

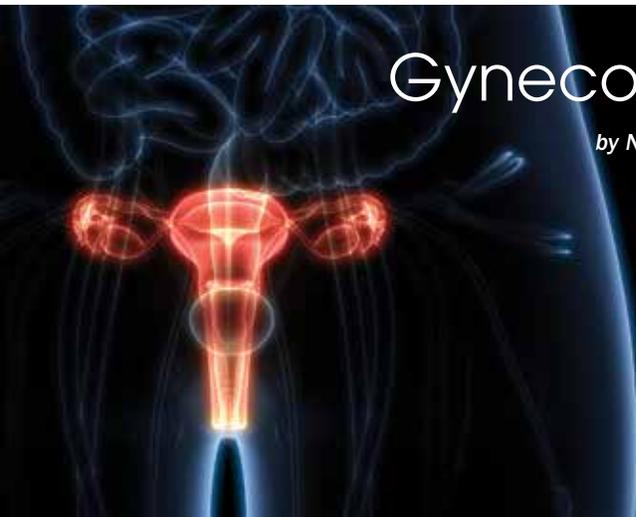


## Finding a Knowledgeable Medical Team 101

### Your medical team

**R**heumatologists have the primary responsibility for managing Sjögren's and usually are the lead of your "medical team." That is why, when seeing a new physician or any of your many specialists, it is important to establish clear guidelines regarding your medical management, which means clarifying what things that doctor will be managing versus what your rheumatologists and/or primary care physician will oversee. All of these healthcare providers make up your "medical team." However, it is crucial that your lead physician has all of the information regarding your diagnoses, treatment plans and prescriptions that your entire medical team is providing. This will help the lead physician better manage your case.

[continued page 2 ▼](#)



## Gynecology | Urology and Sjögren's

by Nancy Carteron, MD, FACR

**S**jögren's is an autoimmune inflammatory disease targeting exocrine glands, including the vestibular glands (vulva). Lymphocytic perivascular infiltration of predominately CD4+ T-helper cells can result in gland destruction and decrease in lubrication by glairy fluid. Vaginal dryness and itching, painful intercourse (dyspareunia) and frequent yeast infections contribute to decrease in quality of life (QOL), including sexual dysfunction.

[continued page 4 ▼](#)



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### “Medical Team 101” *continued from page 1* ▼

It is important to find a doctor who is both a good partner in treating your disease, as well as a good listener. While we know this can be very difficult, it is needed to make sure you are getting the attention your disease requires. One of the best ways to find a physician in your area is to contact your local support group or support phone contact. You can do this by visiting [www.sjogrens.org](http://www.sjogrens.org).

### What medications to ask your doctor about

A Sjögren's patient's treatment path should be decided on a case-by-case basis after the potential benefits and side-effects are weighed by patients and their healthcare providers. Currently, a number of different medications are available that might be used to manage symptoms. However, at the present time there is no single medication that has been conclusively proven to slow the progression of Sjögren's or cure the disease.

Success in using disease-modifying agents to treat closely related disorders like systemic lupus and/or rheumatoid arthritis has led physicians to utilize some of these treatments in Sjögren's as well. The two most popular choices at present include Plaquenil® (hydroxychloroquine)® (hydroxychloroquine) and intravenous rituximab. The decision to prescribe these specific medications is made on a case-by-case basis after careful consideration of potential risks and benefits.

In addition, many patients also are prescribed corticosteroids as well as prescription products to treat their various symptoms including but not limited to dry eyes, dry mouth, gastrointestinal and joint pain symptoms. As the SSF continues to release Sjögren's Clinical Practice Guideline Sheets, be sure to ask your physician about the recommend treatment options listed.

The SSF is dedicated to research into studies that help us better understand the full benefit of these treatments as well as working with companies to help develop new therapeutics that can treat the disease as a whole. The SSF is excited about the current pipeline for treatments that are being investigated by companies, and we continue to be at the forefront at working with and encouraging these companies to move forward.

