CONQUERING Sjögren's

March/April 2024

April is Sjögren's Awareness Month!

Sjögren's FOUNDATION

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A Letter from your CEO, Janet E. Church

Welcome to the March/April 2024 edition of *Conquering Sjögren's*! I always love this particular edition each year because it heralds Sjögren's Awareness Month in April. As it is the 40th anniversary of the Foundation, April 2024 is particularly special because we are celebrating the progress that we have made over the past four decades.

As always, we will be holding our *National Patient Conference* in April, and we will continue to present the conference in a virtual format to reach more people who want to learn about Sjögren's and connect with fellow patients. We are changing our technology platform this year, which will allow us to offer more sessions, community rooms, and exhibitor and sponsor areas. There will even be a special event on Friday, April 5th — which we will highlight later in March. We are very excited about this new platform, and we think you will be too!

We will also be showcasing patients during April to give light to the many faces of this disease. Our goal is to bring greater awareness that Sjögren's is more than dry eyes and dry mouth and that it also affects men and women at any age.

Our advocacy efforts are in full action at the Foundation, and we anticipate some big wins this April! Stay tuned to learn more about these efforts. Although we are not ready to share the specifics, I do want you to know that we are working tirelessly to bring greater awareness about Sjögren's to the U.S. Congress and to different agencies in government.

Turning to this edition of *Conquering Sjögren's*, I'd like to draw your attention to the article about January's *State of Sjögren's*. This is our clinician and researcher education event about the disease, and it is our goal to draw in more and more professionals each year. This year, we partnered with National Jewish Health to provide continuing medical education (CME) for both doctors and nurses! Not only did our professionals have the opportunity to receive CME credits for attending our virtual event, but we are now launching a CME online course that will endure until our next *State of Sjögren's* in January 2025. As soon as we have this program live, we will be informing everyone to send their own clinicians to the course so they can become better educated about Sjögren's. I encourage you to read the article and learn what was covered this year— it was a huge success, and we thank our experts for volunteering their time to educate their peers.

We also highlight new research awards from the National Institutes of Health (NIH), and we, of course, highlight patients and our incredible volunteers. For this edition, we chose to bring you information about dryness and new tips to consider. At the Foundation, we do like to message outwardly that Sjögren's is more than dryness, but symptoms of dryness are still a considerable burden for us!

As we prepare for the many activities this Sjögren's Awareness Month, I would like to stress that we cannot do any of our work without you! Whether you volunteer your time or donate to support our efforts, you are not only making a difference to other patients, but you are helping us drive greater awareness and knowledge about this disease that impacts so many lives. Thank you! ■

STATE OF Sjögren's

Highlights: The Many Faces of Sjögren's

Healthcare professionals, researchers, and other professional stakeholders from a broad range of specialties joined the Sjögren's Foundation on January 26th for the third annual *State of Sjögren's*, which focused on the "Many Faces of Sjögren's" and the difficult-to-diagnose patient. The goal of the *State of Sjögren's* is to provide an update on best medical practices and current research related to Sjögren's at the beginning of each year for our medical and scientific colleagues. This was the first year that the event was accredited for continuing medical education (CME), thanks to the Foundation's collaboration with National Jewish Health.

Sjögren's Foundation Initiatives

The State of Sjögren's began with Janet E. Church, Sjögren's Foundation President & CEO, providing an update on the Foundation's work this past year. The Foundation has worked diligently to increase opportunities for provider education and resources, which included providing clinical trial training for ESSDAI on STEP, creating and collaborating on several professional CME courses, networking at new healthcare professional and research conferences, and publishing the Pulmonary Clinical Practice Guidelines in CHEST. Based on the Foundation's *Living with Sjögren's* survey, approximately 83% of Sjögren's patients had at least one nervous system related health condition. This and other data support the development of the clinical practice guidelines on peripheral nervous manifestations in Sjögren's, which are in the final stages of development.

The Foundation has also expanded its research outreach by investing in Proposal Central, a database that will streamline our research grant process and provide access to more researchers. Over the past two years, the Foundation has funded more than $1.3 million in research. This past year, the research grant mechanisms were revamped to include more mechanisms as well as an increase in funding.

The Foundation was also involved in many advocacy efforts, which included submitting a request for dental coverage to the Centers for Medicare and Medicaid Services, informing Congress of the benefit of prescription to over-the-counter switch for many preventive therapies for Sjögren's patients, and providing research input for the Office of Autoimmune Disease Research.

The virtual event will be converted into an enduring CME course on our Sjögren's Training and Education Platform (STEP) and will remain open until next January. Please let your healthcare team know that they can learn more about the enduring course and how to receive accreditation at https://sjogrens.org/researchers-providers/state-of-sjogrens.

After the update from the Sjögren's Foundation, the Chair of the Foundation's Medical and Scientific Advisory Council and moderator for the State of Sjögren's event, Alan Baer, MD, provided a brief overview of the program and introduced the seven expert speakers for the day.

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The Many Faces of Sjögren's

Thomas Grader-Beck, MD, Associate Professor at John's Hopkins University, was the first speaker who discussed the "Many Faces of Sjögren's" and focused on the heterogeneity of the Sjögren's patient population. The spectrum of symptoms and system involvement that Sjögren's patients experience can drastically vary compared to the more commonly known symptoms - dryness, pain, and fatigue. Dr. Grader-Beck described ESSDAI (EULAR Sjögren's Syndrome Disease Activity Index) as a good tool for determining the framework of Sjögren's, but that it does not encompass the entire spectrum of system involvement and should not be used as a diagnostic metric.

The differences between male and female Sjögren's risk associations and prevalence were also described– including that males have a higher risk of lymphoma and more serious ocular complications compared to females who have more pronounced ocular and oral dryness. Juvenile Sjögren's, which includes childhood and adolescent patients, presents with more frequent parotid swelling, fevers, and skin and kidney disease compared to adult Sjögren's patients. Elderly Sjögren's patients present with less joint pain but much more frequent and severe oral involvement and interstitial lung disease.

Research efforts to improve patient identification and grouping produced data that classify Sjögren's patients by their symptoms versus disease burden, which provides important patient perspective data for clinicians and researchers. As we gain more information on Sjögren's, our knowledge about disease onset and clinical manifestations may change, as many patients were diagnosed long after onset of symptoms. It is important for healthcare professionals to continue to improve recognition and diagnosis of the disease.

The Difficult-to-Diagnose Patient

Astrid Rasmussen, MD, PhD, Oklahoma Medical Research Foundation, next presented on the difficult-to-diagnose patient. Although Sjögren's is the second most common systemic autoimmune disease, approximately 50% of patients remain undiagnosed. She further describes that classification criteria are not the same as diagnostic criteria. In fact, there is no single diagnostic or gold standard test for Sjögren's. Research must be homogeneous— meaning that the research has to have uniform sampling from a population, which is why classification criteria exist.

