

The Moisture Seekers

Sjögren's Syndrome Foundation



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SjogrensSyndromeFoundation

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An Inside Look at Sjögren's and Overlapping Connective Tissue Diseases

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 (SSF) is publishing a series of articles featuring 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.

The SSF would like to thank Dr. Kevin Fleming for authoring the fourth article in this series, a focus on the overlap of Sjögren's and Fibromyalgia.

Fibromyalgia and Sjögren's

by Kevin C. Fleming, MD, Director, Fibromyalgia Clinic, Mayo Clinic, Rochester, MN

Fibromyalgia and osteoarthritis are the two most common rheumatic disorders. Fibromyalgia is a non-autoimmune disorder of undetermined origin characterized by widespread muscle and joint pain, and not arising from known inflammatory, infectious or degenerative causes. Studies have identified a prevalence of fibromyalgia that varies from 2% to 8% of the US population, thus affecting from 6-25 million persons. The American College of Rheumatology (ACR) diagnostic criteria for fibromyalgia includes chronic widespread pain and a symptom severity scale. This scale includes fatigue, un-refreshing sleep, cognitive complaints, and multiple somatic symptoms. Using the criteria, fibromyalgia affects twice as many females as males, similar to other chronic pain conditions.



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SSF in Action!

Fighting for a Sjögren's Therapeutic!



The Sjögren's Syndrome Foundation (SSF) is committed to getting a therapeutic developed for Sjögren's and that is why we are so excited about recent advancements that are being made by both the SSF and our pharmaceutical partners!

As many of you know, the SSF has been involved in clinical trial development since 2009 when the late Elaine Alexander, MD had the vision to start to encourage pharmaceutical companies to look at Sjögren's when thinking about their drug development pipeline.

Today, thanks to the leadership of Dr. Theresa Lawrence Ford as well as SSF Medical and Scientific Advisory Board Chair Dr. Nancy Carteron, the SSF is seeing a wave of momentum toward developing a Sjögren's therapeutic!

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Fibromyalgia most commonly affects individuals without any underlying rheumatic disease, but is also reported in patients with rheumatic diseases having structural pathologies, such as rheumatoid arthritis and osteoarthritis. The prevalence of fibromyalgia in Sjögren's has been reported to range from 12-31%. (See Table 1)

Table 1

Prevalence of fibromyalgia in patients with rheumatologic diseases

Ankylosing spondylitis	12.6 %
Behcet's disease	5.7 %
Familial Mediterranean Fever	7.1 %
Gout	1.4 %
Lupus (SLE)	13-32 %
Osteoarthritis	10.1 %
Polymyalgia rheumatica	6.9 %
Rheumatoid arthritis	6.6 %
Sjögren's	12-31 %
Vasculitis	25 %

Dry Eyes and Mouth

Sjögren's is a chronic heterogeneous autoimmune disorder causing immune destruction of exocrine glands, especially the lacrimal and salivary glands. This reduces the production of tears and saliva, resulting in the sicca complex of dry mouth (xerostomia) and dry eyes (keratoconjunctivitis sicca).

Patients with fibromyalgia also experience sicca symptoms, but in contrast to Sjögren's, the mucosal dryness in fibromyalgia arises instead from one or more non-immune factors, such as sympathetic hyperactivity, medication side effects, mouthwash use, mouth breathing (e.g., sleep apnea), and non-rheumatologic eye or mouth disorders. The xerostomia and xerophthalmia in fibromyalgia lacks the heavy lymphocytic infiltration of the salivary glands and damage to the eye epithelium found in Sjögren's. Similarly, fibromyalgia lacks laboratory test evidence of autoimmunity such as high titers of rheumatoid factor, antinuclear antibodies, or anti-SSA(Ro) and SSB(La). Patients with oral and ocular dryness without Sjögren's have been found to experience impairments in quality of life, anxiety, depression, and fatigue equal to those with Sjögren's. While subjective dryness is similar between these two groups, objective tests (Schirmer's test and salivary flow) show that dryness is worse in Sjögren's.

