CONQUERING Sjögren's

May/June 2025

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This is Sjögren's

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Letter from Our President & CEO:

Advocating for Patients and Protecting the Progress We've Made

Janet E. Church
President & CEO,
Sjögren's Foundation

As we close out Sjögren's Awareness Month, I've been reflecting on all we've accomplished and what still lies ahead.

This year's National Patient Conference (NPC) was the perfect way to kick off Sjögren's Awareness Month. We had representation from all 50 states, Washington, D.C., Puerto Rico, and 20 countries! Not only was the content incredibly valuable, but what struck me most were the connections being made throughout the conference. Whether it was in the chat box during a session or in the "Sjögren's Communities" virtual rooms, you could feel the strength of this community. We all came together to connect, learn, thrive, and support each other. That energy carried us through the entire month of April with our Sjögren's Awareness Month campaign!

Sjögren's is getting more attention. Awareness is growing. Clinical trials and research have been expanding. There is real momentum behind this disease in a way we haven't seen before.

But as we gain ground, we must stay focused and protect the progress we've made. The growing awareness and research around Sjögren's didn't just happen on their own. It's taken years of hard work. And we know we can't let up now.

On March 25, we hosted a Congressional Briefing in partnership with Lupus Therapeutics and the Office of Autoimmune Disease Research at National Institutes of Health (NIH). Held in recognition of Autoimmune Disease Awareness Month, the briefing highlighted the growing burden of autoimmune diseases like Sjögren's and lupus and the urgent need for greater research investment, education, and public awareness, especially for Sjögren's as it lags behind other autoimmune diseases.

Our job is to make sure the patient voice is always in the room. During the briefing, I had the opportunity to speak personally about the patient experience. I shared with Congressional representatives what it's like to live with Sjögren's, the long delays in diagnosis, the financial and emotional toll, and the lack of treatment options. I presented eight Sjögren's patient stories so Congress staffers could understand the impact this disease has on people's lives.

When I asked the Hill staffers how many people had heard of Sjögren's, only a few people raised their hands. That's why this work is so critical.

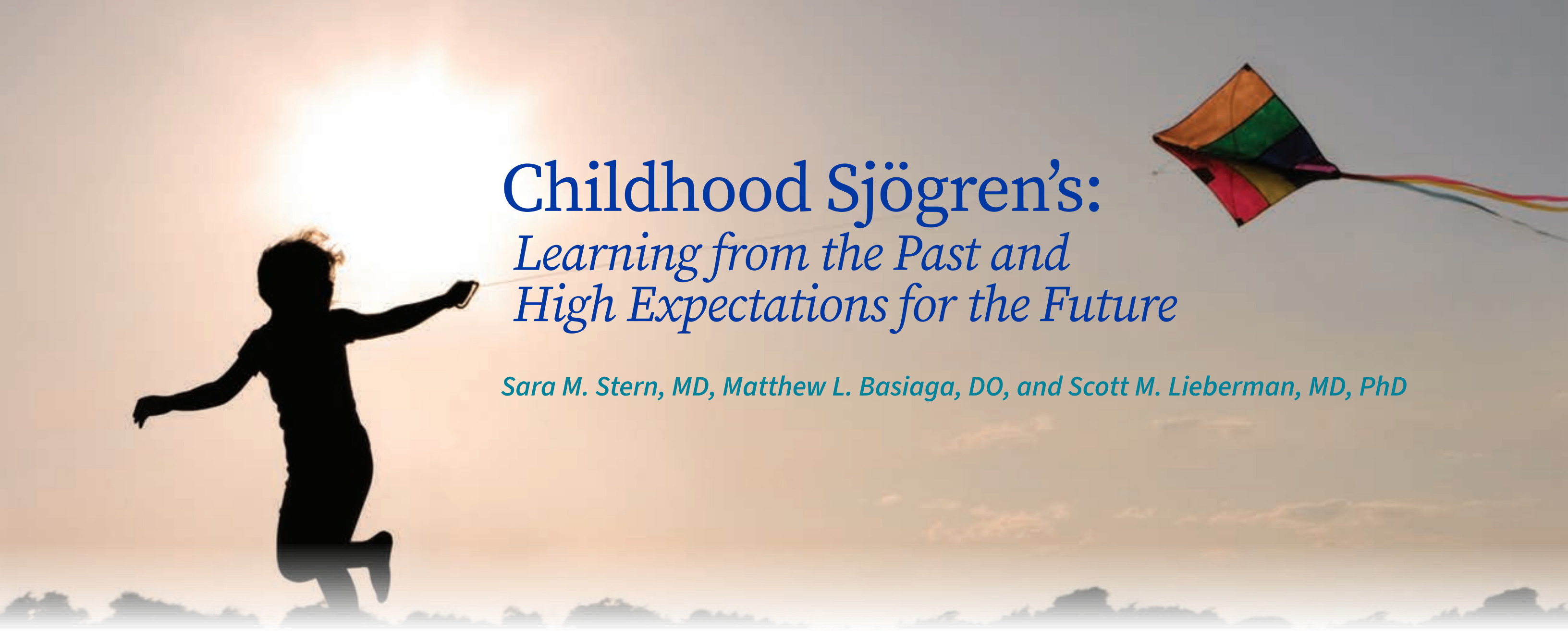
Just one day before the briefing, a House Resolution (H.Res.245) was introduced once again by Representative Joseph D. Morelle (D-NY-25), officially recognizing April as Sjögren's Awareness Month and reaffirming Sjögren's as a serious, systemic autoimmune disease. We're incredibly grateful to Representative Morelle for continuing to champion this resolution for the second year in a row and helping to keep Sjögren's in the national conversation.