Unfortunately, this requirement means that many Sjögren's patients are excluded from research based on classification criteria, which include a diagnosis by a positive Sjögren's autoantibodies (SSA/Ro or SSB/La) test or a positive labial salivary gland biopsy. However, approximately 30% of Sjögren's patients are negative for Sjögren's autoantibodies. To further complicate diagnosis, Sjögren's patients often present with rheumatoid factor (RF) and antinuclear antibody (ANA), which can lead to misdiagnosis or underdiagnosis of Sjögren's patients.

In an OMRF study, it was determined that 35% of patients diagnosed with another autoimmune disease had undiagnosed Sjögren's, while only 17% of Sjögren's patients were identified as having another overlapping autoimmune disease. Of the 55% of patients in the OMRF cohort with no prior autoimmune diagnosis, 44% of these patients were ultimately diagnosed with Sjögren's. This data shows the magnitude of misdiagnosis and underdiagnosis for Sjögren's patients. Although clinical diagnosis is drastically down compared to where it once was, to under five years from onset of symptoms, the discrepancy in time of diagnosis may lead to further damage due to delayed preventive and therapeutic strategies.

International Nomenclature Initiative

Dr. Baer then discussed the International Nomenclature Initiative, which involves both patients and clinicians working to reach consensus on the language we use for Sjögren's. By far the most important recognition is that Sjögren's is not a syndrome but rather a distinct, prevalent, and systemic autoimmune disease. This is an ongoing initiative and the final outcomes will be shared once available.

Non-canonical Autoantibodies for Sjögren's

Darise Farris, PhD, who is the Director of the OMRF Sjögren's Research Clinic, focused her talk on determining whether Sjögren's patients who are negative for Sjögren's autoantibodies— SSA/Ro and SSB/La antibodies— have other detectable autoantibodies. Novel autoantibodies in the plasma of Sjögren's patients were found, which included 8 proteins that were preferential to both Sjögren's autoantibodies- positive and -negative patients and 16 proteins that were preferential to Sjögren's autoantibodies- negative patients only.

A proof-of-concept study that included other autoimmune diseases as well as non-autoimmune disease controls showed that there were 30 total proteins that were preferential to Sjögren's autoantibodies- negative patients. The analysis showed that this model could be predictive in determining Sjögren's autoantibodies- negative patients as well as Sjögren's autoantibodies- positive patients as well as controls. This study was a small sample size from a

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single center, so future studies will need to focus on a larger sample size from multiple centers. The Sjögren’s Working Group within the Foundation for the National Institutes of Health (FNIH) Biomarkers Consortium has selected the described approach to determine other biomarkers for patient identification and grouping, which will include over 400 patients and three centers. If approved, the study is scheduled to launch in 2024.

On the Horizon: Research to Improve Diagnosis

Athena Papas, DMD, PhD, Johansen Professor of Dental Research at Tufts School of Dental Medicine, described the ongoing research effort and challenges to create a diagnostic assay using the saliva of Sjögren’s patients. Specifically, Dr. Papas is determining the saliva exosome, which are extracellular vesicles (thin-walled sac) that carry proteins, lipids, and genetic material that can provide valuable information about how Sjögren’s disease develops and progresses. One of the largest challenges with developing a saliva assay to determine genetic differences between patients is contamination from the oral microbiome— bacteria, fungi, and viruses that live in the mouth. To overcome this challenge, a saliva exosome assay was optimized for the profiling of human long non-coding RNA (small chain of genetic material that does not give code for proteins). Analysis of this data showed the discovery of newly identified gene signatures and that the interferon pathway, which is part of pro-inflammatory signaling, was implicated in Sjögren’s.

The study also determined that the newly identified gene signatures could predict and separate SSA/Ro negative Sjögren’s patients from SSA/Ro positive patients. This research provides potential for a non-invasive, molecular method of diagnosing Sjögren’s.

Unlocking Early Detection: Salivary SSA/Ro Autoantibodies in Sjögren’s Disease (SjD) and non-SjD sicca

David Wong, DMD, DMSc, Director of the Dental Research Institute at University of California Los Angeles, discussed his research efforts to develop a salivary biomarker assay as a diagnostic tool for detecting Sjögren’s in patients. In saliva, SSA/Ro and SSB/La autoantibodies are readily detectable in Sjögren’s patients who not only test positive for serum Sjögren’s autoantibodies, but also test negative for serum Sjögren’s autoantibodies. The saliva biomarker assay was able to discriminate against Sjögren’s patients compared to both non-Sjögren’s sicca and controls. Furthermore, this provides evidence of localized disease development and progress in the salivary gland of Sjögren’s patients. Further validation is required for this study, but data suggest that positivity for salivary Sjögren’s autoantibodies can be an early detection and diagnostic tool for Sjögren’s.

Sjögren’s Clinical Trials: Progress and Barriers

Daniel Wallace, MD, Chair of the Sjögren’s Clinical Trials Consortium, focused his presentation on the clinical trials that are currently in progress for Sjögren’s. Currently, most of the FDA-approved treatments are for common symptoms of Sjögren’s, such as dry eye (5) and dry mouth (2). For a long time, there were no potential therapies in clinical trials to treat systemic Sjögren’s — now there are 18 among phase I (3), phase II (10), phase III (4), and phase IV (1) clinical trials. He further described the targets in the pipeline for systemic therapies, which include improved anti-CD40 and anti-CD40L, BAFF and BAFF-R inhibitors, and interferon signaling pathway targets, among others.

While the pipeline therapies are promising, the FDA has not approved any drug to specifically treat Sjögren’s, and it’s been 25 years since pilocarpine and cevimeline were approved for dry mouth. Clinical trials for Sjögren’s still face many core issues. Among these issues are that many patients do not meet classification criteria necessary to be enrolled in a clinical trial and as such there is an insufficient number of studies in the U.S. with enough patients to participate in meaningful clinical trials. Furthermore, many current studies do not improve oral and ophthalmologic manifestations as a primary endpoint. To address some of these issues, a number of organizations and working groups set out to improve the classification criteria by which Sjögren’s patients are evaluated and included in clinical trials.

To conclude, this last year has been an exciting one filled with new research, promising diagnostic tools, and potential systemic therapies for Sjögren’s patients on the horizon. The Foundation looks forward to another year of progress as we continue to commit to our mission of creating a community where patients, healthcare professionals, and researchers come together to conquer the complexities of Sjögren’s. ■

Editor’s Note:

The research on diagnostic tools and potential biomarkers described in this article is still ongoing and not yet ready for clinical use. The purpose of sharing this information is to relay new discoveries and the potential of current research in Sjögren’s to healthcare professionals and other researchers in our *State of Sjögren’s* course. The Foundation will continue to keep you updated on the progress of these studies and the availability of new diagnostic tools.

