

CONQUERING Sjögren's

November/December 2023

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CONQUERING Sjögren's

Volume 4, Issue 6



Conquering Sjögren's Newsletter is published by the Sjögren's Foundation Inc.,
10701 Parkridge Boulevard, Suite 170, Reston, VA 20191.

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Happy Holidays!



Janet E. Church
CEO Sjögren's Foundation

Hello Sjögren's Foundation Members and happy holidays! Every year when I write this letter, I am so surprised at how time flies and how quickly we are looking at upcoming celebrations with family and friends. I love writing our year-end letter because it gives me an opportunity to stop and reflect on our accomplishments during the calendar year. And this year, there has been significant forward movement for the Sjögren's community! I am proud of what we have achieved for patients with increased support, education, and advocacy and thrilled with the advancements we see in research and clinical trials. It has been a year filled with orchestrating relationships and priorities and guiding incredible work with our volunteers, Board of Directors, researchers, and Pharma. Let's take a look at this year's accomplishments.

This year, we focused on expanding provider education across certain specialties to highlight the need for multidisciplinary care. Whenever we speak to providers, we leverage the *Living with Sjögren's* survey data to drive home that Sjögren's is serious, systemic, and prevalent.

We started the year with our annual State of Sjögren's. This year's focus was on neurological manifestations in Sjögren's, and we had 400 clinicians attending. The Foundation also attended and/or presented posters at several conferences aimed at different professional audiences and specialty areas including the American College of Rheumatology Annual Meeting with over 7,000 rheumatologists in attendance and the American Autonomic Society Conference, which included clinicians and researchers who engage with the autonomic nervous system. The Foundation has strategically expanded our presence and attended four new con-

ferences in support of our multi-specialty education efforts, including: the American Academy of Neurology's (AAN) Annual Meeting; the American Thoracic Society's (ATS) International Conference in Washington, where we highlighted our Pulmonary Clinical Practice Guidelines; the American Association of Nurse Practitioners (AANP) National Conference; the Rheumatology Nurses Society Annual Meeting; and the Rheumatology Advanced Practice Provider (RhAPP) Conference.

Our attendance and content presentations were very well received at all events, and we look forward to these audiences attending our upcoming State of Sjögren's this January, which will focus on the difficult-to-diagnose patient and will offer continuing medical education (CME) credits for nurses and physicians. In addition to in-person education, we have three online CME courses running currently; these are produced by PriMed, by PRIME CME, and a newly launched program from National Jewish Health with a focus on pulmonary issues.

We also expanded our research program by adding new grant mechanisms. This past spring, we awarded the Foundation grants, which included our first Dynamic grant (details are in last month's *Conquering Sjögren's*). We also saw advancement by our Sjögren's Team for Accelerating Medicines Partnership (STAMP) for the FNIH/NIH AMP® AIM project!

This year, we also leaned into advocacy efforts by submitting a proposal to the Centers for Medicare and Medicaid to include coverage for medically necessary dental care. We covered this extensively in last month's *Conquering Sjögren's*. We also hired a new firm to help

“Letter from CEO” *continued from page 3* ▼

us with strategic advocacy efforts with Congress, including presenting a new Resolution that updates the government on the facts about Sjögren’s and Sjögren’s patients. Our 2024 advocacy efforts will continue pushing these projects forward!

April was an exciting month as it is Sjögren’s Awareness Month, and in addition to our successful National Patient Conference with 1,400 attendees, we launched a new Patient-to-Patient program. This program encourages patients to submit their personal stories to us and we present them on our website and social media; the presentation of stories clearly demonstrates that Sjögren’s can affect anyone and that it impacts people differently. Patients also offer their own advice to other patients. We closed out April by ringing the NASDAQ bell and presenting Sjögren’s to millions of people around the world!

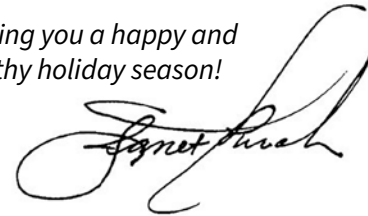
This past year has also seen a significant increase in clinical trials coming to market. Last year we saw three clinical trials for systemic Sjögren’s complete, and as I wrote this letter, we have 2 trials in process and three more preparing to launch. Hope for better treatment is around the corner!

Our Support Group program has also expanded, and we now provide more support groups across the country. Supporting patients is integral to the Foundation

and in fact, it is why the Foundation was created! Forty years ago in September 1983, Elaine K. Harris held the first support group to help patients better understand their disease and how to manage it. Forty years is an amazing milestone, and we will be celebrating it throughout the year!

As we welcome in the holiday season, I also am looking forward to 2024 and how we can continue to advance what we know about Sjögren’s and how we can improve the quality of life for all patients. As we say goodbye to 2023, I want to thank the Foundation staff for their commitment to patients, our volunteers who bring Sjögren’s education and support to local communities, our Board of Directors who give their time to ensure our mission is moving forward, and our donors who are committed to helping us achieve all our goals. And I especially want to thank you! I am grateful for your support, and I am honored to lead this organization as we fight together to conquer the complexities of Sjögren’s.

