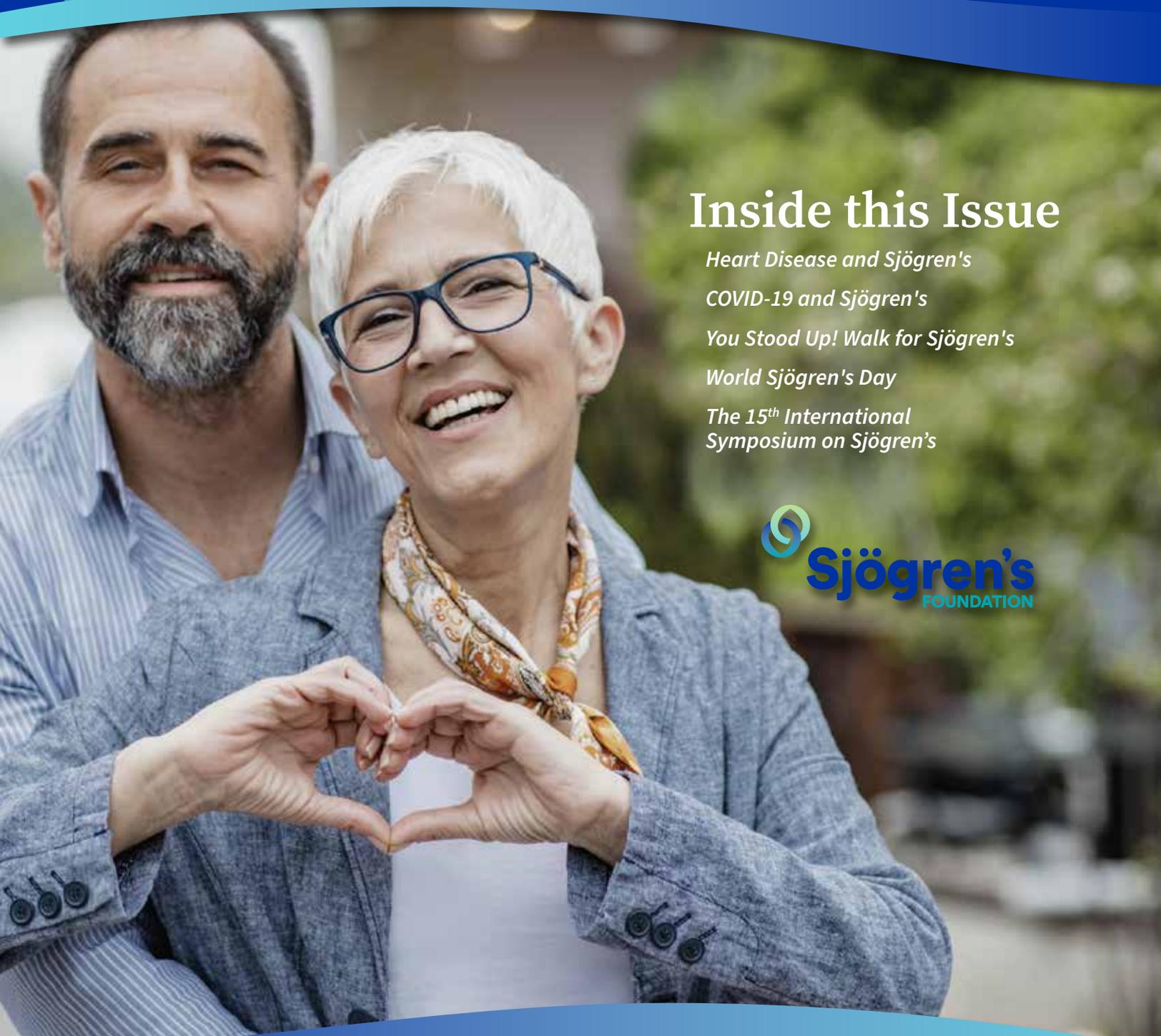


# CONQUERING Sjögren's

September/October 2022



## Inside this Issue

*Heart Disease and Sjögren's*

*COVID-19 and Sjögren's*

*You Stood Up! Walk for Sjögren's*

*World Sjögren's Day*

*The 15<sup>th</sup> International  
Symposium on Sjögren's*





### 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

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, FACP

Michael Brennan, DDS, MHS

Steven E. Carsons, MD

Nancy L. Carteron, MD, FACP

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, FACP

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, FACP

#### Chief Executive Officer

Janet E. Church

#### Editor

Elizabeth Trocchio Bryant

e-mail: [info@sjogrens.org](mailto:info@sjogrens.org)

[www.sjogrens.org](http://www.sjogrens.org)

## Table of Contents

Heart Disease and Sjögren's	3
COVID-19 and Sjögren's	7
You Stood Up! Walk for Sjögren's	10
World Sjögren's Day	13
The 15 <sup>th</sup> International Symposium on Sjögren's	15
In Memory and In Honor	19

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](http://www.sjogrens.org) or call us at: (301) 530-4420.

## CONQUERING Sjögren's

Volume 3, Issue 5



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

Copyright ©2022 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.



# Heart Disease and Sjögren's

by Nancy L. Carteron, MD, FACR



Glossary of terminology on page 5

**H**ear disease is under-recognized in Sjögren's. Risk of heart disease is increased in autoimmune diseases, including Sjögren's (Melissaropoulos 2020, Wu 2018). The following can occur in Sjögren's: accelerated atherosclerosis, heart block, pericarditis, myocarditis, pulmonary hypertension, dysautonomia, Raynaud's, increased cardiovascular risk factors (hypertension, hyperlipidemia, diabetes). The severity and duration of inflammation are important factors.

## Case Studies

Bartoloni et al (2015) looked retrospectively at a cohort of 1,343 primary Sjögren's compared to matched controls, and found **MI** ("heart attack") and **heart failure** were more common in Sjögren's. Hypertension (high blood pressure) and hypercholesterolemia (high lipids) were more prevalent and smoking, obesity, and diabetes less prevalent in Sjögren's. Intriguing observation was low white blood cell count (leukopenia) associated with increased risk of **angina**.

