CONQUERING Sjögren's

November/December 2024

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Sjögren's FOUNDATION

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Letter from Our President & CEO:
Celebrating 40+ Years of Progress, Thanks to You

Janet Church
President and CEO,
Sjögren's Foundation

Hello Sjögren's Foundation Members and happy holidays! It's hard to believe it is already the end of 2024. This year has flown by so quickly! Now that I have the opportunity to reflect on 2024, I am excited to share our accomplishments and the momentum we are seeing in Sjögren's. This momentum will stimulate new research, guide more patients to the Foundation for education and support, and educate more professionals on patient care for Sjögren's. All of these events will provide greater awareness of the disease to the public and the need for funding to Congress. It's been a busy year, and the work we've accomplished is truly laying the groundwork for greater success in the future. And to me, success means that every patient is accurately diagnosed and treated so that they can live a good quality of life, full of meaning. Let's take a look at this year's accomplishments.

We Celebrated 40 years of Progress!

The Sjögren's Foundation was founded in September 1983 and so we have been celebrating 40 years of progress since then! This is a significant milestone to mark! On October 28, 2024, we closed out our celebration and we are into our 41st year.

We kicked off January 2024 with our 40 Years of Progress Timeline. I am very proud of the 40-year timeline we created and published in the Jan/Feb 2024 Conquering Sjögren's issue (If you became a member after this issue, do go to the archives on the member side of our website for your own copy). We celebrated at the National Patient Conference, all throughout Sjögren's Awareness month (April), in all our 2024 Walk for Sjögren's events, and World Sjögren's Day!

Although we still have a long way forward, we certainly have made progress in the past 40 years!

Sjögren's Syndrome OFFICIALLY Changed to Sjögren's Disease!

If you have not heard, Sjögren's disease is now the official worldwide name of the disease! The Sjögren's Foundation has been leading the charge, since 2015, to ensure that the words we use to describe Sjögren's communicate that it is serious and systemic. We are excited that the international Sjögren's community followed our lead and also adopted the disease name change to Sjögren's disease. The term "secondary Sjögren's" meant to label that a patient has Sjögren's plus another autoimmune disease, was also discarded, as it connoted that Sjögren's was "less than" the other disease(s). I encourage you to read the entire history of the process on our website at www.sjogens.org. I want to personally thank the Foundation's own Kathy Hammitt, Vice President of Medical and Scientific Affairs, for leading this charge, being a key taskforce member, and working with the international patient and professional community to make this happen!

House Resolution #1094 Presented

One of my favorite accomplishments this past year is the impact of our advocacy! It took us two full years, but in 2024, U.S. Representative Joseph Morelle (D-NY) stepped up and presented our NEW Sjögren's resolution that corrects the name of our disease, states that the disease is serious and systemic, highlights that 4 million Americans have Sjögren's—of which 50% are undiagnosed—, and highlights the need for more research funding. This is now an official federal document that Congress can refer to when discussing funding! If you have not read it, please do! Just Google "House Resolution #1094 —

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118th Congress (2023-2024)" and it will be presented to you.

Patient Support and Programs

Everything we do is with the patient front and center! As a Sjögren's patient myself, this perspective is easy. I understand the struggles patients have daily. That is why our patient materials, conferences, support groups, and membership program are so important.

We continue to expand our Support Groups to ensure we can help as many patients as we can, and I want to thank our Support Group Leaders for their service to the Foundation and their fellow patients! We also added a new channel for patient support through the Inspire platform. Inspire is our newest support partnership that allows patients to chat directly with one another. A benefit of Inspire is that you can also connect easily with other disease groups and we have also presented *Ask the Doc* sessions from within the Inspire Sjögren's community. You can reach the group by clicking through from our website.

Healthcare Provider Education

We continue to press forward with our professional education programs. This year, we launched our first continuing medical education (CME) program that is attached to our January *State of Sjögren's* professional event. This CME lives on the Foundation's Sjögren's Training and Education Platform (STEP) for professionals. We will continue to add CME programs here as well as continue to partner with our external CME providers to train more doctors. In the past few years, we have trained over 13,000 providers with our CME programs and we are focused on growing that number each year!

Research, Research, Research!

There is exciting research happening for Sjögren's! In this *Conquering Sjögren's*, we highlight two of our most important research projects to date: The FNIH AMP® AIM program and the SGENE project. This year, we funded the third year for the AMP® AIM program, and we funded SGENE in 2023. For the Foundation Research Grants, we funded five research projects this year. We also just funded the first year of the new Sjögren's Biomarkers Consortium with the FNIH, which will kick off in 2025.

The clinical trial space for Sjögren's is incredibly busy with multiple potential treatments to help patients. This year, we have been working with ten different companies all in a clinical trial phase or coming into a phase for a Sjögren's therapy. This truly is an exciting time as I hope we will have a new therapy on the market within the next three years.

With all the momentum we've been building the past few years, I am looking forward to 2025 and how we can continue to advance what we know about Sjögren's and how we can improve the quality of life for all patients. As we say goodbye to 2024, I want to thank the Foundation staff for their commitment to patients, our volunteers who bring Sjögren's education and support to local communities, our Board of Directors who give their time to ensure our mission is moving forward, and our donors who are committed to helping us achieve all our goals. And I especially want to thank you! I am grateful for your support, and I am honored to lead this organization as we fight together to conquer the complexities of Sjögren's. ■

Wishing you a happy and healthy holiday season!

Janet Church
President and CEO,
Sjögren's Foundation

Recap of Sjögren's at ACR Convergence 2024

The American College of Rheumatology (ACR) Convergence 2024 was held from November 14th-19th in Washington, D.C. just a few miles away from the Foundation's office in Reston, VA. This is the largest meeting for the rheumatology community every year with more than 10,000 healthcare providers, pharmaceutical companies, patient advocacy groups, and researchers, where they meet and discuss important topics in rheumatology, including prevention, diagnosis, and therapies for all rheumatic diseases.

Last year there was an increased focus on Sjögren's compared to years past, but this year there was an even larger increase in Sjögren's-related research with more sessions on Sjögren's. There were 77 Sjögren's-related scientific abstracts, 16 abstract sessions including Sjögren's-related work— two poster, one oral—, and three provider training sessions— which is significantly more than last year.

Sessions on Sjögren's

On Thursday, November 14th, a trainee education session was led by Dr. Sara McCoy themed "Sjögren's: Beyond Sicca." This was part of ACR's Fellows-in-Training program that is dedicated to helping rheumatology professionals— a medical student, resident, or fellow— navigate early stages of their careers. This was an opportunity for Dr. McCoy to share her expertise in Sjögren's and educate those early in their careers about this complex, serious, and systemic disease beyond the dryness.

In addition to scientific and medical research sessions, ACR provides continuing medical education opportunities for healthcare professionals to build or enhance their clinical skills. On Friday, November 15th, there were two lectures on Sjögren's in an advanced rheumatological ultrasound course designed to build more pragmatic approaches to incorporate ultrasound techniques as diagnostic tools for evaluating Sjögren's. "Systems rheumatology: Clinical Utility of Ultrasound in Sjögren's and Its Differentials," which discussed the use of ultrasound in diagnosing Sjögren's, was presented by Dr. Eugene Kissin. The lecture on "Salivary Glands and Sjögren's," which was presented by Dr. Jemima Albayda, Dr. Fawad Aslam, Dr. Heather Benham, Dr. Robert Fairchild, Dr. Eugene Kissin, Dr. Mark Matza, Dr. Amanda Nelson, Dr. Midori Nishio, and Dr. Howard Yang, provided hands-on skill building by using scanning models with actual pathology ultrasounds on salivary glands of patients with Sjögren's.