Combatting Dryness:

Patients Share Their Favorite Tips and Advice

Winter and spring seasons can present additional challenges for Sjögren's patients, especially around dryness. Depending on where you live, this time of year can be cooler, with a drier climate, and a variety of weather changes. Cooler and drier weather can exacerbate symptoms for Sjögren's patients due to lower humidity, drier air blowing from HVAC systems, smoke from cozy fires, and other conditions that can contribute to your symptoms. To help you combat dryness, we asked patients to submit their favorite tips that help them most. This article highlights what patients shared!

Editor's Note: *The advice and products mentioned are solely recommendations by our patients for what helps them reduce their symptoms. The Sjögren's Foundation does not endorse the products mentioned in this article. If you are experiencing worsening symptoms, please contact your physician immediately.*

Dry Mouth, Nasal Passages, and Airways:

Dry air (outside and inside) can be a key contributor to increased symptoms of dry mouth and nasal passages. In dry mouth where your salivary glands do not produce enough saliva, staying hydrated and using the right products consistently can help stimulate saliva production and keep the mouth moistened when saliva isn't being produced. Sjögren's patients also often have decreased mucous production in their nasal passages, causing a drier nose that can create sores. The function of mucous is to filter the air we breathe in and to keep our nasal and sinus passages and throat from becoming dry. The lower humidity of the cold outside air or the constant blowing of inside also reduces the moisture in your mouth and nasal passages. Without the protection of saliva and mucous, these conditions can make your dry symptoms worse. Similarly, lower humidity and change in temperature can irritate your throat and lungs. Here are some of your tips and over-the-counter products for reducing the symptoms of dry mouth and dry airways:

Tips and Advice

- Leave a water bottle in areas of high use, such as by your bed, in your car, in your travel bag, by your desk, etc. so that you can always have water within reach.
- Carry a water bottle with different handles and openings, especially for when flare-ups occur so that you can open them with more ease- different situations require different types of water bottles.
- Wear a mask to cover your nose and mouth. Masks often trap moisture and increase the humidity of air the wearer breathes in. Use these in especially dry conditions, such as around a fire, on an airplane, and in a dry office building. There is also the added benefit of offering some protection from viruses and other pathogens or irritating air pollutants.
- Avoid foods and beverages that can cause dryness or inflammatory symptoms, such as salty foods, high-acidic foods, garlic, onions, caffeine, chilis, sugar, etc.
- Avoid direct air exposure from fireplaces, wood-burning stoves, space heaters, and fans.
- Apply Vaseline, Aquaphor, or other hydrating ointments and balms on the lips and slightly in or around the nose to prevent them from drying out.

  Note: *Some ointments that contain humectants, like glycerin and hyaluronic acid, can be tricky in dry, low humidity conditions. Humectants, in general, are designed to hydrate but in dry, low humidity conditions they can also pull moisture away from the mouth, skin, nose, and lips. If you notice drier symptoms, discontinue use.*
- Be sure to only use ointments very sparingly in your nose; inhaling ointment into your lungs can be dangerous.
- Use a humidifier to help with moisture and humidity in the air. Be sure to use either a self-sterilizing hu-

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midifier or change the distilled water every 2 weeks to prevent bacteria, mold, and fungus growth and release into the air. Washing with diluted vinegar every week can help keep your humidifier clean.

- Use Dry Mouth mints at bedtime, especially Xylimelts by Oracoat.
- Gargle with Biotene, and other approved oral rinses and medications to help with dry/sore throat and dry mouth.
- Breathe in steam from a hot bath, shower, or a pot of boiled water to help with dry throat, nasal passages, and lungs.

Please also see our Clinician’s Corner on page 12, where Dr. Mabi Singh, DMD, MS discusses “Overcoming the Sensation of Dryness of the Mouth (Xerostomia)”.

Dry Eyes

The blast of dry air to your face by cold winds or the HVAC system can leave your eyes irritated and drier than before. The cold air doesn’t hold as much humidity and can cause what little tears Sjögren’s patients produce to evaporate more quickly. Couple this with the drier air caused by heating systems and it can lead to worsening of dry eye symptoms. Please see the January/February issue of Conquering Sjögren’s, where we asked ophthalmologist, Esen Akpek, MD, for her advice on winter dryness and dry eyes in our Clinician’s Corner. Here are your tips for dry eye:

Tips and Advice for Dry Eyes

- Apply eye ointment at bedtime to help keep moisture in at night.
- Use a warm compress throughout the day and heated eye masks at night.
- Wear onion goggles or other protective eyewear when outside or near a heat source like a fireplace or wood stove.

Bonus Advice and Products for Hair, Skin, and Nails

- Put on lotion and gloves to cover your hands and retain moisture before going outside.
- Apply a thick layer of coconut oil on your fingers and nails, wait 10-15 minutes, and then rub into hair and scalp.
- Apply thick cream lotions or baby oil immediately after a shower and then towel dry.
- Apply Aquaphor or Vaseline on your feet and put on socks at bedtime.

We want to thank all our patients who wrote about their favorite tips and advice for dryness! Some are good old standbys (that will always be helpful) and we hope some new tips and advice help you. No matter the advice, the key to dryness is to stay on top of it and don’t let any part of your body get too dry before you treat it again! ■

Sjögren’s Disease Research Study

Study Title: **Sjogren's Team for Accelerating Medicines Partnership (STAMP)**

Sponsor: National Institutes of Health - AMP AIM

Purpose: To determine the cause of Sjogren's disease; to improve our understanding of it; and, to help find new therapies using powerful, cutting-edge technologies. This is not a treatment or "drug trial".

Sites:
UC San Francisco / UC Berkeley - contact: (510) 318-2159 or SJOGRENS@UCSF.EDU
Johns Hopkins Sjogren's Center (Baltimore, MD) - contact (410) 550-6492 or (410) 550-9821
Oklahoma Medical Research Foundation (OKC, OK) - contact (405) 868-9412 or SJOGRENS@OMRF.ORG

Assessments for this study (eye, mouth, and physical exam, as well as ultrasound) will be provided at no cost. Research results that are used for Sjögren's classification will be returned to you.

You may be eligible if you are 18 or older with at least one of the following:

Dry Eyes
Previous Sjögren's' diagnosis
Multiple dental cavities/caries
Dry mouth
High rheumatoid factor (RF)
High anti-nuclear antibodies (ANA)
OR Positive anti-Ro/SSA, anti-La/SSB
Swollen parotid salivary glands

Study Assessments:

Physical Exam, Ultrasound of Salivary Glands
Dental Exam & Saliva Collection
Eye Exam
Minor Salivary Gland Biopsy (requires a small incision inside the lower lip)
Blood/Urine Collection & Health Questionnaires

40 Years Sjögren’s FOUNDATION

Sjögren’s Disease Research Study Sponsored by National Institutes of Health— AMP® AIM

The purpose of this study is to determine the cause of Sjögren’s disease; to improve our understanding of it; and, to help find new therapies using powerful, cutting-edge technologies. This is not a treatment or “drug trial”.

