CONQUERING Sjögren's

January/February 2025

Recognizing Women Who Are Changing the Face of Sjögren's Research and Patient Care

Inside this Issue

Sjögren's FOUNDATION

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CONQUERING Sjögren's
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Letter from Our President & CEO:

Ringing in 2025: Milestones, Vision, and New Beginnings

Janet Church
President & CEO,
Sjögren's Foundation

What an amazing 2024! Last year, we hosted our annual conferences and programs for both patients and providers, we celebrated our 40th anniversary, ushered in several new clinical trials, funded six significant research projects, presented a new resolution to Congress recognizing Sjögren's as a serious and systemic disease (H-Res #1094, 118th Congress) and officially solidified our disease name change from Sjögren's syndrome to Sjögren's disease. Thank you to the Foundation staff, Board of Directors, volunteers, members and donors for all you do to support our mission and ensure such great success!

As we step into 2025, we have an eye on supporting many clinical trials, presenting a new *State of Sjögren's* continuing medical education course for healthcare professionals, anticipating the release of our new peripheral nervous system (PNS) clinical practice guidelines, expanding our advocacy efforts to reflect administration changes, and of course, producing all of our annual education and support programs! While 2024 set the stage for many areas, 2025 will be all about growth and new advancements in what we know about Sjögren's and how to treat it. I couldn't be more excited to experience what 2025 has to offer Sjögren's patients!

As we look ahead, it's clear that 2025 will be a year of growth and innovation for Sjögren's research, treatments, and patient care. Alongside these exciting advancements, we are also celebrating the incredible contributions of individuals who have dedicated their lives to advancing innovation in Sjögren's. This issue of *Conquering Sjögren's* highlights some of our women scientists who have made a lasting impact in the field. February 11th is International Women in Science Day and what a perfect opportunity to showcase these talented women! Also in this issue, we share the kickoff of the 2025 Walk for Sjögren's program as well as the save-the-date announcement for the National Patient Conference. Join me in ringing in 2025!

Thoughts on my cataract surgeries and healing process

In the July/August 2024 edition of *Conquering Sjögren's*, I wrote about my eye surgery journey throughout the year. The journey began in mid-2023 when I started making plans to improve my dry eyes and prepare for cataract surgery. Dr. Akpek and I laid out a schedule that included surgery on my left eye to repair my conjunctiva, followed by months of eye preparation with serum tears and antibiotic and steroid ointments prior to my cataract surgery in July of this past year. This 8-month plan was all to improve the dryness for a successful healing process after cataract surgery.

In December 2023, I had the conjunctivochalasis surgery to "smooth out" the folding conjunctiva (the tissue layer covering the white part of the eye and inner eyelids) that was exacerbating my dry eyes. My left eye is quite a bit drier than my right, so I first had surgery on my left eye. It did improve my dry eye! I chose not to move forward with my right eye because I did not feel the same level of dryness or annoyance with the folding conjunctiva.

To truly improve my severe dry eye for the July surgery, I tried a few approaches that included multiple applications of serum tears every day followed by nighttime use of steroid ointments intermittently from April to July. While using the steroid ointment, I

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needed to be monitored for eye pressure. To reduce the number of times I needed to go into the office for eye pressure measurements, I stopped the steroid ointment and used Systane® Nighttime ointment. This regiment improved my cornea damage and improved the dry eye enough to conduct the surgeries.

NOTE*: In order to obtain the best outcomes from cataract surgery, the procedure should be delayed, if necessary, in order to aggressively manage the dry eye. In addition, all other concurrent ocular surface diseases such as blepharitis, superior limbic keratoconjunctivitis, conjunctivochalasis, or eyelid problems should be addressed well before the cataract removal surgery. From Dr. Akpek's article on cataract surgery on page 5 of the July/August 2024 issue. As a Member of the Foundation, you have access to this issue and past "Conquering Sjögren's" issues on the member side of the website.*

In July of this year, I had cataract surgery— right eye first, then left (as it is my dominant eye and drier even after the conjunctiva surgery). The cataract surgeries were not difficult for me, but I was surprised that it took a bit longer before I could fully read or work post-surgery—I'd say about four or five days. I could see clearly the second day, but the eye strain and fatigue were significant issues if I spent more than 30 minutes of focused work at a time. So, I rested the first two days and eased back into reading and computer work over the next two days.

I had two challenges during my recovery. The first was the excessive dry eye! Even with the regimen of eyedrops and ointments for several months, I still had significant dry eye before the surgeries and it was worse afterward. It took about two months for my right eye to come back to its "usual" dry eye level and my left eye has just recently come back to a more manageable level of dryness (five months post-surgery).

The second challenge was an issue I was not aware of— dysphotopsia and, more precisely, "negative dysphotopsia." Negative dysphotopsia is caused by the way light interacts with the new artificial lens. It seems as if the light bounces off the edge of the lens and causes this arc shadow (usually at the temporal side of the eye). While healing, I could see a grey arc in my peripheral vision of my eye. This happened with my right eye, but it eventually improved and is not very noticeable. The process of the lens "settling in" took about a month. My left eye had a stronger arc and after five months, I can still see it. To be clear, it does not impair my eyesight; it is a shadow that is more significant in darker environments when my pupil is dilated. I have been told that it is unlikely that this will improve as the lens in my left eye has already settled in. I do wonder if it is stronger on my left eye, since that is my dominant eye. I was told that this is not a common occurrence, but it does happen and has a greater occurrence for those patients with light eyes (which mine are). For many, the issue subsides, as it did for my right eye.

Despite the challenges posed by dysphotopsia, these effects are minor compared to the benefits I got from my surgery. I rarely notice the dysphotopsia in sunlight; but I really notice it when watching a movie at night with the room dark and the light image flaring from the TV. I can tolerate that just fine!

I love my new eyesight!

The greatest benefit from the cataract surgery has been better eyesight! I can work at my computer, read a book, and see my car's dashboard clearly all without glasses! I can also see a bit better for night driving (although my dry eye does still make night driving a challenge).

The entire year of surgeries and healing took more time and discomfort than I was anticipating, but it was worth it! I was never in actual pain, but the elevated dryness post-surgery and the healing time from the trauma of surgery was more uncomfortable than my friends had shared. I believe my experience was more challenging than the average surgery, and yet, I'm so glad I did it! I hope sharing my story helps those of you who have eye surgeries in your future. My experience of extra dryness and healing time…and the dysphotopsia… are not the average experience patients have, but it does happen. If this happens to you, I hope you too feel the trade-offs are worth the end result!

NOTE*: In the May/June 2023 issue of "Conquering Sjögren's" (page 13), Dr. Akpek writes about the conjunctivochalasis surgery I had. It is titled "An Eyeball Tummy Tuck". You can also read my earlier article. As a Member of the Foundation, you have access to this issue and past "Conquering Sjögren's" issues on the member side of the website.* ■

An Update on OMERACT: Sjögren's Disease

Authors: Dana Direnzo, MD, Divi Cornec, MD, Maureen Rischmueller, MD, Simon Bowman, MD, Raphaèle Seror, MD, PhD, Sara McCoy, MD, PhD, on behalf of OMERACT Sjögren's Disease Working Group (https://omeract.org/working-groups/sjogrens)

Sjögren's Disease and Clinical Trials

As of today, there are no FDA-approved drugs available to improve Sjögren's disease (SjD) activity. Physicians, advanced practice providers, and patients alike all hope for effective treatments with a tolerable side effect profile. A standard approach to testing drugs is to perform a Phase I trial for which the main goal is to establish safety. A Phase I trial is typically small and does not necessarily need to show the drug is effective. If the drug has an acceptable safety profile, a Phase II trial is performed. Typically, a Phase II trial is performed using a randomized placebo-control approach. These trials measure the effect of a drug (or other treatment) compared to placebo. This comparison is important because of high placebo-response rates. Phase II trials are typically larger and ideally show both safety profile and efficacy. A Phase III trial is a large, randomized placebo-controlled trial whose purpose is to confirm the drug is effective and garner further data on safety.

