

CONQUERING Sjögren's

January/February 2026

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First-Ever Peripheral Nervous System Clinical Practice Guideline: What Patients Should Know

How Sjögren's Affects the Nervous System

Now Available: Treatment & Care Resources on Our Website

*Your 2026 Sjögren's Care Checklist
Nervous System on a Chip*



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CONQUERING Sjögren's

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What Is the PNS Clinical Practice Guideline and Why It Matters for Patients

The Sjögren's Foundation is proud to have led the creation of the first-ever *Clinical Practice Guideline for Evaluation and Management of Peripheral Nervous System Manifestations in Sjögren's Disease*. The guideline, published in the American College of Rheumatology's journal *Arthritis Care & Research*, is a major milestone for the Sjögren's community.

This important guideline provides clear recommendations to providers to help them better evaluate and manage the disease's impact on the peripheral nervous system (PNS) — which can include symptoms like burning, tingling, numbness, stabbing pain, dizziness, balance problems, and more. For many people living with Sjögren's, nerve-related symptoms like these can be some of the most debilitating or overlooked parts of the disease, as they may appear gradually, come and go, or be mistaken for anxiety or unrelated issues. The Sjögren's Foundation hopes that the new guideline helps lead to earlier recognition and better coordinated care for Sjögren's patients who have these symptoms.

How Sjögren's Impacts the Peripheral Nervous System

The PNS is the part of the nervous system made up of all the nerves that branch out from the spinal cord and run throughout the rest of the body. The peripheral nerves and brain send information back and forth via the spinal cord, and the PNS carries out commands coming from the brain.

When Sjögren's affects the PNS, it can cause symptoms such as tingling, burning, numbness, nerve pain, or issues with digestion, bladder function, or blood pressure. Between 8% and 60% of people with Sjögren's report PNS symptoms. What's more, PNS symptoms can precede a Sjögren's diagnosis in up to

90% of cases — underscoring that for many people, these symptoms begin long before their care team considers an autoimmune cause.

These symptoms can profoundly affect daily life, interfering with sleep, work, exercise, and basic activities. And without clear guidance for providers, patients often encounter challenges like delayed diagnosis or difficulty getting referred to the right type of specialist.

This is exactly what motivated the Sjögren's Foundation to develop the new PNS guideline.

What is a Clinical Practice Guideline (CPG)?

A clinical practice guideline (CPG) is a carefully developed set of recommendations that help doctors diagnose and treat a disease or condition using the best available research evidence. They play an important role in improving care — especially for complex diseases like Sjögren's that involve many different body parts or systems.

The Sjögren's Foundation is one of very few non-profit patient advocacy organizations to develop CPGs for medical providers, and we're proud of our role in ensuring patients receive more consistent, evidence-based care for Sjögren's disease.

Why the New PNS Guideline Matters

The new PNS CPG provides a clear roadmap for identifying, evaluating, and treating PNS manifestations of Sjögren's. It introduces standard language and definitions to help reduce confusion and offers tools for doctors across specialties including neurologists, rheumatologists, and primary care providers. The recommendations are grounded in research, clinical expertise, and meaningful input from patients.

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Plus, they were guided by the Sjögren’s Foundation’s *Living With Sjögren’s* patient survey, which highlighted how often nerve-related symptoms affect daily life.

The guideline contains information to help the wide range of doctors who care for Sjögren’s patients recognize and treat PNS symptoms and manifestations. Because PNS symptoms often show up long before other Sjögren’s symptoms, providers like primary care doctors can play a critical role in early recognition.

The guideline includes:

- 31 best practices for diagnosing and evaluating PNS symptoms
- 20 evidence-based treatment recommendations
- Standardized names and descriptions for different types of neuropathies (nerve damage) to improve communication across specialties

For patients, this means your doctor will have a clearer map to follow — from recognizing and diagnosing PNS symptoms to treating them.

How the Sjögren’s Foundation Developed the Clinical Practice Guideline

The development of this guideline reflects years of careful work, collaboration, and patient advocacy by the Sjögren’s Foundation and our partners. The Sjögren’s Foundation launched its initiative to develop clinical practice guidelines more than a decade ago, with a goal to improve the quality of Sjögren’s care in the United States. The initiative brings together leading experts in evidence-based medicine, major medical organizations, practicing clinicians, and patient representatives.

The PNS guideline took nearly 5 years to complete and involved over 95 collaborators, including doctors across many specialties, researchers, and Sjögren’s patients. The Foundation used a rigorous, transparent process that included a literature review and structured evidence reviews. As part of the rigorous methodology, the group followed a consensus-building process to engage feedback from experts and ensure alignment across the recommendations.

Establishing the Guideline’s Credibility

A key step in establishing clinical practice guideline credibility — and helping to ensure doctors will follow the guideline — is peer review by other experts who weren’t involved in developing the guideline. In the case of the PNS guideline, it underwent a full peer-review process and was accepted for publication in *Arthritis Care & Research*, a highly respected rheuma-

tology journal. Acceptance in such a journal reflects the strength of the evidence review, the quality of the guideline methodology, and the importance of the guideline in improving care for people with Sjögren’s who experience PNS involvement.

The guideline is open access, which means it’s free for anyone to read. The Foundation made this investment so that all providers and Sjögren’s patients can access the full recommendations without needing a subscription. We encourage all Sjögren’s patients to read the guideline and share it with their providers!