A meta-analysis of ten observational studies of 165,291 patients (Yong 2018) found increased cardiovascular disease and artery stiffness in Sjögren's. A meta-analysis is a statistical analysis that combines results from multiple scientific studies investigating the same question. This type of analysis can be used to identify a reproducible ("true") finding.

A case-series (Rantapaa-Dahlqvist 1993) looked at 27 consecutive Sjögren's patients with echocardiogram (ECHO, heart ultrasound). Nine patients (33%) had current or past evidence of **pericarditis**, which is inflammation of the lining around the heart (pericardium). Four of the nine patients had focal decrease

function of heart muscle (left ventricle), commonly a result of prior ischemia. Ischemia, decreased blood flow to tissue, can lead to heart damage and decreased pumping of oxygenated blood body tissues. Ten patients had angina, palpitations, dyspnea (shortness of breath), chest pressure. 13 patients reported Raynaud's, and 15 joint pain (arthralgia), with four patients having joint inflammation (synovitis). Subsequent studies have confirmed current or past pericarditis (up to 30%), and myocarditis.

Pulmonary hypertension (PH) occurs in Sjögren's, as with other autoimmune diseases. ECHO can screen for elevated right heart pressure, and right heart catheterization establish the diagnosis. PH can lead to heart dysfunction. A Turkish study (Kobak 2014) of 47 patients found elevated PASP>30 mmHg in 23%, and PASP>35 mmHg in 5 patients, by ECHO. PASP (pulmonary artery systolic pressure 25 mmHg supports a diagnosis of PH. PH leads to right-sided heart failure (cor pulmonale) and can lead to death, if not effectively treated. Left heart dysfunction, both systolic & diastolic, has also been reported in Sjögren's.

Congenital Heart Block (CHB) occurs in 2% of babies of SSA+ (Ro)/SSB (La) antibody mothers, with increased incidence if CHB occurred in prior pregnancy. Although rare, heart block has been reported in SSA+/SSB+ adults. A study of 119 CHB cases born to SSA+ mothers (Mofors 2019, Swedish National Patient Registry) found cardiovascular co-morbidity increased over time and included cardiomyopathy, heart failure, cerebral infarction and autoimmune disease. diagnosis. Also, 128 siblings of CHB affected children had increased risk of autoimmune disease over time.

continued page 4 ▼

## “Heart Disease” *continued from page 3* ▼

Increased risk of developing heart disease in Sjögren’s has been established, and as with rheumatoid arthritis and lupus, it needs to be considered in diagnosis and prevention plans. A retrospective cohort analysis of 4,175 newly diagnosed Sjögren’s found 365 patients with coronary heart disease (CHD) (Wu 2018, Taiwan National Health Insurance Research Database). CHD risk increased by 4% per year over 12 yrs. Cardiovascular disease was the leading cause of death, not lymphoma. An earlier study from Taiwan examined 3,352 primary Sjögren’s incident cases between 2005 and 2007 (Weng 2011). Estimated annual incidence was 6.0 per 100,000 inhabitants. Mortality rate was 33.4 per 1,000 case person-years for men and 11.4 for women, a 3-fold higher male mortality.

### *Established risk factors for cardiovascular disease include*

An increased index of suspicion for cardiovascular disease and thromboembolic events is warranted in Sjögren’s. Established risk factors for cardiovascular disease include:

- High blood pressure
- High lipids
- High glucose/diabetes
- Smoking
- Obesity
- Chronic kidney disease
- Chronic liver disease
- Chronic inflammation

Risk factors unique to women include: (Maffei 2019)

- Hormone medications
- Menopause
- Premature ovarian failure
- Endometriosis
- Recurrent pregnancy loss
- Phospholipid antibodies/pro-clotting

### *Summary*

- Heart disease and cerebral vascular disease are increased in Sjögren’s

- Severity and chronicity of inflammation increases risk
- Myocardial infarction, pericarditis, myocarditis, pulmonary hypertension, heart failure, heart block (conduction abnormality), arrhythmias can occur
- Modifiable risk factors: hypertension, weight, lipids, smoking, exercise, nutrition
- Female risk factors: hormones, primary ovarian failure, phospholipid antibodies
- Discuss cardiovascular risk factor assessment with your primary physician, rheumatologist, OBGYN, pulmonologist, and cardiologist for overall risk-assessment

### *Citations*

- Agca et al, EULAR recommendations for cardiovascular disease risk management in patients with rheumatoid arthritis and other forms of inflammatory joint disorders 2015/2016 update. *Ann Rheum Dis* 76(1):17-28, 2017. PMID: 27697765
- Bartoloni et al, Cardiovascular Disease Risk Burden in Primary Sjögren’s Syndrome. *J Int Med* 278:185-192, 2015. PMID: 25582881
- Beltaï et al, Cardiovascular Morbidity and Mortality in Primary Sjögren’s Syndrome: A Systematic Review and Meta-Analysis. *Arthritis Care Res (Hoboken)* 72(1):131-139, 2020. PMID: 30570824
- Kobak et al, Pulmonary Arterial Hypertension in Patients with Primary Sjögren’s Syndrome. *Autoimmune Dis*:710401.doi:10.1155/2014/710401. Epub 2014 Jan 9. PMID: 24511390
- Maffei et al, Women-Specific Predictors of Cardiovascular Disease Risk - New Paradigms. *In J Cardiol* 286:190-197, 2019. PMID: 30803890
- Melissaropoulos et al. Primary Sjögren’s Syndrome and Cardiovascular Disease. *Curr Vasc Pharmacol* 18(5):447-454, 2020. PMID: 31995009
- Mofors et al, Comorbidity and Long-Term Outcome in Patients with Congenital Heart Block and Their Siblings Exposed to Ro/SSA Autoantibodies in Utero. *Ann Rheum Dis* 78:696-703, 2019. PMID: 30808622
- Rantapää-Dahlqvist et al, Echocardiographic Findings in Patients with Primary Sjögren’s Syndrome. *Clinical Rheumatology* 12:214-218, 1993. PMID: 8358981
- Weng et al, Incidence and Mortality of Treated Primary Sjögren’s Syndrome in Taiwan. *J Rheum* 38:706-708, 2011. PMID: 21239759
- Wu et al, Increased Risk of Coronary Heart Disease among Patients with Primary Sjögren’s Syndrome. *Sci Rep* 8:2209, 2018. PMID: 29396489
- Yong et al, Association between Primary Sjögren’s Syndrome, Cardiovascular and Cerebrovascular Disease. *Clinical and Experimental Rheumatol* 36:190-197, 2018. PMID: 29600936



## Heart Disease and Sjögren's Glossary

**Angina:** a type of chest pain caused by reduced blood flow to the heart. A symptom of coronary artery disease.

**Arrhythmias:** a problem with the rate or rhythm of your heartbeat. It means that your heart beats too quickly, too slowly, or with an irregular pattern.