It is an exciting time for the Sjögren's disease community because a growing number of drugs have met their Phase II clinical trial endpoints and multiple drugs are moving to a Phase III study. As these drugs come down the pipeline, it becomes important to consider how these studies are designed. The design of the study might impact real world administration of the drug. Important features of trials that might have broader consequences include the type of patients used in the initial study (for example, including patients who are anti-SSA antibody positive) or the type of endpoint used for the clinical trial, among others.

Current Outcome Measures

Although clinical trials usually measure many parameters, the most important measurement is called the primary endpoint. The primary endpoint should measure the efficacy of the drug and should be relevant to the clinician and patient. A multitude of secondary endpoints are usually measured. The instrument most used to assess the main symptoms of SjD is the EULAR (European Alliance of Associations for Rheumatology) Sjögren's Syndrome Patient Reported Index (ESSPRI). This simple and validated tool is completed by patients and evaluates the intensity of their symptoms, from no dryness/fatigue/pain to the maximal imaginable on a numerical scale of 0 to 10.[1] Other SjD instruments that are used to measure symptoms include Profile of Fatigue and Discomfort-Sicca Symptoms Inventory-Short Form, the Sjögren's Syndrome Symptom Diary, and the Functional Assessment of Chronic Illness Therapy-Fatigue, among others.[2-4] These instruments are highly correlated.

Systemic disease activity is commonly measured with the EULAR Sjögren's Syndrome Disease Activity Index (ESSDAI).[5] One third to half of SjD patients experience extraglandular organ involvement, contributing to high systemic disease "activity". Features such as constitutional symptoms, pulmonary, cutaneous, muscular, central nervous system, peripheral nervous system, or articular involvement are rated from none, to high and scored numerically. However, the ESSDAI and dryness symptoms are often poorly [6-9] or inversely correlated.[10] Thus, measures that evaluate SjD systemic disease activity encompass diverse manifestations related to different domains of the disease but may fail to account for the impact of disease on patient quality of life. Furthermore, current disease activity instruments might not encompass all salient disease domains. For example, ESSDAI does not measure tear and saliva production. Finally, instruments such as the ESSDAI showed a high placebo response rate.[11, 12] There remains a critical

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need to develop/identify an optimized primary outcome for SjD clinical trials.

OMERACT

Outcome Measures in Rheumatology (OMERACT) is an international volunteer-based, not-for-profit organization that develops outcomes for clinical trials with a methodologically rigorous approach. OMERACT working groups comprise diverse stakeholders including patients, industry representatives, healthcare providers, researchers, and methodologists. Stakeholders have a global representation and include at least three continents. The SjD OMERACT working group has over 200 members from every continent except Antarctica. This large and diverse representation is critical to ensuring that developed outcomes are applicable to SjD patients worldwide. This OMERACT effort had its first meeting in 2023.

In general, the OMERACT process is divided into two steps.[11,12] The first step is to identify key aspects of disease that must be addressed in clinical trials. This first step tells us what aspect(s) of disease we are going to measure. These key aspects of disease are called domains and must reflect how a patient feels and functions.

The SjD working group is in this first phase called domain generation. We have performed a broad literature review to determine what domains have been used before in clinical trials.[13] After incorporating physician, researcher, patient, and industry opinions, we generated a comprehensive list of disease domains that stakeholders think should be included in clinical trials.[14] We must also ensure that our understanding of patient experience is accurate and up to date. We are currently performing a literature review of previous work that has studied the SjD patient experience. After we have collated these data, we will verify with SjD patient focus groups that we have recorded the SjD patient experience in an accurate manner. Once we have a broad and updated understanding of the patient experience, we will distill the identified patient experience themes into domains. Next, we will collate all of our domains into a list and we will vote iteratively on the most important domains through a methodologically standardized process. All members of OMERACT will participate in the voting process. At the end of this first phase, we will have identified a "core domain set" that must be included in all SjD clinical trials. We anticipate completion of this phase of our OMERACT work in the next 1-2 years.

After we have finalized our core domain set, we will start the second half of OMERACT - working to match instruments that can measure the outcomes from each domain. We will find candidate instruments through literature searches. If we find a pre-existing instrument that measures the core domains, we determine if these instruments are feasible and methodologically rigorous. In the case of SjD, instruments exist including the Sjögren's Tool for Assessing Response (STAR), which is currently being prospectively validated[15] and Composite of Relative Endpoints for Sjögren's Syndrome (CRESS), another recently published instrument to assess response to intervention in SjD clinical trials.[16] If no pre-existing instrument exists or existing instruments are deemed acceptable, OMERACT will work to develop new instruments.

We hope that through the OMERACT process, we can optimize clinical trial endpoints in SjD. Ultimately, we hope this will translate to outcomes that are easily interpretable, clinically relevant, and lead to improved therapeutic implementation. ■

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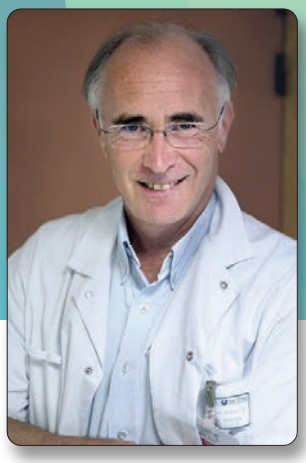
necessity

NEw Clinical Endpoints in primary Sjögren's Syndrome: an Interventional Trial based on stratifYing patient

Advances in the NECESSITY project



Prof. Xavier Mariette; Scientific Coordinator of the NECESSITY Project

Sjögren's disease (SjD) is an autoimmune disease that has been well documented to have a debilitating impact on the quality of life of patients. Sjögren's patients often experience symptoms such as dryness in the mouth, eyes, lungs, skin, and genitalia, as well as joint pain, swelling, and extreme fatigue. One in three patients with SjD may experience inflammation spreading beyond their moisture-secreting glands, leading to damage in other organs. Moreover, it is now established that patients with SjD are at an increased risk of developing lymphoma, frequently located in the salivary glands. Although treatments are available to manage symptoms (such as artificial tears, anti-inflammatory drugs, and painkillers), there is currently no cure for SjD.

NECESSITY Project

The NECESSITY project was established by a consortium of academics and industry partners, aiming to leverage various levels of expertise in the autoimmune field to address some of the unmet needs in Sjögren's disease and develop better treatments for patients. One of the hallmarks of Sjögren's disease is that the manifestation of SjD in patients can differ greatly in terms of their symptoms and how these symptoms change over time. This variation in the underlying mechanisms behind the disease in SjD patients makes it challenging to design clinical studies that can effectively evaluate patients' responses to new treatments. One of the three primary goals of the NECESSITY trial was to develop a new composite score, the candidate Sjögren's Tool for Assessing Response (STAR) composite responder index, which was created by the NECESSITY consortium in 2021 with the active contribution of the Patient Advisory Group comprised of patient experts in Sjögren's disease. The need for a new score arose due to mixed results coming out from clinical trials using the ESSDAI or ESSPRI composite scores.

