

CONQUERING Sjögren's

July/August 2025

Inside this Issue

*Debby's Story: You Took Action,
She Matched It*

***What You Need to Know
About AI-Generated Health
Information***

*Aligning Nervous System
Terminology in Rheumatology
and Neurology*

*World Sjögren's Day
Wall of Honor*

*Join Our Virtual Fall Walks
in the Northeast, West
Coast and Texas*

*The Role of Salivary
Autoantibodies
in Redefining Sjögren's*

*It's Official: Name Change
to Sjögren's Disease*



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e-mail: info@sjogrens.org

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Table of Contents

Debby's Story: You Took Action, She Matched It 3

Living with Sjögren's Patient Survey 5

What You Need to Know About
AI-Generated Health Information 7

Aligning Nervous System Terminology
in Rheumatology and Neurology 11

Name Change to Sjögren's Disease 13

World Sjögren's Day Wall of Honor 14

Join Our Virtual Fall Walks in the
Northeast, West Coast and Texas 16

The Role of Salivary Autoantibodies
in Redefining Sjögren's 17

In Memoriam & In Honor 19

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Debby's Story: Raising Her Voice and Matching Yours

*Sjögren's Foundation Donor
Matches Each World Sjögren's
Day Pledge with a Donation*

Before her diagnosis, Debby Vivari knew something wasn't right. She had trouble wearing contact lenses, even the soft ones. "I had a friend who worked in vision care who jokingly said, 'I can get a dog to wear contacts, you'll be fine.' But I just couldn't do it. They hurt. It didn't make sense at the time." She also had more cavities than most people she knew and often felt tired for no clear reason. But the symptom that really changed everything was the sudden onset of insomnia.

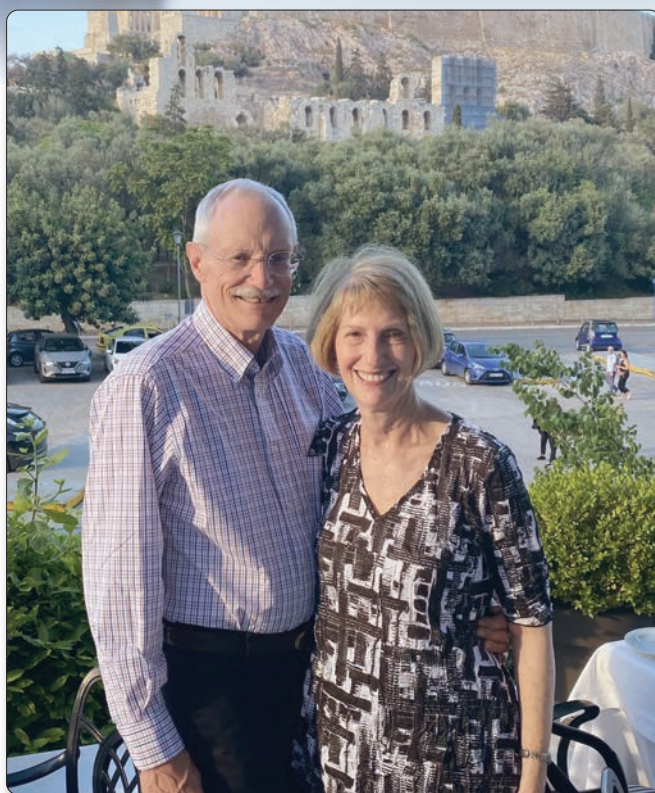
"I have always been a world class sleeper. If it was dark, I was sleeping. If we were driving home from some place in the winter, and it was 6 o'clock, I would sleep." So, when she suddenly couldn't sleep at all, it was terrifying.

"I was turning into a lunatic," she said. "I had two teenagers at home. And I was still working. And, you know, I kept up a good front at work because I was working up to being a very senior person at my job."

Her search for answers started with a sleep study at a hospital lab in Washington, D.C. She felt out of place from the start and didn't quite fit the typical sleep clinic profile. She barely slept that night, and in the morning, the technician told her, "Okay, you can get up. You win. You slept less than anybody else."

She tried all kinds of treatments: behavioral routines, medications, new specialists. Nothing really worked. "It was just terrible."

Eventually, she found a sleep specialist at Johns Hopkins who helped her taper off the old medications and build a new plan. "That guy who I still see or talk to if I don't need to see him... said, 'Okay, we



Debby and her husband Bruce

need different drugs. But the first thing we have to do is get you off what you're on. So, it's going to get worse before it gets better."

More symptoms started to show up, and luckily, her primary care doctor referred her to a rheumatologist who pulled the pieces together. That's when Debby first heard the word Sjögren's. "Of course, I had never heard of it, just like nobody else has ever heard of it." Suddenly, the dry eyes, fatigue, and strange sleep patterns made sense. Dry mouth started a year later and other symptoms continued to show up.

continued page 4 ▼

“Debby’s Story” *continued from page 3 ▼*

Getting diagnosed didn’t solve everything. It meant figuring out how to manage a disease that affects almost every part of daily life.

“People don’t realize how exhausting Sjögren’s is. Even on days when you look fine, you’re not.”