The first medical and scientific session kicked off on Saturday, November 16th with a session that discussed the recognition, prevention, and management or oral complications, interstitial lung disease, renal disease, and lymphoma in Sjögren's. The session titled, "Unmet Needs in Sjögren's: Recognition, Prevention, and Management" was moderated by Dr. Robert Hal Scofield and Dr. Blake Warner. The presenters of this session were Dr. Leslie Laing, Dr. Scott Lieberman, and Dr. Sara McCoy, who focused on best practices for the management of dryness, glandular pathology in Sjögren's, and the pulmonary and renal manifestations in Sjögren's.

Following this session, Matt Makara, MPH, Senior Director of Medical and Scientific Affairs at the Sjögren's Foundation presented on the Foundation's collaborative approach to developing clinical practice guidelines. This brief presentation highlighted the work that's been done to create guidelines, the work that is

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ongoing, and encouraged healthcare professionals to engage in the process and with the Foundation.

On Sunday, November 17th, a session was held to discuss novel imaging and therapeutics in Sjögren's. Since diagnosis and treatment options continue to challenge physicians, this session covered novel therapeutics based on imaging advances to help better diagnose and manage patients with Sjögren's including indications for acquiring histopathology and interpretation of their results to guide therapy. Dr. Alan Baer spoke first on the challenges of disease-modifying therapy in Sjögren's and was followed by Dr. Alojzija Hocevar, who discussed novel imaging and therapeutics. The session ended with a clinical trial update in Sjögren's presented by Dr. George Bruyn.

The last session on Sunday explored the disease pathogenesis of the glandular and extra-glandular immune response with an emphasis on T cell and epithelial biology. Dr. Mohammad Haj Dezfulian presented on "Unbiased Antigen Discovery in Sjögren's." The next presentation given by Dr. Sarthak Gupta described the role of JAK-STAT signaling and interferon-drive immune activation in Sjögren's. Lastly, Dr. Gwenny Verstappen focused on the interplay of epithelial and immune cells in salivary glands of patients with Sjögren's.

There were two Sjögren's poster sessions for basic and clinical science that included a combined 48 abstracts. Non-Sjögren's specific poster sessions also contained a combined 29 more abstracts on Sjögren's-related work. Of the submitted abstracts, the ACR chose six for oral presentation on Monday, November 18th, 2024. The following six abstracts were chosen:

- *Deciphering Salivary Gland Inflammation in Sjögren's Reveals Shared and Autoantibody-Specific Immune Cell Heterogeneity by Jun Inamo, MD, PhD, University of Colorado School of Medicine*
- *Identification of Molecular Biomarkers for Sjögren's Disease Stratification via a Deep Learning Foundation Model Dedicated to Immune-Mediated and Inflammatory Disease by Vincent Bouget, MSc, Scienta Lab*
- *Risk of Atherosclerotic Cardiovascular Events and Venous Thromboembolism in People with Primary Sjögren's : A Danish Cohort Study by Pierre Loiseau, MD, CHU Amiens-Picardie*
- *Genetically-engineered Ro-specific Regulatory T Cells to Treat Primary Sjögren's Disease by Zhi Feng Sherman Lim, PhD, Monash University*
- *Multicenter Validation of a Machine Learning Foundation Model to Diagnose Sjögren's Disease and Identify Histological Biomarkers for Disease Stratification by Vincent Bouget, MSc, Scienta Lab*
- *Transcriptomic Stratification Predicts Response to Rituximab, Abatacept or the Association of Hydroxychloroquine and Leflunomide in 3 Randomized Controlled Clinical Trials in Sjögren's Disease by Baptiste Chevet, MD, MSc, University Hospital of Brest*

Foundation Luncheon

On Sunday, November 17th, the Foundation hosted our annual luncheon to discuss updates on Foundation news, research advancements, and this year hosted a meeting with the clinical trial consortium. This invite-only event had more than 100 attendees including clinicians, researchers, and industry.

This year's theme was "The Missing Link: The Nervous System & Sjögren's," which focused on the Foundation's work on neurological clinical practice guidelines and further discussion on neurological clinical endpoints in research and clinical trials. This event was moderated by Dr. Alan Baer, Chair, Sjögren's Foundation Medical & Scientific Advisory Council and Director of the Sjögren's Clinic, John's Hopkins University.

The luncheon began with important updates from the Foundation by Janet Church, President and CEO of the Sjögren's Foundation, including the change of the disease name to Sjögren's disease, our Congressional Resolution that states our new disease name and the seriousness of the disease to express the need for more government funding increased provider education efforts, including more continuing medical education courses on Sjögren's. The Foundation also gave appreciation for the changing landscape of clinical trials and the increased interest in helping patients with Sjögren's, and shared concerns about the lack of clinical trial sites available for patients and encouraged discussions of how to increase these numbers.

Dr. Steven Carsons, Chair of the Sjögren's Foundation Clinical Trial Practice Guidelines and Chief of the Division of Rheumatology, Allergy, and Immunology at New York University Long Island School of Medicine, gave an update on the alignment between rheumatology and neurology of nomenclature for peripheral nervous system neuropathies and the process involved in the completion of the clinical practice guidelines.

A presentation of the clinical trial endpoints, mainly ESSDAI (EULAR Sjögren's syndrome disease activity index) and clinESSDAI, was given by Dr. Daniel Wallace, Chair of the Sjögren's Foundation Clinical Trials Consortium and Professor of Medicine at Cedars-Sinai Medical Center and David Geffen School of Medicine at University of California Los Angeles. He discussed the critical role of endpoints in clinical

trials and emphasized the inconsequential scoring of the peripheral and central nervous system domains, including the importance of improving the scoring of the neurological domains to provide meaningful neurological endpoints in clinical trials.

Next, Dr. Brent Goodman, Autonomic and Neuromuscular Neurology Specialist, Chief Medical Officer at Metrodora Institute, provided commentary and led a discussion on neurological clinical endpoints and where they are now and how they can improve.

Lastly, Dr. Baer provided highlighted Foundation research grantees whose projects have focused on neurological involvement in Sjögren's. This presentation demonstrated that research is and has been taking place that will help elucidate what we know about the nervous system and Sjögren's. The luncheon ended with Dr. Baer announcing the Foundation's Outstanding Abstract Award for ACR Convergence 2024.

Poster Sessions

This year the Foundation collaborated with Robert Fearon to present in the Patient Perspectives poster session at ACR Convergence. Robert Fearon is a patient with Sjögren's that shared his story in his poster titled "Finding the Balance: Regaining My Strength While Living with Sjögren's & POTS." It was important to show providers and researchers what patients experience and how they manage their symptoms.

The Foundation also presented two neurological posters entitled "Developing Clinical Practice Guidelines in Sjögren's" and "Neurological Complications in Sjögren's: Occurrence and Impact on Patient Quality of Life."

