

CONQUERING Sjögren's

May/June 2021

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Letter from CEO, Janet E. Church



*Janet E. Church
Sjögren's Foundation President and CEO*

It is with great enthusiasm that I am writing my first newsletter update as the new President and CEO of the Sjögren's Foundation. As a Sjögren's patient myself, I understand the challenges of living every day with Sjögren's. And I am extremely honored to lead this remarkable organization as we fight for the millions of people suffering with this disease.

Many of you know me as a patient advocate supporting the Foundation as a member of the Board of Directors for eight years and Board Chair for the past three years. But you may not know my story. Like so many other Sjögren's patients, I had a six-year journey to receive a correct diagnosis. It wasn't until I was hospitalized for aseptic meningitis that my doctors realized I was seriously ill. It was nine months after my hospitalization that I was correctly diagnosed. It was then that I was told that Sjögren's was the "easy autoimmune disease." I did not understand how something significantly altering my life could be considered easy!

Then I found the Sjögren's Foundation, where I learned about my disease and how it can impact a patient's life. It was the Foundation that confirmed for me that Sjögren's is systemic, serious and prevalent. Knowing that allowed me to understand why I was suffering and that I needed to develop a strong personal health program.

My story is a reflection on the Foundation's mission for patients. And as your CEO, I want everyone in our community to know that we are here for you and we are fighting for you!

As I take on this leadership role, I am grateful to work with such talented staff and dedicated volunteers, donors, and healthcare professionals to further the Foundation's mission and vision. In addition to patient programs, the Foundation places Sjögren's in front of the medical and scientific communities, as well as government agencies. There has never been a more exciting time in Sjögren's with new therapeutics in clinical trials and significant research being done on biomarkers. There is a new horizon in the way we think about and treat Sjögren's!

I am proud of the Foundation's work as we lead the charge to ensure that this disease is recognized as systemic, serious and prevalent so that all patients get the care and support needed. Together we will reach our vision of creating a community where patients, healthcare professionals and researchers come together to conquer the complexities of Sjögren's.

Thank you for welcoming me into your Sjögren's family.

Sincerely,

Janet E. Church
*Sjögren's Foundation
President and CEO*

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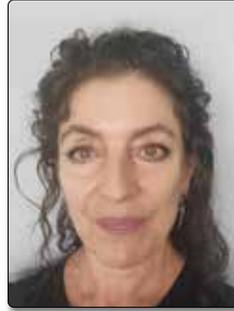
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Using Food as Medicine: Immune Boosting Strategies

A Conversation with Registered Dietician, Lauri Lang, RDN, LDN, CLT, Regarding Strategies for Sjögren's and Boosting Your Immune System through Nutrition



*Lauri Lang, RDN, LDN, CLT
Holistic Dietician Nutritionist, Yogi
Lauri Lang Concierge Wellness
laurilang.com*

Why is it important to look at food as medicine?

Our intake of food is one of the key factors that impacts our exposome. The exposome is a concept that has emerged from the branch of science known as omics, and the exploding science of epigenetics. The exposome can be defined as a measure of everything to which we are exposed from the time we are in utero until the end of life. The food that we consume is a chief player in the switching on and off of genes, both positively and negatively. Other players affecting the exposome include all manner of the exposure, at the very cellular level, that our lifestyle habits impact. This includes movement, thoughts, environmental toxins, and more.

It is my mission to educate, encourage and inspire people to take charge of what we can control! There are so many things that we can't, but the nourishment that we take into our bodies is something we have great agency over! The benefits of improved nutritional intake shown in disease prevention and treatment as well as enhancing well-being, immune-boosting, graceful aging and longevity are well-documented. A major mechanism through which those benefits occur is by reducing inflammation.

The *Food as Medicine* movement has been around for decades, and the original quote: "Let Food be thy Medicine, and Medicine be thy Food" is attributed to Hippocrates circa 400 BCE. It is more recently that this idea is being embraced by physicians and scientists as a primary part of treatment rather than relying solely on medication. The emerging field of Culinary Medicine, under the umbrella of Lifestyle Medicine, is a testament to mainstream medicine and science

acknowledging the importance of this concept as a crucial ingredient in the recipe of good health.

Are there any foods that should be included in a daily / weekly diet?

Absolutely! I will begin by describing some nutrients that are critical to boosting our immunity, reducing inflammation and contributing to our overall health, vitality and well-being. I will then translate that into some examples of delicious, appealing and vibrant food sources where these nutrients are found. Even in the midst of contradictory recommendations regarding optimal nutrition, the presence of abundant amounts of vegetables and fruits are central to most lists. Omega-3 fatty acids are a headlining anti-inflammatory nutrient, and other good fats, particularly monounsaturated fats, also make the *Food as Medicine* list. There are a few herbs and spices that must be highlighted as well. Let's begin with these ideas for regular inclusion. While all vegetables and most fruits have a myriad of health benefits, I am going to focus on two families of vegetables, and one category of fruit.

First, the cruciferous family of vegetables is one of my favorite topics to speak about! These veggies were in on the ground floor of knowing that food fights cancer, has detoxifying properties and boosts immunity. A piece of trivia is that, as these vegetables begin to sprout and grow, a common feature they share is a cross in the leaf. The list of crucifers includes broccoli, cauliflower, cabbage, brussel sprouts, kale, collard greens, arugula and more. I absolutely recommend veggies in this family for daily

“Using Food as Medicine” *continued from page 5* ▼

inclusion in nearly everyone’s diet! Sometimes the trick is increasing the occasional half cup of these veggies at dinner to a therapeutic dosage level. I help clients to develop plans to accomplish this goal within the framework of their lifestyles and preferences.

The second vegetable family I recommend for daily or frequent inclusion is the allium family. Some benefits of allium intake may include lowering cholesterol and blood pressure, reduction of cancer risk through reducing inflammation, reducing cell and DNA damage, immune boosting, as well as possessing some antibacterial and antiviral properties. All members of the onion family are alliums: purple, scallions, leeks, chives, white and yellow onions. Garlic and shallots are the other alliums. Alliums are super flavorful and including them regularly in food prep can not only confer these benefits, but also assist in reducing intake of other less healthy flavor boosters like butter and salt. I’m going to spotlight berries and pomegranate seeds as superstar high antioxidant/ low glycemic index fruits to focus on for increased intake.

