

CONQUERING Sjögren's

November/December 2021

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A Letter from Your CEO, Janet E. Church



The holiday season is certainly a time for family but it is also a time of reflection and preparation. This year, my reflection is all about the Foundation and gratitude. I am grateful to have the opportunity to lead this organization and I am immensely grateful that you, the Foundation members, have so generously welcomed me as President and CEO. In many ways, it has been a transformative year for the Foundation with leadership change, considerable research investments, and increasing clinical trials for new therapies that show promise for patients. I am incredibly proud of what the Foundation staff has accomplished this year and excited to turn to the new year and continue our work!

And that brings me to preparation! The work ahead is significant, and we have been focused on preparing for the future. I am excited about what we will learn about Sjögren's in the next several years and how the Foundation will continue to grow to meet the needs of patients, researchers, and medical providers.

In this issue of *Conquering Sjögren's*, we highlight our recent research award recipients and our victory of successfully updating the medical ICD-10 codes. We also touch on several key areas of the Foundation's mission including research, medical provider education and patient support:

Research into new therapeutics

Now is a particularly exciting time in the development of new therapeutics for Sjögren's. Currently, we are working with 15 companies in clinical trials for 21 systemic therapies that will treat the entire disease. Because the disease impacts each patient differently, we are hoping that multiple treatments come to market so patients can find a therapy that works best for them. There are also companies working on new therapies for dry eye and dry mouth symptoms. I encourage you to look for more information from the Foundation about upcoming clinical trials and how you can help move these clinical trials forward and bring new treatments to market.

Awareness among medical professionals

Through the development of clinical practice guidelines for Sjögren's, patients will eventually see standardized care in how healthcare providers treat, manage, and monitor their disease. This Foundation initiative gives providers a roadmap for treating the disease. With four sets of guidelines currently published on our website, we are currently working on the next set focusing on the peripheral and central nervous systems. In the new year, we will continue to make education for medical professionals a top priority, so all know that Sjögren's is serious, systemic and prevalent!

Patient support

As a patient, I know how important it is to have education and support! The Foundation continues to provide COVID-19 updates, member town hall meetings, support groups, awareness ambassadors, conferences, events, and the online Smart Patients forum. Although the pandemic has prevented us from gathering in person, we have had great success coming together virtually. In fact, we have served double the number of patients because virtual programs allow more patients access! We do hope to come back together in live settings in the future, but I am very proud of the many ways our Sjögren's community has come together virtually. If you have not tried a virtual event, I invite you to look into these opportunities to connect.

It is truly my honor to lead this organization and continue to foster our vision to bring patients, healthcare professionals and researchers together to conquer the complexities of Sjögren's. On behalf of the volunteer Board of Directors and the Foundation staff, thank you for your support.

Wishing you and your family a joyous and healthy holiday season.

Sincerely,

A handwritten signature in black ink, appearing to read "Janet Church".

Sjögren's Foundation Announces New Research Grants

The Sjögren's Foundation is excited to announce the selection of four research grant recipients for the new fiscal year, which includes two High Impact Grants and two Pilot Grants. Additionally, the Foundation has provided no-cost extensions to a portion of our current grantees to allow for extra time due to the continuing barriers to work that many have experienced as a result of the COVID-19 pandemic.

Visit www.sjogrens.org to learn more about the Foundation's research grant opportunities.

2021-2022 Sjögren's Foundation High Impact Research Grant Recipients



Cintia S. de Paiva, MD, PhD
Associate Professor of Ophthalmology,
Baylor College of Medicine - Ocular Surface Center, Department of Ophthalmology, Houston, TX

Project Title
Investigating oral and conjunctival gene transcriptome signature in Sjögren's at the single cell level

Abstract

Sjögren's is an autoimmune disease that causes dry eye and dry mouth. Decreased saliva causes difficulty chewing and swallowing, dental caries, and oral infections. Dry eye causes ocular symptoms, including irritation, blurred vision, and eye perforation in severe cases. Sjögren's patients typically see multiple doctors searching for a diagnosis, with a significant burden to the individual and society. Some Sjögren's patients with dry eye have minimal or no dry mouth symptoms. We believe that cells from the eye surface and mouth taken from patients with dry eye and dry mouth carry a distinct gene signature from patients

with dry eye only and control subjects. We propose to use a novel technique that can identify the genes from the eye and the mouth at a single-cell level. Identification of a Sjögren's gene expression signature would provide relevant diagnostic markers that could be used in the future.



Sara S. McCoy, MD, MS
Assistant Professor, University of Wisconsin School of Medicine and Public Health, Department of Medicine, Division of Rheumatology, Madison, WI

Project Title

Comprehensive profiling of Sjögren's autoantibodies identified from a novel whole peptidome array

Abstract

Sjögren's is a common autoimmune disease that affects the glands responsible for saliva and tear production, as well as many other organ systems, and ultimately leads to noticeable reduction in quality of life. Despite the frequency and severity of Sjögren's, diagnosis and treatment is hindered by the lack of highly sensitive and specific diagnostic testing and a paucity of novel therapeutic targets. We have identified hundreds of new autoantibodies by using cutting-edge whole peptidome array technology, which studies over 5.9 million peptides from every human protein. With this project, we will confirm these candidate autoantibodies, providing innumerable targets to both improve Sjögren's diagnosis and deepen our understanding of the causes of Sjögren's, ultimately driving development of new therapies. The results of this study have the potential to improve the lives of Sjögren's patients through advancements in diagnosis and treatment, current unmet needs in Sjögren's.

