

# CONQUERING Sjögren's

July/August 2021

## Inside this Issue

*Meet Your Board Chair*

*Ask the Expert*

*Why Language Matters*

*Sjögren's: The Patients' Perspective*

*You Stood Up: Congratulations  
Team Sjögren's*

*Clinician's Corner: Treatment  
Options for Extreme Dry Eye*





## Board of Directors

### Chairman of the Board

Donald E. Thomas, Jr., MD, FACP, FACR

### Chairman-Elect

Susan Barajas

### Treasurer

Ava Wu, DDS

### Secretary

David Schrader

Alan Baer, MD

Chadwick Johr, MD

Tammy Dotson

Katie Forte

Kim Kelley, PharmD

Allissa Latham

Robyn Laukien

Theresa Lawrence Ford, MD

Monica McGill, EdD

Jonathan Morse, MSc

Jason Nichols, OD

Timothy Niewold, MD, FACR

Vidya Sankar, BS, DMD, MIIS

## Medical and Scientific Advisors

### Chairman

Alan Baer, MD

Esen Akpek, MD

Penny A. Asbell, MD, FACS, MBA

Herbert S. Baraf, MD, MACR

Richard Brasington, MD, FACR

Michael Brennan, DDS, MHS

Steven E. Carsons, MD\*

Nancy L. Carteron, MD, FACR

Troy Daniels, DDS, MS\*

Denise L. Faustman, MD, PhD

H. Kenneth Fisher, MD, FACP, FCCP

Gary Foulks, MD, FACS

S. Lance Forstot, MD

Philip C. Fox, DDS\*

Robert I. Fox, MD, PhD, FACP\*

Theresa Lawrence Ford, MD, FACR

Tara Mardigan, MS, MPH, RD

Austin Mircheff, PhD

John Daniel Nelson, MD, FACS

Kelly Nichols, OD

Athena Papas, DMD, PhD

Ann Parke, MD

Andres Pinto, DMD

Nelson Rhodus, DMD, MPH

Vidya Sankar, DMD, MHS

Daniel Small, MD, FACP

Neil Stahl, MD

Frederick B. Vivino, MD, FACR

Jeffrey Wilson, MD, FACR

### Chief Executive Officer

Janet E. Church

### Editor

Elizabeth Trocchio Bryant

e-mail: [info@sjogrens.org](mailto:info@sjogrens.org)

[www.sjogrens.org](http://www.sjogrens.org)

# Table of Contents

Meet Your Board Chair: Don Thomas, MD, FACP, FACR	3
Ask the Expert: Dr. Don Thomas	5
Why Language Matters	9
Sjögren's: The Patients' Perspective	11
In Memoriam / In Honor	13
You Stood Up: Congratulations Team Sjögren's Runners and Walkers!	15
Clinician's Corner: Treatment Options for Extreme Dry Eye	17

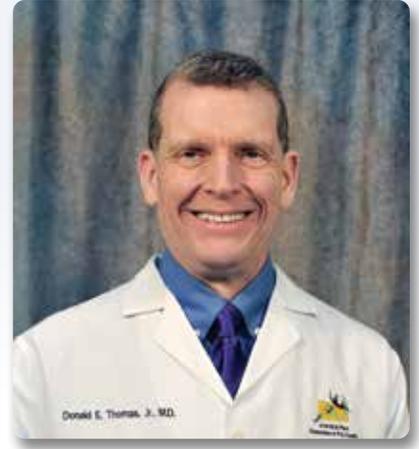
Don't miss out on the latest information and research, become a member of the Sjögren's Foundation and receive the *Conquering Sjögren's* newsletter six times a year. It's easy to join. Sign up through our website at: [www.sjogrens.org](http://www.sjogrens.org) or call us at: (301) 530-4420.



Conquering Sjögren's Newsletter is published by the Sjögren's Foundation Inc.,  
10701 Parkridge Boulevard, Suite 170, Reston, VA 20191.  
Copyright ©2021 Sjögren's Foundation Inc. ISSN 0899-637.

**DISCLAIMER:** The Sjögren's Foundation Inc. in no way endorses any of the medications, treatments, or products mentioned in advertisements or articles. This newsletter is for informational purposes only. Readers are advised to discuss any research news, drugs, treatments or products mentioned herein with their healthcare providers.

# Meet Your Board Chair: Dr. Don Thomas



*Don Thomas, MD, FACP, FARC*

In 1993, as a rheumatology fellow at Walter Reed Army Medical Center in Washington, D.C., I was asked to see a woman in the intensive care unit. She was in her mid-50s and was admitted with chest pain, shortness of breath, and had a large amount of fluid around her lungs (called a pericardial effusion). Her workup showed that she was antinuclear antibody (ANA) positive, so I was asked if systemic lupus was the cause of her heart problem. I still remember how pleasant she was and what a wonderful smile she had. However, I also remember how scared and frightened her husband was, sitting at her bedside, holding her hand.

On physical exam, the main thing that struck me as odd was how dry her mouth and eyes were. I did a Schirmer test that showed very little tear production. Her lab abnormalities were classic for Sjögren's disease, but her heart problem was unusual. One of our ear, nose, and throat specialists performed a minor salivary gland lip biopsy, which confirmed Sjögren's. Steroids and hydroxychloroquine (Plaquenil) quickly brought her back to her previous self (except for the dry eyes and dry mouth). I cared for this delightful woman until the day I left Walter Reed in 1998. It was hard to say goodbye to her and her husband because I had grown to know both of them well over those years. However, she felt like her old self again, and I knew I was leaving her in good hands with my fellow rheumatologists at Walter Reed.

This was my introduction to Sjögren's. It was not the "benign" disease that just caused nuisance dry eyes and dry mouth. It could be severe, attacking major internal organs, and needed to be taken seriously. This, along with my growing interest in its sister autoimmune disease, systemic lupus erythematosus, led me to have a special interest in these disorders. In my private practice in Greenbelt, Maryland (just outside Washington, D.C.) at Arthritis and Pain Associates of Prince George's County, I began to build up a practice that included many patients with systemic autoimmune disorders.

Early on, I learned the importance of empowering patients to learn about their disease and to learn how to live with and control their disorder. So I became involved in patient advocacy organizations and regularly gave talks to patient groups, hoping to motivate others to do the right things for their health. I guess my enthusiasm showed. One day, out of the blue, I received a call from the health editor at Johns Hopkins University

### “Meet Your Board Chair” *continued from page 3* ▼

Press. She asked me if I would write a patient education book about lupus. I had never written a book in my life, and I was already incredibly busy, so I was hesitant. However, my inner voice said, “This is Johns Hopkins; I can’t say ‘no!’” This was how my patient education book “The Lupus Encyclopedia: A Comprehensive Guide for Patients and Families” was “born.” It was published in 2014. Because 30% of lupus patients also have Sjögren’s disease, of course, I included a thorough chapter on Sjögren’s as well.

Since then, I have been fortunate to help educate many more patients outside of my private practice. The internet allowed me to have a Facebook page and blog ([www.lupusencyclopedia.com](http://www.lupusencyclopedia.com)) where I now have over 29,000 followers from all over the world. It is always nice to hear from patients from the United States and other countries. They tell me how helpful certain blog articles are for their healthcare improvement. Just as important, I often learn important things from them as well.