There are three omega-3 fatty acids, EPA, DHA and ALA, to target for regular (daily or frequent) inclusion, first via food sources, and/or adding supplemental sources as well. Omega-3 fats are definitely superstar anti-inflammatory nutrients. EPA and DHA are generally found in fish as the largest quantities, and there are other lesser sources. The American Heart Association recommends eating two 3 1/2 oz servings of non-fried fish every week. Their recommendations emphasize eating oily fish like salmon, mackerel, herring, lake trout, sardines or albacore tuna. This is not only good for your heart, but also for all organ systems, inflammation levels, and brain health, including mental health. ALA is the omega-3 fatty acid found in vegetable sources. EPA and DHA more efficiently deliver these benefits than ALA alone. The sources of ALA also deliver powerful benefits, and is converted into EPA and DHA by our bodies, although not always efficiently. The richest sources of ALA are flaxseeds, chia seeds, hemp seeds and walnuts. There are many delicious and healthy ways of increasing our intake of these foods regularly.

In particular for people with Sjögren’s, supplementing with flax oil can soothe some symptoms like dry

eyes. When it comes to spices, I have to mention turmeric and ginger at the very least. Whether you purchase the fresh roots for grating/slicing into foods or drinks, or stock the ground versions in your spice collection, regular utilization of these spices can reduce inflammation, boost immunity and soothe symptoms as well. A wonderful nightcap that contains both of those spices is a golden milk recipe. This is a staple in India, is delicious, therapeutic and comforting!

What dietary supplements should I discuss with my doctor?

There are many physicians, scientists, and other health professional experts who have written much on the topic of what to include in supplement protocols to optimize our health, boost immunity, reduce inflammation and prevent/treat disease/conditions. I will offer a few very basic suggestions here to discuss with your doctor of choice.

The first supplement on that list is vitamin D. I suggest you initiate the process of finding the necessary level of vitamin D3 to consume daily so that your serum or blood level reaches what is considered to be an optimal protective level (50-80 ng/mL or whatever your doctor sets as your goal). That could mean advocating for a serum vitamin D screening. A multi-vitamin mineral supplement can be an insurance policy secondary to better food choices. Ask your doctor if she/he has a recommendation for a particular formula.

An omega-3 supplement or supplements can greatly enhance well being from an inflammatory standpoint, a neurotransmission (brain health/mood) improvement perspective, as well as helping with skin, hair and general moisture levels in all areas of the body. Enlist your doctor’s or other healthcare expert’s assistance in determining your therapeutic dosage.

Alterations in gut bacteria may negatively impact people with Sjögren’s, other autoimmune conditions, and the general population. Including a good probiotic in your supplement regimen could help with this. If you are on any medications that deplete your levels of CoQ10, suffer from fatigue, or have a desire to increase your energy, consider asking your doctor about supplementing with CoQ10. ■

You Stood Up!

Sjögren's Awareness Month



Thank you for supporting Sjögren's Awareness Month. Our April #ThisIsSjögrens campaign was created to highlight the many faces of Sjögren's, because you are the voice and face of the Foundation. It is the collection of your experiences that truly portrays this complex disease.

To create a better understanding of the disease, every day in April, the Foundation shared a different patient's story using one or more of our social media channels. While the short daily posts only gave one small glimpse into living with Sjögren's, by the end of April, we hope these 30 posts show that the disease is serious, systemic and prevalent.

Below are six stories of people featured in this year's inspiring campaign. View all 30 #ThisIsSjögrens posts by visiting www.sjogrens.org. And even though the 2021 Awareness Month has passed, every day is an opportunity to start a conversation about Sjögren's and how it affects you.

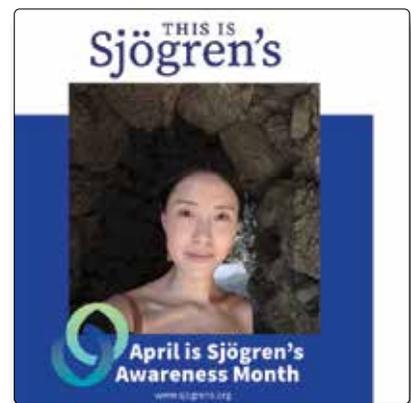
Cassandra 40 *(diagnosed at 35)*

My best Sjögren's tip is it's okay to say NO. This disease sucks your energy in a way that healthy people cannot understand. Sometimes you have to say no to parties or gatherings. If you are tired or know that you need to conserve energy for the next day. It's upsetting, but friends and family should understand. Don't push yourself into a disease flare. #ThisIsSjögrens



Ingrid 35 *(diagnosed at 30)*

The Sjögren's community and the Foundation has been a great source of comfort for me, especially in the beginning when I was told that the only symptoms for Sjögren's would be dry eyes and dry mouths. The research publications and awareness efforts of the Foundation has lent credibility to my complaints of systemic symptoms. It has helped me to educate my family members and even some physicians about my condition. #ThisIsSjögrens



Dominick 45 *(diagnosed at 32)*

It's important to know that Sjögren's symptoms mimic other illnesses and this disease doesn't only affect women. More men are being diagnosed every day. If you are living with Sjögren's, do not let a physician tell you that they can't help you. There is help. I know it's difficult but if your doctor doesn't know about the disease, find one that does. #ThisIsSjögrens



“You Stood Up” continued from page 7 ▼

Ellen 61
(diagnosed at 42)

My three most difficult Sjögren’s symptoms are fatigue, dry eyes and a dry cough (which, based on the looks I get, is often mistaken for COVID-19). To effectively cope with my disease, I’ve had to accept that taking multiple medications is OK. It was a hard decision because I had tried various diets/supplements/etc and I couldn’t make it work for me. #ThisIsSjögrens



Adoré 20
(diagnosed at 14)

Sjögren’s is a serious and systemic disease that affects your entire body. I wish people understood that it’s not easy to live with Sjögren’s and sometimes symptoms can hit you like a bus out of nowhere. I find strength in this community because I know I’m not the only one struggling and I want to be there for other patients. #ThisIsSjögrens



Cyndi 52
(diagnosed at 43)

Since I was diagnosed with Sjögren’s, I have learned to find my voice, know my limitations and not be ashamed when my body is telling me to take a step back. I want to encourage all patients to find their voice. It took me years to find mine. Don’t be silent – don’t try to hide your disease – once you own it, you actually gain all of your power back! #ThisIsSjögrens ■



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What to Know: The COVID-19 Vaccine and Sjögren's



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

The Foundation understands that while many patients have already received their COVID-19 vaccine, others may still have questions about the safety and effectiveness of the vaccines as well as questions about next steps after being vaccinated. With this in mind, we hope you enjoy this in-depth "Ask the Doctor" article featuring Cassandra Calabrese, DO, and member of the Foundation's COVID-19 Vaccination Committee.

