's discouraging to be in the ER and need to describe Sjögren's to your doctors/nurses. My best tip is to keep talking about the disease. Our pain, our story connects us and that helps."



Randy K., 49
(diagnosed during mid-thirties)

"I wish people understood that this complex disease affects both men and women of all ages. As a patient, remember to stay informed and keep asking questions. Never assume that things can't change."

Conquering the Complexities of Sjögren's

Day 1



Day 30

Kick Off Your Fall with Team Sjögren's in Philadelphia!



We're looking for runners or walkers to join our Team Sjögren's Training Program for the Rock 'n' Roll series Philadelphia Half Marathon and 7.6K race. Follow our program and we will prepare you to WALK or RUN either the Half Marathon (13.1 miles) or their inaugural 7.6K (4.72 miles) race on Sunday, September 15, 2019 in Philadelphia!

The SSF has a limited number of spots for this epic fall event and we hope you'll be one of them! By taking part, you will get to enjoy the Rock 'n' Roll Marathon Series oldest event in historic Philadelphia as we participate alongside 20,000 other walkers/runners from all over the world!

Both walker friendly courses take you on a city tour through beautiful Philadelphia. Those individuals completing the Half Marathon will traverse 13.1 miles and those who decided to run or walk the 7.6K will cover 4.72 miles and be one of the first to rock an all new distance in this inaugural race. Whichever you choose, you will be cheered on by bands, cheerleaders and supportive spectators throughout the route!

The best part, is that even if you have never run or walked such a distance, the staff and our team trainer will help guide you through the entire process and ensure you are ready to participate in September! Our Team is always full of walkers and runners – so don't fret if you aren't a runner – Team Sjögren's was designed for you! Our plan takes people from the couch to the course!

In addition, you will be increasing awareness for Sjögren's, as well as, helping raise crucial funds for Sjögren's research and education. If you don't feel you can walk or run in this event, do what so many other patients have done and recruit someone else – your husband, wife, sister, cousin, daughter, son or friend – and have them walk or run in your honor.

We hope you will join us in beautiful Philadelphia this fall!

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



As a Team Sjögren's member, you will receive:

- World-class training from our Team Trainer
- Leadership and mentorship from past runners and SSF staff
- Hotel room accommodations in Philadelphia
- Airfare reimbursement
- Opportunity to join a team of those wanting to make a difference
- And much much more

SSF EVENT CALENDAR

To learn more about SSF events, please visit www.sjogrens.org or contact Jessica Levy at (301) 530-4420 ext. 218 or email jlevy@sjogrens.org.

JUNE	<p>Dallas Walk for Sjögren's Saturday, June 22, 2019 Parks at Arlington</p>	
SEPTEMBER	<p>Team Sjögren's Philadelphia Sunday, September 15, 2019 Philadelphia, Pennsylvania</p>	
OCTOBER	<p>Los Angeles Area Walk for Sjögren's Saturday, October 19, 2019 La Mirada Community Regional Park</p>	
NOVEMBER	<p>Austin Area Walk for Sjögren's Saturday, November 9, 2019 The Parks Mall at Arlington</p>	

Start an event in your area!

With the summer events underway we've also started planning for the fall and winter! We want to make a **BIG** awareness impact in as many communities as we can this year and need your help! Maybe there is already a Sip for Sjögren's or Walkabout in your area and you would like to get involved. Or maybe you are motivated and want to start an event in your area. Contact Jessica Levy at (301) 530-4420 x218 or by email at jlevy@sjogrens.org to learn how you can get involved.



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Celebrating Elaine Harris and Dr. Henrik Sjögren

On March 17, 2019, Steven Taylor, SSF CEO, flew to New York to celebrate the 95th birthday of Elaine K. Harris who founded the SSF.

Elaine started the Foundation 35 years ago, as a frustrated patient determined to learn more about her disease. Today, the SSF serves thousands of patients and has grown into a powerhouse organization, breaking down barriers worldwide in the field of Sjögren's. The many achievements that the SSF has seen would not be possible if it wasn't for Elaine being a source of hope for all patients.

With World Sjögren's Day on July 23rd right around the corner, the Foundation continues celebrating those who paved the way for the SSF!

World Sjögren's Day commemorates the birthday of Henrik Sjögren, the Swedish ophthalmologist who first identified the disease in 1933. More importantly, this day is meant to put a face on the millions of people who live with this disease and help raise Sjögren's awareness.

World Sjögren's Day gives everyone touched by Sjögren's a vehicle to reach out and educate those close to them – family, friends, co-workers, neighbors, etc. – about the disease. It is the ideal opportunity for you to have your voice heard and share your story.

On July 23, we encourage you to join with the SSF and Sjögren's organizations around the world to raise awareness of this complex and serious disease. Visit www.sjogrens.org to learn how you can join in the celebration of what would have been Dr. Henrik Sjögren's 120th birthday! ■



Steven Taylor, SSF CEO, and Elaine K. Harris, SSF Founder, at Elaine's 95th Birthday



Dr. Henrik Sjögren

 **in memoriam**

In Memory of Eileen Florence Guldin

Pat Chorzelewski
Jane Howland Grim
Lori Mulligan
The Marini Family
Your LourMurray Team

In Memory of Jack Wilder Beam

Love, Mom and Dad (Chad and Elizabeth Beam)

In Memory of James "My Jim" Joseph Lawlor Jr.

