

# CONQUERING Sjögren's

September/October 2023

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## CONQUERING Sjögren's

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## A Letter from your CEO, Janet E. Church



In this issue of *Conquering Sjögren's*, we are covering a lot of ground! With our keen interest in funding more Sjögren's research, we are highlighting our 2023 Foundation Research Grant recipients. This year, we awarded two Pilot Grants and one High Impact Grant. We also awarded our first Dynamic Grant, which we invested in to help expand their genetics research. The Dynamic Grant is one of our new funding mechanisms, which along with updated Foundation Grant policies and a new Partner Grant policy are designed to attract even more proposals in the future.

This past spring, we also invested in advocacy efforts, and we will give you a full update on this work, especially with the Centers for Medicare and Medicaid (CMS), in this Issue. Every issue, we also like to present information on a Sjögren's symptom or manifestation. September 13<sup>th</sup> is Interstitial Lung Disease (ILD) Day, and we take a deeper look at ILD and what you need to know so you can spot early signs to present to your healthcare provider.

### *A Year of Celebration!*

Our opening article in this *Conquering Sjögren's* is all about the very first support group—held by Elaine K. Harris—that kickstarted the creation of the Sjögren's Foundation. That support group was held in September 1983, which means that the Foundation is 40 years old, and we are celebrating! From September 2023 through next September, you will see this new 40<sup>th</sup> logo incorporated into our Foundation logo and many of our programs. Marking important milestones, such as this, is part of bringing more awareness to this disease so that

people understand that Sjögren's is serious, systemic, and deserves attention. Keep an eye out for this logo and join in while we commemorate 40 years of supporting Sjögren's patients, educating providers, funding research, and advocating for all Sjögren's patients!

I thank Elaine— for not only being our founder, but our first volunteer. I also want to thank all our volunteers and staff over the years who have made the Sjögren's Foundation what it is today. Together, we will conquer the complexities of this disease! ■



*Look for this incorporated into our programs throughout the year.*

# The Sjögren's Foundation Turns 40 *Thanks to Elaine Harris!*



*Early support group, Elaine is in the center.*



Elaine K. Harris was diagnosed with Sjögren's in early 1983, and that sparked the beginning of what grew to become today's Sjögren's Foundation with national and international reach and accomplishments. She was frustrated by how long it took to identify that the symptoms she was experiencing was a disease called Sjögren's Syndrome. After diagnosis, she attempted to learn more about her disease and how to manage it. However, she became discouraged by the lack of information that existed about Sjögren's. There was no Foundation and no internet to search, and after a lengthy process trying to find information, Elaine was able to find only two documents that even mentioned the disease. Determined to take control of her health and learn more about her symptoms, Elaine used her past community involvement to start a local support group with the only other Sjögren's patient that she met—the secretary of her doctor. Initially determined to simply meet other patients and start a support group, she ended up achieving so much more by growing that support group into what today is the Sjögren's Foundation.

*"Faced with Sjögren's, Elaine Harris singlehandedly mustered the determination to combat the disease by planting the seeds for the Foundation. An example of one bettering the lives of many."*

**Steve E. Carsons, MD,**  
*Sjögren's Foundation Medical and  
Scientific Advisors Founding Member*

That first support group meeting was held in September 1983 at Long Island Jewish Medical Center with the help of her physician. Six months later, the first issue of *The Moisture Seekers* newsletter, which has now evolved into *Conquering Sjögren's*, was published. In the summer of 1985, the Foundation was incorporated. The first board of directors was then established with Elaine Harris becoming the first president of the Sjögren's Syndrome Foundation. There were many wonderful volunteers and leaders who guided the Foundation's growth. In 2003, the leadership torch was passed to Steven Taylor, who grew the organization in the Washington D.C. area and clarified its mission to:

- Support and Educate patients and their loved ones;
- Educate and provide credible resources for healthcare providers;
- Be the voice of all patients through advocacy efforts;
- Encourage and Fund innovative research to learn more about Sjögren's and how to better diagnose, manage, treat, and ultimately cure this disease.

In 2020, the Foundation changed its name to the Sjögren's Foundation and launched the global nomenclature initiative to drop the term "syndrome" and change the name of the disease to Sjögren's disease worldwide to better reflect the true impact of this disease. In 2021, the torch was passed to Janet Church to lead the organization into the next



chapter, where we will see more research funded, an expansion of provider education across specialties to support multi-disciplinary care, and new systemic therapies preparing to come to market.

Today, the Foundation has grown into a powerhouse organization with passionate staff and dedicated volunteers, breaking down barriers worldwide in the field of Sjögren's. All of this has been possible because one determined woman, who knew that more had to be done for patients, launched a national support effort that became the Foundation and envisioned the future.

On June 7, 2022, we lost Elaine— at the age of 98—but her legacy will live on in the people that she helped and all the patients whose lives are impacted by the work of the Foundation that she established. ■

*“As a Sjögren’s patient myself, I am deeply grateful that Elaine created this organization because it was the single most important source of information and support for me when I was diagnosed. Elaine’s clear vision will forever live on in the Foundation as we continue to carry the torch and advocate in honor of all patients.”*

**Janet E. Church,**  
Sjögren’s Foundation President & CEO



***At the Foundation, supporting our patients is a critical part of our mission.***

*If you or your loved ones would like to find a Sjögren’s support group in your area, please visit our Support Groups & Networks at*  
<https://sjogrens.org/living-with-sjogrens/support-groups-networks>.






# Ready, Set, Trot

*Trot for the Sjögren's Foundation as we celebrate our 40<sup>th</sup> Anniversary!*

Announcing our new Turkey Trot Kit to raise awareness! Just gather family and friends, purchase your kit, and trot on down to your local Thanksgiving Turkey Trot.