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Muscle and Joint Pain

More than half of patients with Sjögren's have systemic involvement including lung, kidney, neurologic and dermatologic effects. But musculoskeletal manifestations are among the most common comorbidities of Sjögren's, including arthralgias and myalgias. In Sjögren's with musculoskeletal pain, it is important to differentiate articular from non-articular, and inflammatory from non-inflammatory. Patients may report subjective joint pain (arthralgia) and/or synovitis (arthritis), but the two features should be detailed separately. Arthritis can be defined as inflammation of one or more joints, characterized by joint pain and stiffness, with heat, redness and swelling on physical examination. Sjögren's associated inflammatory arthritis can occur from months to years after the diagnosis of Sjögren's. When coupled with radiographic erosions, a positive joint scan, and/or positive anti-CCP antibodies consistent with rheumatoid arthritis, this can be classified as "rheumatoid arthritis + Sjögren's," which occurs in 7% of Sjögren's patients. Patients with "rheumatoid arthritis + Sjögren's" tend to have less advanced radiographic changes than patients with rheumatoid arthritis alone, suggesting that Sjögren's may have a moderating effect on the severity of rheumatoid arthritis, if present.

Non-erosive symmetrical arthritis has been reported in some 15-40% of Sjögren's patients, but non-inflammatory arthralgias are also common. For Sjögren's patients with persistent pain, an associated rheumatoid arthritis is suggested by: upper extremity joint involvement (MCP, PIP, wrist, elbow), synovitis on exam, joint deformities, bone erosions on x-ray/MRI, a positive joint scan, elevated erythrocyte sedimentation rate (ESR), and C-reactive protein (CRP), and positive rheumatoid factor and anti-CCP antibodies. Cases of true arthritis in Sjögren's typically involve fewer than five joints, with a more asymmetric distribution, whereas non-inflammatory arthralgias are mostly symmetric. Some Sjögren's patients do show a pattern of erosive osteoarthritis. The development of a single swollen joint is more likely to be gout or an infectious arthropathy (disease of the joints).

When muscle pain is prominent in Sjögren's (rather than arthralgias), polymyositis, polymyalgia rheumatica, inclusion-body myositis, and statin-related myopathy should be considered. Vasculitis, steroid myopathy, thrombotic and paraneoplastic processes can present with weakness and/or pain. In these cases, inflammatory markers and creatine kinase are usually elevated, electromyography is often abnormal, and muscle biopsy may be diagnostic.

In general, fibromyalgia is found in about 1 of 5 patients with Sjögren's. Fibromyalgia has no known biologic marker, and lacks autoimmune and inflammatory serologies. The chronic widespread musculoskeletal pain in fibromyalgia is most often continuous, but waxes and wanes in severity, and patients can experience flares of significant worsening.

Why Fibromyalgia Hurts

In contrast to rheumatologic diseases such as rheumatoid arthritis, pain in fibromyalgia can arise in the absence of musculoskeletal involvement. The origin of pain in fibromyalgia comes not from muscle, joint or nerve injury or destruction, but from central sensitization. Central sensitization can be defined as a state in which the peripheral and central nervous systems amplify sensory input across many organ systems. This enhanced response to sensation includes plasticity at a nerve level that increases sensitivity for subsequent stimulation. Central sensitization results in changes in brain activity that can be detected by functional magnetic resonance or positron emission tomographic imaging and electrophysiologic studies.

On a cellular level, central sensitization results from multiple processes altering the function of nociceptive neurons. These processes include increases in membrane excitability, facilitation of synaptic strength, and decreases in inhibitory transmission (disinhibition). Affected neurons display spontaneous activity, reduced activation threshold, and enlarged receptive fields. Heightened sensitivity results in the perception of pain from non-painful stimuli (allodynia) and greater pain than would be expected from painful stimuli (hyperalgesia). Hypersensitivity amplifies the sensory response elicited by normal inputs such as innocuous stimuli and normal body sensations. As a result, the perception of pain and discomfort may no longer be coupled to the intensity, duration, or even the presence of painful peripheral stimuli. Central sensitization can also occur as a result of repeated peripheral nerve and brain stimulation from disorders that produce chronic pain such as destructive arthritis from rheumatoid arthritis or "rheumatoid arthritis + Sjögren's."