We hope you will visit our website www.sjogrens.org to view all our COVID-19 resources, including a free member Town Hall Webinar on the COVID-19 Vaccine with Dr. Calabrese.

Ask the Doctor with Dr. Calabrese

"As a person with Sjögren's, should I receive a vaccination for COVID-19?"

Yes

"What if I have already had COVID-19?"

It is still important to get vaccinated against COVID-19 even if you already had the infection. Recovering from a COVID-19 infection does create some natural immunity, but it does not last, and if your infection was mild or asymptomatic, you might not have any protection.

"What if I'm pregnant or planning to become pregnant?"

The CDC, Society for Maternal Fetal Medicine and American College of Obstetrics and Gynecology all advocate for pregnant and breastfeeding women to get vaccinated against COVID-19. We have learned that pregnancy is a risk factor for doing poorly if infected with COVID-19. There are no safety concerns for vaccinating those planning to become pregnant, and this group should be offered COVID-19 vaccine as well.

"Is any one of the currently authorized COVID-19 vaccines recommended more than another one for Sjögren's patients?"

I recommend patients receive whichever vaccine is offered to them soonest. However, women younger than 50 years old should be aware of the rare but increased risk of the Johnson & Johnson's Janssen vaccine's adverse event and that there are other COVID-19 vaccine options available for which this risk has not been seen. For women less than 50 years of age who have opportunity to be vaccinated with one of the mRNA vaccines, this could be considered.

"Does the vaccine prevent COVID-19 or just lessen the symptoms if contracted, or both?"

The vaccines both prevent symptomatic and asymptomatic infections.

"Does having Sjögren's or other autoimmune diseases make you more or less susceptible to vaccine side effects?"

There is not data to suggest this.

“COVID-19 Vaccine” *continued from page 9* ▼

“What symptoms might occur after I have the COVID-19 vaccine? How long do these symptoms typically last?”

Common symptoms after the COVID-19 vaccine, which are called “reactogenicity” because they are the result of your immune system revving up to making antibodies against the virus, include local and systemic symptoms. Local symptoms might include arm pain, redness or swelling. Systemic symptoms might include fever, chills, muscle or joint pain, fatigue and headaches. These symptoms should resolve within 1-2 days and are reflective of your immune system doing its job.

“Should I get the vaccine during a Sjögren’s flare?”

Given the known reactogenicity (arm pain, headache, fever, etc.) that can occur with the COVID-19 vaccines, I feel it is always preferable to not get vaccinated during a flare. However, if that is when your vaccine is scheduled, there are no safety concerns and this is not a contraindication to get vaccinated.

“I have heard conflicting info on whether Tylenol has any impact on the vaccine. Is it OK to take Tylenol if you are having reactions to the vaccine? What about taking prescription NSAIDs?”

It is OK to take a Tylenol or an NSAID for symptoms that develop after the COVID-19 vaccine, such as arm pain or headache. It is not recommended to take Tylenol or NSAIDs before these symptoms develop or to prevent them, but it is perfectly fine to take them to treat the symptoms once they develop.

“Can therapies taken by Sjögren’s patients – DMARDs or a biologic such as rituximab – reactivate a COVID-19 infection?”

There is no data to suggest this.

“Should I talk to my doctor about temporarily stopping my immunosuppressive drugs, like methotrexate and rituximab, or treatments of chronic steroids/ steroid injections while receiving the vaccine?”

Yes, you should talk to your doctor about your immunosuppressive drugs prior to scheduling your COVID-19 vaccine, in particular the following drugs:

- a. Methotrexate
- b. Rituximab

Rituximab has the most negative effect on COVID-19 vaccine effectiveness and your vaccine will have to be timed appropriately around your rituximab infusions. Methotrexate has less of an impact,

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CDC Recommends Use of Johnson & Johnson’s Janssen COVID-19 Vaccine Resume

The Centers for Disease Control and Prevention (CDC) and the U.S. Food and Drug Administration (FDA) recommend that use of Johnson & Johnson’s Janssen (J&J/Janssen) COVID-19 vaccine resume in the United States, after a temporary pause.

Reports of adverse events following the use of the J&J/Janssen vaccine suggest an increased risk of a rare adverse event called thrombosis with thrombocytopenia syndrome (TTS). Nearly all reports of this serious condition, which involves blood clots with low platelets, have been in adult women younger than 50 years old.

A review of all available data at this time shows that despite the new safety signal regarding thrombosis with thrombocytopenia, the benefit of the J&J/Janssen vaccine still far exceeds its risks. However, women younger than 50 years old should be especially aware of the rare but increased risk of this adverse event and that there are other COVID-19 vaccine options available for which this risk has not been seen.

For any specific concerns about the vaccine, the Foundation recommends speaking with your physician or healthcare provider.

Johnson & Johnson’s Janssen COVID-19 Vaccine Symptoms of Concern

For three weeks after receiving the vaccine, you should be on the lookout for possible symptoms of a blood clot with low platelets. These include:

- Severe or persistent headaches or blurred vision
- Shortness of breath
- Chest pain
- Leg swelling
- Persistent abdominal pain
- Easy bruising or tiny blood spots under the skin beyond the injection site

Seek medical care right away if you develop one or more of these symptoms. ■

The Sjögren's Foundation Thanks All Who Contributed to the Development of the Pulmonary Guidelines in Sjögren's

The Sjögren's Foundation wishes to thank the many experts who helped make the pulmonary Clinical Practice Guidelines possible. This includes members of the Topic Review Group, the Chairs of the Foundation's guidelines initiative and those who served on the Consensus Expert Panel, which provided the Delphi-type process for ascertaining feedback on the proposed Recommendations and the Clinical Rationale on which they were based.