*Last Day to order to receive by Thanksgiving weekend is November 8<sup>th</sup>*



## **Kit 1 Includes: \$35**

- New Sjögren's 40th **Short Sleeve** Cotton T-shirt
- Sjögren's Foundation Face Mask
- Sjögren's "Turkey Trot" Medal
- "Stronger than my Sjögren's" wristband
- "What is Sjögren's?" Brochure

## **Kit 2 Includes: \$47**

- New Sjögren's 40<sup>th</sup> **Long Sleeve** Cotton T-shirt
- Sjögren's Foundation Face Mask
- Sjögren's "Turkey Trot" Medal
- "Stronger than my Sjögren's" wristband
- "What is Sjögren's?" Brochure

*Order your Sjögren's Foundation Turkey Trot Kit by scanning the QR Code to the right, calling (301) 530-4420, or online at [www.sjogrens.org/shop](http://www.sjogrens.org/shop).*





# Sjögren's Foundation *In Action!*

## *Sjögren's Foundation Leads the Fight for Medicare Coverage of Dental Services*

**W**e are all aware of the critical need to take care of our oral health in Sjögren's and manage the impact that oral complications can have on our disease. This is why the Sjögren's Foundation was so quick to take advantage of the opportunity when the Centers for Medicare and Medicaid Services (CMS) opened the door last November to consider specific circumstances under which dental care was medically necessary for Medicare recipients. The Foundation has been working long and hard since then to obtain dental coverage for Sjögren's and other autoimmune disease patients under Medicare.

We are disappointed, however, to report that despite the Foundation's and our patients' phenomenal efforts, CMS decided it cannot provide coverage for our population of patients under its current mandate. While the decision itself is disheartening, we want you to know that we are pleased that CMS did hear our plea and expressed understanding of the need for oral care in Sjögren's and related disorders. CMS publicly addressed and embraced the oral-systemic connection in our diseases when it released its mid-July ruling.

CMS first offered the opportunity for consideration of candidates for medically necessary dental care under Medicare when it issued its Calendar Year (CY) 2023 Physician Fee Schedule last fall. The Foundation took on a leadership role under the auspices of the Consortium for Medically Necessary Oral Health Coverage (also referred to as the Oral Health Consortium, <https://www.oralhealthconsortium.org>) by chairing the Autoimmune Diseases Working Group. We wanted to ensure the voice of Sjögren's patients was heard loudly and clearly! We gathered a top-notch

healthcare professional advisory team (see page 9), and other patient advocacy organizations representing those with lupus, rheumatoid arthritis, and scleroderma joined in support of our submission (see page 9). Our request for coverage was presented to CMS by the February deadline of this year. This and subsequent presentations to CMS and federal legislators and agencies highlighted data, clinical evidence, and compelling patient stories, which drove home the urgent need to expand dental coverage to this population of Medicare beneficiaries.

### *The Foundation's Request for Coverage*

The World Health Organization (WHO) states that "Oral health affects people physically and psychologically and influences how they grow, enjoy life, look, speak, chew, taste food and socialize, as well as their feelings of social well-being." The Sjögren's Foundation built on this premise and the oral health manifestations in Sjögren's that add to our patients' health needs in its proposal to CMS. You can find the link to our CMS proposal in our blog about Medicare dental coverage at [www.sjogrens.org/blog](http://www.sjogrens.org/blog) or scan the QR code below.

*Sjogren's  
CMS Proposal*



*continued page 8* ▼

*"The Foundation engaged in a remarkable effort on behalf of our patients," says Foundation CEO Janet Church. "I want everyone to know that this is just the start of a broad and continuous educational initiative with government, and we will use the support we are building to help us meet future patient needs."*



## “Medicare” *continued from page 7* ▼

Our key points included the following concepts along with 73 references in support of the evidence we provided.

- Oral manifestations are an integral part of a systemic autoimmune disease process, and each impacts the other. The Sjögren’s Foundation recently obtained eleven international diagnostic codes used (known as ICD codes) by healthcare providers for Sjögren’s, including a specific code citing oral complications of our disease. These codes clearly demonstrate that Sjögren’s is truly a systemic autoimmune disease that includes dental involvement as an integral, common, and serious diagnosis.
- When oral manifestations are not managed and treated in a timely manner, complications and damage often lead to extensive oral problems and affect patients’ quality of life and systemic health.
- Oral bacteria, which is increased in a dry mouth, can spread to the lungs, heart, and other body organs and potentially lead to sepsis. Gum disease (periodontitis) has been linked to the development of cardiovascular disease (CVD). Tooth loss, which is increased in a dry mouth, has been linked to higher mortality from CVD. Treatment of periodontitis has been shown to improve outcomes in CVD.
- Resolving oral infection of the mucosa, teeth, and gums as well as reducing oral inflammation and tooth loss reduces the systemic impact that these features have on a patient’s autoimmune disease.
- A dry mouth makes it difficult to swallow and digest foods, and lack of saliva can increase the occurrence of gastro-esophageal reflux disease (GERD, or acid reflux). GERD can cause a dramatic increase in tooth decay and erosion as well as esophageal lesions that can turn cancerous. All these symptoms can impact nutrition.
- Commonly prescribed therapies, including nonsteroidal anti-inflammatory disease agents (NSAIDs),

corticosteroids, and immunosuppressive therapies, can exacerbate oral symptoms and their effects on autoimmune disease symptoms.

