

Lupus and Sjögren's

by Donald E. Thomas, Jr., M.D., FACP, FACR, RhMSUS, CCD

While Sjögren's was named after a physician, Dr. Henrik Sjögren (the ophthalmologist who described many characteristics of the disease in 1933), lupus gets its name from the Latin word for wolf (lupus). The term lupus has been used as a term to name diseases since the Middle Ages. We know this because of a letter written by one of the very first people affected by lupus. In 959 AD, a priest named Eracle was chosen to be the Bishop of Liege (located in what is today Belgium) by Pope John XII. The bishop wrote that he was afflicted by a disease that caused pain throughout his body and open sores on his skin. The sores looked as if a wolf had bitten him, which was the reason for the name of the disease, lupus. A 12th Century account states

[continued page 2 ▼](#)

2019-2020 Research Grant Recipients



First Grantees Under New SSF Revamped Program

The Sjögren's Syndrome Foundation is excited to announce the selection of the 2019-2020 research grant recipients – the first under the newly revamped SSF Grant Program. This new program offers two distinct grant types, the SSF High Impact Research Grant at \$75,000 and the SSF Pilot Research Grant at \$25,000. Additionally, our research review committee has renewed three excellent research grants from the 2018-2019 awardees.

[continued page 8 ▼](#)



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“Lupus” *continued from page 1* ▼

that Bishop Eracle’s doctors treated him by placing the carcasses of two freshly killed chickens on his skin every morning and night. Although this helped him feel better, his condition worsened to the point that he was dying from lupus. It wasn’t until he prayed to be healed at the shrine of Saint Martin in Tours, France that he was cured of his lupus by Saint Martin and Saint Brice. Bishop Eracle was so appreciative that he returned to Liege where he built a church in gratitude. The church was named after Saint Martin to commemorate this event. Today, you can visit the “Basilica of Saint Martin” in Liege, Belgium: the church that was originally built because of the disease called lupus.

After that, lupus was used as a name for diseases that

caused scarring lesions on the body. Before modern medicine and the ability to separate diseases (using microscopes and cultures), these lesions were due to very different disorders. The infection tuberculosis causes “lupus vulgaris,” an inflammatory disease called sarcoidosis caused “lupus pernio,” and the autoimmune disease “lupus erythematosus” causes other rashes as described below. This article is about lupus erythematosus. Erythematosus is a medical term meaning “red-colored” and refers to the fact that the rashes of lupus are often pink or reddish.

The greatest risk factor for developing an autoimmune disorder is the existing presence of an autoimmune disease. Overlaps are common and often complex. This is why the Sjögren’s Syndrome Foundation is dedicated to featuring articles showing the overlap of Sjögren’s with other connective tissue disorders, which include a review of the major features of those disorders and comments on how the presence of the other diseases may impact the expression of Sjögren’s and vice versa.

continued page 4 ▼

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smartpatients.com/ssf



“Lupus” *continued from page 2* ▼

There are several different forms of lupus. **Neonatal lupus** occurs in newborn babies. It is caused by the passage of autoantibodies from the mother through the placenta and then into the unborn baby where those antibodies can sometimes attack the baby’s organs. The most common antibody that does this is anti-SSA antibody (discussed later in this article), commonly found in patients with Sjögren’s. Pregnant women who have Sjögren’s are at an increased risk of having babies born with neonatal lupus. Fortunately, this only occurs in around 3% of anti-SSA positive mothers. In some babies, the SSA antibodies can attack the heart, most commonly causing heart block (called congenital heart block) where the baby’s heart’s electrical system doesn’t work normally. Congenital heart block due to neonatal lupus often requires the use of a pacemaker to keep the heart working properly. Other babies with neonatal lupus will develop a red rash (most commonly on the face) as soon as they are exposed to ultraviolet light. The rash looks exactly like the sun-sensitive rashes that some Sjögren’s patients get as well as being similar to a type of lupus rash called subacute cutaneous lupus. Because this rash is due to the mother’s SSA antibodies that are circulating in their baby’s bloodstream, it disappears at about eight months of age when these antibodies are replaced by healthy antibodies from the baby’s own immune system. Unfortunately, the damage to the heart in those who have congenital heart block is usually permanent due to damage to the heart’s electrical system.