A Community Effort — and a Step Forward

The creation of the guideline is the result of a remarkable collaborative effort involving clinicians, researchers, patients, and Foundation staff. The Foundation thanks them for their collective effort and dedication to make this guideline possible.

But our work’s not done — the Foundation continues to invest time, staff, and resources to strengthen the care patients receive for nervous system manifestations. This effort reflects our long-standing commitment to the Sjögren’s community and our vision to increase awareness and understanding of nervous system involvement.

This is a major step forward — for Sjögren’s providers and patients alike.

Putting the Guideline Into Practice

We encourage all Sjögren’s patients to take a few minutes to read through the guideline. Understanding how the guideline describes PNS symptoms — and the steps doctors are encouraged to take to evaluate and treat them — can help you be more informed.

If you’re experiencing PNS symptoms, you may want to share the guideline with your care team so your providers have access to the same evidence-based recommendations. For example, bringing a copy to appointments can help you describe what you’re experiencing and help your doctor provide you with the right diagnosis and treatment.

You can access a PDF version of the executive summary of the guideline on the Sjögren’s Foundation website, along with additional resources designed to support better care. ■

Scan the QR code to read the full blog post and to download the executive summary of the guideline.



The Nervous System and Sjögren's Disease



Sjögren's is a **systemic autoimmune disease**. Normally, the immune system works to keep your body healthy — for example, by killing germs or healing wounds. But with a systemic autoimmune disease like Sjögren's, something goes wrong with the immune system that causes it to harm the body's own organs and tissues. Researchers, too, are investigating ways in which the nervous system interfaces with the immune system and leads to the development of Sjögren's and many of its symptoms.

Everyone with the disease experiences Sjögren's differently. It can affect any part of the body — including the nervous system. When Sjögren's impacts the nervous system, it can cause a wide range of symptoms. Many people with Sjögren's report experiencing at least some neurological (having to do with the nervous system) symptoms. And in some cases, neurological symptoms can be one of the first signs of Sjögren's disease.

About the Nervous System

The nervous system is a complex body system that's made up of 2 main parts:

- The **central nervous system (CNS)** is the brain and spinal cord (a large bundle of nerves that runs along the backbone). The brain sends out commands to the rest of the body, and the spinal cord carries information to and from the brain.
- The **peripheral nervous system (PNS)** is all the nerves that branch out from the spinal cord and run throughout the rest of your body. The peripheral nerves and the brain send information back and forth via the spinal cord, and the PNS carries out commands coming from the brain.

The 2 systems work together to send messages, signals, and information throughout the body. The nervous system controls or impacts many important body processes — including things like thinking, breathing, moving, digestion, seeing, hearing, and feeling.

The PNS is made up of 2 subsystems — the **autonomic nervous system (ANS)** and the **somatic nervous system (SNS)**. The ANS helps to regulate (control) body processes you don't have to think about — like breathing, making your heart beat, digesting food, or regulating your body temperature. The SNS helps to guide your movements by carrying signals from the CNS to your muscles.

How Sjögren's Disease Affects the Nervous System

Sjögren's disease can affect any part of the nervous system. Symptoms can be different depending on which part of the nervous system is impacted.

Experts aren't yet sure exactly how many people with Sjögren's have neurological symptoms — and they're still working to understand all the ways that Sjögren's can affect the nervous system.

Disease mechanisms are biological processes that cause a disease to happen (or get worse). There are a few possible mechanisms that scientists think may cause neurological symptoms in Sjögren's:

- **Vasculitis:** This happens when the immune system attacks or damages the body's blood vessels. This means that parts of the nervous system, such as the brain, might not be getting enough blood flow.

“Nervous System” *continued from page 5* ▼

- **Inflammation:** Inflammation is when the body releases certain chemicals to respond to a problem in the body, like an injury or infection. But when the immune system isn’t working properly — like in an autoimmune disease like Sjögren’s — it might produce inflammation when it isn’t needed. Over time, this can damage your body’s healthy tissues, including your nerves.
- **Problems with the glymphatic system:** The glymphatic system is like the brain’s waste management system. It moves a fluid called cerebrospinal fluid (CSF) throughout the brain to clean it and keep it working properly. The glymphatic system is only active during sleep, so it’s possible that having sleep problems (which are common in Sjögren’s patients) can impact how well it’s working.
- **Problems with the blood-brain barrier:** The blood-brain barrier is a membrane inside the blood vessels inside your brain. It helps to protect your brain by keeping germs, toxins, and other harmful substances being carried through the blood vessels from getting into your brain tissue. Scientists think that inflammation can damage the blood-brain barrier.

Keep in mind that these aren’t the only possible disease mechanisms that may cause Sjögren’s to affect the nervous system. There’s still plenty that experts don’t know about how Sjögren’s disease works.

Neurological Signs and Symptoms of Sjögren’s Disease

There’s a wide range of neurological signs and symptoms that are associated with Sjögren’s disease. Many patients report that they started experiencing neurological symptoms long before other well-known Sjögren’s symptoms, like dry eye or dry mouth.

If Sjögren’s affects the **CNS**, it can cause:

- **Headaches or migraines**
- **Aseptic meningitis:** This is when the membranes around the brain and spinal cord (the meninges) are inflamed. It can cause headache, stiff neck, fever, light sensitivity, or fatigue (feeling extremely tired).
- **Myelopathy:** This affects the spinal cord, which is part of the central nervous system (CNS). It occurs when the spinal cord is damaged due to compression, inflammation, or reduced blood flow (called ischemia). Symptoms may include

weakness, numbness, coordination problems, or difficulty with balance. Myelopathy often worsens over time if not treated.