Dr. Nancy Carteron presented on "Developing Clinical Practice Guidelines for Sjögren's." This presentation described the process of creating our peripheral nervous system (PNS) clinical practice guidelines. PNS manifestations occur frequently in Sjögren's disease and can encompass mononeuropathy, polyneuropathy, and autonomic neuropathy.

Dr. Ghaith Noaiseh presented the poster on "Neurological Complications in Sjögren's: Occurrence and Impact on Patient Quality of Life."

Foundation Booth & Professional Awareness

We enjoyed meeting the many healthcare professionals and researchers that stopped at our booth this year. Many providers stopped by to ask about Sjögren's, the Foundation, and how best to support their patients. We offered information about our clinical practice guidelines (CPGs), the availability of research grants, CME opportunities, and more.

Matt Makara, Senior Director of Medical and Scientific Affairs, also presented in a special session for non-profit organizations called "Meet the Funders." This session provided details about the Sjögren's Foundation's research grant opportunities, in hopes to gain more interest in Sjögren's research.

We look forward to next year's ACR Convergence 2025 that will be held in the Windy City—Chicago, Illinois! ■

Ting Yang, MSc, PhD candidate accepting the Foundation's Outstanding Abstract Award

Sjögren's FOUNDATION Outstanding Abstract Award Winner

Every year at ACR Convergence, the Sjögren's Foundation recognizes top investigators for their exceptional research in Sjögren's with the Foundation's Outstanding Abstract Award. We were impressed by the number and quality of Sjögren's-related research abstracts presented at ACR Convergence this year and would like to congratulate all abstract authors who had their remarkable work accepted.

The Outstanding Abstract Award is chosen by a panel of distinguished professionals, and we would like to thank them for reviewing and providing feedback on the abstracts. With almost 80 Sjögren's- related abstracts this year, it was difficult to choose just one winner.

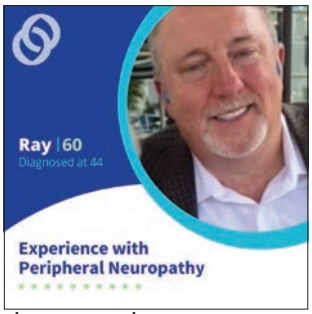
Ultimately, the selection committee chose Ting Yang, MSc, PhD candidate from University Medical Center Groningen for their project entitled, "Fibroblast-driven Ttek Activation May Drive Acinar Cell Dysfunction in Sjögren's Disease, Prior to Lymphocytic Infiltration." The project aimed to determine the mechanisms that occur before lymphocytic infiltration of salivary glands. They found that activated fibroblasts are present before lymphocytic infiltration and that they can activate Ttek cells— a subset of CD8+ T cells that express granzyme K, which can trigger acinar cell (cells that produce saliva) dysfunction. This work has implications for identifying the first stages of salivary gland pathology in Sjögren's. ■

Highlighting Men with Sjögren's Disease

In honor of Men's Health Awareness Month, the Sjögren's Foundation highlighted our male patient experience living with Sjögren's disease. We wanted to highlight men with Sjögren's, who do not get enough attention in a historically promoted "women's disease." Current data suggests that the ratio of men to women with Sjögren's is 1 in 10, and because of this, men with Sjögren's have not received the attention and research needed to understand their experience and how it may differ from female patients. Because we estimate that 50% of Sjögren's patients are undiagnosed, there is a possibility that the ratio of male to female Sjögren's patients is higher.

Below, we highlight three men— Ray, David, and Robert— with Sjögren's that have different backgrounds and, as with all Sjögren's patients, have heterogenous symptoms and paths in their journey to diagnosis and treatment. After their stories, we will share current research on male patients with Sjögren's.

Experience with Sjögren's in Men: Highlights from Patient Stories



Are there any symptoms or conditions you think are specific to male patients with Sjögren's that you believe other men with Sjögren's should be monitoring?

"Everyone's Sjögren's journey is different. I believe there may be many more common denominators to consider as common for men with Sjögren's, we just don't know. A few that come to mind are peripheral neuropathy, GERD (gastroesophageal reflux disease), lack of sleep, etc. GERD is really an ominous factor as uncontrolled acid reflux can damage the esophagus, that may potentially lead to cancer. Peripheral neuropathy can readily be excused away, as in its early stages, in my belief, may feel like water under the feet, or a string tied around a toe, or even be diagnosed as Morton's Neuroma.

What are your most common symptoms and what is your most debilitating symptom?

"Believe it or not, one of my worst issues, is lack of a good night's sleep! One of the best things that I've done to work with Sjögren's is to see a sleep neurologist.

My most debilitating symptom is peripheral neuropathy. I use gabapentin to manage this. I also have a 'double crush' in my left foot. I have a crushed nerve there that at times causes much worse pain than my neuropathy. Having size 12 wide foot doesn't help me much either when shopping for shoes. It is so hard to find shoes that fit, coupled with my crushed nerve, and neuropathy! That's why I do not often buy shoes. My wife has to make me go shoe shopping!"

Do you feel it was harder for you to get a diagnosis of Sjögren's due to the stereotypes around the "typical" Sjögren's patient?

"Absolutely! I have been told by numerous doctors that I had nothing wrong with me even though I had obvious abnormalities in my labs. I was told that the lab abnormalities were 'non-specific,' and was eventually diagnosed with rheumatoid arthritis. I asked them why did they diagnose me with rheumatoid arthritis instead of Sjögren's? I was told 'you're a man and men don't get Sjögren's!' MEN DO GET SJÖGREN'S!!!!!"

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Please share how were you diagnosed with Sjögren's and by what type of doctor.

"My gastroenterologist suspected Sjögren's as he was investigating gastrointestinal (GI) symptoms and referred me to a rheumatologist who confirmed the diagnosis. While my symptoms have been pretty typical of the kinds of things Sjögrens patients experience - I do think my path to diagnosis was less common and I'm very appreciative that my gastroenterologist was advanced and broad in his thinking."

What are your most common symptoms and what is your most debilitating symptom?

"I have challenges with fatigue, brain fog, dizziness, dryness and digestive issues. The best ways for me to manage fatigue and related symptoms have been mindfulness, meditation, and pacing - which includes saying no sometimes and stopping before I get to my limit. The winter season brings increased dryness, so I use extra eye drops and a humidifier.

Fatigue is my most difficult symptom. I've had to trade some interests for others. It's hard to know how much energy I'll have to complete tasks or enjoy experiences. So I manage my calendar, say no to things I think will be too much and try to be present. Meditation helps and I use pacing to stop well short of where I think my limit lies - that's a big shift from the 'just push through' and 'try harder' messaging we are used to, but pushing past my limit is totally counterproductive for me."

Is there any advice you would like to share with your fellow men with Sjögren's?

"Yes - Sjögren's in men is real - the disease is serious and systemic. But you are not alone and there are others to support you. There are lots of resources to tap at the Foundation to educate yourself so you can advocate for your own care. And it's also more than okay to ask for help."

Can you describe your experience with your Sjögren's diagnosis?