**Atherosclerosis:** is a hardening and narrowing of your arteries caused by cholesterol plaques lining the artery over time. It can put blood flow at risk as your arteries become blocked.

**Cardiomyopathy:** a disease of the heart muscle that makes it harder for your heart to pump blood to the rest of your body. Cardiomyopathy can lead to heart failure.

**Congenital heart block (CHB):** is a rare condition that affects the heart's electrical system, which controls and coordinates its pumping function. In infants affected by this condition, the electrical signal that spreads across the heart and causes it to contract and pump blood, is slowed or completely interrupted.

**Congestive heart failure (CHF):** occurs when your heart muscle doesn't pump blood as well as it should. Certain conditions, such as narrowed arteries in your heart (coronary artery disease) or high blood pressure, gradually leave your heart too weak or stiff to fill and pump efficiently.

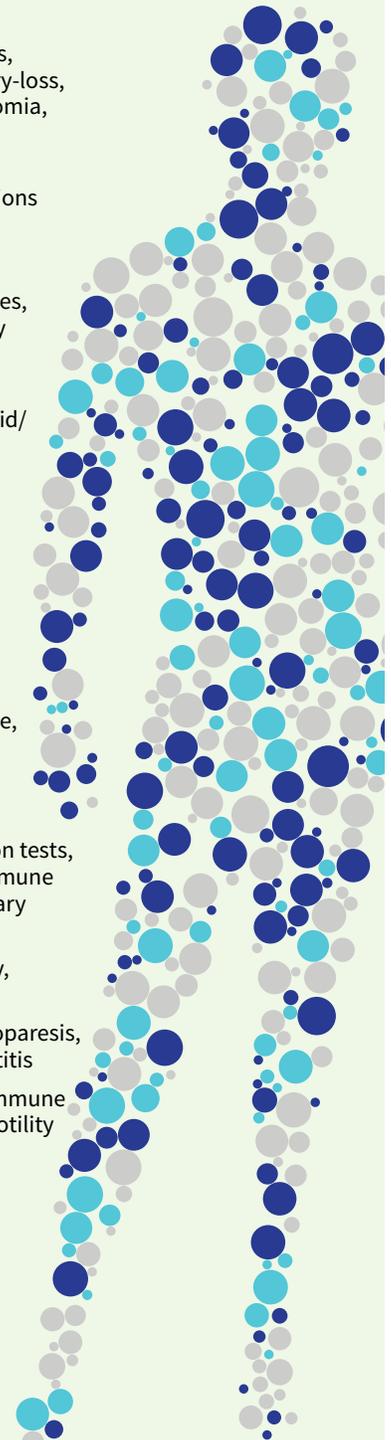
**Diastolic:** relating to the phase of the heart-beat when the heart muscle relaxes and allows the chambers to fill with blood.

**Dysautonomia:** is an umbrella term used to describe several different medical conditions that cause a malfunction of the Autonomic Nervous System. The Autonomic Nervous System controls the "automatic" functions of the body that we do not consciously think about, such as heart rate, blood pressure, digestion, dilation and constriction of the pupils of the eye, kidney function, and temperature control.

*continued page 6* ▼

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

- Neurological problems, concentration/memory-loss, "brain fog," dysautonomia, headaches
- Dry eyes, corneal ulcerations and infections
- Dry nose, recurrent sinusitis, nosebleeds
- 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, skin sensitivity to UV light
- Recurrent bronchitis, interstitial lung disease, pneumonia
- Arthritis, joint/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, interstitial nephritis including renal tubular acidosis, glomerulonephritis
- Vaginal dryness, vulvodynia; chronic prostatitis



LEARN MORE  
[sjogrens.org](http://sjogrens.org)

**“Glossary”** *continued from page 5* ▼

**Dyspnea:** shortness of breath. Often described as an intense tightening in the chest, air hunger, difficulty breathing, breathlessness or a feeling of suffocation.

**Echocardiogram (ECHO):** heart ultrasound that uses sound waves to produce images of your heart. This common test allows your doctor to see your heart beating and pumping blood.

**Heart palpitations:** the feelings of having a fast-beating, fluttering or pounding heart.

**Hyperlipidemia:** also known as dyslipidemia or high cholesterol, means you have too many lipids (fats) in your blood.

**Hypertension:** high blood pressure.

**Myocarditis:** an inflammation of the heart muscle (myocardium). Myocarditis can affect your heart muscle and your heart’s electrical system, reducing your heart’s ability to pump and causing rapid or abnormal heart rhythms (arrhythmias).

**Pericarditis:** swelling and irritation of the pericardium, the thin saclike membrane surrounding your

heart. Pericarditis often causes chest pain and sometimes other symptoms. The sharp chest pain associated with pericarditis occurs when the irritated layers of the pericardium rub against each other.

**Phospholipid antibodies:** when antibodies attack phospholipids, cells are damaged. This damage causes blood clots to form in the body’s arteries and veins. (These are the vessels that carry blood to your heart and body.)

**Pulmonary hypertension (PH):** a type of high blood pressure that affects the arteries in your lungs and the right side of your heart.

**SSA:** Sjögren’s associated antigen A (anti-Ro). About 40-60% of Sjögren’s patients are positive for anti-SSA.

**SSB:** Sjögren’s associated antigen B (anti-La). About 20-30% of Sjögren’s patients are positive for anti-SSB.

**Synovitis:** inflammation of the tissues lining a joint.

**Systolic:** relating to the phase of the heartbeat when the heart muscle contracts and pumps blood from the chambers into the arteries. ■

# Protect Your Teeth from Dry Mouth



**Dry mouth can wreak havoc on your teeth by creating an acidic oral environment that favors harmful plaque bacteria.**

**BasicBites®** soft chews provide extra enamel support by coating and replenishing teeth with key nutrients also found in healthy saliva. These vital teeth-protecting nutrients can be in very short supply if you have dry mouth.