- **Encephalopathy:** This is a general term for when the brain isn’t working as it should. Some symptoms linked to encephalopathy include having “brain fog” (trouble remembering or concentrating), confusion, seizures, difficulty speaking or understanding language.
- **Cognitive impairment:** This is trouble thinking, remembering, or paying attention. Some research has shown that cognitive impairment is worse when Sjögren’s disease activity is high.

If Sjögren’s affects the **PNS**, it can cause:

- **Peripheral neuropathy:** This is a general term for when your peripheral nerves are damaged or don’t work as they should. There are many different types of peripheral neuropathies. Depending on which nerves are involved, symptoms can include motor symptoms (trouble moving, muscle weakness or paralysis, or uncontrolled movements), sensory symptoms (tingling, numbness, clumsiness or trouble balancing, and pain), or autonomic symptoms (like problems with your blood pressure, sweating too much or not enough, bladder or bowel issues, or trouble with sex).
- **Cranial neuropathies:** This can also occur as part of peripheral neuropathy. Cranial neuropathies is when a cranial nerve (any of the 12 main nerves that run from the brainstem to the head, neck, or trunk) is damaged or isn’t working properly. They affect the cranial nerves, which control sensation and movement in the face, head, and neck. One example is trigeminal neuropathy, which affects a cranial nerve responsible for facial sensation. It can cause facial numbness, tingling, or sharp, shooting pain in the face or jaw.
- **Small fiber neuropathy:** This is a type of peripheral neuropathy that’s been identified in some people with Sjögren’s disease. The most common symptoms of small fiber neuropathy are having a tingly or “pins-and-needles” feeling in your hands or feet or legs and arms, numbness, or a change in sensation in the extremities (known as a “stocking and glove sensation”, as if normal feeling is dulled by clothing). This type of neuropathy can sometimes be painful or described as “burning.” When small nerve fibers are damaged, symptoms of autonomic nervous

system dysfunction can occur. These might include heart palpitations (when it feels like the heart is pounding or skipping beats) or not being able to feel pain or temperature changes on a small part of your body.

- **Radiculopathy:** This affects the nerve roots as they exit the spinal cord and is considered part of the peripheral nervous system (PNS). It occurs when a nerve root is compressed or irritated. Symptoms may include pain, numbness, tingling, or weakness that travels along the affected nerve. Symptoms can improve over time, sometimes with little or no treatment.
- **Ataxia:** This symptom is when movement of the body is uncoordinated. The muscles, sensory nerves, and brain can all be involved in ataxia. People with ataxia may be unsteady when walking, have trouble with fine motor skills (using the hands for precise tasks, like buttoning a shirt), be clumsy, or have trouble speaking clearly.
- **Dysautonomia:** This is a broad term for when the ANS — the part of the PNS that controls body processes you don't have to think about — isn't working as it should. It can cause a wide range of symptoms, including dizziness or lightheadedness (such as after you stand up from lying down), brain fog, problems digesting food, and problems with the glands that produce moisture (like the tear ducts or salivary glands).

Keep in mind that there's some overlap between the CNS and PNS when it comes to symptoms. For example, both problems with the CNS and the PNS can cause pain or brain fog. That means it's not always easy to tell exactly what's causing a neurological symptom.

If you notice any neurological signs or symptoms, talk with your doctor **right away**. Some nervous system problems can be serious — so it's important for your doctor to evaluate your symptoms and determine exactly what's causing them. That way, you can get treatment if you need it.

Managing Neurological Signs and Symptoms of Sjögren's Disease

Neurological signs and symptoms of Sjögren's can have a big impact on your day-to-day life and how you feel — and they can be challenging to manage.

If you have neurological symptoms, you can:

- **Share them with your doctor.** Be sure to talk with your primary care doctor, rheumatologist (a doctor who treats conditions like Sjögren's), or a neurologist (a doctor who specializes in nervous system

health) about any neurological symptoms you have — especially if you have symptoms that are new, change over time, or make it difficult to do normal things, like walking, speaking, or sleeping.

- **Ask for a referral to see a neurologist.** If you're not already seeing a neurologist, consider asking your current doctor if they can refer you. A neurologist is an expert in diagnosing and managing neurological problems.
- **Keep track of your symptoms with a symptoms log.** Write down information like when a symptom started, how long it lasted, and how much it bothered you. It's a good idea to make note of what you were doing or how you were feeling before a symptom started too. Share the log with your doctor at your appointments.
- **Prioritize healthy habits.** You can't always prevent neurological problems from happening. But taking steps to protect your nervous system can help you feel better and make existing symptoms easier to manage. Healthy habits to promote nervous system health include getting enough sleep, limiting alcohol, and staying hydrated.

Depending on the symptoms you're experiencing, your doctor might recommend certain tests to learn more about your condition. For example, they may suggest doing an MRI (a type of imaging test) to check your brain or spinal cord or a sleep study (when you spend a night in a special sleep lab to help diagnose sleep problems).

Treatment for neurological symptoms also depends on your specific symptoms. Some treatments are aimed at improving your symptoms or making them easier to manage. Other treatments focus on controlling the immune system to stop it from damaging the nervous system further.

Get Support for Managing Sjögren's Disease

If you're experiencing neurological symptoms of Sjögren's disease, know that you're not alone. When Sjögren's affects the nervous system, it can have a big impact on your daily life.