- Non-Hodgkin lymphoma, which occurs at a higher incidence in Sjögren’s patients, often starts in the salivary glands. Regular dental appointments with examination of the glands are critical to early identification of this potential development.
- Older Americans already face greater susceptibility to oral infection, inflammation, gum disease, tooth loss, GERD, and lack of good nutrition, so complications from dry mouth in Sjögren’s substantially increase these risks, posing a significant public health problem for those who are 65 and older.

### *CMS Ruling*

CMS has been grappling with how to interpret the mandate to allow medically necessary dental care and was able to provide important clarification in its CY2024 ruling. CMS stated in this ruling that its current view of the restrictions around Medicare coverage for dental services means stakeholders must establish an inextricable link between dental services and the success of an already covered Medicare service. CMS explained further that its coverage could not be based on diagnoses of chronic diseases, even when oral complications were integrally related to those diseases and could lead to an exacerbation of those symptoms and even to other non-related systemic symptoms. A clear example of eligible coverage under CMS’s interpretation of its mandate would be for dental care before someone undergoes joint replacement surgery. The full 1,920-page ruling can be accessed by those who want to view it as well as the most relevant pages from this document for a shorter summary from the Foundation’s blog on this topic.”

### *Sjögren’s Foundation and Patient Members in Action!*

The Sjögren’s Foundation dove into many meetings this year with federal legislators and agencies to educate them about our patients’ dental needs and tell our stories. We are especially grateful to so many of our members who contacted their U.S. Senators and Representatives to make them aware of our submission to CMS and the need for patients to have access to and financial help with dental care. Some of our members even arranged meetings with congressional offices for themselves as well as the legislator’s constituent, and Foundation staff.

The Foundation took advantage of two opportunities to present directly to CMS this spring. First, a

**For more information on oral care and caries prevention, please read the Sjögren’s Foundation Clinical Practice Guidelines for Oral Management at**



**<https://sjogrens.org/researchers-providers/clinical-practice-guidelines>**



## “Medicare” *continued from page 8* ▼

Foundation-led meeting with Foundation CEO Janet Church and Vice President of Medical and Scientific Affairs Kathy Hammitt, our Medical and Scientific Advisory Board Chair Dr. Alan Baer (Johns Hopkins University), and oral medicine specialists Dr. Athena Papas (Tufts University) and Michael Brennan (Atrium Health and Wake Forest University) in which we all presented and took questions from CMS. Next, the Foundation continued to convey information to CMS in a meeting held by the Oral Health Consortium. In addition to the CMS meetings, Church and Hammitt met with their own legislators, and Hammitt participated in consortium meetings with:

- The White House
- The Office of Management and Budget (OMB)
- The Department of Health and Human Services (HHS)
- The Senate Finance Health
- The Senate Committee on Health, Education, Labor, and Pensions (HELP)
- The House Committee on Ways and Means

### Oral-Medical Advisory Team

#### Alan Baer, MD

Director, Jerome L. Greene Sjögren’s Syndrome Center, Johns Hopkins University, Chair, Sjögren’s Foundation Medical and Scientific Advisory Council

#### Michael Brennan, DDS, MHS

Chairman, Department of Oral Medicine and Director of the Sjögren’s Syndrome and Salivary Disorders Center, Carolinas Medical Center; Professor, Wake Forest University

#### Athena Papas, DMD, PhD

Professor, Diagnostic Sciences-Oral Medicine, Dr. Erling Johansen Endowed Professorship in Dental Research, Diagnosis and Health, and Interim Dean of Research, Tufts University School of Dental Medicine

#### Vidya Sankar, DMD, MHS

Associate Professor and Division Director for Oral Medicine, Department of Diagnostic Sciences; Postgraduate Program Director, Oral Medicine, Tufts University School of Dental Medicine; President, American Academy of Oral Medicine

#### Domenica Giovanna Ciaglia Sweier, DDS, PhD

Clinical Professor, Director of Predoctoral Clinical Education and Director of Geriatric Dentistry, University of Michigan School of Dentistry

#### Ava Wu, DDS

Clinical Professor, Sjogren’s Clinic, University of California Berkeley School of Optometry; Professor, University of California San Francisco School of Dentistry

- The House Committee on Energy and Commerce
- Key House and Senate Congressional Caucuses

While the latest ruling is a setback for all of us, we should all be proud of our efforts to engage policy-makers across Congress and the Administration as well as highlighting the need to expand dental coverage under Medicare to the autoimmune disease population. We are deeply grateful to those of you who responded to our Action Alert by contacting legislators, joining Foundation staff in meeting with some of these offices, and providing personal stories to illustrate our clear need for dental services in Sjögren’s. Together, we clearly succeeded in increasing awareness of the needs of Sjögren’s patients among policy officials, and we are building support for the future. ■

### Autoimmune Disease Patient Advocacy Group Supporters

- Sjögren’s Foundation (Chair)
- Arthritis Foundation
- Autoimmune Association
- International Foundation for Autoimmune & Autoinflammatory Arthritis (IArthritis)
- Lupus and Allied Diseases Association, Inc.
- Lupus Foundation of America
- National Scleroderma Foundation

**Stay updated on current Sjögren’s clinical trials and how they can benefit you.**

***New phase 3 trials are starting soon!***

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.



# Advocacy Update:

## Michigan Becomes First State to Rise to the Call of Action for Sjögren's Awareness



As part of the Sjögren's Foundation's initiative to substantially raise awareness of Sjögren's on Capitol Hill, the Foundation has proposed that the U.S. Senate and House Resolution officially declare April as Sjögren's Awareness Month. This resolution would not only establish April as a nationally endorsed month for highlighting the needs of Sjögren's patients but also offers a means for us to expand education about our disease among federal legislators. While former U.S. Representative Louise Slaughter (NY) read into the Congressional Record the naming of Sjögren's Awareness Month in 1998, our current resolution provides for a more official and up-to-date pronouncement of the month and engages broader support across both the U.S. Senate and House. We have learned so much about Sjögren's over the last 25 years, so it is critical for us to convey the latest information to our legislators!