Wishing you a happy and healthy holiday season!




\$32 members
\$38 non-members



Do You Have the Latest Edition of The Sjögren's Book?

The *Sjögren’s Book*, Fifth Edition is a comprehensive and authoritative guide, produced by the Sjögren’s Foundation and its medical advisors and edited by a leading authority on autoimmune disorders.

This expanded edition provides readers with an easily readable and understandable book that includes important added content on areas not covered in previous editions.

With more than fifty chapters written by leading experts, this book illuminates the major clinical aspects of the disease and is loaded with practical tips and advice as well as scientific advancements in the field.

Recognized as the #1 resource for Sjögren’s sufferers, this reliable and informative guide is the first place for patients to look when they have questions about this disabling disease. It is a valuable aid that patients can use while discussing their illness with their physician and family members. Available in our website shop at www.sjogrens.org/shop or use the QR code to the left.



Meet the new Executive Committee of the Board of Directors

The Sjögren's Foundation is governed by a Board of Directors made up of patients, healthcare providers, caregivers, and people who may perform a role that is beneficial to the Board. To be considered for a Board seat, an individual must meet specific criteria including a level of knowledge about Sjögren's disease, what it is like to live with the disease, and how their specific background can enrich the Board and therefore the guidance of the Foundation. Each Board seat is for three years, and the seat can be renewed for another three-year term.

A potential board member is vetted by the Governance Committee (comprised of current Board members) and then presented at the May Board of Directors' meeting to be voted in. Each new Board member term begins on July 1st, which is the first day of our fiscal year. The Board of Directors for the Foundation meets three times per year to review the activities and needs of the Foundation, and to discuss long term plans that will most benefit patients.

As is true for every Board, the Foundation has an Executive Committee that has a Chair, an Immediate Past Chair, a Secretary, and a Treasurer. The Executive Committee can also have a Chair-elect. The Executive Committee and the CEO/President of the Foundation meet a minimum of nine times per year, once per month in months where there is no Board meeting. To serve on the Executive Committee, appointees must have served on the Board of Directors for several years and have a deep understanding and involvement in volunteering for the Foundation. The purpose of the Executive Committee is to oversee the Board of Directors, work closely with the CEO/President to ensure that the goals for the Sjögren's Foundation are progressing, and to act as collaborators with the CEO when new concerns or opportunities arise.

All goals and priorities are set by the CEO/President at the end of a fiscal year and presented to the Board at the May Board meeting. The goals are then revised and presented at the first Board meeting of a new fiscal year and adopted as the activities of record for that year. Goals are often similar on standard operations of the Foundation (such as patient support groups, conferences, and research grants), but they always support our key Mission pillars which are as follows:

- Support Sjögren's patients and their loved ones through education, resources, and services
- Provide credible resources and education for healthcare professionals
- Serve as the voice for all Sjögren's patients through advocacy and awareness initiatives
- Lead, encourage and fund innovative research projects to better understand, diagnose and treat Sjögren's

On July 1st, the torch was passed to the Foundation's new Executive Committee of the Board of Directors and all members have been working with the Foundation for many years! Let's meet the new Executive Committee of the Board of Directors:



***Susan Barajas, MBA
Chairperson of the Board***

Susan Barajas has five years' experience as a Foundation Board member as she enters her first year as the Chairperson of the Board. After her diagnosis with Sjögren's, Susan attended our National Patient Conference where she learned about the support the Foundation provides patients

“New Executive Committee” *continued from page 5* ▼

through their patient advocacy and other activities. She knew it was an organization that she wanted to be a part of, and she felt she had much to contribute!

Before joining the Board, Susan was in the military and has over 30 years of working experience as a civilian with the Federal government as an auditor and manager. She has also spent many years as an active volunteer for the Foundation in various roles including Support Group Leader, Awareness Ambassador, Patient Support Volunteer, Walks for Sjögren’s volunteer and Team Sjögren’s volunteer and runner. Susan brings her energy and passion to help all patients to the Executive Committee.



**Donald E. Thomas, MD,
FACP, FACR, RhMSUS
Immediate Past Chair,
Board of Directors**

Dr. Don Thomas is the preceding Board Chairperson and takes the role of the Immediate Past Chair to allow for continuity between the old and new Executive Committee of the

Board of Directors. After years of treating Sjögren’s and other autoimmune patients as a Rheumatologist, Don met former Foundation CEO Steven Taylor at a DC Rheumatism Society meeting where he learned about the Foundation and its exciting work. Impressed by the Foundation’s patient advocacy, initiatives in promoting clinical trials for better therapies for Sjögren’s, and the establishment of clinical practice guidelines, he agreed to become a board member in 2018. Three years later, Don became the Board Chairperson for the Foundation.

Currently, he is an editorial board member for our healthcare professional newsletter *Sjögren’s Quarterly* as well as a favorite speaker at Foundation conferences and an instructor of two online CME training programs for Primary Care providers. He is also a Clinical Associate Professor at the Uniformed Services University and has just finished the second edition of his renowned book “The Lupus Encyclopedia: A comprehensive guide for patients and healthcare providers.”