Get support in managing neurological symptoms of Sjögren's — or other Sjögren's symptoms — from your doctor or a neurologist. ■

Start 2026 Strong: Your Annual Sjögren's Care Checklist



The start of a new year is a natural time to pause, take stock, and think about your health goals. For people with Sjögren's, regular check-ins with your care team can help you stay ahead of symptoms and spot changes early.

Sjögren's care can be expensive and require lots of time and energy, and trying to do everything at once can feel overwhelming. If cost or time is a barrier, focus first on the steps that help prevent the biggest problems later. For example, preventive dental care and fluoride treatments can cost less now than managing cavities and restorative procedures later. Do what you can, and build from there over time.

Also, it is completely normal if you do not check every box every year. This checklist is here to help you prioritize and plan, **not to add pressure**.

Key Checkups to Put on the Calendar

Before your year fills up, plan ahead for the annual appointments that keep your health on track whether for your Sjögren's or your general health. These visits give you and your care team a chance to check in on symptoms, adjust treatments, and make sure you're getting the support you need. Here are the key appointments to consider scheduling this year (and every year!).

This checklist is meant to support all parts of your health: Sjögren's specific care, routine preventive care for the rest of your body, and mental well-being. Many people end up doing only the Sjögren's related visits because they are managing symptoms, so consider this a reminder to care for your whole health too!

Routine Core Visits For Many People With Sjögren's

These providers often make up the foundation of your yearly plan.

- **Primary Care Provider:** Schedule a primary care visit to review medicines, preventive screenings, and any new symptoms. This is also an opportunity to get non-Sjögren's care and screenings, like testing your cholesterol and blood sugar. And your doctor can help to keep your whole care team aligned for the year ahead.
- **Rheumatologist:** It's important for a rheumatologist to monitor systemic involvement and adjust your treatment as needed. Make sure to talk through your flare patterns, joint pain, fatigue, and any changes in dryness.
- **Eye Care Provider (Optometrist or Ophthalmologist):** Regular eye exams can catch dryness-related issues early and make sure your current treatments are working. If your dry eye is more severe, or if you have other eye conditions that need monitoring as you age, you may benefit from seeing an ophthalmologist. Optometrists also frequently manage dry eye patients and, in many states, can prescribe dry eye therapies. Ask whether additional testing, like tear production tests, could help guide your care. If you take hydroxychloroquine (Plaquenil), talk with your eye care provider about the right monitoring plan for you, including tests like a visual field test, and whether you should be seen more than once a year.
- **Dentist:** Regular dental visits help prevent cavities and infections linked to dry mouth. Ask your dentist about prescription fluoride toothpaste, which many people with Sjögren's benefit from. If you have more severe dry mouth or frequent cavities, ask whether fluoride gel and remineralizing or mineralizing products could help protect your teeth. Share any new dryness or sensitivity

so your dentist can tailor prevention and comfort strategies. Some people with Sjögren's do better with more frequent preventive visits, such as cleanings every 3 to 4 months. Ask your dentist what schedule fits your risk and symptoms.

- **Gynecologist** (for those who need one): Schedule a yearly visit to address dryness, hormonal changes, and recommended screenings, like Pap tests or mammograms. It's also a chance to talk about comfort, including any concerns that affect your intimate life, and ask about options that may help.

Other Specialists, Based On Your Symptoms and Referrals

Depending on how Sjögren's affects you, your primary care provider or rheumatologist may recommend additional specialists. These might include but aren't confined to:

- **Dermatologist**: Dryness, rashes, and skin changes can all show up with Sjögren's. Get a yearly skin check to help you manage symptoms and monitor any new or changing spots.
- **Ear, Nose, and Throat (ENT) Doctor or Allergist**: If you deal with sinus issues, throat dryness, or allergies, these visits can help you stay comfortable. Work with these professionals to monitor recurring concerns and find options for relief.
- **Cardiologist (heart doctor)**: Some people with Sjögren's may need heart-related care, especially if they have risk factors like high blood pressure, high cholesterol, chest pain, shortness of breath, or a history of heart disease. A cardiologist can help monitor heart health, evaluate symptoms, and manage risks over time.
- **Pulmonologist (lung doctor)**: Sjögren's disease can sometimes affect the lungs, not just the eyes and mouth. This may show up as a chronic dry cough, shortness of breath, or frequent respiratory infections, even if symptoms seem mild at first. In some people, Sjögren's can cause inflammation in the airways or lung tissue. A pulmonologist can help evaluate breathing symptoms, order lung function tests or imaging if needed, and guide care if lung involvement is suspected.
- **Nephrologist (kidney doctor)**: Sjögren's disease can affect the kidneys in some people, often without clear symptoms early on. A nephrologist can help monitor kidney function, explain test results, and address concerns before problems become more serious.

- **Gastroenterologist (GI doctor)**: Sjögren's can affect the digestive system, not just the mouth and eyes. A gastroenterologist can help evaluate persistent digestive issues, determine whether they may be related to Sjögren's, and recommend treatments to improve comfort and nutrition.
- **Neurologist (nerve doctor)**: Sjögren's can involve the nervous system in some people. This may show up as numbness, tingling, burning pain, weakness, balance issues, headaches, or problems with concentration or memory. These symptoms can vary from mild to more disruptive. A neurologist can help assess whether nerve involvement may be contributing to your symptoms and support symptom management if neurological issues are part of your Sjögren's experience.