2021-2022 Sjögren's Foundation Pilot Research Grant Recipient



Addy Alt-Holland, PhD
Associate Professor, Tufts School of Dental Medicine, Department of Endodontics, Boston, MA

Project Title

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

Abstract

Sjögren's is a progressive autoimmune disease involving chronic inflammation of exocrine glands that results in many comorbidities, including 'dry mouth', 'dry eye', and systemic cutaneous symptoms, such as 'dry skin'. Novel biomarkers that enable diagnosis, and can be easily integrated in the dental clinic, are sorely lacking. We developed a novel, non-invasive method to obtain epidermal metabolites. It allows for the identification of skin metabolic signatures, which show potential new biomarkers in different clinical studies. The goal of this study is to define epidermal and salivary metabolic signatures, which distinctively correlate with Sjögren's diagnosis. Combination of saliva based and sweat-based epidermal metabolic profiling has an immense potential to serve as a novel, sensitive and non-invasive diagnostic tool that, one day, may be added to the Consensus Criteria for Sjögren's and allow for early diagnosis and monitoring disease progression, inform disease management programs, and guide patient care.



Jason H. Melehani, MD, PhD
Clinical Fellow, Stanford University - Department of Medicine, Division of Rheumatology and Division of Pulmonary, Allergy and Critical Care Medicine, Stanford, CA

Project Title

A prospective observational comparison of treatment response in Sjögren's-related lung diseases to primary idiopathic lung diseases

Abstract

Patients with Sjögren's commonly experience a wide range of lung diseases which combined are among the greatest contributors to reduced health-related quality of life and lead to increased mortality. Sjögren's-related lung diseases are classified and treated in the same manner as the primary lung dis-

eases they resemble. Whether this approach is optimal has not been evaluated thoroughly. In this study, we will screen patients with interstitial lung disease or bronchiectasis, two of the most serious manifestations, for oral dryness to identify patients whose lung disease is due to underlying Sjögren's. We will compare the clinical course of these two groups to evaluate whether patients with Sjögren's-related lung disease have unique clinical features and are uniquely responsive to immunosuppressive therapy. This study will be the first prospective and largest direct comparison of patients with Sjögren's-related lung disease to the primary lung diseases they resemble.

Extended 2020-2021 Research Grants

Sharmila Masli, PhD
Boston University

Project Title

Tear biomarkers for differential diagnosis of Sjögren's vs. non-Sjögren's dry eye

Description

The ability to identify Sjögren's-related dry eye can facilitate earlier diagnosis of Sjögren's. This study proposes to identify tear components that differentiate Sjögren's vs. non-Sjögren's dry eye. Such tear components can form the basis for a diagnostic test that helps clinicians detect Sjögren's earlier and manage treatment effectively to prevent development of serious complications.

Seunghee Cha, DDS, PhD
University of Florida College of Dentistry

Project Title

Integrated transcriptomic profiling of recurrent parotitis in pediatric Sjögren's for assessment of mitochondrial RNA regulators

Description

This application will uncover the gene signatures of juvenile Sjögren's immune cells with high-throughput sequencing. Our preliminary data suggest that mitochondrial RNA may elicit the inflammatory signatures in monocyte. We will determine how such altered gene signatures of juvenile Sjögren's monocyte in the blood affects immune cell phenotype in the target tissue. We hypothesize that robust inflammation in recurrent parotitis of juvenile Sjögren's presents more distinct mitochondrial RNA dysregulation compared to juvenile Sjögren's without recurrent parotitis or adult Sjögren's. Our ultimate goal is to establish the scientific foundation for juvenile Sjögren's diagnostic criteria and targeted therapeutic interventions. ■

Sjögren's Foundation Research Awardee Update:

Interview with David T. Wong, DMD, DMSc
University of California, Los Angeles, CA



David T. Wong, DMD, DMSc

2020-2021 High Impact Research Grant

Project Title EFIRM[†] Liquid Biopsy for Early Detection of Sjögren's and Sicca Patient

Q Your project, "EFIRM[†] Liquid Biopsy for Early Detection of Sjögren's and Sicca Patients," was the Foundation's 2020-2021 High Impact Research Grant. Were you happy with the results during your one-year grant period?

A During the one-year grant period, we developed and clinically verified the performance of the saliva anti-SSA/Ro-52 immunoassay. It can impactfully serve as a screening test to distinguish Sjögren's and autoimmune-sicca from non-autoimmune sicca and healthy. The proposed saliva SSA/Ro-52 immunoassay can benefit patients in obtaining accurate diagnosis and appropriate treatment to improve outcome. The novel EFIRM[†] platform addresses an unmet clinical need by non-invasively quantify saliva anti-SSA/Ro-52, permitting early detection in sicca and seronegative patients, while minimizes health-care burden.

Q Have you continued this research since the completion of the study?

A Our lab has continued with Sjögren's research under the support of the National Institutes of Health (NIH). We aim to validate the EFIRM immunoassay in additional clinical cohorts and further the understanding of the pathogenesis of Sjögren's to permit timely therapeutic intervention early in the disease, before irreversible destruction of the salivary gland by local autoimmunity.

Read the Foundation's full interview with Dr. Wong on our website or scan the QR code.



[†]Electric field-induced release and measurement (EFIRM): a novel diagnostic platform.



