

CONQUERING Sjögren's

March/April 2023

*Help Spread Awareness
During Sjögren's
Awareness Month*

Inside this Issue

2nd Annual State of Sjögren's

New Dysautonomia Grant Award

Top 15 Tips for Oral Candidiasis

Clinical News

2023 National Patient Conference





Board of Directors

Chairman of the Board

Donald E. Thomas, MD, FACP, FACR

Chairman-Elect

Susan Barajas

Treasurer

Ava Wu, DDS

Secretary

David Schrader

Alan Baer, MD, Chair MSAB

Vatinee Bunya, MD, MSCE

Chadwick Johr, MD

Tammy Dotson

Katie Forte

Brent P. Goodman, MD

Nishant Gupta, MD

Tom Iatesta

Kimberly Kelley, PharmD

Allissa Latham

Robyn Laukien

Scott Lieberman, MD

Sara McCoy, MD, PhD

Jonathan Morse, MSc

Jason Nichols, OD, MPH, PhD, FAAO

Vidya Sankar, DMD, MHS

Daniel Wallace, MD, CTC Chair

Medical and Scientific Advisors

Chairman

Alan Baer, MD

Esen Akpek, MD

Penny A. Asbell, MD, FACS, MBA

Herbert S. B. Baraf, MD, MACR

Richard Brasington, MD, FACR

Michael Brennan, DDS, MHS

Steven E. Carsons, MD

Nancy L. Carteron, MD, FACR

Troy Daniels, DDS, MS

Denise L. Faustman, MD, PhD

H. Kenneth Fisher, MD, FACP, FCCP

Gary Foulks, MD, FACS

S. Lance Forstot, MD

Philip C. Fox, DDS

Robert I. Fox, MD, PhD, FACP

Theresa Lawrence Ford, MD, FACR

Tara Mardigan, MS, MPH, RD

Austin Mircheff, PhD

John Daniel Nelson, MD, FACS

Kelly Nichols, OD

Athena Papas, DMD, PhD

Ann Parke, MD

Andres Pinto, DMD

Nelson Rhodus, DMD, MPH

Vidya Sankar, DMD, MHS

Daniel Small, MD, FACP

Neil Stahl, MD

Jeffrey Wilson, MD, FACR

Chief Executive Officer

Janet E. Church

Editor

Elizabeth Trocchio Bryant

e-mail: info@sjogrens.org

www.sjogrens.org

Table of Contents

2 nd Annual State of Sjögren's	3
Grant Award: Kamal R. Chémali, MD	5
Top 15 Tips for Oral Candidiasis	7
Walk for Sjögren's Calendar	8
In Memory & In Honor	9
Clinical News	10
2023 National Patient Conference	17

Don't miss out on the latest information and research, become a member of the Sjögren's Foundation and receive the *Conquering Sjögren's* newsletter six times a year. It's easy to join. Sign up through our website at: www.sjogrens.org or call us at: (301) 530-4420.

April is Sjögren's Awareness Month

CONQUERING Sjögren's Volume 4, Issue 2



Conquering Sjögren's Newsletter is published by the Sjögren's Foundation Inc.,
10701 Parkridge Boulevard, Suite 170, Reston, VA 20191.

Copyright ©2023 Sjögren's Foundation Inc. ISSN 0899-637.

DISCLAIMER: The Sjögren's Foundation Inc. in no way endorses any of the medications, treatments, or products mentioned in advertisements or articles. This newsletter is for informational purposes only. Readers are advised to discuss any research news, drugs, treatments or products mentioned herein with their healthcare providers.



STATE OF Sjögren's

Meeting Recap: The 2nd Annual State of Sjögren's

On Friday, January 27, 2023, the Sjögren's Foundation held the second annual State of Sjögren's, an event that brought together Sjögren's experts from across specialties in the fields of patient care and research. The goal of the State of Sjögren's is to get medical professionals and researchers on the same page about the most current happenings and best practices related to the disease. Through information sharing, including updates on clinical trials and drug therapies, Sjögren's subject matter experts can further collaborate to improve the future for Sjögren's patients.

Sjögren's Foundation CEO, Janet Church, began with an overview of the Foundation's work by reviewing the Foundation's mission key pillars. The Foundation works to complement the efforts of medical experts and researchers, particularly when it comes to improving patient outcomes. This includes investing more than \$1 million in research between April 2020 and November 2022, developing provider education courses and offering conferences to address unmet patient needs, promoting multidisciplinary care, and emphasizing that Sjögren's is a serious and systemic disease. Church also shared an update on the international Nomenclature Initiative, which involves both patients and clinicians working to reach consensus on the language we use for Sjögren's.

Eleven medical professionals and researchers shared their current work on the varied manifestations of Sjögren's disease. Alan Baer, MD, MACR, Professor of Medicine and Director of the Jerome L. Greene Sjögren's Center at the Johns Hopkins School of Medicine, moderated the State of Sjögren's event and began with an overview of Sjögren's and the need to implement a more intensive strategy for diagnosing and treating the disease. Having an accurate diagnosis for

patients from the start of their journey ensures more viable treatment options for disease management. Dr. Baer also discussed the role of medical specialists – particularly ophthalmologists, rheumatologists, and dental providers – in treating the varied symptoms of Sjögren's and the broad heterogeneity of the disease. Only by accurately diagnosing Sjögren's as a systemic autoimmune disease, will medical providers be able to help patients manage their symptoms and offer new therapies as they become available.