When indiscriminate federal budget cuts were announced across the Department of Health and Human Services, we issued a public statement expressing our concern. Cuts to National Institutes of Health (NIH), Food and Drug Administration (FDA), and Centers for Disease Control and Prevention (CDC) programs threaten not only Sjögren's research but the entire autoimmune community. We will continue to speak out and meet with government officials to protect research and the needed support our community deserves.

In this issue of *Conquering Sjögren's*, we're spotlighting the many ways we're keeping momentum going:

- A feature on childhood Sjögren's that highlights new research, diagnostic challenges, and why pediatric-specific studies are key to improving care
- A deeper look at our recent congressional briefing and federal advocacy
- A recap of the National Patient Conference and key education sessions
- Several patient stories that brought the realities of living with Sjögren's to the forefront during Sjögren's Awareness Month

We're not slowing down. Our 2025 Sjögren's Research grants will be announced in June. July 23rd is World Sjögren's Day, and in August we will launch the next *Living with Sjögren's* patient survey. We're already looking forward to engaging with you and the broader community in meaningful ways! ■



Childhood Sjögren's:

Learning from the Past and High Expectations for the Future

Sara M. Stern, MD, Matthew L. Basiaga, DO, and Scott M. Lieberman, MD, PhD

Sjögren's disease is often described as a condition causing profound dryness in middle-aged women. However, we now know that this process occurs over many years before the development of the profound dryness. Consequently, when Sjögren's is diagnosed in children, it rarely manifests as profound dryness. Children often seek medical care for recurrent episodes of pain and swelling in their parotid gland(s), either one side or both sides of their face becoming painfully enlarged. This acute parotitis (inflammation of the parotid gland) tends to resolve within a week in most children but can recur as frequently as multiple times per month. While it is the most common presentation, parotitis occurs in only approximately 50% of children with Sjögren's. Other children may have inflammation in their saliva- and/or tear-producing glands without any pain or swelling. These children often seek medical care for other symptoms including joint or muscle pain, fatigue, or specific organ involvement. Similar to adults, Sjögren's in children can affect any part of the body and the symptoms early in the disease tend to be relatively non-specific (that is, not obviously affecting the saliva- and tear-producing glands). We and others are actively studying Sjögren's in children with the goal of defining features to help guide earlier diagnoses, better treatments, and more information to help predict if/when additional medications may be needed to prevent progression to the debilitating features common later in adulthood.

There have been many exciting updates in childhood onset Sjögren's in the past year, and we highlight several here. A number of case series (medical research study design where researchers describe the characteristics and outcomes of a group of individuals) have added to our understanding of less common disease manifestations. A Czech group reported a case of tubulointerstitial nephritis (kidney condition characterized by inflammation of the tubules and the surrounding tissue) in a teenage boy with Sjögren's and reviewed reports of ~50 children with kidney involvement, suggesting up to 20% of children with Sjögren's may develop kidney involvement. While this is higher than reported in adults with Sjögren's, the majority of cases included interstitial nephritis similar to adults.[1] A Turkish group reported a teenage girl with severe headache and demyelinating (damage or destruction of the myelin sheath, a protective coating around nerve fibers in the brain and spinal cord) central nervous system involvement due to Sjögren's.[2] They suggest considering Sjögren's in any child with neurologic symptoms without an alternate explanation including severe headaches, blurred vision, muscle weakness, seizures, and confusion.

In an attempt to standardize the process of evaluating children with Sjögren's, researchers and caregivers developed a diagnostic algorithm to guide physicians on recommended tests based on presenting symptoms.[3] Researchers from the University of Florida created the "Florida Scoring System" to help stratify or classify children with suspected Sjögren's into different groups utilizing machine learning. Over 200 children were included in the study and stratified into three groups based on presenting symptoms and numerous laboratory and other test values. The hope is that this risk stratification will assist in decision making around diagnostic test ordering and monitoring for disease evolution over time.[4]

One of the diagnostic challenges in childhood disease is the minor salivary gland biopsy, which is a cornerstone for diagnosis in adults but may not be as reliable early in disease. A French group retrospectively analyzed 66 patients who underwent a minor salivary gland biopsy prior to age 18 years to determine if a positive result was associated with the diagnosis of Sjögren's.[5] They found that in isolation the "lip" biopsy performed poorly in making a diagnosis of Sjögren's.

While 23 of the 66 had a positive biopsy, only 13 of the 23 were diagnosed with Sjögren's based on the 2016 ACR/EULAR classification criteria developed for adults. Conversely, a negative biopsy was rarely associated with eventual Sjögren's. Only 3 patients among the 43 with a negative biopsy were diagnosed with Sjögren's. This emphasized the importance of performing an adequate number of diagnostic tests to ensure appropriate diagnosis given limits to each in children. This report contributes to growing evidence supporting the need to not prematurely make or refute the diagnosis of Sjögren's based on incomplete testing.