### What to take to a doctor's appointment

You should be prepared for a new doctor's appointment and know your specific objectives for that visit. If this is your first visit to a doctor, it is essential to give them a copy of all your medical records.

*continued page 4* ▼

The Moisture Seekers® Newsletter is published by the Sjögren's Syndrome Foundation Inc.,  
10701 Parkridge Boulevard, Suite 170, Reston, VA 20191.

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## Dry Brittle Nails and Sjögren's

by Adam I. Rubin, MD

**B**rittle nails are characterized by hardness, peeling, crumbling, fissures, excess longitudinal ridges or lack of flexibility of the finger and toe nails. This sometimes causes pain and interferes with normal daily activities. Although no clear association between Sjögren's and nail disorders has been reported, Sjögren's patients frequently complain of this problem. Many different der-

matologic conditions including some autoimmune disorders, infections, dryness and certain medications can affect the nails.

### Here are few tips to help

- Keep the nails short. This prevents the nails from catching on things or acting as a lever and causing further damage.
- Avoid biting the nails, pulling on them or other tasks that cause repeated trauma.
- Avoid excess contact with water or chemicals (including nail polish remover) which can cause dryness.
- Protect the nails when performing wet work by using rubber gloves and cotton glove liners.
- Avoid excess hand washing and exposure of nails to water.
- Use moisturizer on your nails multiple times per day and reapply the moisturizer after your hands come in contact with water. You can use the same moisturizer used for your dry skin.
- Steer clear of cosmetic products such as artificial nails and nail wraps which can cause damage.
- Avoid nail polish and hardeners. However, if used, leave on as long as possible to help retain moisture.
- After removing polish, moisturize the nails and give them a break from cosmetic products before re-application.
- If your dermatologist approves, try a course of biotin if you have brittle nails.
- If you're diagnosed with a fungal infection of your nails, your dermatologist can discuss a variety of treatment options which are available. ■

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- Judith S., MOISYN User



The natural science behind dry mouth relief.

## “Medical Team 101” continued from page 2 ▼

They will not have time to read it over during your appointment, but they can keep it on file to review after your first visit.

It is also key to show your physician that you want to be an active participant in your care. Make sure to tell them about all of your daily care. Bringing with you a typed list of medications with dosage (including over-the-counter products and supplements) can be helpful.

In addition, keeping a symptoms journal or diet journal can be beneficial to recognize new or worsening symptoms along with foods that can

trigger a flare. The SSF Tracking Your Symptoms Worksheet can be useful tool (see page 5).

And finally, if you have questions for that healthcare provider, bring a list and hand it to them to review. This will help expedite their answers and make sure you get as many answers as possible in one appointment. The healthcare provider can sometimes quickly review a list of questions and tell you which ones are most important to be concerned about and which questions he/she can address at another appointment. Not only will you leave with more answers, but your healthcare provider will appreciate your organization. ■

## “Gynecology | Urinary” continued from page 1 ▼

In addition to vaginal dryness (common), the following occur in Sjögren’s:

- Lichen planus and Lichen sclerosis
- Vaginal yeast infections
- Cervical dysplasia and cancer, especially in setting of HPV (human papilloma virus)
- Interstitial cystitis (~10%) | pelvic pain relieved by voiding; urgency, and frequency
- Endometriosis (4-fold increase) | pelvic pain around menses, excessive bleeding, back pain, painful urination
- Primary ovarian failure (20%) | premature menopause, infertility

## Treatment Tips

- Topical estrogen products (vaginal cream, pill, ring) or systemic Hormone Replacement Therapy (HRT)
- Topical lubricants for dryness (see SSF Product Directory for a list of vaginal moisturizers)
- PAP or visual inspection (if prior hysterectomy) every 1-2 years;| PAP yearly and colposcopy for high risk patients
- Lichen planus or sclerosis may warrant topical steroids
- Antifungals (topical or oral) for frequent or severe vaginal yeast infections