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Clinical Practice Guidelines: Pulmonary Manifestations in Sjögren's

As part of the Sjögren's Foundation's ongoing initiative to develop the first-ever U.S. clinical practice guidelines for Sjögren's— we are proud of our newest set of guidelines focusing on pulmonary manifestations in Sjögren's that was published in January 2021.

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. Clinical practice guidelines for pulmonary manifestations in Sjögren's were 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.

We encourage you to view all of the Foundation's current guidelines, which are published and available on www.sjogrens.org.

Published Sjögren's Clinical Practice Guidelines:

- Pulmonary Manifestations in Sjögren's
- Systemic Manifestations in Sjögren's Patients
- Oral Management: Caries Prevention in Sjögren's Patients
- Ocular Management in Sjögren's Patients



“COVID-19 Vaccine” *continued from page 10* ▼

but your provider may still discuss the option of holding off on a dose or two of methotrexate after your COVID-19 vaccine, but this is not right for every patient and should be decided only after a discussion with your doctor.

“If someone has allergies, asthma, eczema, and/or medication allergies, do they have an increased likelihood of developing an ‘allergic’ reaction to the vaccine?”

No.

“Once vaccinated, is it still recommended to use caution (masks, social distancing, hand washing, etc.)?”

Yes, this is still very important. While the vaccines are very effective, they are not 100% effective, so you still could become infected, and infect others, with COVID-19. It will be important to keep up masking, social distancing and other infection prevention measures until the vast majority of the population is vaccinated and there is less COVID-19 circulating in the community.

“Can you still transmit COVID-19 after being vaccinated?”

Yes, while the vaccines are very effective, they are not 100% effective, so there is a slight chance you still could become infected with COVID-19 and then

go on to infect others, especially those who are not yet vaccinated.

“I’ve been vaccinated, but I’m hearing a lot of talk about a COVID-19 booster shot. What information is available for the booster and is it recommended for Sjögren’s patients?”

At present there is no information on this. The duration of protection from the COVID-19 vaccines is not yet known, so it is possible that booster vaccines will be needed every year. It is also possible that booster vaccine doses made for the new variants will be administered.

“Do the recommendations for the COVID-19 vaccine apply to other vaccines for Sjögren’s patients?”

The COVID-19 vaccines use different technology than other, currently recommended, vaccines, such as influenza and pneumococcal. The COVID-19 vaccine is also being used in a pandemic situation – attempting to vaccinate large amounts of people in a short period of time, so the recommendations are still a bit different. What does apply, is to always talk to your provider about what vaccines you might be due for. Rituximab does reduce the effectiveness of essentially all other recommended vaccines, so this should be discussed as well if you are on rituximab.

Please visit www.sjogrens.org to learn more about recommend vaccines for Sjögren’s patients. ■

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Sjögren’s Foundation Virtual Event Calendar

Join fellow patients, family and friends as we gather virtually for the Texas Walk for Sjögren’s Opening Ceremony, where you can hear from Sjögren’s experts and enter to win door prizes. Then celebrate our strength as you walk through your neighborhood or other safe area.

Register and learn more about how to fundraise to receive your 2021 Walk for Sjögren’s T-shirt and other prizes!

June Texas Virtual Walk for Sjögren’s Saturday, June 26, 2021

events.sjogrens.org



IN MEMORIAM

In Memory of Barbara Kennedy

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Willia Townsley

In Memory of Brenda Koplin

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Gaylen Grody
Nancy Morse

In Memory of Carole Stenzel

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Yee Tieng Ho

In Memory of Daisy Walters

Lenny Kosier Family
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Mary Ward

In Memory of Dorothy Selleck

Florence Selleck

In Memory of Dr. Harry Speira

US Charitable Gift Trust

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Christina Lea

In Memory of Ella Jane Sisler

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Peggy Cassity

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In Memory of Jeri Courcy

Genevieve Magliari

In Memory of Jodie Graves

Suzanne Fickel

In Memory of Lala Hatcher

Cheryl Hall

In Memory of Margaret Hartman

Susan Carney

In Memory of Mary Wasner

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Harold and Alinda Wasner
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Mark and Virginia Berger
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Wanda Bonney
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Ed and Lynn Gottlieb
Marie Anderson
Michael Piechocki
Lee Ann and Michael Crochunis

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John Leavy

Ellen and Michael Leavy
Kathleen McGuigan
Lauren Brown and Tim Mayer
Lauren Eisbrenner
Charles Mace

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John and Cathy Austin
Steven Koskie

In Memory of Toni Dorame

David and Barbara Niles
Ed Katz
Kim McIntosh
Jim and Sally Sandoval
Robert and Victoria Gonzalez
Lovie and Chris Holguin
Teri Krawitz
Edward Katz
Keith Frankel