Prominent visceral hypersensitivity can affect every organ system and produce significant discomfort or dysfunction, which can become chronic and persistent. Over time, these amplified sensations frequently provoke recognizable symptom clusters, which can be

"Sjögren's and Fibromyalgia" continued from page 3 ▼

diagnosed as fibromyalgia, chronic headaches, irritable bowel syndrome, chronic pelvic pain, irritable bladder/interstitial cystitis, and chronic fatigue, among others.

As a result of central sensitization, fibromyalgia is a common complication in rheumatologic diseases such as Sjögren's with synovitis, but sensitization and fibromyalgia pain can occur even in the absence of demonstrable muscle or joint pathology. Given the vast differences in treatment between inflammatory arthritis and fibromyalgia, it is crucial to recognize when central sensitization is causing pain, rather than (or in addition to) joint inflammation or destruction. Because both of these disorders can result in increased pain, physical limitations and fatigue, the symptoms may be interpreted as increased rheumatologic disease activity, resulting in the prescription of pain medicines (NSAIDs, opioids, or cannabinoids), or the initiation/higher doses of steroids or immunosuppressive/biologic agents.

This differential diagnosis can be rather difficult, but the lack of inflammatory markers, synovitis on examination, or a negative joint scan makes fibromyalgia more likely. Pain inconsistent with or out of proportion to the degree of damage evident on radiographic imaging should also suggest fibromyalgia. Pain symptoms unresponsive to immunosuppressives, biologics, or steroids should also raise concerns for fibromyalgia, as should the chronic use of narcotics for pain relief. It is useful to recognize that in central sensitization disorders like fibromyalgia, pain catastrophizing also increases perceived pain severity. Notably, pain catastrophizing is a significant predictor of pain severity in both seropositive and seronegative Sjögren's.

Consideration for the presence of fibromyalgia/central sensitization in the management of rheumatologic diseases increases the likelihood of treatment success, at least in part by making an accurate diagnosis of the cause of symptoms. Behavioral interventions aimed at limiting pain catastrophizing can also be helpful in fibromyalgia.

Depression

Depression affects from 30-50% of patients with Sjögren's. Notably, fibromyalgia is significantly more common in Sjögren's patients with moderate-to-severe depression compared to Sjögren's patients having mild or no depression. Assessing for depression using standardized interviews or questionnaires is recommended when chronic pain is present.

Vitamin D

Low serum 25-hydroxy vitamin D3 levels are associated with increased pain in fibromyalgia. The risk of vitamin D deficiency is increased in autoimmune conditions such as lupus, rheumatoid arthritis, Sjögren's, and scleroderma. Of note, Sjögren's patients with fibromyalgia have been shown to have significantly decreased vitamin D levels compared to Sjögren's without fibromyalgia. Assessing for serum 25-hydroxy vitamin D3 levels is recommended when chronic pain is present.

Memory Complaints

In fibromyalgia, patients often complain of memory loss and reduced concentration. Impairments in working /short term memory, verbal memory, and verbal fluency have been demonstrated in fibromyalgia, said to mimic "20 years of aging." Frontal subcortical cognitive impairments similar to fibromyalgia has previously been reported in patients with Sjögren's, lupus, multiple sclerosis, depression and other chronic pain disorders.

While the mechanisms underlying frontal cognitive dysfunction remain unclear, studies do suggest reduced concentration and memory in part because pain itself is attention-demanding, impeding or negating other memory functions. Chronic pain results in reduced capacity for focus, with resultant attention deficits. Poor sleep is common in fibromyalgia and other chronic pain disorders, which can further impair daytime alertness and concentration. Medications may also play a role, especially narcotics, anticonvulsants, benzodiazepines, and muscle relaxants.