New ICD-10 Codes for Sjögren's!

The Sjögren's Foundation is excited to share that the new ICD-10 codes for Sjögren's took effect October 1, 2021. This initiative, which was done in partnership with the American College of Rheumatology (ACR), has culminated in a successful effort to revise the existing ICD-10 code for Sjögren's. These changes are expected to be folded into the ICD-11 code for international use.

This initiative, which began in 2017, was undertaken with the recognition that the existing ICD-10 (International Statistical Classification of Diseases and Related Health Problems, 10th revision) code for Sjögren's (M35.0, Sicca syndrome [Sjögren]) did not represent the disease and contributed to misinformation and confusion. Changes to the code, which are mentioned in detail later in this article, will benefit providers, investigators, researchers, insurers, and, of course, patients, and address key complications of Sjögren's that were not included in the previous code.

Rationale for this Initiative

The previous code used "Sicca syndrome" and "Sjögren's" synonymously. While at one point this may have been a prevailing thought, we know that using these terms interchangeably is inaccurate for a variety of reasons.

Sicca is a symptom and not a disease, while Sjögren's is a distinct systemic autoimmune, rheumatic disease

that can affect multiple organs and body systems. Dryness certainly occurs in Sjögren's, but dryness alone does not represent the disease and the many other symptoms involved. Furthermore, sicca includes many non-Sjögren's patients who may have dryness symptoms for numerous reasons, including radiation for head and neck cancers, graft-versus-host disease and as a side effect of certain medications.

Further justification was found when looking at classification criteria. Sjögren's classification criteria has never used either "sicca" nor "sicca syndrome," and no criteria exist for "sicca syndrome." Using the 2002 American European Consensus Criteria (AECC) and the 2016 ACR-EULAR criteria as examples, we can see that these criteria rely primarily on serology and biopsy, and in no way indicate that Sjögren's be defined by sicca.

The previous ICD-10 code created confusion, contributed to misinformation and was potentially detrimental to patients, whose diagnosis carried an incorrect label, which can influence subsequent difficulty with insurance reimbursement, clinicians, who may be unsure of how to best code the disease, study investigators and researchers, who may have trouble accurately identifying Sjögren's patients for clinical trials and data acquisition, and insurers, who grapple with inaccuracy, which can influence reimbursement to both patients and providers.

"ICD-10 Code" continued from page 7 ▼

What Changed?

The following changes took effect in October 2021:

Tabular Modifications

M35 Other systemic involvement of connective tissue

Revise	M35.0	Sicca syndrome [Sjögren] Sjogren syndrome Add Add Excludes1: Dry mouth, unspecified (R68.2)
Revise	M35.00	Sicca Sjögren syndrome, unspecified
Revise	M35.01	Sicca Sjögren syndrome with keratoconjunctivitis
Revise	M35.02	Sicca Sjögren syndrome with lung involvement
Revise	M35.03	Sicca Sjögren syndrome with myopathy
Revise	M35.04	Sicca <u>Sjögren</u> syndrome with tubulo-interstitial nephropathy
New code	M35.05	Sjögren syndrome with inflammatory arthritis
New code	M35.06	Sjögren syndrome with peripheral nervous system involvement
New code	M35.07	Sjögren syndrome with central nervous system involvement
New code	M35.08	Sjögren syndrome with gastrointestinal involvement
New code	M35.0A	Sjögren syndrome with glomerular disease
New code	M35.0B	Sjögren syndrome with vasculitis
New code	M35.0C	Sjögren syndrome with dental involvement
Revise	M35.09	Sicca <u>Sjögren</u> syndrome with other organ involvement

It is important to note that patients with symptoms of dryness who cannot definitively be linked to Sjögren's, can still be designated under the symptoms section of the ICD code.

The Process

From the onset, those involved knew this would be no small task. However, the importance of this initiative helped motivate a team of multi-disciplinary experts, represented by a non-profit, professional society, academia, industry, rheumatology, pediatric rheumatology,

primary care, neurology, gastroenterology, pulmonology, nephrology, oncology, ophthalmology and oral medicine, to convene and collaborate on the best course forward.

After a series of meetings and discussions, a proposal was submitted to the ICD-10 Coordination and Maintenance Committee (C&M), a federal interdepartmental committee comprised of representatives from the Centers for Medicare and Medicaid Services (CMS) and the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS), with suggestions for modifications to the code for Sjögren's.

Excitingly, the proposal was accepted for presentation at the Fall C&M meeting taking place near Baltimore, MD, in September 2018. Here, Dr. Alan Baer represented the SF, ACR and the multi-disciplinary team who informed the proposal by expertly explaining the rationale for why changes to the Sjögren's code are needed. Dr Baer's presentation was followed by a presentation by a CDC representative detailing the specific tabular changes that were being requested.

A period for public comment took place in the subsequent months after the meeting, during which few questions were raised. However, as the group learned, because questions had been raised, the proposed changes would need to be revised to address the questions and the proposal presented at the Spring C&M meeting in March 2019.

This time, only a CDC representative was needed for the presentation of the proposal, and Kathy Hammitt, Vice President of Medical and Scientific Affairs, was on hand to provide perspective on the few questions that were raised. An additional public comment period was then held but resulted in no major issues being put forth.