For more information, please visit visit https://info.sjogrens.org/stamp-sjogrens-disease-study or scan the QR code to view the flyer prepared by the Sjögren’s Team for Accelerating Medicines Partnership (STAMP).

Patient-to-Patient Stories:

Sjögren's Isn't Just Dryness

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.

To follow our theme of Combatting Dryness, our Patient-to-Patient will focus on those that selected dryness as one of their most difficult symptoms. Although these patients experience dryness, their range of symptoms and systemic involvement show the heterogeneity of Sjögren's and that their symptoms aren't just dryness.

The Foundation wants to thank everyone who has shared their story, and we look forward to sharing more of your stories during Sjögren's Awareness Month in April. Please see page 18 for how you can contribute by sharing your stories during our April Awareness campaign.

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.

Melissa

(Age: 46, diagnosed at 46)

I wish I knew that Sjögren's was more than dryness in the body. When I first started feeling bad, the fatigue was overwhelming, but the pain all over my body was frustrating. One day it would be my hips and ankles, the next my individual toes would ache. It was hard to make sense of it because the pain points did not seem related or consistent. Choosing to take medication to help me manage the pain has helped give me my life back!

The Impact of Sjögren's

I am in my first 6 months of being diagnosed and I have had to learn I cannot do as much as I did before. I have to rest and on the really tough days, I ask for help from friends and family. Being diagnosed is a complete lifestyle change!

Best Advice

Taking time to walk every day, keep up my water intake, meal plan, and get a massage. Do not feel crazy when your pain is different from day-to-day, listen to your body and rest.

Your Go-To Products/Tools

Tylenol Arthritis, Seabuckthorn oil is helpful for dry eyes & mouth, and a gluten-free diet is worth the planning and sacrifice!

Douglas

(Age: 73, diagnosed at 72)

I'm sicker than I act or look. I've noticed difficulty with the effects of Sjögren's on male sexuality, including erectile dysfunction, desensitization, and orgasm. I also experience lightheadedness and fatigue. My dryness has improved, since being on hydroxychloroquine.

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The Impact of Sjögren's

I'm somewhat down, but not severely. I lack energy and desire to engage in my usual activities- Apathy. Friends should reach out more to do activities and exercise, it seems I do almost all the reaching out.

Best Advice

Talk to your Rheumatologist and take your meds. When you can, make yourself exercise and do activities like seeing friends. Take it all one day at a time.

Your Go-To Products/Tools

Eye drops, lip balm, mouth moisturizer, and prescription fluoride toothpaste as well as hydroxychloroquine and Cialis®.

Kristina

(Age: 44, diagnosed at 43)

My first symptoms were neuropathy and Orthostatic Hypotension. My dryness symptoms didn't start until two years into my journey. Couple that with mostly "normal" labs and doctors were baffled as to what to do with me. But thanks to the Sjögren's Foundation and other resources, I knew what I had. I just had to fight for over four years to get a lip biopsy to prove it, which I did! Trust your gut.

The Impact of Sjögren's

Sjögren's has greatly impacted my life. I had to substitute the boxing gym for a recumbent bike. I had to reduce my work hours from 60 hours a week to 35 hours a week. I had to change what I put into my body, which can feel isolating when friends and family can eat or drink what they want.

I wish I gave more credit to stress and the impact it now has on my health. Even mild-moderate work stress at a sustained level can drastically increase my symptoms. Pushing through isn't the answer, but finding balance is.

Now that I have a diagnosis and treatment, many of my symptoms are better, such as neuropathy, Orthostatic hypotension, and fatigue. However, I still really struggle with dry eyes, excessive thirst, gastrointestinal issues, and muscle pain and weakness.

Best Advice

Educate yourself. Too many times I was more knowledgeable than the specialist that was supposed to help me. It is frustrating, but I'm proud that I haven't taken the time to familiarize myself with the latest research, because I could see how easily I would have believed the outdated and false information being fed to me.

I learned to take breaks with intention. Walk away from the computer to do a little tai chi or cuddle with my pets. I also believe in therapy, especially with a therapist that understands chronic illness. Lastly, get lost mentally. Escape in a book, get distracted in the garden or go for a walk with some happy dogs.

Your Go-To Products/Tools

I have many favorite Sjögren's products. My top 3 would be Nalgene bottle (with Liquid I.V.® once per day), electric eye mask (timer and temperature control), and Thera Tears eye drops.

I also highly recommend a health tracking app. I personally use Bearable. Sometimes when we are go, go, go or stuck in our ways, we can't see even obvious connections between factors and symptoms. Using an app helps see the data in black and white.

Cyndi

(Age: 54, diagnosed at 41)

I was diagnosed the same day that Venus Williams announced she was diagnosed with this disease that no one could pronounce. I was terrified when I saw the effects it had on her and anticipated the same for myself. Very scary times. I attended a Sjögren's conference with my husband and soaked in all that I could. From that day forward I felt I took my power back!

Knowledge is power. The more you know the more you can prepare for a flare. Most difficult realization for me was that getting the flu, or a sinus infection was no longer just an infection. Every SINGLE time for me a sickness causes a Sjögren's flare and I'd be down for the count. Once I learned that a cold would no longer be just a cold, I took better care of myself.

The Impact of Sjögren's

When I was diagnosed it was IMPOSSIBLE for me to get health insurance through my husband's (or my) employer. I remember getting a letter of denial stating my prognosis was not one that would be accepted because my life expectancy was unknown. That was devastating (and untrue). Insurance companies needed to be educated about Sjögren's and progress has been made in that regard.

Currently, my symptoms include nosebleeds (and more nosebleeds), dry eyes, joint pain (x12), and brain fog.

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Best Advice

Use your voice. Don't be afraid to say No. Don't be afraid to stay in and rest and practice self-care. Don't feel guilty about putting yourself and your health first.

Sleep with water by your bed. Often, I will wake up coughing and almost choking from dry mouth (and throat). Hydrate, Hydrate, Hydrate.

Your Go-To Products/Tools

Lumify – it's for redness but truly it keeps my eyes lubricated for hours.

Lindsie

(Age: 41, diagnosed at 38)

For me eye dryness has been one of the worst symptoms I deal with. I have had Sjögren's spot and ulcers on my corneas and it's all from Sjögren's and dryness. The ulcers I get in my nose and mouth can be painful. So, I have to make sure and take meds I am prescribed and drink lots and lots of water daily. Exercise regularly and eat healthy and it helps minimize symptoms. Really listen to your body.

The Impact of Sjögren's

There are these different steps to add to your daily routine like extra lotions for dryness, eye drops, medications, etc. Sjögren's is life changing and it wears on you emotionally because you cannot do what you have been able to do before Sjögren's— it can even be draining.

Pain and dryness are the most difficult symptoms. The amount of dryness in the eyes, mouth, vagina, and nasal passages can really affect you, while the joint pain, body aching, and fatigue can just drain you.