- Refer to Urogynecologist for interstitial cystitis and pelvic pain symptoms ■



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**Clinicians Report®, March 2016 Dry Mouth Survey Results**

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\*Survey of 1168 dentists, March 2016 Clinicians Report®, an independent, non-profit, dental education and product testing foundation. Citation available at [oracoat.com](http://oracoat.com)

<sup>†</sup>These statements have not been evaluated by the Food and Drug Administration. This product is not intended to diagnose, treat, cure or prevent any disease.

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

# Tracking Your Sjögren's Symptoms

## Work Sheet

Date: \_\_\_\_\_

### Additional notes about daily activities/results:

#### Sleeping Notes

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Bed Time: \_\_\_\_\_

Hours of Sleep: \_\_\_\_\_

Times Getting up for Medication: \_\_\_\_\_

#### Activity Notes

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Neurological problems, concentration/memory-loss (brain fog), headaches

Dry eyes, corneal ulcerations, and infections

Dry nose, recurrent sinusitis, nose bleeds

Difficulty swallowing, heartburn, reflux esophagitis

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

Recurrent bronchitis, pneumonia, interstitial lung disease

Dry skin, vasculitis, Raynaud's phenomenon

Arthritis, muscle pain

Stomach upset, gastroparesis, autoimmune pancreatitis

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

Peripheral neuropathy (numbness and tingling in the extremities)

Vaginal dryness, vulvodynia (women)/ chronic prostatitis (men)

**Sjögren's Syndrome Foundation**

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

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



# You Stood Up!

## *This is Sjögren's Photo Booth*

During the 2019 SSF National Patient Conference, the Foundation hosted a fun photo booth to kick off our *Conquering the Complexities of Sjögren's* awareness campaign.

The photo booth was created to build on the SSF's new vision statement: "To create a community where patients, healthcare professionals and researchers come together to conquer the complexities of Sjögren's." This was done to help others visualize the disease because Sjögren's is commonly referred to as an invisible disease. While many patients experience debilitating symptoms, people cannot always physically see them, which can create a misunderstanding about the seriousness of the disease.

The SSF photo booth was one way to help bring our campaign to life and help others better understand the reality of living with the disease. At the booth, patients could pick from one of seven signs that resonated the best with them. Each sign included one of the following messages:

- This is Sjögren's
- 4 million Americans suffer from Sjögren's #ThisIsSjögrens
- I wake up everyday hoping a treatment is developed #ThisIsSjögrens
- You can't see the profound fatigue #ThisIsSjögrens
- My body is attacking itself #ThisIsSjögrens
- #ThisIsSjögrens
- I support all Sjögren's patients  
This is Sjögren's

Thank you to everyone who participated in our photo booth for standing up and sharing your story. We hope these pictures inspire you, like they inspired us. Learn more about this campaign by visiting [www.sjogrens.org](http://www.sjogrens.org). ■

*Keep an eye out for more information from the 2019 SSF National Patient Conference in next month's issues of The Moisture Seekers.*







# Clinical News



## High Percentage of Fibromyalgia Patients Test Positive for Sjögren's Autoantibodies

A recent analysis found that nearly one-third of fibromyalgia patients tested positive for a Sjögren's biomarker, and of that group, the majority tested positive for at least one tissue specific autoantibody. Fibromyalgia patients (n=185) were tested for either the classic autoantibodies (SS-A/Ro, SS-B/La, ANA and RF) and early tissue specific autoantibodies (SP-1, CA6, PSP) (n=151) or just the early tissue specific autoantibodies (n=34). In the group of 151 patients, 49 tested positive for Sjögren's autoantibodies, with four testing positive for the classic Sjögren's markers, 40 testing positive for early Sjögren's markers and five testing positive for both the early and classic markers. In the group of 34, 10 patients tested positive for early Sjögren's markers. Across both groups, 55 patients were positive for the early markers (SP-1, CA6, PSP). Specifically, 83.6% were positive for SP-1, 12.7% were positive for CA6 and 20% were positive for PSP. Notably, 14.5% of these patients were positive for more than one early marker.