Candidate STAR Responder Index and NECESSITY Clinical Trial

The candidate STAR is a composite responder index that includes all the main disease features in a single tool and is designed for use as a primary endpoint in SjD randomized control trials.[1] The rigorous and consensual development process applied to the candidate STAR score ensured its face and content validity. The candidate STAR showed good sensitivity to change and is set to be prospectively validated by the NECESSITY consortium in a dedicated randomized control trial. The use of the candidate STAR score is beginning to gain traction in the world of clinical trials, with two recent publications using STAR to evaluate clinical responses to treatment, where the candidate STAR score showed positive outcomes.[2,3]

The current objective of the NECESSITY project is to prospectively validate the candidate STAR score through the clinical trial (NCT05113004) that is currently ongoing in eight countries, with over 30 centers across Europe involved in recruiting Sjögren's patients into the study. Over 190 patients have already been included in the study. A strength of the NECESSITY trial is its two-cohort study design, allowing the inclusion of patients with both high and low systemic activities, thus enabling the evaluation of patients with the characteristically varied manifestations of Sjögren's disease.

Sjögren's Disease Patient Stratification

A secondary goal of the NECESSITY project is to identify new ways of stratifying Sjögren's patients. An interesting development from the NECESSITY

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teams was the identification of different phenotypes of Sjögren's disease. The study, involving over 900 patients from two French cohorts (University Paris-Saclay and ASSESS), identified three distinct subgroups of patients with varying clinical expressions and prognoses. Group 1 consisted of patients with few symptoms but high B-cell activity, Group 2 included those with significant systemic manifestations, and Group 3 comprised patients with many subjective symptoms but low systemic activity.[4]

The findings, validated across both cohorts, revealed that disease activity and symptom severity worsened over time in Group 1, with some developing lymphomas, as did some patients in Group 2, while no lymphomas were reported in Group 3. The study's results suggest that these subgroups have different pathophysiological mechanisms, which could inform future clinical trials and improve patient stratification.[4]

New biomarkers in Sjögren's disease

The last objective of the NECESSITY project is to find new biomarkers associated with different subtypes of the disease, predictive of complications or associated with response to treatment. Two recent papers from the consortium illustrates this task. The first one led by QMUL London showed blood and tissue biomarkers associated with the response assessed by STAR to rituximab in the TRACTISS trial.[5] The second one led by Servier found consensus transcriptomic genes modules for stratifying the disease.[6] Lastly, a special thanks to the TRANSMAT database developed by the NECESSITY consortium, which collects clinical and biological data from numerous cohorts and clinical trials run in Europe, as well as numerous other studies involving blood and tissue biomarkers that will be conducted in the future.

For more interesting information and publications regarding the activities of the NECESSITY project please follow us on social media:

- Webpage: www.necessity-h2020.eu

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Language Matters: *Changing Sjögren's Syndrome to Sjögren's Disease*

The Sjögren's Foundation is excited to announce that the international Sjögren's community has officially changed the disease name from Sjögren's syndrome to Sjögren's disease. This change helps to better indicate the serious and systemic nature of Sjögren's. The term "secondary Sjögren's" meant to label that a patient has Sjögren's plus another autoimmune disease, was also discarded and will be replaced with "associated" to indicate the significance of both (or several) diseases in a patient's overall health.

The Sjögren's Foundation has been leading the charge to ensure that the words we use to describe Sjögren's communicate that it is serious and systemic. This initiative was approved by the Foundation's Board of Directors at the December 2015 Board of Director's Meeting, so we have been actively working on this initiative since January 2016.

We led the way by officially changing the name of the Sjögren's Syndrome Foundation to the Sjögren's Foundation in 2019.

In 2021, we published a Letter to the Editor in the American College of Rheumatology's official journal, *Arthritis and Rheumatology*: Baer AN and Hammitt KM. Sjögren's Disease, Not Syndrome. *Arthritis Rheumatol*. 2021 Jul;73(7):1347-8. PMID: 33559389.

In 2022, we continued our international effort to change the name of our disease from "Sjögren's syndrome" to "Sjögren's disease" and to discard the term "secondary Sjögren's." The international Sjögren's community created a task force— comprised of patients, doctors, and clinician scientists— to guide the consensus process and create the survey process used by the Sjögren's community about nomenclature.

As of now, several major institutions and scientific/medical journals have changed the name to Sjögren's disease, including several American College of Rheumatology journals, most institutions in the National Institutes of Health (NIH), and the Foundation of the NIH. Since 2019, there have been over 100 published scientific/medical journals that have used Sjögren's disease instead of Sjögren's syndrome.

We are proud to announce that we succeeded in this effort! The task force has written an abstract proclaiming the nomenclature change, and it is currently awaiting publication in a scientific journal.

Conclusions on Nomenclature

Final consensus was reached as follows:

1. The term "Sjögren's disease" should replace "Sjögren's syndrome."
2. "Sjögren's" without "disease" is an acceptable way to refer to the disease, especially once it's been cited as "Sjögren's disease."
3. The acronym "SjD" should be used as an abbreviation for "Sjögren's disease", replacing SS and SjS.
4. The descriptor "associated" should be used in lieu of "secondary" for Sjögren's disease occurring in association with a second systemic autoimmune disease for which classification criteria are fulfilled.
5. "Sjögren disease" is the preferred terminology in clinical practice, without differentiation as to primary and associated forms. An appreciation of the common association of Sjögren's with other systemic autoimmune diseases may have value in clinical evaluation of affected patients and in clinical decision-making.
6. The differentiation between "primary" and "associated" Sjögren's is recommended for scientific studies to define a homogeneous population.
7. The choice of using the possessive or non-possessive form of Sjögren's and spelling variants (o, oe, ö), should be left to the individual or journal preference. ■

Step Up for Sjögren's

Walk Anywhere, Support Sjögren's Patients Everywhere

Walk for Sjögren's

Get your walking shoes ready - it's time to Step Up for Sjögren's! Join us for the Walk for Sjögren's, whether at one of our live events or virtually from wherever you are. Together, we can raise awareness and critical funds to support the Sjögren's Foundation's mission and the millions of people living with Sjögren's disease.

This year's theme, Step Up for Sjögren's, underscores the power of coming together and making progress. By walking and fundraising, you're bringing awareness to the disease, amplifying the voices of those affected, driving innovation and research, and building a supportive community for patients and their families.

Register today at sjogrens.org/walks and take the first step in making a meaningful impact. Every step makes a difference—let's Step Up for Sjögren's!

Our Walk for Sjögren's Spring Season kicks off during Sjögren's Awareness Month in April!

April	**VIRTUAL Southeast Walk for Sjögren's** *Saturday, April 5, 2025* **VIRTUAL Southwest Walk for Sjögren's** *Saturday, April 5, 2025*
May	**LIVE Philadelphia Tri-State Walk for Sjögren's in Philadelphia, PA** *Saturday, May 10, 2025* **VIRTUAL National & Mid-Atlantic Walk for Sjögren's** *Saturday, May 31, 2025* **VIRTUAL Colorado Walk for Sjögren's** *Saturday, May 31, 2025*
June	**LIVE Midwest Walk for Sjögren's in Madison, WI** *Saturday, June 21, 2025*

sjogrens.org/walks

Step Up, Raise More, Earn Rewards!

Reward your fundraising efforts with exclusive gear that shows your support and helps spread awareness! Each fundraising level earns that level prize as well as all previous levels' prizes.

Learn more at sjogrens.org/walks

Raise $50
Walk for Sjögren's T-shirt
Wear it proudly to highlight your commitment to Sjögren's disease awareness.

