

CONQUERING Sjögren's

September/October 2021

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CONQUERING Sjögren's

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A photograph of a woman and a man riding bicycles on a beach. The woman is in the foreground, smiling, wearing a light pink cardigan over a striped shirt. The man is in the background, also smiling, wearing a blue jacket over a white shirt. They are riding on a sandy beach with the ocean in the background.

Back to Basics

In the busy day-to-day life, it is often easy to forget about fundamentals in managing your health. As we enter fall, the Sjögren's Foundation thought we would use this time to write about "back to basics" in terms of managing your Sjögren's health. In this issue, we are focusing on the fundamental needed to make you, your own best advocate!

Your Medical Team

As most patients know, rheumatologists 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 the prescriptions that your entire medical team is providing. This will help the lead physician better manage your care.

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. Ask if you're able to have your records sent before your visit, or bring

them with you. 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 or diet journal can be beneficial to recognize new or worsening symptoms, along with foods that can trigger a flare. See our "Tracking Your Sjögren's Symptoms" worksheet on page 13. You can also ask your doctor if they're interested in receiving free professional educational materials regarding Sjögren's treatment from the Foundation. If they're interested, let them know they can contact the Foundation to have the materials mailed to their office.

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. Learn more Sjögren's fundamentals by visiting www.sjogrens.org. ■

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Common Medications Used to Treat Sjögren's

by Donald Thomas, MD, FACP, FACR, Sjögren's Foundation Board Chair

There are many over-the-counter and prescription drugs that can help Sjögren's patients feel better. I will not discuss the numerous over-the-counter medications used for pain and moisture nor the prescription pain medications. However, I will concentrate on the oral prescription drugs used to increase moisture and calm the immune system. The following descriptions are brief. For complete information, ask your doctor or pharmacist.

Salagen® (pilocarpine) and Evxac® (cevimeline)

These two drugs are approved by the U.S. Food and Drug Administration (FDA) to increase saliva in the treatment of dry mouth. They are prescribed when other dry mouth treatments (such as xylitol gum, xylitol lozenges, and artificial saliva) do not provide enough mouth moisture. Although FDA-approved to treat dry mouth, they also improve other dry areas such as the eyes, nasal passages, and skin in many people. They can help reduce cough due to a dry windpipe from Sjögren's and improve heartburn (gastroesophageal reflux) by increasing saliva flow down the esophagus. The most common side effect is excessive sweating. A downside of these drugs is that they need to be taken three to four times a day for full effectiveness.

Plaquenil® (hydroxychloroquine, HCQ)

Since Sjögren's is an autoimmune disease where the immune system is overactive, medications that calm the immune system are sometimes needed. Plaquenil is one of the safest drugs used to treat Sjögren's. It can especially be helpful for Sjögren's arthritis, fatigue, and rashes. It is important to get two eye tests done yearly to ensure that it doesn't cause eye problems. It is best to get both a VF (visual field) 10-2 and an SD-OCT (spectral-domain optical coherence tomography) test done yearly. If you are of Asian ancestry, you need

Treatments and Medications Used

Today, there is no cure for Sjögren's, so patients must resort to using a multitude of treatments to help them cope with various symptoms. On average, Sjögren's patients said they use nearly nine (8.8 mean) medications and treatments to help with their Sjögren's symptoms, with an average of over four prescription medications or treatments. Patients living with Sjögren's for a longer period of time (5-9 years) reported using slightly more treatments than patients living with Sjögren's for a shorter period of time (0-4 years) (8.7 vs. 8.2 mean).

Virtually all patients (97%) reported using eye drops, artificial tears, or non-prescription eye ointments for treatment at some time, while a majority said they have used ibuprofen or other anti-inflammatory agents (81%), disease-modifying anti-rheumatic drugs (DMARDs) (67%) and OTC or prescription fluoride (67%), or corticosteroids (62%) for treatment. Younger patients (60 and under) were significantly more likely than patients over 60 to have used health food supplements/ remedies (90% vs. 87%), exercise (88% vs. 83%), and alternative therapies (70% vs. 58%) to treat their Sjögren's.