Managing Sjögren’s, Debby said, takes more than prescriptions. Debby acknowledges that managing it can be especially hard for those without support, information, or access to care — and even with resources, it’s still overwhelming at times.

“You need to be smart, you need to have money and you need to do everything you can to help yourself. Taking care of yourself is...it’s hard. It’s very hard. And I don’t mean to brag, but I’m a relatively smart person, and it’s hard for me to do.”

She pointed out how expensive and difficult it is to manage the condition day to day. “If you can’t afford all of the prescriptions and products you need, all of your symptoms will get worse. And it’s not just dry eyes and dry mouth — Sjögren’s affects your whole body.”

Despite the challenges, Debby kept going. “I decided I’m not going to let anybody tell me what I can (or can’t) do. So, I became PTA president. And I went from working part time to full time.”

Debby recognizes that not everyone can push forward like she did, but she wants to encourage people not to give up and to find things that bring you joy and keep you grounded.

For Debby, one of those things is travel.

“Travel has always been one of my great loves. I try to make it work, but it takes a toll. I have to pack carefully, plan for rest days, make sure I stay hydrated. Sometimes I’ve had to adjust or cancel things, but I still try to go.”

Giving back has also been a constant in Debby’s life. “I started giving a relatively small amount many years ago. And as I was able to give more, that’s what I did. But you don’t have to feel like you have to wait until you give a lot of money. Lots of people giving a little bit adds up to a lot.”

Debby’s journey with Sjögren’s has taught her how isolating, frustrating, and expensive it can be to live with a misunderstood disease, and how important it is to build visibility and support, one small action at a time.

That’s why, this year, Debby turned her experience into action. To help shine a light on this often-overlooked disease, she donated \$2 for every World Sjögren’s Day pledge.

In the weeks leading up to World Sjögren’s Day, we encouraged members of the community to pledge to take



Debby and her sisters (left to right): Andi, Debby, Lisa, Carole

small actions that, together, made a big difference. That could be telling five people about Sjögren’s, wearing blue on July 23rd and tagging the Foundation, sharing their story, or making a gift in support of the community.

Each pledge helped shine a light on Sjögren’s and showed those living with the disease that they are not alone. Together, these actions created greater visibility and support for the Sjögren’s community.

Thanks to Debby, our World Sjögren’s Day Sponsor, Novartis, and our Matching Gift Sponsor, Amgen, more than 1,100 people pledged to take action, nearly 1,000 names were added to the World Sjögren’s Day Honor Wall, and 500 people made donations.

For Debby, every action is a step toward change. Each pledge represents a voice speaking up, a story being shared, or a life being honored. And collectively, these small steps send a powerful message that Sjögren’s deserves to be seen, taken seriously, and understood.

“I want people to get diagnosed faster. I want doctors to listen and take people seriously. And I want the next person going through this to find answers sooner than I did.”

Debby knows that change doesn’t happen all at once. It starts with speaking up at a doctor’s office. Asking questions. Sharing your experience. Taking one small step, then another.

“I realized this disease doesn’t belong to my doctors, it belongs to me. They’re part of my team, but I have to lead it.”

Her story is a reminder that self-advocacy matters and that even when it’s hard, finding your voice and taking ownership of your journey can help you feel more in control. And every action, every story, every conversation, every pledge, is part of something bigger. ■



Sjögren's doesn't look the same for everyone.

Take the Living with Sjögren's Patient Survey and help us show what it's like to live with the disease.

Sjögren's isn't a one-size-fits-all disease. For some, it's relentless fatigue. For others, nerve pain or severe dryness. Some live with brain fog, while others battle serious organ involvement. Take the *Living with Sjögren's Patient Survey* and tell us what it's like living with Sjögren's disease.

Taking the survey helps:

- Show how serious and varied Sjögren's really is so doctors, researchers, and decision-makers better understand what patients face
- Push for new and better treatments that truly address what people are going through
- Improve support, resources, and education for patients and families living with Sjögren's every day
- It takes about 20 – 25 minutes and is completely confidential
- The survey is open through September 4, 2025.

Take the survey today at sjogrens.org/survey

Frequently Asked Questions

Who should fill out this survey?

This survey was designed and approved for adults age 18 years or older, living in the United States and who have been diagnosed with Sjögren's by a medical professional. Whether you're newly diagnosed or living with it for years, every experience matters and contributes to a more accurate picture of what it means to live with this disease.

Why can't non-U.S. residents participate?

At this time, the survey is designed to collect data that aligns with U.S. healthcare systems and regulatory standards. We recognize the importance of global perspectives and are exploring future efforts to include international patient voices.

Is my personal information safe?

Yes. All responses are confidential. No individual data will be shared, and results will only be reported in aggregate.

Will my name or identity be shared?

No. The survey does not collect identifying information unless you choose to provide it for optional follow-up or additional sharing opportunities.

Why are you asking for demographic?

These details help us better understand how different communities experience Sjögren's. This insight helps inform our outreach, advocacy, and education efforts.

Why is the Foundation conducting this survey?