IN HONOR

In Honor of Adrienne Jones

Ariel Weber

In Honor of Annette McPherson

April McPherson

In Honor of Bob Vollone

Veronica Barker

In Honor of Brenda Koplin

Vene Franco

In Honor of Desiree Peterkin

Carmen Gilmore
Carl Adolph

In Honor of Diane Doyle

Thomas Doyle

In Honor of Emmy Ames

Patricia Garlinger

In Honor of Eyes on Dry Eye Game Show Hosts

Brett Kestenbaum

In Honor of Janet Church

Nancy Crabbe
Steven Taylor

In Honor of Jen Palancia Shipp

Christa Palancia Esposito

In Honor of Katie Madison

Megan Madison

In Honor of Liz Perry

Don Perry

In Honor of Macie Fisher

Sue Rowe

In Honor of Marian Carney

Isabella Horsky

In Honor of Mary Ann Jefferson

Carol Knight

In Honor of Mary Anne Hines

Holly Phelps

In Honor of Mary Wyman

Isabella Horsky

In Honor of Steven Taylor

Nancy Crabbe
Shari Kafton

In Honor of Therese Marie Pope

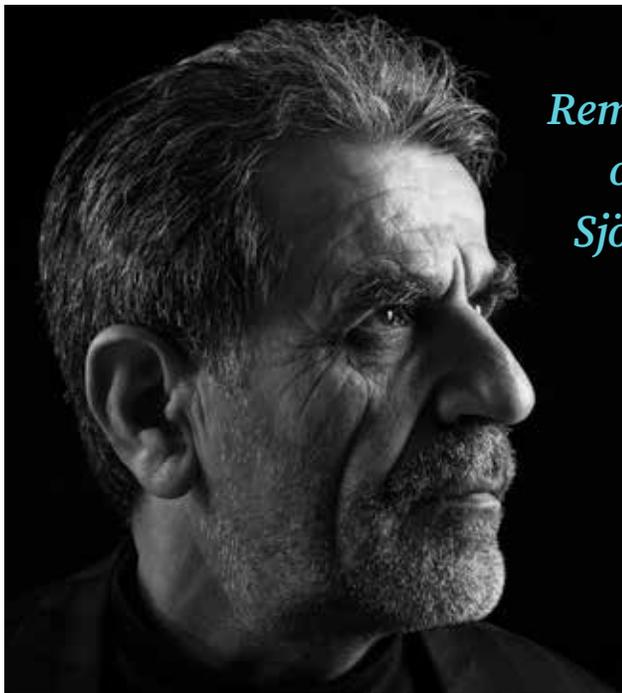
Joyce Pope

In Honor of Utku Cosar

Sharon Bear

In Honor of The Engagement of Yale Sosin to Gillian Vander Tuig

Bonnie Sosin



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



“Pulmonary CPG” continued from page 11 ▼

Consensus Expert Panel

Pulmonology

Rahul Gupta Argula, MBBS, MPH

Associate Professor of Medicine, Director, Pulmonary Vascular Disease Clinic, Medical Director, Respiratory Therapy services, Division of Pulmonary, Allergy, Critical Care and Sleep medicine, Medical University of South Carolina

Joseph Barney, MD, MSPH

Associate Professor Pulmonary and Critical Care Medicine, University of Alabama at Birmingham

Ryan Boente, MD

Assistant Professor of Clinical Medicine, Associate Fellowship Program Director, Division of Pulmonary, Critical Care, Allergy, and Occupational Medicine, Indiana University School of Medicine

Charles D. Burger, MD

Professor of Medicine, Consultant, Division of Pulmonary Medicine, Department of Medicine, Mayo Clinic, Jacksonville, FL

Gregory P. Downey, MD

Professor, Executive Vice President, Academic Affairs, Department of Medicine, Division of Pulmonary, Critical Care & Sleep Medicine, National Jewish Health

James Gagermeier, MD

Associate Professor, Pulmonary and Critical Care Medicine, Medical Director, Pulmonary Medicine, Loyola University Medical Center

Richard A. Helmers, MD

Pulmonologist, Mayo Clinic Health System, Eau Claire, WI

Justin C. Hewlett, MD

Assistant Professor of Medicine, Department of Medicine, Division of Allergy, Pulmonary and Critical Care Medicine, Vanderbilt University Medical Center

Rebecca C. Keith, MD

Assistant Professor, Department of Medicine, Division of Pulmonary, Critical Care & Sleep Medicine, Interstitial Lung Disease Program, Autoimmune Lung Center, National Jewish Health

Matthew Koslow, MD

Assistant Professor, Department of Medicine, Division of Pulmonary, Critical Care & Sleep Medicine, National Jewish Health

Robert Kotloff, MD

Professor of Clinical Medicine, Director, Harron Lung Centers, University of Pennsylvania Health System

Rachana Krishna, MD

Assistant Professor, College of Medicine, Medical University of South Carolina

Tracy R. Luckhardt, MD, MS

Associate Professor, Pulmonary, Allergy and Critical Care Division, University of Alabama at Birmingham

Keith Robinson, MD, MS

Medical Director, Syneous Health, Miami/Fort Lauderdale, FL

Jay H. Ryu, MD

Professor of Medicine, Consultant, Division of Pulmonary and Critical Care Medicine, Department of Internal Medicine, Mayo Clinic, Rochester, MN

Adrian Shifren, MD

Associate Professor, Medicine, Pulmonary and Critical Care Medicine, Director, Rare Lung Diseases Clinic, Director, Respiratory Therapy, Washington University School of Medicine in St. Louis

Gerald Staton Jr., MD

Professor Emeritus of Medicine, Pulmonary and Critical Care Medicine, Emory School of Medicine

Jeff Swigris, DO, MS

Professor of Medicine, Director, Interstitial Lung Disease Program, National Jewish Health

Robert Vassallo, MD

Professor of Medicine, Consultant, Division of Pulmonary and Critical Care Medicine, Department of Internal Medicine, Consultant, Department of Physiology & Biomedical Engineering, Mayo Clinic, Rochester, MN

Kristen L. Veraldi, MD, PhD

University of Pittsburgh School of Medicine, Division of Pulmonary, Allergy and Critical Care Medicine, Simmons Center for Interstitial Lung Disease at UPMC, VA Pittsburgh Healthcare System

Robert W. Ward, MD

Pulmonologist, University of North Carolina Health, Carolina Lung and Sleep at Pardee, Hendersonville, NC

Rheumatology

Senada Arabelovic, DO

Assistant Professor of Medicine, Tufts University School of Medicine, Division of Rheumatology, Boston, MA

Alan Baer, MD

Director, Jerome Greene Sjögren's Syndrome Clinic, Professor of Medicine, The Johns Hopkins University School of Medicine

Matthew C. Baker, MD, MS

Clinical Chief, Division of Immunology and Rheumatology, Co-Director, Stanford Multidisciplinary Sarcoidosis Program, Clinical Assistant Professor, Department of Medicine, Stanford University

Donald Bloch, MD

Associate Professor of Medicine, Harvard Medical School, Director, Sjögren's syndrome clinic, Massachusetts General Hospital

Philip Cohen, MD

Professor of Medicine and Microbiology/Immunology (Emeritus), Lewis Katz School of Medicine at Temple University,