Cutaneous lupus occurs when the immune system of a person with lupus attacks the skin (“cutaneous” is the medical term for skin). There are several different types of cutaneous lupus. The most common type is called chronic cutaneous lupus erythematosus, CCLE for short (“chronic” refers to conditions that last a long time). There are many different types of CCLE with discoid lupus being the most common. Discoid typically causes disc-shaped (oval to round) rashes that most commonly occur on the face and scalp and, unfortunately, can permanently damage the skin. This damage can lead to permanent

scars, pigment changes, and hair loss. Subacute cutaneous lupus erythematosus, SCLE, causes red rashes, most commonly on the face, arms, chest, and back. They are particularly more pronounced with sun exposure. This form of lupus rash is especially common in lupus patients who are positive with the antibody SSA (the antibody that is so common in people who have Sjögren’s). It is not surprising that some people who have Sjögren’s will also get a sun-sensitive rash that is indistinguishable from the SCLE of lupus. The third major type of lupus rash is called acute cutaneous lupus erythematosus, ACLE (“acute” meaning it occurs for a shorter amount of time). The most common forms of this rash are the classic butterfly rash (also called malar rash) of lupus where there is a red rash on the bridge of the nose and cheeks in the form of a butterfly. ACLE can also cause a red rash on most surfaces of the body, or a red rash primarily on the sun-exposed areas.

Systemic lupus erythematosus (SLE) is a third type of lupus that occurs when the immune system of the person is overactive. It can attack any part of the body, including the skin. While some people who have cutaneous lupus will only have skin involvement and never develop the systemic form of lupus, SLE, around 80% of people who have SLE will also have some form of cutaneous lupus as a part of their systemic involvement. For example, only around 20% of people who have **discoid lupus (DLE)** will ever evolve to have other organs of the body affected with lupus (in other words, develop SLE). However, close to 100% of people who have ACLE (e.g., the butterfly rash) will develop SLE.

The fourth major form of lupus is called **drug-induced lupus (DIL)**. DIL occurs when a medication causes the immune system to become overactive and causes the person to develop lupus (especially lupus rashes, arthritis, pleurisy, and many of the lupus antibodies). However, in DIL, the lupus problems resolve after the medicine is stopped. Today, the most common medicines to cause DIL are Enbrel, Humira, Remicade (all three are U.S. Food & Drug Administration-approved to treat rheumatoid arthritis), hydralazine (a blood pressure medicine), and procainamide (a

heart medicine).

Therefore, the potential connections between lupus and Sjögren's are that women with Sjögren's can potentially have a baby with neonatal lupus due to her SSA antibodies, and Sjögren's patients can develop a sun-sensitive rash that appears the same as SCLE. However, the most commonly encountered connection is that some people with Sjögren's will initially be thought to possibly have SLE. Other Sjögren's patients can develop SLE in addition to their Sjögren's (called an overlap). Both Sjögren's and lupus occur in people who are born with genes that can alter the function of the immune system, causing them to have that particular autoimmune disease. Some of the same genes that cause Sjögren's can also cause lupus. It is not at all uncommon to have people with lupus and Sjögren's in the same family due to these genes. Most people who inherit these genes never develop an autoimmune disease at all. It appears that these diseases occur when the genetically predisposed person (i.e., they are born with the genes) are exposed to a trigger that "turns them on." Some examples of highly suspected triggers include cigarette smoking, ultraviolet light (sun) exposure, low vitamin D levels, stress, and certain infections (especially Epstein Barr virus, which causes mononucleosis). Why some people who are born with similar genes end up getting classic SLE (for example, develop a butterfly rash), and others will end up having their immune system attack primarily the glands of the body causing dryness (leading us to call it Sjögren's) is not fully known. It may have to do with the particular set of genes that the person inherits, which triggers turn the disease on, and exactly which genes are activated and in what manner. Much research is being done on this subject.