While a lip biopsy is often utilized in children, other salivary glands are more frequently biopsied at specific hospitals. A Dutch group that more commonly utilizes parotid biopsy compared differences in histopathology (examination of diseased tissues) between children and adults with Sjögren's. They found that children often had more significant immune cell infiltration compared to adults. This should raise consideration of parotid gland biopsy as a useful method in children given limitations in minor salivary gland biopsy interpretation in children.[6]

Extensive studies on treatment of Sjögren's in children are lacking, but a recent Utah study explored outcomes in children with recurrent parotitis with or without Sjögren's. Similar response to sialendoscopy (minimally invasive procedure used to diagnose and treat problems within the salivary glands) was noted regardless of diagnosis of Sjögren's. Improvement in parotitis frequency was reported to a variety of agents including hydroxychloroquine, methotrexate, mycophenolate mofetil, or rituximab without discernable patterns given the sample size.[7] An Italian group explored trending a variety of laboratory markers over two years to see if these markers correlated with disease activity. ANA (antinuclear antibody) values tended to decline over time with a mild decrease in immunoglobulin G (IgG) levels. No appreciable change in anti-Ro/SSA (SSA- Sjögren's syndrome-related antibodies) values was seen. A decline in disease activity score (ESSDAI- Eular Sjögren's syndrome disease activity index) correlated with the decrease in these laboratory markers.[8] The British Society for Rheumatology recently published guidelines on diagnosis and management of Sjögren's including the first inclusion of pediatric-specific information and recommendations.[9] An Italian paper emphasized the need for meaningful disease activity markers in children. They concluded that without the ability to accurately measure if the disease is improving or not, research into treatment options will falter.[10]

With increasing awareness of Sjögren's in children and increased interest in studying this disease, it has become important to develop a framework of research priorities to improve the lives and care of children with Sjögren's. An international group of researchers, caregivers, and an individual with lived experience convened to develop patient-centered research priorities for Sjögren's in children.[11] Overarching themes were to improve time to diagnosis, create more appropriate diagnostic tests and disease classification for children, increase collaboration between researchers and patients, identify important patient reported outcomes for research and clinical care, and develop research registries to better understand the long-term implications of the disease and response to treatment. The group emphasized the importance of reaching these goals through a three-pronged approach through research, education, and advocacy.

Diagnosing children with Sjögren's is difficult and often delayed, and research should aim to help with these challenges. There was wide recognition of the importance for the creation of child-specific values for common diagnostic tests and that these tests are imperfect in childhood. Research to find better indicators of disease activity and early disease in childhood Sjögren's are crucial. Storing a diverse collection of blood, saliva, and tears will allow interested researchers access to these samples needed to study future disease indicators. Research into saliva disease indicators was particularly appealing due to the ease of collection and the opportunity to gain significant information about children's disease state. Salivary gland ultrasound is a radiation-free test that provides significant information on salivary gland inflammation. Creating standards and a formal approach for evaluating salivary glands in children are needed. The group recognized the importance of creating classification criteria— a standardized definition of a disease for research studies— that is child-centered and appropriate in the pediatric setting. Sjögren's can affect different parts of the body and involving a variety of doctors and specialists is imperative to advance research and education.

Studies that support specific medication use of Sjögren's in children are lacking. More medication studies in children are necessary. There was wide agreement that information completed in adult studies may not apply to children. Repeating adult medication studies in children is important to define their effectiveness and safety in children is a necessary step to improve access to these medications for children.

There is inadequate research on long-term outcomes in children with Sjögren's, but studying outcomes requires time. An international study following children with Sjögren's over time is currently underway. This

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study, generously supported by the Sjögren’s Foundation, will help us understand many unanswered questions including the risk of MALT lymphoma (mucosa-associated lymphoid tissue lymphoma, a type of B-cell lymphoma with an increased risk in Sjögren’s) and other cancers in children with Sjögren’s. More input from experts with lived experiences and their caregivers are essential to maximize relevance and impact of outcomes studies. Their input when discussing research priorities strengthens studies by incorporating their unique and essential perspectives. Understanding the quality of life of children with Sjögren’s is essential to improving our care for children with Sjögren’s, and the input of those with the lived experience and their caregivers is vital to this understanding.

Henry Ford said, “If everyone is moving forward together, then success takes care of itself.” It takes a village to accomplish our goals, and we need your help. We appreciate all the help that you have provided in the past. Please let us know if you want to get more involved in research, education, or advocacy for childhood Sjögren’s at info@sjogrens.org to participate. ■

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World Sjögren’s Day

This World Sjögren’s Day, Take the Pledge.

Donate. Make an Impact.

Join us in honoring World Sjögren’s Day on July 23rd—a day that shines a light on the millions living with this serious and systemic disease.

Why July 23rd? This date commemorates the birthday of Dr. Henrik Sjögren, the Swedish ophthalmologist who first identified the condition in 1929. By listening closely to a patient experiencing dry eyes, dry mouth, and joint pain, Dr. Sjögren recognized a pattern others had missed. His curiosity led to the discovery of what we now know as Sjögren’s disease.

Today, patients still face long delays in diagnosis and limited treatment options. That’s why World Sjögren’s Day isn’t just a commemoration—it’s a call to action.

- Take the World Sjögren’s Day Pledge to raise awareness.
- Make a donation to support vital research and patient programs.
- Visit sjogrens.org/wsd to take the pledge and give today.