"My Sjögren's diagnosis journey is a bit convoluted because it started not looking for Sjögren's at all. When I was 15, I began developing unusual chronic pain, fatigue, and cardiac symptoms. Doctors thought it was pediatric postural orthostatic tachycardia syndrome (POTS) because I also had blood pressure dips and spikes. By the time I turned 18, my symptoms had faded to the point they were not impacting my life. I was mostly symptom free until I turned 26 when the same symptoms came back, but much stronger. I spent two years working with over a dozen doctors to find the root cause. The third neurologist I saw recommended we test for every known disease that overlaps with POTS, including Sjögren's. I had not noticed, but over the two years becoming sick again my eyes had started burning on a frequent basis and I was having trouble swallowing dry foods. Multiple tests for salivary gland activity returned positive for Sjögren's. From one perspective, I received a Sjögren's diagnosis quickly after turning 28, but from another perspective, I might have been living with Sjögren's for half my life."

What has your experience been as an underrepresented group with Sjögren's?

"I think everyone with Sjögren's is underappreciated in medicine right now, having POTS is also underappreciated, and being a younger man with that combination is very underrepresented. Looking back, there were plenty of signs I had low disease activity for years, but I only started receiving intensive help when I had high disease activity, and I started advocating for myself. I'm thankful I found medical providers who are patient-centric, listen to my concerns, and are willing to explore solutions with me.

My biggest struggle with Sjögren's as a man has been managing fatigue. I feel like the traditional male social role asks us to ignore exhaustion to stay productive. Before I became severely ill, I frequently brought up fatigue as a complaint in doctor visits, but both my doctors and I thought it was because I worked in a high stress industry. Everyone else was tired as well.

I wish there were better ways of talking about pain and fatigue, especially in medical contexts and as part of an autoimmune disease. I think it is hard to communicate how impactful these symptoms are on a 1-10 pain scale during a medical intake. I also wish the medical community were more open to exploring autoimmune disease in male patients and younger patients. They make up a minority of cases."

Thank you Ray, David, and Robert for allowing us to share your stories and help other men with Sjögren's know that they are not alone.

Highlights from Recent Studies on Men with Sjögren's Compared to Women with Sjögren's

Unfortunately, research on differences in men with Sjögren's and women with Sjögren's is limited. How-

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ever, the few studies that have been performed do show differences in risk factors of the disease as well as comorbidities.

A recent study in *Seminars in Arthritis and Rheumatism* showed that males were more susceptible to comorbid conditions like hyperlipidemia, hypertension, and cancer compared to females.[1] Males also had higher disease activity based on ESSDAI (European Alliance of Associations for Rheumatology Sjögren's Syndrome Disease Activity Index) scores and had higher constitutional, lymphadenopathy, pulmonary, and liver involvement. Laboratory analyses showed that males had a lower incidence of high-titer ANA, IgM hypergammaglobulinemia, neutropenia, and anemia.

Another study in *Frontiers in Medicine*, found that men with Sjögren's had a higher risk of developing cardiovascular diseases than women with Sjögren's.[2] While a couple of studies have shown that men with Sjögren's had less dryness and serologic responses[3,4] but had a higher prevalence of parotid enlargement and interstitial lung disease compared to women with Sjögren's.[3]

While research studies have shown subtle differences between comorbidities and symptoms of men and women with Sjögren's, more research studies are needed to further explain not only sex differences but the overall diversity in clinical manifestations experienced by all patients with Sjögren's.

To view Ray, David, and Robert's full patient stories, please visit https://sjogrens.org/menwithsjogrens or scan the QR code to the right.

References

1. Fang J, Wang J, Luo J, et al. Clinical stratification of 1318 primary Sjögren's syndrome patients. *Semin Arthritis Rheum*. 2024;68:152537. doi:10.1016/j.semarthrit.2024.152537
2. Bruno KA, Morales-Lara AC, Bittencourt EB, et al. Sex differences in comorbidities associated with Sjögren's disease. *Front Med* (Lausanne). 2022;9:958670. Published 2022 Aug 4. doi:10.3389/fmed.2022.958670
3. Zhang Y, Chen JQ, Yang JY, Liao JH, Wu TH, Yu XB, Huang ZW, He Q, Wang Q, Song WJ, Luo J, Tao QW. Sex Difference in Primary Sjögren Syndrome: A Medical Records Review Study. *J Clin Rheumatol*. 2023 Aug 1;29(5):e78-e85. doi: 10.1097/RHU.0000000000001962. Epub 2023 Apr 17. PMID: 37068269; PMCID: PMC10368225.
4. Park Y, Lee J, Park SH, Kwok SK. Male patients with primary Sjögren's syndrome: A distinct clinical subgroup?. *Int J Rheum Dis*. 2020;23(10):1388-1395. doi:10.1111/1756-185X.13940

The Sjögren's Genetics Network (SGENE) - Expanding Our Understanding of the Heritable Contributions of Sjögren's Disease in Diverse Populations

Astrid Rasmussen, MD, PhD
Kandice L. Tessneer, PhD
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Challenges in effective Sjögren's disease (SjD) patient care are rooted in heterogeneous and poorly understood disease mechanisms coupled with a lack of clinically useful molecular biomarkers for patient diagnosis, stratification, and the availability of targeted therapies.[1] Autoantibody testing for canonical anti-Ro/SSA is often performed to support a suspected diagnosis of SjD, but 20-40% of SjD patients are seronegative for these autoantibodies.[2] Invasive labial minor salivary gland biopsies are used to detect histopathological infiltration and organization of immune cells into foci surrounding the ductal structures of the gland; a hallmark of SjD. Unfortunately, because the procedure is invasive, biopsies are rarely done more than once, if at all, and, therefore, are not amiable to repeat testing for disease monitoring in the clinical setting.[3] Defining the heritability of SjD and how specific genetic risk variants dysregulate underlying molecular mechanisms may provide new insights into the pathways that drive SjD etiology. Moreover, heritable contributions have the potential to be biomarkers useful for improved diagnostic strategies, and, ultimately, for more personalized treatment options.

While SjD is one of the most common autoimmune diseases with prevalence estimates ranging from 0.2-0.39%[4] and increasing incidence rates since 2000,[5] the lack of large clinical cohorts and well-characterized patients is one of the major reasons few large-scale genetic studies have been done. The progress in SjD genetics pales in comparison to Genome Wide Association Studies (GWAS) of related autoimmune diseases including systemic lupus erythematosus (SLE), rheumatoid arthritis, and multiple sclerosis, each including more than 10,000 cases (100,000 for multiple sclerosis) and 100s of identified genetic risk loci.[6] Prior to 2013, genetic association studies in SjD were limited to about 30 publications that collectively evaluated ~20 candidate genes in cohorts that were substantially underpowered, even by standards of the time, and resulted in highly inconsistent replication. As a response to this knowledge gap, the Sjögren's Genetics Network (SGENE) was established by Kathy (Moser) Sivils in April 2009 with the goal of developing large-scale, high-quality gene discovery projects. Dr. Christopher Lessard, at that time a graduate student in the Sivils lab, participated in SGENE from its inception, working on the early genetic studies.

SGENE started as an informal collaboration of international SjD investigators, most of them in academic institutions in Europe. A pre-existing Scandinavian Sjögren's Consortium had already been established by Dr. Gunnel Nordmark (University of Uppsala, Sweden), which made it a natural starting point for an expanded international collaboration. In short order, the network grew to include researchers from 17 institutions, as shown in **Figure 1**.