We're collecting insights directly from people living with Sjögren's disease to better understand the day-to-day challenges, needs, and priorities of our community. The purpose of the study is:

- To provide researchers with valuable data on the wide range and severity of symptoms experienced by individuals living with Sjögren's.
- To raise greater awareness across the broader Sjögren's community, including patients, caregivers, and healthcare providers.

“Survey” *continued from page 5 ▼*

- To educate regulatory agencies and pharmaceutical companies about the urgent need for new and systemic therapeutics for Sjögren’s disease.
- To gain deeper insight into the lived experiences of Sjögren’s patients and better understand how the disease impacts daily life.

How will the results be used?

The data collected will be analyzed and compiled into a published report by the Sjögren’s Foundation.

This report will be shared publicly and used in meetings with researchers, healthcare professionals, pharmaceutical companies, and policy leaders. We’ll also integrate the findings into our ongoing awareness efforts, including website content, educational materials, and advocacy campaigns, to ensure the lived experiences of patients are reflected in everything we do. In some cases, we may highlight key findings in media outreach or presentations to help amplify the patient voice. ■



Sjögren’s Foundation **National Patient Conference 2025**



Missed the 2025 National Patient Conference?

You can still Connect, Learn & Thrive!

The 2025 National Patient Conference may be over, but you can still access recordings of the event until October 12, 2025 — including presentations on managing Sjögren’s and new Sjögren’s research.

If you previously registered and/or attended the conference, you can access recordings of all main stage events. Simply sign into Accelevents using your registration credentials.

If you were unable to pre-register for the conference this past spring, you can purchase access to the conference recordings for \$100. Get details and purchase the recordings by scanning the QR code.

Scan the QR code to access the recordings or visit sjogrens.org/NPC.



What Sjögren's Patients Need to Know About AI-Generated Health Information

If you've ever looked up a symptom online or asked a chatbot a question about living with Sjögren's, you're not alone. These days, it's easy to find health information online — and some of it is now generated by artificial intelligence (AI). But while AI can be a helpful tool, it also comes with some challenges.

Whether you're newly diagnosed or have been managing Sjögren's for years, being able to judge whether online information is trustworthy matters now more than ever. That's why we're breaking down what AI is, how it shows up in online health content, and what

you can do to make sure you're getting accurate, useful information to support your health journey.

What is Artificial Intelligence?

Artificial intelligence, or AI, is a type of computer technology that can analyze large amounts of information and generate responses. Some of the tools you may have heard of include ChatGPT, Microsoft Copilot, or Google Gemini. These platforms use AI to answer questions, summarize topics, or help with writing.

Here's an example of what it might look like when asking an AI platform, like ChatGPT, a health question:

ChatGPT ▾

↑ Share ...

Does Sjögren's cause GI issues?

Yes, **Sjögren's can cause gastrointestinal (GI) issues**, although they're **less commonly discussed** than symptoms like dry eyes or mouth. GI symptoms in Sjögren's vary widely and may be caused directly by the disease — or by related conditions, medications, or overlapping autoimmune disorders.

“AI” continued from page 7 ▼

But AI isn’t limited to special tools — it’s also becoming part of traditional search engines. For example, Google and Bing now include “AI-generated overviews” in their search results. This means that when you type in a question, the answer you see at the top of the page might be generated by AI rather than written by a medical expert.

Here’s an example of an AI Overview on Google:

The screenshot shows a Google search interface. The search bar contains the query "Are frequent sinus infections related to Sjögren's?". Below the search bar, the "AI Mode" tab is selected. The "AI Overview" section provides a summary: "Yes, frequent sinus infections, specifically chronic rhinosinusitis (CRS), are related to Sjögren's syndrome." It then details how Sjögren's syndrome contributes to frequent sinus infections through three points: Dryness, Mucociliary Dysfunction, and Chronic Inflammation. To the right, there are three related search suggestions with thumbnails: "The difference in pathogenic bacteria...", "Chronic Sinusitis: Symptoms, Causes &...", and "Sjögren's and Your Body | Arthritis Foundation".

Google Are frequent sinus infections related to Sjögren's? X 🔊 🔄 🔍

AI Mode **All** Images Short videos Forums Shopping Videos More ▾ Tools ▾

✦ AI Overview

Yes, frequent sinus infections, specifically chronic rhinosinusitis (CRS), are related to Sjögren's syndrome. 🔗

How Sjögren's contributes to frequent sinus infections:

- **Dryness:** Sjögren's is an autoimmune disorder that attacks the glands that produce moisture, including those in the nasal passages. This dryness (xerorhinia) can impair the normal functioning of the nasal passages and lead to problems like nasal congestion and crusting, which can set the stage for infections.
- **Mucociliary Dysfunction:** The condition disrupts the body's ability to clear mucus effectively. Normally, cilia (tiny hair-like structures) and healthy mucus work together to trap and remove debris and pathogens from the nasal passages and sinuses. In Sjögren's, this process is impaired, increasing the risk of infection.
- **Chronic Inflammation:** The autoimmune inflammation in Sjögren's can affect the sinonasal mucosa, further contributing to CRS.