While this national effort has just begun, we want to highlight an amazing accomplishment in Michigan that followed our initial member Action Alert in the spring. Michigan State Representative Sharon MacDonell introduced House Resolution #HR 0086 naming April as Sjögren's Awareness Month, and this resolution passed the state legislature on April 26<sup>th</sup> this year! We applaud this achievement that will now serve as a model for similar Foundation efforts in other states. See Bill Text: MI HR0086 | 2023-2024 | 102nd Legislature | Enrolled | LegiScan at <https://legiscan.com/mi/text/hr0086/id/2792921> for the full resolution presented by 16 Michigan state legislators! ■



## Sip in Style while Raising Sjögren's Awareness!



### ***NEW Sjögren's Foundation Bistro Mug***

Our new Sjögren's Foundation bistro mug is perfect for the upcoming season change. The stainless-steel, double-wall insulated mug will keep warm beverages- hot- and cool beverages- cold. This teal blue mug with our logo in white will be sure to match those oranges and yellows of fall and winter whites. Cozy up this season and raise awareness for Sjögren's!

**Member Price: \$32**

**Non-Member Price: \$36**



### ***Sjögren's Foundation Water Bottle***

Featuring a sleek design, this high-end reusable water bottle will help you quench and conquer your day! The water bottle is easy to open and refill and is temperature-controlled to keep your beverages the way you like them. Whether you are volunteering for a fall walk, working out, or sipping at home, this is ideal for raising awareness for Sjögren's and keeping you hydrated on the go!

**Member Price: \$35**

**Non-Member Price: \$38**

Order your Sjögren's Foundation merchandise by scanning the QR Code below, calling (301) 530-4420, or online at [www.sjogrens.org/shop](http://www.sjogrens.org/shop).





# Foundation Revamps Research Program to Improve the Future of Sjögren's

**T**he Sjögren's Foundation is excited to announce the launch of a revamped research grants program that includes higher funding amounts for our existing grants as well as the development of two new funding mechanisms.

These changes are the result of six months of discussion with the Foundation's Research Committee and are in support of our Mission pillar to lead, encourage and fund innovative research projects to better understand, diagnose and treat Sjögren's. Our hope is that these changes convey our support to investigators and continue to place us as a leader in the field who is always considering how to best support our research community and ensure that Foundation offerings are attractive to both new and seasoned Sjögren's researchers.

Detailed overviews of each offering, including applications and FAQs are available on the Foundation's website, and highlights of the changes and additions are provided in the below descriptions.

*“By substantially expanding our research grants program, we hope to spark those important and novel discoveries that will open new windows into our understanding of Sjögren's. This, in turn, should lead to much-needed improvements in the way we manage and treat our disease. Research, after all, holds the key to finding solutions for our deepest hopes and dreams for the future of all Sjögren's patients.”*

— **Kathy Hammitt, VP, Medical & Scientific Affairs**

## ***What's changing with our Pilot Grant?***

The Sjögren's Foundation Pilot Grant was created to assist investigators in conducting feasibility studies, collecting preliminary data, or other research assistance necessary to advance their project to help prepare them to pursue additional, larger forms of grant funding.

Starting in FY24, the Pilot Grant will now offer twice as much funding as before and is increasing from \$25,000 to \$50,000! Also changing is the duration of the grant. For the past few years, Pilot Grants have been awarded for one-year in duration. Now, applicants can submit projects between one and two years in duration.

## ***What's changing with our High Impact Grant?***

The Sjögren's Foundation High Impact Grant was created to support more fully developed research proposals that already have preliminary data and the methodology in place to expand or move forward into the next phase of the project.

Starting in FY24, the High Impact Grant will increase in funding from \$75,000 to \$100,000! Similar to Pilot Grants, applicants for a High Impact Grant can now submit projects between one and three years in duration, rather than just a single year, as has been the case in the last few grant cycles.

“Grants” continued from page 11 ▼

**New Funding Opportunity: Dynamic Grants**

The new Dynamic Grant was created to support time-sensitive and critical work that falls outside of the Foundation’s normal grant cycle and funding opportunities (e.g., Pilot and High Impact Grants). The Foundation has full administrative oversight of Dynamic Grants and they will operate in a similar manner to the Foundation’s traditional grant offerings, if awarded.

Applicants for the Dynamic Grant are initially asked to provide a brief overview of their project that includes an explanation of the anticipated project outcomes and their significance, the scientific strengths of the project and how they’re applicable to Sjögren’s, any existing gaps in research that their work will address, and a justification for the time sensitive nature of the project. From here, the Foundation’s Research Committee will provide feedback and a response that informs the investigator whether they are invited to submit a full application.

See page 14 to learn more about our first Dynamic Grant awardee.

**New Funding Opportunity: Partner Grants**

Similar to the new Dynamic Grant, the new Partner Grant was created to support time-sensitive and critical work that falls outside of the Foundation’s normal grant cycle and funding opportunities. Where this mechanism differs is that the Foundation may not have administrative oversight, so the application and administrative process may be handled by another group or institution. An example of how this could work would be the Foundation along with another, relevant, institution are providing an investigator with funds, and the partner institution is overseeing the administrative aspects of the grant.