By 2010, a system to manage and protect the SGENE materials and data had been established, ethical approvals were in place, and DNA samples of well-characterized subjects meeting the American-European Classification Group (AECG) criteria for SjD were being genotyped using the Immunochip SNP array at the Oklahoma Medical Research Foundation (OMRF) in Oklahoma City, USA. Through these efforts, SGENE published the first large-scale genetic study of SjD in people of European ancestry, identifying six regions outside the human leukocyte antigen (HLA) that exceeded genome-wide significance.[7] Collectively, these loci are important in various innate and adaptive immune processes, including antigen presentation (HLA), Type 1 and 2 Interferon pathways (IRF5, IL12A, OAS1), T and B lymphocyte function (STAT4, CXCR5, BLK, PRDM1), and NFkB signaling (TNIP1, TNFAIP3).

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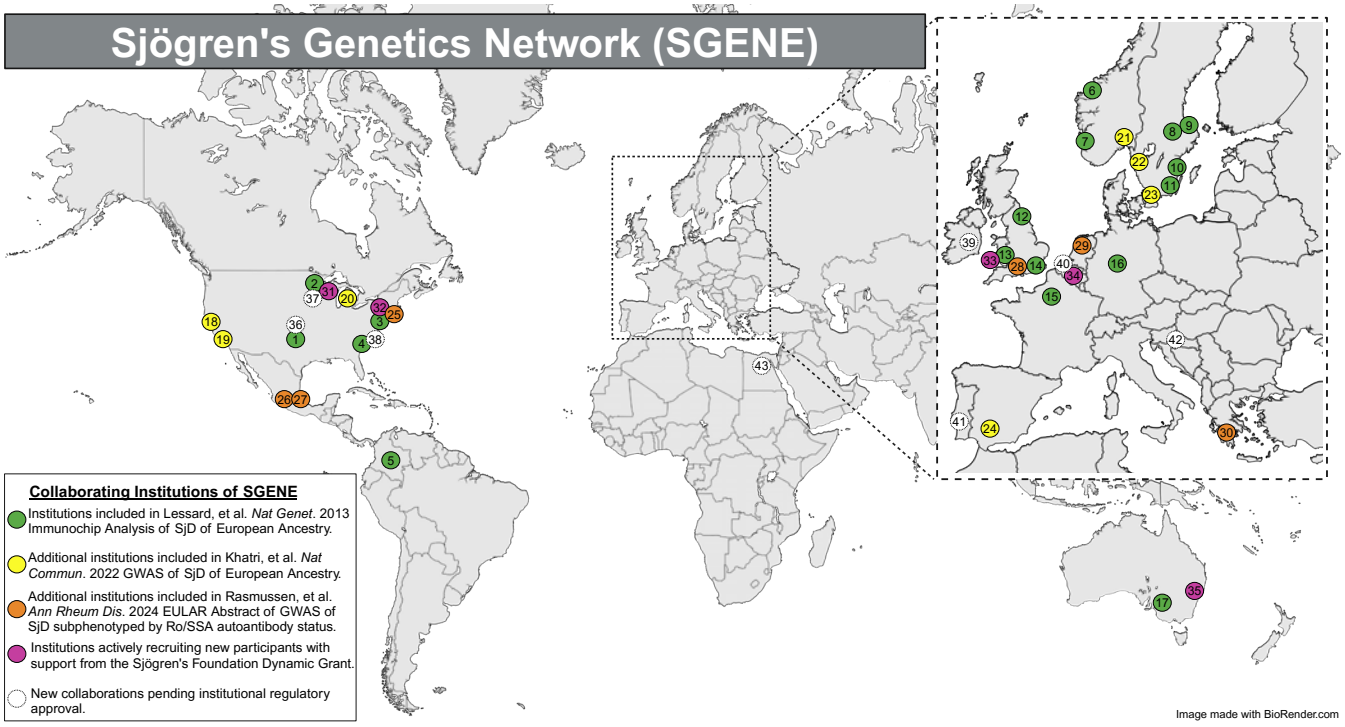
"SGENE" continued from page 11 ▼

Figure 1



Multiple additional publications have been derived from the results of the initial genome-wide study, including the fine mapping of variants in OAS1, an SjD-associated gene with relevant roles in the interferon pathway and anti-viral responses;[8] and three articles analyzing the effects of X chromosome dosage on the risk of SjD.[9-11] While the 2013 study significantly advanced the field of SjD genetics, the relatively small sample size lacked sufficient power for several genetic associations to exceed genome-wide significance ($p < 0.5$ E-08).

Through diverse engagement activities, including hosting individual visits and an international SjD meeting at OMRF, as well as in-person meetings at international conferences, SGENE has expanded its membership. Under Dr. Lessard's leadership (2020 onwards), new collaborators have joined SGENE to reach a critical mass of investigators and leaders in the field who share an interest in the biology of autoimmune rheumatic illnesses. The network's focus has expanded to include subjects of non-European ancestry with a variety of SjD subphenotypes. Central to the latter goal is the homogenization of detailed clinical data that is being collected across the network.

In 2022, SGENE published the largest GWAS to-date using ~3900 SjD cases of European ancestry.[12] The study identified 10 novel genetic risk loci associated with SjD and increased the total number of genetic risk loci from 12 to 22. Notably, one of the identified novel risk loci, TYK2, was first reported in lupus in 2005,[13] leading to the development of a drug now entering Phase II clinical trials in SLE and psoriatic arthritis;[14, 15] as well as Phase III trials in plaque psoriasis[16, 17] and more recently, in SjD.[18] In addition, our group reported the first polygenic risk score model for SjD and described the impact of genetic variants in salivary gland tissue.[12] Similarly intriguing are the 74 genetic regions showing suggestive association,[12] which supports the notion that increasing the discovery power of future GWASs through the recruitment and genotyping of additional cases will uncover added genetic risk associations. At this stage, we postulate that generating genotyping data from diverse populations with sufficient clinical information to facilitate subphenotype analyses is arguably more critical than simply increasing the total sample size. For example, current studies lack patients of different racial and ethnic backgrounds and/or patient subsets likely to have a higher genetic predisposition (i.e. children). Similarly, patients seronegative for the canonical SjD-associated autoantibodies, in particular anti-Ro/SSA, are currently underrepresented. To achieve a comprehensive view of SjD heritable traits will require expanding our collaborations to novel sites that span multiple racial groups and technical capabilities.

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Sjögren's Foundation

Fall Focus Conference 2024

Did You Miss the Foundation's Recent Fall Focus Conference, All About the Eyes?

The Sjögren's Foundation recently held their 2024 Fall Focus Conference: *Looking Deeper into Ocular Manifestations of Sjögren's*. Sjögren's patients know all too well about that dry, gritty, sand-in-your-eyes feeling. Dry eyes affect 95% of Sjögren's patients and is stated to be one of the greatest daily challenges of living with this disease. Without healthy tear production and lubrication, eye damage can occur, affecting comfort and sight. Whether your dry eye symptoms are mild or severe, understanding proper care and management is critical. This conference recording will give you the information you need to care for your eyes at every stage.

