CONQUERING Sjögren's

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Sjögren's Foundation®
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An Update on Medicare Drug Pricing Reform

Recent federal action is reshaping how pharmacy benefit managers (PBMs) do business and what that could mean for your prescription drug costs. Congress recently passed comprehensive reforms targeting PBMs as part of the Consolidated Appropriations Act, 2026, while the Federal Trade Commission (FTC) secured a landmark settlement with one of the nation's largest PBMs.

These new rules are designed to increase transparency and accountability in how PBMs operate, with the goal of ensuring that savings from drug discounts actually benefit patients and the Medicare program.

What are PBMs and Why Does this Matter?

Pharmacy benefit managers are companies that act as intermediaries between drug manufacturers, pharmacies, and health plans. They negotiate drug prices, decide which drugs are covered (the "formulary"), and process prescription claims. PBMs have faced criticism for keeping a portion of manufacturer rebates and discounts for themselves rather than passing those savings on to patients and health plans.

For people living with Sjögren's, who often rely on multiple medications to manage symptoms like dry eyes, dry mouth, joint pain, and fatigue, the cost and coverage of prescription drugs is a critical issue. These new developments aim to make the drug pricing system more transparent and fair.

What the New Law Does: Medicare Part D Reforms

Beginning January 1, 2028, PBMs serving Medicare Part D prescription drug plans must:

- **Pass through all rebates and discounts**: PBMs will be required to pass 100% of the rebates and discounts they receive from drug manufacturers to the Medicare drug plan rather than keeping a portion for themselves.
- **Limit PBM fees to flat-dollar amounts**: PBM compensation must be a flat dollar fee for actual services performed. PBMs can no longer charge fees based on a percentage of a drug price or tie their compensation to rebates, discounts, or formulary placement decisions. This "delinking" is intended to remove incentives for PBMs to favor higher-priced drugs.
- **Provide detailed reports**: PBMs must submit annual reports to drug plan sponsors and the government that include information on drug pricing, rebates, pharmacy reimbursements, and any financial relationships with affiliated pharmacies, brokers, or consultants.
- **Create a way to report violations**: The law establishes a confidential process for pharmacies, drug plans, manufacturers, and others to report potential PBM violations with protections against retaliation.

These legislative reforms apply specifically to Medicare Part D prescription drug plans (including Medicare Advantage plans that offer drug coverage). They do not directly regulate PBMs operating in the commercial (employer-sponsored) or individual insurance markets. However, federal regulation of PBMs in Medicare may set a precedent that encourages states and Congress to pursue similar reforms for commercial plans in the future.

FTC Settlement: What It Could Mean for Commercial Insurance

The PBM industry is remarkably concentrated: although roughly 65 companies operate in the space

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How a Digital Reset Can Help You Manage Sjögren's

We live in a digital age where many aspects of our day are tied to a tech device. Devices like smartphones, tablets, and computers are commonly used at jobs or in schools. People also use these devices for personal activities like communicating via text or email, watching TV shows or movies, shopping, playing games, reading news, or checking social media.

On average, a person spends almost 7 hours a day online. Studies have highlighted some of the adverse effects of too much digital device use, including depression, anxiety, stress, and poor sleep quality. But there are also positive aspects to using devices. One of the major benefits is social connection; people can use digital devices and social media to meet people, maintain relationships, and find community and support.

When it comes to digital device use, it's important to find a balance that works for you. If using digital devices is having more negative than positive impacts on your daily life, you could consider a digital reset to get back on track. A digital reset involves reducing or eliminating the use of digital devices or certain media for a period of time. This could look like taking a break from social media, limiting the amount of time you watch the news or other TV programs, or scheduling time away from screens.

People with Sjögren's disease may benefit from a digital reset if they notice that digital device use is negatively affecting them.

Digital Device Use and Sjögren's Disease

Digital devices can offer practical support for people with Sjögren's disease and help you find important health information and connection. But spending too much time on digital devices may have a negative impact on your mental health. Knowing how digital devices can help you manage Sjögren's — and knowing the signs of overuse — can help you use digital devices in ways that are supporting your health instead of harming it.

Digital Devices Can Help You Find Information, Support, and Connection

Many Sjögren's patients use digital devices as tools to help them navigate their disease. For example, they can access trustworthy resources online — like those from the Sjögren's Foundation — to learn more about their disease, get tips for dealing with their symptoms, and find the latest news about Sjögren's research. Patients can also use digital devices as a way to stay connected with others, like loved ones or even doctors who may not be nearby. Some patients may even be able to use devices to work from home when symptoms flare up.

Digital devices can also be a way for Sjögren's patients to find emotional support. Living with Sjögren's disease can cause a significant emotional burden; you may feel anxious, depressed, or isolated. Digital devices and social media platforms can provide a way for you to connect with others in the Sjögren's community who understand what you are going through. The Sjögren's Foundation also offers online support groups and a patient community through Inspire where people living with Sjögren's can share experiences and support one another. Having access to these groups can reduce feelings of isolation and the overall emotional burden of living with Sjögren's disease.