Brent P. Goodman, MD, Neurologist at the Mayo Clinic, discussed the ways in which Sjögren's affects the nervous system, potential complications requiring strategic, targeted therapeutics, and the interaction between Sjögren's and remodeling and regeneration in the nervous system. Dr. Goodman then introduced the other panel members focused on the neurological manifestations of Sjögren's, whose current research focuses on how various body systems are impacted by the disease. Lucinda A. Harris, MS, MD, Professor of Medicine at the Mayo Clinic – Alix School of Medicine, discussed the ways in which the gastrointestinal system impacts Sjögren's, including a dry mouth impacting dietary habits, GERD, the presence of H. pylori, and liver diseases. Robert I. Fox, MD, PhD, Rheumatologist at Scripps, discussed the impact of headaches and migraines on Sjögren's patients and how pituitary adenylate cyclase-activating polypeptide (PACAP) may be released and lower pain thresholds. Kate Hackett, PhD, Clinical Academic Occupational Therapist and Associate Professor Occupational Therapy at Northumbria University, focused on the connection between pain, fatigue, and sleep patterns in Sjögren's patients. Many patients experience night wakings due to pain, dryness symptoms, a more frequent need

“State of Sjögren’s” *continued from page 3* ▼

to use the bathroom, sleep apnea, and insomnia. Through sleep diaries and assessments, providers were able to suggest potential interventions focused on activities like rest breaks and gentle exercise.

Next, Kathy Hammitt, Vice President of Medical and Scientific Affairs at the Sjögren's Foundation, introduced panelists who shared updates on groundbreaking research. Dr. Caroline Shiboski, Professor of Olfacial Sciences at the University of California – San Francisco, discussed her research focused on the progression of Sjögren's, which is a unique opportunity to better understand the heterogeneity of the disease. This is part of the Accelerating Medicine Partnership Auto-immune and Immune-Mediated Diseases (AMP-AIM) effort, and the public-private partnership between NIH, bio-pharmaceutical companies and NPOs to research therapeutics. Dr. Nancy McNamara from the University of California - Berkeley, discussed her research to understand corneal nerve loss and the potential impact of the regeneration of lacritin as a part of regenerative therapy. Dr. Anat Galor, Ophthalmologist at the University of Miami, discussed her research on the role of the gut microbiome composition in affecting dry eyes. And lastly in this group, Dr. Vidya Sankar, Division Director for Oral Medicine and Diagnostic Sciences at Tufts University, discussed her research on the use of radiation

in gene therapy on salivary glands. In all, by focusing on the heterogeneity of the disease, the researchers hope this will lead to new therapies for patients.

Sara McCoy, MD, PhD, Rheumatologist at the University of Wisconsin, Madison, discussed the history of placebo-controlled drug trials in Sjögren's as well as various drug therapies being assessed in clinical trials, including ivalumab, iscalimab, and dazodalibep. Finally, Daniel J. Wallace, MD, Professor of Medicine, Cedars-Sinai Center/David Geffen School of Medicine at the University of California – Los Angeles, discussed the core issues in clinical trials in North America, including patients fulfilling criteria for Sjögren's disease and other autoimmune diseases, that clinical trials are weighted towards extra glandular disease (as opposed to glandular, which is prominent among Sjögren's patients), and a lack of cohorts with extraglandular disease with significant activity to participate in clinical trials. Dr. Wallace suggested a few remedies for these issues, including establishing a Clinical Trials Task Force to include patients and medical experts as well as continuing to meet at the American College of Rheumatology's Annual Convergence to focus on improving the barriers in U.S. clinical trials.

This is an exciting time in the field of Sjögren's research and we look forward to the future for all Sjögren's patients. ■



Stay updated on current Sjögren's clinical trials and how they can benefit you.

New phase 2 trials are happening now!

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.



Sjögren's
FOUNDATION



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



Foundation Award: New Grant on Dysautonomia & Sjögren's

The Sjögren's Foundation is excited to share that in addition to awarding our new Pilot and High Impact grants, a \$50,000 grant has been awarded to Dr. Kamal Chémali to study the prevalence of elevated *Mycoplasma pneumoniae* titers in Sjögren's and other autoimmune disorder-associated neuropathic postural orthostatic tachycardia syndrome (neuropathic POTS).

Dr. Chémali, an associate professor of neurology at University Hospitals Cleveland Medical Center, has focused his research and career on autonomic nervous system disorders, small fiber neuropathies (SFN) and autoimmune autonomic neuropathies.