Tips for Planning and Preparing for Appointments

A little preparation can go a long way toward helping you make every moment with the doctor count:

- Schedule early when you can as many specialists book out weeks or months in advance, so getting on the calendar helps you keep momentum.
- Share your symptoms log and note any changes since your last visit, including what's working and what your concerns are.
- Bring a list of your medications, including over-the-counter products, supplements, and eye or oral care products.
- Write down your questions ahead of time — that'll help you make sure you get answers before your appointment's over.
- Ask providers to share notes or updates with your other specialists so your care team stays connected.
- Consider spacing appointments throughout the year to avoid feeling overwhelmed.

If it's helpful, ask a trusted person, like a family member or close friend, to join you for appointments — they can take notes, help you remember questions, and offer support when discussing next steps

Supporting Your Well-Being Beyond Appointments

Managing Sjögren's isn't only about what happens in the doctor's office. Daily habits can make a meaningful difference in how you feel throughout the year. At the same time, self-care can be exhausting, espe-

“Check List” *continued from page 9* ▼

cially when you are managing a chronic disease. Do your best and choose what feels most doable. When you are deciding which appointments or habits to prioritize, it can help to talk with your rheumatologist or primary care provider about what is most important for your health. Making these choices together can help ensure you are not skipping something that is critical for your individual situation, while still caring for the non Sjögren’s parts of your health too.

- **Keep a symptoms log:** Track any changes in dryness, fatigue, other symptoms (like neuropathies), and flares to help you and your providers get a better picture of your health. Even brief notes on what changed, when it happened, and what helped can help you get the most out of your appointments.
- **Build a gentle movement routine:** Movement can support joint health, overcome fatigue, maintain flexibility, and help with brain fog. Keep in mind that movement doesn’t have to be intense — walking, stretching, yoga, or low-impact exercise can help you feel better day to day. Be sure your routine includes simple strength exercises, like using weights or resistance bands, to help keep your muscles strong as you age.
- **Refresh your skin care habits:** Daily moisturizing can help prevent skin irritation and discomfort. Using a humidifier at home, especially in the winter, can also keep your skin, nasal passages, and eyes more comfortable. If you

spend time outdoors, add daily sunscreen to help protect your skin.

- **Keep up with eye and oral care:** Drinking water regularly, using saliva-support products (look for products with xylitol), and following your eye care plan can make ongoing dryness easier to manage. These habits can reduce irritation and support long-term comfort. If dry mouth is a major issue for you, ask your dentist about prescription fluoride toothpaste, fluoride gel, and remineralizing products to help lower cavity risk.
- **Check in on your mental well-being:** Living with a chronic condition can be draining. Take a moment to ask yourself how you’re coping — and whether talking with family, friends, a counselor, or a support group could help you feel more supported.
- **Practice gratitude and meditation:** Meditation is a simple, evidence-based way to reduce stress and support your emotional and physical well-being. Adding a quick gratitude practice can help you feel more balanced and resilient. Try using this mindset journal worksheet to get started.

Putting Your Health First in the New Year

A new year’s beginning is the perfect time to hit pause and put your health first. Scheduling a few key appointments now can help you feel prepared, supported, and ready for whatever the year ahead brings. You don’t have to manage Sjögren’s alone — your care team, loved ones, and the Sjögren’s Foundation are here to help you move forward with confidence. ■



Share Your Sjögren's Story This April

Help raise awareness during Sjögren's Awareness Month

April is Sjögren's Awareness Month, and we are inviting members of our community to share their stories. Patient experiences help raise understanding, foster connection, and remind others they are not alone.

Whether you are newly diagnosed, managing daily symptoms, or navigating care and treatment, your story can make a meaningful impact. Stories may be shared on the Sjögren's Foundation website, social media, email, or other Awareness Month materials. You are welcome to share as much or as little as you feel comfortable with.

Interested in participating?

Scan the QR code below:



Thank you for helping us raise awareness and amplify the patient voice this April.

Treatment & Care: New Tools and Resources Now Available on Our Website

Announcing new online resources to support your Sjögren's journey



Receiving the right treatment and care are important parts of your Sjögren's disease journey. The Sjögren's Foundation is here to help you better understand your disease and explore the options available to Sjögren's patients. Our Treatment and Care webpages bring key resources together in one place, so you can learn about treatment approaches, understand clinical trials, and explore which healthcare professionals may be part of your care team.

Treatments for Sjögren's

The Treatments for Sjögren's webpage provides an overview of the different ways Sjögren's disease may be managed, recognizing that symptoms and treatment needs vary from person to person. It explains both systemic (whole-body) therapies and organ-specific treatments, along with approaches for managing common symptoms such as dry eyes, dry mouth, and dryness throughout the body.

This resource also highlights the importance of working closely with a healthcare team, including specialists when needed, to develop an individualized treatment plan. The page reinforces that there are currently no therapies approved by the U.S. Food and Drug Administration (FDA) specifically for Sjögren's disease, underscoring why ongoing research and clinical trials remain essential.