Flares are very hard. In addition to Sjögren's, I have Lupus as well so knowing the difference of each flare is important and figuring out which disease is causing the symptoms is challenging.

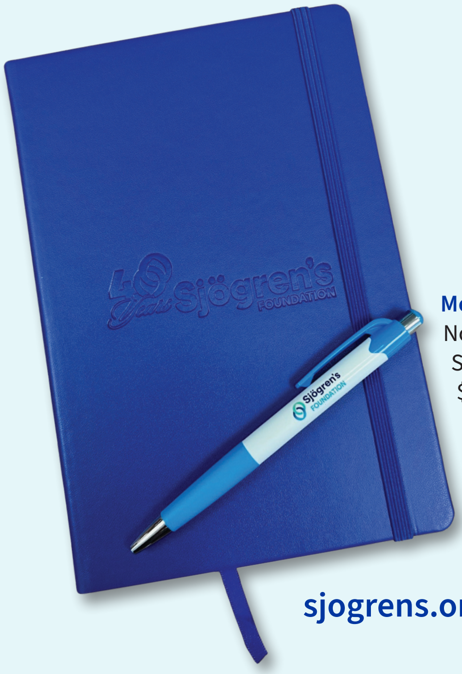
Best Advice

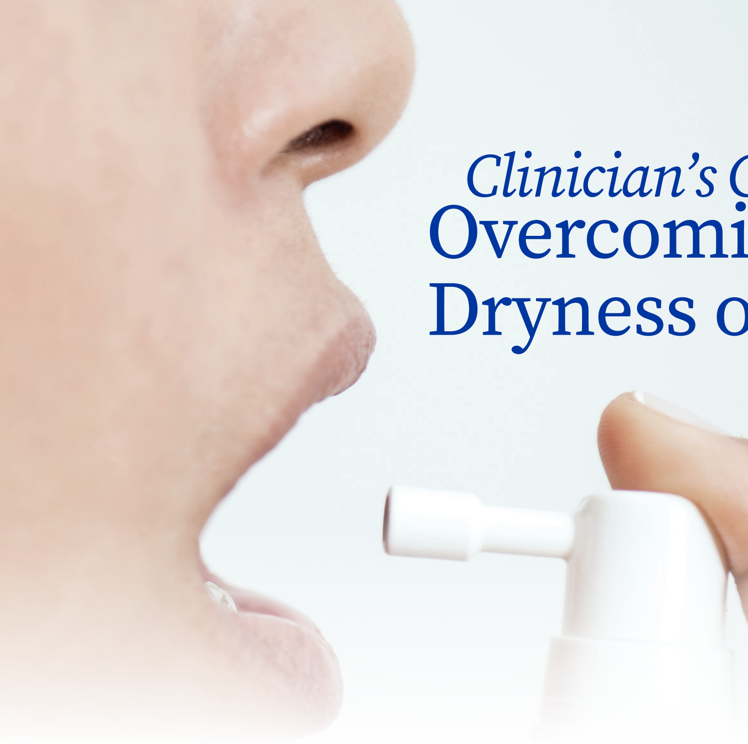
Listen to your body. When I am fatigued or exhausted feeling I must rest because if I don't the flare up that comes along is no fun at all. Talk openly and frankly with your doctors, sometimes you have to educate them on the disease. Advocating for yourself when you know something is off or not normal don't give up or take what they tell you and just go with it. If it doesn't sound right keep pushing for answers because you know your body best. They may see you in their office on a good day, but they don't see all the bad days and those are the days you need more help or intervention from them.

Your Go-To Products/Tools

Lubricating eye drops, moisture lubricating gel for vaginal dryness, lozenges for dry mouth.

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. ■





Clinician's Corner:

Overcoming the Sensation of Dryness of the Mouth *(Xerostomia)*

Dr. Mabi Singh DMD, MS
Professor, Oral Medicine Service,
Department of Diagnostic Sciences,
Tufts University School of Dental
Medicine, Boston MA

The subjective sensation of dryness in the mouth, known as xerostomia, typically results from hypofunction (decreased function) or reduced production of saliva by the salivary glands. Salivary characteristics can range from watery to thick, foamy, viscous, ropey, stringy, to complete absence of saliva, depending on the functioning of the remaining salivary glands to produce water and salivary proteins. At times, changes in physical characteristics may give the perception of having too much saliva (subjective sialorrhea), even though the volume is lessened. Hypofunctioning of the salivary glands leads to the reduced production of saliva and the subjective perception of dryness in the mouth. Treatment and relief from the sensation of dryness hinge upon the ability of the salivary glands to produce saliva, and the same treatment may have different outcomes individually. Additionally, the mouth is a highly dynamic organ involved in the clearance of contents, requiring multiple approaches for effective management and relief of dryness.

Some suggestions and explanations for relief from subjective sensation of dryness of mouth.

- Perception of dryness increases with an increase in friction in the mouth, as one of the principal functions of saliva is to lubricate. When this function is reduced or lost, normal and simple activities like eating, speaking, and swallowing become challenging. Application of viscous lipids (fats) or thick gels or oral health products directed for the relief of oral dryness on the mucosal surfaces, including the inner lips, can help reduce friction and trap moisture under the fatty film layer. To create the slippery layer, breaking Vitamin E caplets, pulling oil such as olive, sesame, coconut, or using products designed for such purpose in mouth may be helpful. Nipple creams, lipstick, or chap sticks containing petrolatum or lanolin products may also be helpful for dried and chapped lips.
- Due to the repeated attempt to wet the lips by sticking the tongue out, habits can be developed and these repetitive movements may cause tongue irritation and translate into burning sensation.
- Gustatory (sense of taste) or mechanical stimulation with chewing gum, lozenges, candies, mucosal adhesive tablets with mint flavors, and Xylitol can enhance saliva stimulation depending on the availability of the working salivary glands. However, care should be taken when introducing strong flavors such as mint, as there may not be enough saliva to dilute the taste, which could potentially lead to irritation or discomfort, even a burning sensation. Since the oral cavity is a dynamic organ and the contents are cleared quickly these have to be introduced repeatedly depending on how dry the mouth is.

Introducing products containing “arginine” or L-arginine, such as toothpaste or candies or soft chews, into the mouth not only stimulates salivary flow but also can lower acidity by raising pH levels through neutralizing acidity. This may slow down the growth of cavity-causing bacteria and Candida (yeast). It is advisable to dissolve candies slowly rather than chewing them, as the teeth of Sjögren's patients are typically brittle or heavily restored.

continued next page ▶

- Salivary proteins, such as mucins, are effective wetting and lubricating agents and are abundant in unstimulated saliva. Thus, even if hydration levels are optimal, the loss of salivary proteins may induce a sensation of dryness in the mouth. Frequent sipping of water may wash away mucins from the mouth, and the hydration caused by the introduction of water to oral tissue may be temporary or even result in a feeling of increased dryness afterwards. It may be more beneficial to drink a glass of water, as hydration is essential for our bodies, and introduce something (such as chewing gum or lozenges or tablets that stick to gum or cheek) into the mouth rather than taking big and frequent sips. Alternatively, taking very small sips of water solely to wet the oral tissue without swallowing may help hydrate and retain, instead of wash away, the salivary proteins in the mouth.