- **Activates beneficial pH-raising bacteria**
- **Fortifies enamel - Neutralizes sugar acids**
- **Free Shipping on all orders - Quantity Discounts Available**



*“Through my personal experience with Sjögren’s Syndrome coupled with my dental hygiene background, I have become an expert on dry mouth (xerostomia) and methods to address its symptoms. BasicBites are a great and delicious tool to combat the effects dry mouth can have on your oral pH and your teeth. That’s why I use BasicBites as a part of my daily routine.”*

Brooke Crouch is a registered dental hygienist, published author, national speaker, consultant, and Sjögren’s patient. She is the founder of Brooke Crouch Dental Consulting LLC.

**Protect your teeth today!**

Visit [basicbites.com/sjogrens](http://basicbites.com/sjogrens) or call 516-484-4500

©2022 Ortek Therapeutics Inc. BasicBites is a registered trademark of Ortek Therapeutics Inc.

**Sugar-Free**  
*Just 15*  
**calories each**



**Ortek**  
Therapeutics, Inc.

*A Oral Care Beyond the Brush*

# COVID-19 & Sjögren's: What You Need to Know about COVID BA-5 and Vaccines

*Interview with Cassandra Calabrese, DO, and member of  
the Foundation's COVID-19 Vaccination Committee*



**T**he Sjögren's Foundation understands that many patients continue to have questions about COVID-19, new variants, and the safety and effectiveness of the vaccine.

While we are all tired of being cautious about COVID-19, now is not the time to let down our guard! The new variant of Omicron called BA-5 is the most infectious variant yet and as Sjögren's patients, we must stay vigilant about the vaccine, masking, and hand washing. It is also worth looking at the timing of your last booster shot to determine your best plan to stay safe. Vaccination and boosters are still our best defense to either not contracting COVID-19 or if you do, being able to avoid serious infection and possible hospitalization.

In better news, there are now excellent tools in our toolbox to treat symptomatic COVID-19, including two oral antivirals (PAXLOVID™ and molnupiravir) and a monoclonal antibody called bebtelovimab. These treatments are all indicated for persons with risk factors for getting extreme sickness with COVID-19, which includes age of 65 or older, various co-morbidities (like chronic lung disease, diabetes, and others) and those on immunosuppressive medications. If you are concerned you might have COVID-19, it's important to quickly do a rapid home test as well as call your doctor to see if you are eligible for one of these treatments.

To help us understand more about BA-5 and what we need to do now, Dr. Cassandra Calabrese is answering some questions to guide us to our best plan as Sjögren's patients.

**Q** *Dr. Calabrese, can you explain what the new COVID-19 Omicron BA-5 variant is and how prevalent it is in the US? Is this the only variant now?*

**A** BA.5 is currently the dominant circulating variant in the U.S. as well as worldwide, making up about 80% of cases. It is a subvariant of Omicron. The remainder of cases are due to other Omicron subvariants, like BA.4.

**Q** *What is recommended, in terms of vaccines/boosters and safety protocols to avoid contracting this variant?*

**A** It is recommended to be up to date with COVID-19 vaccines and boosters, which remains challenging given the ever-changing recommendations, and because recommendations differ based on immune status (immunocompromised vs. not).

Currently, for non-immunocompromised persons, it is recommended to receive the initial two mRNA vaccines (Pfizer or Moderna), followed by a 3<sup>rd</sup> booster dose as well as a 4<sup>th</sup> booster dose. For immunocompromised persons, it is recommended to receive three initial mRNA vaccine doses, followed by a 4<sup>th</sup> and in some cases a 5<sup>th</sup> dose (boosters). The 5<sup>th</sup> dose recommendation is based off the concept that vaccine protection wanes over time, but there are very little

*continued page 8 ▼*

## ***Are patients with Sjögren's Immunocompromised/Immunosuppressed?***

Not all Sjögren's patients have compromised immune systems. This specific risk factor is for those who regularly take drugs to suppress the immune system. Examples include prednisone, methylprednisolone, Imuran, azathioprine, methotrexate, leflunomide, Arava, CellCept, mycophenolate, Rituxan, cyclophosphamide.

Please note that hydroxychloroquine (Plaquenil) does NOT suppress your immune system and does not increase any risk for a more serious illness from COVID-19.

**“COVID-19”** *continued from page 7* ▼

data demonstrating benefit of getting a 5<sup>th</sup> dose in immunocompromised persons. It is not wrong to get a 5<sup>th</sup> vaccine if recommended but have not told any of my patients to chase after this 5<sup>th</sup> dose quite yet.

**Q** *It's been over six months since my last booster shot, do I need another one? What if I got a booster 3 months ago or have had COVID-19 in the last few months?*

**A** The answer to this question must factor in a couple things, with the most important being has the person had COVID-19 infection. For persons who have received 3 or 4 vaccines plus having COVID-19 infection within the past 6 months, that infection essentially counts as an “immune boost,” in which case I have been recommended patients to hold off for the “Fall booster.”

**Q** *Do the current Pfizer and Moderna vaccines/boosters protect me against this variant?*

**A** While the currently vaccines are not formulated to specifically protect us against BA.4, all the vaccines currently protect us against severe COVID-19 infection.

**Q** *What is the new Novavax vaccine? Is it interchangeable like getting either Pfizer or Moderna booster?*

**A** It is very exciting to have a new COVID-19 vaccine with a different platform/technology, but Novavax is currently recommended only for initial vaccines series, not as a booster. This would be for people who have not yet received any COVID-19 vaccines. I suspect that one day it will be available as a booster. For now, it is a great option for anyone who has not been vaccinated against COVID-19 due to allergy or contraindication to one of the other vaccines.