Fibromyalgia Treatments

If fibromyalgia is confirmed, patients can benefit from treatment programs based on nonpharmacologic treatment principles for chronic pain. Such programs address the cognitive aspect of fibromyalgia, reduced symptom-focused behaviors (focus on what one can control), negative thinking, maladaptive emotions and cognitions, avoidance behaviors, and catastrophizing. Hypervigilance, health anxiety and somatization should also be reviewed. Cognitive retraining techniques, paced breathing/meditation, exercise therapy, medications, narcotic effects, social needs and demands, returning to work and other topics are important to discuss. (See Table 2 on page 6)

The serotonin norepinephrine reuptake inhibitors (SNRIs: duloxetine, milnacipran), gabapentinoids (pregabalin, gabapentin), and γ -hydroxybutyrate have

continued page 6 ▼

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"Sjögren's and Fibromyalgia" continued from page 4 ▼

Table 2

Nonpharmacologic Treatments for Fibromyalgia

Biofeedback
Chiropractic manipulation
Cognitive behavioral therapy
Complementary therapies (myofascial release massage, acupuncture)
Creative work (art, coloring books, music, dance, gardening, hobbies)
Graded aerobic exercise
Hypnotherapy
Meditative movement therapies (tai chi, yoga, qigong)
Mind-body techniques
Paced breathing/meditation
Patient education
Sleep hygiene
Strength training
Transcutaneous electrical nerve stimulation
Water-based exercise
Workbooks (anxiety, PTSD, behavior modification)

demonstrated efficacy in fibromyalgia. Tricyclic agents (nortriptyline, amitriptyline) have also been shown to be effective, but the association of long-term use of

anticholinergic medications and dementia raises concerns. It is important to note that the chronic use of opioids for pain management can amplify pain, called opioid-induced hyperalgesia. Narcotics may not only worsen chronic pain, but can also lead to dependence, the effects of overuse (constipation, sedation, cognitive dysfunction), and the risks of abuse (including overdose and death). Chronic non-cancer pain that becomes unresponsive to NSAIDs or disease modifying agents and requires opioid management is in itself a harbinger for fibromyalgia/central sensitization.

Conclusion

Musculoskeletal pain is a common complaint in Sjögren's. It is important to identify whether these symptoms reflect fibromyalgia or are related to an inflammatory or destructive arthritis or myopathy, because treatment may need to include potent disease-modifying immunologic medications. Notably, fibromyalgia patients have symptoms that significantly overlap with Sjögren's, including myalgias, arthralgias, oral and ocular dryness, fatigue, depression, and cognitive complaints. Fibromyalgia can complicate chronic rheumatologic disorders, especially when pain and depression are involved. Physical examination, laboratory testing, radiographic testing, response to therapy, and a high index of suspicion can help differentiate between these diagnoses. Fibromyalgia treatments can include various medications, but must also be approached by nonpharmacologic measures. Opioids should be avoided. ■



Missed the 2016 National Patient Conference?

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.

Sjögren's Syndrome Foundation



You Stood Up!

Donated Billboards for Sjögren's Awareness

The Lamar Advertising Company is one of the largest outdoor advertising companies in North America. Lamar offers a variety of billboard, interstate logo and transit advertising formats and has the largest network of digital billboards in the United States.

Founded over 100 years ago, in 1902, Lamar has always believed in giving back to the community. Each year, Lamar supports nonprofit organizations by donating available advertising space on billboards, digital displays and transit formats. They partner with various local and national organizations to help promote their great work and this past March/April, the Sjögren's Syndrome Foundation (SSF) was one of those lucky non-profits that benefited from Lamar's generosity.


When Seattle volunteers Rose and Doug Dethloff mentioned their role on the Seattle Walkabout Committee to their daughter, and Lamar employee, Sheila, she was more than willing to inquire about Lamar donating space to promote Sjögren's and the Walkabout. While Lamar is a large and growing company, they are also a very tight knit family-oriented company and try to help "their family" whenever they can. They were more than happy to be able to help Sheila and in turn the SSF. As if that wasn't enough, Sheila's husband Scott is a graphic designer and didn't hesitate in donating his services to design the creative for the space.

Lamar ended up donating a remarkable eight digital boards. The digital boards were located in different locations throughout the Seattle area and were up for more than a month. The most exciting aspect of the donation were all the people that told us they saw the sign and the incredible awareness it helped create for Sjögren's.