Downsides of Too Much Digital Device Use

Despite the many benefits of using digital devices while living with Sjögren's disease, there can also be some significant drawbacks. Long periods of screen time can worsen certain Sjögren's symptoms like headaches, brain fog, fatigue, dry eye, and eye fatigue/pain. Other habits like scrolling through social media and reading the news can cause stress. Stress can worsen certain Sjögren's symptoms, including brain fog and fatigue, or make them harder to manage. For some people, stress can cause a flare. Using digital devices prior to bedtime or while in bed can make it harder to fall asleep or get good quality sleep. Many people with Sjögren's have trouble with getting to sleep or staying asleep, so it's a good idea to avoid screen time around bedtime (and even when you awake in the middle of the night).

If you are noticing that digital device use is having negative impacts on your overall health and well-being, consider doing a digital reset. This reset could improve Sjögren's symptoms and help you better manage the disease.

Signs That You May Need a Digital Reset

You may benefit from a digital reset if you:

- Feel mentally depleted after spending time reading the news or going through social media
- Have dry eyes or headaches after extended periods of screen time
- Experience more frequent symptom flares
- Stay up late or wake up early to get on your phone
- Have even more trouble concentrating or remembering things
- Substitute online connections with in-person, meaningful connections or have lost interest in being social with other people

These feelings or experiences can be signs that digital device use is having a negative impact on you.

The Benefits of a Digital Reset

For Sjögren's patients, a digital reset can be one way to improve symptom management. Some benefits of doing a digital reset include:

- **Less stress**. Lowering stress can improve a variety of Sjögren's symptoms, including pain, brain fog, and fatigue.
- **Better sleep quality**. Although sleep is difficult for some Sjögren's patients, a digital reset, especially around bedtime, can be one step towards improving sleep and getting more rest.
- **Improved cognitive function**. Whether it's screen time or certain social media apps, digital device use can be mentally draining. Changing your digital device habits can improve your capacity to process information and remember things.

How to Do a Digital Reset

There are many ways to do a digital reset, and it's important to tailor your reset to your life and needs. The goal is to find an approach that works best for your lifestyle; this reset should ultimately lead to improving your Sjögren's symptoms and finding balance with digital devices in your life.

Follow these steps to try a digital reset:

- **Reflect on your device usage**. Think about how digital devices support or harm your health. For example, meeting virtually with a Sjögren's support group may help you manage your condition, while spending too much time on social media before bed could lead to poor sleep. Understanding where devices help or hurt can help you tailor your digital reset to your needs.
- **Make a plan for your reset**. Think about the approach you want to take for your reset. Start by taking small steps, focusing on changing just 1 habit at a time. Some ideas you can try include:
  - **Set tech-free hours during your day**, such as avoiding screens before bedtime.
  - **Limit time on certain apps**, such as social media or games — individual apps may let you set a time limit, or you can download a separate app to create limits.
  - **Take regular breaks from screens**, such as using the 20-20-20 rule (every 20 minutes, look at something 20 feet away for 20 seconds).
  - **Try intentionally planning a digital-free weekend** to step away from screens and reset.
  - **Replace screen time with other activities**. It can help to view your digital reset as an opportunity to add a new, healthy habit to your day. You could try replacing your screen time with activities you enjoy, like getting outside, reading a book, taking some time for meditating or mindfulness, spending time with family and friends, or even trying a new hobby like crafting or cooking.
- **Get support**. Talk to other Sjögren's patients about whether they've done a digital reset and

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today, just three of them process approximately 80% of all prescription drug claims. That concentration makes a recent Federal Trade Commission (FTC) settlement with one of the nation's largest PBMs, especially noteworthy. While the new legislation focuses on Medicare, the FTC's action could carry broader implications for individuals covered by employer-sponsored or individual insurance plans.

The FTC alleged that the PBM's rebate practices encouraged drug manufacturers to keep list prices high. Here's why that matters to you: if your copay or coinsurance is based on a drug list price rather than what the PBM actually pays for it from the drug manufacturer, you end up paying more out of pocket. The FTC estimates the settlement could reduce patient costs for drugs like insulin by up to $7 billion over 10 years.

Under the settlement, the PBM must offer plan sponsors (like employers and insurance companies) options that base your out-of-pocket costs on what the PBM actually pays for a drug, not the inflated list price. The PBM must also stop favoring high-cost versions of drugs when lower-cost identical versions are available.

It's important to note that these changes currently apply only to the one PBM covered by the settlement, and whether you see any benefit depends on what your employer or insurance plan chooses to do. The FTC has also brought cases against other major PBMs, but those have not yet been resolved. If similar settlements follow, the impact on the commercial market could be broader.