**Vidya Sankar, DMD, MHS
Treasurer**

Dr. Vidya Sankar is our new Treasurer for the Executive Committee of the Board of Directors. She has been involved with the Sjögren’s Foundation since 1998, when she received her specialty training in Oral

Medicine at the National Institutes of Dental Research (NIDCR). Oral Medicine is the specialty of dentistry that deals with treating medically complex patients, patients with salivary gland dysfunction and those with mucosal diseases.

Vidya was the first recipient of the Sjögren’s Foundation Student Fellowship Award while at the NIDCR, where she was involved with several clinical trials involving therapeutic options for Sjögren’s including biologic and traditional disease modifying anti-rheumatic drugs. Unfortunately, those early clinical trials did not offer promising results, but Vidya continued to help patients manage their oral symptoms and has continued with research. She has met many patients that have a very difficult time finding oral care providers familiar with their disease and the dental complexities associated with Sjögren’s and is determined to help improve upon this challenge for patients.

Vidya also holds appointments as the President of the American Academy of Oral Medicine as well as Division Director and Associate Professor at Tufts University School of Dental Medicine. She was previously a member of the Sjögren’s Foundation Board and returned to the Board in 2021, where she participates in several steering committees to advance classification and treatment of Sjögren’s. Her priorities are to increase awareness for the specialty of Oral Medicine to patients and the medical professionals who care for patients with Sjögren’s as well as facilitate access to oral medicine providers in an effort to optimize their oral care and enhance their quality of life.

“These are exciting times with new opportunities for the Foundation to assist in getting ground-breaking therapies to market, fund innovative research, and find additional ways to educate medical personnel about Sjögren’s. I’m thrilled to lead the Board of Directors and support the Foundation as we work together to advance these and other areas.” — Susan Barajas, Chairperson, Board of Directors



Patient -to- Patient

The Foundation wants to thank everyone who has shared their story. We believe our patients drive this community by sharing their stories and to other patients, letting others know they are not alone. We will continue to provide an outlet for real patients to give real advice and share their experiences as they move through life with this complex disease.

Each Patient-to-Patient story discusses a specific symptom or aspect of living with Sjögren's. They are a unique look into how individuals manage their disease. These stories are shared once a month for patients to share directly how they are effectively coping with the disease and offer advice for others.

Current Patient-to-Patient topics include:

- Chronic pain
- Joint pain
- Fatigue and getting diagnosed
- Sore Throat
- Balancing emotions and Sjögren's

We encourage you to go to our Patient-to-Patient page to see our past and future stories as well as how you can be featured by visiting <https://sjogrens.org/living-with-sjogrens/patient-to-patient-stories>.



Carson

(Age: 21, diagnosed at 19)

Patient-to-Patient Topic

Chronic pain, neck and back

I've been dealing with the pain since I was 18. No doctors would listen because I was so young. My labs were

positive for Sjögren's. I still haven't found any type of therapies or medications that truly help with the pain on a daily basis, but I have hope that there will be something at one point.

The Impact of Sjögren's

The impact has been both physical and emotional. I am no longer able to run marathons and my job in healthcare has become increasingly challenging with pain flare ups. I'm also no longer able to do the things most people my age can do. It's hard to sit for over 30 minutes, so it is difficult to attend college.

Best Advice

You're not crazy, the pain is real and you need to find doctors that listen to you and advocate for you. Also, don't push yourself past your limits, know when it is too much and allow your body to properly rest.

Your Go-To Products/Tools

Aleve rubbing gel, hot rice packs

“Patient-to-Patient” *continued from page 7* ▼



Sophia

(Age: 32, diagnosed at 29)

Patient-to-Patient Topic

Joint pain

Joint pain with Sjögren's can be completely debilitating. At times, it has flared up and derailed my plans entirely because I am unable to move without experiencing pain.

My advice is to listen to your body and don't feel guilty about missing out or needing to put yourself first.

The Impact of Sjögren's

Sjögren's has impacted me in every way possible. Physically- I'm in debilitating pain, and the dryness alone is difficult to manage. Emotionally- it takes a toll on my mental health. Financially- it's costly to keep up with appointments, medications, and treatment. It's overall just hard to endure.

Best Advice

Find the right tools to help you alleviate some of the pain. In my experience, it never fully subsides but certain tools and medications can help ease the pain. Morning and night routines are a must for me. Lastly, find a doctor who prioritizes your needs and advocate for yourself in spaces you may not have the support you need.

Your Go-To Products/Tools

Voltaren, heat pads, and a mobility aid- if needed



Katherine

(Age: 40)

Patient-to-Patient Topic

Fatigue and getting diagnosed

When I was diagnosed with Sjögren's, I had never heard of it before. I was told it was just dry eyes and dry mouth, end of story. I was (and am) suffering from debilitating fatigue and brain fog, but my rheumatologist insisted those symptoms were unrelated to my multiple autoimmune disorders. It was only when I started reading about Sjögren's on the Foundation's website that I was able to connect the dots. Once I was able to finally stop searching for the cause of my symptoms, I was able to start trying to effectively manage them.