A synopsis of what Dr. Chémali will study and hopes to achieve is shared below in an abstract of his proposal:

Sjögren's is notorious for causing SFN, which is present in a majority of POTS cases (the combination

is termed "neuropathic POTS"). *Mycoplasma pneumoniae* (MP) causes up to 40% of community acquired pneumonias, and is a possible cause of immune-mediated large-fiber neurologic disorders, such as Guillain-Barré syndrome. Its effect of small fibers is less known. We found significant elevation of MP IgG titers in the serum of most individuals with neuropathic POTS associated with autoimmune disorders, predominantly Sjögren's, departing significantly from the general population prevalence. We propose the pathogen may therefore contribute to autonomic C and A delta nerve fibers dysfunction, leading to autonomic disorder through an autoimmune mechanism. Such a conclusion would trigger the search for an autoimmune disease, mainly Sjögren's, in patients with neuropathic POTS and elevated MP titers, leading to a more targeted and effective core treatment of these conditions with immune modulation. ■

Donate Your Old Vehicle

Call us or scan the code below to get more information.

(301) 530-4420





Get fast relief from Sjögren's mouth sores.

Step 1 Gently removes yeast and bacteria in a matter of seconds

Step 2 Reduces pain & inflammation to promote healing



VISIT [BENOVA.NET](https://www.benova.net) FOR \$20 OFF YOUR FIRST ORDER



Find Support and Advice from Your Local Sjögren's Support Group!




Attend free meetings and connect with others living with Sjögren's while also learning how to best manage your disease with presentations from area healthcare professionals.

To find your local Sjögren's Support Group, contact the Sjögren's Foundation at www.sjogrens.org.

These local groups provide:

- Patient-to-patient sharing
- Informative presentations by healthcare professionals
- An opportunity to connect and exchange helpful coping techniques



Top 15 Tips for Oral Candidiasis (Thrush) in Sjögren's

These tips were taken from the Sjögren's Foundation Patient Education sheet by Nelson L. Rhodus, DMD, MPH, FICD.

Oral candidiasis, or thrush, is a common problem in dry mouth patients. Thrush can cause oral burning and pain. The appearance of thrush in a dry mouth patient often is atypical and appears as red and irritated instead of the typical white cottage-cheesy. The tongue may show grooves, and the corners of the lips appear red and crusty (called angular cheilitis). Here are some tips to help:

- 1 Schedule regular professional care and follow up.
- 2 Treat the underlying condition of dry mouth.
- 3 Practice excellent oral hygiene.
- 4 Change your toothbrush frequently when oral candidiasis is active.
- 5 Increase oral moisture through use of sugar-free gum, lozenges, and artificial salivas.
- 6 Sip water frequently and rinse after eating or drinking if you can't brush.
- 7 Talk to your dentist or rheumatologist about taking Evoxac® (cevimilene) or Salagen® (pilocarpine) to increase salivary flow.
- 8 If any of your medications list dryness as a side effect, talk with your doctor about alternatives.
- 9 Limit sugar and foods that contain yeast, such as wine, beer, and bread.
- 10 Increase intake of acidophilus through unsweetened yogurts with live lactobacillus acidophilus or capsules.
- 11 Avoid caffeine and alcohol, both of which can increase dryness.
- 12 Don't use mouthwashes containing alcohol.
- 13 If you smoke – Stop! Sometimes a combination of treatments is necessary if the problem is severe.
- 14 Clean dental prostheses every day with an anti-fungal preparation and avoid wearing them at night.
- 15 Check the Sjögren's Foundation Product Directory – available online, free of charge to all members – to see the many products available for dry mouth. ■



STRONGER THAN SJÖGREN'S

Join a Spring Walk for Sjögren's Event!

Walk for Sjögren's is a national awareness and fundraising program that takes place across the country every spring and fall. But Walks are so much more! They are an amazing series of events where patients build community together, interact with Sjögren's experts, and raise funds for important initiatives. With our 2023 theme, "Stronger than Sjögren's," we invite you to join us at one of our virtual events, or at our LIVE event in Philadelphia and show your community how you can be stronger than Sjögren's!

At each event, there will be doctors available to answer patient questions, an update on Foundation activities, and door prizes. Perhaps most importantly, it is an opportunity to educate family and friends about the disease, while also raising critical funds.

If you're interested in attending and would like to learn more, please contact Jessica Levy at jlevy@sjogrens.org or visit events.sjogrens.org.