We are extremely thankful for Rose, Doug, Sheila, Scott and everyone at Lamar for helping make this happen. Most of all, we are grateful for the opportunity to increase Sjögren's awareness in such an exciting way. There are so many different ways that you can help support the SSF and/or an SSF event and this was certainly one of the most unique. ■



Doug & Rose
at the Seattle
Walkabout




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"SSF in Action" continued from page 1 ▼

These potential therapies will not just treat a symptom of the disease but bring the hope of treating the disease as a whole. And as you all know, this will be the first time Sjögren's would have a systemic therapy for the entire disease.

That is why the SSF is leading the charge to ensure that compounds and molecules that have the potential to help Sjögren's patients are being tried through clinical trials. Together, with our pharmaceutical partners, we are proud to say that we are currently looking at over 20 compounds/molecules, all in the hopes of finally providing relief for our Sjögren's patients.

This past November, the SSF Clinical Trials Steering Committee met to discuss where we stand in drug development and review all of the companies that are working in Sjögren's. At this meeting, it was determined that the SSF should continue our work with the US Food and Drug Administration (FDA) by educating them about the need for a Sjögren's therapeutic while also learning about what the SSF could do to facilitate safe, effective, yet speedy clinical trials. Just this spring, SSF staff including Steven Taylor, CEO, and Kathy Hammitt, VP of Medical & Scientific Affairs, have attended FDA trainings and meetings to learn more about patient engagement in clinical trials, recruitment for clinical trials and how to successfully design trials. All of these meetings will help the SSF facilitate discussions with our pharmaceutical partners to ensure their success at looking at their compounds and molecules.

This past March, the SSF held our first meeting between the SSF's medical experts in Sjögren's and our pharmaceutical partners' lead clinical trial staff to discuss barriers to successful clinical trials in Sjögren's, how to define measures of success as well as what we can do collectively with the FDA to ensure that Sjögren's therapeutics are reviewed properly and efficiently.

This same group will meet once again in 2016 to continue our dialogue and make progress in this very area. Together, working with these important partners, we know we can help speed up the development of a therapeutic! And the SSF is surely representing the voice of the Sjögren's patients in every meeting to ensure that these partners understand what it is like to live with Sjögren's, what symptoms are most important to patients and what a patient is willing to do in a clinical trial!

And finally, in addition to convening such important meetings, the SSF is embarking on collecting data from patients about Sjögren's and how it affects their quality of life. Just recently, the SSF mailed out our 2016 patient survey as this is one step in collecting data for our partners as well as for the FDA on the burden of Sjögren's. We encourage all of you to take time to complete this survey as this data will be critical in our next steps of working with all involved in clinical trials!

We encourage you to watch future issues of this newsletter to learn more about our work in clinical trials and hope that you will all consider helping us as we embark on a transformation of Sjögren's that will change the disease for generations to come! ■

This is Sjögren's

April was Sjögren's Awareness Month and this year the SSF used 30 phrases to help close the gap between the reality of living with Sjögren's and the perception that many non-patients may have of the disease, with our *This is Sjögren's!* poster and social media campaign.

To help others visualize and understand what it is like to suffer from Sjögren's, the Foundation posted a different phrase on social media every day in April that reflected what it's like to live with the disease.

Each phrase gave a small glimpse into the life of a Sjögren's patient and by the end of April we hope the 30 phrases showed the complexity and seriousness of the disease. Below are the phrases from this year's April Awareness Campaign.

- 1 Living with Sjögren's means I look healthy on the outside, however my disease is attacking my internal organs and destroying me from the inside out.
- 2 Sjögren's means living with a disease you don't understand and hating the feeling of always being sick.
- 3 Living with Sjögren's is losing your teeth too young. I rarely smile or talk in public since my inability to produce saliva has caused embarrassing tooth decay.
- 4 On the days that I can barely get out of bed because of Sjögren's fatigue, I think, "this is one more day of life that I have lost."
- 5 I'm 23 and struggle to open lids and bottles because of the debilitating pain I experience daily in my hands and wrists. I am so young but I feel weak everyday.
- 6 Sjögren's means living in daily pain but constantly hearing, "you don't look sick."
- 7 Sjögren's means taking it one day at a time.
- 8 I lost my passion for dining out because Sjögren's has affected my ability to chew and digest most foods.
- 9 Living with Sjögren's means you no longer have control over your own body. Fatigue, pain, digestive complications and more – your body can turn on you in the blink of an eye.
- 10 Severe joint and muscle pain has made me unable to help my family with daily household chores and I feel like a burden to the people I love most.