Together, we can honor the past, raise awareness today, and build a stronger tomorrow for Sjögren’s patients.

Advocacy in Action!

The Sjögren's Foundation Hosts a Congressional Briefing to Advocate for Sjögren's, Lupus, and All Those Living with Autoimmune Diseases, and Acknowledges New House Resolution 245.

Janet Church, President & CEO, Sjögren's Foundation

On March 25, 2025, the Sjögren's Foundation, Lupus Therapeutics, and the Office of Autoimmune Disease Research (OADR-ORWH) represented the voices of millions on Capitol Hill. To honor Autoimmune Disease Awareness Month, the Sjögren's Foundation hosted a congressional briefing to educate members of Congress and their staff about the rise in autoimmune diseases and the urgent need for greater recognition, research investment, and better support for patients living with Sjögren's disease and other chronic conditions such as lupus. The briefing was titled *Chronic Disease Burden: Sjögren's, Lupus, and the Autoimmune Crisis*.

The timing of the event couldn't have been more powerful. Less than 24 hours before the briefing, House Resolution 245 (H.Res.245) was introduced by Representative Joseph D. Morelle (D-NY-25). The resolution recognizes Sjögren's as a serious and systemic autoimmune disease and officially confirms April as Sjögren's Awareness Month. This strong show of support by Representative Morelle gave even greater weight to the message we brought to Washington during our congressional briefing: Sjögren's disease and the autoimmune disease crisis in this country cannot be ignored, and that research and education must be prioritized and funded. Additionally, this resolution will be a key reference document for policymakers working to promote better understanding of Sjögren's.

Autoimmune diseases affect up to 50 million Americans, and that number continues to rise. Yet despite the burden these diseases cause, public understanding, health education, research, and federal investment have lagged far behind, especially for Sjögren's. Sjögren's remains largely misunderstood, even within the medical community. It's still too often seen as a minor nuisance, rather than the complex, systemic, and life-altering disease it truly is!

The congressional briefing was a formal opportunity to build awareness about Sjögren's, share autoimmune disease patient perspectives, emphasize the impact and overlap of autoimmune diseases and to highlight the need for critical research directly with the people who shape federal health priorities. We were joined by a powerful lineup of experts and leaders in research, public health and clinical care.

Dr. Vicki Shanmugam, Director of the NIH's newly established Office of Autoimmune Disease Research, provided insight into the national strategy to better coordinate autoimmune disease research. She emphasized the Congressional directives guiding their work: developing a comprehensive NIH-wide strategic research plan, identifying emerging areas of innovation, fostering collaboration across Institutes and Centers, evaluating the current research portfolio, and improving data infrastructure through a centralized, publicly accessible research repository.

Dr. Dan Wallace, a renowned rheumatologist and longtime Sjögren's and lupus advocate, explained how Sjögren's frequently overlaps with other auto-

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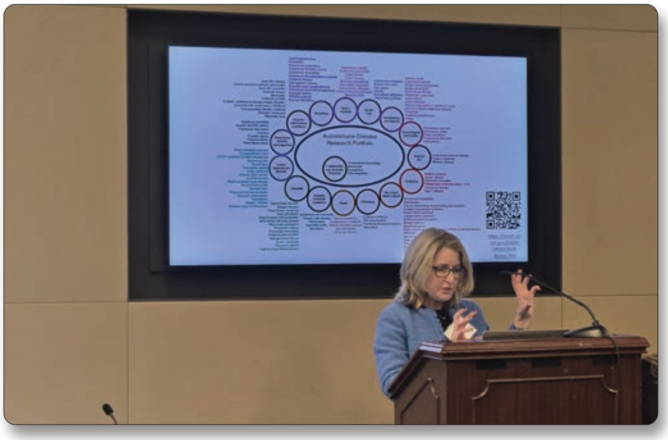

Dr. Vicki Shanmugam, Director of the NIH's newly established Office of Autoimmune Disease Research

immune diseases, especially lupus. He stressed the importance of better diagnostic tools and highlighted how co-occurring autoimmune diseases often delay treatment and worsen outcomes. He called for more inclusive, multi-disease research, as learning more about these diseases will aid in diagnosis, management, treatment, and development of therapies.

Dr. Dan Wallace, a renowned rheumatologist and longtime Sjögren's and lupus advocate

Dr. Stacie Bell, Chief Clinical Research Officer at Lupus Therapeutics, the clinical affiliate of the Lupus Research Alliance, talked about the clinical trial landscape and the need for innovation. Drawing from her professional and personal experience, she highlighted barriers to participation, like lack of provider awareness and infrastructure, and stressed the importance of making trials more inclusive, accessible, patient-centered and part of standard of care.

Dr. Stacie Bell, Chief Clinical Research Officer at Lupus Therapeutics, the clinical affiliate of the Lupus Research Alliance

Janet Church, President and CEO of the Sjögren's Foundation, and Sjögren's patient, spoke from the heart about the very real challenges the Sjögren's community faces, including lack of awareness about the disease. She asked the audience to acknowledge if they had heard of Sjögren's, and only 20% of the people raised their hand. Janet then presented details about the disease and what it is like to live with the disease, including the frustration many patients feel after years of searching for answers, only to face long delays in getting a diagnosis. She talked about the financial toll the disease can take, from medical expenses to lost income, and how difficult it is to manage symptoms that affect nearly every part of the body and every aspect of daily life. Janet also spoke about the emotional weight that comes with the disease itself and how patients feel misunderstood or overlooked, even by healthcare providers.