An interesting similarity between SLE and Sjögren's is that they occur more commonly in females. Around 90% of SLE and Sjögren's patients are women. This is partially explained by the influences of the person's hormones on the diseases (for example, lupus is much more common in women of childbearing age and not uncommonly will flare up during menstrual cycles). However, some of the genes that cause Sjögren's

and lupus are located on the X-chromosome, therefore, women (who have two X chromosomes in each cell of their body) are twice as likely to inherit those genes than men (who only have one X chromosome). A recent study even showed that there can be a rare genetic problem where some women with lupus and Sjögren's can have even three sets of X-chromosomes (this phenomenon is much rarer in healthy women).

When someone then develops an autoimmune disease caused by these genes and environmental triggers, it can sometimes be difficult to tell whether someone has Sjögren's or SLE. One reason for this is that they share many of the same blood test abnormalities. Almost all SLE patients are positive for anti-nuclear antibody (ANA), and most people with Sjögren's are also positive for it. Around 30% of people who have SLE will have SSA antibodies (SSA stands for "Sjögren's Syndrome A") while around 70% of Sjögren's patients will be positive for it. An interesting thing about SSA antibodies is that this antibody was initially discovered in SLE and Sjögren's patients around the same time in separate laboratories. The doctors who discovered it in Sjögren's patients called it SSA antibody (naming it after the disease), while those who found it in a lupus patient named it "Ro" antibody, incorporating part of the patient's name into the antibody. Later, it was discovered that anti-SSA and anti-Ro were the same antibodies. A similar thing occurred with SSB antibody and La antibody (discovered respectively in a Sjögren's patient and a lupus patient). Other lab tests commonly found in both SLE and Sjögren's include rheumatoid factor (RF), elevated gammaglobulins (polyclonal gammopathy), elevated double-stranded DNA (though more common in SLE), low C3 and C4 complement levels (though more common in SLE), low white blood cell counts and anemia due to inflammation.

To make things more complicated, both SLE and Sjögren's can cause inflammation (swelling and pain) of the joints (arthritis), inflammation around the heart and lungs (pericarditis and pleurisy), scarring of the lungs (interstitial lung disease), liver inflammation (hepatitis), mouth sores, subacute

“Lupus” continued from page 5 ▼

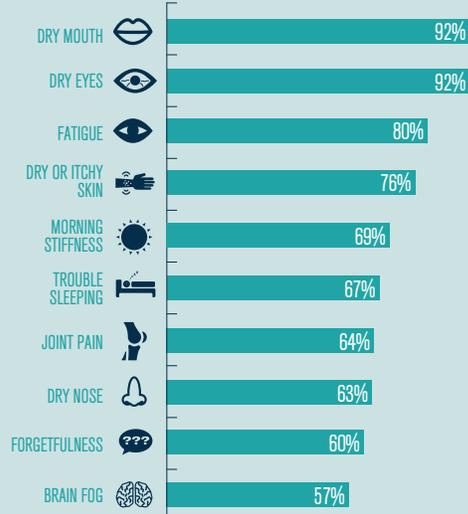
Most Common Symptoms Experienced

The vast majority of Sjögren’s patients reported having experienced dry eyes (97%), dry mouth (97%), fatigue (94%), dry or itchy skin (93%), trouble sleeping (91%) and forgetfulness (90%) over the last year. Most said that their dry mouth (92%), dry eyes (92%), and fatigue (80%) symptoms occurred almost weekly or more frequently.

Patients 60 years of age and under said they were more likely than patients over age 60 to experience brain fog (i.e., confusion, forgetfulness, and lack of focus and mental clarity) (66% vs. 53%) and joint pain (67% vs. 62%) almost weekly or more frequently. Patients over 60 years of age reported that they were more likely than patients 60 years of age and under to experience dry nose (65% vs. 59%) and photosensitivity (sunlight) (64% vs. 56%) almost weekly or more frequently.

Half of Sjögren’s patients with severe dryness (53%) also have severe fatigue.

Common Symptoms Experienced Almost Weekly or More Frequently



cutaneous lupus-like rash, Raynaud’s (where the fingers turn white or blue with cold), fatigue, and fevers. None of the above lab tests or organ problems are seen only in Sjögren’s or SLE. Also, both Sjögren’s and lupus can involve the kidneys (usually noted as increased protein in the urine picked up while testing urine samples). However, they usually affect the kidneys in very different ways. The doctor can obtain a small piece of a patient’s kidney with a tiny needle inserted through the skin (called a kidney biopsy) and examine it under the microscope to tell whether the kidney involvement is due to SLE or Sjögren’s. Sometimes we need to get a biopsy of the salivary glands (lip biopsy) to diagnose Sjögren’s.