What This Means for Sjögren's Patients

If you are enrolled in a Medicare Part D plan, these reforms are intended to make drug pricing more transparent and ensure that manufacturer discounts help lower costs for you and the Medicare program (beginning in 2028). While it is too early to predict the exact impact on individual drug prices or out-of-pocket costs, the law's focus on transparency and accountability is a meaningful step forward. For those with commercial insurance, these rules do not apply directly to your plan, but ongoing federal and state attention to PBM practices may lead to broader reforms in the future.

The Sjögren's Foundation will continue to monitor implementation of new legislation and the progression of the future FTC enforcement, and push for policies that make treatments more affordable and accessible for people living with Sjögren's disease. ■

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what helped them. You can also connect with others through the Sjögren's Foundation's online patient community on Inspire or through Foundation support groups, where patients often share tips and experiences.

- **Track your progress and check in with yourself**. After at least 2 weeks of trying these new habits around your digital devices, reflect on how you're doing and if you've noticed any positive changes. It may be useful to keep a journal and track how your symptoms are changing over the course of your digital reset.
- **Consider making long-term changes**. Your digital reset could be temporary, but there may be habits from your experience you want to keep as part of your daily routine. For example, maybe you are sleeping better since you turned off your phone around bedtime or made your bedroom a device-free zone. Your dry eye symptoms may have improved since taking more frequent breaks from your screens. If you're seeing benefits from your digital reset, consider making some of the changes permanent.

Changing habits can be challenging — and it's normal to feel frustrated as you work through your digital reset. But remember that building healthier digital habits can have a positive impact on your health and well-being over time, and even small changes count. For people living with Sjögren's disease, creating space for rest, stress management, and supportive routines can be an important part of caring for your overall health. ■

The 20th Anniversary of the Biomarkers Consortium at the Foundation of the National Institutes of Health (FNIH)

The Sjögren's Foundation joined in celebrating the 20th anniversary of the Biomarkers Consortium at the Foundation for the National Institutes of Health's (FNIH) annual Biomarkers Consortium Symposium in early February. The two-day event brought together scientists, regulators, industry leaders, and patient advocates to reflect on two decades of progress and discuss the future of biomarker science.

Throughout the meeting, speakers emphasized the importance of collaboration across sectors and the shared goal of making healthcare more personalized, efficient, and effective for patients. The symposium highlighted how biomarkers—measurable biological indicators such as blood tests, imaging findings, or genetic signals—are transforming medicine by helping healthcare providers diagnose disease earlier, monitor how patients respond to treatments, and improve the development of new therapies.

FNIH also highlighted major achievements from the past two decades. One notable success was the development of the first FDA-qualified surrogate endpoint for osteoporosis. Osteoporosis is a condition characterized by low bone mass and increased bone fragility, and people with Sjögren's disease have a significantly higher risk of developing it.[1] Surrogate endpoints are substitute measurements used in clinical trials instead of traditional outcomes such as disability, disease severity, or mortality. Because surrogate endpoints maintain a strong scientific relationship to clinical outcomes—similar to how blood pressure or tumor size can predict health outcomes—they can significantly speed up the development of new therapies.

The new FDA-qualified surrogate endpoint for osteoporosis is the DEXA scan, a non-invasive imaging test that measures bone density and determines fracture risk. Previously, patients often needed to experience fractures before qualifying for certain clinical trials, which the DEXA scan does not require to determine fracture risk. Using DEXA scans as a surrogate endpoint allows researchers to identify high-risk patients earlier, reducing the time and cost of trials and enabling more patients to participate.

Another major theme of the symposium was the growing role of artificial intelligence in analyzing medical images and pathology. Speakers discussed both the promise of these technologies and the importance of ensuring that AI-based tools remain accurate, reliable, and validated. A separate session explored how inflammation is a common thread connecting many diseases. Participants discussed opportunities for collaboration among different Biomarkers Consortium working groups to share insights and lessons learned from their respective biomarker research and validation efforts.

One of the keynote addresses featured an inspiring story from Dr. David Fajgenbaum, who went from being a healthy third-year medical student to becoming critically ill with a rare condition, Castleman disease. At the time, there were no effective treatments and no clinical trials available for new therapies. Determined to find a solution, Dr. Fajgenbaum began searching for potential treatments by studying the biology of his disease and exploring opportunities to repurpose existing drugs.

His approach was based on the idea that many diseases share underlying biological pathways, meaning that a drug developed for one condition might also be effective for another. After identifying an overactive biological pathway contributing to his illness, he and his team searched for existing drugs that targeted that pathway. They ultimately discovered a 25-year-old medication originally used as an immunosuppressant for kidney transplant patients. Since

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Lupus and Sjögren’s Disease

What is Lupus?

Lupus, or systemic lupus erythematosus (SLE), is a chronic (long-term) autoimmune disease. An autoimmune disease is when the body’s immune system attacks its own organs and tissues. It can cause pain and inflammation in any part of the body.

Having one autoimmune disease — like Sjögren’s or lupus — makes it more likely for you to have another one. Some research suggests that approximately 10% of people with Sjögren’s also have lupus.