The difference in pathogenic bacteria...
Aug 2, 2022 — Abstract *
Background. Chronic...
BMC Infectious Diseases

Chronic Sinusitis: Symptoms, Causes &...
What causes chronic sinusitis? Your sinuses are a...
Cleveland Clinic

Sjögren's and Your Body | Arthritis Foundation
Upper Respiratory System. If your nasal

Benefits of Using AI

There’s no denying that AI can make it easier to access health information quickly. Some of the benefits include:

Convenient summaries: AI can provide a high-level overview of a topic in seconds. That’s especially helpful if you’re looking for a general understanding of a health topic before diving deeper.

Accessible information: Some AI platforms are free, and many platforms are easy to use, especially for basic searches or questions.

Support for research: Scientists and researchers studying Sjögren’s can use AI tools to process large sets of data and identify patterns more efficiently.

However, when it comes to something as complex as Sjögren’s disease, AI doesn’t tell the whole story.

Drawbacks of Using AI

While AI has many benefits, there are also important limitations — especially for people seeking reliable health information. Here are a few drawbacks to be aware of:

It’s not always clear where the information comes from. AI platforms may not tell you what websites or sources they pulled from, making it hard to know if the information is trustworthy.

Information might be outdated or incorrect. AI isn’t always up to date with the latest research. That means the health information they give you might be incomplete, misleading, or just plain wrong — especially for

complex conditions like Sjögren's. For example, AI responses might still mention "Sjögren's syndrome," even though the name was changed to Sjögren's disease. You can see an example of this in the Google AI overview screenshot provided.

AI might not tell the whole story. AI tools don't search the whole internet — they rely on a limited set of websites or data, which means you might miss out on important details.

These drawbacks don't mean you shouldn't use AI at all. Rather, it's important to think critically about the information AI offers — and cross-check it with trusted sources.

How to Know if Online Health Information is Credible

Whether you're using AI-generated tools or reading through the results of a search engine query, here are some strategies to help you figure out whether the health information you find is reliable.

Don't be fooled by how "official" results sound. AI-generated answers are often polished and professional — but that doesn't necessarily mean they're accurate.

Look for labels. On Google or Bing, pay attention to phrases like "AI Overview" or "Copilot Answer." These signal that the information was generated by AI.

Check the source. Look for websites that end in .gov, .edu, or .org — for example, the Sjögren's Foundation, the Centers for Disease Control and Prevention, the National Institutes of Health, or the Mayo Clinic. These sites are more likely to be updated regularly and to be grounded in science.

Look for an author — and think about their credibility. Look for an author's name or check for an "About Us" page on a website. Knowing who created the content you're reading — and thinking critically about why they wrote it — can help you determine whether to trust the information.

Check the date. Health research is constantly evolving. Try to stick with information that was published or reviewed in the past few years.

Look for references. Trustworthy sites often link to research studies or name their medical reviewers. If there are no citations or experts listed, it can be a sign that the information isn't accurate.

Compare information across multiple sites. Don't rely on one blog or AI answer. If several credible websites agree, it's more likely the information is accurate.

If you're unsure about something you read online — especially if it suggests changing your treatment plan — bring it up with your doctor at your next appointment. They can help you understand what applies to your situation.

The Sjögren's Foundation: Your Partner in Understanding Sjögren's

We know that searching the internet for reliable health information about a complex disease like Sjögren's can be overwhelming — and with AI in the mix, it's even more complicated. That's why we're committed to providing accurate, science-based, and up-to-date information about Sjögren's disease — and why we're actively working to improve how AI platforms represent Sjögren's.

As AI tools become more common, we're advocating for better, more accurate data so that AI can be a force for good in the Sjögren's community. For example, we have a leadership role in the Foundation for the National Institutes of Health (FNIH) Accelerating Medicines Partnership® Autoimmune and Immune-Mediated Diseases (AMP® AIM) program, a massive research initiative that is rethinking prior assumptions about four select autoimmune diseases, including Sjögren's, and taking a fresh approach that is expected to lead to breakthroughs in our knowledge. This partnership between 20 organizations within the public, private, and not-for-profit sectors is using new tools and technologies to help researchers better understand autoimmune disease and develop new drugs to treat it — and we're here to make sure these advancements benefit the Sjögren's community.

We're also a member of the National Health Council (NHC), advocating for Sjögren's patients and working to promote increased access to affordable, high-value, and sustainable health care. The Foundation and NHC understand that AI will continue to shape the future of health care — and that advocating for patients' rights means being part of key conversations about AI, health equity, and patient-centered innovation.

To get accurate information about Sjögren's disease and learn more about how the Foundation advocates for Sjögren's patients, visit our website, subscribe to our blog, and follow us on social media. ■



Celebrating the Sjögren's Stars Who Stepped Up for Sjögren's During the Spring Walk Season

We can't kick off our Fall Walk for Sjögren's events without first recognizing the extraordinary people who made our Spring Walk season such a success. Congratulations and thank you to our Walk for Sjögren's Stars in Spring 2025! These dedicated champions raised \$1,000 or drove significant outreach and sponsorship.