In 2016, I met our previous CEO, Steven Taylor, at our D.C. Rheumatism Society meeting. He told our group about all the exciting things that the Sjögren’s Foundation was doing for patients. I immediately knew I wanted to participate and help. When Steve called me and asked me to join the National Board of Directors, I said “yes” without hesitation. As a Board Member, I have been awestruck at all the Sjögren’s Foundation accomplishments. They truly go above and beyond what a patient advocacy group of this size is expected to do. We all want a charitable organization to spend its money in the most effective manner possible, and the Sjögren’s Foundation hits all the marks:

- Developed guidelines for managing dry eyes, dry mouth, arthritis, and lung inflammation that help doctors worldwide care for Sjögren’s patients better.

- Work tirelessly with pharmaceutical and research companies to work on developing effective, safe drugs for Sjögren’s. Many are now in clinical trials, and we hope that one day one of them will become our first FDA-approved drugs for Sjögren’s.
- Hold one of the largest, most effective patient education conferences (the Sjögren’s Foundation National Patient Conference) that provides its members with practical advice from leading experts in the field.
- Provide a regular newsletter (*Conquering Sjögren’s*) full of practical advice and tips for its members.
- Publish a high-quality newsletter (*Sjögren’s Quarterly*) for healthcare providers packed full of the latest research findings and up-to-date treatment advice for Sjögren’s patients.
- Publish a high-quality book (*The Sjögren’s Book*) for both patients and health care providers that goes into great detail about every aspect of Sjögren’s and its treatment (look for our next edition coming out in 2022).
- Have a CEO and staff who work tirelessly and enthusiastically, all with one purpose in mind: to help improve the lives of Sjögren’s patients.

When I received a phone call from Steven Taylor last year asking me to become the Chair of the National Board of Directors of the Sjögren’s Foundation, I was flattered and humbled.

Just like our wonderful CEO, Janet Church, the Sjögren’s Foundation staff, and the amazing group of talented National Board Members, I simply want to serve you, our Sjögren’s Foundation members, and patients to the best of my ability.

Hoping to help make a difference in your lives now and in the future.

Thank you for this opportunity,  
Don Thomas, MD, FACP, FACR



### **Are You a Spouse or Partner of Someone Living with Sjögren’s?**

The Foundation knows how supporting and/or caring for someone with a chronic illness, like Sjögren’s, can be very rewarding but it also has a significant impact on your life, too.

Please contact the Foundation at (301) 530-4420 or send an email to [info@sjogrens.org](mailto:info@sjogrens.org) and sign-up to receive specialized mailings, educational information, and notices about teleconference support group meetings for spouses and partners of Sjögren’s patients.





# Ask the Expert:

## Don Thomas, MD, FACP, FACR

**Q** *“Is an iron deficiency common with Sjögren’s and do you recommend an iron transfusion?”*

**A** Iron deficiency is not a common problem with Sjögren’s. It is much more common in people who have its sister autoimmune disease, lupus. However, this does not have to do with the disease (lupus). It is because lupus most commonly occurs in women of child-bearing age and therefore are prone to iron deficiency due to blood loss from monthly menstruation. One of the most important things to remember about iron deficiency is that a cause must always be found. If it occurs in a man or in a non-menstruating woman, then a bleeding source must be found. This can be obvious (such as a recent surgery or bleeding episode) or not obvious. If not obvious, we usually do endoscopies where a stomach doctor (gastroenterologist) looks down into the esophagus and stomach (upper endoscopy) or up into the colon (colonoscopy) to see if a bleeding source can be identified. We usually try to normalize the iron in someone with iron deficiency using an iron supplement. However, if someone doesn’t tolerate it (such as due to it being too constipating) or if pills don’t correct the iron deficiency, then we will give IV (intravenous) iron.

**Q** *“What bloodwork is common once receiving a Sjögren’s diagnosis and how often should it be performed?”*

**A** We check labs to monitor disease activity, since these may be useful to see how the person does over time, assess how they respond to treatment, and help identify possible disease flares (increased disease activity). These tests include looking for low C3 and low C4 complement levels, elevated gammaglobulins (polyclonal gammopathy) on serum protein electrophoresis (SPEP), elevated cryoglobulins (proteins that clot easily in cooler temperatures), and elevated erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP). If cryoglobulins are neg-

ative, they are usually not repeated unless the person develops a problem commonly seen with them (such as inflammation of skin blood vessels, vasculitis). The others (C3, C4, SPEP, ESR, CRP) can be helpful to follow in some patients to assess disease activity. However, how often this should be done is unknown and varies widely between physicians.

A complete blood cell count (CBC) can help see if there are any low blood counts related to the Sjögren’s or if there is a side effect to any medications used to treat the Sjögren’s. A metabolic (chemistry) panel can help follow the kidney function and to ensure there is no inflammation of the liver, which can occur in some Sjögren’s patients. A urine sample along with a random urine protein-to-creatinine ratio is usually performed to see if there is any evidence of kidney inflammation from Sjögren’s. Again, it is unknown how often these tests (CBC, chemistry panel, urine sample) should be done.

Some labs are also performed if particular scenarios occur. For example, a creatine phosphokinase (CK or CPK) level may be checked in someone with muscle weakness to see if that person muscle inflammation (myositis) from Sjögren’s, but this is a rare problem. Thyroid function tests and vitamin B12 levels are also done in someone with fatigue to ensure that an underperforming thyroid gland (hypothyroidism, such as from Hashimoto’s thyroiditis) or vitamin B12 deficiency are not the causes. In a person with diarrhea, unexplained weight loss, or vitamin malabsorption, checking antibodies for celiac disease (also called gluten-sensitive enteropathy) is important since this appears to occur more often in people with Sjögren’s.

Approximately half of Sjögren’s patients will develop an overlap syndrome with another systemic autoimmune disease (such as lupus or rheumatoid arthritis). Therefore, if any problems occur that can be seen in these disorders, labs that can be helpful in diagnosing them would be important to obtain.

Some patients can have a high amount of one gammaglobulin on their SPEP (called a monoclonal

*continued page 8* ▼



# Use Your Voice to Celebrate World Sjögren's Day



**W**orld Sjögren's Day was established to commemorate the birthday of Dr. Henrik Sjögren, the Swedish ophthalmologist who discovered Sjögren's.

World Sjögren's Day, July 23, celebrates the man who has helped all patients find answers to their health questions and is the ideal opportunity for you to have your voice heard. We encourage you to celebrate this day by using your voice and educating those close to you that Sjögren's is serious, systemic and prevalent.

You can also recognize World Sjögren's Day by making a donation to the Sjögren's Foundation. Donate in honor of yourself, a loved one, or the doctors and nurses in your life who help you manage your Sjögren's. Your support will allow the Foundation to keep building on, and advancing, Dr. Sjögren's work while also continuing to use our voice to support all Sjögren's patients. And together, we can conquer the complexities of Sjögren's!