Purchase 6-month access to the entire line up of conference recordings for the 2024 Fall Focus Conference. Access Includes:

A Foundational Overview of the Ocular Manifestations in Sjögren's
Vatinee Bunya, MD, MSCE, Penn Medicine, Scheie Eye Institute

Therapeutic Management Strategies for Sjögren's-associated Dry Eye: Risks, Benefits and Alternatives
Nancy McNamara, OD, PhD, MS, UC Berkley- Sjögren's Clinic

Neurotrophic & Neuropathic Issues with Sjögren's and related eye complications
Anat Galor, MD, MSPH, University of Miami - Bascom Palmer Eye Institute

Beyond Medications: Interventional Treatments for Treating Ocular Issues in Sjögren's Patients
Esen Akpek, MD, John Hopkins University School of Medicine – Jerome L. Green Sjögren's Disease Center

Exciting Ocular Research Updates
Cintia de Paiva, MD, Baylor College of Medicine and Sharmila Masli, PhD- Boston University School of Medicine

Members: $40 *(with code sent in November/December member update)*

Non-Members: $60

Conference details and registration can be found at:
https://www.accelevents.com/e/2024ffc
or scan the QR code.

Thank you again to our Fall Focus Sponsor!

AMGEN

"SGENE" *continued from page 12* ▼

Currently, the SGENE membership includes 43 institutions, 44 principal investigators, and numerous co-investigators across 16 countries. Thanks to the invaluable support of a Sjögren's Foundation Dynamic Grant, we have also diversified our collaborative strategies. We have witnessed great enthusiasm from our colleagues in less economically developed areas abroad, spanning from South America to Northern Africa. However diverse these groups may be, they share one common barrier to participation: lack of funds or infrastructure to draw blood samples, extract DNA, and/or ship it to the US. Thus, with the financial support from the Sjögren's Foundation, we are acquiring DNA extraction kits (blood or buccal swabs) and providing them directly to our collaborators in a manner tailored to their needs. For those that can draw blood and have access to a lab, we provide the kits and the training in our SGENE protocol. If blood collection is a barrier, we can provide buccal swab kits from which the DNA will be extracted. None of this would be possible without the remarkable resourcefulness and enthusiasm shown by our new collaborators, who are eager to ensure their patient population is adequately represented in the research.

Recently, we tested the power of subphenotype analysis and have promising preliminary data. Past SGENE genetic association studies used SjD as the trait of interest, but when we subset SjD cases based on the presence of anti-Ro/SSA antibodies in serum (2,898 cases with anti-Ro/SSA and 1,313 without), we identified strikingly different association patterns. Anti-Ro/SSA(+) SjD showed a much stronger HLA association (odds ratio (OR) ≈ 4) than all SjD cases (OR ≈ 3), while the HLA association was completely lost in the anti-Ro/SSA(-) cases.[19] This supports the hypothesis that different biological mechanisms underlie each subphenotype and that, only with diverse participants in sufficient numbers, will we be able to fully dissect these subtleties.

Future Directions

Beyond the discovery of novel genetic associations in SjD, the central goal of SGENE is to translate genetic discoveries into functional and actionable knowledge. Thus, going forward, our research will move into the post-GWAS era focusing on a deeper understanding of the function and role in pathogenesis of the risk alleles identified thus far, particularly within the glandular tissue and in immune cell subsets. To achieve such knowledge, we must integrate our genetic results with multi-omic findings and develop in vitro models (i.e. induced pluripotent stem cells (iPSC)-derived cell lines) harboring the risk alleles. In recent years, the interest in rare genetic variants with large effects has re-emerged in SLE and other autoimmune diseases.[20] To address such heritable mechanisms, we intend to recruit trios of children with SjD and their parents and perform whole genome sequencing analyses.

SGENE has proven to be a highly productive collaboration resulting in the most detailed analysis of genetic contributions to SjD thus far. However, there is still a very large gap in knowledge and unmet needs for those whose life is affected by SjD. It is our commitment to continue advancing the field and recognizing the vast heterogeneity of the disease. Our goal of increasing the sample size of these genetic studies well beyond 10,000, and towards the >100,000 cases analyzed in MS, will enable further study of the subphenotypes of the disease. ■

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References

1. Rasmussen A, Ice JA, Li H, Grundahl K, Kelly JA, Radfar L, Stone DU, Hefner KS, Anaya JM, Rohrer M et al: Comparison of the American-European Consensus Group Sjögren's syndrome classification criteria to newly proposed American College of Rheumatology criteria in a large, carefully characterised sicca cohort. *Ann Rheum Dis* 2014, 73(1):31-38.
2. Brito-Zeron P, Acar-Denizli N, Ng WF, Zeher M, Rasmussen A, Mandl T, Seror R, Li X, Baldini C, Gottenberg JE et al: How immunological profile drives clinical phenotype of primary Sjögren's syndrome at diagnosis: analysis of 10,500 patients (Sjogren Big Data Project). *Clin Exp Rheumatol* 2018, 36 Suppl 112(3):102-112.
3. Fisher BA, Jonsson R, Daniels T, Bombardieri M, Brown RM, Morgan P, Bombardieri S, Ng WF, Tzioufas AG, Vitali C et al: Standardisation of labial salivary gland histopathology in clinical trials in primary Sjögren's syndrome. *Ann Rheum Dis* 2016.
4. Qin B, Wang J, Yang Z, Yang M, Ma N, Huang F, Zhong R: Epidemiology of primary Sjögren's syndrome: a systematic review and meta-analysis. *Ann Rheum Dis* 2015, 74(11):1983-1989.
5. Conrad N, Misra S, Verbakel JY, Verbeke G, Molenberghs G, Taylor PN, Mason J, Sattar N, McMurray JJV, McInnes IB et al: Incidence, prevalence, and co-occurrence of autoimmune disorders over time and by age, sex, and socioeconomic status: a population-based cohort study of 22 million individuals in the UK. *Lancet* 2023, 401(10391):1878-1890.
6. Thorlacius GE, Bjork A, Wahren-Herlenius M: Genetics and epigenetics of primary Sjogren syndrome: implications for future therapies. *Nat Rev Rheumatol* 2023, 19(5):288-306.
7. Lessard CJ, Li H, Adrianto I, Ice JA, Rasmussen A, Grundahl KM, Kelly JA, Dozmorov MG, Miceli-Richard C, Bowman S et al: Variants at multiple loci implicated in both innate and

adaptive immune responses are associated with Sjögren's syndrome. *Nat Genet* 2013, 45(11):1284-1292.