From Philadelphia to Madison and across all our virtual events, your efforts have brought much-needed attention to Sjögren's. We're proud to celebrate each one of you who showed up for the Sjögren's community.

2025 Southeast Virtual Walk for Sjögren's April 5, 2025

Alicia Morin
Fred Fernandez
Irma Rodriguez
Karen Marshall
The Parker Family
Suzanne Wixson

2025 Southwest Virtual Walk for Sjögren's April 5, 2025

The Gales Family
Maria Davis
Mary Jo Monten
The Ruth Family

2025 Mid-Atlantic & National Virtual Walk for Sjögren's May 31, 2025

Bonnie Elverum
Mary Beth Parks-Ackerman
Patricia Delaha
Dr. Guada Respicio Duque

2025 Philadelphia Tri-State Walk for Sjögren's, Live May 10 2025

Chris Iatesta
Tom Iatesta
Harold Friedman
Lindsey Hatfield
The Katznelson Family
Lisa Shea
Mary Anne Hines
Dr. Vatinnee Bunya
Laurie MacKimmie

2025 Colorado Virtual Walk for Sjögren's May 31, 2025

Amy Zappia
Francine Fruman
Jessica Levy
Phyllis Walsh

2025 Midwest Walk for Sjögren's, Live June 21, 2025

Amy Kraus
Chloe Harvick
Kathy & Denny Lawrence
Sarah Paterson
Dr. Scott Lieberman
Dr. Sara McCoy



Recommendations for Aligned Nomenclature of Peripheral Nervous System Disorders Across Rheumatology and Neurology

As part of our mission to improve care and quality of life for those living with Sjögren's disease, the Sjögren's Foundation recently brought together a panel of rheumatologists and neurologists to develop evidence-based clinical practice guidelines (CPGs) for peripheral nervous system (PNS) involvement in the disease. During this process, an unexpected but critical issue came to light. Across medical literature and even within clinical teams, the terminology used to describe nerve involvement in

Sjögren's has been inconsistent and confusing.

This lack of shared language can have real consequences for patients. When providers use different terms to describe the same symptom or diagnosis, it can create barriers to care, delay treatment, and make it harder for patients to get clear answers about what they are experiencing.

To help address this gap, the Foundation and the PNS guideline panel developed a standardized set of

continued page 12 ▼

Aligned Nomenclature of Peripheral Nervous System Disorders Across Rheumatology and Neurology

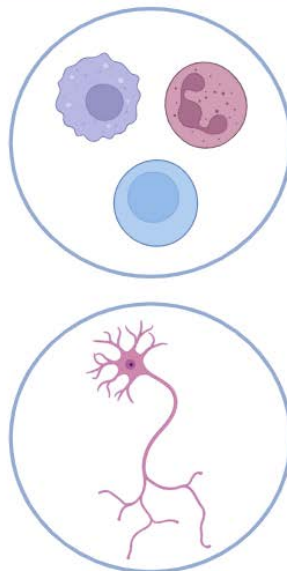
Sjögren's disease is a systemic autoimmune disease that affects the entire body

- Peripheral Nervous System
- Central Nervous System
- Gastrointestinal
- Lung
- Liver
- Kidney
- Genitourinary
- Arthritis
- Muscle pain
- Dry eyes/nose/skin/mouth
- Swollen, painful salivary glands
- Fatigue
- Vasculitis
- Lymphoma



(c) Sjogren's Foundation 2021

Management of peripheral nervous system (PNS) manifestations of Sjögren's disease requires collaboration across rheumatologists and neurologists



Aligned nomenclature for PNS manifestations harmonizes the terminology & communication among specialists



(c) Sjogren's Foundation 2024

GANGLIONOPATHY
MONONEUROPATHY
VASCULITIC NEUROPATHY
LARGE FIBER NEUROPATHY
SMALL FIBER NEUROPATHY
DEMYELINATING POLYRADICULONEUROPATHY
AUTONOMIC NERVOUS SYSTEM NEUROPATHY

“Nomenclature” *continued from page 11* ▼

definitions for the types of peripheral neuropathies that can occur in Sjögren’s. **That work has now been published in *Arthritis & Rheumatology*, the official journal of the American College of Rheumatology. Scan the QR code to access this work.**

The article outlines seven categories of nerve involvement in Sjögren’s. Each one includes a definition, how it can present, what might cause it, how it’s diagnosed, what’s happening in the body, and how healthcare providers evaluate it. These definitions were carefully developed so that providers across specialties can use a shared framework when discussing Sjögren’s-related nerve symptoms.

The full Clinical Practice Guidelines for peripheral nervous system involvement in Sjögren’s are complete and awaiting publication. As soon as they’re available, we’ll share them with our members. You’ll be the first to know.

If you experience nerve-related symptoms or are unsure how they fit into your Sjögren’s diagnosis, consider bringing this article and the *Arthritis & Rheumatology* article to your next medical appointment. It’s a great way to spark conversation and make sure your care team is using the most up-to-date information when it comes to nerve involvement in Sjögren’s. ■



Scan to read "Recommendations for Aligned Nomenclature of Peripheral Nervous System Disorders Across Rheumatology and Neurology" in *Arthritis & Rheumatology*

Help Us Better Support You – Update Your Information

Sjögren’s affects everyone differently, and we want to make sure the information and resources you receive truly reflect your experience.