Raise $300:
Waist Bag/Fanny Pack
Perfect for keeping essentials or other small items close at hand.

Raise $600: Backpack
Step up in style with a Sjögren's Foundation backpack.

Raise $1,000: Sjögren's Star
Join an exclusive group of top fundraisers and get recognition on the Sjögren's Foundation website!

We'd also like to recognize our presenting and major sponsors from our most recent 2024 Northeast and West Coast Walk for Sjögren's:

Northeast: Barajas Family Trust | CariFree | NYU Langone Health Division of Rheumatology | The Axelrod & Harkavy Families | The Laukien Family | The Martin Family | The Schrader Family | In Memory of Jennifer L. Stark

West Coast: Berkeley Optometry Sjögren's Clinic, Drs. McNamara, Wu & Carteron | Art Specialties, Inc.| Barajas Family Trust | CariFree | Intrepid Eye Society

Recognizing Women Who Are Changing the Face of Sjögren's Research and Patient Care

In honor of International Day of Women and Girls in Science on February 11th, we are recognizing women for their amazing work in Sjögren's (SjD) research. These talented women have either received grants from the Foundation for their work in Sjögren's research and/or made significant contributions to Sjögren's research while also increasing awareness and/or improving patient care management. While it is impossible for us to include every woman who has made significant contributions to the field, we have featured a select few U.S.-based women scientists and listed all of our grant recipients and their contributions from 2018 to present. While this list is not all inclusive of the talented women that have contributed to Sjögren's research nor all the accomplishments made by the women mentioned, we truly have some of the most dedicated women scientists working in Sjögren's research. We are grateful for their contributions and the influence they have as mentors and leaders in Sjögren's.

Featured Women Scientists Continuing to Rise as Stars in Sjögren's Research

Sara McCoy, MD, PhD

Dr. Sara McCoy, MD, PhD, has been at the forefront of changing the landscape of research in Sjögren's as a clinician scientist, as seen by, for example, her work as co-chair of the Sjögren's Working Group for Outcome Measures in Rheumatology (OMERACT), an organization dedicated to building better diagnostic measures and clinical outcomes for patients. She is a faculty member in the Division of Rheumatology at the University of Wisconsin-Madison, where she started a Sjögren's Clinic in 2016 and later built a Sjögren's biorepository (a facility that stores and manages biological samples for research and laboratory use.)

She was the recipient of a High Impact Grant from the Foundation in 2021 for her research proposal titled, "Comprehensive profiling of Sjögren's autoantibodies identified from a novel whole peptidome array." This work— now published in the *Annals of Rheumatic Diseases*— led to the discovery of novel autoantibodies that could potentially be used to diagnose Sjögren's in patients who are SSA antibody negative, which is believed to be approximately 30-40% of the patient population with Sjögren's. Overall, Dr. McCoy has been an author on more than 40 publications since 2012, some of which are included below.

In 2023, Dr. McCoy was named as one of six investigators selected to receive funding from the Office of Women's Health Research Leadership Scholars Program for her work, where the long-term goal is to generate therapies that target the pathogenic role of salivary gland mesenchymal stromal cells (SG-MSCs) in Sjögren's.

As a rheumatologist, Dr. McCoy also spends her time creating and presenting educational material for other practicing healthcare professionals and medical students, where she is dedicated to improving patient care management and awareness for Sjögren's. Dr. McCoy also serves as a member of the Board of Directors for the Sjögren's Foundation.

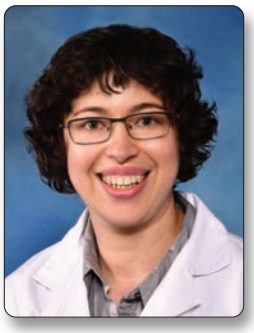
Notable Publications:

Fisher BA, Mariette X, Papas A, et al. Safety and efficacy of subcutaneous iscalimab (CFZ533) in two distinct populations of patients with Sjögren's disease (TWINSS): week 24 results of a randomised, double-blind, placebo-controlled, phase 2b dose-ranging study. *Lancet*. 2024;404(10452):540-553. doi:10.1016/S0140-6736(24)01211-X

Parker M, Zheng Z, Lasarev MR, et al. Novel autoantibodies help diagnose anti-SSA antibody negative Sjögren disease and predict abnor-

mal labial salivary gland pathology. *Ann Rheum Dis*. 2024;83(9):1169-1180. Published 2024 Aug 27. doi:10.1136/ard-2023-224936

McCoy SS, Woodham M, Bartels CM, Saldanha IJ, Bunya VY, Maerz N, Akpek EK, Makara MA, Baer AN. Symptom-Based Cluster Analysis Categorizes Sjögren's Disease Subtypes: An International Cohort Study Highlighting Disease Severity and Treatment Discordance. *Arthritis Rheumatol*. 2022 Sep;74(9):1569-1579. doi: 10.1002/art.42238. Epub 2022 Aug 3. PubMed PMID: 35594474; PubMed Central PMCID: PMC9427679.



Rachael Gordon, MD. PhD

Dr. Rachael Gordon, MD, PhD, is a rising star in Sjögren's research and rheumatology. She recently accepted the position of Assistant Professor of Medicine in the Division of Rheumatology and Clinical Immunology at the University of Pittsburgh Medical Center (UPMC). She started the first Sjögren's Center at UPMC, which provides comprehensive care for patients with Sjögren's and is building a translational research program to better understand Sjögren's and advance research for innovative therapies.

In 2023, Dr. Gordon was accepted into the OMERACT Fellows Program that focuses on providing early-career researchers and clinicians with opportunities to engage with experienced mentors from around the world and develop relevant career skills. As an OMERACT fellow, Dr. Gordon has worked with others in the Sjögren's Working Group to identify the core domains for SjD to be used in interventional clinical trials.

Though her prior research focus was determining disease mechanisms in lupus, she has since focused her lab's research on Sjögren's. She was awarded with a Pilot Research Grant from the Foundation in 2023 for her proposal titled, "Investigating the Role of IL-12 in Sjögren's Disease Pathogenesis." Recently, she was awarded the Distinguished Fellow Award from the Association of Rheumatology Professionals (ARP) at the American College of Rheumatology (ACR) Convergence 2024, which recognizes clinical and research fellows who are in a rheumatology fellowship training program and who have performed meritoriously.

Notable Publications:

Gordon RA, Nguyen Y, Foulquier N, et al. The Sjögren's Working Group: The 2023 OMERACT meeting and provisional domain generation. *Semin Arthritis Rheum*. 2024;65:152378. doi:10.1016/j.semarthrit.2024.152378

Nguyen Y, Beydon M, Foulquier N, et al. Identification of outcome domains in primary Sjögren's disease: A scoping review by the OMERACT Sjögren disease working group. *Semin Arthritis Rheum*. 2024;65:152385. doi:10.1016/j.semarthrit.2024.152385

Gordon RA, Cosgrove HA, Marinov A, et al. NADPH oxidase in B cells and macrophages protects against murine lupus by regulation of TLR7. *JCI Insight*. 2024;9(16):e178563. Published 2024 Jul 23. doi:10.1172/jci.insight.178563

Dana DiRenzo, MD, MHS

Dr. Dana DiRenzo, MD, MHS, has been leading the way for improving the quality of life for patients with Sjögren's. She completed her rheumatology fellowship at Johns Hopkins Hospital, where she subsequently became a faculty member and joined their Sjögren's Center. There, she was a member of the Mindfulness Team that developed meditations aimed at stress reduction and improvement of quality of life in people with rheumatic diseases.