8. Li H, Reksten TR, Ice JA, Kelly JA, Adrianto I, Rasmussen A, Wang S, He B, Grundahl KM, Glenn SB et al: Identification of a Sjögren's syndrome susceptibility locus at OAS1 that influences isoform switching, protein expression, and responsiveness to type I interferons. *PLoS Genet* 2017, 13(6):e1006820.
9. Sharma R, Harris VM, Cavett J, Kurien BT, Liu K, Koelsch KA, Fayaaz A, Chaudhari KS, Radfar L, Lewis D et al: Rare X chromosome abnormalities in systemic lupus erythematosus and Sjögren's syndrome. *Arthritis Rheumatol* 2017, 69(11):2187-2192.
10. Harris VM, Sharma R, Cavett J, Kurien BT, Liu K, Koelsch KA, Rasmussen A, Radfar L, Lewis D, Stone DU et al: Klinefelter's syndrome (47,XXY) is in excess among men with Sjögren's syndrome. *Clin Immunol* 2016, 168:25-29.
11. Harris VM, Liu K, Cavett J, Kurien BT, Alarcon-Riquelme ME, Harley JB, Sivils KL, Weisman MH, Rasmussen A, Scofield RH et al: Rare X chromosome abnormalities in systemic lupus erythematosus and X chromosome aneuploidies in Sjögren's syndrome: Comparison to systemic lupus and rheumatoid arthritis. *Scandinavian Journal of Immunology* 2015, 81(5):417-417.
12. Khatri B, Tessneer KL, Rasmussen A, Aghakhanian F, Reksten TR, Adler A, Alevizos I, Anaya JM, Aqrawi LA, Baecklund E et al: Genome-wide association study identifies Sjögren's risk loci with functional implications in immune and glandular cells. *Nat Commun* 2022, 13(1):4287.
13. Sigurdsson S, Nordmark G, Goring HH, Lindroos K, Wiman AC, Sturfelt G, Jonsen A, Rantapaa-Dahlqvist S, Moller B, Kere J et al: Polymorphisms in the tyrosine kinase 2 and interferon regulatory factor 5 genes are associated with systemic lupus erythematosus. *Am J Hum Genet* 2005, 76(3):528-537.
14. Mease PJ, Deodhar AA, van der Heijde D, Behrens F, Kivitz AJ, Neal J, Kim J, Singhal S, Nowak M, Banerjee S: Efficacy and safety of selective TYK2 inhibitor, deucravacitinib, in a phase II trial in psoriatic arthritis. *Ann Rheum Dis* 2022, 81(6):815-822.
15. Morand E, Pike M, Merrill JT, van Vollenhoven R, Werth VP, Hobar C, Delev N, Shah V, Sharkey B, Wegman T et al: Deucravacitinib, a tyrosine kinase 2 inhibitor, in systemic lupus erythematosus: A phase II, randomized, double-blind, placebo-controlled trial. *Arthritis Rheumatol* 2023, 75(2):242-252.
16. Armstrong AW, Gooderham M, Warren RB, Papp KA, Strober B, Thaci D, Morita A, Szepietowski JC, Imafuku S, Colston E et al: Deucravacitinib versus placebo and apremilast in moderate to severe plaque psoriasis: Efficacy and safety results from the 52-week, randomized, double-blinded, placebo-controlled phase 3 POETYK PSO-1 trial. *J Am Acad Dermatol* 2023, 88(1):29-39.
17. Strober B, Thaci D, Sofen H, Kircik L, Gordon KB, Foley P, Rich P, Paul C, Bagel J, Colston E et al: Deucravacitinib versus placebo and apremilast in moderate to severe plaque psoriasis: Efficacy and safety results from the 52-week, randomized, double-blinded, phase 3 Program fOr Evaluation of TYK2 inhibitor psoriasis second trial. *J Am Acad Dermatol* 2023, 88(1):40-51.
18. A study to evaluate the efficacy and safety of deucravacitinib in adults ith active Sjögren's syndrome. ClinicalTrials.gov identifier NCT05946941 Updated August 1, 2024 Accessed August 20, 2024 https://clinicaltrials.gov/study/NCT05946941
19. Rasmussen A RM, Khatri B, Tessneer KL, Pontarini E, Bombardieri M, Rischmueller M, Wahren-Herlenius M, Kvarnström M, Witte T, Bootsma H, Verstappen GMPJ, Kroese FGM, Vissink A, Pringle S, Tzioufas AG, Mavragani C, Baer AN, Alarcon-Riquelme ME, Martín J, Mariette X, Nocturne G, Pers J-O, Gottenberg J-E, Ng W-F, Shiboski CH, Taylor KE, Criswell LA, Warner BM, Farris AD, James JA, Scofield RH, Guthridge JM, Wallace DJ, Venuturupalli S, Brennan MT, Imgenberg-Kreuz J, Rönnblom L, Baecklund E, Eloranta M-L, Aqrawi LA, Palm Ø, Brun JG, Hammenfors D, Jonsson M, Appel S, Bucher SM, Forsblad-d'Elia H, Mandl T, Eriksson P, Nordmark G, Lessard CJ: Genome-wide Association Study of Ro/SSA+ and Ro/SSA- Sjögren's cases in the Sjögren's Genetic Network (SGENE) demonstrates divergent genetic architecture in patient subphenotypes. *Ann Rheum Dis* 2024, 83:38-39.
20. Xu L, Zhao J, Sun Q, Xu X, Wang L, Liu T, Wu Y, Zhu J, Geng L, Deng Y et al: Loss-of-function variants in SAT1 cause X-linked childhood-onset systemic lupus erythematosus. *Ann Rheum Dis* 2022, 81(12):1712-1721.

Walk for Sjögren's 2024

CONQUERING SJÖGREN'S ONE STEP AT A TIME
Celebrating 40 Years

Celebrating a Successful 2024 Walk for Sjögren's! Thank You for Conquering Sjögren's, One Step at a Time!

Walk for Sjögren's is a national awareness and fundraising program that takes place across the country every fall and spring. It's an amazing series of events where patients build community together, interact with Sjögren's experts, and raise funds for important initiatives including research, education and support efforts. Each year we have a different theme and for 2024, our theme was *Conquering Sjögren's, One Step at a Time!* as we celebrated the Foundation's 40 years of Sjögren's progress.

We wanted to take a moment to thank everyone who stepped up by supporting our Walks this year to help us continue to make progress and make a difference and improve patient's lives. The Foundation continued to hold virtual events with live walks in Philadelphia and Madison, Wisconsin; at every event our Sjögren's community really Sjö-ed up and participated!

Our success is because of YOU, our amazing participants, fundraisers, volunteers, and supporters. Thank you for being a part of our journey to conquer the complexities of Sjögren's. The funds raised allow us to continue providing valuable programs and services, advocating for patients, and funding research to change the future of Sjögren's. Thanks to your support, we raised over $250,000 from Foundation Walk events.

We'd like to thank our Chairs of each walk, our Stars, and our sponsors!

2024 Walk for Sjögren's Event Chairs

Southwest – Virtual Spring ..... Yolanda Gales

Southeast – Virtual Spring ..... Lois Pippin & Suzi Wixson

Mid-Atlantic & National – Virtual Spring ..... Mary Beth Parks-Ackerman

Philadelphia Tri–State – Live Spring ..... Chris & Tom Iatesta

Texas – Virtual Spring ..... Paula Aicklen

Midwest in Madison, WI – Live Spring ..... Amy Kraus

Colorado – Virtual Spring ..... Jessica Levy

Northeast – Virtual Fall ..... Amy Courchesne & MaryBeth Walter

West Coast – Virtual Fall ..... Rayna Keen

Thank you to everyone who joined and increased awareness by taking part in a Walk event!

Walk for Sjögren's Stars

Congratulations and thank you to our Walk for Sjögren's Stars in 2024! They contributed to the success of a Walk for Sjögren's with their outstanding outreach and by raising $1,000 or more. View our 2024 Sjögren's Stars and learn more about our walks by visiting https://sjogrens.org/get-involved/walk-for-sjogrens or scan the QR code below.