That’s why we’re asking you to update your information with the Sjögren’s Foundation. By sharing details like your connection to Sjögren’s, how and when you were diagnosed, and a bit of general demographic information, you help us better understand the patient community we serve.

This information allows us to personalize the support we offer, create more relevant programs, and advocate more effectively on behalf of all patients.

Scan the QR code to update your information.



Name Change to Sjögren's Disease Published in *Nature Reviews Rheumatology*

We are proud to share that *Nature Reviews Rheumatology* has published the manuscript formalizing the international consensus to change Sjögren's syndrome to Sjögren's disease. This is a pivotal moment for the entire Sjögren's community!

For any major scientific initiative, especially one that impacts clinical practice and terminology, publication in a peer-reviewed journal is critical. This step ensures the name change is formally accepted internationally by medical organizations, research institutions, and academic institutions, and paves the way for widespread adoption in research, diagnosis, treatment, and education.

This newly published manuscript represents the culmination of years of advocacy, research, and collaboration. Retiring the term "syndrome" isn't just a shift in language, it's a meaningful correction that better reflects the seriousness of the disease and validates the lived experiences of millions around the world.

Note: In the United States, the Sjögren's Foundation recommends usage of the term "Sjögren's disease," in keeping with the prevalent use of the

possessive form of medical eponyms in U.S. medical literature, healthcare records, patient advocacy, healthcare communications, and at medical institutions. Spelling of the name can be with or without the umlaut (ö).

We are calling on the Sjögren's community, organizations, publications, media, and healthcare providers to review and update references of "Sjögren's syndrome" to "Sjogren's disease" as well as dropping the use of "primary" and "secondary." Download and take the published manuscript to your doctors and ask them to make the changes to their websites, their writings, and any research that they do! ■

Scan to access the published manuscript.





Honor Wall

This World Sjögren's Day, we invited our community to take action in honor of someone impacted by the disease. The names listed here represent loved ones, caregivers, health care providers, and patients — each one honored through a pledge to raise awareness or a donation to support our mission. Thank you to everyone who took part and helped bring more visibility to Sjögren's.

“Myself For Never Giving Up Looking For Answers.”

“The Doctors Who Really Care And Work To Ensure We Are Heard And Cared For.”

“Myself And All The Other Sjögren's Warriors.”

“Those Who Are Still Undiagnosed.”

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continued page 18 ▼

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Step Up for Sjögren's at Our Fall Walks: Northeast, West Coast and Texas

October

Virtual Northeast Walk for Sjögren's *New York & New England States*

Saturday, October 4, 2025 • 10am ET

Register today: sjogrens.org/northeast

Virtual West Coast Walk for Sjögren's *California, Idaho, Nevada, Oregon, Washington*

Saturday, October 4, 2025 • 10am PT/1pm ET

Register today: sjogrens.org/west

November

Virtual Texas Walk for Sjögren's

Saturday, November 1, 2025 • 10am CT/11am ET

Register today: sjogrens.org/texas

Incentives

Raise \$50

Walk for Sjögren's T-shirt

Wear it proudly to highlight your commitment to Sjögren's disease awareness.



Raise \$300:

Waist Bag/Fanny Pack

Perfect for keeping essentials or other small items close at hand.



Raise \$600: Backpack

Step up in style with a Sjögren's Foundation backpack.



Raise \$1,000: Sjögren's Star

Join an exclusive group of top fundraisers and get recognition on the Sjögren's Foundation website!

How to Get Involved:

- Register and create your fundraising page
- Raise \$50 or more to earn exclusive Sjögren's Walk gear
- Join us on Zoom for a special program including an "Ask the Expert" session, celebration, and prizes
- Walk your way with family, friends, or solo

Exciting Update: We are using a new, easier-to-use Walk website this year! You will need to register and create a new user name and password. If you are a returning participant and have any questions, please email walk@sjogrens.org.

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The Role of Salivary Autoantibodies in Redefining Sjögren's Disease Phenotypes

1,3,6 Martha Tsaliki, PhD, 1,2,3,4R. Hal Scofield, MD

1. Arthritis & Clinical Immunology Research Program, Oklahoma Medical Research Foundation; 2. Departments of Medicine and Pathology, College of Medicine, University of Oklahoma Health Sciences Center; 3. Department of Pathology, University of Oklahoma Health Sciences Center; 5. Oklahoma City US Department of Veterans Affairs Medical Center, Oklahoma City, Oklahoma, USA; 6. Onassis Foundation Scholar



Martha Tsaliki, PhD



Hal Scofield, MD

Saliva has often been referred to as a “mirror of the body’s health,” offering a wealth of biological information that can reflect systemic conditions¹. In Sjögren’s disease (SjD), where the salivary glands are directly affected, saliva offers a unique window into disease pathogenesis and serves as a potential source of biomarkers. Despite this, the use of salivary autoantibodies as diagnostic tools remains underexplored. One contributing factor to this is the lack of standardized protocols for saliva collection, processing, and screening of salivary autoantibodies. Currently, there is no universally accepted guideline for saliva collection, leading to significant variability in samples obtained from different clinical centers. This heterogeneity poses challenges in data consistency and comparability, ultimately hindering the development of reliable saliva-based diagnostic tools for SjD.