three tests annually (the preceding two tests plus a VF 24-2 or a VF 30-2). If your doctor cannot do an SD-OCT or VF 10-2, it is OK to substitute one of these with a fundus autofluorescence (FAF) or a multifocal

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Sjögren's Top 5

What Your Rheumatologist Should Be Monitoring For

by Daniel J. Wallace, MD

1. Is there evidence for extraglandular Sjögren's?

Some people with extraglandular Sjögren's may have interstitial lung disease, renal tubular acidosis, swollen lymph glands, or inflammatory scarring of the bile ducts (biliary cirrhosis). Being identified with extraglandular Sjögren's usually warrants systemic immune suppressive therapy with agents such as azathioprine, methotrexate, cyclophosphamide or rituximab. The treating physician should use their tools to screen for the spread of Sjögren's to new areas with imaging or laboratory testing, which allows one to be proactive and treat the disease early.

2. Screening for lymphoma

Over a 15-20 year period of observation, 8-15% of Sjögren's patients develop a lymphoma. Screening for symptoms of early lymphoma include asking a patient about swollen glands, fevers, weight loss and new onset of fatigue. A physical examination can detect lymph nodes, evidence for a "wasted"

appearance, or an enlarged spleen. I perform a serum protein electrophoresis (a \$30 blood test) on my Sjögren's patients every 6 months. Often, early lymphomas can be detected with the development of an extra protein on this determination, which is known as a "MGUS" or monoclonal gammopathy of uncertain significance. Most Sjögren's associated lymphomas are of a specific variety known as "MALT" that, if identified early, responds well to treatment.

3. Looking for overlapping Sjögren's

Sjögren's patients can have features of other autoimmune conditions such as rheumatoid arthritis, inflammatory myositis, biliary cirrhosis, scleroderma, Hashimoto's thyroiditis or lupus, while still being "mostly" Sjögren's. These features may warrant certain anti-inflammatory interventions. This would include corticosteroids for inflamed muscles, drugs that promote more oxygen to dilate the vessels of the hands for individuals with Raynaud's (often seen with scleroderma or lupus),

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"Common Medications" *continued from page 5* ▼

electroretinography (mfERG) test.¹ Make sure to show your eye doctor this paragraph to ensure you are getting the correct tests performed (you should be your own best health advocate to ensure you are getting the proper exams).

Immunosuppressant drugs

These are stronger than Plaquenil and decrease (or suppress) immune system activity rather than just calm it down. They include methotrexate, mycophenolate mofetil, azathioprine, and cyclophosphamide. These are the most common immunosuppressants used for Sjögren's. Since they suppress the immune system, they can increase the risk of developing infections, so they should not be used during any periods of active infection. They often require blood counts and liver enzymes to be measured regularly to ensure that they are not causing any problems in the bone marrow (where blood cells are made) and liver. Steroids and B-cell depletors are also immunosuppressants and are discussed below.

Corticosteroids (steroids)

Steroids such as prednisone and Medrol® (methylprednisolone) also suppress the immune system. Steroids work much faster than the preceding drugs. Unfortunately, most people get side effects from them. We like to use the lowest doses possible and get our patients off steroids as soon as possible. Common side effects include weight gain, broken bones from osteoporosis, worsening diabetes, moodiness, cataracts, and insomnia.

B-cell depletors

A type of white blood cell called B-cells is overactive in Sjögren's. Some patients may benefit by using medications that calm down these B-cells. You may see this referred to as "B-cell depletion" when reading Sjögren's medical literature. The two drugs used are Rituxan® (rituximab) and Benlysta® (belimumab). They are both liquids requiring infusion into a vein (IV) or self-injection under the skin (SQ). ■

References

- 1 Marmor MF, et al. Recommendations on screening for chloroquine and hydroxychloroquine retinopathy (2016 revision). *Ophthalmology* 2016;123(6):1386.



How to Talk with Your Family about Sjögren's

by Sarah Schafer, MD, and Sjögren's Patient
Special acknowledgment to Teri Rumpf, PhD and
Julia Oleinik, RN for their contributions to this article.
This article was first published in Foundation's The
Moisture Seekers newsletter.