Some problems are so typical for SLE and Sjögren’s that when they occur, the diagnosis is easier. For example, the butterfly rash, hair loss, low platelet counts, a type of anemia called hemolytic anemia or having a positive blood test called anti-Smith antibody can make it much easier to make a diagnosis of SLE. The problems that are primarily seen in Sjögren’s are dry eyes, dry mouth, joint pain, fatigue dry, itchy skin, and other dryness problems. If these occur in someone who has additional problems that are more typical of Sjögren’s (for example, a high SSA antibody, high RF, and polyclonal gammopathy, all of which

are more classic for Sjögren’s, but not 100% specific), then a doctor may feel comfortable in

continued page 14 ▼



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‡In people with dry mouth who use 2 discs while sleeping and 4 more during the day.



You Stood Up!

Thank you for Celebrating World Sjögren's Day!

On July 23rd, Sjögren's Syndrome Foundation (SSF) members and people from around the globe joined together in recognizing World Sjögren's Day.

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 an opportunity to talk about Sjögren's and share the message that it is a serious and complex disease. The Foundation was truly thrilled by all of the donations we received, the thousands of Sjögren's fact sheets downloaded, the large number of posts shared on social media and messages about how you celebrated the day in your community.

Your generosity raised a remarkable \$17,000 for SSF programs and research!

Although World Sjögren's Day has now passed, the fight against Sjögren's continues. While it certainly made an impact, one day alone is not enough to conquer the complexities of Sjögren's. We must continue to work together and strive to carry on our momentum. We encourage you to look for ways to become more involved with the SSF in the upcoming months.

Thank you for your continued support of the Foundation and all your efforts throughout the year to help make every day feel like World Sjögren's Day! ■

Staff at the SSF national office handing out awareness materials on World Sjögren's Day.



Social media shows their support on World Sjögren's Day.



“Research Grants” *continued from page 1* ▼

2019-2020 SSF High Impact Research Grant Recipient



Kristi Ann Koelsch, PhD

*Assistant Professor of Research
Dept. of Medicine, College of Medicine,
University of Oklahoma Health
Sciences Center Oklahoma City, OK*

Project Title

*Salivary Anti-Ro Defines a New
Phenotype of Sjögren's Syndrome*

Abstract

Sjögren's syndrome is characterized by a lymphocytic infiltration of the salivary glands as well as anti-Ro (or SSA) in the serum. Neither research classification nor clinical diagnosis can be made without at least one of these two features. We have studied subjects attending a comprehensive sicca evaluation clinic who had dry eyes, dry mouth, objective findings of lacrimal and salivary gland dysfunction but no serum autoantibodies and no focal lymphocytic infiltration. In a substantial subset of these subjects we find anti-Ro in the saliva. Some subjects have both IgA and IgG anti-Ro, while others have only IgA anti-Ro. This project will fully characterize this group of patients, who may represent a previously unrecognized phenotype of Sjögren's syndrome, or an intermediate stage from which some will develop classical Sjögren's syndrome.

2019-2020 SSF Pilot Research Grant Recipient



**Emily Anne Lanzel, DDS,
MS**

*Visiting Assistant Professor
University of Iowa, College of
Dentistry, Iowa City, IA*

Project Title

*Salivary Biomarkers for
Diagnosis of Childhood
Sjögren's Syndrome*

Abstract

Diagnosing childhood Sjögren's syndrome is difficult. Childhood Sjögren's syndrome is not

well-defined, it often presents differently than adult cases, and child-specific criteria have not yet been established. Development of a reliable diagnostic biomarker, evaluated through non-invasive means, would be a huge advance with immediate clinical impact on more reliably diagnosing childhood Sjögren's syndrome allowing for interventions aimed at prevention of long-term organ damage and irreversible symptoms. The objective of this study is to identify reliable diagnostic biomarkers that may be used to diagnose childhood Sjögren's syndrome. We hypothesize that chemokines, cytokines, and biomarkers associated with the presence of CD4+ T cell, CD8+ T cell, and B cell infiltration in the salivary glands of children with Sjögren's syndrome should be detectable in their saliva.