Saliva and tears are among the least invasive biofluids that can be collected from patients to screen for the presence of autoantibodies. Developing more comprehensive and standardized tools for clinical use could significantly enhance early detection of SjD and facilitate the identification of patients in the early stages of disease, leading to a more timely diagnosis and better patient outcomes.

In our lab at the Oklahoma Medical Research Foundation, we study autoantibodies in both Sjögren’s disease and non-Sjögren’s Disease sicca (NSjDS) patients, aiming to better understand their role in disease pathogenesis and their potential to improve the accuracy of disease diagnosis and classification. It is important to note that medical diagnosis differs from research classification criteria. A medical diagnosis is made by healthcare professionals, such as rheumatologists, who consider a wide range of symptoms, lab tests, and clinical judgment to determine if a patient has SjD. In contrast, research classification criteria are used by scientists to ensure consistency in studies and clinical trials. The most commonly used standard in Sjögren’s research is the 2016 ACR-EULAR Sjögren’s Classification Criteria, which focuses on specific clinical features and test results to categorize patients for research purposes². This distinction is crucial because some patients who don’t meet the strict research criteria may still receive a medical diagnosis of SjD based on their symptoms and clinical presentation. Non-Sjögren’s Disease sicca patients are individuals who experience dryness symptoms but don’t meet the current classification criteria². These patients represent an under-

“Autoantibodies” continued from page 17 ▼

served population and are often excluded from clinical trials despite experiencing a significant symptom burden.

In my doctoral research, I have identified salivary autoantibodies, such as anti-Ro (or SSA) and anti-La (or SSB), in many of these NSjDS patients, even when the same biomarkers are undetectable in their blood. While these patients exhibit oral and ocular dryness nearly identical to that seen in SjD patients, they fail to meet classification criteria and are consequently excluded from research and clinical trials. Many NSjDS patients also face challenges in accessing specialized care, like being seen by a rheumatologist, simply because they lack a formal rheumatic disease diagnosis—yet they continue to suffer from severe dryness that significantly impacts their quality of life.

This gap highlights a critical need in the field to revisit and expand current classification criteria, both through the discovery of new biomarkers as well as stratification of patients based on unique disease manifestations. Exploring disease endotypes—subgroups of patients categorized by distinct biological mechanisms—could help classify and diagnose patients more accurately, whether their signs and symptoms are systemic or localized³. Integrating autoantibody screening from both blood and saliva could offer a more comprehensive approach, capturing patients who might otherwise be overlooked. After all, given the widely recognized heterogeneity in presentations of SjD, shouldn't our diagnostic tools reflect this complexity?

Researchers have already shown that autoantibodies appear in the blood of SjD patients years before they

experience any symptoms^{4,5}. These autoantibodies are produced by antibody-secreting cells (ASCs), which often gather in the salivary glands and play a key role in the disease⁶. Since the direct product of the salivary glands is saliva, it is possible that these autoantibodies that are locally produced in the glands can appear in detectable levels in the saliva before they appear in the blood of such patients, making saliva a highly valuable and crucial biomarker for the early detection of Sjögren's disease. ■

References

1. Kulkarni R. The Mouth is the Mirror to the Body:: Oral-Systemic Health. *Dela J Public Health*. 2023;9(1):50.
2. Shiboski CH, Shiboski SC, Seror R, Criswell LA, Labetoulle M, Lietman TM, et al. 2016 American College of Rheumatology/ European League Against Rheumatism classification criteria for primary Sjogren's syndrome: A consensus and data-driven methodology involving three international patient cohorts. *Ann Rheum Dis*. 2017;76(1):9-16.
3. Tarn JR, Howard-Tripp N, Lendrem DW, Mariette X, Saraux A, Devauchelle-Pensec V, et al. Symptom-based stratification of patients with primary Sjogren's syndrome: multi-dimensional characterisation of international observational cohorts and reanalyses of randomised clinical trials. *Lancet Rheumatol*. 2019;1(2):e85-e94.
4. Jonsson R, Theander E, Sjostrom B, Brokstad K, Henriksson G. Autoantibodies present before symptom onset in primary Sjogren syndrome. *JAMA*. 2013;310(17):1854-5.
5. Theander E, Jonsson R, Sjostrom B, Brokstad K, Olsson P, Henriksson G. Prediction of Sjogren's Syndrome Years Before Diagnosis and Identification of Patients With Early Onset and Severe Disease Course by Autoantibody Profiling. *Arthritis Rheumatol*. 2015;67(9):2427-36.
6. Tengner P, Halse AK, Haga HJ, Jonsson R, Wahren-Herlenius M. Detection of anti-Ro/SSA and anti-La/SSB autoantibody-producing cells in salivary glands from patients with Sjogren's syndrome. *Arthritis Rheum*. 1998;41(12):2238-48.