"This is Sjögren's" continued from page 9 ▼

- 11 I want to start a family with my husband but worry about my ability to have a healthy pregnancy.
- 12 Sjögren's means constantly wondering if people think you're lazy or a hypochondriac, because those without the disease cannot truly understand the extreme exhaustion.
- 13 Sjögren's means living in uncertainty. I wonder what will happen if I plan a trip for next month or a year from now. What will my health be like then?
- 14 Living with Sjögren's means putting on a brave face for others and for myself. I will not let this disease rule my life because if I give in to it, then it wins.
- 15 My inability to produce tears causes extreme eye discomfort and makes me prone to chronic eye infections.
- 16 Living with Sjögren's means I have to remind myself daily not to let this disease steal my joy because it's already trying to physically rob me of too much!
- 17 Neuropathy pain, tingling and numbness have taken away my daily mobility.
- 18 Sjögren's means my body fights itself every day.
- 19 Living with Sjögren's means you have to become your own best advocate! No two patients are alike and finding what works for you can be a difficult but necessary process.
- 20 Joint pain, aching muscles, fatigue and inability to sleep are an everyday occurrence.
- 21 Sjögren's has started to attack my lungs and I have difficulty breathing and performing everyday tasks.
- 22 Living with Sjögren's means that I have to make the most of the extra special days where I'm not too tired.
- 23 I worry about my family's financial future because I am unable to work anymore.
- 24 Living with Sjögren's means choosing a medication that will help with my fatigue and joint pain but knowing it will make my eyes drier and more painful.
- 25 Sjögren's means being ignored by the government's health policy and unable to find adequate health and dental insurance.
- 26 Sjögren's means I wake up in the morning with my eyes glued shut.
- 27 Living with Sjögren's completely changes your life. It affects you and your family emotionally, physically and mentally.
- 28 Sjögren's is balancing your life within the limitations the illness poses. Enjoying your good days, managing your bad days and not losing hope!
- 29 This terrible disease sets a "new normal" way of life, which is "not normal" at all.
- 30 I wake up each day hoping a treatment is developed that will allow me to live an active and normal life again. ■

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Ask the Doctor:

Diagnosing Men and Children with Sjögren's

Q *Is there any speculation as to what's driving this big upswing in the diagnosis of men and children with Sjögren's?*

A My gut feeling is that it has to do with the improvements in awareness and medical and dental education in recent years.

The Sjögren's Syndrome Foundation (SSF) has spent years trying to train the physicians and nurse practitioners about how prevalent and serious the disease is. We finally have a celebrity who unfortunately was diagnosed with Sjögren's and although nobody likes to see somebody become ill, it has done a lot to help the entire public realize how serious it is, particularly the idea that people look a lot better than they feel and that it may take years to diagnose it unless you take the symptoms seriously.

I can tell you at the University of Pennsylvania, where I work, the oldest medical school in the United States, we only started giving our first Sjögren's lecture to the first year medical students a few years ago. And that was only after years of me fighting with the curriculum committee to get it included in the rheumatology course for the first year students. So, we've made a lot of progress and I think that's an example of the benefits of all this work.

– Frederick B. Vivino, MD, MS, FACP

Did you know?

The SSF has support groups for men and parents of children living with Sjögren's.

If you are interested in joining either of these support groups, please contact the Foundation at 800-475-6473 or email tms@sjogrens.org to sign-up and receive specialized mailings, focus group information and notices about teleconference support group calls.

To view all SSF Support Groups, please visit www.sjogrens.org. ■



This is Sjögren's...