A Team Effort

This effort was no-doubt strengthened by the multi-disciplinary team who provided their time and expertise in guiding this project. The Sjögren's Foundation is sincerely grateful to the advisory team, who provided integral help throughout the entire process, and would like to recognize and thank the following individuals:

Alan N. Baer, MD

Director, Jerome Greene Sjögren's Syndrome Clinic & Professor of Medicine, Johns Hopkins University School of Medicine (Rheumatology)

Scott Lieberman, MD

University of Iowa (Pediatric Rheumatology)

Judith Furlong, MD

ProMedica Physicians Family Medicine (Primary Care)

Theresa Lawrence Ford, MD

CEO & Medical Director, North Georgia Rheumatology Group (Rheumatology)

Julius Birnbaum, MD

Co-director, Jerome Greene Sjögren's Syndrome Clinic, Johns Hopkins University School of Medicine (Neurology & Rheumatology)

Frederick Vivino, MD

Director, Sjögren's Syndrome Center, Perelman School of Medicine at the University of Pennsylvania (Rheumatology)

Augustine Lee, MD

Mayo Clinic, Jacksonville, FL (Pulmonology)

Nancy Carteron, MD

University of California San Francisco, University of California Berkeley, School of Optometry, Sjögren's Clinic (Rheumatology)

Marie Hogan, MD

Mayo Clinic, Rochester, MN (Nephrology)

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ICD-10 Coding – What it means for you!

Ask the expert with Kathy Hammitt,
Sjögren's Foundation's Vice President of
Medical and Scientific Affairs

Q *How does the new ICD-10 coding help me as a patient?*

For anyone on your healthcare team who does not have a full understanding of Sjögren's, the new coding opens their eyes to the fact that Sjögren's is a systemic and potentially severe disease. Your healthcare providers will see the many complications listed under Sjögren's when they check off your diagnosis and key symptoms under the ICD coding system. This will not only remind them to take this broader view of Sjögren's every time a Sjögren's patient comes through their door, but it will help your providers to manage your care better by leading them to check for these potential complications in their Sjögren's patients.

Q *Does this mean that my doctor can simply adjust my diagnosis code?*

Your doctor applies an ICD code to every patient who visits them and with every visit. That coding now automatically shifts to "Sjögren's" instead of "sicca syndrome." The coding number your healthcare providers have always used remains the same; it's the content that has changed. In addition, if you have another condition or disease in the ICD coding that used to list "sicca syndrome" as a complication, the verbiage has now changed to read "Sjögren's" instead of "sicca syndrome."

Q *Does this help with insurance covering more procedures related to the disease?*

While the official intent of ICD coding does not include facilitating health insurance coverage, it will affect such coverage. Having codes that demonstrate severe complications of the disease in your medical

record will be seen by insurance providers and should assist in obtaining better coverage.

Q *Does the code apply to dental issues?*

One of the new codes is for dental involvement. This increases awareness on the part of your healthcare providers that dental issues are a major complication of Sjögren's. We do not yet have the experience as to whether this might help with insurance coverage of dental work due to Sjögren's. The Sjögren's Foundation currently is partnering with other groups to ensure oral care is an integral part of medical care. In addition, we have joined the Consortium for Medicare Dental Coverage to obtain dental coverage under Medicare. Currently, the U.S. House Energy & Commerce and Ways & Means Committees have both advanced legislation as part of their reconciliation package instructions that would add a dental benefit to Medicare Part B. This legislation now moves forward in the U.S. House and is being negotiated in the Senate. Once coverage is obtained under Medicare, this fact can be used to leverage a drive to obtain coverage under other health insurance.

Q *Why is Sjögren's referred to as a syndrome in the codes and not a disease?*

The Sjögren's Foundation has launched a major effort to change the language around Sjögren's to ensure that it is seen as systemic, serious, and prevalent. This includes dropping "syndrome" from our name and from all Sjögren's Foundation materials. We want

"ICD-10 Code" continued from page 8 ▼

Lance Forstot, MD
Corneal Consultants of Colorado (Ophthalmology)

Vidya Sankar, DMD
Brigham and Women's Hospital (Oral Medicine)

Richard Ambinder, MD, PhD
Johns Hopkins University School of Medicine (Oncology)

Katerina Shetler, MD
Palo Alto Medical Foundation (Gastroenterology)

Jo Annah Jensen
Novartis (Industry)

Steven Taylor
Sjögren's Foundation

Kathy Hammitt
Sjögren's Foundation

Antanya Chung
American College of Rheumatology

A special thank you to Alan Baer, MD, for presenting, in-person, at CMS headquarters during the ICD-10 Coordination and Maintenance Committee meeting in September 2018. Dr. Baer's presence and presentation very eloquently made a case for the proposed changes and helped set us apart by being one of the only presenters outside of CMS and CDC staff during the event.

The Sjögren's Foundation would also like to recognize Antanya Chung and the American College of Rheumatology for their support and collaboration on this important initiative.

The original version of this article appeared in the Fall 2019 issue of *Sjögren's Quarterly*. After publication, unforeseen delays in implementation were experienced, and this article is being reprinted as a reminder to our subscribers of the important changes that will be taking place. ■

Remember your loved ones and special occasions with a donation to the Sjögren's Foundation in their name.



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Sjögren's Foundation In Action!



Foundation Partners for First-Ever ILD Day

The Sjögren's Foundation was proud to partner for the first Interstitial Lung Disease (ILD) Day on September 15, to drive awareness of ILD. Pulmonary complications occur much more frequently in Sjögren's than is often recognized by healthcare providers and are a potentially serious complication of Sjögren's. As many as 65% of asymptomatic Sjögren's patients will have abnormal pulmonary imaging, highlighting the need for awareness of pulmonary manifestations in Sjögren's.