Stamatina J. Danielides, MD

Assistant Professor, Department of Internal Medicine, Division of Rheumatology, Allergy and Immunology, Virginia Commonwealth University School of Medicine

Maria Danila, MD, MSc, MSPH

Associate Professor, Division of Clinical Immunology and Rheumatology, University of Alabama at Birmingham

Paul F. Dellaripa, MD

Associate Professor, Harvard Medical School, Division of Rheumatology, Immunology and Allergy, Brigham and Women's Hospital

Theresa Lawrence Ford, MD

Medical Director, North Georgia Rheumatology Group

Robert I. Fox, MD, PhD

Scripps Memorial Hospital and Research Center, La Jolla, CA

Thomas Grader-Beck, MD

Assistant Professor, Johns Hopkins School of Medicine, Baltimore MD

Chadwick R. Johr, MD

Co-Director, Penn Sjögren's Center, Associate Program Director Combined Internal Medicine and Pediatrics Residency Program, Assistant Professor of Clinical Medicine, Division of Rheumatology, Perelman School of Medicine at the University of Pennsylvania

Stuart Kassin, MD

Distinguished Clinical Professor of Medicine, University of Colorado Denver School of Medicine

Tamiko Katsumoto, MD

Clinical Assistant Professor, Stanford University

Apostolos Kontzias, MD

Associate Professor of Clinical Medicine, Stony Brook Medicine

Kirsten Koons, MD

Chief Resident, Department of Internal Medicine, University of Virginia

Vasileios C. Kyttaris, MD

Assistant Professor of Medicine, Harvard Medical School, Director, Rheumatology Training Program, Beth Israel Deaconess Medical Center

Janet Lewis, MD

Associate Professor Medicine, Division of Rheumatology, University of Virginia

Scott M. Lieberman, MD, PhD

Associate Professor of Pediatrics, Division of Rheumatology, Allergy and Immunology, Carver College of Medicine, University of Iowa

Sara S. McCoy, MD, MS

Assistant Professor, Department of Medicine, Division of Rheumatology, University of Wisconsin – Madison

Timothy Niewold, MD

Judith and Stewart Colton Professor of Medicine and Pathology, Director, Colton Center for Autoimmunity, NYU Grossman School of Medicine

Ghaith Noaiseh, MD

Associate Professor of Medicine, Division of Allergy, Clinical Immunology, & Rheumatology, Department of Internal Medicine, The University of Kansas Medical Center

Thomas G. Osborn, MD

Rheumatology Department, Mayo Clinic, Rochester, MN

Schartess Culpepper Pace, MD

Faculty, University of Miami, Division of Rheumatology



	Non-Member	Member	Qty	Amount
The Sjögren's Syndrome Survival Guide by Teri P. Rumpf, PhD, and Kathy Hammitt. A complete resource, providing medical information, research results, and treatment methods as well as the most effective and practical self-help strategies.	\$20	\$17		
The Sjögren's Book , Fourth Edition edited by Daniel J. Wallace, MD. The 2011 edition of the Sjögren's handbook has been completely revised and expanded with all new chapters and the latest information on Sjögren's.	\$32	\$28		
The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease by Susan Blum, MD, MPH. This book shares Dr. Blum's four-step program to help autoimmune patients reverse their symptoms, heal their immune systems and prevent future illness.	\$25	\$22		
You Don't Look Sick! Living Well with Chronic Invisible Illness by Joy H. Selak, and Steven S. Overman MD. One woman's journey through the four stages of chronic illness: Getting Sick, Being Sick, Grief, and Acceptance and Living Well.	\$16	\$14		
Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop by Norman Latov, MD, PhD. Peripheral neuropathy is a widespread disease, yet many people do not even realize they have it.	\$19	\$16		
You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life by Mims Cushing and Norman Latov, MD. A compendium of tips, techniques, and life-task shortcuts that will help everyone who lives with this painful condition.	\$19	\$16		
Healing Arthritis: Your 3-Step Guide to Conquering Arthritis Naturally by Susan S. Blum, MD, MPH (Author), Mark Hyman (Foreword).	\$24	\$20		
A Body Out of Balance by Ruth Fremes, MA, and Nancy Carteron, MD, FACR. A Sjögren's patient and a doctor offer their authoritative insight into one of the most common yet most misunderstood autoimmune disorders.	\$16	\$13		
The Memory Bible: An Innovative Strategy for Keeping Your Brain Young by Gary Small, MD. This program has helped thousands of people improve their ability to remember everyday issues like where their car is parked as well as more important abilities to think fast and maintain a healthy brain.	\$16	\$13		
Grain Brain: The Surprising Truth about Wheat, Carbs, and Sugar – Your Brain's Silent Killers by David Perlmutter, MD (author) and Kristin Loberg (contributor). A #1 New York Times bestseller – the devastating truth about the effects of wheat, sugar, and carbs on the brain, with a 4-week plan to achieve optimum health.	\$25	\$20		
How to Live Well with Chronic Pain and Illness – A Mindful Guide by Toni Bernhard. The book addresses challenges created from chronic illness to help readers make peace with a life turned upside down.	\$17	\$14		
Shipping and Handling: U.S. Mail: \$7 for first item + \$2 for each additional item				
Sub-Total:				
Membership (new/renewal): Includes <i>Conquering Sjögren's</i> newsletter, member pricing on books and more benefits.		\$36 each		
Please consider an additional contribution: <input type="checkbox"/> \$25 <input type="checkbox"/> \$50 <input type="checkbox"/> \$75 <input type="checkbox"/> \$100 <input type="checkbox"/> \$250 <input type="checkbox"/> \$500 <input type="checkbox"/> Other: _____				
Total Amount Due:				

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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.