The Impact of Sjögren's

Getting the diagnosis has allowed me to stop blaming myself for my fatigue, thinking I'm weak and just need to keep pushing. I work a lot less now and my family's finances have certainly suffered for it.

Best Advice

Rest when you need to rest. If you keep trying to push through, you could make your situation worse. I also go to acupuncture, which has really helped even though I didn't think it would, and since that has been so effective, I do Qigong most mornings. Make caring for yourself a priority. It really is the only way you'll be able to then extend care to others.

Your Go-To Products/Tools

Systane Balance eye drops, microwavable eye mask, sleep



Jean

(Age: 57, diagnosed at 45)

Patient-to-Patient Topic

Sore Throat

For over a decade, I was treated for presumed acid reflux or viruses because of chronic sore throat pain.

After an endoscopy showed no acid reflux and my ENT couldn't discover the cause of my sore throats, I continued to search for help. My search took me to a world-renowned institution where the ENT determined I needed testing for a systemic cause. I am thankful for the rheumatologist. He referred me to who diagnosed me based on my symptoms and her expertise since I am seronegative.

Editor's Note: *Seronegative means that the patient did not have anti-SSA/Ro or anti-SSB/La antibodies present- common antibodies used to help diagnose Sjögren's.*

The Impact of Sjögren's

I can no longer play tennis as much as I want, and it's hard to start tasks due to the fatigue. I don't want my fatigue to prevent my friends from inviting me to activities with them.

Best Advice

Advocate for yourself with your doctor if you have a medical problem that isn't being resolved. Also, stay active as much as you can, but know what your limit is so you don't over-exert yourself.

Your Go-To Products/Tools

I avoid foods that are acidic, spicy, salty, or crunchy. I use fruit-flavored toothpaste, gum, etc. instead of mint. Luden's wild honey lozenges. Plaquenil.



Evelyn

(Age: 57, diagnosed at 45)

Patient-to-Patient Topic

Balancing emotions and Sjögren's

Every time I'm stressed at work or going through some troubles personally, my symptoms get worse. My eyes turn very red and hurt and I feel very tired where most times I'm not able to even leave bed. It's very hard to explain this and it does not sound concerning and weird.

The Impact of Sjögren's

Emotionally a lot, because I am the only one in my family that has it and no one gets me. It is hard

to explain that some daily activities represent big challenges sometimes. Physically, I've gone through a lot- as anyone that has Sjögren's. I keep discovering symptoms every now and then, so I've learned to be kind to my body and to listen to it. Financially, the impact has been minor because I have a really good insurance that covers it 100%, so I have that relief.

Best Advice

Find the right words to talk to yourself and be kind. Listen to your body and prioritize yourself. To say NO, and to rest when my body needs. It's fundamental to rest in order to function almost normal.

Your Go-To Products/Tools

Xylimelts™ and Optive Fusion eye drops. Take Omega-3 (just omega-3), three times a day — it helps with the symptoms a lot.

All stories come from the patient's voice. The listing of any products does not constitute an endorsement of those products. We strongly advise that you consult with your physician, dentist and/or pharmacist regarding your treatment plan and finding what is right for you. ■

“New Executive Committee” *continued from page 6* ▼



Katie Forte

Secretary, Board of Directors

Katie Forte is the Secretary for the Executive Committee of the Board of Directors. She has been a board member for two years and has previously served as co-chair for the New York State Walk. Katie was instrumental in

launching our new website a few years ago as a committee member. As a leader in entertainment, social

media and content marketing, Katie has launched many successful concerts, benefits, and theater productions as well as chairing our Walk for Sjögren's in New York.

Katie utilized the Foundation as a resource after her diagnosis and vowed to serve as patient advocate for Sjögren's. She decided to publicly speak about and loudly voice how Sjögren's disease affects patients and what the Foundation can offer patients. ■

“I am stronger than Sjögren's because of this incredible community of patients, caregivers, and medical professionals that the Foundation brings together - all fighting for awareness and advancement in care. The Foundation and the Walk for Sjögren's quite literally changed my life for the better after I got sick. During my journey when I felt isolated due to what my body was experiencing, I heard the phrase ‘sharing your story may be the key that unlocks someone else's prison.’ If I can help just one person, I know I have made a difference.” — Katie Forte, Secretary, Board of Directors



Clinician's Corner: Dry Eyes: Treat Your Eyelids with Respect



Sally Primus, MD
Board-Certified
Comprehensive Ophthalmologist

Our understanding of dry eye disease has changed dramatically in the last decade, leading us to understand that not only can dry eyes result from not enough tears but also from imbalanced tears. A good tear consists of a base layer of mucous, followed by an aqueous (water-like) layer, and topped with an oil layer. The tears are spread evenly across the eye with tight and active eyelids.