### Citation

Applbaum E & Lichtbroun A. Novel Sjögren's autoantibodies found in fibromyalgia patients with sicca and/or xerostomia. *Autoimmun Rev.* 2018 Dec 17. pii: S1568-9972(18)30293-3. doi: 10.1016/j.autrev.2018.09.004. [Epub ahead of print].

## Lymphoma Diagnosis Precedes Sjögren's Diagnosis in Large Percentage of Patients

Investigators found that Sjögren's remains undiagnosed until after lymphoma diagnosis in a substantial number of patients, particularly men. Being male (39% vs 10%, p=0.006), enlarged lymph nodes during the disease (61% vs 27%, p=0.01), mucosa-associated lymphoid tissue (MALT) lymphoma (50% vs 22%, p=0.02), and salivary gland lymphoma (61% vs 26%, p=0.006) were more common in patients with a pre-existing lymphoma at Sjögren's diagnosis compared to those without. Sjögren's patients with a diagnosis of malignant lymphoma (n=224) before or after their Sjögren's diagnosis were identified by linking the Swedish National Patient Register (1964-2007) with the Cancer Register (1990-2007).

### Citation

Vasaitis L. Comparison of patients with and without pre-existing lymphoma at diagnosis of primary Sjögren's syndrome. *Scand J Rheumatol.* 2018 Nov 13:1-6. doi: 10.1080/03009742.2018.1523456. [Epub ahead of print]

## Efficacy of Xerostom<sup>®</sup> on Dry Mouth in Sjögren's Patients

Xerostom<sup>®</sup> mouthwash and toothpaste may help to alleviate side effects of xerostomia in Sjögren's patients and improve quality of life, but researchers feel that additional efficacy studies with larger groups of patients are needed. For this study, Sjögren's patients were placed in test

**“Clinical News”** *continued from page 9* ▼

(n=13) and control (n=11) groups and used the given products three times per day for 28 days. Visual analogue scores for xerostomia and the Oral Health Impact Profile-14 (OHIP-14) were used at baseline and after treatment. Importantly, significant improvements in OHIP-14 were noted in the treatment group.

**Citation**

Lopez-Pintor RM et al. Effects of Xerostom<sup>®</sup> products on xerostomia in primary Sjögren’s syndrome: a randomised clinical trial. *Oral Dis.* 2018 Dec 17. doi: 10.1111/odi.13019. [Epub ahead of print]

**Unexplained Cough and Sjögren’s**

The purpose of this study was to evaluate patients with an unexplained cough for undiagnosed Sjögren’s. A total of 24 patients were identified from a single location, 22 of which agreed to participate in the evaluation. Included patients pre-

sented with an unexplained cough and concomitant dry eye and were evaluated by pulmonologists, rheumatologists and ophthalmologists specializing in autoimmune disease. Patients were asked to complete a variety of tests, including the Leicester Cough Questionnaire, spirometry, antibody testing and a series of ophthalmologic exams. At four years, a follow-up questionnaire was administered via telephone. Of the 22 patients involved, eight were diagnosed with Sjögren’s. At follow-up, 37% of the Sjögren’s patients reported that their cough improved while 64% of patients without Sjögren’s noted improvement. This finding supports the consideration for adding an unexplained cough to the diagnostic algorithm for Sjögren’s. ■

**Citations**

Koslow M, Kivity S, Vishnevskia-Dai V, Ben-Dov I. Unexplained cough: it is time to rule out Sjögren’s syndrome. *Clinical Rheumatol.* 2018. doi/10.1007/s10067-018-3987-4



# Learn more about Clinical Trials in Sjögren’s!

The SSF now has a section on its website devoted to clinical trials in Sjögren’s. Visit <http://www.sjogrens.org/home/about-sjogrens/clinical-trials-whatsinvolved>.