In 2021, Dr. DiRenzo joined the Penn Sjögren's Center at the University of Pennsylvania (UPenn) as an assistant professor of Clinical Medicine. She also serves on the steering committee for OMERACT and actively contributes to the Sjögren's and Myositis Working Groups. She leads the Prospective Longitudinal Study to Understand Sjögren's (PLUS) at UPenn.

This year, Dr. DiRenzo was awarded the Foundation's Dynamic Research Grant for her proposal titled, "Development of a Core Outcomes Set of Domains for Sjögren's Disease."

Notable Publications:

Tison A, Jousse-Joulin S, Consigny M, et al. Are ultrasound salivary parenchymal lesions more severe in primary Sjögren patients with a longer disease duration? A cross-sectional study. *Rheumatology* (Oxford). Published online December 19, 2024. doi:10.1093/rheumatology/keae690

Dayno R, George MD, Blum M, DeQuattro K, Kolasinksi S, DiRenzo D. Description of self-efficacy for managing symptoms and emotions in a large rheumatology clinic population. *Clin Exp Rheumatol*. 2024;42(11):2175-2182. doi:10.55563/clinexprheumatol/2dohgg

Quéré B, Saraux A, Carvajal-Alegria G, et al. Reliability Exercise of Ultrasound Salivary Glands in Sjögren's Disease: An International Web Training Initiative. *Rheumatol Ther*. 2024;11(2):411-423. doi:10.1007/s40744-024-00645-6

Highlighted Members of the Board of Directors, Sjögren's Foundation and Leaders in Sjögren's Research

Vatinee Bunya, MD, MSCE

Contributions

Harold G. Scheie Chair & Associate Professor of Ophthalmology; Co-Director, Penn Dry Eye & Ocular Surface Center; Director, Women in Ophthalmology Mentoring Initiative, Scheie Eye Institute, University of Pennsylvania; Director of Clinical Research, Scheie Eye Institute; Member of the Board of Directors, Sjögren's Foundation

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"Women in Sjögren's" *continued from page 12* ▼

Dr. Vatinee Bunya, MD, MSCE, is an expert in the study of dry eye and ocular surface diseases. She cares for patients with dry eye and Sjögren's, and the focus of her research is to develop better ways to measure dry eye and to screen patients for Sjögren's.

Selected Sjögren's-Related Publications

Nguyen BJ, Gupta AS, He J, et al. Corneal Epithelial Thickness in Sjögren's Disease: A Pilot Study. *Clin Ophthalmol*. 2024;18:2175-2182. Published 2024 Jul 30. doi:10.2147/OPTH.S456621

Nortey J, Shiboski C, Rose-Nussbaumer J, Bunya VY, Lietman T, Gonzales JA. How Are Sicca Signs and Symptoms Associated With Depression Among Men Classified With and Without Sjögren Disease?. *Am J Ophthalmol*. 2023;247:96-102. doi:10.1016/j.ajo.2022.09.016

Vidya Sankar, DMD, MHS

Contributions

Associate Professor, Oral Medicine and Diagnostic Sciences at Tufts School of Dental Medicine; Division Director for Oral Medicine and Diagnostic Sciences, Tufts School of Dental Medicine; Program Director for Oral Medicine residency; Immediate Past President (2023-2024) of the Executive Committee, American Academy of Oral Medicine (AAOM); Associate Editor in the Oral Medicine Section of the Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology (OOOO) journal; Treasurer of the Executive Committee on the Board of Directors, Sjögren's Foundation

Dr. Vidya Sankar, DMD, MHS, is an expert in oral medicine research with research expertise in salivary gland dysfunction that includes study in Sjögren's, oral mucosal diseases, and oral complications of cancer therapy. She specializes in research on oral manifestations underlying systemic disease.

Selected Sjögren's-Related Publications

Carsons SE, Vivino FB, Parke A, et al. Treatment Guidelines for Rheumatologic Manifestations of Sjögren's Syndrome: Use of Biologic Agents, Management of Fatigue, and Inflammatory Musculoskeletal Pain. *Arthritis Care Res* (Hoboken). 2017;69(4):517-527. doi:10.1002/acr.22968

Sankar V, Noll JL, Brennan MT. Diagnosis of Sjögren's syndrome: American-European and the American College of Rheumatology classification criteria. *Oral Maxillofac Surg Clin North Am*. 2014;26(1):13-22. doi:10.1016/j.coms.2013.09.001

Ava Wu, DDS

Contributions

Professor, Orofacial Sciences at University of California San Francisco (UCSF) School of Dentistry; Director of the Sjögren's Clinic, UCSF; Former member of the Board of Directors, Sjögren's Foundation

Dr. Ava Wu, DDS, is an oral medicine specialist. She is an expert in studying the development of Sjögren's and the clinical management of oral manifestations of Sjögren's. She has published over 50 articles on aspects related to Sjögren's and lectures frequently on the topic. Dr. Wu served on the Board of Directors for the Sjögren's Foundation and dedicated eight years of service.

Selected Sjögren's-Related Publications

Clinical practice guidelines for oral management of Sjögren disease: Dental caries prevention. *J Am Dent Assoc*. 2016 Apr; 147(4):295-305. Zero DT, Brennan MT, Daniels TE, Papas A, Stewart C, Pinto A, Al-Hashimi I, Navazesh M, Rhodus N, Sciubba J, Singh M, Wu AJ, Frantsve-Hawley J, Tracy S, Fox PC, Ford TL, Cohen S, Vivino FB, Hammitt KM, Sjögren's Syndrome Foundation Clinical Practice Guidelines Committee. PMID: 26762707.

Associations between salivary gland histopathologic diagnoses and phenotypic features of Sjögren's syndrome among 1,726 registry participants. *Arthritis Rheum*. 2011 Jul; 63(7):2021-30. Daniels TE, Cox D, Shiboski CH, Schiødt M, Wu A, Lanfranchi H, Umehara H, Zhao Y, Challacombe S, Lam MY, De Souza Y, Schiødt J, Holm H, Bisio PA, Gandolfo MS, Sawaki T, Li M, Zhang W, Varghese-Jacob B, Ibsen P, Keszler A, Kurose N, Nojima T, Odell E, Criswell LA, Jordan R, Greenspan JS, Sjögren's International Collaborative Clinical Alliance Research Groups. PMID: 21480190; PMCID: PMC3128201.

Caroline Shiboski, DDS, PhD, MPH

Contributions

Professor, Orofacial Sciences at University of California San Francisco (UCSF) School of Dentistry; Lead principal investigator for Sjögren's Team for Accelerating Medicines Partnership (STAMP); Primary Author for American College of Rheumatology (ACR) and the European League Against Rheumatism classification criteria for Sjögren's; Contributor to Sjögren's Working Group, OMERACT

Dr. Caroline H. Shiboski, DDS, PhD, MPH, is a world-renowned expert in Sjögren's research and focuses on the oral manifestations caused by immune system dysfunction, which includes Sjögren's, oral cancers, and infectious diseases. She contributed significantly to the classification criteria used in clinical trials for Sjögren's and is an active participant in many international working groups, including OMERACT and

STAMP (you can read about her work with STAMP in the Nov/Dec issue of *Conquering Sjögren's* on page 18.)