- Enclosed is my gift of \$\_\_\_\_\_ to support the Foundation's initiatives and programs.
- I am interested in learning more about how to make a stock donation.
- Please send me information about listing the Sjögren's Foundation in my will.

***Thank you for your support of the Sjögren's Foundation.***

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

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Telephone \_\_\_\_\_ E-mail \_\_\_\_\_

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

MasterCard  VISA  Discover  AmEx Card Number \_\_\_\_\_ Exp. Date \_\_\_\_\_

Signature \_\_\_\_\_ CC Security Code \_\_\_\_\_

NEW

# Trouble swallowing pills due to dry mouth?

## Phazix<sup>®</sup> can help!



Phazix<sup>®</sup>

Pill Swallowing Gel

### Helps the medicine go down!<sup>™</sup>

Phazix is a clear, pleasant tasting gel used to make pill swallowing easy.

- Lubricates the mouth and throat to slide pills down smoothly
- Eliminates the need for mixing with food or crushing medications
- No known drug interactions

Buy Now at  
**amazon.com**

Visit [phazix.com/sjogrens](https://phazix.com/sjogrens)  
for a sample.

*continued page 8* ▼

arkray USA, INC.<sup>+</sup>

Minneapolis, MN 55439 • 800.566.8558 • [www.arkrayusa.com](http://www.arkrayusa.com)

©ARKRAY USA, Inc. All rights reserved. PH-1382-v1 Rev. 01/21

“Ask the Expert” continued from page 5

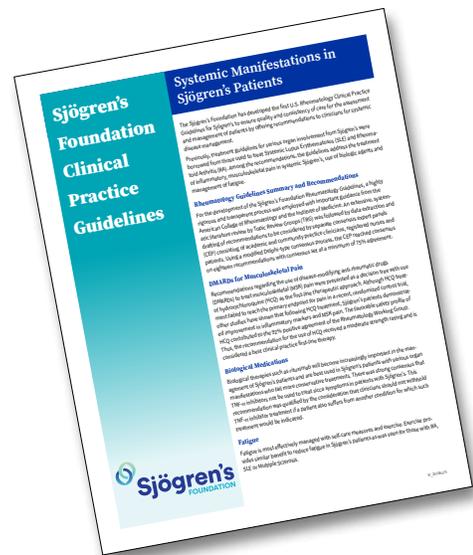
gammopathy). If this occurs, we do a workup to ensure that the person doesn't have any type of cancer related to it (such as multiple myeloma), and we monitor their levels regularly. Fortunately, the vast majority of patients with this problem never develop cancer related to it.

“What are treatment options for Sjögren's fatigue?”

Evaluating fatigue in Sjögren's patients is complex, since the treatment varies a lot with the cause. For example, medications that calm down the immune system (such as hydroxychloroquine and rituximab) may be beneficial in the person with fatigue due to immune system overactivity from their Sjögren's. However, the treatment of thyroid disease would be important for the person with an abnormally working thyroid causing fatigue, and regular aerobic exercise is the treatment of choice in the person with fibromyalgia-related fatigue.

In 2016, the Sjögren's Foundation published its landmark clinical practice guidelines, “Treatment Guidelines for Rheumatologic Manifestations of Sjögren's: Use of Biologic Agents, Management of Fatigue, and Inflammatory Musculoskeletal Pain.” Over

1,000 studies regarding fatigue and Sjögren's and related disorders were evaluated, with the 10 highest quality research studies ultimately used to help define the best management of fatigue in Sjögren's. The only treatment that had the most evidence of being beneficial was to do regular exercise. The evidence for this recommendation was so strong, that it received 100% agreement among the experts who worked on this important paper. Visit www.sjogrens.org to view all Foundation's Sjögren's clinical practice guidelines.



Supporting Saliva's Natural Defenses



Proven Enzyme Formulation

for Dry Mouth Care

www.SALIVEA.com

Available at: amazon

@saliveacare /salivedrymouthcare



# Why Language Matters

by **Florian Kollert, MD**

*Department of Rheumatology, Immunology, and Allergology, Inselspital, University Hospital Bern, Bern, Switzerland*

and

**Benjamin A. Fisher, MD**

*Institute of Inflammation and Ageing, College of Medical and Dental Sciences, University of Birmingham, Birmingham, UK.*

*National Institute for Health Research (NIHR) Birmingham Biomedical Research Centre and Department of Rheumatology, University Hospitals Birmingham NHS Foundation Trust, Birmingham, UK.*

Historically, Sjögren's has been classified into "primary" and "secondary" disease. "Primary" Sjögren's is defined as a standalone entity occurring in the absence of another systemic autoimmune disease, whereas "secondary" disease is associated with the presence of rheumatoid arthritis (RA), systemic lupus erythematosus (SLE) or systemic sclerosis (SSc), for example. Notably, the presence of a coexistent autoimmune disease is very common in Sjögren's (approximately 30% overall), when organ specific autoimmunity is also included.

In our recently published article (Kollert & Fisher, *Rheumatology*) we reviewed the historical justification for the distinction of "primary" and "secondary" Sjögren's based on genetics, clinical presentation, chronology, histology and serology, and found it difficult to justify the dichotomy based on existing evidence. We therefore recommend further research, and advocate abandoning the term "secondary" unless strong evidence emerges of a pathological difference between these subsets. We further argue for a nomenclature including the associated disease (Sjögren's in association with...) to not only emphasize the second autoimmune disease but also Sjögren's itself. In our perspective, Sjögren's is an under-researched disorder, a situation that is even worse for patients with so called "secondary" disease. This stands in sharp contrast to the potential impact of Sjögren's on quality of life, even when compared to other systemic rheumatological disorders. Accordingly, it has been shown in a study analyzing patients with rheumatoid arthritis, systemic sclerosis, lupus and Sjögren's, that patients with Sjögren's have the lowest levels in certain domains of quality of life (vitality, social function) and the second lowest levels after systemic sclerosis in all investigated quality of life scores. Moreover, patient-reported symptoms are stronger predictors of

quality of life as compared to systemic manifestations in Sjögren's, illustrating the high importance of these symptoms for all Sjögren's patients including those with other systemic autoimmune diseases.

"Secondary" can also imply a temporal aspect suggesting that Sjögren's often manifests after the associated autoimmune disease. However, the literature clearly shows that Sjögren's comes first in a considerable proportion of patients, which speaks against a chronological basis for the historical terminology. Although we found no convincing evidence for a difference in phenotype between "secondary" and "primary" Sjögren's, going beyond obvious differences caused by an overlap with the associated disease, we did find some suggestions that the clinical phenotype of the associated disease may sometimes differ. It is conceivable that these differences may relate to an interaction between the pathophysiology of Sjögren's and that of the associated disease. For example, patients with rheumatoid arthritis and Sjögren's exhibit a more aggressive rheumatoid arthritis phenotype including more bone erosions. For lupus, it has been shown that patients with concomitant Sjögren's responded better to a B cell-targeted therapy (epratuzumab) than patients with lupus alone. This might be due to more pronounced B cell activity in these patients, which might also underlie the observation that rheumatoid arthritis patients with Sjögren's have higher disease activity. It can be hypothesized that rheumatoid arthritis patients with Sjögren's might respond better to treatment modalities targeting B cells and maybe even interferon (e.g. rituximab, JAK inhibitors), which warrants study.