ILD symptoms can include shortness of breath, cough, sputum production or chest pain. Onset of ILD in Sjögren's may increase with time following diagnosis of Sjögren's.

Clinical practice guidelines for pulmonary manifestations in Sjögren's were recently developed under the leadership of the Sjögren's Foundation to improve early identification, evaluation and consistency of care by primary care physicians, rheumatologists and pulmonologists.

Visit www.sjogrens.org to learn more about the Foundation's, "Pulmonary Clinical Practice Guidelines for Sjögren's" and ILD Day.



Foundation Joins Patient Groups to Support Drug Pricing Policy

The Sjögren's Foundation joined more than 50 other patient groups in signing and sending letters to members of Congress on the importance of drug pricing policy, concerns, priorities, and solutions for individuals with autoimmune disease.

These letters, which were coordinated by the American Autoimmune Related Diseases Association (AARDA), shared concerns related to foreign reference pricing, which included issues with the use of Quality Adjusted Life Years (QALY) and their inherent discrimination and restriction when applied to disabilities and chronic illness access to medicines, as well as restrictions to access to vital medicines now and the lack of future cures. Solutions included in the letter included the consideration to count copay assistance toward a deductible and instituting a policy for out-of-pocket caps as well as ensuring that discounts go directly to patients. ■

The letters, in their entirety, can be viewed online: <https://www.aarda.org/aarda-50-patient-groups-send-letter-key-members-congress-drug-pricing-priorities-autoimmune-patients>

Season of Giving

This year has been filled with a multitude of both challenges and victories. Every year is different but this one has been filled with more change than normal. During another unprecedeted year, the Sjögren's Foundation is especially proud of the successes and accomplishments we achieved in 2021 and we are grateful for the privilege of being there for patients at difficult times to ensure that they get the support they need.

We want to take the opportunity to thank every volunteer, healthcare professional, and donor, whose support and generosity has greatly impacted our work and efforts. The Foundation's successes are because of YOU!

While we know there will continue to be challenges ahead, we are so excited for all that 2022 has in store for us. Enthusiasm and anticipation are building around amazing research investments, increased opportunities to educate healthcare professionals, expanded efforts around clinical trials, taking advantage of the *Living with Sjögren's* patient survey to better understand the experiences of Sjögren's patients and increase awareness in the Sjögren's community at-large, and continued movement towards new and systemic therapeutics for Sjögren's. We look forward to sharing it all with you in the new year.

The past couple of years has proven what we can overcome and achieve when we work together. As the year comes to a close, we ask you to please consider making a year-end gift. Your generosity will help shape the future of Sjögren's and is critical to our success.

We thank you for investing in us, volunteering with us, and sharing our passion and vision for the future. We wish you and your loved ones a happy, healthy, and safe holiday season and New Year.



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You Stood Up!

Celebrating the retirement of beloved physician and Sjögren's champion, Dr. Fredrick B. Vivino!

Sjögren's expert and exceptional Sjögren's Foundation medical leader, Frederick B. Vivino, MD, retired this summer from the University of Pennsylvania, where he saw many Sjögren's patients and directed the Penn Sjögren's Center at the Perelman School of Medicine.