Selected Sjögren's-related Publication

Shiboski CH, Shiboski SC, Seror R, et al. 2016 American College of Rheumatology/European League Against Rheumatism classification criteria for primary Sjögren's syndrome: A consensus and data-driven methodology involving three international patient cohorts. Ann Rheum Dis. 2017;76(1):9-16. doi:10.1136/annrheumdis-2016-210571

Urbanski UG, Taylor TK, Flynn FE, Gosh GA, Patel PR, Norouzi NA, Davidson DB, Poon PA, Chu CC, Nititham NJ, Fragiadakis FG, Eckalbar EW, Combes CA, Criswell CL, Ye YJ, Shiboski SC. Single-cell RNA-sequencing of PBMCs highlights the central role of anti-SSA antibodies and its association with Interferon-stimulated genes in the expression of Sjögren's disease. La Revue de Médecine Interne. 2024 Dec 1; 45:a385-a386.

List of Women Foundation Research Grant Recipients

2024

Jennifer King, MD, PhD

Abstract: *Molecular Phenotyping of Treatment Responsive Sjögren's Patients*

Contributions: Associate Professor at the University of California Los Angeles David Geffen School of Medicine; Serves as a significant contributor to the Foundation's Peripheral Nervous System Clinical Guidelines and alignment of Neurology and Rheumatology nomenclature

Selected Sjögren's-related Publication:

Noaiseh G, Deboo A, King JK, et al. Recommendations for Aligned Nomenclature of Peripheral Nervous System Disorders Across Rheumatology and Neurology. *Arthritis Rheumatol*. Published online November 3, 2024. doi:10.1002/art.43050

Abigail Koppes, PhD

Abstract: *Parsing Dysautonomia in a Dish: Neural Exposure to Exogenous Sjögren's Patient Derived Serum*

Contributions: Associate Professor, Chemical Engineering, Northeastern University; Recipient of the NIH R21 Trailblazer in 2017; Co-investigator on a 2019 American Heart Association Innovative Project Award; Co-investigator on a 2016 NIH Biomedical Research Partnership R01 between Northeastern, MIT, and Boston Children's Hospital.

Selected Sjögren's-related Publication:

Note: *This is the first time Dr. Koppes is working in Sjögren's research, but she has created an organ-on-a- chip system to look at neuron responses after inflammatory cues. Here is an article on the development of this system:*

Hosic S, Bindas AJ, Puzan ML, et al. Rapid Prototyping of Multilayer Microphysiological Systems. *ACS Biomater Sci Eng*. 2021;7(7):2949-2963. doi:10.1021/acsbiomaterials.0c00190

Eiko Yamada, DDS, PhD

Abstract: *Exploring Target Cells Contributing Higher Interferon Status Through cGAS-STING Pathway in Sjögren's Disease*

Contributions: Research fellow, Salivary Disorders Unit, National Institutes of Health, National Institute of Dental and Craniofacial Research (NIDCR)

Selected Sjögren's-related Publication:

Gupta S, Yamada E, Nakamura H, et al. Inhibition of JAK-STAT pathway corrects salivary gland inflammation and interferon driven immune activation in Sjögren's disease. *Ann Rheum Dis*. 2024;83(8):1034-1047. Published 2024 Jul 15. doi:10.1136/ard-2023-224842

2023

Anat Galor, MD, MSPH

Abstract: *Defining and Understanding Neurologic Manifestations of Sjögren's Based on Ocular Surface Phenotype*

Contributions: Professor of Ophthalmology at Bascom Palmer Eye Institute of the University of Miami; Head of Ocular Surface Program Miami Veteran Affairs Medical Center

Selected Sjögren's-related Publication:

Sanchez V, Dobzinski N, Fox R, Galor A. Rethinking Sjögren Beyond Inflammation: Considering the Role of Nerves in Driving Disease Manifestations. *Eye Contact Lens*. 2024;50(5):200-207. doi:10.1097/ICL.0000000000001068

2021

Addy Alt-Holland, PhD

Abstract: *Metabolic profiles of salivary and epidermal biomarkers for Sjögren's diagnosis*

Contributions: Professor, School of Dental Medicine, Endodontics at Tufts University; President of The Society form In Vitro Biology Board of Directors

Selected Sjögren's-related Publication:

Alt-Holland A, Huang X, Mendez T, et al. Identification of Salivary Metabolic Signatures Associated with Primary Sjögren's Disease. Molecules. 2023;28(15):5891. Published 2023 Aug 5. doi:10.3390/molecules28155891

Cintia S. de Paiva, MD, PhD

Abstract: *Investigating oral and conjunctival gene transcriptome signature in Sjögren's at the single cell level*

Contributions: Professor, Caroline Elles Endowed Professorship, Department of Ophthalmology at Baylor College of Medicine; President, International Ocular Surface Society; Editor-in-Chief of The Ocular Surface journal

Selected Sjögren's-related Publication:

Schaefer L, Trujillo-Vargas CM, Midani FS, Pflugfelder SC, Britton RA, de Paiva CS. Gut Microbiota From Sjögren syndrome Patients Causes Decreased T Regulatory Cells in the Lymphoid Organs and Desiccation-Induced Corneal Barrier Disruption in Mice. *Front Med* (Lausanne). 2022;9:852918. Published 2022 Mar 9. doi:10.3389/fmed.2022.852918

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2020

Seunghee Cha, DDS, PhD

Abstract: *Integrated Transcriptomic Profiling of Recurrent Parotitis in Pediatric Sjögren's for Assessment of Mitochondrial RNA Regulators*

Contributions: Professor, Department of Oral Medicine, Director of Center for Orphaned Autoimmune Disorders (COAD) at the University of Florida College of Dentistry, Member of the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Childhood Sjogren Disease (cSjD) Workgroup and the International cSjD Workgroup

Selected Sjögren's-related Publication:

Drew K, Kronlage R, Cha S, Thatayatikom A, Schrepfer T. Long-term efficacy of sialendoscopy in treating childhood Sjögren's disease with chronological monitoring by salivary gland ultrasonography: A novel approach. *Pediatr Rheumatol Online J*. 2023;21(1):83. Published 2023 Aug 13. doi:10.1186/s12969-023-00870-3

Sharmila Masli, PhD

Abstract: *Tear Biomarkers for Differential Diagnosis of Sjögren's vs. non-Sjögren's Dry Eye*

Contributions: Associate Professor, Opthalmology, Boston University Chobanian & Avedisian School of Medicine, Graduate Medical Sciences; Member of the OMERACT Sjögren's Working Group; Associate Editor for Antigen Presenting Cell Biology

Selected Sjögren's-related Publication:

Masli S, Akpek EK. Reduced tear thrombospondin-1/matrix metalloproteinase-9 ratio can aid in detecting Sjögren's syndrome etiology in patients with dry eye. *Clin Transl Sci*. 2022;15(8):1999-2009. doi:10.1111/cts.13316

2019

Emily Lanzel, DDS, MS

Abstract: *Salivary Biomarkers for Diagnosis of Childhood Sjögren's*

Contributions: Clinical Assistant Professor of Oral Pathology, Radiology, & Medicine at the University of Iowa School of Dentistry and Dental Clinics

Selected Sjögren's-related Publication:

Gomez Hernandez MP, Starman EE, Davis AB, et al. A distinguishing profile of chemokines, cytokines and biomarkers in the saliva of children with Sjögren's syndrome. *Rheumatology* (Oxford). 2021;60(10):4765-4777. doi:10.1093/rheumatology/keab098

Kristi Koelsch, PhD

Abstract: *Salivary Anti-Ro Defines a New Phenotype of Sjögren's*

Contributions: Associate Professor at University of Oklahoma Health Sciences Center (UOHSC) and Oklahoma Medical Research Foundation (OMRF). Dedicated 10 years as a Sjögren's research group member at UOHSC and OMRF, where her contributions significantly impacted the understanding of B cell and antibody involvement in Sjögren's. Though she passed away in 2022, Dr. Koelsch's contributions endure through ongoing publications and citations of her research.