In both Sjögren’s disease and lupus, there can be high levels of antibodies (proteins produced by your immune system that are meant to attack germs) called SS-A and SS-B. Having high levels of these antibodies in your blood is a sign that your immune system isn’t working as it should.

Signs and Symptoms

Symptoms of lupus can overlap with symptoms of Sjögren’s disease. This can make diagnosing either condition challenging, since they can be very similar. This overlap can also make it difficult to tell which disease is responsible for a specific symptom, especially early on.

Symptoms that can occur in both lupus and Sjögren’s disease may include:

- Fatigue
- Joint pain, stiffness, or swelling
- Mouth sores
- Muscle pain
- Skin changes, including sun sensitivity
- Headaches
- Cognitive difficulties, sometimes described as brain fog
- Anxiety or depression
- Nervous system involvement, including numbness, tingling, or pain
- Lung inflammation
- Low blood cell counts
- Blood vessel inflammation, also called vasculitis

Not everyone experiences the same symptoms, and symptom severity can vary widely from person to person.

How Are Lupus and Sjögren’s Related?

Lupus and Sjögren’s disease share similar immune system pathways. In both conditions, the immune system becomes overactive and attacks the body’s own tissues. These shared immune pathways help explain why lupus and Sjögren’s disease can occur together, why symptoms may overlap across multiple organ systems, and why diagnosis can sometimes be challenging.

Sjögren’s disease, lupus, and other autoimmune diseases also do not have a single known cause. However, research shows that genetic factors may increase a person’s risk of developing these conditions.

You cannot inherit lupus or Sjögren’s directly, but you may inherit genes that increase your risk of developing one of these conditions. While autoimmune diseases like lupus tend to run in families, there’s no simple inheritance pattern. This means that you can carry genes linked to lupus without necessarily developing the disease.

Some of these genes can cause more than one type of autoimmune disease (e.g. lupus or Sjögren’s). Therefore, it is not unusual for people with Sjögren’s to have family members who have rheumatoid arthritis, thyroid disease, lupus, and related disorders.

Yet, many Sjögren's patients have no family members with an autoimmune disease.

Studies of identical twins help illustrate this point. Twin studies in lupus (SLE) show that 25% of identical twins in their 20s where one has lupus ultimately develop SLE. This suggests that even when people share the same genes, most do not both develop lupus, suggesting that environmental triggers and other factors play a major role.

Autoimmune Diseases Often Occur Together

Autoimmune diseases often do not occur in isolation. Many people with an autoimmune disease have more than one autoimmune disorder, a pattern sometimes called autoimmune clustering or polyautoimmunity.

Research shows that approximately 20% of patients with one autoimmune disease have a second one, and 20% with two autoimmune disorders have a third. Sjögren's disease and lupus are especially likely to occur together, and each disease can increase the risk of developing the other.

Because symptoms can overlap across autoimmune diseases, people may see multiple specialists for different symptoms before receiving all their diagnoses. This can make the diagnostic process longer and more complicated, especially when symptoms affect different parts of the body.

How Lupus And Sjögren's Disease Can Affect the Body Differently

Although lupus and Sjögren's disease share many symptoms, each condition can also affect the body in different ways.

Lupus may be more likely to cause:

- Kidney inflammation, known as lupus nephritis
- Central nervous system involvement, including seizures or stroke
- Fever due to lupus
- Hair loss
- Swollen lymph nodes
- Skin rashes, including the butterfly shaped malar rash
- Discoid lesions
- Subacute cutaneous lupus
- More frequent or severe headaches

Some people experience features of both diseases. Having one diagnosis does not rule out the presence of the other.

How Is Lupus Diagnosed?

Like Sjögren's disease, lupus can be difficult to diagnose. There's not one clear test for lupus. Instead, doctors usually look at the whole picture of your health, symptoms, and tests to make a diagnosis. To diagnose lupus, a doctor may:

- **Review your health history and symptoms**. Your doctor will likely ask you questions about your health and what symptoms you're experiencing. Keeping track of your symptoms in a symptom log can help your doctor understand your condition. You can write down things like when a symptom started, how long it lasted, how much it bothered you, and what you were doing or how you were feeling before it started.
- **Do a physical exam.** If you have any physical symptoms of lupus — such as a skin rash — your doctor can do an exam to help inform their diagnosis.
- **Order tests**. Certain types of tests — including a complete blood count, antibody tests, or blood clotting time tests — can indicate that you might have lupus or another autoimmune disease. But none of these tests can tell for certain if lupus is what's causing your symptoms.

Challenges of Diagnosing Both Lupus and Sjögren's Disease

Because the signs and symptoms of lupus and Sjögren's are similar, doctors may sometimes not realize that both conditions are present. For example, if your doctor has already diagnosed you with lupus, they may not be "looking" for a Sjögren's diagnosis — or vice versa.

But if you have lupus and Sjögren's, it's important to get diagnoses for both. Knowing whether you have both conditions gives you and your doctor a fuller picture of your health and puts you in a better position to manage both diseases. Keep in mind that overlap between these two diseases is common — if you've been diagnosed with one condition and think you also have the other, share that with your doctor. And it's okay to ask them to check again — even if they've already checked in the past.