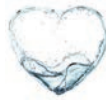
To read more about Martha's work, see the full publication at:

Tsaliki M, Cavett J, Kurien BT, Bruxvoort C, Lewis VM, Ice JA, Dave D, Khosravani S, Grundahl K, Lessard CJ, Rasmussen A, Sivils KL, Farris AD, Koelsch KA, Scofield RH. A cross-sectional observational study of patients with sicca with salivary autoantibodies defines a potential new phenotype of Sjögren's disease. *Ann Rheum Dis*. 2025 May 3:S0003-4967(25)00880-5. doi: 10.1016/j.ard.2025.03.012.

“Wall of Honor” continued from page 15 ▼

Others With It" • Sheri L. Honors "Myself" • Gina S. Honors "Me" • Carolina V. Honors "Myself I Lupus And Sjögren's" • Lynne K. Honors "No One" • Robin S. Honors "Myself" • Phyllis C. Honors "Me" • Laura G. Honors "Laura Galindo" • Donna A. Honors "All Those Affected" • Michelle L. Honors "All Who Suffer" • Joie S. Honors "Myself" • Lupita A. Honors "Maria (Lupita) Alvarez" • Amelia L. Honors "Myself" • Shaunita L. Honors "Shaunita Lee" • Cindy W. Honors "Cindy White" • Kathy H. Honors "Everyone With Sjögren's!" • Soraya Z. Honors "To My Friends And Family" • Elaine P. Honors "My Daughter Aaliyah" • Chelsea L. Honors "Me" • Lisa B. Honors "Lisa B" • Marilyn R. Honors "My Self" • Stacey L. Honors "Stacey Carlson" • Ginette D. Honors "My Fellow Sjögren's Warriors" • Cheryl K. Honors "Myself" • Carolyn C. Honors "Myself" • Kelly G. Honors "Kelly Gundy And Katie Milligan" • Melissa S. Honors "Myself" • Amanda L. Honors "Me" • Jasmine P. Honors "All Of Those Who Struggle In Their Day To Day Lives Whether They Know They Have This Disease Or Not. It's Challenging, It's Difficult, It's Emotional, It's So Much That Some People Will Never Understand But You're Doing So Well And There Is That Light At The End Of The Tunnel! So Keep Going! <3" • Elizabeth S. Honors "Sue Degraw" • Helen J. Honors "Johnny Kelly" • Belinda C. Honors "My Mom" • Teri C. Honors "Myself" •

Candace R. Honors "Myself" • Barbara C. Honors "Carolyn Turner" • Katherine J. Honors "Katherine Jones" • Yvette B. Honors "Yvette Perales" • Sharon B. Honors "Sharon" • Kimberly M. Honors "Everyone Whom Has Ever Battled This Horrible Disease + Their Loved Ones, Friends, Etc." • Brenda C. Honors "Brenda Case" • Amy J. Honors "Myself" • Jennifer B. Honors "No One Specific, All The Other Sjögren's Warriors Out There!" • Bonnie E. Honors "All The Strong Warriors Battling This Disease!" • Brianna O. Honors "Myself" • Lydia P. Honors "Lydia Plastas" • Ramona F. Honors "Me" • Sharon M. Honors "Brenda K. Goodwin" • Yulonda R. Honors "Yulonda Ruiz" • MARA B. Honors "LAURA MAXWELL" • Debbi H. Honors "Ann Hoeler" • Trish M. B. Honors "Trish M Badi (Myself)" • Bonnie S. Honors "Debby Vivari" • Cot'y F. Honors "Myself" • Tubble C. Honors "Myself" • Dolores K. Honors "Dolores Kalar" • Pamela G. Honors "Myself" • Beth S. Honors "Myself" • Dora T. Honors "Myself" • Ronald M. Honors "Jennifer Miller" • Jennifer M. Honors "Myself" • Victoria H. Honors "Myself" • Gina S. Honors "Gina Stewart" • Kathleen S. Honors "Kathy Sitzman" • Sarah M. Honors "All Sjögren's Patients" • Susanne C. Honors "My Husband" • Don M. Honors "Karin Knowles" • Diana B. Honors "Members Of The WI Sjögren's Support Group" • Jennifer R. Honors "Jennifer Reiswig" • Rodella R. Honors "Rodella



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John Burke

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Gary Richardson

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Gary Davis
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Linda Fischer
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In Honor of Kathleen Whittaker
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*Due to the overwhelming response from our community,
we couldn't fit all of the names in this publication.
To view the full World Sjögren's Day Honor Wall, visit
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Conquering Sjögren's

Sjögren's Foundation Inc.
10701 Parkridge Blvd., Suite 170
Reston, VA 20191
Phone: (301) 530-4420
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It's Here: The Living with Sjögren's Patient Survey Is Open

***Take the survey by
September 4, 2025***



Sjögren's affects everyone differently — men, women, young adults included. That's why we need a full picture of the patient experience. Take the Living with Sjögren's Patient Survey by September 4th and help show the true impact of this disease.

Learn more about the survey on page 6.

Take the survey at sjogrens.org/survey