**Q** *Is EVUSHELD™ an option for protecting me against BA-5 and does it matter if I'm taking biologic? What if I got EVUSHELD 3 or 6 months ago?*

**A** Evusheld is an IM injection of two monoclonal antibodies designed to provide protection against COVID-19 infection for up to six months. It is

authorized for use in immunocompromised persons on medications that blunt COVID-19 vaccine responses (like RITUXAN® [rituximab] and CellCept® [mycophenolate mofetil]), as well as persons who have contraindications to receiving COVID-19 vaccines. If you received Evusheld, there are now recommendations to receive another dose after six months. So far, it appears to be protective against BA.5.

**Q** *Any statement about immune compromised to help guide people?*

**A** I encourage my patients to maintain common sense by practicing good hand hygiene, masking in crowded public spaces including at airports and on airplanes, and surround themselves with smart, vaccinated persons. Unfortunately, at this point it is not reasonable to expect to never get COVID-19, so being aware of exposures, symptoms, knowing when to test and who to call to ask about treatments like PAXLOVID™ is very important.

**Q** *Is it important to be continue wearing masks? How effective is masking and hand sanitizing for protecting us against current variants?*

**A** YES! We need to continue to wear masks and washing/ sanitizing our hands to protect ourselves and our community.

**Q** *What is your personal safety protocol, and what would you add to a protocol for a Sjögren's patient?*

**A** Again, I encourage my patients to maintain common sense by practicing good hand hygiene, masking in crowded public spaces including at airports and on airplanes, and surround themselves with smart, vaccinated persons. Unfortunately, at this point it is not reasonable to expect to never get COVID-19, so being aware of exposures, symptoms, knowing when to test and who to call to ask about treatments like Paxlovid is very important.

*Thank you Dr. Calabrese for keeping us informed about COVID-19, vaccines, and new therapies that help us stay as safe as possible. Visit [www.sjogrens.org](http://www.sjogrens.org) to view all the Foundation's COVID-19 Updates for Sjögren's patients and General Vaccine Information. ■*

# Team Sjögren's Goes Turkey!

*This Thanksgiving, we hope you will consider participating in Team Sjögren's Goes Turkey!*

What a great way to start your day of giving thanks— representing Team Sjögren's in your community with our special Turkey Trot T-shirt design. By purchasing a T-shirt or kit and walking or running in your area, you are increasing awareness for Sjögren's and helping raise crucial funds for Sjögren's research.

Even if there's not an official Turkey Trot race in your area this year, consider creating your own! Ask family and friends to join you for a morning walk in your neighborhood on Thanksgiving morning while wearing your Sjögren's Turkey Trot T-shirts!



***Kits will ship November 1<sup>st</sup>***

## **Kit 1 Includes: \$35**

- New Team Sjögren's Short Sleeve Cotton T-shirt
- New Sjögren's Foundation Face Mask
- New Certificate of Participation and Medal
- "I am stronger than my Sjögren's" wristband
- 3 "What is Sjögren's?" Brochures

## **Kit 2 Includes: \$45**

- New Team Sjögren's Long Sleeve Cotton T-shirt
- New Sjögren's Foundation Face Mask
- New Certificate of Participation and Medal
- "I am stronger than my Sjögren's" wristband
- 3 "What is Sjögren's?" Brochures

*Order your Team Sjögren's Turkey Trot Kit by calling (301) 530-4420, or online at [www.sjogrens.org](http://www.sjogrens.org).*



*To learn more about the Team Sjögren's Training program, where you can train for a 5K, 10K or Half-Marathon, email Kalla at [Kford@sjogrens.org](mailto:Kford@sjogrens.org).*



## *Thank you for supporting a Fall 2021 – Spring 2022 Walk for Sjögren's!*

**W**alk for Sjögren's is a national awareness and fundraising program that takes place across the country every fall and spring. It's an amazing series of events where patients build community together, interact with Sjögren's experts, and raise funds for important initiatives. While the Sjögren's Foundation is currently planning the fall Walk for Sjögren's events, we wanted to take a moment to thank everyone who stepped up by supporting our Walks this past year! The Foundation continued to hold virtual events and our Sjögren's community really Sjö-ed Up by participating in one of our regional virtual Walks for Sjögren's. These events were intimate and very rewarding bringing the Sjögren's community together in the best way possible. It was exciting to see the increase in participation by holding the walks virtually, allowing the walk participants to invite their friends and family to join them at the event regardless of where they were located.

Our success is because of YOU, our amazing volunteers, and supporters. Thank you for being a part of our journey to conquer the complexities of Sjögren's. The funds raised allow us to continue providing valuable programs and services, advocating for

patients, and funding research to change the future of Sjögren's. Thanks to your support, we raised over \$248,000 from Foundation Walk Events!

### *Thank you for Supporting a Fall 2021– Spring 2022 Walk for Sjögren's*

The Foundation was thrilled and honored to have Horizon as our 2022 National Walk Sponsor. Thank you, Horizon, for your generosity, support, and commitment to our Sjögren's community and our fight against Sjögren's! We also thank Eye Eco and Barajas Family Trust for sponsoring every Walk this year. We were truly grateful for ALL our amazing Walk sponsors at every level. Every single sponsor demonstrated a commitment to supporting local Sjögren's communities while generously impacting the overall success of the Walks.

### **Our Fall 2021 Virtual Walk for Sjögren's events:**

- New England Walk for Sjögren's
- California Walk for Sjögren's
- New York State Walk for Sjögren's
- Pacific Northwest Walk for Sjögren's



All fall Foundation Walk events will be held virtually. Patients can now sign-up for a fall virtual Walk and celebrate their circle of strength by including their family and friends. We hope that you will join us and use your voice to help raise awareness and funds in your community.