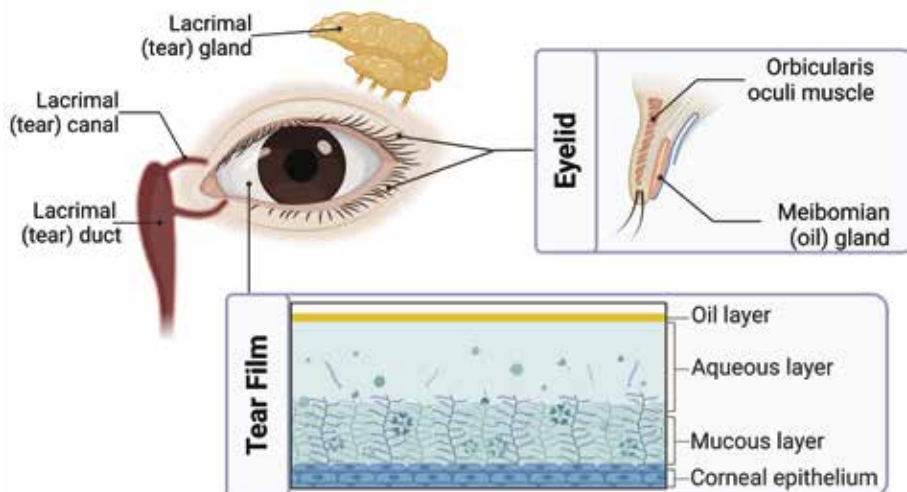
Patients with Sjögren's disease are unable to make the middle aqueous layer of the tears.¹ While most of our focus in treating patients with Sjögren's disease has been reducing the inflammation in the lacrimal (tear) gland and replacing the aqueous layer with artificial tears, it is becoming more important to keep the oil production and eyelid function as good as possible to help stabilize the small amount of tears that Sjögren's patients make.

How you apply your eyedrops matter

The eyelids are designed to hug tight to the eye, like windshield wipers. Constant touching and rubbing of the eyelids can weaken the delicate structures.² Over time, this leads to loose eyelids and conditions such as ectropion or floppy eyelid syndrome. When the eyelids can no longer function as "wipers," then any natural or artificial tears placed in the eye will not distribute evenly. This leads to worsening dry eye symptoms.

Because patients with Sjögren's are typically using eye drops many times a day for decades, the proper technique is critically important for how your eyelids will function in your older age.

Many instruction manuals that show the "proper technique" for instilling eye drops are designed for people prescribed drops for a week or a month. These pictures often show pulling the lower eyelid



down to create a “pocket” and dropping the tears in there. Unfortunately, pulling the lower eyelid down like that for years can significantly loosen the lower eyelid, creating yet another problem.

How should you put eye drops in?

There are several techniques that can be used. Some doctors will recommend laying down and placing a drop on the inner corner of a closed eye and then opening your eye to allow the drop to fall in. One concern with this method is that bacteria from the skin can then go into the eye as well.

My preferred method is to tilt your head back and look as far up and behind as you can. This causes the upper eyelid to pull out of the way. Then hold your bottle above the eye and allow the drop to fall into the eye. You can also do this with your head tilted to the side if you need a mirror to place your drops. The goal of any of these techniques is to minimize the touching of your eyelids.

How can you keep your eyelid oil glands happy?

The oil portion of your tears comes from oil glands inside your eyelids.³ Entire books have been written

on how to improve production from eyelid oil glands (meibomian glands), but some simple things patients can do is regular heat therapy with heated rice bags or masks, and making sure your diet contains plenty of Omega-3 fatty acids, which are also available over the counter in the supplement section of your pharmacy.

If your dry eye symptoms are worsening despite using your drops regularly, it may be worth talking to your eye doctor to check your eyelid and oil gland function to make sure you are maximizing your tear film quality. ■

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Sjögren's Foundation Fall Focus Conference 2023

On October 14th the Foundation produced our annual Fall Focus conference. This year, our topic was *Exploring the Complexities of Oral Health in Sjögren's* with six expert speakers and a Foundation update from Janet Church, President and CEO. With 93% of Sjögren's patients experiencing dry mouth, the information provided at the conference is vital for everyone.

One of the more important points that we learned in the conference is that every Sjögren's patient needs to take very good care of their mouth! Dr. Athena Papas, one of our expert presenters, shared that a patient can only discern that their mouth is dry once they have lost 50% of their saliva production. At 50% reduction, the absence of saliva is already causing harm. So, it is important that you begin a strict regimen of oral

care as soon as you are diagnosed with Sjögren's in order to prevent progression of oral issues. Routine care should include three to four cleanings per year, fluoride treatment three times per year, daily care of brushing and flossing, and prescription fluoride toothpaste used at night (and left on teeth if possible).

Other tips were shared with us including the importance of massaging your salivary glands to help prevent blockage and to increase flow. To learn how to massage your glands, just follow the Foundation's Patient Education Sheet on *How to Massage Salivary Glands* on page 13. You can find other education and Tip Sheets on our website at Sjogrens.org under Resources, and we encourage you to purchase the recording of the Fall Focus to learn more about the best ways to manage oral health with Sjögren's. ■



Did You Miss the Foundation's Recent Conference, Exploring the Complexities of Oral Health in Sjögren's?