Janet stressed that Sjögren's isn't just about dry eyes and dry mouth, a common misunderstanding. It's a complex, systemic disease that causes profound fatigue, dryness throughout the body, pain, cognitive dysfunction (like brain fog), neuropathies, organ damage, gastrointestinal issues, and increased risk for lymphoma. Despite Sjögren's disease affecting more than 4 million people, there are still no FDA-approved systemic therapies for the disease and research funding and public awareness lag far behind other autoimmune diseases.

We didn't just bring challenges to the congressional briefing but highlighted and pushed for solutions. The Sjögren's Foundation is proud to take an active role in two major research initiatives with the Foundation for the National Institutes of Health (NIH)., and stressed the importance of continued funding for these research programs: The Accelerating Medicines Partnership/Autoimmune & Immune-Mediated Diseases (AMP®AIM) project which is exploring rheumatoid arthritis, lupus, psoriatic arthritis, and Sjögren's, studying each condition individually and collectively to uncover shared mechanisms and differences; and the soon-to-be-launched Sjögren's Biomarkers Consortium, which aims to identify biomarkers that could transform diagnosis and treatment. Our involvement in these partnerships helps ensure that Sjögren's is represented in cutting-edge research driving progress across autoimmune and rheumatic diseases.

Throughout the briefing, we made clear what's needed from Congress to truly move the needle on Sjögren's and autoimmune disease research. We urged members to:

- Continue learning about autoimmune disease and the patient experience.
- Increase federal funding for autoimmune disease research, especially for diseases like Sjögren's that have long been underfunded and overlooked.
- Fund the Office of Autoimmune Disease Research's upcoming strategic plan to advance autoimmune research support and develop better diagnostic tools.
- Encourage research into overlapping diseases together to improve efficiency and accelerate understanding, diagnosis, treatment.

The House Resolution and the congressional briefing are both important and provide an opportunity to represent the voice of patients, but it's just the beginning. As changes occur at the Department of Health and Human Services, the Sjögren's Foundation will continue advocating every day for the needs of our patient community. We are committed to ensuring that Sjögren's stays on the radar of policymakers, so Sjögren's research continues, and we are committed to educating healthcare leaders about this disease and the true impact on patients living with the disease.

Left to right: Janet Church, Dr. Stacie Bell, Dr. Dan Wallace, Dr. Vicki Shanmugam

We encourage you to take a moment to thank Representative Morelle for his leadership and support. Rep. Morelle's office was so moved by the support and feedback they received for leading the resolution last Congress (H.Res.1094). It certainly played a role in him leading our new resolution this Congress (H.Res.245). ■

Here's how you can reach him:

- Submit a message of thanks via our online form and we will share with Representative Morelle: https://www.sjogrens.org/morelle
- Call his office directly: (202) 225-3615
  - Use the sample message below as a guide, but feel free to personalize your message. Sharing your own story or perspective can make an even greater impact when contacting your member of Congress.
  - Thank you for introducing a congressional resolution on Sjögren's disease! Your leadership helps bring much-needed awareness to this disease and the challenges patients face. Your support makes a meaningful difference.

Contact his office on social media

- Use the sample message below as a guide, but feel free to personalize your message.
  - Thanks for supporting Sjögren's disease and increased awareness and research. It means so much to me and others battling Sjögren's.
- Reach out on Twitter/X or tag in your message: @RepJoeMorelle (https://x.com/RepJoeMorelle)
- Reach out on Facebook or tag in your message: https://www.facebook.com/RepJoeMorelle
- Reach out on Instagram or tag in your message: https://www.instagram.com/repjoemorelle

This is Sjögren's

Each person living with Sjögren's disease has a unique journey. In this issue, we're honored to share the stories of a few patients from Sjögren's Awareness Month. From navigating diagnosis to advocating for awareness and hope, these stories illuminate the many ways our community continues to conquer Sjögren's, every single day.

Shelby

"Sjögren's has had a significant impact on my physical health. In addition to dry eyes and dry mouth, I deal with fatigue, brain fog, and joint pain/swelling. I end up getting cavities often, I have scarring in my right eye, and I have sun sensitivity. It definitely gets me down sometimes thinking about what life would be like without this disease, but I try to keep positive!

It's been so helpful getting to hear others share their experiences. When I was first diagnosed, finding a community helped me navigate the diagnosis and learn tips and tricks for managing symptoms.

Just like with any other invisible illness, I just wish that our symptoms weren't so easily dismissed by others. Some days I'm moving slow, I'm having trouble talking, or I just need a day of rest, and that's due to a disease I can't control. A little patience goes a long way."

Thomas

"Sjögren's has been a very effective Hoover vacuum sucking most of my primary resources in my life. As with many Sjögren's patients, a diagnosis took some time, my being a man, just compounded the puzzle. Once recovered, I was not able to return to my position as a flight attendant as no doctor could guarantee I would remain stable working at 30,000 ft. Through support of my friends and family I made it through the devastation to my entire life.