Clinical Trials and Sjögren's Disease

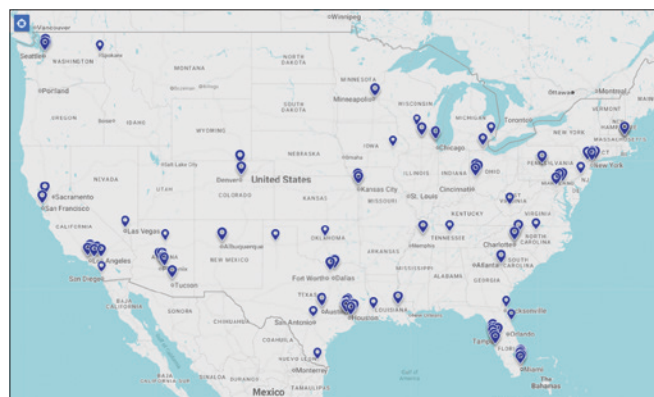
Clinical trials are a critical step in developing medicines and therapies for Sjögren's disease. Trials may study systemic treatments or therapies focused on specific symptoms of Sjögren's, such as dry eye or pulmonary complications.

For some patients, participating in a trial is about access to new options and expert monitoring. For

others, it is about helping researchers learn more about Sjögren's and improving care for future patients. The Foundation's clinical trials overview explains what clinical trials are, how they work, and key concepts like trial phases, eligibility criteria, informed consent, and potential benefits and risks.

Find a Sjögren's Clinical Trial

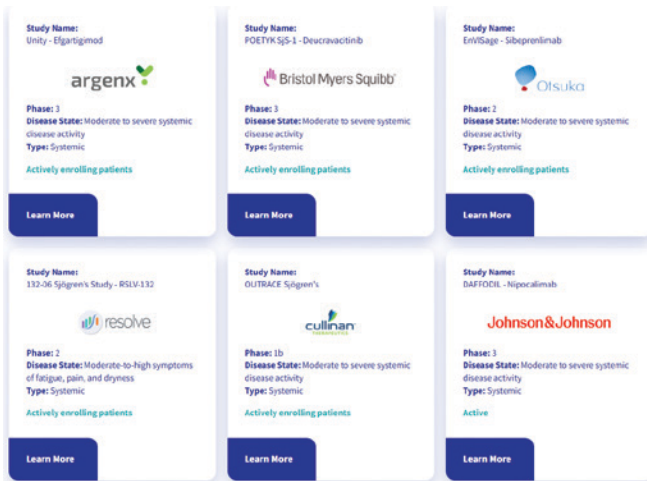
To help patients explore opportunities closer to home, the Foundation offers a Find a Clinical Trial webpage with an interactive map and state listings of Sjögren's clinical trials in the United States. You can search by location and travel radius, review recruiting sites, and learn more about participating. The page also directs patients to ClinicalTrials.gov for a complete listing of Sjögren's trials worldwide.



Find clinical trials near you using our new map feature on our website.

Clinical Trials Sponsored by Corporate Members

Some Sjögren's clinical trials are sponsored by Corporate Members of the Sjögren's Foundation. This webpage provides a clear snapshot of clinical



Check out active trials and find information on completed trials sponsored by Foundation Corporate Members.

trials that are current/ongoing, actively enrolling, or completed. It also includes key details such as study phase, disease state focus (systemic vs. symptom-focused), and where each trial stands in the research process. For completed trials, the page may also note when study data and findings are available.

Patient Clinical Trial Stories

Hearing from other patients can be one of the most helpful ways to understand what trial participation can look like in real life. The Foundation's patient story page features video stories from individuals like Teala, Donna, and Terry, who share why they chose to participate, what questions they asked, and what the experience meant to them. These videos are avail-



Terry's Clinical Trial Story

Terry was diagnosed with Sjögren's disease in 2020 after years of illness. After learning about clinical trials through the Sjögren's Foundation, she and her husband carefully researched available studies, weighing factors such as travel, time commitment, potential placebo, and whether they felt comfortable with an experimental medication. Despite the challenges of long monthly travel and an intensive enrollment process, Terry chose to participate. Over time, she experienced meaningful improvements that allowed her to return to daily activities, reconnect with friends, and eventually join a long-term extension study. For Terry, participation helped restore not only her health, but her ability to fully engage in life again.

[Watch Her Story ▶](#)

able through the Foundation's website and on our YouTube channel, and they highlight an important reminder: participation is always a personal choice. It's okay to take time, ask questions, and involve your family and care team in the decision.

Healthcare Professionals Treating Sjögren's Disease

Because Sjögren's can affect the body in different ways, care often involves a team. The Foundation's healthcare professional resource outlines the types of providers who may be involved depending on your symptoms, such as primary care providers, rheumatologists, ophthalmologists/optometrists, dentists, ENT specialists, dermatologists, gynecologists, and other specialists. It also reinforces an essential part of living with Sjögren's: finding a care team you can trust, one that makes you feel respected, supported, and heard.

Together, these resources reflect the Foundation's ongoing commitment to empowering patients with trustworthy information, amplifying the patient voice, and supporting progress toward better treatments and care for the Sjögren's community.

Scan the QR code to visit our Treatment and Care webpage, where you can explore all of these resources including treatment options, clinical trials, patient stories, and care team guidance. ■



Hear patients like Terry share their experience with clinical trials.

Nervous System on a Chip: Spotlight on Research Grant Recipient Dr. Abigail Koppes



Dr. Abigail Koppes

Many scientists have personal connections to their research topic. Dr. Abigail Koppes is driven by her lived experience as a Sjögren's patient. Her experience with difficult symptoms and a diagnostic odyssey motivated her to use her expertise to study autoimmune diseases like Sjögren's. Dr. Koppes is an Associate Professor at Northeastern University and a recipient of a Sjögren's Foundation's 2024 Pilot Research Grant. This funding supports Dr. Koppes' neural engineering research to better understand how Sjögren's affects the nervous system and is a step toward future therapies that could improve life for people living with Sjögren's and related disorders.