Patients with "secondary" Sjögren's are often excluded from clinical trials and were not incorporated in the development of the most recent classification criteria

*continued page 10 ▼*

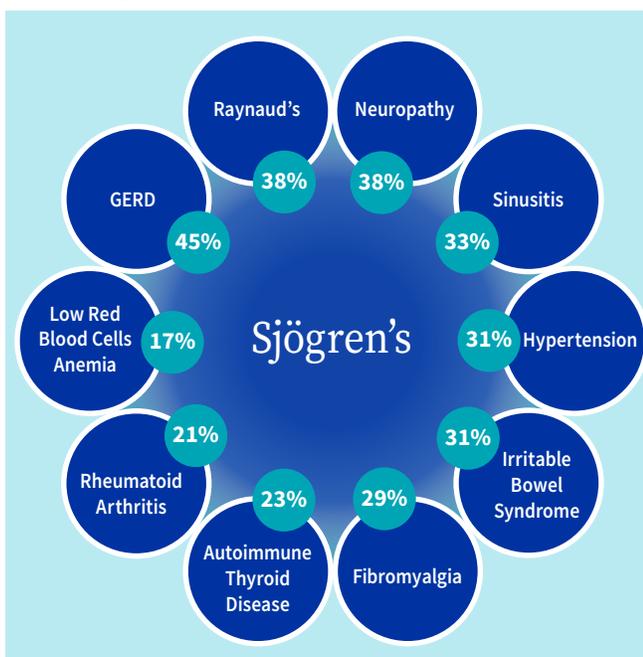
## “Language” *continued from page 9* ▼

for Sjögren’s. They were considered in the widely used 2002 criteria but neither histopathology nor autoantibodies were necessary for classification as “secondary” Sjögren’s. Thus, recent clinical trials investigating new compounds for patients with Sjögren’s typically recruit patients with primary Sjögren’s only. So it seems unclear if a drug which is eventually proven to have efficacy for these “primary” Sjögren’s patients; will be accessible to patients with “secondary” disease also. Conversely, studies of other systemic autoimmune diseases such as lupus or rheumatoid arthritis have typically not excluded patients with concomitant Sjögren’s. This provides a largely unexplored opportunity to derive additional early signals of potential efficacy in Sjögren’s. Even in the absence of salivary gland biopsy, anti-Ro positive patients meeting the 2016 ACR/EULAR criteria recruited in large clinical trial programs targeting rheumatoid arthritis, lupus and systemic sclerosis, could have assessment of patient reported outcomes for dryness alongside unstimulated salivary flow. Many such patients have been treated with novel agents in the past and we may have missed multiple opportunities to generate evidence to support a drug-specific mode of action in Sjögren’s, or to investigate Sjögren’s as a potential stratification for treatment response in the investigated disease.

Admittedly, there are often pragmatic and understandable reasons for focusing research on “primary” disease, in order to have a more homogenous cohort and reduce the presence of confounding factors. However “secondary” disease, when feasible, should not be neglected. Further research should seek to

either establish the similarity between Sjögren’s in the presence or absence of another systemic autoimmune disease when meeting the same classification criteria, or else provide a stronger justification than currently exists for this historic distinction. This will also avoid the risk that patients with “secondary” disease are unnecessarily excluded from novel treatments arising from current development programs. In some situations, inclusion/exclusion criteria for clinical trials could be adjusted to allow recruitment of “secondary” patients. However, this would require careful consideration of classification, drug mechanism, trial objectives and trial outcome measures. At one end, a drug targeting glandular disease with salivary flow as outcome may have no reason to exclude patients with another systemic autoimmune disease, whereas at the other end, assessment of systemic disease might be complicated by the presence of other diseases. However, polyautoimmunity is very common in rheumatology, and we need to understand how best to apply our therapeutic options within this complex setting.

Taken together, as there is currently no evidence for a major difference between the phenotype of “secondary” and “primary” Sjögren’s we argue in favor of using the same set of classification criteria for both. Moreover, we take the side of abandoning the term “secondary” in favor of “Sjögren’s in association with” to emphasize not only Sjögren’s but also the associated autoimmune disease. The overlap between different systemic autoimmune diseases should be regarded as an opportunity to foster drug development and to further stratify our available treatment modalities and to personalize our therapies. ■



## Other Diagnosed Health Conditions

There are many known comorbidities or manifestations of Sjögren’s that can occur in conjunction with the disease. *Living with Sjögren’s* survey respondents reported having been diagnosed by a healthcare provider with an average of five other health conditions, including Gastroesophageal Reflux Disease (GERD) (45%), Raynaud’s (38%), Neuropathy (38%), Sinusitis (33%), Hypertension (31%), and Irritable Bowel Syndrome (31%).

# Sjögren's: the patients' perspective



*by Katherine Morland Hammitt, MA  
Sjögren's Foundation's Vice  
President of Medical and  
Scientific Affairs, and  
Sjögren's Patient*

**W**hy is the patient's perspective important? First and foremost, the patient is the ultimate beneficiary of the important work done by clinicians and researchers. A better understanding of Sjögren's patients will lead to greater success in managing patients and finding new treatments. I and millions of Sjögren's patients thank all of those who are working to find better biomarkers, learn more about risks and complications, improve clinical trial endpoints, and engage in basic scientific research that will elucidate the disease process and provide better future therapies.

Patients are grateful to clinicians who want to learn about the difficulty of living with Sjögren's, thereby increasing one's empathy and understanding; about what is most important to patients, so clinical time with patients is well spent and researchers focus on developing therapies that are most meaningful; about how to run clinical trials in a way that will entice more patients to participate; about patients, overall, so we better understand elements such as which symptoms are most prevalent and which are most bothersome, who is more susceptible to specific complications so we are monitored for those, and who is affected by the disease so we can better diagnose Sjögren's and learn to recognize it in populations that were not traditionally diagnosed.

Sjögren's has long taken a back seat to other related diseases such as rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE), but as a Sjögren's patient myself, and in a leadership role with a major organization that represents those with Sjögren's and works with other organizations around

the world, we can no longer remain silent about the devastation wrought by this common, yet complex, disease. And, yes, it is common and much more prevalent than most in healthcare recognize. A 2008 study by the U.S. Centers for Disease Control, National Institutes of Health, and Arthritis Foundation found a range of 0.4 to 3.1 million in the U.S. alone for those with Sjögren's and who did not have another major autoimmune rheumatic disease.<sup>1</sup> Compare this to their finding of 161,000-322,000 with SLE and 1.3 million with RA, and Sjögren's is at least tied with RA numbers, if not surpassing it.

We need to work together to increase awareness of Sjögren's. Sjögren's remains under-recognized and misdiagnosed. While recent Sjögren's Foundation efforts were successful in reducing the time to diagnosis from 6 to 2.8 years, too many Sjögren's patients remain undiagnosed and untreated. Patients not yet diagnosed with Sjögren's are being seen in pulmonary, oncology, gastroenterology and neurology clinics and not being referred for diagnosis and treatment of a systemic disease. They are seen for repercussions of dry eye by ophthalmologists, dry mouth by dentists, vaginal dryness by gynecologists, interstitial cystitis by urologists or family practitioners and not getting a proper diagnosis of Sjögren's.