Sjögren's has taught me patience, to look at life's gifts from the positive, research and be as prepared as possible for the prognosis...I wish people knew how debilitating this disease can be and understand if occasional fatigue, mouth sores or other symptoms interferes with daily life/plans. 'Funny, you don't look sick.'

Research and find out all you can about your particular case. There are a lot of similarities within the Sjögren's community while just as many differences. Stay positive and don't obsess...Do not take the diagnosis as an excuse to bow out of life. Stay on track and keep getting on with plans and dreams."

Cynthia

"Most people don't understand that Sjögren's is a hidden disability. Many friends and family don't quite understand why Sjögren's patients avoid human interaction for the safety of our compromised weak autoimmune health condition.

Gradually build a routine that fits your needs and preferences. I enjoy lap swim three days a week, relax in sauna, walk 3 miles, chair yoga, take naps and I joined a stretch class... During hard days, I love putting 1000-piece puzzles together, painting and embroidery to relax my mind."

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Lauren

"Sjögren's had taught me how ableist I didn't realize I was. I used to think life wouldn't be worth living if I didn't have my intelligence and have full control of my faculties. Turns out life is still amazing even with short term memory problems, brain fog, and episodes of confusion. I was completely wrong.

Tell your doctor about all your symptoms, even non-physical ones. I've had significant mental problems because of Sjögren's: brain fog, short term memory issues, bouts of confusion. It's scary, and it shouldn't be kept from your doctors.

Find out what works for you mentally to keep going. Maybe how much you love your friends and family. Maybe it's throwing your emotions into art, writing, or physical activity. Maybe it's being spiteful towards Sjögren's, like 'screw you Sjögren's my eye drops, probiotics, plaquenil, and physical therapy will defeat you'. Or, 'Haha Sjögren's, I'm still gonna be alive in the next hour, next 15 minutes, next 30 seconds'. Whatever you need to do to get through the pain."

Arauca

"Due to my Sjögren's worsening and flare ups becoming more aggressive, I had to transition careers which caused me to financially struggle for awhile. It also changed my life. As a dancer, I can no longer do the same movements I once did with full expression. Even a couple of minutes of movement feels like an hour run.

I wish people knew my Sjögren's isn't what a Google search will tell them. It's not dry eyes and mouth. It's extreme fatigue, it's pain in my joints and muscles. It's migraines that turn into extreme pain near my neck. It's esophageal dysmotility. It's me being okay one day and disabled the next.

My best Sjögren's tip is to carry an emergency kit. Having a small pill case with your essentials in case you forget to take them, having eye lubricants, dry mouth lozenges and things essential to your Sjögren's experience."

Robyn

"It's the hidden disability! Just because you can't measure pain, fatigue and dryness doesn't mean it isn't having a major impact on your life. Most doctors underestimate the impact as a systemic disease… It is a systemic disease and deserves to be taken seriously!

Joint pain mainly affects my small joints - hands, wrists, knees and feet but I have widespread osteoarthritis in my lower back, neck, pelvis and knees associated with hyperflexibility. I've had Sjögren's since 1996 so I've been dealing with it for a long time! The best treatment I have found is movement! I do a weekly physiocise class with a physio and a do a daily physio routine to keep my joints strong and flexible. I also do an aquarobics routine daily which I really enjoy because it supports the joints in the water."

Ella

"When I was 17, I was diagnosed with Sjögren's. I had severe parotid gland swelling. It looked like two baseballs were on the side of my face. I get severe cavities, dry eyes and mouth, joint pain and I cannot smell. Your symptoms will frustrate you so badly, but along the way you will find things that work for you.

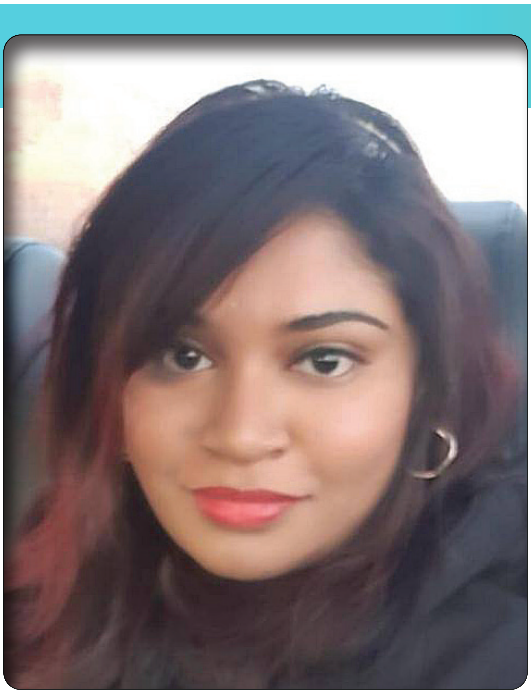
I feel like I'm 80 years old in a 18-year old's body. I am in pain every day. My joints my jaw my head. I'm emotionally drained. I try and keep my stress under control but having stress causes a flare up and having a flare up causes more stress and it's just a big circle.

Not everything your doctors say will be true. You have to remember you have this disease they don't. Find people who have this disease because those are the only people that truly get it.