The Sjögren's mouth is complex and more than "just dry"; it requires special attention and care to help prevent serious implications on your overall health and quality of life. Get all the vital information you need to manage your oral health!

Purchase access to the recording of the entire Fall Focus 2023 Conference, which includes these sessions:

Understanding the Oral Cavity & Glands

Blake Warner, DDS, PhD, MPH
NIH, National Institute of Dental and Craniofacial Research

Basic Prevention and Care of the Sjögren's Mouth

Andres Pinto, DMD
Case Western Reserve University, School of Dental Medicine

Your Smile: A Patient's Guide to Obtaining Medical and Dental Coverage for Sjögren's- related Dental Treatment

Danielle Brown, *My Smile Insured*
Sandy Buechler, *ImpleMed Dental Resources*

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University of California San Francisco Health

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Tufts University School of Dental Medicine

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Mike Brennan, DDS
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Patient Education Sheet

How to Massage Salivary Glands

The Foundation thanks Ava J. Wu, DDS for authoring this Patient Education Sheet. Dr. Wu is a Clinical Professor and Co-Director of the Salivary Gland Dysfunction Clinic, School of Dentistry, University of California, San Francisco

If a sharp and stabbing pain occurs in one of your salivary glands right before or while eating or drinking, the cause might be an obstruction (a stone or mucous plug). In rare cases, associated gland swelling can accompany the discomfort. Here are some tips for massaging or “milking” the gland that might help:



Figure 1A:

The parotid glands are located bilaterally in the cheek area in front of your ear and have a “tail” area that can extend over the lower jaw.



Figure 2A:

The submandibular and sublingual glands are located bilaterally under your jaw and tongue with the sublingual gland closer to the chin.



Figure 1B and 2B:

Place two fingers on the body or tail area of the parotid, Or under the jaw for the submandibular/ sublingual glands.

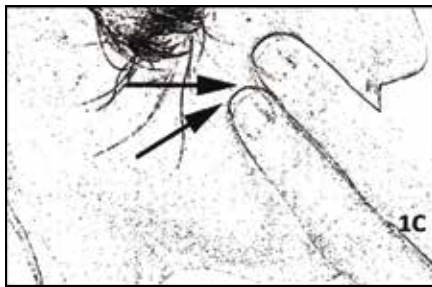


Figure 1C and 2C:

Sweep fingers forward with gentle pressure as indicated by the black arrows. This will encourage movement of saliva past a possible obstruction or constriction and into the oral cavity.



Additional Tips:

- Stay well hydrated to encourage the flow of saliva through the gland.
- Temporarily avoid foods and beverages that cause the pain and possible swelling.
- Apply warm compresses to the area to increase comfort.
- Ibuprofen may be taken temporarily to decrease pain and inflammation.
- Talk to your doctor about use of a mucolytic agent for 5-10 days to thin the saliva and allow it to easily pass through the salivary ducts.

In all cases of salivary gland swelling and associated pain a medical professional should be consulted as soon as possible to determine the cause.

For more information on Sjögren's, contact the Sjögren's Foundation at:
 10701 Parkridge Blvd., Suite 170, Reston, VA 20191 • 800-475-6473 • www.sjogrens.org.



Clinical Trials and You, the Patient!

What to know and how to advocate for yourself when considering volunteering for a clinical trial

Clinical trials are an important and necessary component of clinical research. Clinical trials are how medical interventions – including therapies and prescription drugs – are determined to be safe and effective for use in patients with a given disease, such as Sjögren’s.

The clinical research process ultimately improves treatment for patients through the innovation, development, testing, and approval of new therapies. However, clinical trials **require** participation from patients – the clinical trial process is dependent on volunteers and cannot be completed without them.

People with Sjögren’s disease are in an exciting position to contribute to clinical research **right now** through their participation in ongoing and new Phase 2 and Phase 3 clinical trials. No therapy has yet been approved to treat the systemic manifestations of Sjögren’s and lessen the disease’s severity. However, current and future clinical trials are moving ever closer to approval of therapies that will improve the lives of people with Sjögren’s.

The best time to participate in a clinical trial is now! Read below to learn more about clinical trials, how to participate, and what to consider before you volunteer.

What to Know about Clinical Trials

Clinical trials are currently recruiting participants all over the world, including in the U.S. To be eligible to participate in a clinical trial, patients must meet inclusion criteria set for that study– for example, being of a certain age and having a confirmed diagnosis of disease. It is essential for all participants to meet the same inclusion criteria so that as many factors as possible can be controlled and the potential impact of the intervention or drug being tested can be observed.