Selected Sjögren's-related Publication:

Koelsch KA, Cavett J, Smith K, et al. Evidence of Alternative Modes of B Cell Activation Involving Acquired Fab Regions of N-Glycosylation in Antibody-Secreting Cells Infiltrating the Labial Salivary Glands of Patients With Sjögren's Syndrome. *Arthritis Rheumatol*. 2018;70(7):1102-1113. doi:10.1002/art.40458

2018

Kimberly Jasmer, PhD

Abstract: *P2Y2 Receptor as Therapeutic Target in a Sjögren's Mouse Model*

Contributions: Assistant Professor Oral Immunology & Infectious Diseases at University of Louisville School of Dentistry; 2024-2025 President-elect for Salivary Research Group (SRG) and 2023-2024 SRG Program Chair within the International Association for Dental Research (IADR)

Selected Sjögren's-related Publication:

Jasmer KJ, Woods LT, Forti KM, et al. P2Y2 receptor antagonism resolves sialadenitis and improves salivary flow in a Sjögren's syndrome mouse model. *Arch Oral Biol*. 2021;124:105067. doi:10.1016/j.archoralbio.2021.105067

Melodie Lynn Weller, PhD

Abstract: *The Impact of a Global Increase in Hepatitis Delta Virus (HDV) exposure on the Incidence of Sjögren's Diagnosis*

Contributions: Assistant professor, Division of Microbiology and Immunology, School of Medicine at University of Utah, Patent for instrument to measure salivary flow

Selected Sjögren's-related Publication:

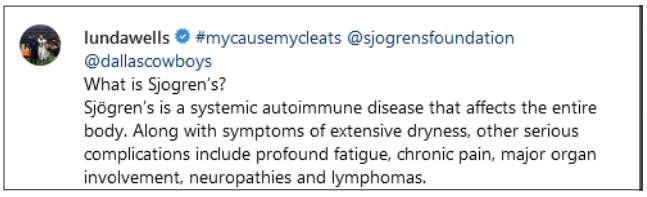
Weller ML, Gardener MR, Bogus ZC, et al. Hepatitis Delta Virus Detected in Salivary Glands of Sjögren's Syndrome Patients and Recapitulates a Sjögren's Syndrome-Like Phenotype in Vivo. *Pathog Immun*. 2016;1(1):12-40. doi:10.20411/pai.v1i1.72 ■

You Stood Up!

My Cause My Cleats

Every year, the National Football League (NFL) players and coaches participate in a fundraising campaign called My Cause My Cleats. Players and coaches wear custom cleats or sneakers that showcase causes important to them to spread awareness for something that is bigger than football. Lunda Wells, the tight-end coach for the Dallas Cowboys, chose to represent the Sjögren's Foundation for the fourth year in a row. He honored his wife Tiffany Wells, a patient with Sjögren's, along with the four million Americans who have Sjögren's. Ari Solomon designed Coach Wells' shoes again this year along with hundreds of other cleats and shoes for the My Cause My Cleats campaign. Coach Wells also took his design to several social media platforms to inform his followers that Sjögren's is a serious and systemic disease.

NFL MY CAUSE MY CLEATS



The My Cause My Cleats game day was December 9th, 2024, when the Dallas Cowboys unfortunately fell to the Cincinnati Bengals by a late game touchdown. While the Cowboys didn't win the game, they sure won our hearts by showcasing the seriousness of Sjögren's disease. Check out Coach Lunda Wells with his current and past designed shoes for My Cause My Cleats. ■

IN HONOR

In Honor of Joseph Albert
Patricia Albert

In Honor of Jill Anthony
Rona Altman

In Honor of Sunny Baek
Jordan Nadell

In Honor of Susan Barajas
Debra Baxter

In Honor of AnnMarie R Beaulieu, RN
Lynn P. Beaulieu, MD, LTC (Ret)

In Honor of Ina Begoun
Richard Begoun

In Honor of Nancy Beja
Nancy Kaufmann

In Honor of Janine Bensman
Robert Bensman
Irene Goldstein

In Honor of Dianne Berry
Matthew Berry

In Honor of Mary Bowman
David Muehl

In Honor of Wendy Budd
Brenda Kahn

In Honor of Stefanie Campbell
Ellen Campbell

In Honor of Diane Carey
Dennis DiRicco

In Honor of Rachel Chalom
Joseph Chalom

In Honor of Linda Champion
Benjamin Butler

In Honor of Beth Chase
Don and Mary Schock

In Honor of Dr. and Mrs. Bart Chernow
Anne Schmitt

In Honor of Dorothy Cleary
John Cleary

In Honor of Virginie Cloutier
Martin Bernier

In Honor of Barbara Ann Colchin
Jeanette Wright

In Honor of Heatherley Doan
Sylvia Dian

In Honor of Deborah Dudley
Marie Eckenrode

In Honor of Anne Economou
Kathleen Azzaro

In Honor of Anne and Ken Economou
Mary Rosenfeld

In Honor of Charlotte Edwards
Flora Metz

In Honor of Bonnie Flagg
Frances Gamble

In Honor of Madeline Friedman
Jeanette Friedman

In Honor of Teresa Grenier
Janet Egner

In Honor of Cecile Haley
Alvin Haley

In Honor of Mary Anne Hines
Holly Phelps

In Honor of Carol Hirashiki
Jennie Handy

In Honor of Susan Horst
Carol Watson

In Honor of Dennis and Linda Howard
Martha Costa

In Honor of Michael Hurth
Douglas Allen

In Honor of Dr. Namieta Janssen
Suzanne Trapani

In Honor of Adrienne Jones
Ariel Weber

In Honor of Heera Kamboj
John Cole

In Honor of Nancy Kirkpatrick
Paul and Katherine Bills
Noreen Wolansky

In Honor of Denise Klavon
Marie Rudert
Tamaya Tereshkova

In Honor of Robyn Laukien
Christopher Park
Stacy Rubin

In Honor of Jessica Levy
Debra Baxter

In Honor of James Lyle
Michael Lyle

In Honor of Chris, Teri, and Dakota Makulec
David Makulec

In Honor of Lucy March
Judy Rabinovitz

In Honor of Paula Markowitz
Theresa and Lee Markowitz

In Honor of Dr. Sara McCoy
Debra Maier

In Honor of Judy McDowell
Jocelyn Davis

In Honor of Bernadette Meyer
Joe Meyer

In Honor of Darla Morreissey
Douglas Morrissey

In Honor of Lindsay Noble
Patrick Noble

In Honor of President Judge Margherita Patti-Worthington
Mary Foradora

In Honor of Susan Paul-Souza
Lisa DiMarino

In Honor of Judy Pearl
Rebecca Pearl

In Honor of David Perkins
Sarah Perkins

In Honor of Liz Perry
Don Perry

In Honor of Dr. Ronald M. Peterson, PhD
Patricia Peterson

In Honor of Julianne Pinkerton
Patricia Pinkerton

In Honor of Julie Reeve
Nancy Ragonese

In Honor of Lee Reeve
Douglas Swift

In Honor of Margaret Rothman
Barbara Stockman

In Honor of Pat Schleicher
Kathryn Simonson

In Honor of Lois Stein
Harvey Stein

In Honor of Thomas Stoll
Rebecca Dotterer

In Honor of Dr. Donald Thomas
Herb and Cheryl Baraf

In Honor of Grace Tiger Aquilino
JeanMarie Panagakos

In Honor of Kim Vaughn
Kelly Titus

In Honor of Becky Vercollone
Heidi Brantley

In Honor of Hortensia Villada
Hortensia Valdes Villada

In Honor of Nancy Visocki
Gail Berkoff

In Honor of Margaret Blessing Voshell
Marcia Wood

In Honor of Niña Williams
Jacqueline Baptiste

In Honor of Steve and Kathleen Workman
Andrea Dowdy

In Honor of Paula Yelsey
Ellen Monsma

In Honor of Teresa Zulla
Chris Copley

In Honor of Barbara
Katherine Dillon

In Honor of Behnaz
Kathleen Kelley-Hoppe

In Honor of Paul and Pat
Mary-Margaret Lovejoy

In Honor of My Mom
Danielle Pawlus

In Honor of My Beautiful Mama
Vanessa Rivera

Your Story Can Inspire: Share and Help Us Connect, Learn, & Thrive during Sjögren's Awareness Month