**Links on this page take you to:**

- An article by Theresa Lawrence Ford, MD, the SSF Medical and Scientific Advisory Board Chair and Chair of the SSF Clinical Trials Consortium
- A list of clinical trials in Sjögren’s that are currently recruiting Sjögren’s patients

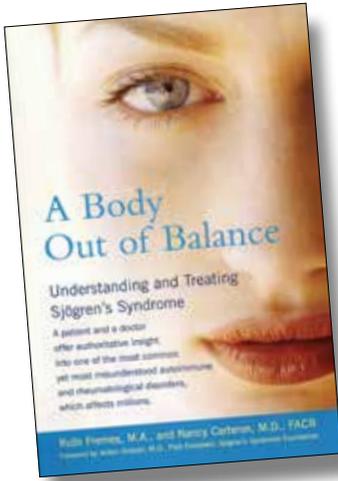




**E**xploring Sjögren's is our new YouTube video series that explores Sjögren's and the daily lives of our patients. We have created six episodes for season one that discuss Sjögren's as a disease and the work being done to help conquer the complexities of Sjögren's. The first episode premiered on April 30<sup>th</sup>, with a new episode airing each following Monday. Two of the episodes specifically focus on living with Sjögren's and how our patients cope. Visit [www.sjogrens.org](http://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! ■





## A Body Out of Balance: Understanding and Treating Sjögren's Syndrome

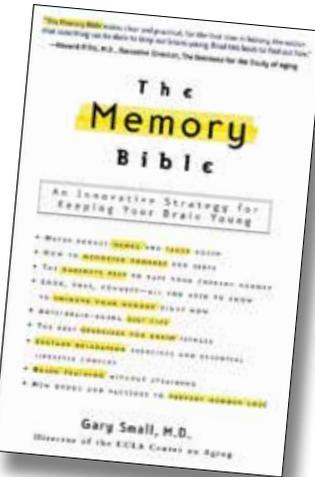
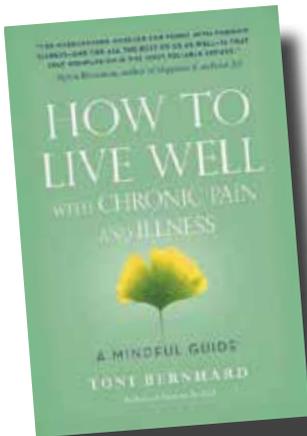
by Ruth Fremes, MA and Nancy Carteron, MD, FACR

One of the most common yet underrecognized autoimmune and rheumatological disorders, Sjögren's, affects more people than rheumatoid arthritis and lupus combined. *A Body Out of Balance* provides a comprehensive guide to a wide array of symptoms, traditional and complementary treatments, and invaluable coping methods, so patients may devise a personal treatment plan.

Cowritten by a woman living with the disease and by a physician who has treated Sjögren's patients, this indispensable resource will enhance awareness and demystify this often-misunderstood disorder.

Member Price: \$13

Non-Member Price: \$16



## The Memory Bible: An Innovative Strategy for Keeping Your Brain Young

by Gary Small, MD

We all forget things sometimes - our keys, a phone number, the reason we went to the market - and our forgetfulness only increases with age. According to Dr. Gary Small, director of the UCLA Center on Aging, we can easily eliminate much of this problem with his innovative memory exercises and brain fitness program. This program has helped thousands of people improve their ability to remember every day issues like where the car is parked, as well as the more important ability to think fast and maintain a healthy brain for life.