In both lupus and Sjögren's disease, blood tests may show high levels of autoantibodies. Autoantibodies are proteins made by the immune system that mistakenly target the body's own cells.

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beginning treatment with this repurposed drug, Dr. Fajgenbaum has been in remission for 11 years.

Currently, Dr. Fajgenbaum works at the University of Pennsylvania and has dedicated his career to helping patients with Castleman disease and other conditions that lack effective treatments. He founded both the Castleman Disease Collaborative Network and the nonprofit organization Every Cure. Every Cure has developed innovative computational frameworks to prioritize drug repurposing across many diseases and has already advanced 14 repurposed drugs. In his talk, Dr. Fajgenbaum emphasized the critical role of biomarker discovery in uncovering disease mechanisms, identifying new therapeutic targets, and monitoring treatment responses—not only to guide precision medicine but also to potentially uncover hidden cures for patients.

About the FNIH Biomarkers Consortium

The Biomarkers Consortium is a pre-competitive public–private partnership founded in 2006 to accelerate the discovery, development, and regulatory acceptance of drug development tools, including biomarkers and surrogate endpoints. These tools help improve the prevention, diagnosis, and treatment of disease.

The consortium is guided by four steering committees—Cancer, Inflammation and Immunity, Metabolic Disorders, and Neuroscience— and includes leaders from the National Institutes of Health (NIH), the U.S. Food and Drug Administration, the Centers for Medicare & Medicaid Services, nonprofit organizations, academic institutions, and more than 70 life sciences companies.

In 2018, the Biomarkers Consortium identified Sjögren’s disease as a priority area in its strategic plan, and the Sjögren’s Working Group was established the following year. The Sjögren’s Foundation is proud to participate in this working group, which launched its project, Molecular Characterization and Diagnostic Biomarkers of Sjögren’s Disease, last fall. ■

Citation

1. Zhao Q, Li J, Zou J, et al. Association between Sjögren syndrome and osteoporosis: A bidirectional Mendelian randomization study. *Medicine* (Baltimore). 2025;104(29):e43072. doi:10.1097/MD.0000000000043072

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Common antibodies seen in both conditions include:

- Antinuclear antibodies, also called ANA
- Rheumatoid factor, or RF
- Anti-SSA (sometimes called anti-Ro) antibodies
- Low complement levels

About 60 to 70 percent of people with Sjögren’s disease test positive for anti-SSA/Ro antibodies. In lupus, about 20 to 60 percent of people test positive for the same antibody.

These shared biomarkers can support a diagnosis, but they do not tell the whole story. Some people with lupus or Sjögren’s disease may have negative antibody tests, especially early in the disease.

In both lupus and Sjögren’s disease, blood tests may also show elevated gamma globulin levels on a test called serum protein electrophoresis, or SPEP. This is sometimes described as polyclonal hypergammaglobulinemia.

Elevated gamma globulin levels are a sign that the immune system is highly active and producing increased amounts of antibodies. This finding supports the presence of ongoing immune system activation but does not by itself confirm a diagnosis.

Because autoimmune diseases often overlap and evolve over time, it is possible to receive an additional diagnosis years after the first one or to even have the name of the diagnosis changed completely.

What Does Having Lupus And Sjögren’s Disease Mean For Me?

Living with any autoimmune disease can be a challenge. Lupus and Sjögren’s can both have a big impact on your daily life, physical health, and mental health.

Both lupus and Sjögren’s can have a wide range of symptoms and affect any part of the body. Each case is different. If you have both lupus and Sjögren’s disease, it’s important to work with your doctor to come up with a treatment plan that meets your individual needs. Treatment for either condition may involve lifestyle changes or taking medicines. Your doctor can give you advice about how to manage your symptoms and limit or prevent further damage from your immune system to the rest of your body.

If you see more than one doctor — which is common for diseases like lupus and Sjögren’s — it’s important that they’re all aware of your diagnoses and treatments. ■

Walk for Sjögren's
2026

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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 –
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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 participation supports the 4 million Americans living with Sjögren's disease by helping to:

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Dysautonomia and Sjögren's Disease

Sjögren's can affect all parts of the body, including the nervous system. For some people, Sjögren's affects their autonomic nervous system (ANS) — the part of the nervous system that controls body processes that you don't have to think about, like making your heartbeat or regulating your body temperature. When the ANS is impacted by Sjögren's, it can cause a problem called dysautonomia (also called autonomic dysfunction). Dysautonomia is a general term for when the autonomic nervous system isn't working as it should.

Signs and Symptoms of Dysautonomia in Sjögren's Disease

Dysautonomia can cause a range of signs and symptoms — and not everyone has the same symptoms.