Diane Lawlor

In Memory of Jean Bartlett

The Velardi Family Foundation

In Memory of Jean Sosin

The Yelsey Family
Bela and Eruch Daruwala

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Greg Dolnack

In Memory of Joe Rubin

Teresa Quale

In Memory of Naomi Nord

Friends and Family of Naomi
Thomas and Dorothy Nord

In Memory of Randy Krasson

Ellen and Jerry Reibstein

In Memory of Rita Kagan

Ellen and Jerry Reibstein

In Memory of RoseAnn Talty

Sandra Tremblay

In Memory of Shirley Mullenax

The Jackson Family
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Lynne Maxwell
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Richard Spore

In Memory of Susan Freedman

Elaine Burrick

 **in honor**

In Honor of Laura Dour

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In Honor of Elaine Harris

Dr. Michael and Dorene Sedrish
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In Honor of Jessica Levy

Barbara Berger

In Honor of Donna Ferchill

Lynn and Terry (Mom and Dad) Arneri

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Charlotte Anderson

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In Honor of Patricia Goldberg

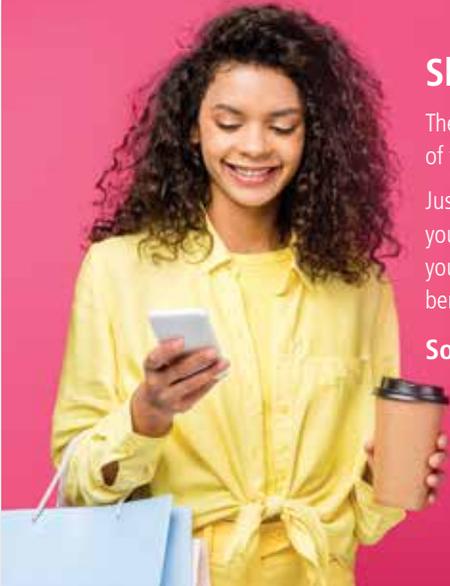
Charlie, Nicole, Jade, Sebastien and Baby Neo Haag

In Honor of Erin Bloomsburgh

Terry Bloomsburgh



Remember your loved ones and special occasions with a donation to the SSF in their name.



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The Sjögren's Syndrome Foundation has partnered with online retailers who will donate a portion of your purchase to the SSF, so shopping online is now an easy way to contribute to Sjögren's!

Just visit www.sjogrens.org/shopforsjogrens and click through the links provided so that your purchases will benefit the SSF. Once you select the "Sjögren's Syndrome Foundation" as your charity of choice, whenever you return to these retailers and log in, any shopping you do will benefit the SSF. It's that simple!

Some of our partners include:   You shop. Amazon gives.

Amazon is the most popular online stores in the world, offering a wide variety of products.

 iGive.com offers exclusive deals with over 700 brand name stores you know and love, with a specified percentage of each purchase coming back to the SSF.



2019 National Patient Conference Audio Talks Available

Get all the vital
information you need
in a downloadable
audio format

Audio talks of the most popular talks from our 2019 SSF National Patient Conference in Woburn, Massachusetts, are now available with the follow-along PowerPoint presentation printouts.

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	Non-Member	Member	Non-Member	Member		
The Complexities of Sjögren's: An Overview by Theresa Lawrence Ford, MD	\$30	\$18	\$32	\$20		
Oral Manifestations of Sjögren's by Vidya Sankar, DMD, MHS	\$30	\$18	\$32	\$20		
Fatigue and Sjögren's by Donald E. Thomas, Jr., MD	\$30	\$18	\$32	\$20		
Understanding Blood Changes and Lab Results by Alan N. Baer, MD	\$30	\$18	\$32	\$20		
Ocular Manifestations of Sjögren's by Esen K. Akpek, MD	\$30	\$18	\$32	\$20		
Nutrition, Wellness and Autoimmune Disease by Lauri Lang, RDN, LDN	\$30	\$18	\$32	\$20		
How Sjögren's Can Impact the Central Nervous System by Edward A. Maitz, PhD	\$30	\$18	\$32	\$20		
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Conquering the Complexities of Sjögren's

2019 National Patient Conference

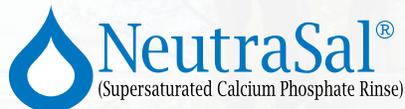
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Sjögren's Book Table

Walk for Sjögren's Registration

"This is Sjögren's" Photo Booth



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

EXPLORING SJÖGREN'S
Hosted by Steven Taylor

Sjögren's ("SHOW-grins") is a systemic autoimmune disease that affects the entire body.
#ConqueringTheComplexitiesOfSjögrens

Sjögren's Syndrome Foundation

The banner features a large blue speech bubble on the left containing the title 'EXPLORING SJÖGREN'S' and the host's name 'Hosted by Steven Taylor'. On the right, there is a blue box with white text describing Sjögren's as a systemic autoimmune disease and providing a hashtag. The Sjögren's Syndrome Foundation logo is in the top right corner.

Exploring Sjögren's is our new YouTube video series that explores Sjögren's and the daily lives of our patients.

We have created six episodes for season one that discuss Sjögren's as a disease and the work being done to help conquer the complexities of Sjögren's. In addition, two of the episodes specifically focus on living with Sjögren's and how our patients cope.

The first episode premiered on April 30th, with a new episode airing each following Monday. Visit www.sjogrens.org to view our new YouTube series.



Special thanks Brad Lemack from Lemack & Company, our Executive Producer, and all the physicians, researchers and patients who took part in season one of this important project! ■