## **October 2022**

**New England Walk for Sjögren's**  
*Saturday, October 1, 2022*

**West Coast Walk for Sjögren's**  
*Saturday, October 22, 2022*

**New York State Walk for Sjögren's**  
*Saturday, October 22, 2022*

**Our Spring 2021 Virtual Walk for Sjögren's events:**

- Southwest Walk for Sjögren's
- Florida & Georgia Walk for Sjögren's
- Mid-Atlantic & National Walk for Sjögren's
- Philadelphia Tri-State Walk for Sjögren's
- Colorado Walk for Sjögren's
- Texas Walk for Sjögren's

*Thank you to everyone who joined and helped increase awareness by being a part of one of our events.*



## Thank You to our National, Presenting and Major Sponsors



National Walk Sponsor



### Presenting and Major Walk Sponsors

\* Presenting Sponsors in Bold

#### Mid-Atlantic & National

Eye Eco  
Barajas Family Trust  
Arthritis & Pain Associates  
of PG County  
Arthritis & Rheumatism  
Associates, P.C.  
Loudoun Smile Center  
Johns Hopkins Jerome L.  
Greene Sjögren's Center  
Ben & Jerry's - Rockville, MD  
Kathy & Denny Lawrence

#### Texas

**The Bromberg Family**  
**The Rubenstein Family**  
Eye Eco  
Barajas Family Trust  
Fagadau, Hawk, & Swanson, MD  
Houston Methodist

#### Colorado

#### Colorado Eye Consultants Denver Tech Dentistry

Eye Eco  
Barajas Family Trust  
Colorado Center for  
Arthritis & Osteoporosis  
Jim & Joan Walsh Foundation

#### Pacific Northwest

Eye Eco  
Barajas Family Trust  
The Sjögren's Clinic at the UC  
Berkeley  
Kantor & Kantor

#### Florida & Georgia

**Oil Solutions Group**  
Eye Eco  
Barajas Family Trust

The Wixson Family  
The Fred R. Fernandez &  
Irma R. Rodriguez Foundation  
North Georgia  
Rheumatology Group

#### California

Eye Eco  
Barajas Family Trust  
Gonda Family Foundation  
Intrepid Eye Society  
The Sjögren's Clinic at  
the UC Berkeley  
Kantor & Kantor  
Wallace Rheumatic  
Studies Center  
Ziena Eyewear

#### New York

Eye Eco  
Barajas Family Trust

The Axelrod &  
Harkavy Families  
The Herder Family  
The DeFruscio Family  
Nancy Roberts  
Casale Rent-All

#### Philadelphia Tri-State

**The latesta Family**  
Eye Eco  
Barajas Family Trust  
Leventhal Sutton & Gornstein  
Bassett Home Furnishings  
Metal Prep Company, Inc.  
Penn Sjögren's Center &  
Division of Rheumatology  
Scheie Eye Institute  
Penn Medicine Valley Forge  
St. Luke United

Methodist Church  
The Vivino Family

#### Southwest

Eye Eco  
Barajas Family Trust  
Mayo Clinic  
The Gales Family  
The Kelley Family  
The Ruth Family  
Gilbert Center For  
Family Medicine

#### New England

Eye Eco  
Barajas Family Trust  
Rheumatology Associates  
The Taylor Family  
The Caron Family in Loving  
Memory of Karen T. Caron

**PRESERVATIVE FREE**

**RECOMMENDED DOCTOR CREATED**

**thera tears**  
dry eye therapy  
LUBRICANT EYE DROPS

**A Drop Like No Other™**

**IMMEDIATE LONG LASTING RELIEF**

**Like No Other Dry Eye Drop in the World**

Discover the silky hydration of TheraTears® with the 5 vital electrolytes found in natural tears.

Learn more at [theratears.com](http://theratears.com)

# World Sjögren's Day 2022



On July 23<sup>rd</sup>, people from around the world joined together in recognizing World Sjögren's Day. The Sjögren's Foundation was pleased to see more than 3,000 downloads of the Sjögren's fact sheet, and the thousands of individuals reached via social media to share their Sjögren's journey and support other patients.

The Foundation was also grateful for all the generous donations we received in recognition of World Sjögren's Day. New this year, the Foundation was extremely excited to have Horizon Therapeutics pledge a dollar-for-dollar match this year up to \$30,000. Because of Horizon's amazing match, the Foundation saw the most funds ever raised on World Sjögren's Day with a total raised of over \$60,000! We sincerely thank Horizon for helping make this the best World Sjögren's Day ever.

World Sjögren's Day was a great success, increasing much needed awareness about this life-altering disease, and raising valuable funds to further the Foundation's research and awareness efforts. But while an impact was certainly made, one day alone is not enough to conquer the complexities of Sjögren's. Even though World Sjögren's Day has now passed, the fight against Sjögren's certainly continues!

We hope everyone will stay engaged with the Foundation and we encourage you to contact the Foundation if you have any questions, would like any additional information, are interested in volunteering or getting further involved in any way, or if we can assist you or a loved one fighting Sjögren's.

Thank you for all you do to increase awareness about Sjögren's. Together we will make a difference! ■

*Supporting Saliva's Natural Defenses*



## Proven Enzyme Formulation

for **Dry Mouth Care**

[www.SALIVEA.com](http://www.SALIVEA.com)

Available at:  
**amazon**

 @saliveacare  /salivedrymouthcare



# Sjögren's Foundation 2022 Fall Focus Conference

October 15, 2022  
12pm – 4:30pm ET

## *Join us on October 15<sup>th</sup> for the Sjögren's Foundation Fall Focus Conference: Wellness Strategies to Help Manage Sjögren's Symptoms*

**A**t the Sjögren's Foundation, we know that living with this disease is challenging and when you add the stress of daily life it can be difficult to make your wellness choices a priority. Even with the best intentions, researching and understanding these natural wellness strategies is time consuming and confusing. This conference is designed to help you understand the science behind everyday lifestyle choices and the impact they may have on our bodies and our Sjögren's, with the goal of empowering you to make the best choices to help manage inflammation and symptoms.