Member Price: \$13

Non-Member Price: \$16

## How to Live Well with Chronic Pain and Illness - A Mindful Guide

by Toni Bernhard

Chronic illness creates many challenges, from career crises and relationship issues to struggles with self-blame, personal identity, and isolation. Toni Bernhard addresses these challenges and many more, using practical examples to illustrate how mindfulness, equanimity, and compassion can help readers make peace with a life turned upside down.

Member Price: \$14

Non-Member Price: \$17

This book can be purchased using the order form below, online at [www.sjogrens.org](http://www.sjogrens.org) or by contacting the Sjögren's Syndrome Foundation office at 800-475-6473.

	Non-Member Price	Member Price	Qty	Amount
<b>A Body Out of Balance</b> by Ruth Fremes, MA and Nancy Carteron, MD, FACR	\$16.00	\$13.00		
<b>The Memory Bible</b> by Gary Small, MD	\$16.00	\$13.00		
<b>How to Live Well</b> by Toni Bernhard	\$17.00	\$14.00		
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Sjögren's Syndrome Foundation  
*Legacy of Hope*



If you would like to receive information on how you can *Leave a Legacy* to support the Sjögren's Syndrome Foundation's critical research initiatives or to support one of our many other programs, please contact Steven Taylor at 800-475-6473.

*Leave A Legacy – Remember Us in Your Will*

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



# Walk for Sjögren's: Celebrating our Strength

The Walk for Sjögren's is a national fundraising program designed to raise awareness and crucial funds to support Sjögren's research and education. This non-competitive family fun event provides an opportunity for participants to learn more about Sjögren's, connect with area health-care providers and others living with Sjögren's.

## Circle of Strength

We are proud to celebrate and recognize the personal strength of Sjögren's patients and those that support them every day! That is why we host "Circle of Strength" ceremonies and activities at each Walk, to recognize people who give Sjögren's patients their strength and determination to continue to fight each day!

Each Circle of Strength member and the Sjögren's patient they support will receive special recognition and a Walk wristband to proudly identify themselves as a champion for Sjögren's!



## Earn Great SSF Prizes!

Raise Funds – You can make a difference – reach out to your friends, family and companies in your local community and tell them about Sjögren's. Ask for donations to support your Walk efforts. If you raise funds, you can earn the following:

\$40 – \$99	Official Walk for Sjögren's T-shirt
\$100 – \$299	Official Walk for Sjögren's T-shirt and Sjögren's Star Medal
\$300 – \$499	Official Walk for Sjögren's T-shirt, Medal and Hat
\$500 +	Official Walk for Sjögren's T-shirt, Medal, Hat and Sport Duffle Bag



# SSF EVENT CALENDAR

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

## Join in the fun! 2019 SSF Special Event Calendar

The SSF is very excited for all of our events coming this Spring. Look at our special event calendar below to see if there is a Walk for Sjögren's or other SSF event coming to your area. Register today!

MAY

### DC Metro Area Walk for Sjögren's

Saturday, May 18, 2019

SSF National Office, Parkridge Center, Reston, VA

JUNE

### Denver Walk for Sjögren's

Saturday, June 8, 2019

The Hudson Gardens

### Dallas Walk for Sjögren's

Saturday, June 22, 2019

The Parks at Arlington

## Start an event in your area!

With the Spring 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 Walk for Sjögren's or other SSF event 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](mailto:jlevy@sjogrens.org) to learn how you can get involved.





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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*

# Sjögren's Fast Facts

- Sjögren's is pronounced "SHOW-grins".
- The primary symptoms of Sjögren's are dry eyes, dry mouth, fatigue and joint pain, but the disease is systemic, affecting the entire body.
- Sjögren's is one of the most prevalent autoimmune disorders, striking as many as 4,000,000 Americans.
- Early diagnosis and proper treatment may prevent serious complications and greatly improve the quality of life for individuals living with Sjögren's.
- It takes an average of 2.8 years to receive a proper diagnosis.
- The SSF is the only national organization focused on increasing research, education and awareness for Sjögren's.

**Sjögren's 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.**