Signs and symptoms associated with dysautonomia may include:

- Heart rate and blood pressure problems, including dizziness or fainting
- Problems with the muscles in the esophagus (the tube that carries food from the mouth to the stomach) and digestive tract
- Bladder problems, such as urinating more than normal or not being able to hold urine
- Problems with moisture glands throughout the body, including the tear ducts, salivary glands, and glands that produce mucus
- Vision problems, including blurry vision or problems with the pupils opening and closing to adjust to changes in brightness
- Breathing problems, such as shortness of breath
- Problems with regulating the body temperature, including not sweating enough to stay cool or sweating too much
- Brain fog
- Trouble keeping your balance
- Sleep problems, like trouble falling or staying asleep, or not feeling rested after waking up

Keep in mind that it can be difficult to know if certain symptoms are caused by autonomic dysfunction or because a specific organ is being impacted by Sjögren's.

When certain dysautonomia signs or symptoms happen together, doctors may recognize them as a specific syndrome or disorder. For example:

- **Orthostatic intolerance (OI)**: When a person experiences symptoms such as dizziness, feeling faint, blurry vision, or lightheadedness when they stand or sit up. OI symptoms usually go away or get better when a person lies down. POTS (postural orthostatic tachycardia) is a type of OI that some people with Sjögren's have that may cause symptoms like significant and sustained dizziness, shortness of breath, or a racing heartbeat.
- **Gastrointestinal dysmotility**: When muscles along the gastrointestinal (digestive) tract don't move food through the tract as they should. This can cause symptoms like nausea, vomiting, feeling full without eating very much food, constipation, stomach pain, or diarrhea.
- **Autonomic neuropathy**: When nerves that are part of the ANS are damaged. Autonomic neuropathy can cause a range of symptoms (for example, sweating more than normal or not enough, dizziness, or trouble swallowing), depending on which nerves are impacted. One type that Sjögren's patients may experience is called small fiber neuropathy. Small nerve

fibers help gather information about pain and temperature and send it to the brain. Small fiber neuropathy symptoms include painful tingling or burning in your hands and feet, lightheadedness, not being able to feel pain or temperature in a small part of your body, and sweating more than normal.

Like other nervous system manifestations of Sjögren's disease, dysautonomia may be underrecognized in the Sjögren's community. That means more people with Sjögren's may have dysautonomia than have been formally diagnosed with the condition.

For some people, nervous system signs and symptoms — including dysautonomia — may be the first signs that they have Sjögren's disease. In some cases, nervous system problems may happen years before other, more well-known Sjögren's symptoms, like dry eye or dry mouth.

Causes of Dysautonomia in Sjögren's Disease

Sjögren's experts aren't exactly sure what causes dysautonomia in Sjögren's disease. Researchers are working to learn more about how the 2 conditions are related.

Based on the research that's been done so far, experts believe that chronic inflammation from Sjögren's disease may damage nerves that are part of the ANS — including the vagus nerve, which carries signals between your brain, heart, and digestive system. Abnormal activity in the immune system because of Sjögren's may also block nerve cells from sending signals properly.

Diagnosing Dysautonomia in Sjögren's Disease

Dysautonomia can be a difficult condition to diagnose because its symptoms overlap with other conditions. Diagnosing dysautonomia usually involves ruling out other conditions that could be causing your symptoms. For example, infections or heart disease can cause some of the same symptoms as dysautonomia.

If you think you may have dysautonomia, it's important to talk with your primary care doctor, a rheumatologist (a doctor who treats conditions like Sjögren's), or a neurologist (a doctor who treats the nervous system) about your concerns. They may ask questions to learn about your symptoms, recommend tests to check how well your ANS is working, or do an exam.

Tests to check for dysautonomia depend on the symptoms you're experiencing, but could include:

- **Tilt table test**: For this test, a doctor will measure your heart rate and blood pressure as a device called a tilt table moves your body from a lying-down position to standing.
- **Heart tests**: These may include tests like an electrocardiogram (or ECG) that records your heart's electrical activity.
- **Sweat test**: This test checks how well the nerves that signal your body to sweat are working.
- **Pupillometry**: This test measures the size of your pupils.
- **Ultrasound**: If your symptoms include bladder problems, your doctor may use this imaging test to check your bladder.
- **Blood tests**: These may include tests to check for antibodies that could be a sign of autoimmune disorders or to measure levels of neurotransmitters (chemicals that the nervous system uses to send signals).

Managing Dysautonomia in Sjögren's Disease

There's no cure for dysautonomia. But lifestyle changes or treatments can help you manage the symptoms and make it easier for you to go about your daily life.

Treatment options for dysautonomia depend on your specific symptoms. If you have dysautonomia, work with your doctor to make a treatment plan that works for you. Management may include:

- Medicines to treat Sjögren's disease — If Sjögren's is contributing to your dysautonomia, taking medicines to treat it can help improve your dysautonomia symptoms.
- Drinking plenty of water — Staying hydrated can help prevent big changes in your blood pressure, which may improve symptoms like dizziness or lightheadedness.
- Consuming more salt — Salt can also help prevent big drops in blood pressure, which can help if you have OI symptoms.