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“Pulmonary CPG” continued from page 14 ▼

Ruben Peredo-Wende MD

Assistant Professor, Chief of the Division of Rheumatology, Director of the Rheumatology Fellowship Program, Albany Medical College

Stanley Pillemer, MD

President, American Biopharma Corporation

W. Neal Roberts Jr., MD

Professor of Medicine, University of Kentucky

Elliot Rosenstein, MD

Professor of Medicine, Sidney Kimmel Medical College at Thomas Jefferson University, Director, Institute for Rheumatic & Autoimmune Diseases, Overlook Medical Center, Atlantic Health System

Amit Sachdev, MD

Assistant Professor, Director of the Division of Neuromuscular Medicine, Michigan State University

Nora Sandorfi, MD

Associate Professor of Clinical Medicine, Perelman School of Medicine at the University of Pennsylvania

Barbara Segal, MD

Rheumatologist, Inland Hospital, Saint Paul, MN

Chokkalingam Siva, MD

Associate Professor, Fellowship Program Director, University of Missouri School of Medicine

Daniel Small, MD, MMSc

Chair Dept of Rheumatology, Mayo Clinic Healthcare System, Mayo Franciscan, La Crosse WI.

Robert F. Spiera, MD

Director, Scleroderma and Vasculitis Program, Hospital for Special Surgery, Attending Rheumatologist, Hospital for Special Surgery, Professor of Clinical Medicine, Weill Cornell Medical College, Attending Physician, New York-Presbyterian Hospital, Weill Cornell Medical Center

James Topilow, MD

Resident, Department of Internal Medicine, University of Virginia

Edward L. Treadwell, MD

Professor of Medicine/Rheumatology-Immunology, Department of Internal Medicine, Brody School of Medicine-East Carolina University

Frederick B. Vivino, MD

Chief, Rheumatology, Penn Presbyterian Medical Center, Director, Penn Sjögren's Center, Professor of Clinical Medicine, Perelman School of Medicine at the University of Pennsylvania

Elizabeth Volkmann, MD, MS

Assistant Professor, Co-Director, CTD-ILD Program, Division of Rheumatology, Department of Medicine, University of California, Los Angeles

Daniel J. Wallace, MD

Associate Director, Rheumatology Fellowship Program, Board of Governors, Cedars-Sinai Medical Center, Professor of Medicine, Cedars-Sinai Medical Center, David Geffen School of Medicine Center at UCLA, In affiliation with Attune Health

Scott Zashin, MD

Dallas Rheumatology, Presbyterian Hospitals, and University of Texas Southwestern Medical School, Dallas, TX

Patients & Family of Patients

Evelyn J Bromet, PhD

Distinguished Professor, Department of Psychiatry, Stony Brook University

Jeanne Dale

Winetka, IL

Judith A. Furlong, MD

Family Medicine, ProMedica Physicians Family Medicine

Kerry L. Neall, MD

Emergency Medicine, Orlando Health, South Lake Hospital, Orlando, FL

Lynn M. Petruzzi, RN, MSN

Formerly, West Shore Surgery Center, Mechanicsburg, PA

Sarah Schafer, MD

Public Health and General Preventive Medicine, Oakland, CA

Heidi Kukla, RN, BSN, CCRN,

Critical Care, Elliot Hospital, Manchester, NH

Celebrating World Sjögren's Day

On July 23rd, we hope you will join with the Foundation to celebrate World Sjögren's Day and the birthday of Dr. Henrik Sjögren, the Swedish ophthalmologist who first identified the disease in 1933.

In addition to honoring Dr. Sjögren, World Sjögren's Day gives everyone touched by the disease a vehicle to reach out and educate those close to you about Sjögren's. It is meant to put a face on the millions of people who live with this disease and is the ideal opportunity for you to have your voice heard.

Leading up to World Sjögren's Day, and especially on the day itself, talk about Sjögren's with the people in your life. Share your story and educate others. By doing so, you are helping spread the message that Sjögren's is a serious and complex disease that deserves to be recognized.

We encourage you to visit www.sjogrens.org to learn more about how you can use your voice to join in the celebration of what would have been Dr. Sjögren's 122nd birthday.



Putting the health and safety of everyone first, our National Patient Conference will be a virtual event. You will experience the same valuable educational topics from leading Sjögren's experts from the comfort of your own home and computer.

Join us for this two-day event on
Friday, June 11th – 1:00 pm - 5:00 pm (EDT)
Saturday, June 12th – 1:00 pm - 5:30 pm (EDT)

This two-day online educational experience will help you take control of your health while you learn how to manage and understand your Sjögren's symptoms and complications from leading Sjögren's experts.

PLEASE NOTE

Registrants must have a device with internet access to join the conference.

Recorded videos of each lecture will be available to registrants for 30 days after the conference.

You can also register online at <https://www.sjogrens.org/npc-registration>



QUESTIONS? Call 301-530-4420 or visit www.sjogrens.org

“Conquering Sjögren’s Together”

Sjögren’s: An Overview

Donald E. Thomas, Jr., MD, a rheumatologist and Chair of the Sjögren’s Foundation Board of Directors, has a special interest in systemic autoimmune diseases, especially Sjögren’s. He is in private practice in Maryland, but also enjoys teaching health care providers about Sjögren’s in his capacity as an Associate Professor of Medicine at the Uniformed Services University of the Health Sciences in Bethesda, Maryland. Dr. Thomas will present a comprehensive explanation of the range of symptoms that Sjögren’s patients experience, explain their causes, and offer treatment options and practical tips for managing them.

Clinical Practice Guidelines for Pulmonary Complications

Augustine S. Lee, MD, MS, is a pulmonologist and Associate Professor of Medicine at the Mayo Clinic College of Medicine and Science in Jacksonville, Florida. Here, Dr. Lee also serves as Chair of the Division of Pulmonary, Allergy/Immunology and Sleep Medicine, Director of the Chronic Cough Clinic and co-Director of the LAM Clinic. Dr. Lee co-led the Foundation’s initiative to develop the first-ever U.S. clinical practice guidelines for pulmonary disease in Sjögren’s. Pulmonary manifestations occur much more frequently in Sjögren’s than is often recognized by healthcare providers and are a potentially serious complication of the disease. As part of the Foundation’s ongoing effort to develop clinical practice guidelines for Sjögren’s, Dr. Lee will share information from these newly published guidelines focused on identifying, evaluating, managing and treating pulmonary disease in Sjögren’s – an effort that is the culmination of many years of work and a major step forward for our community.

Conquering Sjögren’s: What’s Next?