Spring 2023 – Walk for Sjögren's Calendar

April

Virtual Mid-Atlantic & National Walk for Sjögren's
Saturday, April 1, 2023

May

LIVE Philadelphia Tri-State Walk for Sjögren's
Saturday, May 13, 2023

June

Virtual Texas Walk for Sjögren's
Saturday, June 10, 2023

Virtual Colorado Walk for Sjögren's
Saturday, June 10, 2023

events.sjogrens.org





IN MEMORIAM

In Memory of Barbara Meyer

Leonard Smally

In Memory of Bonnie Tarnoff Litton

Naomi and Neil Arnold

In Memory of Carol Richards

Laura Richards and The Richards Family
Kimberly Moore

In Memory of Delores M. Callahan

Martha DiRienzi

In Memory of Elaine Harris

Linda Jean Harris

In Memory of Ella Whitten Sisler

Darla Rae

In Memory of Evelyn Cudney

David Whittaker

In Memory of Gail Azerrad

Tracy McCubbin
Pauline Kaner

In Memory of Joan Arruda

Pajes Sterman
Judi Mansing

In Memory of Mary McHard

John Gill

In Memory of Joan F. (Borstel) Bocchino

Joseph R. Mario

Stephen and Patricia Capuccio

Patricia Newman

Donald and Gillian Capuccio

Margaret Boucher

Rose Richard

In Memory of Joan Polcari

Martin Fetherston

Albert Ettinger

In Memory of Joan Roberta Barela

Nadina Kezel

In Memory of John Trocchio

Kathy Ivory

In Memory of Marguerite (Peggy) McAllen

Laura Mackin

In Memory of Marlene Press

Rochelle Golus

In Memory of Mary Janett McHard

John Gill

In Memory of Mary Lou Ballenger

Susan Singleton

In Memory of Mazelle Baird

Emily Borden

In Memory of Pamela Starlene Taylor

Kathleen Vocks

In Memory of Patricia and Elfrieda Frank

Diane L. Stadtmiller, MA, CIW, PA-C

In Memory of Precious Driver

Brandi Berba

Nancy Murphy

Laura Woller

In Memory of Sharon Maksymec

Bonnie Davies

William Reil

Matt and Kristy Wagner

Judith Greenwald

Anita Mueller

Alan Urban

James and Susan Russell

In Memory of Shirley Miller Reed

Judith Reed

In Memory of Sue Cabrera

Ronald and Rita Blake

Patsy Miller

K. Michael and Cynthia Pitman

IN HONOR

In Honor of Mr. & Mrs. Larry Levin

Hannah Kaplan

In Honor of Candace Cam

Chirag Patel

In Honor of Carol L. Hrvatin

Ronald Hrvatin

In Honor of Cecile Haley

Alvin Haley

In Honor of Elaine Levin

Barbara Bernheim

In Honor of Jackie & Bertha Darby

Jody Shy

In Honor of Kathrine Woodman Furlong

Sheila Smith

In Honor of Kathryn Donnelly

Elvira Albert

In Honor of Lari Lopp

Karyn DeParis

In Honor of Linda B. Harris

Georgia L. Hobbs

In Honor of Myra Bahme

Donna Weinberg

In Honor of Liz Perry

Don Perry

In Honor of Noah Rumpf

Altschul Fund

In Honor of Shauna Hansen

Katie McManus



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



Clinical News



Sjögren's Not Associated to Worse Outcomes After Total Hip Arthroplasty

A retrospective, case-control, study of Sjögren's patients with avascular necrosis of the femoral head (ANFH) (n=32) and matched controls with osteoarthritis (n=64) found similar hip function and health-related QoL outcomes after an average follow-up period of 5 years.

Both groups had similar preoperative hip function, but those with Sjögren's had worse EQ-VAS compared to controls ($p < 0.05$). Postoperatively, there was no difference in EQ-VAS and VAS scores improved in both groups at final follow-up (Sjögren's = 1.51 ± 0.94 ; Controls = 1.45 ± 1.17 ; $p > 0.05$).

Satisfaction scores in both groups were high (Sjögren's = 94.72 ± 3.96 ; Controls = 95.14 ± 4.22 , $p > 0.05$). Four patients in the Sjögren's group did require the use of walking aids at last follow-up, but did not experience pain or functional decline of the hip joint.

The authors noted that occurrence of incision complications and reaching TT8 were higher in the Sjögren's group, however, no differences were observed in the rate of 90-day readmission, reoperation, or overall revision.

Citation

Li S, Yang Y, Ma R, et al. Primary Sjögren's syndrome is not associated with poor outcomes after total hip arthroplasty: a retrospective case-control study with a matched cohort of osteoarthritis patients. *Clin Rheumatol*. 2022 Oct;41(10):3075-3082. doi: 10.1007/s10067-022-06256-2. Epub 2022 Jun 28. PMID: 35763156; PMCID: PMC9243796.

Association Between Thyroid Diseases and Sjögren's

Data from one meta-analysis, three retrospective studies, and three literature reviews within the past twenty years that ended June 5th, 2022, found evidence of an increased risk of autoimmune thyroid disease or hypothyroidism in patients with Sjögren's instead of hyperthyroidism.

Sjögren's and autoimmune thyroid disease have a similar pathophysiology. CD4+ T cells are predominant in the gland infiltrate and HLA-DR3 and HLA-B8 are strongly expressed among patients with both diseases. Chemokines such as CXCL10 have also been linked to glandular destruction in these pathologies.

The authors note that regular assessment of thyroid stimulating hormone (TSH) levels, aTg and thyroid peroxidase (TPO) antibody testing is crucial for early diagnosis of hypothyroidism or for evaluating risk for sjögren's patients especially those with a positive family history of thyroid disorders.

Citation

Kaur H, Alazze M, Thandavaram A, et al. Increased threat of thyroid diseases in patients with Sjögren's syndrome: A systematic review. *Cureus*. 2022 Aug 16;14(8):e28062. doi: 10.7759/cureus.28062. PMID: 36120277; PMCID: PMC9477098.

