

CONQUERING Sjögren's

January/February 2023

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2023

The Year to Focus on Your Wellness

Living with Sjögren's means taking care of both your physical and emotional symptoms. To help kick-start your wellness plan in 2023, we are sharing a few parts of the recent Fall Focus Conference that focused on wellness strategies to help manage Sjögren's symptoms. Below you can learn stress reduction techniques from Dr. Donald Thomas' talk, *Physical Impact of Stress & Relationship to Sjögren's Symptoms* and some simple exercise tips from Dr. Zoe Morris' talk, *How Exercise Can Reduce Fatigue and Ease Inflammation*.

Stress Reduction Techniques

Reprinted with permission from "The Lupus Encyclopedia: 2nd Edition," in production, Johns Hopkins University Press and taken from the 2022 Fall Focus talk, *Physical Impact of Stress & Relationship to Sjögren's Symptoms*, by Donald Thomas, MD, FACP, FACR, Sjögren's Foundation Board Chair

Stress Reduction Programs Improve:

- Pain
- General well-being
- Physical function

Stress Reduction Techniques:

- Identify the stressors in your life so you can work on decreasing their ill effects on you.
- Practice daily mindfulness (such as breathing exercises).
- Set realistic expectations (rather than goals that are too large) and plan ahead.
- Learn to say "no" to increased work and duties.
- When you have children, learn to say "no" to additional activities other than what is essential for your family and health.

- Do yoga and/or tai chi.
- Ask for help in doing activities. Proactively lighten your load.
- Prioritize the important things in your life; cut out less important activities.
- Get biofeedback training from a professional to decrease anxiety and stress.
- Prepare ahead of time for any major activity. Practice good time management.
- Avoid unhealthy foods such as sweets, carbohydrates, greasy foods, and "fast food."
- Do not skip healthy, planned meals.
- Plan for periods of rest and relaxation in your routine every day.
- Say positive things to yourself and compliment yourself for doing something well. Do not think negative things about yourself.
- When running errands or going to appointments, get ready early. Give yourself more time than you think you need. Plan on arriving early for any occasion.
- Exercise regularly.
- Schedule appointments and errands during less busy times, such as early Saturday mornings. This decreases stress from traffic, waiting in long lines, etc.
- Try not to argue with others. Learning and accepting that everyone has differing opinions or ways of doing things. Many conflicts are not very important. Take a deep breath, relax, leave before an argument begins.

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“Wellness” *continued from page 3* ▼

- Consider counseling to learn better communication skills if you have difficulties with relationships.
- Live at or below your means. Don’t try to keep up with the “Joneses” or loved ones. Staying out of debt decreases stress. Always ask yourself, “Is this something I truly need, or just something I want?” before purchases.
- Whenever you feel stressed, put it into perspective compared to the important things in life (health, family, religion). “Do not sweat the small stuff.”
- Schedule at least eight hours of sleep a night. Practice good sleep hygiene.
- At work, request job accommodations needed for your medical condition. Get help from organizations like www.askjan.org.
- If you can work from home, it can lower stress with less travel and time flexibility.

How Exercise Can Reduce Fatigue and Ease Inflammation

Taken from the 2022 Fall Focus talk, How Exercise Can Reduce Fatigue and Ease Inflammation, by Zoe Morris, PhD, CEP

What is inflammation?

- When the immune system recognizes and removes harmful and foreign stimuli and begins the healing process.
- Inflammation can be either acute or chronic.
- Persistent, low-grade inflammation contributes to many chronic health conditions.

Acute versus chronic inflammation

Acute Inflammation:

It starts rapidly, becomes severe in a short time and may last for a few days. This process enables repair and cell turnover in multiple tissues.

Symptoms include:

- Redness
- Heat
- Swelling
- Pain
- Loss of function

Chronic inflammation

Begins slowly and lasts several months to years. It is a risk factor for a broad range of conditions and diseases.