I wish I knew that I would be okay. Less than two years ago, sitting in a hospital bed was the scariest feeling I have ever felt but now I have so much support behind me and I feel like I finally understand this disease."

continued page 14 ▼

“This Is Sjögren's” continued from page 13



Kay

“I try to live as “normal” a life as possible, flare-ups and random infections often hit hard—bringing extreme fatigue, joint pain, severely dry skin, breathing difficulties, and even eye sensitivity to light. Some days, I can’t manage even half of what I did the day before. Emotionally, it’s incredibly taxing. I often worry about being left out, misunderstood, or looked down upon. I feel constant pressure to keep up and perform, even when my body is begging me to rest. Despite trying to stay positive, the emotional toll can leave me feeling sad and defeated. Financially, it’s equally challenging. The cost of ongoing treatments like immunosuppressants, Plaquenil, and prednisolone already puts a strain on my budget.

I wish people knew that Sjögren’s is more than just dryness or fatigue—it’s an invisible illness that affects every part of my life. Some days, I may look fine on the outside, but inside, I’m dealing with pain, exhaustion, and symptoms that can be unpredictable and overwhelming. I wish people understood that I’m not being lazy or flaky when I cancel plans or need extra rest—it’s because I’m listening to my body. Most of all, I wish others could see that while I may be strong and capable, I’m also carrying a lot, and a little compassion or understanding can make all the difference.

To be honest, what truly keeps me going—especially on the hardest days—are my concert and travel memories. The first six months after my diagnosis, I was in really bad shape. I could barely function like I used to—it was one of the darkest periods of my life. One day, I stumbled upon old photos and posts of myself. I remembered the joy, the energy, and how alive I felt. That version of me—that experience—became my motivation. I want to feel that again. I want to create more memories like that. And that hope keeps me going.”

Barbara

"I was diagnosed with Sjögren's in my mid-forties soon after I began to experience dry eyes and mouth as well as fatigue. At age fifty I experienced forced retirement from my position as a registered nurse because I had used up all of my paid time off after surgery for back-to-back rotator cuff repairs. Other physical issues related to Sjögren's over the years had also eaten into my accumulated sick leave benefits.

My position in a large medical school as an RN in the Department of Pediatrics for 32+ years came to an abrupt and sudden end mandated by HR. No problem they said. You can draw short term disability then file for SSDI. You'll be fine. Have your office cleaned out by 5:00 today! I was not able to fight back the tears. At age 50, I had a lot left to give but Sjögren's and the prevailing culture that anyone with a disability is a company liability and waste of resources, cut that short.

I wish my loved ones and friends could truly understand what I go through every single day of my life. I never feel fully rested and it's frustrating to have to acknowledge my limitations and to miss out on activities because I'm just too darn tired. I wish they truly understood that my whole body is affected by this disease and that I often hide how I feel because frankly I loathe being a complainer. I hate relying on others for help when I was always the one everyone depended on at home and at work when someone else was in need."

Bostyn

"I was diagnosed at 5 years old. I had severe redness under my eyes and it felt like sand was in them. I also got huge bumps in my parotid glands that were very painful. This disease is hard to manage but I have very good doctors and my mom and dad to help me.

Sjögrens makes it really hard for me to run and play... I may look fine on the outside but on the inside I hurt and I'm tired.

I make sure to tell my parents how I am feeling so they can get me what I need... I am better than Sjögren's and I am not going down without a fight." ■

Connecting, Learning, & Thriving at the 2025 National Patient Conference

Sjögren's Foundation
National Patient Conference 2025

The Sjögren's Foundation's National Patient Conference on April 11th and 12th brought together Sjögren's patients, experts, and advocates from all 50 states, Washington D.C., Puerto Rico, and 20 countries. The conference's virtual format and programming provided attendees with ample opportunities to Connect, Learn, & Thrive? — the theme for the 2025 conference.

A Look Back at This Year's Event

More than 1,200 people registered for this year's virtual conference, which included main stage sessions with Sjögren's doctors and researchers, an exhibit hall with conference sponsors, and Sjögren's community areas for connecting via chat and video. Attendees got to strengthen their understanding of Sjögren's disease, learn about advances in research, and access tips for managing Sjögren's.

Deepening Understanding of Sjögren's Disease

Anyone living with Sjögren's knows that the disease is much more than the often-quoted symptoms of dry eyes and dry mouth. Rather, it's a disease that impacts many different body systems — and its symptoms have a significant impact on Sjögren's patients' lives.

Conference attendees benefited from presentations by Sjögren's experts who explained what we know about how Sjögren's impacts different body systems, discussed the types of symptoms patients might experience, and provided actionable tips to help patients live well with Sjögren's:

- Dr. Brandon Law gave an overview of Sjögren's disease, with a focus on symptoms that have a significant impact on daily life — such as fatigue — and how to better manage them.
- Dr. Michael Brennan discussed how Sjögren's impacts oral health and what Sjögren's patients can do to address dry mouth.
- Dr. Nadia Mohyuddin presented on how patients can manage Sjögren's ear, nose, and throat symptoms and prevent related complications.
- Dr. Daniel Wallace educated attendees about other autoimmune diseases that can overlap with Sjögren's — such as lupus, rheumatoid arthritis, and scleroderma.
- Dr. Lee Guo spoke about Sjögren's impact on eye health and what patients need to know to manage dryness and protect their eyes.