Get Support for Managing Sjögren's Disease

Dysautonomia and other Sjögren's disease symptoms can have a big impact on your daily life. If you're living with dysautonomia and Sjögren's, know that you're not alone.

Remember to talk with your doctor about any dysautonomia symptoms you notice. They can help you manage these and other Sjögren's symptoms. ■

Living with Sjögren's? Share Your Story

April is Sjögren's Awareness Month, and we are inviting members of our community to share their experiences living with the disease. Personal stories help raise awareness, foster connection, and remind others in the Sjögren's community that they are not alone.

Whether you are newly diagnosed, managing daily symptoms, or navigating treatment and care, your perspective can make a meaningful impact.

This year we will also be accepting video submissions for the first time. Patients will be able to share their story in their own words, and their stories may be featured on the Sjögren's Foundation website, social media, and other Awareness Month materials.

Patients are welcome to share as much or as little as they want about their experience living with Sjögren's. Every story is unique.

You are welcome to share as much or as little as you feel comfortable with.

Interested in participating?

Scan the QR code below or visit https://info.sjogrens.org/april-awareness to submit your story.

Sjögren's FOUNDATION®

REGISTER TODAY AT:
sjogrens.org/npc

2026 National Patient Conference

Friday, April 10 – 12:30 pm - 5:00 pm (ET)
Saturday, April 11 – 12:30 pm - 4:30 pm (ET)

The Sjögren's Foundation invites you to join us for an exciting and empowering two-day virtual experience at the 2026 National Patient Conference! This year, on April 10 and 11, we will come together to connect and learn so you can thrive while living with Sjögren's disease.

The National Patient Conference is the Sjögren's Foundation's largest educational event, bringing together patients and talented medical experts to provide the latest information about Sjögren's disease and how to manage symptoms.

Participate from the comfort of your home while still benefiting from live expert sessions, Q&As, and patient community connections.

This year's event will cover:

- Our foundational program, ***Overview of Sjögren's Disease***
- A review of the ***2025 Living with Sjögren's®*** Patient Survey
- How Sjögren's affects the gastrointestinal, cardiovascular, and pulmonary systems
- Oral and ocular management
- A review of our new Peripheral Nervous System Clinical Practice Guideline
- Sjögren's research presented by Sjögren's Foundation Research Grant recipients

A popular cornerstone of the Sjögren's Foundation-conference experience is the chance to have your questions answered by experts. At the end of our clinical sessions, youwill have the opportunity to ask our speakers questionsabout their presentation topics. We are also excited to announcethat we will be bringing back the popular "Chat with a Doc" session featuring Dr. Donald Thomas!

We look forward to seeing you at this year's conference! Come to connect with other Sjögren's patients, learn from experts, and gain the knowledge you need to thrive with Sjögren's disease!

Sjögren's FOUNDATION®

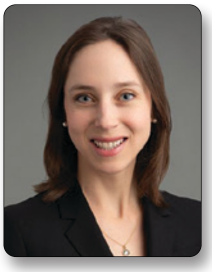
Register today at
sjogrens.org/npc

Day one – Friday, April 10 *(All times are Eastern Time)*

12:30pm Welcome and Opening Remarks

Janet E. Church
Sjögren's Foundation President & CEO

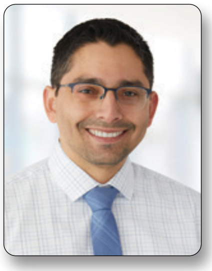
12:40pm Overview of Sjögren's Disease



Sara McCoy, MD, PhD

Dr. McCoy will present a comprehensive review of Sjögren's disease, including the range of symptoms patients experience. She will give special attention to the difficulties that can occur in diagnosis and the symptom presentations not covered in the other conference presentations.

1:30pm Oral Manifestations in Sjögren's



José Maldonado-Ortiz, DDS, PhD

Understanding the daily care needed to minimize the impact on your oral health is critical for Sjögren's patients. Approximately 93% of patients report experiencing symptoms associated with dry mouth, and report that dental care is their largest medical expense. Dr. Maldonado-Ortiz will cover the range of issues that can be caused by dry mouth and offer recommendations for successful management.

2:10pm Exhibit Hall Open!

Attendees can visit our exhibit hall and talk with company representatives from our sponsors to learn how they support Sjögren's patients!

2:30pm Your Gastrointestinal System and Sjögren's

Lucinda Harris, MD

Dr. Harris will discuss the different gastrointestinal issues associated with Sjögren's, including dysmotility, gastroesophageal reflux disease (GERD) gastroparesis, IBS, and more. This session will help you understand how to decipher your symptoms and get the correct care and treatment needed for best management.

3:10pm Foundation Update

Janet E. Church
Sjögren's Foundation President & CEO

Janet will discuss the exciting mission focused work at the Foundation. The Sjögren's field is advancing! Learn how the Foundation is meeting the challenge to ensure patients' needs are met. Janet will also present data from the 2025 *Living with Sjögren's*® Patient Survey.