Dental Implants Improve OHRQoL in Dentate Sjögren's Patients

A multicenter, prospective, cohort study involving dentate Sjögren's Patients (n=17) and dentate non-Sjögren's controls found that the Oral Health-Related Quality of Life (OHRQoL) improved significantly in the Sjögren's group after receiving implant-supported crowns ($p < 0.05$).

Thirty-seven implants to replace missing premolars were placed in patients within the Sjögren's group and 26 implants were placed in those in the non-Sjögren's group. Marginal bone-level changes, patient satisfaction, and OHRQoL were assessed by standardized dental radiographs and validated questionnaires, respectively, at baseline and after placement of the superstructure at one, six, twelve, and eighteen months.

At eighteen months, Sjögren's patients experienced a 100% implant survival compared to the control group (96.2%) and the mean marginal bone loss was non-significant at 1.10 ± 1.04 mm and 1.04 ± 0.75 mm, respectively ($p = 0.87$). Clinical performance and all outcome measures were similar between the groups ($p > 0.05$), however, patient satisfaction, and OHRQoL remained significantly higher among controls at all incremental evaluations.

Citation

Maarse F, Fennis W, Twisk JWR, et al. Dental implants in dentate primary and secondary Sjögren's syndrome patients: a multicenter prospective cohort study. *Clin Oral Implants Res.* 2022 Sep 22. doi: 10.1111/clr.13998. Epub ahead of print. PMID: 36136091.

Association Between Parotid Swelling and the Development of (NHL) Sjögren's

A multicenter study of Sjögren's patients (n=144) and controls (n=222) found parotid swelling was an early symptom and a predictor of non-Hodgkin's lymphoma (NHL), with a longer durations of parotid swelling increasing this risk.

Parotid swelling was found in 41.8% of the Sjögren's group at symptom onset compared to 15.32% in controls (OR: 4.47, 95% CI: 2.29, 8.73; $p < 0.001$). At Sjögren's diagnosis, parotid swelling was found in 52.48% compared to 14.09% of controls (OR: 6.30, 95% CI: 3.26, 12.16; $p < 0.001$). In 108/139 cases (77.70%), parotid swelling was recorded at any time between Sjögren's

diagnosis and NHL diagnosis, as well as at the last follow-up for controls 60/222 (27.03%) (OR 10.66, 95% CI: 5.66, 20.09; $P < 0.001$).

The authors suggest an annual evaluation of parotid swelling, to include a baseline salivary gland ultrasound and biopsy, if any other salivary and lachrymal gland that is persistently swollen in Sjögren's patients. ■

Citation

DeVita S, Isola M, Baldini C, et al. Predicting lymphoma in Sjögren's syndrome and the pathogenetic role of parotid microenvironment through precise parotid swelling recording. *Rheumatology (Oxford).* 2022 Sep 5:keac470. doi: 10.1093/rheumatology/keac470. Epub ahead of print. PMID: 36063040.

Th9 Cells' Role in the Pathogenesis and Progression of Sjögren's

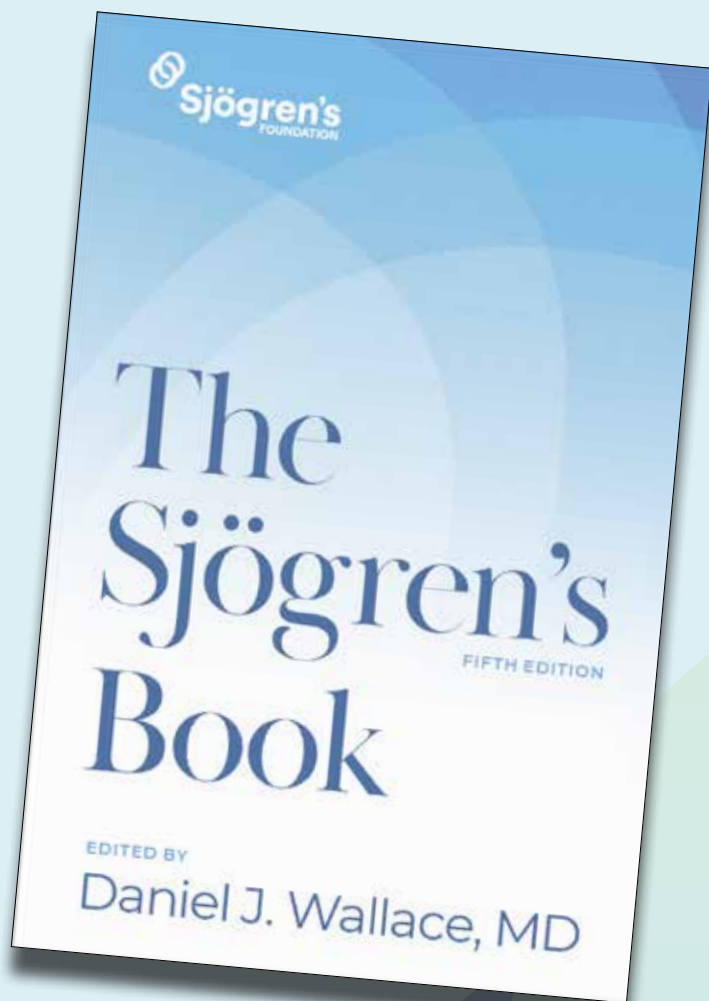
An experimental study of Sjögren's patients (n=20) and matched controls (n=20) found Sjögren's patients had significantly higher levels of Th9 CD4+ T cells and IL-9 (3.83 ± 1.12) than controls (0.34 ± 0.16 ; $t = 13.868$, $p < 0.001$). There was a significant difference in salivary flow rate between the Sjögren's group and controls (0.50×0.35 vs 4.25×0.64 , $t = 22.875$, $p = 0.001$) and the globulin level was higher in the Sjögren's group (32.73 ± 5.24) than in the control group (23.00 ± 2.62 ; $t = 7.423$, $p = 0.001$).