"I look healthy on the outside, however my disease is attacking my internal organs and destroying me from the inside out"

"Sjögren's has started to attack my lungs and I have difficulty breathing and performing everyday tasks"

"I rarely smile or talk in public since my inability to produce saliva has caused embarrassing tooth decay"

"I lost my passion for dining out because Sjögren's has affected my ability to chew and digest most foods"

"Joint pain, aching muscles and inability to sleep is an everyday occurrence for me"

"My inability to produce tears causes extreme eye discomfort and makes me prone to chronic eye infections"

"This terrible disease sets a 'new normal' way of life, which is 'not normal' at all"

"I wake up each day hoping a treatment is developed that will allow me to live an active and normal life again"

Sjögren's ("SHOW-grins") is a systemic autoimmune disease that affects the entire body. Along with symptoms of extensive dryness, other serious complications include profound fatigue, chronic pain, major organ involvement, neuropathies and lymphomas.

Neurological problems, concentration/memory-loss, dysautonomia, headaches

Dry nose, recurrent sinusitis, nose bleeds

Dry mouth, mouth sores, dental decay, difficulty with chewing, speech, taste and dentures

Fatigue, vasculitis, lymphoma, dry skin, rashes

Arthritis, muscle pain

Peripheral neuropathy, Raynaud's

Dry eyes, corneal ulcerations and infections

Swollen, painful parotid/salivary glands

Difficulty swallowing, heartburn, reflux, esophagitis

Recurrent bronchitis, interstitial lung disease, pneumonia

Abnormal liver function tests, chronic active autoimmune hepatitis, primary biliary cholangitis

Stomach upset, gastroparesis, autoimmune pancreatitis

Irritable bowel, autoimmune gastrointestinal dysmotility

Interstitial cystitis

chronic prostatitis

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in memoriam

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In Memory of Donna Jordon

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Graziano's Lawn Care	Irina Hamlin
Janice and Harry Young	Jerrilyn Smith
Kathy and Larry Moylan	Kelly and Dan Colantuoni
Linda Bennett	Lynn and Michael Brady
Mark and Bonnie Montana	Mark and Kristin Chanatry
Mr. and Mrs. Anthony Chement	Mr. and Mrs. George Murad
Mr. and Mrs. Norm Stamboly	Nancy and Peter Sinram
Nancy Ellinwood	Nancy McNair
Nicholas and Sharon Calogero	Pamela and Kerry Maring
Patrick and Lauren Taylor	Ralph and Danyse Fusco
Richard and Marilyn Joseph	Sandra Mancuso
Sarah Chetnik	Sarah Kunze
Thomas and Jane Hagerty	William and Laureen Hamlin

In Memory of Fritz Marsa

David Marsa

In Memory of Helen Mumphy

Dian Rowan, James Isbell JR and Al Mumphy

In Memory of Herbert Harris

Elaine Harris

In Memory of Jean Piemeisel

Keli Backes

In Memory of Joan Coleman

Bill and April Gott

Donna Pinto

The Callaghan Family

In Memory of Marjorie Karp

Howard and Alice Roth

In Memory of Mark Benjamin Roberts

Giggy Thanheiser

Ron and Carolyn Bernell

In Memory of Patrica Millspaugh

Theresa Millspaugh

In Memory of Patrica and Elfrieda Frank

Diane Stadtmiller and CNY/Syracuse Support Group

In Memory of Robert Green

Elaine and Larry Levin

In Memory of Ruth Wall and Ruth Beddis

Millie Romanelli

In Memory of Toby Douglas Wilt

Steve and Jackie Stuckey

In Memory of Virginia Bobbitt

Brewer and Worley Family's

Ted and Terri Calverley



in honor

In Honor of Anita Reisdorf

Alex Reisdorf

In Honor of Brady Hutchison

BHHS Student Council

In Honor of Deirdre Perl

Elyse & Marc Satalof

In Honor of Demi Cross

Daughters of Penelope Athena Chapter 10

In Honor of Dr. Fred Vivino

Bruce & Judith Brickman

In Honor of Dr. Harry Spiera

Elaine Harris

In Honor of Eileen Guldin

Tina Lea

In Honor of Heather Kaye

Jeanne Himy

In Honor of John Canady aka Polar Bear

Estefania Canady aka Little Mango with Tapatio

In Honor of Nancy Carter and Bill Griffin

Joanne Carter

In Honor of Sara Cashen

Celia Baldwin and Bruce Catania

In Honor of Sherree Meyers

Toni Maher

In Honor of Yvette Gontkovsky

Von Lee



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Do we have your e-mail address?