IN MEMORIAM

In Memory of Lucille Adler
Victoria Vandewater

In Memory of Kum Hwa Ashburn
James Ashburn

In Memory of AnnMarie R. Beaulieu, RN
Lynn P. Beaulieu, M.D.

In Memory of Janine Bensman
Irene N. Goldstein

In Memory of Leonard Berenfield
Rebecca and Greg Berenfield

In Memory of Roosevelt Blackburn
Louise Blackburn

In Memory of Joan Bocchino
Robert Miller

In Memory of Heidi Ann Burke
John Burke

In Memory of Patricia Burns
Patricia Brown

In Memory of Randy Byrd
Diana Burt

In Memory of Colleen Cronlund
Martin Cronlund

In Memory of Leona Diamond
Beth Ann Hatfield

In Memory of Cynthia Dickerson
Ronald L. Dickerson

In Memory of Charlotte Edwards
Donna Sipe

In Memory of Florence Fox
Janis Fox

In Memory of Guadalupe Garcia
Ellen O'Brien-Garcia

In Memory of Carol Ann Gergel
James Gergel

In Memory of Alice Glupe
Margaret WrenGlupe

In Memory of Anne Fracassa
Paul and Stacey Bodi
Kathleen Connealy
Yoriko Cronin
Colleen Eovaldi
Jacqueline Fracassa
Marcia Freedman
John Hegarty
Paul and Eileen Horbal
Michele Hoxie
Lynn Kloc
Janice LaMothe
Claudia Meeks
Hollie Nelosn
John Nelson
Richard Pearson
Thomas Perez
Mary Smith
Mark Wrobel

In Memory of Jan Gordon
Kevin McCaffrey

In Memory of Carolyn McNutt Hall
Dixie Fulton Williamson

In Memory of Betty Hardgrave
Kathy Sivils

In Memory of Julie Hellenbrand
Jay Hellenbrand
Paul Hellenbrand

In Memory of Pat Kelley
Kimberly Kelley

In Memory of Helen A. Kinlan
Patrick V. Kinlan

In Memory of Sheila Kinsella
Shiela Wright

In Memory of Rosemary Kuhl
James Kuhl

In Memory of Bonnie Litton
Linda Phillips

In Memory of Sharon Maurer
Mary Beth Hansen
Michael Maurer
Lynn and Howard Orenstein
Barbara and Peter Sheehan
Eleanore Simi
Lisa Wolf
West Sand Lake Volunteer Fire Co. #1

In Memory of Betty McMinn
Julie McMinn

In Memory of Waneta and John Mehaffey
William and Kathleen Balcom

In Memory of Shirley Miller
Ann Miller and Becky Duehring
Carolyn McLeod
Helen Nowak

In Memory of Margaret E. Morris
Alison Morris

In Memory of My Mother
Ellen Healey

In Memory of Jennifer Paragano
Nancy Hehir

In Memory of Ellen Peterson
Carl Peterson

In Memory of Mary Pridgen
Mary Beth Humphrey

In Memory of Dianne Rhein
Emma O'Brien

In Memory of Connie Rodriguez
Fred Fernandez and Irma Rodriguez

In Memory of Ella Whitten Sisler
Darla Rae
Joe Sisler

In Memory of Linda Patterson Slappey
Tony Patterson

In Memory of Dr. Robert Spiera
Jeff and Julie Kuhn

In Memory of Jennifer Stark
Amy and Shawn Courchesne

In Memory of Suzanne Sullivan
Stephen and Sharon Marlow
Bette Jo Sullivan

In Memory of Hang Ngan Tsang
Thao Doan
Cindy Hwang
Grace Leung
Tony Leung
Kawei Tsang

In Memory of Jane Vosika
Frederick Wynn

In Memory of Marilynn Walman
Laura Gardy

In Memory of Annie Webster
Janette Webster

In Memory of Ruth Welch
William Welch

In Memory of Charles Borchelt
Carole Borchelt

In Memory of Claude W. Wilson
Warren David Harless

In Memory of Shirley Ziff
Catherine Ziff

In Memory of Beloved Members of the Panico and Garrison Families
Elizabeth Panico-Garrison

In Memory of Bree
Amy Semanscin

In Memory of Ray
Melanie Olesky

In Memory of Vijayamma
Manoj Pillai

April is Sjögren's Awareness Month, a time when we come together as a community to amplify the voices of those living with Sjögren's disease and bring much-needed attention to this complex and often misunderstood disease. Through storytelling, we want to increase awareness of the disease, unite the community, and shine a spotlight on the experiences of those living with Sjögren's.

This year, we're celebrating the month with a special focus on the theme 'Connect, Learn, & Thrive,' highlighting the ways our community grows stronger through shared experiences and support. We want to feature stories from patients and those affected by Sjögren's— stories that capture the challenges, triumphs, and moments that define life with Sjögren's. Each day in April, we'll showcase a new story on our website and social media.

If you would like your story to be featured in this year's campaign, please fill out the form linked below. We will share 30 stories of real patients throughout the month of April and all stories submitted are eligible to be featured by the Foundation.

Thank you for sharing your story to help shine light on the diversity of the millions of patients living with Sjögren's. Your story can help others feel seen, understood, and inspired.

To share your story, please visit sjogrens.org/april or scan the QR code.

Conquering Sjögren's
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Fax: (301) 530-4415

If you would like to receive this newsletter but are not currently a Member, please contact us at (301) 530-4420

Sjögren's Foundation
National Patient Conference 2025

Save the Date!

Virtual National Patient Conference 2025: Connect, Learn, and Thrive!

Friday, April 11th & Saturday, April 12th
12:30-5:30pm (ET)

Mark your calendar for an exciting and empowering virtual experience! This year on April 11th and 12th we will come together to connect and learn so you can thrive while living with Sjögren's disease!

We have an amazing line-up of sessions and community time at this year's conference that you won't want to miss! At every National Patient Conference, Sjögren's experts present an overview of the systemic nature of Sjögren's disease, as well as in-depth looks at oral and ocular manifestations to help you manage your dry eyes and dry mouth. This year, we will also highlight how Sjögren's effects the cardiovascular system, ears, nose & throat, and your neurological system. Sjögren's researchers will present the interesting research happening now, as well as a session on what we are learning about different patient profiles. Last but not least, we will be bringing back the popular "Ask a Doc" session with expert rheumatologist Dr. Donald Thomas, MD, for one hour on both Friday and Saturday!

Join us so you can connect with other Sjögren's patients, learn from experts and gain the knowledge to thrive with your Sjögren's disease!

Sjögren's FOUNDATION