Janet Church

Sjögren’s Foundation President & CEO

The Sjögren’s Foundation continues to launch new patient, healthcare and research focused initiatives that are changing the direction of Sjögren’s. Join Janet Church, CEO of the Foundation, as she shares exciting updates about clinical trials, clinical practice guidelines as well as other projects that are on the horizon for Sjögren’s patients!

Ocular Manifestations of Sjögren’s

Esen K. Akpek, MD, is the Bendann Professor of Ophthalmology and Rheumatology and Director of the Ocular Surface Diseases and Dry Eye Clinic at the Wilmer Eye Institute, Johns Hopkins University School of Medicine, Baltimore, Maryland. Dr. Akpek is also the Associate Director of the Jerome L. Greene Sjögren’s Syndrome Center at Johns Hopkins and a member of the Sjögren’s Foundation Medical and Scientific Advisory Council, the Foundation’s Clinical Trials Consortium and past national board member. Dr. Akpek is a world-renowned leader in the fields of inflammatory ocular disease and dry eye and will describe the latest dry eye therapies, covering the extensive range of options.

Product Showcase

Kimberly Kelley, PharmD

Sjögren’s patients use a number of over-the-counter and prescription products to treat their various complications. Kimberly Kelley, a Doctor of Pharmacy in Arizona for 35 years with an expansive career, a Sjögren’s Foundation Board Member, and a Sjögren’s patient, will highlight the vast array of products that are available for Sjögren’s patients.

Oral Manifestations of Sjögren’s

Vidya Sankar, DMD, MHS, is Associate Professor and Division Director for Oral Medicine, Department of Diagnostic Sciences, Tufts University, School of Dental Medicine in Boston, Massachusetts. She is also a current member of the Sjögren’s Foundation Medical and Scientific Advisory Council and a past national board member. Dr. Sankar will provide insights into how Sjögren’s impacts your oral health including tooth decay as well as share with us information to help manage and minimize the effects of dry mouth issues.

Social Security Disability for Sjögren’s

Stacy M. Tucker is a partner with Kantor & Kantor, LLP, a law firm specializing in representing individuals whose health, disability, and life insurance claims have been denied. Ms. Tucker will bring her wealth of knowledge of the inner workings of disability insurance and healthcare to help attendees understand and navigate the often complex workings of the Social Security Disability system.

Sjögren’s and Joint Pain

Rochelle Rosian, MD, is a rheumatologist and Staff Member, Department of Rheumatic and Immunologic Diseases at the Cleveland Clinic in Solon, Ohio, where she also serves as Director of Regional Rheumatology. Dr. Rosian has a general rheumatology practice, with special interest in rheumatoid arthritis, Sjögren’s, psoriatic arthritis and lupus. During her career at Cleveland Clinic, Dr. Rosian has been involved with medical division committees, World Class Service, resident and medical student education and the Center for Patient Experience and Healthcare Communication. Dr. Rosian will add to your understanding of the many causes of joint pain and Sjögren’s and will offer tips to help you cope as well as possible treatment regimens.

COVID-19 and Sjögren’s Update

Alan Baer, MD, is a rheumatologist and Professor of Medicine at the Johns Hopkins School of Medicine in Baltimore, Maryland, where he is also Director of the Jerome L. Greene Sjögren’s Syndrome Center. Additionally, Dr. Baer is engaged in clinical research studies focused on Sjögren’s, both at Johns Hopkins and the National Institutes of Health (NIH). Currently, he is Chair of the Foundation’s Medical & Scientific Advisory Council and the Foundation’s Sjögren’s-COVID-19 Vaccination Committee, a member of the Foundation’s Clinical Trial’s Consortium Steering Committee and a member of the Board of Directors. Dr. Baer will provide the latest information on COVID-19, the vaccine and what Sjögren’s patients should know.

Genetics and Sjögren’s Research

Christopher J. Lessard, PhD, is an Associate Member of the Genes and Human Disease Research Program at the Oklahoma Medical Research Foundation (OMRF) in Oklahoma City, Oklahoma, and an Adjunct Associate Professor in the Department of Pathology at the University of Oklahoma Health Sciences Center. Dr. Lessard is a former Sjögren’s Foundation research grant recipient and he and his team at the OMRF have recently been awarded a five-year, \$3.7 million-dollar grant from the National Institutes of Health to continue his ongoing efforts to understand how genetic variations lead to Sjögren’s disease. Dr. Lessard will share an overview of this exciting research with us!

“Exploring Sjögren’s Spotlight” explained...

This year’s Conference will include breaks – entitled “Exploring Sjögren’s Spotlight” – to hear brief interviews with product company representatives, Sjögren’s patients, and medical experts.



“Conquering Sjögren’s Together”

2021 VIRTUAL National Patient Conference Registration Form

Registration Form Must be Received by June 9th OR Register Online: sjogrens.org/npc-registration

1 Registrant

Name _____

Street Address _____

City _____ State _____ Zip _____

Telephone _____ E-mail _____

2 FEES – please check appropriate fee

	Member	Non-Member
	\$80.00	\$100.00
	<input type="checkbox"/>	<input type="checkbox"/>

3 PAYMENT – Mail to Sjögren’s Foundation, 10701 Parkridge Blvd., Suite 170, Reston, VA 20191

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

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Signature _____

Refunds must be made in writing. Registrants whose written requests are received by May 14th will receive a 75% refund. After that time, we are sorry that no refunds can be made.



QUESTIONS? Call 301-530-4420 or visit www.sjogrens.org



Conquering Sjögren's

Sjögren's Foundation Inc.
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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

Save the Date!

Childhood Sjögren's Virtual Conference

One Day Virtual Conference

Date: September 18, 2021

Time: 11-3pm (EST)

Sjögren's in children is likely more common than is currently appreciated. Children with Sjögren's tend to present differently than adults, which is why the Foundation has created a conference program specifically for families who have a child affected by Sjögren's.

Topics covered include:

- Overview of Sjögren's in Children
- Parotitis and How to Prevent Dental Decay
- Ophthalmology Issues in Sjögren's
- Current Projects Focused on Sjögren's in Children

Watch for more conference details in next month's issue of the *Conquering Sjögren's* newsletter and on the Foundation's website – www.sjogrens.org.



 **Sjögren's**
FOUNDATION