**General considerations for all grant types:**

As before, these funding opportunities are open to both junior and senior investigators located at a U.S.-based university or research institution. Additionally, this program continues to recognize and prioritize research into the causes, prevention, detection, treatments, and cure for Sjögren’s and is open to investigators from all fields of study relevant to Sjögren’s. ■

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# Sjögren's Foundation Announces New Grantees for 2024

The Sjögren's Foundation is excited to announce the selection of three new research grant recipients for the current fiscal year, which includes one High Impact Grant and two Pilot Grants. Additionally, the Foundation has provided no-cost extensions to a portion of our prior grantees as they finish their projects. Under a new funding mechanism, the Foundation has also awarded our first Dynamic Grant. Visit [www.sjogrens.org](http://www.sjogrens.org) to learn more about our research grants and our current and past grantees.

## *High Impact Grant: 2023-24*



**Harim Tavares dos Santos,  
DDS, PhD**  
*Postdoctoral Fellow,  
University of Missouri*

**Project Title**  
*The Role of Tuft Cells in  
Salivary Gland Immunity*

### **Abstract**

Tuft cells are rare chemosensory cells capable of producing an unusual spectrum of biological effector molecules, such as interleukins, eicosanoids and neurotransmitters. Previous studies have shown that tuft cells are capable of triggering immune responses in different organs via chemosensory transduction. Although tuft cells have been detected in salivary glands, their functions in this organ are unknown. The aim of this project is to explore role of tuft cells in salivary gland immunity. This grant application proposes (1) to investigate tuft cell distribution and function in salivary gland epithelium; (2) to determine tuft cell chemosensory components in salivary gland epithelium; (3) to determine the role of tuft cells in salivary gland immunity utilizing a Sjögren's disease-like mouse model and human specimens. Together, the new generated information will allow a better understanding of tuft cell biology in the salivary glands and provide therapeutic targets for salivary gland diseases.

## *Pilot Grants: 2023-24*



**Anat Galor, MD, MSPH**  
*Staff Physician, Miami Veterans Affairs  
Hospital, Professor of Ophthalmology,  
Bascom Palmer Eye Institute, University  
of Miami*

**Project Title**  
*Defining and Understanding  
Neurologic Manifestations of Sjögren's  
Based on Ocular Surface Phenotype*

### **Abstract**

Sjögren's disease (SjD) can present with a variety of ocular and systemic manifestations. Dry eye (DE) symptoms are a known manifestation of SjD. But beyond dryness, it is recognized that many individuals with SjD have chronic ocular surface pain, which is multifactorial in nature and associated with peripheral and central nervous system abnormalities. Our central hypothesis is that the phenotype of ocular surface pain out of proportion to clinical signs of dryness is a harbinger for neurologic dysfunction in SjD. This hypothesis will be tested using a comprehensive protocol that consists of a clinical examination, quantitative sensory testing (Aim 1), and detection of neuro-inflammatory signatures in blood (Aim 2) in individuals with SjD grouped by ocular phenotypes (pain vs. dryness). Our results will examine how ocular phenotypes relate to neurosensory metrics in SjD. Along with advancing understanding of SjD

*continued page 14* ▼

**“2024 Grants”** *continued from page 13* ▼

pathophysiology, these data can be used to develop clinically relevant diagnostic tests that subgroup individuals based on underlying mechanisms, an important first step to developing targeted therapies.

**Rachael Gordon, MD, PhD**

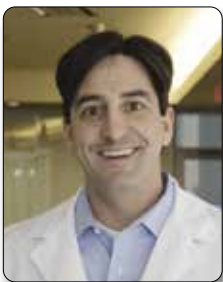
*Rheumatology Fellow,  
University of Pittsburgh*

**Project Title**

*Investigating the Role of IL-12 in Sjögren's Disease Pathogenesis*

**Abstract**

Sjögren's disease (SjD) is a common systemic autoimmune disorder characterized by progressive inflammation of the exocrine glands. The immunopathology driving SjD remains enigmatic and there are no FDA-approved disease modifying treatments. Polymorphisms in IL12A and STAT4 are associated with SjD across multiple cohorts, suggesting a fundamental role for the IL-12A-STAT4-Interferon (IFN)  $\gamma$  axis in SjD. IL-12 and IFN $\gamma$  are intimately linked in positive feedforward loops critical to the development and function of Th1 cells. More recently, our group has discovered a novel role for this axis in inflammatory B cells. We hypothesize that IL-12 promotes SjD. We will test this hypothesis by treating NOD.B10 SjD prone mice with an IL-12 neutralizing antibody and evaluating clinical and immunologic features of disease. Elucidating a pathogenic role for IL-12 in SjD will serve as the rationale for developing a human monoclonal IL-12 antibody for the treatment of SjD and other IL-12-driven diseases.

**Dynamic Grant: 2023 – 2025****Chris Lessard, PhD**

*Associate Member,  
Oklahoma Medical Research Foundation*

**Project Title**

*Expanding Our Understanding of the Heterogeneity and Heritability of Sjögren's in Diverse Populations*

**Abstract**

Defining the genetic susceptibility of Sjögren's will offer insights into the dysregulated molecular mechanisms that influence disease pathology and for therapeutic advances. We recently identified 10 novel risk loci associated with Sjögren's of European ancestry ( $n \sim 3900$  cases). To improve our understanding of how genetic risk loci contribute to disease pathology and

clinical heterogeneity, it is critical to increase our discovery power by acquiring a sufficiently large sample size (goal of 10,000 cases) with adequate clinical information for subphenotype analyses. We have several collaborators that have access to well-characterized patients but do not have the necessary infrastructure to extract DNA. The time-sensitive support from the Sjögren's Foundation will facilitate DNA collection from these sites, thus increasing our sample size, and the ancestral diversity and age of the study population. Leveraging the additional genotype and clinical data will enable the identification of additional risk loci and ask critical subphenotype-specific questions.