There is a growing body of evidence that rich social support networks are important to overall health, immune function and healing. They improve quality of life and facilitate coping with chronic illness. Conversely, negative social interactions create a stress response that have the opposite effect. Support from family members and close friends can be one of the most important resources for you to draw on when dealing with Sjögren's. Skillful communication about your illness is key to nourishing the relationships that matter the most to you. This article only attempts to skim the surface of this complex topic.

Three characteristics of Sjögren's create particular communication challenges.

Untimely

While we're seeing Sjögren's diagnosed in younger patients, many people are being diagnosed in the prime of life, when family responsibilities and careers are in full swing. While some are lucky enough to have mild symptoms, the majority of patients experience flu-like fatigue, pain and brain fog that demand a new, strict energy budget. Jobs may be lost, or hours cut. Frequent medical and dental visits and costly products such as artificial tears strain both schedules and finances. Family dynamics are rearranged by the illness, causing stress, especially if there is little support or strong disagreement about how to meet the new challenge. Single people who become ill may feel particularly vulnerable and alone, wondering how will they ever manage.

Uncertain

Early on, many patients have a hard time accepting that this disease will be a lifelong challenge. The sense of loss and fear of long-term illness can be profound for both patients and loved ones. Symptoms may wax and wane for no obvious reason, although they rarely disappear. This can add to confusion and denial. The initial focus of patients and family members is often "how can we fix this?" Denial can make adjustment to a new normal even more protracted. Sometimes denial persists for years, until it becomes clear that medications and other interventions cannot bring back "life as usual."

Invisible

Sjögren's patients tend to look well most of the time, even when feeling quite ill. The outward appearance of normalcy can make it hard for others to appreciate the severity of your illness. This is made worse when doctors don't address symptoms such as fatigue and pain that make it a struggle to get through the day. Even though Sjögren's is quite common, most doctors are not trained to recognize even typical systemic symptoms and tend to focus on dryness. Some medical websites reinforce this incorrect notion that Sjögren's is mostly about dryness, rather than a serious systemic disease. When presented with this inaccurate portrayal of the disease, family members and patients become understandably confused. Healthcare providers frequently minimize life-changing symptoms or even become dismissive, leaving the patient feeling powerless or invisible. When family members also fail to understand the

“Talking to Family” *continued from page 7* ▼

devastating impact that Sjögren’s can have, the emotional turmoil can be overwhelming.

As a result of widespread misinformation, patients find themselves needing to become “experts” in their disease. Backed with up-to-date knowledge, it is possible to advocate for care and educate healthcare providers when needed. An excellent, reliable source of information can be found at the Sjögren’s Foundation website, www.sjogrens.org. Encourage family members to read it too. It’s really good. It might seem overwhelming and a bit disheartening that you need to learn so much about Sjögren’s, especially early after diagnosis. However, educating yourself will provide essential tools for communication with family, friends and doctors.

Communication with family members

Spouses/partners and other family members suffer grief and loss too. It is important to acknowledge this. Open the discussion early. Ask about their fears regarding the impact of your illness and the uncertainty it creates. Be prepared to revisit this conversation several times. Both you and your significant others will go through loss and grief, although the timing and process is different for everyone.

Despite your best efforts toward clear, empathic

communication with your family, some people may respond with judgment and blame. This often comes as a painful surprise, especially at a time when support feels most needed. Relationship upheaval is typical for people with serious illness. It is important not to blame yourself for the illness, but to develop good self-care with an attitude of deep kindness toward yourself. Attempt to keep lines of positive communication open but set boundaries to protect yourself from negativity.

While unsupportive family members may eventually shift their stance, the approach of trying to educate them repeatedly after several unsuccessful attempts will only result in unnecessary pain. Just having one or two people in your life who truly “get it” can be enough. Recognize that some people may be good at practical support, but unavailable emotionally. The reverse may also occur.

Practical support tips

Practical support, especially from family members, can go a long way in helping you manage your health. Most Sjögren’s patients can participate in a number of activities, especially when family members take over tasks that are particularly challenging for you to do. It takes some trial and error to learn what you can do without compromising your health. Being a

continued next page ►

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good observer of your unique patterns will help you plan the types of activities and pacing that works for you. Even with careful planning, the unpredictable nature of Sjögren's will sometimes knock you down when you don't expect it. It is always good to have a backup plan ready- and soup in your freezer!