  The amount of water needed for an individual depends on factors such as body size, physical activities, and environmental conditions. Ingesting excessive amounts of water beyond the body's requirements may lead to dilution of sodium levels and result in frequent urination.
- The natural rate of saliva production is influenced by the body's circadian rhythm, with production typically being lowest at certain times of the day such as at night. Additionally, environmental factors such as low humidity due to forced hot air heating systems, geographical location, mouth-breathing, and sleep disorders can contribute to increased dryness of the mouth. Methods to reduce moisture evaporation from the mouth may include using a chin strap, taping the mouth, or placing a mucoadhesive tablet on the gums or on the inside of cheek. However, it's advisable to consult with a specialist to prevent potential adverse events and increase effectiveness of such measures. Taking a sialogogue, (many call as saliva pill) (described below) during bedtime can help.
- The average unstimulated salivary flow is approximately 0.3 ml/min, and when it falls below the level of 0.1 ml/min, it is classified as salivary hypofunction. Although oral dryness can be perceived even with normal flow, it is generally accepted that dryness of the mouth becomes noticeable below the level of 0.1 ml/min. One effective method of increasing salivary flow is through the use of prescription sialagogues such as pilocarpine HCl and cevimeline HCl.

  To enhance the tolerability of these pharmaceutical agents, it is advised to gradually increase the dose, a process known as titration. For example, patients should start by taking one tablet (5 mg in the case of pilocarpine HCl) or one 30 mg capsule of cevimeline HCl with food to slow down absorption and reduce side effects such as sweating, increased acid production, chills, or increased heart rate. While these side effects do not affect everyone, they may occur in a small percentage of individuals. Titration helps in overcoming and building tolerance to these medications. Pilocarpine HCl can be taken up to 30 mg a day in divided dosages, and cevimeline HCl up to 3-4 capsules a day. If intolerance develops, lowering to tolerable dosage is suggested.

  The effectiveness of these medications depends on dosage and the availability of functioning salivary glands to increase saliva production. If there are no salivary glands to produce saliva due to advanced conditions of the disease and irreversible damage, there may be minimal relief from dryness even with medication. Individuals with working salivary glands typically respond well to treatment. However, in some cases, the drug may take longer to have an effect in certain individuals, potentially requiring an extended trial period before determining its efficacy. Therefore, it is advisable to persevere with the medication rather than abandoning it immediately.
- Another method to improve salivary flow is applying warm moist heat compresses to the salivary glands and gently massaging them. Professional suctioning or "boogieing" of the parotid and submandibular glands can also help, reducing the formation of mucus plugs or salivary gland stones in the salivary ducts. Additionally, this technique can provide relief from compression on the facial nerves caused by creating pressure on the salivary glands.
- The use of ultrasonic toothbrushes for tongue brushing, electrical stimulation of nerves, mechanical vibration of the salivary glands, and other similar techniques have shown mixed results in increasing saliva production and reducing the subjective sensation of dryness in certain patient populations. Sjögren's patients have reported varied success with acupuncture as well.

In summary, addressing the subjective sensation of dryness can significantly impact the quality of life for sufferers, and it should be tackled through multiple approaches, as not all individuals may respond well to a single method. Relief from dryness largely relies on the remaining functionality of the salivary glands, and there is no single "dry mouth" product that can replace natural saliva. It is important to experiment with different products to find what works best for each individual, and maintaining compliance with the chosen approach is crucial. ■

Sjögren's Foundation 2024
National Patient Conference

Conquering Sjögren's Together– 40 Years of Progress!

Friday, April 5th – 12:30 pm - 5:00 pm (EDT)
Saturday, April 6th – 12:30 pm - 5:30 pm (EDT)

40 Years

The Sjögren's Foundation invites you to join us for our 2024 National Patient Conference! The Sjögren's Foundation is celebrating our 40th year, and we are excited to take this opportunity to bring you a new conference experience. This year's event is a two-day virtual event using a new and improved conference platform. You can expect a richer, more dynamic, virtual conference experience with more sessions and opportunities to connect!

Sjögren's is different for every person diagnosed, which is why educating yourself on the most up-to-date information about this disease is so important. This conference will allow both new and seasoned patients to increase their understanding of the complexities of Sjögren's, connect with fellow patients and learn new daily living tips by:

- Learning from national Sjögren's experts on both foundational and complex symptom topics
- Connecting with other patients in our new patient communities
- Visiting with exhibitors and product representatives in new virtual booths

During the main stage clinical sessions, you will learn from leading Sjögren's experts and you will have opportunities to ask them questions, in real time, right from the comfort of your own home. This has always been a popular cornerstone of the conference experience and treasured by past participants. This year, we are adding a special community session on Friday afternoon to allow an additional opportunity for Q & A with a Sjögren's expert.

Check out this year's conference topics and speakers:

- Sjögren's Overview – Thomas Grader–Beck, MD
- Oral Manifestations of Sjögren's – Vidya Sankar, DMD
- Headaches & Sjögren's – Arun Varadhachary, MD, PhD
- Pediatric Sjögren's Update – Sara Stern, MD
- Ocular Manifestations of Sjögren's – Sezen Karakus, MD
- Healthy Sexual Function Throughout Life – Cuoghi Edens, MD
- Stop Bloq Initiative Overview – Jill Buyon, MD
- Dermatology Concerns in Sjögren's – Natalie Wright, MD
- What is on the Horizon for Sjögren's? – Darise Farris, PhD
- Empowered Patients! – Patient Panel with Foundation Board

Registration

Members– $80 – Note: *members must use discount code to receive discounted rate. Code has been emailed to all current members.*

Non-Members- $100

Learn more about conference topics, speakers, agenda and registration at our conference event page: https://www.accelevents.com/e/2024npc

Please Note: Registrants must have a device with internet access to join the conference. If you register and are unable to attend, or would like to replay a presentation, they will be available after the conference to review.

QUESTIONS?

Call (301) 530-4420, email info@sjogrens.org

Childhood Onset Sjögren's Disease

When the average person thinks about Sjögren's Disease (SjD), I imagine that they do not think about children. However, if you ask someone living with SjD to think about when their symptoms began, a common response is many years prior to diagnosis. Moreover, it is also common for them to recall unexplained symptoms as teenagers later attributed to SjD. In fact, one of the first reports of the typical oral and ocular dryness (sicca) symptoms in the 1930s described the disease in a 17-year-old girl.