Renewed 2018-2019 Research Awards



**Kimberly Jasmer
McDonald, PhD**

*Postdoctoral Fellow, University of Missouri,
Dept. of Biochemistry, Columbia, MO*

Project Title

*P2Y₂ Receptor as Therapeutic
Target in Sjögren's Syndrome
Mouse Model*

Description

Sjögren's is a chronic autoimmune exocrinopathy characterized by lymphocytic infiltration of the salivary and lacrimal glands. Chronic inflammation leads to salivary gland dysfunction and systemic effects including fibrosis, secondary autoimmune diseases, and lymphoma development. Using the NOD.H-2h4,IFN γ ^{-/-},CD28^{-/-} mouse model of Sjögren's, we explore the contributions of P2Y₂R-mediated inflammation to the Sjögren's phenotype. Our preliminary findings demonstrate that P2Y₂R antagonism improves salivation and diminishes inflammation in the submandibular gland (SMG). Additionally, functional P2Y₂R is expressed in SMG B cells. Through the nucleotide activation of P2Y₂R on infiltrating SMG B cells and subsequent chemokine and cytokine release,

continued page 10 ▼



Team Sjögren's Goes Turkey!

Team Sjögren's



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“Research Grants” *continued from page 8* ▼

we hypothesize that P2Y₂R might facilitate the recruitment of peripheral lymphocytes leading to salivary gland destruction, hyposalivation, and chronic inflammation. It is the goal of this proposal to elucidate the role P2Y₂R plays in infiltrating SMG B cell function and evaluate P2Y₂R as a novel therapeutic target for the treatment of Sjögren’s.



Melodie Lynn Weller, PhD
Assistant Professor, University of Utah,
School of Dentistry, Salt Lake City, UT

Project Title

The Impact of a Global Increase in Hepatitis Delta Virus (HDV) Exposure on the Incidence of Sjögren’s Syndrome Diagnosis

Description

We hypothesize that this increase in global HDV exposure may lead to increased Sjögren’s development in susceptible populations. This discovery in connection with the novel HDV profile observed in Sjögren’s patients is highly innovative and warrants immediate investigation. Therefore, we have designed two studies to perform cross-correlative anal-

ysis between HDV and Sjögren’s diagnoses within the Utah population. These studies will provide the foundation for advancement to clinical trials.



Yee Ling Wu, PhD
Assistant Professor, Loyola University
Chicago, Dept. of Microbiology and
Immunology, Maywood, IL

Project Title

Genetic and Phenotypic Polymorphisms of Complement C4 in the Pathogenesis of Sjögren’s Syndrome

Description

We hypothesize that C4 genetic and protein polymorphisms are engaged in disease predisposition and in modulating the clinical presentation of Sjögren’s. We will analyze patient samples using accurate molecular assays for determining C4 gene copy numbers, immunoassays for activated complement protein products and transcriptomic analyses to 1) determine the cause of low C4 in Sjögren’s, and 2) evaluate the utility of combining genetic stratification of C4 and new protein markers in the diagnosis and management of Sjögren’s. ■

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SSF EVENT CALENDAR

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SEPTEMBER

Team Sjögren's Philadelphia
Sunday, September 15, 2019
Philadelphia, Pennsylvania

OCTOBER

**New Hampshire Area Walk for Sjögren's:
In Memory of Karen T. Caron**
Sunday, October 6, 2019
Dorrs Pond at Livingston Park, Manchester, NH

Los Angeles Area Walk for Sjögren's
Saturday, October 19, 2019
La Mirada Community Regional Park

NOVEMBER

One Day Sjögren's Patient Conference
Saturday, November 2, 2019
Hilton Garden Inn Cleveland-Downtown

Austin Area Walk for Sjögren's
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Fatigue and Sjögren's by Donald E. Thomas, Jr., MD	\$30	\$18	\$32	\$20		
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SSF in Action!

Steven Taylor, SSF CEO,
Presents at EULAR 2019



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Steven Taylor (left) and Carlos Gonzalez-Najera (right) presenting a poster at EULAR 2019.