Some patients suffer from symptoms but are not managed medically by anyone. Fatigue, cognitive dysfunction, musculoskeletal pain, ocular and oral symptoms, and peripheral neuropathies can be

*continued page 12 ▼*

**“Patient Perspective”** *continued from page 11* ▼

dismissed as vague, benign, and/or not seen as part of one disease. Patients and healthcare providers can use different terminology for symptoms. For example, unless patients understand what is meant by “dry eye” or “dry mouth,” patients will not describe their symptoms as dryness, and a diagnosis of Sjögren’s might be missed. Instead, we need to learn to ask patients if they have frequent ocular or oral pain and/or irritation, difficulty focusing clearly, frequent eye infections, rampant caries or chipping or cracking of teeth, difficulty swallowing without liquids, genital pain or pain with intercourse.

We must start doing a better job of recognizing Sjögren’s in younger patients and in men. When we focus on Sjögren’s as a disease of middle-aged and post-menopausal women and one that is marked primarily by dryness, we miss important sectors of our population that might have Sjögren’s. We miss the chance to treat patients earlier in the disease process and the ability to learn more about the disease overall, such as how the disease might start, how it progresses over time, and about symptoms and complications with earlier onset. We must do a better job recognizing the many systemic complications of Sjögren’s. We cannot label Sjögren’s as a disease that is solely one of dryness. While, according to the 2016 Sjögren’s Foundation *Living with Sjögren’s* national patient survey conducted by Harris Poll®, dryness is a top complaint and patients do want therapies to alleviate dryness, we also need to recognize the many other symptoms that cause suffering. For example, the same poll shows that 80% suffer from crippling fatigue. Up to 40% of Sjögren’s patient will have neurological symptoms that antedate sicca manifestations, and in one recent study of 184 Sjögren’s patients, an astounding 93% of patients were diagnosed after neurological symptoms appeared.<sup>2</sup> Younger patients are more likely to suffer from chronically swollen salivary glands, musculoskeletal pain, fatigue and neuropathies than dryness. Those with Sjögren’s, more than any other autoimmune disease, are susceptible to blood cancers.<sup>3</sup> We suffer from cognitive dysfunction or “brain fog.” We are susceptible to interstitial lung disease and interstitial nephritis, and mothers with Sjögren’s are at higher risk of having babies with fetal heart block. Sjögren’s is a disease that can affect any organ or bodily system and interferes with our ability to work, be the parent we wish we could be, socialize, and carry out daily activities.

We cannot remain dismissive of so-called “benign symptoms.” Take fatigue: when patients say they are

tired, others often are dismissive and do not understand what this means for a patient. The U.S. National Library of Medicine defines fatigue as “a feeling of weariness, tiredness, or lack of energy.” This does not begin to describe the fatigue endured by Sjögren’s patients. Sjögren’s fatigue is not simply a tiredness that can be alleviated by a nap or good night’s sleep. It’s not a tiredness brought on by working long hours, staying up late to study, or spending hours walking and shopping. It’s not marked by laziness or an unwillingness to do things. Instead, we as patients have described our fatigue as overwhelming, engulfing, earth-shattering, toxic, bone-tired, draining of life force, and feeling crumpled like a piece of laundry. We describe fatigue in terms of what we cannot do, such as get up out of bed or a chair, lift something, perform a basic household task, drive somewhere such as to the grocery store or a medical appointment, and if and when we can do these things, we are exhausted beyond what words can describe.

Words matter. We ask the broader medical and research communities to think about dropping terms such as “syndrome,” “primary” and “secondary.” Just because these terms were coined decades ago does not make them useful or even correct. The Sjögren’s Foundation is leading a charge on behalf of patients and our medical advisors to change our terminology. “Syndrome” means a constellation of symptoms that tend to run together, while a “disease” is a condition that impairs normal functioning and is distinguished by specific signs and symptoms. Thanks to global research efforts, we have made amazing progress in our understanding of Sjögren’s not simply as a group of symptoms but as a disease. While the terms “primary” and “secondary” might be useful shorthand for clinical trial inclusion, these terms become applied broadly. They are not applied to related diseases. Just as one either has or does not have RA or SLE, one either has Sjögren’s or does not. In addition, today’s clinician is not always familiar with how to use these terms properly, leading to confusion for patients and clinicians alike. These terms are not helpful in light of what we now know about Sjögren’s. Words matter. They especially matter to patients, who feel like they have something that is not as bad as a disease when told they have a “syndrome.” Patients feel like their Sjögren’s is “secondary” and not as important as their “primary” disease. Words should matter to our healthcare providers, too, and we are grateful to those who acknowledge that what was described 50 years ago may have evolved and differ from what we know today.



## IN MEMORIAM

### In Memory of Betty Brinamen

Anita Calkin  
Joann Martin  
Mona Fiorno  
Theresa Myers  
Lynne Nunes  
Roslyn Wright  
Mary Chaudoir  
Margo and Bob Siroty  
Dora Hollomon  
Kevin and Virginia Ruesterholz

### In Memory of Carolyn Stull

Amanda Naillé  
Calista Umberger  
Donna Popek  
Dorothy Dutterer  
Susie Warner  
Del and Nancy Trout  
Robert Bullock  
Darlene Sartain  
Lucinda Tracey  
Mary Ellen Michael  
Roberta McGaughran  
Lisa Foreman  
Felicia Albert  
Rebecca Buffington

### In Memory of Debbie Hall Evans

Cynthia Rowe  
Brenda Lang  
Katie Hall

### In Memory of Demetra Petros

Daughters of Penelope

### In Memory of Eileen Guldin

Christina Lea

### In Memory of Elaine Jenkins

Marilyn Lashley

### In Memory of Ella Jane Sisler

Darla Rae  
Joe Sisler

### In Memory of Ellen Proctor

Lola Hooper  
Linda Bell

### In Memory of Ernest Norfolk

Lynne Moseley  
Jennifer Clawes

### In Memory of Gershon Sosin

Bela Daruwala  
Beth Yelsey  
Caryl and Howard Winter

### In Memory of Jane Inman

Mary Ann Frear  
Joanna Mancoll

### In Memory of Jon Merker

Debi Berzon-Leitelt

### In Memory of Leonard Berenfield

Susan Nauman  
Donald Anglim  
Gregory Berenfield  
Susan and Thomas Netzer  
Donald Anglim

### In Memory of Madeline Best

Patricia Irving

### In Memory of Margaret Walders

Kathleen Orié  
Alice Stoyle

### In Memory of Mary Wasner

Hans Wasner  
Amy McCall  
Barbara Boyd  
Carolyn Samsill  
Kurt Wetzel  
Melvin Lewis