Thank you to our National, Presenting and Major Sponsors for the 2024 Walk for Sjögren's Events!

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*** Presenting Sponsors in Bold**

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St. Luke United Methodist Church

FNIH AMP®AIM Research Project and Sjögren's Update, November 2024

by Janet Church
President and CEO,
Sjögren's Foundation

The Sjögren's Foundation is proud to participate in and support the Foundation for the National Institutes of Health (FNIH) Accelerating Medicines Partnership® Autoimmune and Immune-Mediated Diseases (AMP®AIM) collaborative. This, and other research managed by the FNIH are partnerships between the public (NIH), industry (pharmaceutical companies and other related businesses), and patients and the advocacy organizations who represent them, such as the Sjögren's Foundation — which ensures the patient voice is an influential part of the research process.

Historically, we know that Sjögren's is behind other autoimmune diseases in terms of research funding and existing datasets. In response to this, the Sjögren's Foundation believed it was important to support this project at the Steering Committee level, giving us an equal voice on program design and direction as the research and industry partners participating in the program. This commitment is a $500,000 research investment made across 5-years, and made possible by our generous donors.

The FNIH has several AMP® programs focused on different diseases, and the original AMP® for autoimmune disease focused on lupus and rheumatoid arthritis. In 2020, the FNIH expanded this particular AMP® to include Sjögren's and psoriatic arthritis – leading to the new AMP®AIM. The AMP®AIM project is a 5-year research project that will focus on each individual disease followed by looking at diseases across datasets to compare commonalities and differences. This is the single most important research project for Sjögren's to date and the most important translational research project analyzing data from multiple diseases as part of the same effort.

An important part of AMP®AIM are the teams that are assembled, which are made up of the country's top experts and researchers for each disease as well as designated centers where patients can participate in the research. The Sjögren's team is comprised of highly accomplished Sjögren's researchers and clinicians. They all know that Sjögren's is a serious and systemic autoimmune disease and are well versed in the need for multidisciplinary care for patients. This team is called Sjögren's Team for Accelerating Medicines Partnership, or STAMP for short.

Dr. Caroline Shiboski from UCSF (and the contact principal investigator for STAMP), has written a comprehensive look at the AMP®AIM program and STAMP work to date. We encourage you to read about this important research project for Sjögren's! ■

To view and download the full article describing the STAMP research project, please visit https://www.sjogrens.org/stamp-overview or scan the QR code.

Do you receive our member update emails?

Stay updated with the latest from the Sjögren's Foundation! Make sure we have your current email address to receive news about the Foundation, Sjögren's updates, treatment breakthroughs, local Support Group events, and more. Email us at info@sjogrens.org to update your contact information. Rest assured, your contact information will be managed securely. Keep an eye on your inbox for the latest Sjögren's news!

IN MEMORIAM

In Memory of Camela Abatemarco
Anthony Abatemarco

In Memory of Heidi Ann Burke
John Burke

In Memory of Brian G. "Greg" Eader
Gwyn Cannon

In Memory of Dolores L. Friese
Jane Milani

In Memory of Julia Gay
Jessica Taylor

In Memory of Patricia Hoyt Gogulski
Linda Cournoyer

In Memory of Jan Gordon
Kevin McCaffrey

In Memory of Eileen Guldin
Christina Lea

In Memory of Susan Hansen
Bruce Hansen

In Memory of Ernest Donald "Don" Holder
Gwyn Cannon

In Memory of Charlotte "Lotti" G. Nagri (Godschalk)
Lisa Zahn
Eunice Chang

In Memory of Joan Marie Scholz
Paul Wagner

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Brent Houk
Lynne Middleton
Daniel O'Rourke
Lynsey Singleton
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Michael Watkins

In Memory of Jane Vosika
Dawn Maloney

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Caryn Kirkpatrick

In Honor of Nathan Cox
Diana Mascilli

In Honor of Cecile Haley
Alvin Haley

In Honor of Kelly Hudnall
Kristi Hudnall

In Honor of Adrienne Jones
Ariel Weber

In Honor of Kadian's Birthday
Erin Yerra

In Honor of Lindsay Noble
Patrick Noble

In Honor of Frances Perez
Ignacio Perez

In Honor of Liz Perry
Don Perry

In Honor of Teresa Pigna
Chris Copley

In Honor of Pat Shouse
Jackie Staron

Creating a Legacy of Support for Sjögren's Patients

At the Sjögren's Foundation, we are grateful for the generous support of individuals, who through their legacy, are helping to shape the future of all impacted by Sjögren's disease. We would like to pay special tribute to several cherished members of our community who have passed away, and their families, who thoughtfully included the Foundation in their estate plans over the past year:

Sonja Christopher | **Penny Hamond-Wolk** | **Marcia Slater Johnston**
Joyce Lahn | **Lari Lopp** | **Gloria Parker**
Ellen Siepser | **Dorothy Warren** | **Donna Wood**

The Foundation is incredibly grateful for these individuals, and we are honored to continue our efforts in their memory.

Create Your Own Legacy of Support for Sjögren's Patients

Planning for the future is about more than securing your legacy— it's about shaping the future of those who will be impacted after you. By including the Sjögren's Foundation in your estate plan, you can make a meaningful, long-term contribution to the cause that matters most to you.

Your gift, no matter the size, will help us continue our important work and create lasting change for years to come. Whether through a bequest, charitable trust, or retirement account designation, there are many ways to make a lasting difference.

Through a planned gift, you can ensure that your values and passions continue to make an impact long after you are gone. You can also choose to support a specific program or initiative that aligns with your passion. In addition, planned gifts are often more flexible and impactful than one-time donations and provide financial advantages now or in the future through strategic giving.

To learn more about how you can include the Sjögren's Foundation in your planned giving today and how your gift can make a difference, please contact Ben Basloe, Senior Vice President of Operations & Philanthropy at (301) 530-4402, x207 or bbasloe@sjogrens.org.

Conquering Sjögren's
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40 years of progress with more to come

Donate to help us keep up the momentum

As we celebrated our 40th anniversary, we're proud of the milestones we've reached together. This year, we celebrated the historic renaming of Sjögren's syndrome to Sjögren's disease, a global recognition of the serious impact this disease has on patients' lives. With the advancement of exciting new therapies in clinical trials, we're closer than ever to new treatments, offering hope for better options and improved quality of life for those living with Sjögren's.

This year also brought official Congressional recognition of Sjögren's disease through the passing of a House Resolution to establish the disease as serious and systemic with hopes to unlock future government funding for research. Additionally, our collaborative work with global initiatives like STAMP (Sjögren's Team for Accelerating Medicines Partnership), OMERACT, and NECESSITY continues to advance our understanding of Sjögren's to improve diagnosis, prevention, and treatments.

Each of these achievements moves us closer to our ultimate goals: better diagnosis, effective treatment, and, one day, a cure.

As 2024 ends, we reflect on a dynamic year in Sjögren's and excitingly look ahead to the progress and advancements that the future holds. While we continue to make great strides, there is even more work to be done. As we eagerly approach the new year, we ask you for your support to continue the momentum and our impact. Please give a year-end donation and together, we can continue to make a difference for all people living with Sjögren's. We thank you in advance for your support and wish you a joyous holiday season and happy New Year!

Sjögren's FOUNDATION

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