**Continuing Research Grants from Prior Years****Seunghee Cha, DDS, PhD**

*University of Florida College of Dentistry*

**Project Title**

*Integrated Transcriptomic Profiling of Recurrent Parotitis in Pediatric Sjögren's for Assessment of Mitochondrial RNA Regulators*

Dr. Cha is working to uncover the gene signatures of juvenile Sjögren's immune cells with high-throughput sequencing. Preliminary data suggest that mitochondrial RNA may elicit the inflammatory signature in monocyte. Her team will determine how such altered gene signatures of juvenile Sjögren's monocyte in the blood affects immune cell phenotype in the target tissue and hypothesize that robust inflammation in recurrent parotitis of juvenile Sjögren's presents more distinct mitochondrial RNA dysregulation compared to juvenile Sjögren's without recurrent parotitis or adult Sjögren's. Ultimately, their goal is to establish the scientific foundation for juvenile Sjögren's diagnostic criteria and targeted therapeutic interventions.

**Cintia S. de Paiva, MD, PhD**

*Baylor College of Medicine - Ocular Surface Center*

**Project Title**

*Investigating Oral and Conjunctival Gene Transcriptome Signature in Sjögren's at the Single Cell Level*

Dr. de Paiva and her team believe that cells from the eye surface and mouth taken from patients with dry eye and dry mouth carry a distinct gene signature from patients with dry eye only and control subjects. They are using a novel technique that can identify the genes from the eye and the mouth at a single-cell level. Identification of a Sjögren's gene expression signature would provide relevant diagnostic markers that could be used in the future.

**Kemal Chémali, MD***University Hospitals Health System***Project Title***Study of the Prevalence of Elevated Mycoplasma Pneumoniae Titers in Sjögren's and Other Autoimmune Disorder-Associated Neuropathic Postural Orthostatic Tachycardia Syndrome (neuropathic POTS)*

Dr. Chémali is working to determine the role of *Mycoplasma pneumoniae* (MP) in the autonomic C and delta nerve fiber dysfunction that lead to autonomic disorder through an autoimmune mechanism. This insight will help trigger the search for an autoimmune disease, mainly SjD, in patients with neuropathic POTS and elevated MP titers, leading to a more targeted and effective core treatment of these conditions with immune modulation.

**David T. Wong, DMD, DMSc***The Regents of the University of California, Los Angeles***Project Title***EFIRM Liquid Biopsy for Early Detection of Sjögren's and Sicca Patients*

Dr. Wong and his team have developed an electrochemical assay, EFIRM, that can measure the pathog-

nomonic autoantibodies of Sjögren's, Ro and La for the first time robustly and quantitatively in saliva of Sjögren's and sicca patients. They are now testing the hypothesis that salivary IgA, not IgG, to Ro and La are associated with salivary gland tissue destruction as reflected by focal score. Furthermore, the monomeric versus polymeric forms of salivary IgA1 to Ro can discriminate sicca from Sjögren's patients using saliva samples.

Look for an article highlighting Dr. Wong's research on seronegative patients in the next edition of *Conquering Sjogren's!*

**Thomas Grader Beck, MD, PhD***Johns Hopkins University***Project Title***Leveraging Leveraging Electronic Health Record Systems to Establish a Multi-Center Collaboration Platform for Quality of Care and Clinical Research in Sjögren's Disease*

Dr. Grader Beck and colleagues have developed a comprehensive clinical module for Sjögren's that is integrated into the EHR system and are working to implement the module across sites to facilitate high quality standardized data collection. ■

## 2023 Research Highlights from Our Grantees

We're excited to share some recently published research from our grantees this summer and note that many of our other grantees are in the process of publishing their work as well. We are honored to support these brilliant researchers to help us better understand the complexities of Sjögren's!

**Addy Alt-Holland, PhD***Associate Professor, Tufts School of Dental Medicine, Boston, MA, Department of Endodontics*

**Citation:** Alt-Holland A, Huang X, Mendez T, et al. Identification of salivary metabolic signatures associated with primary Sjögren's disease. *Molecules*. 2023;28(15):5891. Published 2023 Aug 5. doi:10.3390/molecules28155891

**Brief Summary**

The Alt-Holland group used a special analysis tool called nuclear magnetic resonance (NMR) to understand salivary metabolite differences that are associated with Sjögren's (SjD) and determine if these differences can help with diagnosis in the clinic. They determined the composition of metabolites in saliva samples from SjD patients and non-SjD patients, and found a subset of metabolites, including glucose, glycerol, taurine, and lactate, that were significantly increased in all SjD patients.

**Read more:** <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10421170>

**David T.W. Wong, DMD, DMSc***Professor, Director for UCLA Center for Oral/Head & Neck Oncology Research (COOR), University of California Los Angeles, Los Angeles, CA, School of Dentistry*

**Citation:** Kamounah S, Tayob N, Chiang S, et al. Immunoassay detects salivary anti-SSA/Ro-52 autoantibodies in seronegative patients with

primary Sjögren's syndrome. *Immunohorizons*. 2023;7(7):554-561. doi:10.4049/immunohorizons.2300043

**Brief Summary**

The Wong group developed a novel immunoassay that could improve the early diagnosis of both seronegative Sjögren's (SjD) patients, and patients with early onset of autoimmune disease. This immunoassay is called the electric field-induced release and measurement (EFIRM) platform and demonstrated that anti-SSA/Ro52 autoantibodies could be detected in the saliva of SjD patients.