### In Memory of Myra Hopkins

Linda and Ron Kafchinski

### In Memory of Sally Dauer

Mary Anne Boyle  
Pat Peffenbach  
Susan Forster

### In Memory of Sandra Haskel

Bobii Bowers

### In Memory of Sandra Mack

Elizabeth Riley  
Pat and Bob Kitson

### In Memory of Shirley Hodgson

Katherine Moore  
Jessica Schlumpf  
Suzanne Arndt

### In Memory of Susan Ciaccio

Cathleen Whelan

### In Memory of Tricia Gooding

Shanmuga Subramanian  
Patricia Hurley  
Diane Chesla  
Melissa Delumpa

## IN HONOR

### In Honor of Adrienne Jones

Ariel Weber

### In Honor of Bobette Morgan

Anonymous

### In Honor of Bonnie Meyer

Joe Meyer

### In Honor of Cathy Lee O'Neill

Barbara Foley  
Dorothy Stearle

### In Honor of Diane Doyle

Thomas Doyle

### In Honor of Ella Witalec

Daniel Witalec

### In Honor of Erin Bloomsburgh

Anonymous

### In Honor of Fred Vivino

Irene Svelka  
Lynn Petruzzi  
Bobette Morgan

### In Honor of Janet Church

Susan Brock

### In Honor of Josephine Sanzone

Anna Haywood

### In Honor of Kathy Hammitt

Raymond & Christine Yuen

### In Honor of Lari Lopp

Isabelle De Fontaines

### In Honor of Lauren Teukolsky

Roselyn Teukolsky

### In Honor of Liz Perry

Don Perry

### In Honor of Matthew Buske

Angela Buske

### In Honor of Nancy Sarow

Donna Reinardy

### In Honor of Roger Greene

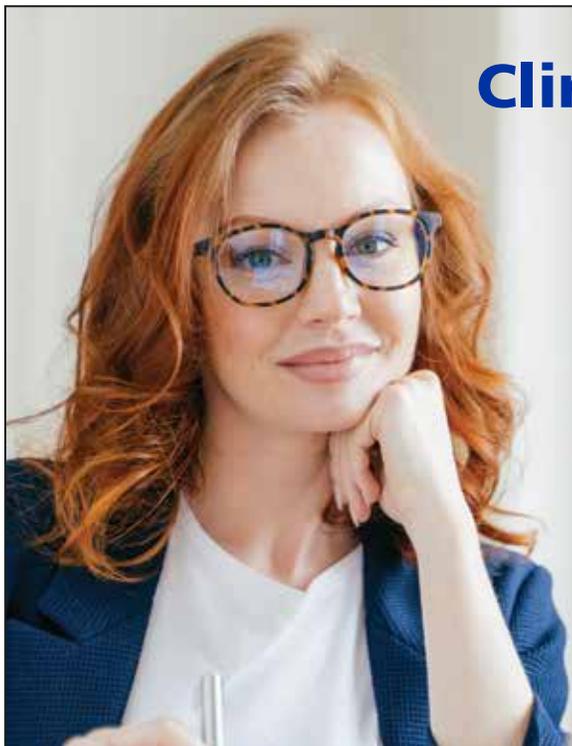
Savanna Wyatt

### In Honor of Susan Barajas

Judith Hooyenga

### In Honor of Teresa Genier

Janet Enger



## Clinical Trials in Sjögren's

Clinical trials are a crucial element in medicine and healthcare to help develop drugs that will treat or possibly cure certain diseases. Researchers use clinical trials to test if a drug works, how well it works, how safe it is and how it compares to any currently available treatments.

The Sjögren's Foundation has a section on its website devoted to clinical trials in Sjögren's and a listing of clinical trials that are currently recruiting Sjögren's patients.

To learn more visit:

[www.sjogrens.org/living-with-sjogrens/clinical-trials](http://www.sjogrens.org/living-with-sjogrens/clinical-trials)



**“Patient Perspective”** *continued from page 12* ▼

Sjögren’s is a disease with a high burden of illness and severe impact on quality of life. While a diagnosis often brings a major and sudden transformation to our lives, it’s the day-to-day struggles that we face that are most often devastating. Rather than the organ failure or major catastrophic event, the constant struggle without a break wears us down emotionally and physically. We crave validation from the healthcare and research communities as well as our friends and families. Many of our symptoms are hidden from sight, and a lack of acknowledgment denigrates our struggles and makes us feel invisible and misunderstood. While we as patients need to speak up more, tell our stories loudly and clearly, and not be fearful about telling others about our symptoms, it’s hard to do this when others are dismissive about our unseen struggles.

As Sir William Osler once said, “If you listen to the patients, they will tell you what is wrong with them.”

*This article is reprinted with permission from, and originally appeared in, Clinical Experimental Rheumatology as part of the 2020 Sjögren’s Supplement, which aims to update readers on a wide range of topics in this complex and rapidly growing field by publishing editorials, reviews and original articles pertinent to Sjögren’s.*

**Citation**

Hammit, KM. Sjögren’s: the patient perspective. *Clin Exp Rheumatol*. 2020 Jul-Aug;38 Suppl 126(4):25-26. Epub 2020 Sep 23. PMID: 33025897.

**References**

1. HELMICK CG, FELSON DT, LAWRENCE RC et al.: Estimates of the prevalence of arthritis and other rheumatic conditions in the United States. Part I. *Arthritis Rheum* 2008; 58: 15- 25.
2. SEELIGER T, PRENZLER NK, GINGELE S et al.: Neuro-Sjögren: peripheral neuropathy with limb weakness in Sjögren’s syndrome. *Front Immunol* 2019; 10: 1600.
3. MACKAY IR, ROSE RR: Autoimmunity and lymphoma: tribulations of B cells. *Nat Immunol* 2001; 2: 793-5.

**Half of Sjögren’s patients with severe dryness (53%) also have severe fatigue.**

**Reliable Dryness Relief**

**Feels like your own natural moisture**

WITH **HYDROLYTE** moisture system

@luyourvagina  
/luvenacare

**To Learn More: Visit [Luvenacare.com](http://Luvenacare.com)**

**WALK FOR Sjögren’s**  
CELEBRATING OUR STRENGTH

Walk for Sjögren’s is a national awareness and fund-raising program that takes place across the United States. To ensure every one’s health and safety with the COVID-19 outbreak, all Fall Walk for Sjögren’s events will continue to be virtual.

We hope that you will join us virtually and experience a Walk for Sjögren’s event that you otherwise might not have been able to attend. View all upcoming walks by visiting [events.sjogrens.org](http://events.sjogrens.org) or contact Jessica Levy at (301) 530-4420 ext. 218.

**We walk for a brighter future for all patients!**

# You Stood Up!

## Congratulations Team Sjögren's Runners and Walkers!

This April, 37 Team Sjögren's runners, including 31 patients, stepped up to fundraise and train for a virtual 5K, 10K, or Half-Marathon. Representing 22 states, these runners raced in their hometowns in honor of Sjögren's Awareness Month and raised an incredible \$7,578.75 for Foundation programs and initiatives.

Team Sjögren's is now recruiting for our next virtual race on Thanksgiving weekend. Follow our program and we will prepare you to walk or run either a 5K, 10K, or Half Marathon distance. The best part is that even if you have never run or walked such a distance, the staff and our team trainer will help guide you through the entire process and ensure you are ready to participate!