Salivary flow rate, ESR, globulin, complement C3, and C4 levels are believed to be closely related to the involvement of Th9+ cells in Sjögren's. Investigators found a negative correlation between the number of Th9 positive cells and salivary flow rate ($R = -0.688$, $p = 0.008$). No correlation between ESR, globulin, complement C3, and C4 levels was observed in the Sjögren's group and the number of Th9+ cells. Thus, Th9+ cells may play a role in regulating salivary flow.

Sjögren's patients had significantly elevated peripheral blood Th9 and serum IL-9 levels, which were correlated with clinical immunological indexes. It appears that Th9 cells and IL-9 are involved in the pathogenesis of Sjögren's.

Citation

Yang J, Su J, Chai K, Liu H. The role of Th9 CD4+ T cells and IL-9 during primary Sjögren's syndrome. *J Clin Lab Anal.* 2022 Aug 9:e24646. doi: 10.1002/jcla.24646. Epub ahead of print. PMID: 35944186.



New Edition

Get the latest edition of this essential Sjögren's book

The *Sjögren's Book*, Fifth Edition is a comprehensive and authoritative guide, produced by the Sjögren's Foundation and its medical advisors and edited by a leading authority on autoimmune disorders.

This expanded edition provides readers with the best medical and practical information on this disease, bringing together current thinking about Sjögren's in an easily readable and understandable book and providing important new content on areas not covered in previous editions.

With more than fifty chapters written by leading experts, this book illuminates the major clinical aspects of the disease and is loaded with practical tips and advice as well as scientific advancements in the field.

Recognized as the bible for Sjögren's sufferers, this reliable and informative guide is the first place for patients to look when they have questions about this disabling disease. It is a valuable aid that patients can use while discussing their illness with their physician and an excellent resource for family members.

\$32 members
\$38 non-members

	Non-Member	Member	Qty	Amount
The Sjögren's Book, 5th Edition Edited by Daniel J. Wallace, MD	\$38	\$32		
Shipping & Handling U.S. Mail: \$7 for first item + \$2 for each additional item				\$7.00
Total Amount				

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

Name _____ Member # _____
Address _____
City _____ State _____ Zip _____
Telephone _____ E-Mail _____









Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) payable to Sjögren's Foundation.

MasterCard VISA Discover AmEx Card Number _____

Exp. Date _____ Security Code _____ Signature _____

THIS IS Sjögren's

<p>As many as 4 MILLION AMERICANS have Sjögren's</p> <p>with an estimated 2.5 MILLION PATIENTS currently undiagnosed</p> 	<p></p> <p>9 OUT OF 10 Sjögren's patients ARE WOMEN</p> 
<p>It now takes an average of</p> <p> 2.8 YEARS to receive a Sjögren's Diagnosis</p> 	<p>The average age of Sjögren's diagnosis is 40 YEARS</p> <p>It can occur in ALL AGE GROUPS</p>  <p>Frequency appears to INCREASE WITH AGE</p>

Sjögren's ("SHOW-grins") is a systemic autoimmune disease that affects the entire body.

- Neurological problems, concentration/memory-loss, dysautonomia, headaches
- Dry eyes, corneal ulcerations and infections
- Dry nose, recurrent sinusitis, nose bleeds
- Dry mouth, mouth sores, dental decay, difficulty with chewing, speech, taste and dentures
- Swollen, painful parotid/salivary glands
- Difficulty swallowing, heartburn, reflux, esophagitis
- Fatigue, vasculitis, lymphoma, dry skin
- Recurrent bronchitis, interstitial lung disease, pneumonia
- Arthritis, muscle pain
- Abnormal liver function tests, chronic active autoimmune hepatitis, primary biliary cholangitis
- Peripheral neuropathy, Raynaud's
- Stomach upset, gastroparesis, autoimmune pancreatitis
- Irritable bowel, autoimmune gastrointestinal dysmotility
- Interstitial cystitis
- Vaginal dryness, vulvodynia (women only); chronic prostatitis (men only)



LEARN MORE
sjogrens.org



Are you looking for a meaningful volunteer experience?

Interested in making a difference in the lives of other Sjögren's patients?

Join us as a Patient Support Volunteer!

Patient Support Volunteers are seasoned Sjögren's patients who are willing to receive calls from newly diagnosed Sjögren's patients. You will provide them with support and Sjögren's information, especially about day-to-day living, coping strategies and available resources. The Foundation is looking for qualified volunteers throughout the country to be part of our growing network of support!