At the recent EULAR European Congress of Rheumatology held June 12th to 15th in Madrid, Spain, Steven Taylor, SSF CEO, along with colleagues from Bristol Myers Squibb presented a poster titled, “Characteristics and Treatments of Patients with Sjögren’s Syndrome in a Real-World Setting.” This presentation shared data gathered from the SSF through the Living with Sjögren’s survey and described patient characteristics and treatment in a real-world setting and categorized patients based on baseline characteristics.

Four discrete patient clusters were identified (recent, slower progressing, second and most severe).

The most differentiating comorbidities across all clusters included gastroesophageal reflux disease, fibromyalgia and Raynaud’s syndrome. The symptoms that impacted patients’ lives the most and that were differentiating across clusters were brain fog, fatigue and forgetfulness. The treatments that were most contrasting were oral comfort agents, followed by DMARDS and secretagogues.

The analyses presented show differences in disease characteristics and treatment across patient clusters, however, it’s important to note that more work is required in order to validate these clusters. ■

“Lupus” *continued from page 6* ▼

making a diagnosis of Sjögren’s. However, it does sometimes take a lip biopsy to know for sure.

Also, studies show that 20% to 30% of SLE patients also have Sjögren’s. When someone has more than one autoimmune disease, it is called an “overlap.” If someone has dry eyes, dry mouth, arthritis, the butterfly rash, a low platelet count, positive ANA, and SSA antibodies, then that person may have both SLE and Sjögren’s. An additional problem is that people can develop one autoimmune disorder (for example, SLE or Sjögren’s), then over time, develop the other autoimmune disorder, seemingly out of nowhere. So, it is important for both the patient and the physician to pay close attention to what the body is doing, and what the blood and urine tests are showing over time.

One huge difference between Sjögren’s and SLE is the availability of proven treatments. Though we use many of the same medicines to treat both with the goal being to calm down the immune system to keep it from attacking the organs, it is generally easier to see responses in people who have SLE compared to Sjögren’s. Many of the problems in SLE can respond relatively quickly (for example,

arthritis, pleurisy, mouth sores, kidney inflammation, rashes, etc.), while the dry mouth and dry eyes occur incredibly slowly over time due to damage and inflammation of the glands. Looking for responses of the glands to medicines that calm down the immune system have thus far been very difficult to evaluate and prove. Thankfully, the Sjögren’s Foundation is currently hard at work, promoting more research (called clinical trials) to try to find medications which effectively treat Sjögren’s.

Fortunately, some of the problems that are shared by SLE and Sjögren’s respond quickly and respond to the same medications. For example, medicines such as hydroxychloroquine (Plaque-nil), methotrexate, azathioprine (Imuran), and prednisone can help the rashes, joint inflammation, and pleurisy of lupus and Sjögren’s.

Possibly, many of you who have read this article did so because your diagnosis of Sjögren’s was considered in addition to the possibility of a diagnosis of lupus at some point. It may have been quite confusing for you and your doctors in sorting out all the pieces of the puzzle to finally reach a correct diagnosis. In some people, it may not be possible to reach a definite diagnosis or answer. I hope that the explanations above help to at least show why it can be so difficult. ■

About the Author



Donald E. Thomas, Jr., M.D., FACP, FACR, RhMSUS, CCD is a rheumatologist who has a special interest in systemic autoimmune diseases such as Sjögren’s and lupus. His desire to educate patients drove him to write the highly acclaimed patient education book, “The Lupus Encyclopedia: A comprehensive guide for patients and families.” He is in private practice at Arthritis and Pain Associates of P.G. County in Greenbelt, MD; is an Associate Professor of Medicine at the Uniformed Services University of the Health Sciences, and proudly serves on the Sjögren’s Foundation Board of Directors. Dr. Thomas’ talk from the 2019 SSF National Patient Conference on “Fatigue and Sjögren’s” is available for purchase on page 12.

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in memoriam

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If we are not listed on the contribution form, you usually may write in the Sjögren's Syndrome Foundation.

Tell your co-workers, friends, and family members how important it is to choose and write in the Sjögren's Syndrome Foundation on their campaign form, too.

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Just think – every dollar counts.

Last year alone – thanks to those who chose to give through their employer's payroll campaign – the Sjögren's Syndrome Foundation was able to increase its Research and Awareness commitments.