Many people are happy to help but might not ask or could assume you are doing fine if you have a part-

ner or other adults in the home. It can be difficult to ask for help, especially if you are the "can do" type of person. It is good to remember that providing support can be beneficial to both givers and recipients. Sometimes support arrives from people you don't expect to come through, while those you think of as close friends or family may not provide support.

Examples of useful responses and communication tools

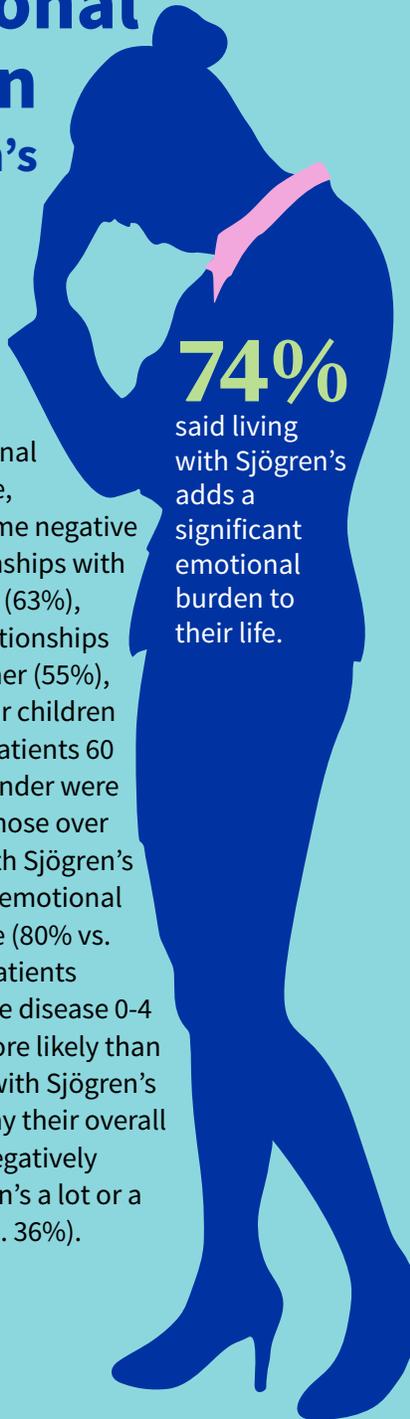
- If you are unsure of a person's awareness or interest, you can ask: "I'm not sure how much you know about Sjögren's- do you want to know more about what's really going on with me?"
- When someone asks if they can help, try to be ready with a specific request such as stopping by with dinner, running errands, childcare, etc. If you are caught off guard, a good response might be: "Can I get back to you? I could really use help, but I am feeling too overwhelmed to think about it right now."
- State your limitations and needs, clearly and without apology. If you are too tired to cook, shop or clean, state that and request specific help from household members. For example: "I'm not well enough to do housework right now. Could you please vacuum and clean the bathrooms once a week?" as opposed to the vaguer, "I need more help with the cleaning."
- Many people go into advice giving mode, offering instant remedies such as the latest diet, various medical regimens, healers etc. This may be motivated by a true desire to help, or it can be a way to distance themselves from your experience. Some possible responses: "Thanks for your concern, I am working closely with my doctor on this," or "I appreciate your concern. I need to do this in my own way and in my own time. It would be great if you could support my choices."
- Dealing with insensitive and judgmental comments, especially if repeated, is difficult. One strategy is to provide the speaker with an opportunity to consider the hurtfulness of their comments, by asking: "Let me understand. Are you saying (repeat hurtful comment)?" The person may back pedal or give their comment more thought. This does not always work.
- If responses to hurtful comments don't work, set boundaries: "It hurts to hear you say this. I am doing my best. Please keep these comments to yourself."

It can be especially difficult when someone close to you clearly does not understand your illness or

Emotional Burden of Sjögren's

Three-in-four patients (74%) said living with Sjögren's adds a significant emotional burden to their life, having at least some negative impact on relationships with friends and family (63%), sex life (59%), relationships with spouse/partner (55%), and caring for their children (19%). Sjögren's patients 60 years of age and under were more likely than those over 60 to say living with Sjögren's adds a significant emotional burden to their life (80% vs. 71%). Sjögren's patients diagnosed with the disease 0-4 years ago were more likely than those diagnosed with Sjögren's 5-9 years ago to say their overall mood has been negatively affected by Sjögren's a lot or a great deal (42% vs. 36%).