The Current Challenge

Considering the natural course of the disease is primarily gland inflammation, a subsequent decrease in gland function, and ensuing dryness— it is not surprising that dryness may not be the first symptom. Several epidemiologic studies over the past twenty years have highlighted that children with SjD are more likely to present with a different set of symptoms compared to adults, including higher rates of salivary gland swelling and sicca symptoms only disclosed when questioned. Similarly, diagnostic testing may not reveal the same degree of gland inflammation or decreased gland function as expected in adults making it harder to support the diagnosis. When children are diagnosed with SjD by experts experienced in the disease, many of them do not fulfill accepted SjD classification criteria. This is most likely because the diagnosis is made in part by relying on the presence of dryness and children may just be in an earlier disease stage. It is also possible that childhood onset SjD represents a different disease course overall. Even after children are diagnosed, we have less information available about the best treatment approach. Most drug trials only include adults who have had SjD for many years. These results may not be generalizable to a 10-year-old child with six months of symptoms.

Our Plan of Action

An international group of pediatric specialists have been working to better understand childhood onset SjD to address the many unanswered questions our patients and families have. This includes establishing if we need to change what normal values are used for diagnostic tests when used in children, understanding the lifetime risk of cancer when the disease occurs at such an early age, identifying treatments that are effective in children, and eventually establishing pediatric-specific criteria to accurately identify children living with SjD.

Through the generous support of the Sjögren's Foundation, the Childhood Onset Sjögren disease Outcomes Network (CHOSON) was established at the Mayo Clinic in 2023. There are already 29 institutions from 12 countries that are either already part of the network or in the process of joining the network. We are enrolling children diagnosed with SjD, children in whom a high level of concern for SjD development exists, children with a laboratory marker for SjD without a current diagnosis, or children with recurrent parotid gland swelling. We are collecting information on their symptoms, physical exams, as well as laboratory and diagnostic test results which are already occurring as part of their routine medical care. We plan on following these children as long as they are willing to remain in the registry. We hope that the results of this collaborative network will eventually improve the lives of people living with SjD. If you or someone you know are interested in participating in the registry, ask your rheumatologist, ophthalmologist, or oral health provider if they are part of the network. If they are not part of the network, please encourage them to join by reaching out to me— Matthew Basiaga, DO, at basiaga.matthew@mayo.edu. ■

Awareness never looked so good!

Limited Edition April Awareness Kit

Sjögren's Soft T-Shirt

Back

Front

Sjögren's Car Magnet

Sjögren's Pen

Sjögren's Bookmark

Sjögren's Shopping Tote

Member: $34
Non-Member: $39

Show your support during Sjögren's Awareness Month by purchasing a limited-edition awareness kit.

Awareness comes in many different forms and this kit is designed to give you items that can create a conversation with family and friends about the disease. The Shopper and Car Magnet spread broad awareness in your community!

These kits will only be available for a limited time. Order your kit by calling (301) 530-4420, online at sjogrens.org/shop or use the form below.

	Qty.	Size: S-2XL	Total
April 2024 Awareness Kit **Member: $34 Non-Member: $39** **New** Sjögren's Foundation Shopper Tote **New** Sjögren's Foundation Pen **New** Sjögren's Foundation Car Magnet **New** 40th Anniversary Timeline with Major Milestones in Sjögren's **New** 40th Anniversary Bookmark Sjögren's Foundation Awareness T-shirt The "This is Sjögren's" Flyer Living with Sjögren's Summary of Patient Survey 3-brochures: "What is Sjögren's", "Dry Eye", and "Dry Mouth"			
Shipping and Handling: U.S. Mail: $9 for first item + $2 for each additional item			$9.00
Total Amount Due			

Mail to: Sjögren's Foundation Inc.
10701 Parkridge Blvd., Suite 170,
Reston, VA 20191 or Fax to: 301-530-4415

Name ______________________ Member # __________

Address ______________________

City ______________ State ______ Zip ______

Telephone ______________ E-Mail ______________

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

☐ MasterCard ☐ VISA ☐ Discover ☐ AmEx Card Number ______________________

Exp. Date __________ Security Code __________ Signature ______________________

You Stood Up!

The Foundation Thanks Our Awareness Ambassadors!

The Sjögren's Foundation would like to express our unwavering gratitude to our Awareness Ambassadors for their participation in our 2023-2024 Awareness campaigns!

Our Awareness Ambassadors are volunteers who go out in their communities to help the Foundation achieve our mission and vision of providing healthcare professionals with credible resources to improve awareness of Sjögren's. They do this by implementing Foundation campaigns, which are targeted at educating healthcare providers in their area about the various manifestations of the disease, new medical and science research outcomes, and current information. The Sjögren's Foundation implements a new campaign for our Awareness Ambassadors 3-4 times per year. We provide new content for each campaign that aligns with other programs we are running at the same time so there are multiple opportunities to engage clinicians on a specific topic.

The Sjögren's Foundation Awareness Ambassador program began in 2011 with the intent to help the Foundation achieve our 5-Year Breakthrough Goal: "To shorten the time to diagnose Sjögren's by 50% in 5 years." Thanks to the help of these amazing ambassadors, we not only met, but we exceeded this goal, taking the time it took to get a diagnosis down from 6 years to 2.8 years!

This past year we asked for volunteers to participate in two Awareness campaigns that focused on continuing medical education for healthcare professionals. For each campaign, Awareness Ambassadors were supplied with handouts and asked to bring them to their healthcare providers when they go for an appointment, or even go to additional offices if they wish to build awareness beyond their own doctors

For the first 2023 campaign, our volunteers distributed information about a new course presented on the PriMed® platform that focused on systemic Sjögren's. The key educational goals for this course were to deliver accurate information about Sjögren's disease and the diverse symptoms patients can present as well as to communicate that proper care of a Sjögren's patient requires a multi-disciplinary approach. The course also describes the multi-system involvement seen in Sjögren's and emphasizes that Sjögren's is far more than dry mouth and dry eyes, and key features healthcare professionals should look for to accurately diagnose a patient.

The most recent Awareness Ambassador campaign focused on the difficult-to-diagnose patient, which included Sjögren's patients who are seronegative for Sjögren's autoantibodies- SSA/Ro and SSB/La. Healthcare providers were also encouraged to attend our State of Sjögren's either virtually or through the enduring course to learn more about the heterogeneity of Sjögren's and research on potential inclusive and non-invasive diagnostic tools. You can read more about the *State of Sjögren's* on page 4 and how your healthcare providers can sign up for our enduring course to receive continuing medical education.

Currently, we have 56 Awareness Ambassadors covering 29 states across the United States. We need more volunteers to cover more areas! If you would like to join future Awareness Ambassador campaigns, please visit https://share.hsforms.com/1dK6c9miwQ1io3-XOIaBbdw3619 or scan the QR code to fill out our volunteer form. Our next campaign is coming up soon!