**Read more:** <https://pubmed.ncbi.nlm.nih.gov/37466644>



# Sjogren's Foundation supports ILD Day

# ILD Day

## Interstitial Lung Disease Awareness and Education

The Foundation partnered with nine organizations to support the Pulmonary Fibrosis Foundation's initiative to expand the understanding of interstitial lung disease (ILD) among patients and healthcare providers. The third annual ILD Day kicks off on Wednesday, September 13<sup>th</sup>, 2023 to promote awareness for ILD.

### *Interstitial Lung Disease (ILD)*

There are over 200 causes of ILD with more than 50,000 Americans newly diagnosed with ILD each year. ILD is characterized by inflammation and/or scarring in the walls and surrounding tissue of the air sacs in the lungs. Inflammation and scarring can affect the lungs' ability to carry oxygen, making it harder to breathe and deliver oxygen to the rest of the body. The damage caused by ILD can be irreversible and worsen over time.

When ILDs involve scar tissue, this is called pulmonary fibrosis (PF). Patients with PF can have low oxygen levels causing them to have difficulty doing everyday tasks, including walking and exercising. There are more than 250,000 Americans living with PF.

Approximately 16% of Sjögren's patients demonstrate pulmonary complications with increased mortality and lower quality of life. However, this figure may be low due to gaps in awareness and education. The most common pulmonary complication in Sjögren's patients is ILD.

### *Symptoms and Risk Factors of ILD*

Symptoms of ILD depend on the severity of the disease. Most Sjögren's patients are asymptomatic in the early stages but will develop dry cough and shortness of breath on exertion. ILD symptoms can include shortness of breath, cough, sputum production or chest pain. The onset of ILD in Sjögren's may increase with time following diagnosis of Sjögren's. ILD may become irreversible and debilitating, including increasing the risk of pulmonary hypertension that can lead to heart failure.

Other lung complications can mimic ILD, but it is always a good idea to check out your lungs when presenting with symptoms!



## Symptom Checker

If you have one or more of the following symptoms, please consult with your doctor about your lungs:

- Persistent, dry cough
- Fatigue and weakness
- Shortness of breath
- Chest pain
- Chronic sputum production
- Loss of appetite and/or unexplained weight loss
- Clubbing of the fingertips (thickening of tissue under fingernails)

Remember, many patients may not have symptoms in the early stages of ILD. However, symptoms and onset of ILD can increase with duration of Sjögren's.

### *Diagnosis and Treatment*

Diagnosis of ILD can be difficult. Patients are encouraged to get chest x-rays, pulmonary function tests, and high-resolution computed tomography (HRCT) scans to help confirm diagnosis and severity of ILD.

Current treatments for ILD are corticosteroids, immunosuppressives, and biologics against inflammatory mediators produced as a part of ILD. Because of the



complexity of Sjögren's and ILD, it is important to have a multidisciplinary team that includes a rheumatologist, primary care physician, pulmonologist, pathologist, radiologist, and, when appropriate, an oncologist.

A committee of rheumatology and pulmonology experts have prepared the Sjögren's Practice Guidelines for Pulmonary Manifestations. These clinical practice guidelines were created to improve the quality of care for Sjögren's patients through the assessment and management of pulmonary manifestations.

Please visit <https://sjogrens.org/researchers-providers/clinical-practice-guidelines> to find the Foundation's clinical practice guidelines for pulmonary manifestations.



### About ILD Day

ILD Day is a collaboration between the Pulmonary Fibrosis Foundation, Arthritis Foundation, Foundation for Sarcoidosis Research, The Myositis Association, PF Warriors, Scleroderma Foundation, Scleroderma Research Foundation, Sjögren's Foundation, and Wescoe Foundation for Pulmonary Fibrosis.

The initiatives of ILD Day include increasing awareness through social media and sharing patient-to-pa-

tient stories as well as hosting an educational webinar on a topic related to ILD each year.

The educational webinar for this year's ILD Day is entitled "Breathing Better with Supplemental Oxygen" and will be held at 12 pm CDT on Wednesday, September 13<sup>th</sup>. The physician speaker will be Jisha K. Joshua, MD, Associate Clinical Professor of Medicine and Director of Advanced Lung Disease Center at University of California, San Diego, and she will discuss the physiology of ILD, the role low oxygen plays in the disease, and therapeutic options for delivery of oxygen. Susan Jacobs, RN, MS, FAAN, research nurse manager for the ILD program at Stanford University, will also present about lifestyle needs for ILD patients and Gary Ewart, MHS, Chief of Advocacy & Government Relations from the American Thoracic Society will discuss advocacy efforts. ■

To register for the ILD Day educational webinar or to learn more information about ILD from the Pulmonary Fibrosis

Foundation, visit [www.ILDDay.org](http://www.ILDDay.org).



## Clinician's Corner: ILD in Sjögren's

by Nishant Gupta, MD

University of Cincinnati, Board Member, Sjögren's Foundation

**I**nterstitial lung disease (ILD) refers to the development of inflammation and/or scarring of the lungs and can be seen in about 10-15% of patients with Sjögren's.

The most common symptoms from ILD include shortness of breath and cough. However, early in the disease course patients may be relatively asymptomatic. This is one of the reasons behind the recommendation to actively screen for lung involvement in patients with Sjögren's in the recently published Guidelines for Pulmonary involvement in Sjögren's (see above for link).

It is also worth noting that ILD may be the presenting manifestation of Sjögren's disease. Thus, it is important to ask about symptoms that might clue towards the possibility of underlying Sjögren's disease when evaluating patients with ILD.