Getting Her Sjögren's Disease Diagnosis

In her early 20s, while in graduate school, Dr. Koppes began to experience severe heartburn and dry eye. At the time, she dismissed the symptoms, chalking them up to too much screen time or allergies. But after she got COVID-19 in 2020, things took a turn for the worse. Her health declined sharply, with severe dry eye, trouble swallowing, fatigue, and other systemic symptoms.

Eventually, a doctor connected the dots and recognized her symptoms as possible signs of Sjögren's. Testing showed 0 tear production, corneal abrasions, and anti-SSB positivity — all key indicators that helped confirm the diagnosis. Over the next three years, she developed additional neurological symptoms, ultimately leading to a diagnosis of autoimmune small fiber polyneuropathy, often referred to

as “neuro-Sjögren's,” mast cell activation syndrome, myalgic encephalomyelitis (ME), and postural orthostatic tachycardia syndrome (POTS).

How Her Personal Journey Shaped Her Research

For many people with Sjögren's, the clinical journey is complex — and Dr. Koppes's own journey was no exception. To manage her health, she built a care team with specialists whose expertise reflected her diagnoses — including a rheumatologist, an ophthalmologist, gastroenterologists, pain specialists, an immunologist, an allergist, and five different neurologists. Beyond ensuring that she receives the right care, the makeup of that multidisciplinary team also inspired her scientific path.

During a sabbatical at Massachusetts General Hospital, Dr. Koppes began to explore questions about the intersection between gut health, the immune system, and the nervous system — mirroring her own intersecting symptoms and the multidisciplinary nature of her care team. She reflects, “You have all these different systems that are controlled by your nervous system — and big crosstalk between cells in lots of different parts of your body, like cells in your nervous system talking to immune cells. It sparked my interest in finding out what the connection is between inflammatory disorders, autoimmunity, viral triggers, and more.”

Driven by myriad unanswered questions, Dr. Koppes began to apply her expertise in neural engineering and regenerative medicine to study how autoim-

immune processes impact nerve health and how the nervous system behaves in diseases like Sjögren's.

Engineering Solutions for Sjögren's Patients

Today, Dr. Koppes leads Northeastern University's Advanced Biosystems for NeuroEngineering Laboratory, where her team is exploring how to repair nerve damage caused by conditions like Sjögren's disease. Many people living with Sjögren's experience nerve-related symptoms — such as burning or stabbing pain, numbness, tingling, dizziness, brain fog, migraine, or digestive problems — yet the underlying causes of this nerve damage are still not fully understood. Dr. Koppes's work focuses on studying how Sjögren's affects the nervous system and finding ways to better understand nerve health and healing. She says, "My main goal is to say if we can figure out the causes, maybe we can get in there and block it from happening earlier."

With support from the Sjögren's Foundation, she and her team are developing innovative materials and techniques to support nerve regeneration and better understand how the nervous system is affected in Sjögren's. One of the most innovative tools they use is a nervous system-on-a-chip, which allows them to study a miniature version of the human nervous system outside the body.

Studying Nerves Outside the Body

Organ chips — small lab devices that model human biology — have been around since the early 2000s. Originally, making these chips required specialized equipment in ultra-clean labs, and the process was slow, expensive, and difficult to modify. Researchers had to layer and etch materials like silicon, similar to how microchips in computers or cell phones are made, to create tiny chambers for cells and fluids.

Dr. Koppes and her team developed a simpler, more flexible approach using makerspace tools like laser cutters and 3D printers. They build chips from inexpensive plastic like what is used in fish tanks, along with special low-gas tape originally developed by NASA. The materials are stacked together like a sandwich to make tiny chambers where nerve cells can grow and be nourished by fluids. These handheld chips are about the size of a standard lab well plate, which allows researchers to use smaller amounts of patient-derived samples while still observing nerve activity.

This approach also gives the lab flexibility to experiment with different shapes, sizes, and numbers of chambers, making it easier to optimize the system

for studying nerve function. The lab even patented this fabrication method, highlighting the innovation behind their work. "We can use these chips to design the exact physiological environment that we want," said Dr. Koppes.

How the Chip Helps Study Sjögren's

Funding from the Sjögren's Foundation's Pilot Research Grant supported the development of the nervous system on a chip. These chips provide a controlled environment where Dr. Koppes's team can introduce human nerve cells — including nerves from the gut — and study how they respond to different factors. "No one has made the gut-brain axis on the chip," explained Dr. Koppes. "We were the first ones to be able to do this." By introducing patient-derived components into the nervous system on a chip, Dr. Koppes's lab can see how they directly affect nerve cells, which may help identify what's driving nerve dysfunction or degeneration in Sjögren's.

Using this system, the lab can ask precise questions about what drives nerve dysfunction and degeneration in Sjögren's. By testing human cells directly in the chips, researchers can see how nerves respond to disease factors or potential therapies without relying solely on animal models. The team is developing ways to monitor the chips in real time and run multiple experiments at once, which allows them to gather more data faster, focus on the most promising therapies, and create a clearer path toward treatments that could improve life for patients. Dr. Koppes explained that this chip technology could speed up the process for finding treatments for diseases like Sjögren's. "Right now, it takes years to go from the lab bench to a clinical trial. And even then, so many drug candidates are lost along the way, especially during the animal testing phase." The hope is that drug candidates could be tested on human samples using these chips, which would eliminate the need for animal testing and move promising drug candidates through the clinical pipeline faster.