If you want to receive all the latest updates from the Sjögren's Syndrome Foundation, then you should make sure we have your most up-to-date e-mail address!

Just like all information you give the Foundation, your e-mail address will remain private and will never be given or sold to an outside organization.

Coordinate a **Bold Blue Day** for Sjögren's!

Help raise awareness by coordinating a Bold Blue Day and be entered to win a LIFETIME MEMBERSHIP to the SSF!

By helping to recruit a company, school or small business to host a Bold Blue Day in your honor – you will be entered to win a SSF Lifetime Membership.

It is very simple. Contact the SSF to receive a Bold Blue Day Recruitment Kit. In this kit you will find information about how to recruit a coordinator to host a Bold Blue Day in your honor. Or you can host one yourself at your place of business!

Once you recruit a coordinator or commit to coordinating one yourself, you will send in a commitment form and then the SSF will send off a kit with all the materials they will need to host their Bold Blue Day. And if they host it by June 30th, you will be entered in a drawing to win a lifetime membership.

So, what is Bold Blue Day?

Imagine your colleagues or classmates trading in their tailored slacks or dresses for a day in blue jeans or blue to raise vital funds for Sjögren's research and awareness. Ask your company or a local company or school to consider hosting a dress down day for the SSF.

How does it work?

People who choose to dress down would donate a suggested amount to the SSF, as their fee for participating. Some companies suggest \$5 while others companies/schools let each person decide how much they want to donate.

What if the company doesn't ever allow jeans?

Then just have a Bold Blue Day – where on a certain day everyone chooses to wear his or her favorite Bold Blue outfit! Then collect donations for the SSF that day as well.

To receive more information or have a Bold Blue Day kit sent to you, contact Bess Atkinson at (800) 475-6473 ext. 218, or batkinson@sjogrens.org to receive your Bold Blue Day kit!

**Win a
Lifetime
Membership**



Awareness Never Looked So Good

Awareness comes in many different forms. Sjö your support of the SSF's mission of increasing research, education and awareness of Sjögren's!



Awareness Wristbands

\$15 for a pack of 10 Sjögren's Awareness Wristbands

Wording:

Conquering Sjögren's – www.sjogrens.org



Team Sjögren's T-shirts

(Sizes S-XL) \$18

Whether you run or not, if you are a patient or know someone with this disease, we are all part of Team Sjögren's. Now you can tell the world by wearing this Team Sjögren's t-shirt. On the front of the shirt is the Team Sjögren's logo. The reverse of the shirt has the logo as well as the message:

In honor of the 4,000,000 Americans who have Sjögren's

	Size	Member	Qty.	Total
SSF Tear Drop Pin		\$5		
Awareness Wristband (10 pack)		\$15		
Team Sjögren's T-shirt (Small)		\$18		
Team Sjögren's T-shirt (Medium)		\$18		
Team Sjögren's T-shirt (Large)		\$18		
Team Sjögren's T-shirt (X-Large)		\$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				
Total Amount Due				



SSF Tear Drop Pins

\$5

If you would like to order multiple pins, please call the SSF office at (301) 530-4420 for a discounted shipping rate.

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

Name _____
Address _____
City _____ State _____ Zip _____
Telephone _____ E-Mail _____

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

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Exp. Date _____ Security Code _____ Signature _____





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

2016 SSF Special Event Calendar

SSF events are organized in an effort to increase Sjögren's awareness in local communities, while raising funds to support research and education. They are also an excellent opportunity to connect Sjögren's patients and their families to others living with the disease.



May

- 21 Northeast Ohio Walkabout**
Oak Grove Picnic Area, Brecksville, Ohio
- 23 New York City Sip for Sjögren's**
Rosenthal Pavilion at NYU, New York, New York

June

- 4 Denver Walkabout and Health Fair**
Hudson Gardens, Littleton, Colorado
- 4 Dallas Walkabout and Health Fair**
Parks at Arlington, Arlington, Texas
- 11 Greater Washington Region Walkabout and Health Fair**
Two Democracy Plaza, Bethesda, Maryland

If there is already an event in your area and you would like to get involved, or learn about starting one, please visit www.sjogrens.org or contact us at (301) 530-4420 x207