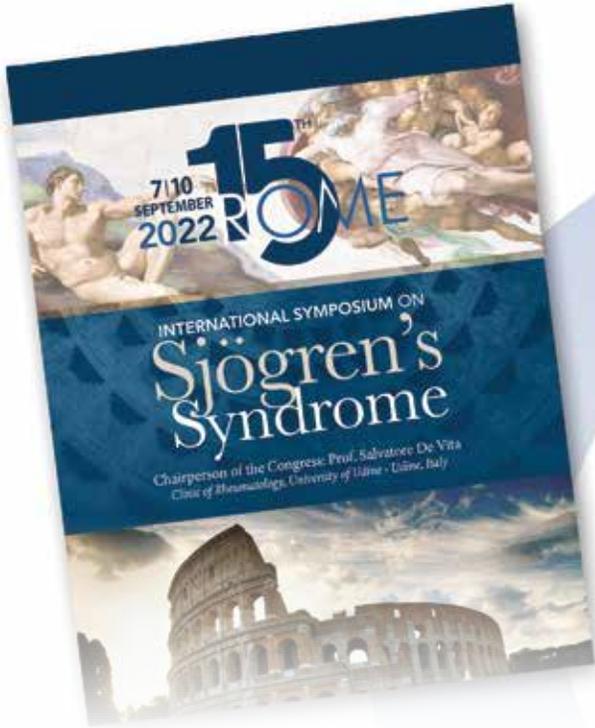
This virtual conference can be enjoyed from your preferred location and will be delivered by experienced professionals who have committed their lives to understanding their areas of expertise. These experts will dive into the science of how stress, food, pain, and exercise impact your body, then they will give you the knowledge and tools you need to try new wellness strategies to compliment your Sjögren's management plan!

*At this year's Fall Focus Conference you will hear from experts on these key wellness topics:*

- The Physical Impact of Stress and Its Relationship to Sjögren's Symptoms
- The Effect of Sleep Disturbance on Pain and Mental Health
- Nutrition Planning for Autoimmune Health
- How Exercise Can Reduce Fatigue and Ease Inflammation

*Conference details and registration are available  
on the Foundation's website – [www.sjogrens.org](http://www.sjogrens.org)  
or by scanning the QR code.*





# Sjögren's Foundation In Action!

*The 15<sup>th</sup> International Symposium on Sjögren's*

The Sjögren's Foundation is excited to be on the front lines during the upcoming International Symposium on Sjögren's (ISSS), to be held in Rome, Italy, September 7-10! This event marks the one time that ALL healthcare professionals (HCPs) from different specialties, researchers, industry, government agencies, and patient leaders gather together to hear the latest information on Sjögren's and engage in discussions around current issues in research and management and treatment.

The Foundation's CEO, Janet Church, Vice President of Medical and Scientific Affairs, Kathy Hammitt, Director of Research and Scientific Affairs, Matt Makara, and many of our Medical and Scientific Advisory Council members will participate in the programs and interact with key international leaders in Sjögren's. Presentations include sessions on pathogenesis, lessons learned from the association with and overlap of Sjögren's with other autoimmune diseases, the need for multi-specialty collaborative care, patient stratification for better clinical management and more successful clinical trials, the debate on lip biopsies versus salivary gland ultrasound, lymphoproliferation – what this means for patients and how it is best monitored, evolving topics in new therapies and health policies, international cooperation, and improving knowledge and patient care through the use of new technology and partnerships between HCPs and engineers.

**Language matters!** We are bringing our Foundation's dialogue about nomenclature to Italy. A full

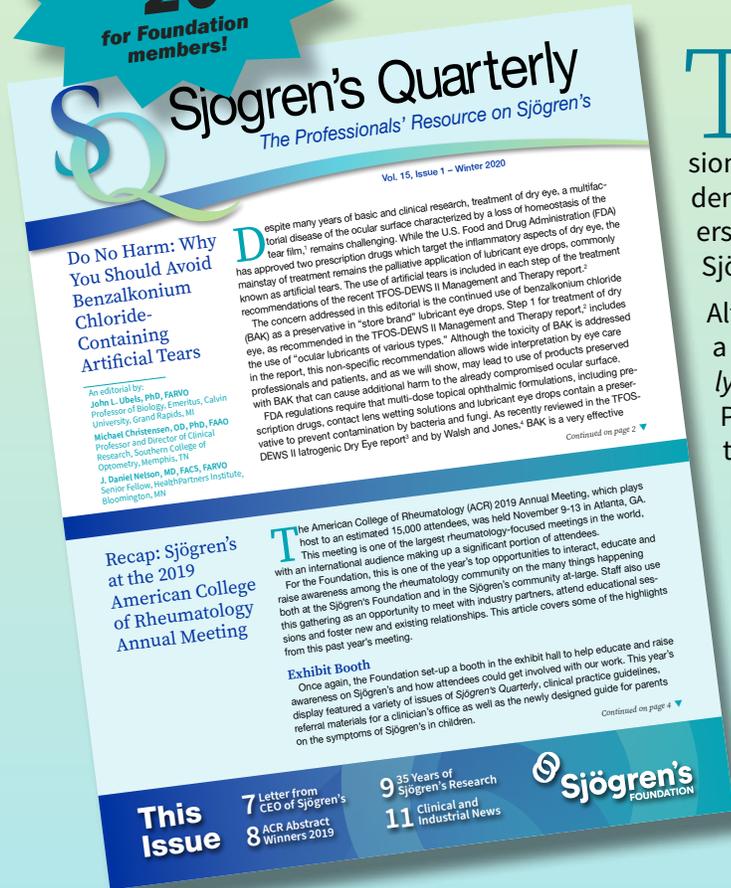
session is devoted to this critical topic, with our Foundation's Medical and Scientific Advisory Council Chair, Dr. Alan Baer, leading the charge for us and partnering with Dr. Manuel Ramos Casals of Barcelona to take the discussion to the international stage. After gathering input from patients on all continents, Kathy Hammitt, a patient herself, will convey the patient view on why some words are denigrating and make our lives harder while a change in the words we use can lift us up and help validate our experiences. WE know that words used to define and describe our disease have repercussions for all stakeholders and especially patients. Hammitt serves on the Steering Committee of this international initiative, and our Foundation's voice will stay strong as we work to garner consensus on behalf of all patients around the world.

The Foundation will present three posters focused on our *Living with Sjögren's* national patient survey, our survey on COVID-19 and Sjögren's, and our clinical practice guidelines initiative. In addition, Foundation staff are authors on six more posters, bringing our visibility to an all-time high of nine posters with Foundation involvement. And finally, our own Foundation's Hammitt was invited to speak on patient needs and how a patient advocacy organization such as ours can play a significant role in transforming the outlook for our disease by communicating the wide array of burdensome symptoms, educating health-

*continued page 18* ▼

# Stay informed. Stay aware. Be your own best medical advocate.

4 issues for just  
**\$20**  
for Foundation  
members!