If you are someone who:

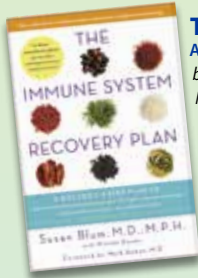
- Has been diagnosed with Sjögren's for 1 year or more
- Has been a Foundation member for at least 6 months
- Is knowledgeable about Sjögren's and the resources available to newly diagnosed patients
- Is known for being a great listener and having a positive outlook

This could be the perfect volunteer opportunity for you!

If you are interested in learning more about how to become part of our team of volunteers. Visit the QR Code below.



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.

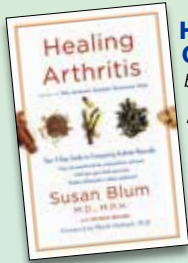
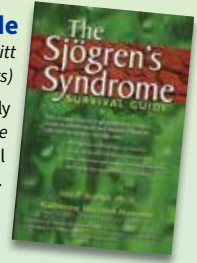
Member Price: \$22 Non-Member Price: \$25

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



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

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



A Body Out of Balance

by Ruth Fremes, 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

	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 Fremes, MA, and Nancy Carteron, MD, FACR	\$16.00	\$13.00		
Shipping & Handling U.S. Mail: \$7 for first item + \$2 for each additional item				\$7.00
		Total Amount		

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

Name _____ Member # _____

Address _____

City _____ State _____ Zip _____

Telephone _____ E-Mail _____

Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) payable to Sjögren's Foundation.

MasterCard VISA Discover AmEx Card Number _____

Exp. Date _____ Security Code _____ Signature _____



Awareness never looked so good!

Sjögren's Awareness Month Kits

Kit #1



\$32 Members
\$37 Non-Members

Kit #2 Includes all of Kit #1 plus...



Sjögren's Eyeglass Case

Sjögren's Eyeglass Cloth



\$42 Members
\$48 Non-Members

Show your support during Sjögren's Awareness Month by purchasing a limited-edition awareness kit.

Awareness comes in many different forms and this kit is designed to give you items that can create a conversation with family and friends about the disease.

These kits will only be available for a limited time. Order your kit by calling (301) 530-4420, online at www.sjogrens.org or use the form below.

	Qty.	Size: S-2XL	Total
Awareness Kit #1			
\$32 ea. Member \$37 ea. Non-Member			
New Sjögren's Foundation Cotton T-shirt			
New Sjögren's Foundation Socks			
"This is Sjögren's" Flyer			
Summary of Major Findings Document			
(3) "What is Sjögren's?" Brochures			
Awareness Kit #2			
\$42 ea. Member \$48 ea. Non-Member			
All contents of Kit #1 plus...			
Sjögren's Foundation Eyeglass Case			
Sjögren's Foundation Eyeglass Cleaner			
Shipping and Handling:			
U.S. Mail: \$7 for first item + \$2 for each additional item			\$7.00
Total Amount Due			

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

Name _____ Member # _____

Address _____

City _____ State _____ Zip _____

Telephone _____ E-Mail _____

Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) payable to Sjögren's Foundation.

MasterCard VISA Discover AmEx Card Number _____

Exp. Date _____ Security Code _____ Signature _____





Sjögren's Foundation 2023 National Patient Conference

The Sjögren's Foundation 2023 National Patient Conference *Conquering Sjögren's Together*

Friday, April 21st – 1:00 pm - 5:00 pm (EDT)

Saturday, April 22nd – 1:00 pm - 5:30 pm (EDT)

The Sjögren's Foundation invites you to join us for our 22nd annual National Patient Conference! This two-day *virtual* educational experience will help attendees understand the complexities of Sjögren's and learn more about the disease and how best to manage symptoms. As the worldwide leader in Sjögren's education, we have engaged a sensational lineup of presenters for this year's event. You will learn from leading Sjögren's experts and you will have opportunities to ask them questions, right from the comfort of your own home, in real time. Topics will include Sjögren's information about the most common symptoms of the disease, as well as manifestations patients should be aware of to protect their health. We will close our conference with a look at Sjögren's research and how it could help transform future treatment.



Register online at www.sjogrens.org



“Conquering Sjögren’s Together”

Day one – Friday, April 21st *(All times are Eastern Time)*

1:00pm Welcome and Opening Remarks

Janet E. Church

Sjögren’s Foundation President & CEO

1:10pm Sjögren’s Overview



Alan Baer, MD

Dr. Baer will present a comprehensive review of Sjögren’s disease including the range of symptoms that patients experience. He will give special attention to issues not covered by other presentations and will offer thoughts on treatment options, practical tips for

managing symptoms, labs needed for best care, and when to add specialists to your medical team.

2:00pm Exploring Sjögren’s Spotlight

2:10pm Lymphoma and Other Cancers in Sjögren’s Patients



Cole Sterling, MD

The development of cancer in Sjögren’s patients is complex and involves an interaction of multiple factors. In this program, Dr. Sterling will present an overview of cancer and how it can manifest in Sjögren’s patients with a special focus on Lymphoma and

treatment options. He will also share what patients can be on the lookout for to try and advocate early if necessary.