The Sjögren's Foundation: Investing in the Future of Sjögren's Research

The Sjögren's Foundation's research grants support research that will benefit patients with Sjögren's — including innovative, patient-centered projects like Dr. Koppes's. By funding early-stage work and researchers who bring new ideas and technologies into the field, the Foundation is helping accelerate discoveries that have the potential to transform care. ■



Registration is Now Open for the 2026 Walk for Sjögren's

Two Ways to Participate. One Powerful Purpose.

Join us this year to walk together in person or virtually nationwide across three Walk for Sjögren's events. Together, we'll raise awareness, build community, and support research, education, and patient programs for people living with Sjögren's disease.

Choose Your 2026 Walk for Sjögren's Event

Philadelphia Tri-State Walk for Sjögren's (In Person)

Saturday, May 2

Wilson Farm Park – Wayne, PA (New Location)

9:30 am ET

Walk for Sjögren's – Your Place, Your Pace! (Virtual)

Saturday, May 16

Nationwide - Virtual

12 pm ET

Walk for Sjögren's – Your Place, Your Pace! (Virtual)

Saturday, October 10

Nationwide - Virtual

12 pm ET

Your Place, Your Pace

Your Place, Your Pace is our new, national virtual Walk, designed to meet you where you are.

Can't join us in person? Walk for Sjögren's – Your Place, Your Pace! gives you the power to be part of the national movement and make a difference right where you are. Create your own walk—gather friends, family, coworkers, or neighbors and walk together in your neighborhood, on a trail, at the gym, or wherever it feels right for you.

Why Walk for Sjögren's?

Walking together helps raise visibility and move progress forward for people living with Sjögren's disease. Funds raised support education, advocacy, research, and resources for patients and caregivers. When you participate in Walk for Sjögren's, you also gain access to exciting national events that bring our community together like Walk Rallies and Ask the Expert sessions.

Ready to Join Us? Register now!

View the full list of 2026 Walk for Sjögren's events and register by scanning the QR code or visiting: walkforsjogrens.org

**Thank You to our National
Walk for Sjögren's Sponsors**

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5th Annual State of Sjögren's: A New Era for Treatments in Sjögren's

A summary of the Sjögren's Foundation's annual professional education event.

The Sjögren's Foundation hosted the 5th Annual State of Sjögren's, a professional education event designed to support healthcare providers who care for people living with Sjögren's disease and to engage researchers advancing the understanding of the disease. While the program is created for clinicians, its ultimate purpose is to improve care, understanding, and outcomes for the Sjögren's community.

This year's State of Sjögren's focused on the future of Sjögren's treatments, featuring expert-led discussions on therapies currently in Phase 3 U.S. clinical trials. Speakers explored how these investigational treatments work in the body, where they are in the research process, and what progress may mean for patients over time.

The program featured presentations from leading Sjögren's experts, including Sara McCoy, MD, Director of the UW Health Sjögren's Clinic; Ghaith Noaiseh, MD, Associate Professor of Allergy, Clinical Immu-

nology, and Rheumatology at KU Medical Center; and Alan Baer, MD, Director of the Jerome Greene Sjögren's Clinic at Johns Hopkins University, who served as moderator.

Throughout the event, speakers shared insights into emerging treatment approaches, trends shaping future standards of care, and how ongoing research may one day lead to more targeted therapies for Sjögren's disease. While there are currently no FDA-approved treatments specifically for Sjögren's, discussions emphasized the growing momentum in research and the importance of continued clinical trials.

By educating healthcare professionals, the Foundation helps ensure that providers stay informed about the latest advances. This supports better conversations in the exam room and more informed, patient-centered care. Events like State of Sjögren's reflect the Foundation's commitment to progress, collaboration, and hope as research continues to move forward. ■

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Liz Hamel

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Kathleen Kelley-Hoppe

In Honor of Ellen
Carl Peterson

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Patricia Pinkerton

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In Honor of Our Daughter Lizzie
Living With Sjögren's Disease
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Joyce Jackson

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A True Sjögren's Hero!
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Richard Bliss
- In Honor of Everyone at The Foundation That Have Helped Make Such Strides For SJD**
Mary Kimball
- In Honor of My Daughter Cindy.**
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Marie Anderson
- In Honor of The Sjögren's Researchers at the National Institutes of Health Dental Clinic**
Elizabeth Theisen



Conquering Sjögren's

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Register Today!

*Virtual National Patient Conference 2026:
Connect, Learn, and Thrive!*

**Friday, April 10 & Saturday, April 11
12:30–5:00pm (ET)**

Join us on April 10 and 11 for an exciting and empowering virtual experience as we come together to connect and learn so you can thrive while living with Sjögren's disease.

Leading Sjögren's experts will share an overview of the systemic nature of the disease, along with in-depth discussions on oral and ocular manifestations to help you better manage dry eyes and dry mouth.

The program will also highlight how Sjögren's can affect the cardiovascular, gastrointestinal, and pulmonary systems, helping patients better understand symptoms beyond dryness, fatigue, and pain. Each clinical presentation will be followed by a live Q&A session, giving attendees the opportunity to ask questions and hear directly from trusted clinicians and experts.

The interactive "Chat with a Doc" session with expert rheumatologist Dr. Donald Thomas, MD, will also return, giving attendees another opportunity to engage directly with a leading Sjögren's specialist.

Register today by scanning the QR code below.