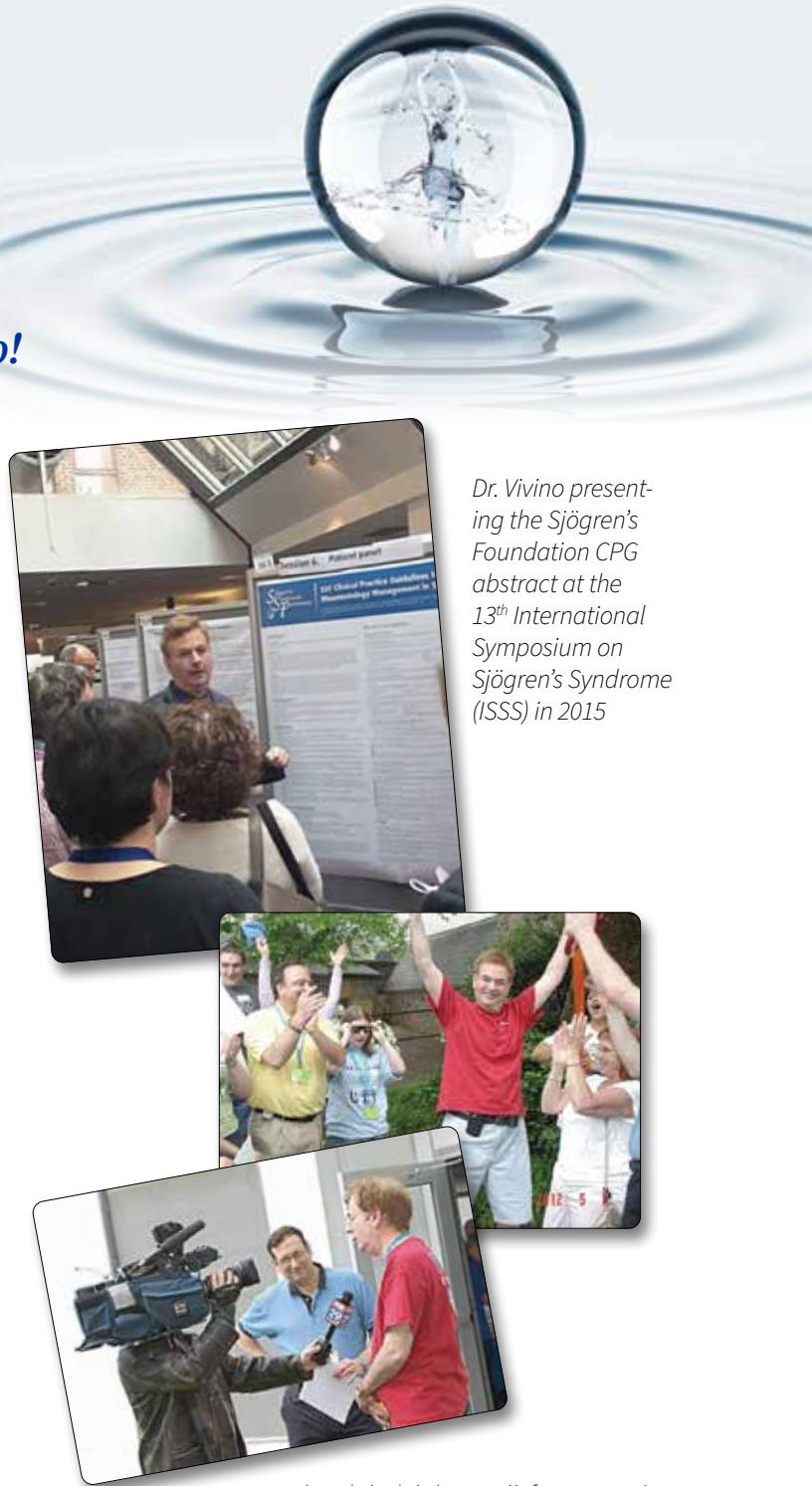
Dr. Vivino first started his career in Sjögren's in 1989 at Presbyterian Medical Center of Philadelphia. Through his work investigating dry mouth treatments, he became passionate about finding a U.S. Food and Drug Administration (FDA) approved medication that was affordable for patients. Dr. Vivino's lab ran successful clinical trials for the first Sjögren's prescription medication, Salagen™, that was approved by the FDA in 1998.

Always putting patients first, Dr. Vivino enjoyed talking at the local Philadelphia Support Group and was a staple at the area's annual Philadelphia Walk for Sjögren's event! Saddened at how often patients described receiving poor medical care, Dr. Vivino recognized the need for increased awareness and education among medical professionals.

Involved in various areas of the Foundation's work, during his tenure on the Foundation's Board and as Chair of the Sjögren's Foundation Medical and Scientific Advisory Board, he launched the first-ever clinical practice guidelines in Sjögren's. Dr. Vivino brought many creative and innovative ideas to the Foundation to further medical education and ensure better care for all patients.

On behalf of the Foundation, we thank you for all you have done for Sjögren's, the Sjögren's Foundation and for being the supreme example of a physician who advocated for patients. Thank you Dr. Vivino!

"To all my Sjögren's friends – remember that no matter how challenging your health issues may be, you should never give up. New discoveries are made all the time and things are always changing. One should never lose hope!"



Dr. Vivino presenting the Sjögren's Foundation CPG abstract at the 13th International Symposium on Sjögren's Syndrome (ISSS) in 2015



Dr. Vivino at the Philadelphia Walk for Sjögren's events in 2012 and 2014

"You Stood Up" continued from page 13 ▼

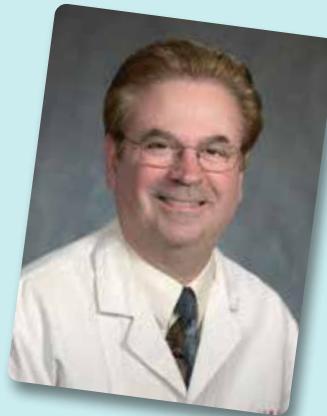
Dr. Vivino's Patient Tip:

If you are looking for a knowledgeable Sjögren's physician, I encourage you to research and visit your nearest Sjögren's specialist or Sjögren's center. Though you may have to travel some distance to receive this care, it could be life changing. In many instances, once the plan of care is established, patients can return to their local providers for regular visits and see the specialist less often. If this is not possible, look for a physician who is willing to learn about the disease. Every patient requires highly specialized, multi-disciplinary, and individualized care.

You can also contact your local Sjögren's Foundation support group and ask for a personal recommendation of a knowledgeable physician. If your doctor isn't familiar with Sjögren's, ask if they'd like to receive information from the Foundation, which they will send to your doctor for free.

A Man of Vision on Behalf of Sjögren's and the Sjögren's Foundation

- Chair, Sjögren's Foundation Medical & Scientific Advisory Board
- 2006-2009 Chair, first-ever Clinical Practice Guidelines for Sjögren's Members
- Sjögren's Foundation Clinical Trials Consortium Steering Committee
- Created the *Sjögren's Quarterly* in 2006 and served as 1st Medical & Scientific Editor Increased education in Sjögren's among Healthcare Professionals



Dr. Fredrick B. Vivino

"ICD-10 Code Q&A" continued from page 9 ▼

Sjögren's depicted as it should be scientifically: a distinct disease and not a syndrome. Unfortunately, language that has been used for decades does not change overnight, and the Centers for Medicare and Medicaid Services retained the word "syndrome." We were fortunate to get the many changes to the ICD-10 coding that we did, including having the main heading for our disease as "Sjögren's" and not "sicca syndrome." Our battle for language changes has just begun, and we'll soon be taking this initiative to the international community to lead a global charge to change the face of Sjögren's! ■

Patient Praise for ICD-10 Coding!