> *"I think there's a very optimistic outlook for Sjögren's moving forward. New treatments are coming — potentially in the next few years." —Dr. Brandon Law*

Highlighting Advances in Sjögren's Research

- The field of Sjögren's research is always changing — and there's still plenty that we don't know about this complex disease. However, experts around the world are conducting research to improve our understanding of Sjögren's causes, manifestations, and treatments.
- In this year's main stage sessions, attendees learned about the state of Sjögren's research — including some exciting new developments!
- Sjögren's Foundation President and CEO Janet Church shared how the Foundation is supporting research on Sjögren's disease.

- Dr. Scott Lieberman educated attendees about childhood Sjögren's and gave updates on research from the International Childhood Sjögren's Workgroup.
- Dr. Brent Goodman explained how Sjögren's affects the nervous system and previewed upcoming clinical practice guidelines for neurology.
- Dr. Sara McCoy presented on studies that describe different Sjögren's endotypes (patient profiles) and how endotypes may impact disease progression and treatment.
- Dr. Christopher Lessard brought attendees up to speed on the latest research on genetics and Sjögren's disease.

"My neurologist consistently dismisses Sjögren's disease involvement in my brain fog, headaches, and thermoregulatory impairment. Thank you for validating my questions!" —2025 Conference Attendee

Answering Patients' Sjögren's Questions

Many Sjögren's patients attend the National Patient Conference because they want to do all they can to better understand the disease.

To help address that need, speakers at the conference's main stage offered Q&A with attendees at the end of their presentations — dedicated time for providing clarifications, additional detail, and actionable advice for managing Sjögren's.

In addition, each day of the 2025 conference featured a "Chat with a Doc" session with Dr. Donald Thomas, rheumatologist and Sjögren's expert. The sessions created a venue for attendees to get answers to Sjögren's questions that weren't addressed in other conference sessions.

Fostering Connections

Living with a disease like Sjögren's can have a big impact on patients' daily lives and mental health. Many people with the disease feel isolated — or even misunderstood by their loved ones, friends, or coworkers who don't have Sjögren's disease.

At the 2025 conference, attendees had opportunities to connect with other people with the disease through virtual Sjögren's community areas. In these forums, Sjögren's patients connected with one another through chat and video to offer support, share their stories, and give advice for living with Sjögren's.

"It's been a very enlightening and validating experience to be part of this conference. Thank you for making us all feel seen and heard!" —2025 Conference Attendee

Advocating on Behalf of Sjögren's Patients

Part of the Sjögren's Foundation mission is working to shape policies that affect Sjögren's patients. Eli Greenspan, the Foundation's advocacy expert, educated conference attendees about how public policies are formed and highlighted the advocacy work the Foundation has done on behalf of Sjögren's patients — such as continued engagement with Centers for Medicare and Medicaid Services (CMS) to improve Medicare dental coverage for Sjögren's patients. He also shared ways that the Sjögren's community can get involved in advocacy, such as contacting elected representatives.

"Advocacy requires a dynamic approach: working with stakeholders and with you — those who understand Sjögren's better than anyone." —Eli Greenspan

Spotlighting our Sponsors

The National Patient Conference was made possible by generous support from our sponsors — Novartis, Bristol Myers Squibb, Amgen, Argenx, and Johnson & Johnson. Conference attendees had the opportunity to connect with sponsors in a virtual exhibit hall. There, representatives shared information about the work that their organizations do to support Sjögren's patients and research, including clinical trials.

Access the 2025 Conference

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

- If you attended the conference, you can access recordings of all main stage events. Simply sign into Accelevents using your registration credentials: accelevents.com/e/2025npc/portal
- If you didn't attend the conference, you can purchase access to the conference recordings for $100. Get details and purchase the recordings: sjogrens.org/npc

Thank you to our attendees for another successful and impactful National Patient Conference. We look forward to welcoming the Sjögren's community to future events! ■

Thank you to our 2025 National Patient Conference Sponsors

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Sjögren's Foundation
National
Patient
Conference
2025

Did you Miss the 2025 National Patient Conference?

Conference Recordings Now Available!

In April the Sjögren's Foundation held the 2025 National Patient Conference. This year's event was attended by over 1,200 patients and loved ones from across the country and around the world, all joining together for two days of connection and learning how to thrive with Sjögren's! If you were hoping to attend but your schedule did not allow, recordings are available for viewing. You will have unlimited access to review the presentations for 6 months.

2025 Conference Presentation Recording Purchase Will Include:

- An Overview of Sjögren's with Brandon Law, MD
- Oral Manifestations in Sjögren's with Michael Brennan, DDS
- Ocular Manifestations in Sjögren's with Lee Guo, OD
- Sjögren's and the Ears, Nose and Throat with Nadia Mohyuddin, MD, FACS
- Managing Overlapping Autoimmune Diseases with Dan Wallace, MD, FACP, MACR
- Childhood Sjögren's Overview with Scott Lieberman, MD, PhD
- Your Neurological System and Sjögren's with Brent Goodman, MD
- Understanding Endotypes and Patient Profiles in Sjögren's with Sara McCoy, MD, PhD
- What We Know About Genetics and Sjögren's with Christopher Lessard, PhD
- Understanding Public Policy and Advocacy with Eli Greenspan, MPH
- Foundation Update with Sjögren's Foundation President and CEO, Janet Church

Register Here: http://www.sjogrens.org/npc

Purchase your recording by October 1, 2025 to receive 6 full months of viewing time!

Cost: $100

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