The best non-invasive way to look for ILD is via chest CT scan. Chest CT can not only help answer whether there is ILD but can also provide useful information regarding the type and severity of ILD. Patients with Sjögren's, especially those with pulmonary symptoms such as shortness of breath and/or cough that lasts beyond a few weeks, should have a low threshold to obtain chest imaging.

In patients with Sjögren's, the diagnosis of ILD can generally be made non-invasively and lung biopsy is not needed in most circumstances. Patients with ILD require long-term monitoring to better understand the disease trajectory and to help make treatment decisions and should be followed in close collaboration by their rheumatologist and pulmonologist.

For an expanded version of this information, please visit Dr. Nishant Gupta's blog post on "ILD in Sjögren's" at [www.sjogrens.org/blog](http://www.sjogrens.org/blog).



# STRONGER

THAN SJÖGREN'S

## Fall 2023 – Walk for Sjögren's Calendar

September

**New England Virtual Walk for Sjögren's**  
*Saturday, September 30, 2023*

October

**West Coast Virtual Walk for Sjögren's**  
*Saturday, October 21, 2023*

**New York State Virtual Walk for Sjögren's**  
*Saturday, October 21, 2023*

[events.sjogrens.org](https://events.sjogrens.org)





## IN MEMORIAM

**In Memory of Joan Arruda**  
The Bloom Family

**In Memory of Dr. Theodore Bedard**  
Mary Cardenas

**In Memory of Frankie Bissette**  
Chris and Jeff Brickhouse  
George Payne  
Jean Smith  
Kay Vest  
Laura Lewis  
Lois Ivey  
Mark and Jill Mansfeld  
Susan Ritchey

**In Memory of Patricia Ann Cwiekalo**  
Yvette Marrin

**In Memory of Hyonmi DelFerro**  
Anne Spratt  
Elizabeth DelFerro  
Jane Ament  
Jean DelFerro  
Joe DelFerro  
Marie Kilpatrick  
Michael Bledsoe  
Robert Meighan

**In Memory of Jan Gordon**  
Kevin McCaffrey

**In Memory of Eileen Guldin**  
Christina Lea

**In Memory of Vicki Knauss**  
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**In Memory of Marion D. Landoski**  
Christine Sommer

**In Memory of Carolyn McNutt Hall**  
Gary Armstrong  
John Stigall  
Laura Gore  
Laurel Martin  
Penny Doyle

**In Memory of Janet Nichols**  
Charlotte and Darry Sands  
Donald and Judith Wenger  
Gary and Marilyn George

**In Memory of Demetra Petros**  
Ekatarene Lawrence  
Victoria Miller

**In Memory of Rita and Edward Quinlan**  
Karen Quinlan

**In Memory of Cathryn Robertson**  
Gordon Seibert

Iza Synnott  
John Dempsey and Mary Scott  
Kimberly Bell  
Laura Bishop  
Laura Cunningham  
Sylvia Wai  
Linda Seibert  
Susan LaHoda

**In Memory of Ella Whitten Sisler**  
Joe Sisler  
Darla Rae

**In Memory of Linda Holyfield Sleeper**  
Brenda Parks

**In Memory of Carolyn Stull**  
Sylvia Brantner

**In Memory of Norma White**  
Amanda Johnston

**In Memory of Vijayamma**  
Manoj Pillai

**In Memory of Heidi Ann Burke**  
John Burke

## IN HONOR

**In Honor of Kristi Alexander**  
Emma Cox

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Susan Levy

**In Honor of Susan Barajas**  
Judith Hooyenga

**In Honor of Dori Bernhard**  
Courtney Quenga

**In Honor of Janet Brandt**  
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Patricia Armstrong  
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Elizabeth Chase  
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Linda Glueck

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Alvin Haley

**In Honor of Lindsey Hatfield**  
Beth Ann Hatfield

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Michael Mazure

**In Honor of Heather Seidenberg  
and Judy Gargan**  
Kathy Moyer

**In Honor of The Devoted Staff at  
The Sjogren's Foundation**  
Carol Watson

*Remember your loved ones and special occasions with a donation to the Sjögren's Foundation in their name.*





## Conquering Sjögren's

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

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# SAVE THE DATE!

October 14, 2023



Join us on Saturday, October 14<sup>th</sup> for the Sjögren's Foundation Fall Focus Conference: Exploring the Complexities of Oral Health in Sjögren's. Sjögren's patients are intimately aware that a dry mouth is more than just a minor inconvenience. Saliva, or lack of it, can have a major impact on your life! The Sjögren's mouth is complex and more than "just dry"; it requires special attention and care to help prevent serious implications on your overall health and quality of life. With dry mouth affects 93% of patients, this is an important topic that affects nearly all people living with Sjögren's. In this program, we will dive deeply into oral health in Sjögren's and explore topics from basic oral function and maintenance to advanced care & restoration options.

This virtual conference will be delivered live by Sjögren's experts in oral medicine, who are committed to researching and understanding the complex Sjögren's mouth. They will help you understand the

structure of the mouth, basic care for supporting daily comfort & preventing quick decline, and lastly, how to handle an advancing Sjögren's mouth. Each expert clinical presentation will be followed by a live question and answer session!

At this year's fall conference, you will hear from experts on these key oral health topics:

- Understanding the Oral Cavity and Glands
- Basic Prevention and Care Considerations for the Sjögren's Patient
- Caring for the Mucosa, Gums and Glands When Problems Arise
- The Advancing Sjögren's Mouth and Dental Restoration Possibilities
- What is on the Horizon for Oral Health and Care in Sjögren's?

Join us on October 14<sup>th</sup> and get the credible information needed to give your mouth the best chance of battling the oral effects of Sjögren's!

Learn more at [www.sjogrens.org](http://www.sjogrens.org) or by scanning the QR code above.