"This is fantastic news. Thank you so much for your hard work! No more being classified as 'just dry eyes and mouth'" – Kathy

"I didn't think this would really affect me, but I work with ICD-10 codes daily and this makes me feel seen in the medical community." – Jennifer

"This. Is. Huge. Thank you to everyone who've worked since 2017 to make this happen." – Amy

"Wow. This is amazing. I'm almost crying, and it feels like a weight has been lifted off. Thank you for all the hard work and advocacy for everyone dealing with this disease." – Jamie

"As a person who has lived with quite an aggressive form of Sjögren's, I loathe having to explain, even to physicians, that the disease process was so much more than dry eyes/dry mouth. I sincerely thank everyone who worked tirelessly to make this update possible!" – Paulina

"This actually brings tears to my dry eyes. Yay!!" – Lisa

"This is the best thing to happen to Sjögren's. It's taken so long to get here, but it's worth it." – Barbara

"As a medical coder and Sjögren's patient, this is exciting. From the bottom of my heart, thank you!" – Misty



Patients Sharing with Patients: *Holiday Tips!*

While the holidays are a time of joy, the Foundation understands that this time of year can also come with added physical and emotional stresses.

Remember to pay attention to your body and take care of both your physical and emotional symptoms. We know the best advice often comes from patients.

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Below, patients share their best tips for managing the holiday season with Sjögren's.

Set your own pace. Decline invitations if you don't feel up to it. It's ok to say "no." – Marsha

Eliminate activities that don't bring you joy. For me, this includes baking (except for a gluten free fruit cake). I also, build rest into every day and schedule in days with zero activities. – Catherine

Don't overdo it. Normal life is hard enough for us. Throw in the holidays, and if you don't watch out, you can easily have a major flare. If you don't feel up to doing something or going somewhere, just say no. Don't risk a flare. – Michele

SCHEDULE quiet rest time into your calendar. And if you can, take a few extra days off work. – Susan

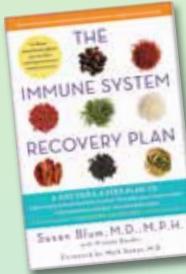
I still have younger kids, so I have them "help" me decide what we are going to do (rather than focus on what I am not - as that list is long). This helps me plan and prioritize. I don't want to waste energy and have every memory of theirs to be of me missing out because I am napping. – Adrienne

When I'm in a flare, and I'm cold and ache all over, I take a warm bath with scented Epsom salts. – Robin

Ask for help if you need it. If you are one of those people who tries to do everything, like all the cooking and cleaning, ask your family to help you. Every little bit helps take away some of the stress of the day. Happy Holidays! – Joann

Set yourself up for success- extra sleep, healthy food, and move every day! – Karin ■

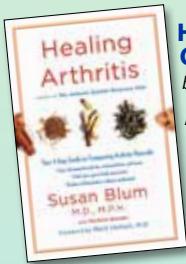
Top 5 Sjögren's Resources from the Foundation Bookstore



The Immune System Recovery Plan:
A Doctor's 4-Step Program to Treat Autoimmune Disease
by Susan Blum, MD, MPH (Author),
Mark Hyman, MD (Foreword), Michele Bender (Contributor)

Dr. Susan Blum, one of the most sought-after experts in the field of functional medicine, shares the four-step program she used to treat her own serious autoimmune condition and help countless patients reverse their symptoms, heal their immune systems, and prevent future illness.

Member Price: \$22 Non-Member Price: \$25



Healing Arthritis: Your 3-Step Guide to Conquering Arthritis Naturally

by Susan S. Blum, MD, MPH (Author), Mark Hyman (Foreword)

Author of the bestselling *The Immune System Recovery Plan* shares her science-based, drug-free treatment plan for the almost fifty million people who suffer from arthritis: an amazing 3-step guide to eliminate the disease naturally.

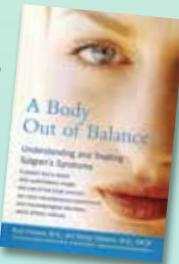
Member Price: \$20 Non-Member Price: \$24

A Body Out of Balance

by Ruth Fremen, MA, and Nancy Carteron, MD, FACR

A Body Out of Balance provides a comprehensive guide to a wide array of symptoms, traditional and complementary treatments, and invaluable coping methods, so patients may devise a personal treatment plan. Cowritten by a woman living with the disease and by a physician who has treated Sjögren's patients, this indispensable resource will enhance awareness and demystify this often misunderstood disorder.

Member Price: \$13 Non-Member Price: \$16

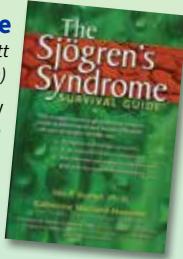


The Sjögren's Syndrome Survival Guide

by Teri P. Rumpf, PhD and Katherine Morland Hammitt (VP of Medical & Scientific Affairs)

Continually one of our best selling and most highly recommended books. *The Sjögren's Syndrome Survival Guide* is a unique resource that provides both educational medical information and proven effective self-care strategies to help you.