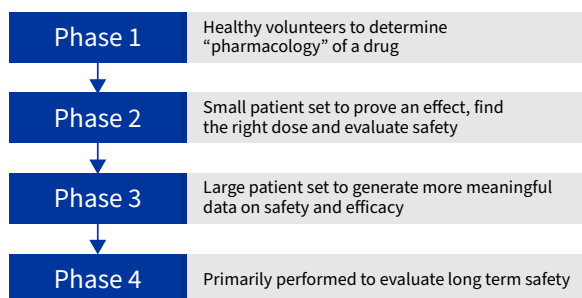
Inclusion criteria may differ from study to study, and just having a diagnosis of Sjögren’s may not be enough to qualify for a particular study. Many other factors, such as the severity of disease, other conditions you may have, and whether you are or could get pregnant during the clinical trial, will determine whether you qualify to participate.

Because qualifying for a trial is not a given for each and every patient with the disease, it is important to keep informed about new trials as they begin so that you can increase your chances of finding a trial for which you are eligible. If you do not qualify for the first trial you are interested in, or if the timing is just not right, don’t get discouraged!

How to Find Out About Clinical Trials Recruiting Now and Near You

The Sjögren’s Foundation maintains a list of actively recruiting clinical trials on our Clinical Trials webpage. On this webpage, you can learn more about clinical trials and search by city and state for trials that are recruiting near you. Each site listing has contact information for the site’s coordinator and/or a link to learn more about the trial. Other resources for learning about clinical trials that are currently recruiting such

Phases of a Clinical Trial



Sjögren’s trials are double blind studies.
A patient receives the drug **OR** a placebo.

as <https://clinicaltrials.gov/> can be found by scrolling further down on the same webpage.

You can also sign up to receive information from the Sjögren's Foundation about clinical trials recruiting near you – visit <https://sjogrens.org/living-with-sjogrens/clinical-trials> to submit your contact information or scan the QR code!

I'm Ready to Participate...Now What?



It's exciting to take part in a clinical trial, contribute to advancing medical science, and help improve treatment options for Sjögren's patients! Participating in a clinical trial is a wonderful thing to be able to do for yourself and for others, but it can also present difficulties and be labor intensive for those who participate.

Clinical trials often require participants to make repeated visits to the clinical trial site or doctor's office over a period of weeks, months, or years. How the drug being studied is administered – such as intravenously (IV) or via infusion – can also present an obstacle to some patients.

As a participant, it is always your right to cease your participation at any time if you should choose. To set yourself up for success with your participation in the trial, think about *what you need* to be able to participate and *ask the trial site coordinator* whether those things can be provided. How far away is the trial site from your home or workplace? Are you in need of childcare accommodations while you are re-

ceiving the therapy being studied or undergoing the necessary and related medical examinations? Would having transportation assistance, a buddy to travel with you, or a financial contribution make it possible for you to successfully participate in the trial?

It is important for clinical trials to include a diverse group of participants that represents the population of persons with the disease in question – this includes people across age groups, races/ethnicities, parental statuses, and employment statuses. Because qualifying for and participating in a trial is not a simple process, eligible participants should not be deterred from coordinating the resources they need to make their clinical trial participation possible! ■

To learn more about Clinical Trials right now, we recommend the following resources:

Visit our Clinical Trial website at:

<https://sjogrens.org/living-with-sjogrens/clinical-trials>



Visit our Blog at:

<https://sjogrens.org/blog>



Grab a copy of the Sjögren's Book (5th Edition) at:

<https://sjogrens.org/shop/the-sjogrens-book-5th-edition>



Thank you to Aquoral Protective Oral Spray for their sponsorship of our 2023 Fall Focus Conference.

Scan the code to visit their website and learn more.





New National Institutes of Health Office Created to Improve and Coordinate Autoimmune Disease Research

Under the direction of the U.S. Congress, the National Institutes of Health (NIH) has established the new Office of Autoimmune Disease Research (OADR) under the guidance of the Office of Research on Women's Health (ORWH) to accelerate progress in autoimmune disease research.

In 2019, Congress asked for the status of autoimmune disease research. The National Academies of Science, Engineering, and Medicine (NASEM) put together a working group to assess the autoimmune disease research portfolio of the National Institutes of Health. As a result, the NASEM working group released the "Enhancing NIH Research on Autoimmune Disease" report in 2022 and described the need for greater coordination across the NIH for autoimmune disease.

- Congress used this report to establish the needs of autoimmune research and created the Consolidated Appropriations Act, 2023 (Public Law 117-328), which created the OADR. The OADR directives are to:
- Coordinate development of a multi-institute and multi-center strategic research plan
- Identify emerging areas of innovation and research opportunity;
- Coordinate and foster collaborative research across institutes and centers;
- Annually evaluate the NIH autoimmune disease research portfolio;
- Provide resources to support planning, collaboration, and innovation; and
- Develop a publicly accessible central repository for autoimmune disease research.

Autoimmune disease research is conducted in 13 of the 27 institutes and centers at the NIH. By centralizing autoimmune disease research at the OADR, this allows coordination of budgeting, planning, and research prioritization.