Our team will be full of walkers and runners – so don't fret – Team Sjögren's was designed for you. Our plan takes people from the couch to the course. In addition, you will be increasing awareness for Sjögren's and helping raise crucial funds for research and education.

If you don't feel you can walk or run in this event, do what so many other patients have done and recruit someone else - your husband, wife, sister, cousin, daughter, son or friend - and have them walk or run in your honor.

To learn more about our upcoming virtual race, please contact Kalla Ford, Team Coordinator, at [kford@sjogrens.org](mailto:kford@sjogrens.org). ■



*“Team Sjögren's runs in honor of all Sjögren's patients...  
**WE ARE TEAM SJÖGREN'S!**”*

# Stay informed. Stay aware. Be your own best medical advocate.

4 issues for just  
**\$20**  
for Foundation  
members!



To increase professional awareness about Sjögren's, the Foundation publishes *Sjögren's Quarterly* – a professional-focused resource geared toward medical and dental professionals, clinicians, researchers, and anyone interested in the latest in Sjögren's research findings and treatments.

Although the content is primarily written for a professional audience, *Sjögren's Quarterly* is not just for doctors and researchers.

If you are interested in subscribing to *Sjögren's Quarterly*, we are offering a special introductory rate of just \$20 for Foundation members. Take charge of your health by keeping on top of the most relevant and best medical information available.

Subscribe to *Sjögren's Quarterly* today, and you might just teach your doctor a thing or two about Sjögren's!

Non-Member Price	Member Price	Qty	Amount
------------------	--------------	-----	--------

<b>A one-year subscription to <i>Sjögren's Quarterly</i></b>	\$50.00	<b>\$20.00</b>		
<b>Total Amount</b>				

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

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Telephone \_\_\_\_\_ E-Mail \_\_\_\_\_

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

MasterCard  VISA  Discover  AmEx Card Number \_\_\_\_\_

Exp. Date \_\_\_\_\_ Security Code \_\_\_\_\_ Signature \_\_\_\_\_



## *Clinician's Corner:* Treatment options for extreme dry eye disease if punctal plugs aren't working

Jennifer B. Nadelmann, MD and Mina Massaro-Giordano, MD

**T**he treatment of dry eye should follow a stepwise approach based upon patients' symptoms and the underlying cause of their condition. Patients should speak with their ophthalmologist about the various options available to treat dry eye disease. While dry eye disease affects millions of patients, there are several treatment options to decrease the impact of the disease on patients' lives.

### **Lubrication**

#### **Artificial Tears**

Over the counter (OTC) artificial tears is often the first line of pharmacotherapy for treating dry eye disease. Artificial tears are used to replace and supplement natural tears. Some artificial tears products include preservatives, which can be associated with toxicity and an allergic response. Preservatives are intended to prevent microbial growth. Artificial tears that contain preservatives should be used no more than 4-6 times daily. Preservative-free drops are advised in patients that require frequent instillation of eye drops or who have pre-existing corneal conditions.

### **Prescription Medications**

#### **Cyclosporine**

Cyclosporine 0.05% (Restasis®) is approved by the U.S. Food and Drug Administration (FDA) to help to decrease inflammation and increase tear production in patients with dry eye disease.

#### **Cequa™**

Cequa™ (cyclosporine 0.09%) is a nanomicellar solution to enhance bioavailability of the drug to ocular tissues while decreasing systemic exposure, was also approved by the FDA to increase tear production in patients with dry eye disease.

#### **Lifitegrast**

Lifitegrast (Xiidra®) is a topical anti-inflammatory agent approved by the FDA for the signs and symptoms of dry eye.

#### **Topical Steroids**

Topical corticosteroids target inflammatory pathways to improve symptoms in ocular surface disease. Short-term therapy with corticosteroids such as loteprednol 0.5% (Lotemax®) can be used to decrease inflammation at the ocular surface.

Risks of corticosteroid therapy include elevation of intraocular pressure and long-term use may lead to the cause of cataracts.

### **Blood Products**

Autologous serum has shown to provide relief in symptoms and improvement of the ocular surface in patients with severe ocular surface disease refractory to standard treatments. Autologous serum eye drops are made from a patient's own blood by segregating the serum from cellular components. Platelet preparations have been used to treat ocular surface disease, including platelet-rich plasma (PRP).

### **Warm Compresses**

The most common technique to relieve meibomian gland disease (MGD) in evaporative dry eye is to apply heat to the eyelid and to physically manipulate the eyelids to express the contents of the meibomian glands. Warm compresses can be performed using a towel or cloth dipped in warm water or commercially available eyelid masks that are microwaveable.

**“Clinician’s Corner”** *continued from page 17* ▼**Eyelid Procedures****Intense pulsed light (IPL)**

Intense pulsed light (IPL) utilizes high-intensity light sources, which is absorbed by the skin tissue and then converted to heat. The FDA approved IPL for the treatment of dry eye disease signs in 2021.

**Vectored Thermal Pulsation (LipiFlow™)**

Lipiflow Vectored Thermal Pulsation System (Tear-Science, Morrisville, NC, USA) clears blockages in the meibomian glands of patients by heating the glands to therapeutic levels by applying localized heat to both inner eyelid surfaces while pulsating pressure is also applied to the outer eyelids. The procedure takes 12 minutes.

**iLux®**

The Systane® iLux® MGD Treatment System (Alcon, Fort Worth, TX) is an eyelid thermal pulsation system device that can be utilized in patients with MGD that applies localized heat and compression. The procedure takes 8 to 12 minutes.

**MiBoThermoflo**

The MiBo Thermoflo (MiBo Medical Group, Dallas TX) is a therapeutic device that utilizes a handheld probe with a double eye pad attached with ultrasound gel to deliver thermoelectric heat through the eyelid to the meibomian glands. The protocol involves an initial 12 minute treatment session per eyelid followed by a session one week later of 10 minutes per eyelid and then a third session two weeks following that is 8-10 minutes per lid.

**TearCare System**

The TearCare® System (Sight Sciences, Menlo Park, CA) is an in-office treatment that takes 12 minutes for patients with dry eye disease that utilizes four electrothermal iLid™ instruments that are affixed to

the external surface of each eyelid through which regulated thermal energy is applied to the eyelids at a constant temperature to melt meibum via a TearCare controller. Following the thermal cycle, a manual meibomian gland expression with expression forceps is performed to remove any resident obstructions.

**Meibomian Gland Probing**

Intraductal meibomian gland probing is performed at the slit lamp, during which a probe is placed into each meibomian gland orifice to mechanically egress its contents.

**Nasal neurostimulation**

Neurostimulation can treat dry eye disease by inducing tear production. The iT-EAR® 100 device (Olympic Ophthalmics Inc., Issaquah, WA) is an FDA approved portable, sonic external neuromodulation device for the treatment of dry eye disease.

**Contact Lenses (Bandage Lenses and Rigid Gas Permeable Scleral Lenses)**

Bandage contact lenses aim to provide comfort and protect the ocular surface against adverse environmental factors. Bandage contact lenses should be used as an adjunct to other treatments.

**Amniotic Membrane**

Cryopreserved amniotic membrane grafts may be used in moderate-to-severe ocular surface disease refractory to maximal medical treatments.