Member Price: \$17 Non-Member Price: \$20

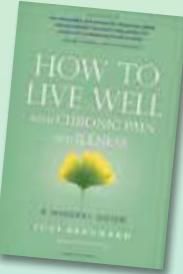


How to Live Well with Chronic Pain and Illness – A Mindful Guide

by Toni Bernhard

Chronic illness creates many challenges, from career crises and relationship issues to struggles with self-blame, personal identity, and isolation. Toni Bernhard addresses these challenges and many more, using practical examples to illustrate how mindfulness, equanimity, and compassion can help readers make peace with a life turned upside down.

Member Price: \$14 Non-Member Price: \$17



	Non-Member	Member	Qty	Amount
The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease by Susan Blum, MD, MPH (Author), Mark Hyman, MD (Foreword), Michele Bender (Contributor)	\$25.00	\$22.00		
The Sjögren's Syndrome Survival Guide by Teri P. Rumpf, PhD and Katherine Morland Hammitt	\$20.00	\$17.00		
Healing Arthritis: Your 3-Step Guide to Conquering Arthritis Naturally by Susan S. Blum, MD, MPH (Author), Mark Hyman (Foreword)	\$24.00	\$20.00		
How to Live Well with Chronic Pain and Illness – A Mindful Guide by Toni Bernhard	\$17.00	\$14.00		
A Body Out of Balance by Ruth Fremen, MA, and Nancy Carteron, MD, FACR	\$16.00	\$13.00		
Shipping & Handling U.S. Mail: \$7 for first item + \$2 for each additional item				
				Total Amount

Mail to: Sjögren's Foundation Inc., 10701 Parkridge Blvd., Suite 170, Reston, VA 20191
or Fax to: 301-530-4415

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Clinical Trials in Sjögren's

Clinical trials are a crucial element in medicine and healthcare to help develop drugs that will treat or possibly cure certain diseases. Researchers use clinical trials to test if a drug works, how well it works, how safe it is and how it compares to any currently available treatments.

The Sjögren's Foundation has a section on its website devoted to clinical trials in Sjögren's and a listing of clinical trials that are currently recruiting Sjögren's patients.

To learn more visit:
www.sjogrens.org/living-with-sjogrens/clinical-trials



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FOUNDATION



What is a Sjögren's Flare?

by Nancy Carteron MD, FACR



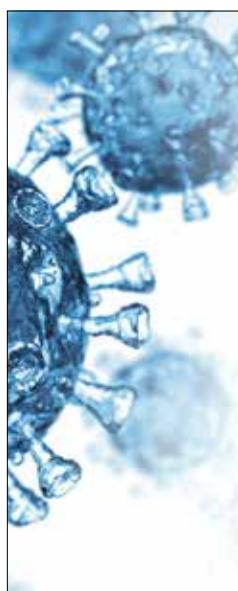
A flare-up, often referred to as a “flare,” is a sudden, severe onset of symptoms. As example, you’ve been managing well, your symptoms have lessened and, having momentarily forgotten the pain and dryness, you’ve been living ‘full out’ as you used to. Then, suddenly, those angry symptoms are back! Several points are worth keeping in mind. First, the symptoms of flares are usually very similar to the symptoms you had when your disease began. If a headache signaled the beginning of your disorder before, the recurrence of a headache may indicate the beginning of a disease flare. If a vague feeling of having flu presaged, you’re going to the doctor when you were diagnosed, and this feeling returns, it is likely to be a flare.

It is for this reason that you must constantly check in and know your body and how it reacts. A certain way of avoiding flares is to write a diary of symptoms whenever you feel them. Linking them to whatever might have triggered them. If, for example, you worked over-long hours, or had an argument with your son’s soccer coach, write it down. In the case of the workload, it will be clear that you need to discuss with your employer your need to arrange your work hours to allow for a rest, and in the case of that soccer blowout, it will be clear that such activities are bad for your health.

Also, this is the time to report to your doctor and talk about new feelings or pains that are unusual. New symptoms may not only indicate a flare, but they may also herald complications of treatment. Treating a flare with attention and care will help you have fewer of them. Step back, take care of yourself, rest more often or make inroads to arranging your workday to allow such things, and you will go a long way towards having fewer occasions of “flare-ups.”

Dr. Carteron is co-author of *A Body Out of Balance*, available for purchase on page 16.

The Sjögren's Foundation COVID-19 Resources and Vaccination Committee Recommendations



The Sjögren's Foundation, in concert with our medical advisors, is continually monitoring the COVID-19 and what the Foundation and our patients should be doing.

The health and safety of our patients is our number one priority, and we continue to provide the support and guidance needed during this time.

The Foundation has established a COVID-19 Vaccination Committee made up of rheumatology and immunization experts. This committee is led by Dr. Alan Baer, a leading rheumatologist, chair of the Sjögren's Foundation's Medical and Scientific Advisory Council and Director of the Jerome L. Greene Sjögren's Syndrome Clinic at Johns Hopkins University.

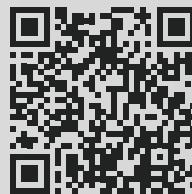
We hope you will visit our website www.sjogrens.org to view all our COVID-19 resources, including patient support information, a document of frequently asked questions, recent member town hall webinars, and our COVID-19 Vaccination Statement and Booster Recommendations for Sjögren's patients.

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in partnership with the
Sjögren's Foundation

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smartpatients.com/partners/sjogrens





Conquering Sjögren's

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