We are truly grateful for our Awareness Ambassadors and appreciate their role in helping us reach our mission. Thank you for standing up to support Sjögren's and your fellow Sjögren's patients! ■

40 Years APRIL IS Sjögren's AWARENESS MONTH

The Sjögren's Foundation began with patients sharing their stories, and now, 40 years later, we still share patient stories to keep Sjögren's awareness alive with our #ThisIsSjögrens campaign.

Every day in April, we will highlight a different patient and show a glimpse into their life with Sjögren's. This year, we will also use this campaign to give a unique "patient-to-patient" viewpoint and dive deeper into various Sjögren's topics with advice directly from other patients. We hope these stories will help create a better understanding of this complex disease and let all patients know that there is support through this community.

Please help us celebrate 40 years by sharing your story with the community!! You can scan the QR code below, or visit https://info.sjogrens.org/april-awareness to fill out the form. We will feature 30 stories in this year's April campaign, and all submitted stories are eligible to be featured by the Foundation.

Thank you for sharing your story to help shine a light on the diversity of the millions of patients living with Sjögren's.

#ThisIsSjögrens

sjogrens.org

IN MEMORIAM

In Memory of Janet Adams
Donald Richer

In Memory of Doris Bergen
Meredith Hackett

In Memory of Joan Bocchino
Robert Miller

In Memory of Heidi Ann Burke
John Burke

In Memory of Karen Desberg
Mike Cummiskey
Jeffrey Weiner

In Memory of Kathleen Crawford
Anne Zimmerman

In Memory of Maria Robles Mijangos
Juan Ruiz

In Memory of Alice Glupe
Karin Blaney

In Memory of Anne Shirley Dolan
William Boyle
John and Shiela Brice
Leslie DeBora
Phil and Mary Ann Fry

In Memory of Marlene Dunham
Margaret Davis
Adrienne Gits
Lana Gits
Joe Jablonski

In Memory of Ella Whitten Sisler
Darla Rae
Joe Sisler

In Memory of Molly Clennan
David Brennan
Ed and Michele Mainey
J.F. McGivern Inc

In Memory of Debra Ann Rakar
Lori Baumiller
Joseph Fierle
Linda Gould
Katherine Maloney
Audrey Wrobel

In Memory of Eileen Guldin
Christina Lea

In Memory of Kellie Young
Allison Browne
Yvette Estrella
Michele Hoff
Rickye Lamm
Sandra Rush
Eric Thompson
Nancy Tsang
Mitzi Wong-Nguyen
Robert Wright
Richard Young
Eleanor Yuen

IN HONOR

In Honor of Janine Bensman
Irene Goldstein
Victoria Hanley

In Honor of Janet Couture
Sandra Desrosiers

In Honor of Yolanda Gales
Esther Perryman
Ned Heeger-Brehm & John Heeger
Stephen Heeger

In Honor of Carol Hirashiki
Jennie Handy

In Honor of Lindsay Noble
Patrick Noble

In Honor of Liz Perry
Don Perry

In Honor of Rachael Roth
Michael Roth

In Honor of Carol Watson
Susan Horst

Notable Awards Funded for Sjögren's Research

The Sjögren's Foundation has exciting news—two major grants funding Sjögren's research were recently awarded by the National Institutes for Health (NIH).

Indiana University School of Dentistry and Regenstreif Institute- Awarded $4.7 million

Investigators at the Indiana University School of Dentistry and Regenstreif Institute have received a U01 grant of $4.7 million over five years from the National Institute of Dental and Craniofacial Research (NIDCR). U01 grants support multi-center clinical studies that include epidemiologic studies, observational studies, and interventional clinical trials. Drs. Thankam Thyvalikakath, Angela Bruzzaniti, and Mythily Srinivasan are the principal investigators of the grant entitled, "Establishing Readiness of Dental Professionals in Practice-Based Research and Interprofessional Care," which will focus on advancing the knowledge and skills of dental students to manage conditions, including Sjögren's Disease, through inter-professional collaboration and will conduct research in community practice settings to address unanswered questions that affect patient care. This grant also supports a clinical study that specifically investigates Sjögren's Disease and will be used to develop a salivary hypofunction (decreased function) index in combination with salivary biomarkers for early detection in patients susceptible to Sjögren's Disease.

Oklahoma Medical Research Foundation (OMRF)- Awarded $5.8 million

Investigators at the OMRF have been awarded a four-year grant in the amount of $5.8 million from the Accelerating Medicines Partnership® in Autoimmune and Immune-Mediated Diseases Program (AMP® AIM) through the National Institute of Arthritis and Musculoskeletal and Skin Diseases. The team, including Drs. Darise Farris, Joel Guthridge, and Christopher Lessard, will work to develop less invasive clinical tools to diagnose patients more effectively and identify new targets for future treatments. The researchers will use blood and tissue biopsy samples donated by Sjögren's patients. Their aims to identify subgroups of patients with Sjögren's by determining the molecular and genetic characteristics that contribute to the heterogeneity of Sjögren's, including the difference between patients who are positive and negative for Sjögren's autoantibodies. The overall goal is to diagnose patients more easily and determine who may benefit from different potential therapies.

The Foundation looks forward to updates and outcomes from these two grants and we are encouraged at the increased recognition for Sjögren's research.

As part of the AMP®AIM program, several studies are recruiting participants. Please see page 8 for information on how and where you can participate for a study with the Sjögren's Team for AMP®! ■

Conquering Sjögren's
Sjögren's Foundation Inc.
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Reston, VA 20191
Phone: (301) 530-4420
Fax: (301) 530-4415

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

Conquering Sjögren's One Step at A Time! Join us in a Spring Walk as we celebrate 40 years of Progress!

Walk for Sjögren's is a national awareness and fundraising program that takes place across the country every spring and fall. But the walks are so much more! They are an amazing series of events where patients build community together, interact with Sjögren's experts, educate family and friends, and raise funds for important initiatives and research. This year, we are commemorating 40 years of Sjögren's progress with our theme: Conquering Sjögren's, One Step at a Time! Join us at one of our virtual events, at our LIVE event in Philadelphia or at our new LIVE event in Madison, WI. If you're interested in attending and would like to learn more, please contact Jessica Levy at jlevy@sjogrens.org, visit events.sjogrens.org, or scan the QR code below.

Spring 2024 – Walk for Sjögren's Calendar

March	**Virtual Southwest Walk for Sjögren's** *Saturday, March 16, 2024* **Virtual Southeast Walk for Sjögren's** *Saturday, March 16, 2024*
April	**Virtual Mid-Atlantic & National Walk for Sjögren's** *Saturday, April 13, 2024*
May	**LIVE Tri-State Walk for Sjögren's in Philadelphia, PA** *Saturday, May 11, 2024*
June	***NEW* LIVE Midwest Walk for Sjögren's in Madison, WI** *Saturday, June 1, 2024* **Virtual Colorado Walk for Sjögren's** *Saturday, June 22, 2024*

events.sjogrens.org

40 Years Sjögren's FOUNDATION