As a leader in research progression, the Sjögren's Foundation joined the effort that led to the NASEM Report and the new office from the very beginning. The Foundation nominated Dr. Scott Lieberman, who co-leads the Sjögren's pediatric registry and serves on the Sjögren's Foundation Board of Directors, to the NASEM working group that developed the "Enhancing NIH Research on Autoimmune Disease" report.



Scott M. Lieberman, MD, PhD, served as a member on the Committee for the Assessment of NIH Research on Autoimmune Diseases. Dr. Lieberman is an associate professor of pediatrics in the Division of Rheumatology, Allergy and Immunology at the Carver College of Medicine, University of Iowa.

Scott M. Lieberman, MD, PhD served as a committee member on the NASEM group for Enhancing NIH Research on Autoimmune Disease. Dr. Lieberman is an associate professor of pediatrics in the Division of Rheumatology, Allergy and Immunology at Carver College of Medicine, University of Iowa.

The OADR-ORWH established the Autoimmune Disease Research Coordinating Committee to provide a forum to support strategic decisions and engagement with community stakeholders and collaborate with autoimmune expertise across institutes, centers, and organizations.

The Sjögren's Foundation is a member organization of the Autoimmune Disease Coordinating Committee along with the Autoimmune Association, which is leading the charge on behalf of all our autoimmune disease organizations in aiding the OADR. Janet Church, CEO, and Kathy Hammitt, VP of Medical and Scientific Affairs, are representing the Sjögren's Foundation and have participated in all meetings held to date with the new office. ■

"We are thrilled to work closely with the new NIH Office of Autoimmune Disease Research and the Autoimmune Association to forge a critical and collaborative relationship that will spark needed research in Sjögren's and related autoimmune diseases." — Janet Church, CEO



STRONGER
THAN SJÖGREN'S

Celebrating a Successful 2023 Walk for Sjögren's! Thank You for Being Stronger than Sjögren's!

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. Each year we have a different theme and for 2023, our theme was Stronger than Sjögren's! We wanted to take a moment to thank everyone who stepped up by supporting our Walks this year showing that every day, you are stronger than this disease!

The Foundation continued to hold virtual events and came back live to Philadelphia; at every event our Sjögren's community really Sjö-ed up and participated! Our success is because of YOU, our amazing volunteers, and supporters. Thank you for being a part of our journey to conquer the complexities of Sjögren's. The funds raised allow us to continue providing valuable programs and services, advocating for patients, and funding research to change the future of Sjögren's. Thanks to your support, we raised over \$240,000 from Foundation Walk events!

We'd like to thank our Chairs of each walk, our Stars, and our sponsors!

Thank you to our Chairs of each Walk for Sjögren's!

2023 Walk for Sjögren's Event Chairs

<i>Southwest Virtual Spring</i>	Yolanda Gales
<i>Southeast Virtual Spring</i>	Lois Pippin and Suzi Wixson
<i>Mid-Atlantic and National Virtual Spring</i>	Bonnie Elverum
<i>Philadelphia Virtual Spring</i>	Chris & Tom Iatesta
<i>Texas Virtual Spring</i>	Paula Aiklen
<i>Colorado Virtual Spring</i>	Jessica Levy
<i>New England Virtual Fall</i>	Allissa Latham
<i>New York Virtual Fall</i>	Katie Forte
<i>West Coast Virtual Fall</i>	Rayna Keen

Thank you to everyone who joined and increased awareness by taking part in a Walk event!



Walk for Sjögren's Stars

Congratulations and thank you to our Walk for Sjögren's Stars in 2023! They contributed to the success of a Walk for Sjögren's with their outstanding outreach and by raising \$1,000 or more. View our 2023 Stars and learn more by visiting events.sjogrens.org or click the QR code below.



Thank you to our National, presenting and Major Sponsors for the 2023 Walk for Sjögren's Events!



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If you would like to receive this newsletter but are not currently a Member, please contact us at (301) 530-4420

Season of Giving



It is truly an exciting time in Sjögren's. 2023 has seen amazing growth and advancements in several key areas including research and clinical trials, patient support, and provider education. The Sjögren's Foundation is incredibly proud of all the many successes and accomplishments achieved in the past year. Additionally, we are humbled and proud to continue to advocate in honor of all Sjögren's patients and to play a key role in delivering support and services to patients in need across the country.

This past year, the Foundation was saddened to lose our beloved founder Elaine Harris, a true advocate for Sjögren's patients. But her mantra "founded by a patient, for patients" remains at the center of what we do by ensuring that the patient, and the patient voice, is never lost in our efforts. And we will carry on her legacy by continuing to always put the patient first.

We are truly grateful that you share our passion and vision to strengthen our Sjögren's community and to conquer the complexities of this complex and serious disease.

As 2023 comes to a close, we reflect on a dynamic year in Sjögren's and excitingly look ahead to the progress and advancements that the future holds. While we continue to make great strides, there is even more work to be done which is why we are asking you for your support as we eagerly approach a new year. Please consider giving a year-end donation and together, we can continue to make a difference for all those living with Sjögren's.

*Wishing you a joyous holiday season
and happy New Year!*

Donate online