2:50pm Exploring Sjögren’s Spotlight

3:00pm Foundation Update



Janet E. Church

Janet Church will share current Foundation updates and will discuss the variety of clinical trials in process that bring hope to patients.

3:30pm Exploring Sjögren’s Spotlight

3:40pm Oral Manifestations in Sjögren’s



Michael Brennan, DDS, MHS

The oral program is a key presentation of this conference as approximately 93% of Sjögren’s patients report they experience symptoms associated with dry mouth. Understanding the daily care needed to minimize the impact on your oral health is critical for Sjögren’s patients.

Dr. Brennan will cover the range of issues that can be caused by dry mouth and offer recommendations for successful management. He will also share what’s new on the horizon for dry mouth and oral care.

4:20pm Product Showcase



Sjögren’s patients use a number of over-the-counter and prescription products to treat their various complications. This session will highlight an array of products that can help Sjögren’s patients learn about new product options to help live more comfortably.

4:50pm Day One Wrap-up

QUESTIONS?

Please visit our National Patient Conference page at www.sjogrens.org or call 301-530-4420

Register online at
www.sjogrens.org



“Conquering Sjögren’s Together”

Day two – Saturday, April 22nd

(All times are Eastern Time)

1:00 pm Opening Remarks & Awards

Janet Church

Sjögren’s Foundation President & CEO

1:30pm Out of Balance: Autonomic Dysfunction in Sjögren’s



Brent Goodman, MD

Do you ever feel lightheadedness upon standing or even experience episodes of passing out? Autonomic dysfunction can be seen in almost 50% of patients with Sjögren’s. In this program, Dr. Goodman will discuss how the autonomic nervous system

is affected in Sjögren’s and the different ways that it can manifest including blood pressure and heart control issues, bladder impairment, and gastrointestinal dysfunction. He will discuss what the symptoms are and ways to treat some of these manifestations.

2:10pm Exploring Sjögren’s Spotlight

2:20pm Ocular Manifestations in Sjögren’s



Esen Akpek, MD

Approximately 98% of Sjögren’s patients experience dry eye. Dr. Akpek will share how Sjögren’s impacts eyes and what you need to know about caring for your dry eyes. She will help you understand the tests that your doctor needs to perform and the available treatments

to help keep your eyes as healthy as possible. She will also share other eye findings that are manifestations of Sjögren’s but less well known.

3:00pm Exploring Sjögren’s Spotlight

3:10pm Interstitial Cystitis and Recurrent UTI’s



Monique Vaughan, MD

When you gotta go, you gotta go! Nearly 61% of Sjögren’s patients report significant urinary symptoms such as recurrent urinary tract infections (UTI’s) and interstitial cystitis, causing pain and the persistent need to urinate. Dr. Vaughan will dive into these two

troubling urological symptoms discussing the physiology, as well as treatment and management options.

3:50pm Exploring Sjögren’s Spotlight

4:00pm Vasculitis in Sjögren’s



Ghaith Noaiseh, MD

Vasculitis is when the blood vessels become inflamed resulting in the narrowing or complete occlusion of these vessels. This can cause interruption to the blood flow and damage to the supplied organs, resulting in several clinical manifestations and laboratory

abnormalities. If you have experienced purpura on your legs, you may have experienced a form of vasculitis affecting the skin. Dr. Noaiseh will give us an overview of vasculitis and discuss how it often manifests in Sjögren’s patients, what to look out for, and the treatment options available.

4:40pm Understanding Research in Sjögren’s



Blake M. Warner, DDS, PhD, MPH, ABOMP

It’s an exciting time in Sjögren’s as research investments are leading to potential therapies! We are learning more about the disease and how it may present in patients differently. In this presentation, Dr. Warner will discuss research that

has influenced our understanding of the disease and how that knowledge is translated into therapies. Learn how biological pathways may be different in each patient and how this could help us transform future treatment. He’ll finish by giving us a glimpse at current research and how it may change what we know about Sjögren’s!

5:20pm Conference Recap and Closing Remarks

Janet E. Church

Sjögren’s Foundation President & CEO

5:30pm Conference Adjourns





Conquering Sjögren's

Sjögren's Foundation Inc.
10701 Parkridge Blvd., Suite 170
Reston, VA 20191
Phone: (301) 530-4420
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

April is Sjögren's Awareness Month

Sjögren's Awareness Month was first established in 1998 when New York Congresswoman, Louise Slaughter, read it into the Congressional Record. The Foundation works to keep the spirit of national awareness alive every April with our #ThisIsSjögrens campaign.

#ThisIsSjögrens was created to highlight you and share the stories of real patients. Every patient has a unique and powerful story to share, and it is the collection of your experiences that portrays this complex disease. We not only want to raise awareness of Sjögren's, but also come together to connect "patient to patient" and share how patients are effectively coping with the disease and offer advice for others.

Every day in April we will highlight a different patient on our website and social media accounts. While each daily post will only give a small glimpse into what is Sjögren's, by the end of the month, we believe these 30 posts will showcase the complexity of the disease.

Visit www.sjogrens.org to learn more about our April #ThisIsSjögrens campaign.



Sjögren's
FOUNDATION