**Conclusion**

In conclusion, there has been a large expansion in treatment modalities available to treat the different causes of dry eye disease. The treatment of dry eye should follow a stepwise approach based upon the patient’s symptoms and the underlying physiology of their condition. ■

## Do we have your current e-mail address?



If you want to receive all the latest updates from the Sjögren’s Foundation, then you should make sure we have your most up-to-date e-mail address! The Foundation is starting to share more information via e-mail, from news about the Foundation and Sjögren’s, to information about the latest treatments and medicines, to local Support Group updates and more. Contact us at [info@sjogrens.org](mailto:info@sjogrens.org) to be certain we have your latest e-mail address in our database, and then keep an eye out in your Inbox for Sjögren’s news.

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

# Join us for the First Childhood Sjögren's Virtual Conference

The Sjögren's Foundation is proud to offer a one-day virtual conference created especially for families of children living with Sjögren's. Experts from across the country will be with us to discuss both foundational and emerging topics related to Sjögren's in children.

## One Day Virtual Conference

**Date: September 18, 2021**

**Time: 11am–3pm (Eastern Time)**

**Register online at:**

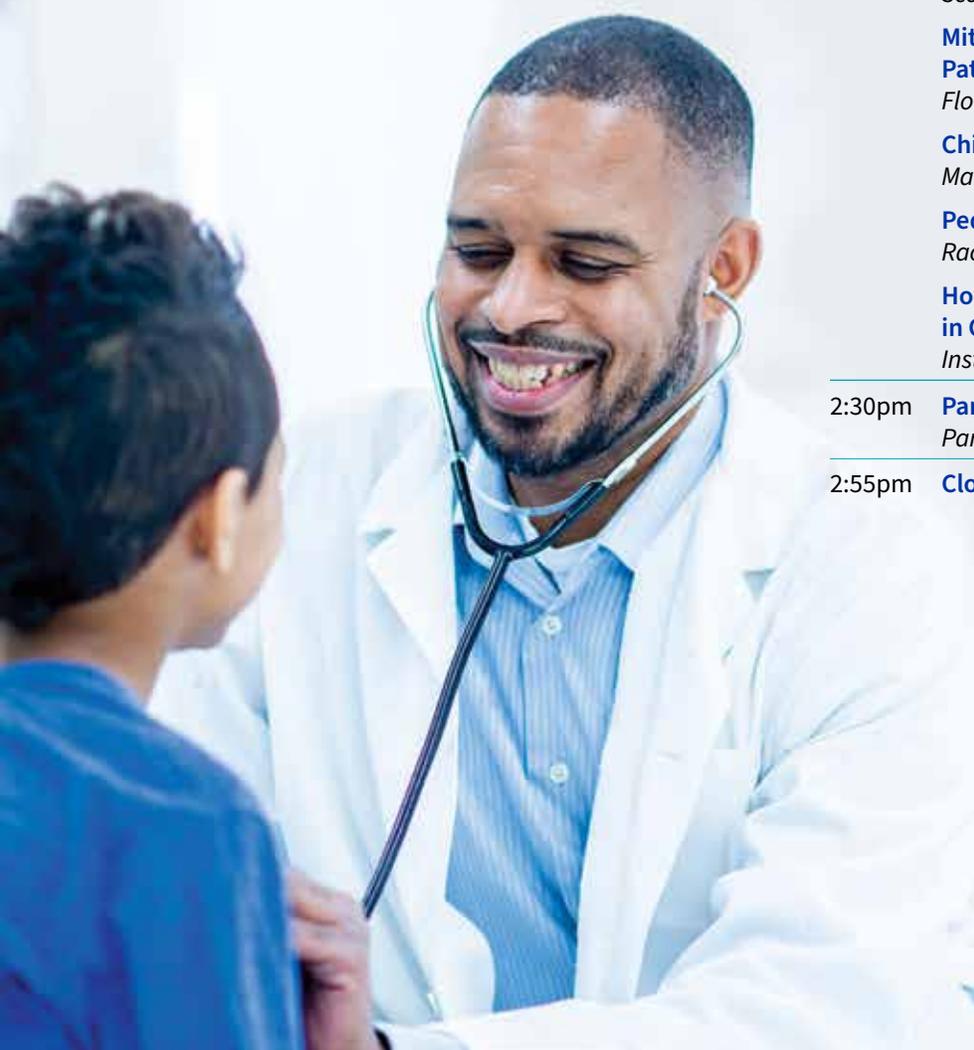


## Schedule and Topics

- 
- 11:00am **Welcome and Opening Remarks**  
*Janet Church, Sjögren's Foundation CEO*
- 
- 11:15am **Overview of Childhood Sjögren's**  
*Sara Stern, MD, University of Utah*
- 
- 12:00pm **Parotitis and How to Prevent Dental Decay**  
*Ava Wu, DMD, University of California San Francisco*
- 
- 12:45pm **Ophthalmology in Childhood Sjögren's**  
*Vatinee Bunya, MD, University of Pennsylvania*
- 
- 1:30pm **Exciting Projects in Childhood Sjögren's**  
*Moderator Scott Lieberman, MD, PhD*
- Salivary Biomarkers in Childhood Sjögren's**  
*Scott Lieberman, MD, PhD, University of Iowa*
- Mitochondrial RNA Regulators in Pediatric Patients** — *Sunghee Cha, DDS, PhD, University of Florida, Sjögren's Foundation Grant Awardee*
- Childhood Sjögren's Registry**  
*Matt Basiaga, DO, Mayo Clinic, Rochester, MN*
- Pediatric Rheumatology Provider Survey**  
*Rachel Randell, MD, Duke University*
- How to Interpret Minor Salivary Gland Biopsies in Children** — *Brian Dizon, MD, PhD, National Institute of Health (NIH)*
- 
- 2:30pm **Panel Discussion**  
*Parent, Provider and Foundation Staff*
- 
- 2:55pm **Closing Remarks** — *Janet Church*

### *Please Note*

*Registrants must have a device with internet access to join the conference*





## Conquering Sjögren's

Sjögren's Foundation Inc.  
10701 Parkridge Blvd., Suite 170  
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*

# Become a Sjögren's Foundation Awareness Ambassador

**T**he Sjögren's Foundation is looking for volunteers to help us raise awareness among the healthcare providers in their community.

Awareness Ambassadors are on the front lines, helping the Foundation achieve our Mission and Vision of providing credible resources and conquering the complexities of Sjögren's through awareness. They do this by implementing the Foundation's campaigns, targeted at educating healthcare professionals in their area about the various manifestations of the disease. Together, these Awareness Ambassadors have reached thousands of healthcare professionals throughout the country, making a tremendous impact on the landscape of Sjögren's in the medical community.

If you are interested in joining the Foundation as an Awareness Ambassador, visit our website [www.sjogrens.org](http://www.sjogrens.org) and choose the "Get Involved" tab, then click "Volunteer" to find out more details and sign up. Or you can email Michele Champigny at [mchampigny@sjogrens.org](mailto:mchampigny@sjogrens.org).

*The Foundation's vision is:*

*"To create a community where patients, healthcare professionals and researchers come together to conquer the complexities of Sjögren's."*