74% said living with Sjögren's adds a significant emotional burden to their life.



You Stood Up!

Walk for Sjögren's Participants Show How Celebrating Our Strength Can Make a Difference

Walk for Sjögren's is a national awareness and fundraising program that takes place across the country every fall and spring. It's an amazing series of events where patients build community together, interact with Sjögren's experts, and raise funds for important initiatives. As the Sjögren's Foundation starts planning for the fall Walk for Sjögren's events, we want to thank everyone who stepped up by supporting our Walks this past year!

To ensure everyone's health and safety with the COVID-19 outbreak, the Foundation moved all of our Walks last year to virtual events. Our Sjögren's community really *Sjö-ed Up* by participating in one of our regional virtual Walks for Sjögren's. The events were intimate and very rewarding bringing the Sjögren's community together in the best way possible. It was exciting to see the increase in participation by holding the walks virtually, allowing the walk participants to invite their friends and family to join them at the event regardless of where they were located.



Celebrating our Resiliency During These Challenging Times!

Our success is a direct result from you, our amazing volunteers and supporters. Thank you for being a part of our journey to conquer the complexities of Sjögren's, especially in these challenging times. The funds you raised allow us to continue providing programs and services, advocating for patients and funding research for the four million people living with Sjögren's. Together we are working to develop new therapeutics to treat this debilitating disease and transform the future for all patients. Thanks to your support, we raised \$245,000 from Foundation Walk Events!

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October Virtual Event Calendar

All fall Foundation Walk events will continue to be held virtually. Patients can now sign-up for a fall virtual Walk and celebrate your circle of strength by including your family and friends. We hope that you will join us and use your voice to help raise awareness and funds in your community.

New England Walk for Sjögren's
(CT, MA, ME, NH, RI, VT)
Saturday, October 2, 2021

California Walk for Sjögren's
Saturday, October 2, 2021

New York State Walk for Sjögren's
Saturday, October 23, 2021

Pacific Northwest Walk for Sjögren's
(WA, OR, ID)
Saturday, October 23, 2021

events.sjogrens.org

Thank you for Supporting a 2020-2021 Walk for Sjögren's

We are truly grateful to ALL of our Walk for Sjögren's Sponsors! These sponsors demonstrated a commitment to supporting local Sjögren's communities across the country, while also generously impacting the overall success of the Walks.

Below is a list of our Presenting and Major level Walk Sponsors:

New England Area Walk for Sjögren's

The Taylor Family • The Caron Family in Memory of Karen T. Caron

California Walk for Sjögren's

Eye Eco • The Sjögren's Clinic at UC Berkeley • Kantor & Kantor • Susan Barajas • Intrepid Eye Society

New York Walk for Sjögren's

Casale Rent-All • The Herder Family

Pacific Northwest

Janice & Robert Schock • Kantor & Kantor

Gabby's Walk for Sjögren's

The Parker Family • Performance Painting Contractors

Southwest Walk for Sjögren's

Spinato's Pizzeria & Family Kitchen • Primus Pharmaceuticals • Mayo Clinic • Doctor My Eyes • Gilbert Center for Family Medicine • The Gales Family

Florida & Georgia Walk for Sjögren's

Oil Solutions Group • The Wixson Family • Fred R. Fernandez & Irma R. Rodriguez Foundation • North Georgia Rheumatology

Mid Atlantic Walk for Sjögren's

Arthritis and Rheumatism Associates, P.C. • Southern Eye Care Associates • Johns Hopkins Jerome L. Greene Sjögren's Center

Colorado Walk for Sjögren's

Colorado Eye Consultants • Colorado Center for Arthritis & Osteoporosis • 58 Dental • Jim & Joan Walsh Foundation

Philadelphia Tri-State Walk for Sjögren's

The latesta Family • Leventhal Sutton & Gornstein • The Metal Prep Company • St. Luke United Methodist Church • Bassett Home Furnishings • Penn Medicine • Scheie Eye Institute • Penn Sjögren's Center & Division of Rheumatology • The Vivino Family