To increase professional awareness about Sjögren's, the Foundation publishes the *Sjögren's Quarterly* – a professional resource geared toward medical and dental professionals, clinicians, researchers, and anyone interested in the latest in Sjögren's research findings and treatments.

Although the content is primarily written for a professional audience, *Sjögren's Quarterly* is not just for doctors and researchers. Patients may benefit from the information, too.

If you are interested in subscribing to *Sjögren's Quarterly*, we are offering a special introductory rate of just \$20 for Foundation members. Take charge of your healthcare by keeping on top of all the best medical information available.

Subscribe to *Sjögren's Quarterly* today, and you might just teach your doctor a thing or two about Sjögren's.

	Non-Member Price	Member Price	Qty	Amount
A one-year subscription to the <i>Sjögren's Quarterly</i>	\$50.00	\$20.00		
<b>Total Amount</b>				

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

Name \_\_\_\_\_  
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 \_\_\_\_\_



# 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](http://www.sjogrens.org/living-with-sjogrens/clinical-trials)

“ISSS” continued from page 15 ▼

care practitioners (HPCs) who might see a Sjögren’s patient, increasing corporate interest in Sjögren’s so that new therapies are developed, ensuring good clinical trial design so therapies have a chance to make it to market, bringing all stakeholders together so the voices of HCPs and patients everywhere join in unison to produce a clear and broadly heard message, driving change in health policies to relieve patient cost burdens, and increasing recognition that Sjögren’s is systemic, serious, and prevalent!

We are looking forward to a gathering of the International Sjögren’s Network, made up of leaders from international patient groups. This special event provides us with an opportunity to learn from one another and create a shared vision so that patients everywhere move forward together to tackle patient needs.

The ISSS brings unique opportunities for us with the Sjögren’s Foundation to engage in high level discussions with leaders from around the world in health-care management, research, and industry so that together, we change the face of Sjögren’s and create a better future for all of us. Look for more information about the ISSS on the Foundation website and in the next issue of the *Conquering Sjögren’s* newsletter. ■

# IT’S TIME

## United Way Combined Federal Campaign State Payroll Deduction

Each fall your local United Way, Combined Federal Campaign, state employee, and private employer payroll deduction campaigns begin. We hope you will remember the Sjögren’s Foundation when choosing where to allocate your donation. **(CFC #10603)**

If we are not listed on the contribution form, you usually may write in the Sjögren’s Foundation.

Tell your co-workers, friends, and family members how important it is to choose and write in the Sjögren’s Foundation on their campaign form, too.

If your employers will not allow you to write in the Sjögren’s Foundation, remind them that we are a national non-profit 501(c)3 organization and qualify for most payroll deduction campaigns. If they need more information, please contact the Foundation at (301) 530-4420.

**Just think – every dollar counts.**

Last year alone – thanks to those who chose to give through their employer’s payroll campaign – the Sjögren’s Foundation was able to increase its research and awareness commitments.

Remember, the Foundation has received the:



## Reliable Dryness Relief



Feels like your own natural moisture



@luyourvagina  
/luvenacare

To Learn More:  
Visit [Luvenacare.com](http://Luvenacare.com)



## IN MEMORIAM

**In Memory of Ann Basile**  
Lynn Battista

**In Memory of Cheryl Nolting**  
Hochstetler Milling  
Plyco Corporation  
Carla Nolting

**In Memory of Elaine Harris**  
Cynthia Hall  
Frances and Phil Ohringer  
Candy and Ira Feinberg  
Holly Reaves  
Janice D'Amato  
Jessica Levin  
AstraZeneca

**In Memory of Ella Sisler**  
Darla Rae  
Joe Sisler

**In Memory of Gable McMichen**  
Krista McMichen

**In Memory of Heidi Ann Burke**  
Nikki Diamond-Jones  
John Burke

**In Memory of Helen Kinlan**  
Patrick Kinlan

**In Memory of Jan Gordon**  
Kevin McCaffrey

**In Memory of Jean Marie Buckley**  
Debbi Frank

**In Memory of Joan Mangani**  
Joy Brown

**In Memory of Joshua Behan**  
Georgia Cameron  
Michelle Pierceall  
Laury and Chris Browning  
Jerry Metz

**In Memory of Lisa Sarnoff**  
Elaine Levin

**In Memory of Lucille Adler**  
Susan Mauro  
Maria Parente

**In Memory of Lucy and Jerry Rose**  
Anne Rose

**In Memory of Marjorie Cohen**  
Lester Jacobson

**In Memory of Sherrill Umbstead**  
Patrick Smith

**In Memory of Teresa Vitale**  
Thomas Vitale

**In Memory of Vera Warsager and Jane Young**  
Marchieta Young

## IN HONOR

**In Honor of Adrienne Jones**  
Ariel Weber

**In Honor of Allison Tam**  
Jeffrey Puglisi  
Joe Puglisi

**In Honor of Annie Hanania**  
Sarah Natale

**In Honor of David Schrader**  
Clare and Paul Schrader

**In Honor of Ella Witalec**  
Daniel Witalec

**In Honor of Everyone with Sjögren's**  
Kathleen Nichols

**In Honor of Janet Church**  
Don Thomas

**In Honor of Jessica Levy**  
Maria Davis

**In Honor of Katherine MacDonald**  
Jeannette Mueller

**In Honor of Kathleen Whittaker**  
Leroy Whittaker

**In Honor of Ken and Anne Economou**  
Debbie Rosenfeld

**In Honor of Kenneth Glass**  
Merle Glass

**In Honor of Kristi Alexander**  
Emma Cox

**In Honor of Liz Perry**  
Don Perry

**In Honor of Matthew Benedict**  
Sandra Benedict

**In Honor of Mr. and Mrs. Clemens B Schaub**  
Jacqueline Jacobs

**In Honor of Rose Young**  
Rose Young

**In Honor of Susan Mark**  
Mom and Dad Feingold

**In Honor of Valerie Bowles**  
Carol Dillon

**In Honor of Wynne Kelley**  
Patricia Nelson

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



## 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*



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

**A**ttend 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](http://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