3:40pm Community Connections!

Attendees can join one of our virtual conference communities and visit with other Sjögren's patients to connect, share and learn!

4:10pm Cardiovascular Health and Sjögren's

Teja Kapoor, MD

Dr. Kapoor will discuss how Sjögren's can impact the cardiovascular system. She will highlight how symptoms related to Sjögren's may present and current management and treatment options for keeping your cardiovascular system protected and healthy.

Day two – Saturday, April 11 *(All times are Eastern Time)*

12:30 pm Opening Remarks & Awards

Janet Church
Sjögren's Foundation President & CEO

12:35pm Stepping through the New Peripheral Nervous System (PNS) Guideline

Arun Varadhachary, MD, PhD

Dr. Varadhachary will discuss why clinical practice guidelines are important and will step us through the new Sjögren's Foundation PNS Clinical Practice Guideline. He will also offer suggestions on how to work with your healthcare provider to address the neurological impacts of Sjögren's.

1:15pm Ocular Manifestations in Sjögren's

Anat Galor, MD, MSPH

Approximately 95% of Sjögren's patients experience dry eye. In this session, Dr. Galor will explain how Sjögren's impacts the eyes and what you need to know to manage dryness and protect your vision. She will discuss the tests your doctor may perform and the available treatments to help keep your eyes as healthy as possible. Dr. Galor will also share information about the neuro-ocular connection in Sjögren's disease.

1:55pm Exhibit Hall Open!

Take a break and visit our exhibit hall to talk with company representatives and learn more about our great sponsors!

2:15pm Pulmonary Manifestations of Sjögren's

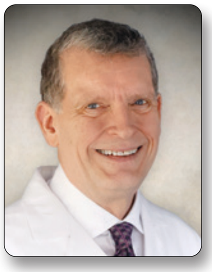
Nishant Gupta, MD

Dr. Gupta will present the different potential pulmonary and respiratory manifestations of Sjögren's, such as cystic and interstitial lung diseases. He will also highlight early signs of pulmonary issues and discuss when to see a specialist.

2:55pm Community Connections!

Join one of our virtual conference communities and visit with other Sjögren's patients to connect, share, and learn!

2:55pm Chat with a Doc



Donald Thomas, MD, FACP, FACR

This session runs for one hour, concurrent with other programming, and allows attendees to ask Dr. Thomas questions about Sjögren's. This session is not meant to offer personal medical advice; however, he will answer general medical questions related to Sjögren's.

3:15pm Research Grant: Bioengineered Multi-functional Organ-Chips for Innervated Sjögren's Disease Modeling

Abigail Koppes, PhD

Dr. Koppes, a 2024 Sjögren's Foundation Research Grant Award recipient, will present her Foundation-funded research on dysautonomia, gastrointestinal dysfunction, and neurological complications in Sjögren's disease. She will discuss how innovative microphysiological "organ-chip" models, developed by her laboratory, will allow researchers to study neuroimmune interactions and how autoantibodies and inflammation affect peripheral and central nervous system function. She will also discuss real-time optical sensing technologies that monitor neural activity and may advance understanding of NeuroSjögren's and targeted therapy development.

3:45pm Understanding the Immune System in Sjögren's Disease

Join us for a short video that will provide a simple, and high-level overview of how the immune system works and what happens when it becomes dysregulated in Sjögren's disease.

Day two – Saturday, April 11 *(All times are Eastern Time)*

3:50pm Epitope Mapping Research Grant: What T Cells Recognize in Sjögren's Disease

Mohammad Haj-Dezfulian, PhD

Dr. Haj-Dezfulian is a 2022 Sjögren's Foundation Research Grant Award recipient. His research uses new high-throughput tools to map what T cells recognize in Sjögren's disease. In this session, he will share findings from his Foundation-funded work, explain how identifying T cell targets can enable more mechanistic studies of disease, and discuss how this approach may inform future diagnostics and more personalized therapies.

4:20pm Conference Recap and Closing Remarks

Janet E. Church

Sjögren's Foundation President & CEO

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Sjögren's Foundation®
National Patient Conference 2026

Register Today!

Hear from Leading Sjögren's Experts

Friday, April 10 | 12:30–5:00PM (ET)
Saturday, April 11 | 12:30–4:30PM (ET)

Hear directly from leading Sjögren's experts on topics including:

- The systemic nature of Sjögren's disease
- Managing dry eyes and dry mouth (oral and ocular manifestations)
- How Sjögren's can affect the cardiovascular, gastrointestinal, and pulmonary systems
- The new Peripheral Nervous System (PNS) Clinical Practice Guideline
- Insights from the 2025 *Living with Sjögren's®* Patient Survey

Interactive sessions include:

- Live Q&A following each presentation
- "Chat with a Doc" with rheumatologist Donald Thomas, MD

Foundation members receive $20 off registration — use code **MEMBER2026** at checkout.

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