Texas Virtual Walk for Sjögren's

The Bromberg Family • The Rubenstein Family • Stacie & James Thomas • Fagadau, Hawk & Swanson, MD

We also want to acknowledge our incredible Sjögren's Walk Stars. These are our individual fundraisers who set the goal and made the commitment to raise \$1,000 or more on their Walk page. They made an impact on the lives of Sjögren's patients by raising vital funds for the Foundation initiatives. Please visit the link below to view the list of our Sjögren's Stars. ■

<https://www.sjogrens.org/get-involved/find-an-event/walk-for-sjogrens/sjogrens-stars>



“Talking to Family” *continued from page 9* ▼

support your efforts to take care of yourself. Relationships that were difficult to begin with may become even more painful. Some relationships do not survive the stress of chronic illness. Family members have a limited capacity for emotional or practical support. If you don't feel supported by those closest to you, being creative about organizing your life, getting support from others, and setting excellent boundaries may be your best strategy. If you are dealing with a

close relationship that seems to be faltering, it can be helpful to seek professional support from someone knowledgeable about chronic disease.

Most importantly, know that the news here is not all bad. Many people do step up to the plate, although they may need prompting. Be patient if they are trying to understand; it takes time to adjust and to learn about Sjögren's. ■

“Walk for Sjögren's” *continued from page 10* ▼

A look back at the Virtual Walk for Sjögren's events:

Fall 2020 Walks

- New England Walk for Sjögren's
- California Walk for Sjögren's
- New York State Walk for Sjögren's
- Pacific Northwest Walk for Sjögren's
- Gabby's Walk for Sjögren's

Spring 2021 Walks

- Southwest Virtual Walk for Sjögren's
- Florida & Georgia Virtual Walk for Sjögren's
- Mid-Atlantic Walk for Sjögren's
- Philadelphia Tri-State Walk for Sjögren's
- Colorado Walk for Sjögren's
- Texas Walk for Sjögren's

Thank you to everyone who joined and helped us increase awareness by being a part of one of our events. ■

**“Sjögren's Top 5”** *continued from page 6* ▼

approaches that halt the development of erosions (bone destruction) with rheumatoid arthritis (e.g., anti-TNFs), ursodiol for biliary cirrhosis, antimalarials for subacute cutaneous lupus rashes in anti-SSA positive patients or thyroid. Identification of an autoimmune overlap can often explain symptoms that may be profound but are not a part of Sjögren's.

4. Don't unnecessarily treat Sjögren's for symptoms that are not related

Sjögren's patients may have high blood pressure, depression and diabetes, as does 25% of the United States. Medications given for these conditions can make dry eye or dry mouth symptoms more severe. Treating such patients with anti-inflammatory medications or diuretics (water pills) is not advisable. Before altering one's Sjögren's medications or their environment, the physician should strive to rule out co-morbidities or co-existing circumstances that may

seemingly worsen Sjögren's symptoms.

5. Screening for head and neck emergencies or areas associated with non-extraglandular Sjögren's

Patients with Sjögren's whose disease is confined to the salivary glands, eye, head and neck areas occasionally develop complications, which may mandate emergent treatment. These include acute inflammation of the parotid gland (parotitis, or Mikulicz's syndrome, with either a stone or focus of inflammation, treated with corticosteroids), corneal ulcerations, blocked salivary ducts (affecting the mouth), and dental caries or abscesses. Most Sjögren's patients see a dentist 2-3 times a year to get their teeth cleaned and are often frequent return visitors to their otolaryngologist (ENT doctor).

In summary, screening for the five features reviewed above, can prevent or promote early treatment of the overwhelming complications with Sjögren's. ■

Team Sjögren's Goes Turkey!

This Thanksgiving, we hope you will consider participating in Team Sjögren's Goes Turkey!

What a great way to start your day of giving thanks—representing Team Sjögren's in your community with our special Turkey Trot T-shirt design. By purchasing a T-shirt or kit and walking or running in your area, you are increasing awareness for Sjögren's and helping raise crucial funds for Sjögren's research.

Even if there's not an official Turkey Trot race in your area this year, consider creating your own! Ask family and friends to join you for a morning walk in your neighborhood on Thanksgiving morning while wearing your Team Sjögren's T-shirts!



Kits will ship November 1st

A Single Kit Includes: \$35

- Team Sjögren's Cotton T-shirt, with new Turkey Trot logo on the front!
- New Sjögren's Foundation Face Mask
- New Certificate of Participation and Medal
- 3 "What is Sjögren's?" Brochures



	Qty.	Size: S-2XL	Total
Single Person Team Sjögren's Turkey Trot Kit	\$35 ea.		
Additional Team Sjögren's Turkey Trot T-shirt	\$20 ea.		
Shipping and Handling: U.S. Mail: \$7 for first item + \$2 for each additional item			
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2021 VIRTUAL National Patient Conference

Conference Highlights

On June 11th and 12th, over 900 people from across the world joined our Sjögren's Foundation virtual National Patient Conference, "Conquering Sjögren's Together." Keeping health and safety as our main priority, the Foundation's Education Committee decided to hold the Conference once again as a virtual event. While our Conferences continue to look a little different this year, thanks to technology and the dedication of both medical experts and patients, we were able to join as a community to learn and share from the comfort of our own homes.

The Foundation knows that not everyone can travel to one of our in-person educational seminars, which is why we were so excited that this year we welcomed registrants from 49 states, as well as Guam and Puerto Rico. In addition, besides the United States, registrants joined from 15 countries including Australia, Canada, England, India, Ireland, Israel, Japan, Mexico, Mongolia, New Zealand, Romania, Romania, Singapore, Taiwan, Trinidad, and Tobago.

Our educational conferences are designed to help patients take control of their health and gain a better understanding of their disease. The 2021 program catered to both newly diagnosed patients and longtime members. During the two-day program, the audience enjoyed informative lectures by expert speakers from around the country.

This year's presentation topics included:

- **Sjögren's: An Overview** by Donald E. Thomas, Jr., MD, Sjögren's Foundation Board Chair
- **Clinical Practice Guidelines for Pulmonary Complications** by Augustine S. Lee, MD, M
- **Conquering Sjögren's: What's Next?** by Janet Church Sjögren's Foundation President and CEO

- **Ocular Manifestations of Sjögren's** by Lee W. Guo, OD, FAAO
- **Product Showcase** by Kimberly Kelley, PharmD
- **Oral Manifestations of Sjögren's** by Vidya Sankar, DMD, MHS
- **Sjögren's & the Long-Term Disability Insurance Claim Process** by Stacy M. Tucker
- **Sjögren's and Joint Pain** by Rochelle Rosian, MD
- **COVID-19 and Sjögren's Update** by Alan Baer, MD
- **Genetics and Sjögren's Research** by Christopher J. Lessard, PhD

In addition to the ten informative lectures, the Conference also included fun, interactive 10-minute sessions called "Exploring Sjögren's" that were held between lectures. During these breaks, attendees heard brief interviews with product company representatives, Sjögren's patients, and medical experts. The Foundation also used an online polling feature and chat box to learn more about patients.

On the second day of the Conference, registrants could join the virtual Volunteer Awards Ceremony. Every year, the Foundation recognizes our most dedicated volunteers through awards that are announced during the Conference. The Foundation 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. ■

Please visit www.sjogrens.org for a list of our honorees from the 2021 National Patient Conference.



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National Patient Conference Patient Testimonials

Thank you so much for this outstanding Conference. This community gives me hope. — Adriana T.

WOW! Perfect presentation – informative and pointedly given for our audience. — Nancy B.

I want to let you know how impressed I am with the quality of this Conference. I'm blown away by the high level of information and the warmth and compassion of the speakers. The chat community is being so helpful and kind to one another; it is so heartwarming. Well worth the time and money. Thank you so much for making this available. — Jen H.

Excellent conference! I've been a patient for 25 years and I always learn something new! — Robin T.

I love being able to meet my fellow Sjogries, but I think I was better able to absorb the information with this virtual format. I could take care of my physical needs without disturbing other people. Thanks to all who put so much work into this Conference! — Diana C.

Thank you for the panel of speakers, the topics, and information. This will help me to be an active participant of my care. — Omarys M.

Thank you to everyone involved in making this Conference happen! Great work! I am so grateful to you all for this opportunity to be a more educated Sjögren's patient. I learned a lot and will be taking my dry eye more seriously thanks to Dr. Guo. — Carolyn W. ■

If you missed the NPC... Get the information and purchase your video download today!

Get all the vital information you need in an easily downloadable video format! Seven of our most popular talks from the 2021 National Patient Conference that was held virtually, are available for purchase. Each talk is 30-40 minutes and comes with the handouts used by the presenter so you can follow along.

Available video downloads from the 2021 Virtual National Patient Conference to purchase include:

- **Sjögren's: An Overview** by Donald E. Thomas, Jr., MD, Sjögren's Foundation Board Chair
- **Ocular Manifestations of Sjögren's** by Lee W. Guo, OD, FAAO
- **Oral Manifestations of Sjögren's** by Vidya Sankar, DMD, MHS
- **Sjögren's & the Long-Term Disability Insurance Claim Process** by Stacy M. Tucker
- **Sjögren's & Joint Pain** by Rochelle Rosian, MD
- **Clinical Practice Guidelines for Pulmonary Complications** by Augustine S. Lee, MD, MS
- **Genetics & Sjögren's Research** by Christopher J. Lessard, PhD

Purchase all talks and receive these bonus presentations.

- **COVID-19 & Sjögren's Update** by Alan Baer, MD
- **Conquering Sjögren's: What's Next?** by Janet Church, Sjögren's Foundation President & CEO
- **Product Showcase** presented by Kimberly Kelley, PharmD

Member Price: \$25 per video

Non-Member Price: \$30 per video

Collection of all 7 downloads:

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These video downloads are an excellent way to have a permanent resource with some of the most vital information available to Sjögren's patients. Purchase just the talks you want to hear or purchase the entire set!

If you have any questions or need additional information you can contact the Foundation office at (301) 530-4420.

www.sjogrens.org/shop





Sjögren's Foundation COVID-19 Vaccination Committee Statement on COVID-19 Booster Recommendation

The Sjögren's Foundation COVID-19 Vaccination Committee concurs with the August 18 announcement by U.S. government health officials recommending all Americans, including all Sjögren's patients, obtain a booster COVID-19 immunization 8 months following the 2nd mRNA COVID-19 vaccination. For those who received a 3rd dose vaccination, new guidance will likely be announced, so watch for news of this guidance from the Sjögren's Foundation.

We emphasize that this recommendation only applies when the U.S. Food and Drug Administration (FDA) has officially sanctioned the safety of the mRNA

vaccinations and the CDC Advisory Committee on Immunization Practices (ACIP) has officially issued its booster dose recommendations.

Boosters are expected to become available starting September 20. Boosters for those who received the J&J COVID-19 vaccination most likely will be recommended, but data analysis has not been completed. The Sjögren's Foundation will let its members know when a recommendation issued on the J&J vaccination.

Please encourage anyone in your family and community who has not yet received a COVID-19 vaccination to do so as soon as possible for their own protection and for the protection of others.

We hope you will visit our website to view all our Sjögren's and COVID-19 resources, including a document of frequently asked questions, and recommended precautions for patients.

Sjögren's COVID-19 Vaccination Committee Chair

Alan Baer, MD

Rheumatology and Director of Jerome L. Greene Sjögren's Syndrome Center, Johns Hopkins, and Chair, Sjögren's Foundation Medical & Scientific Advisory Council Committee

Members

Cassandra Calabrese, DO

Rheumatology and Infectious Diseases, Cleveland Clinic

Steven Carsons, MD

Chief of Rheumatology, NYU Winthrop; Senior Associate Dean, Translational Science Integration; and Chair, NYU-Winthrop Vaccine Center for Treatment and Evaluation

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Katherine M. Hammitt, MA

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Find Support and Advice from Your Local Sjögren's Support Group!

Attend free meetings and connect with others living with Sjögren's while also learning how to best manage your disease with presentations from area healthcare professionals.

To find your local Sjögren's Support Group, contact the Sjögren's Foundation at www.sjogrens.org.

These local groups provide:

- Patient-to-patient sharing
- Informative presentations by healthcare professionals
- An opportunity to connect and exchange helpful coping techniques