Symptoms include:

- Chronic fatigue and insomnia

- Mood disorders
- Gastrointestinal complications
- Weight gain or weight loss
- Frequent infections
- Body pain, arthralgia, myalgia

Exercise and inflammation

- Acute and chronic exercise reduce the inflammatory response
- Lower circulating inflammatory markers
- Increase muscle antioxidant content
- Reduce reactive oxygen species

Exercising with Sjögren’s to Reduce Inflammation Exercise is medicine

- Healthcare providers should view exercise as medicine and use in the correct “dosage,” as an effective patient care “prescription.”
- As with medication, more exercise is not always better.

SMART and FITT Goals

- Think functional goals
- FITT principle stands for:
 - Frequency
 - Intensity
 - Time
 - Type

Where to begin?

- Always check with your doctor before you begin exercising.
 - Get clearance, and ask about side effects of medications, ask about limitations.
- Find a type of physical activity or exercise that you enjoy.
- Always warm up and cool down.
- Stay hydrated.
- Start slowly!
- Listen to your body.

General recommendations

- **Frequency:** 3-5 days per week.
- **Intensity:** Moderate to vigorous.
- **Time:** 150 minutes of moderate or 75 minutes of vigorous per week.
- **Type:** Low impact or low joint stress (walking, swimming, cycling). ■

Did You Miss the Foundation's Recent Conference?



Get all the vital information you need in an easily downloadable video format! Video downloads are available for purchase for the 2022 Sjogren's Foundation Fall Focus Conference.

Wellness Strategies to Help Manage Sjögren's Symptoms

Presentations are delivered by experienced professionals who have devoted their professional lives to understanding their areas of expertise. These experts dive into the science of how stress, sleep, and exercise impact your body and wellbeing. They also share practical tips to help you incorporate these natural wellness strategies into your daily life. Download these conference videos to learn more about complimenting your current Sjögren's management plan with daily lifestyle choices targeted at decreasing inflammation and increasing wellbeing!

Price for the whole set:

Member Price: \$40

Non-Member Price: \$55

Individual talks:

Member Price: \$15

Non-Member Price: \$20



Patient to Patient: What's your New Year's Resolution for Prioritizing your Health?

Sjögren's patients share New Year's Resolutions for putting their health first and their best self-care tips for 2023.

The Foundation knows that the best advice often comes from patients, and we thank those who shared with us. When reading the tips below, remember that every patient is different, and it is important to find what works best for you and your health.

"Invest in myself by eating more wholesome foods and not let my job stress me out!" –Melisa

"Unclutter my house one day at a time." –Harper

"It's ok to be sad, sitting with your feelings is important. Journaling helps me as well." –T.J.

"Start using my water pick, listening to my body, and exercising more." –Sharon

"Stop putting off my general medical check-up." –Dan

"Don't feel guilty about using your sick days and paid time off (PTO)." –Antiana

"Help inform my doctors about things they don't know." –Carol

"Research your doctors the same way you research other important purchases. You're worth it!" –Tammy

"Learn to say 'No.' It's ok to be selfish (a little bit)." –Amy

"Advice is well intended but it might not work for everyone, so don't get discouraged." –Tara

"Surround yourself with people who support and understand you. Fatigue is not the same as tired." –Adrian

"Purchasing a cool mist humidifier this year!" –Elenore

"Get some movement in every day." –Susan

"Prioritizing massage therapy." –Joan ■

Foundation Tip:

For Sjögren's patients, an optimal range of humidity is between 55% and 60% regardless of the ambient temperature.

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New Year, New Mindset

by Janet E. Church, Sjögren's Foundation President and CEO

Have you ever heard the saying, “Where your mind goes, energy flows?” Our mind is an incredibly powerful thing, especially when it is laser focused on a goal or a topic. That focus can either help us achieve greatness or it can cause worry, anxiety, and sadness. Personally, I am more in my head than in my body, which is helpful for leading the Foundation, but if I don't practice my stress management tools and focus my mind on positive intentions, it will create real issues! The compounding stress in my body can cause a Sjögren's flare and my thoughts can turn to rumination. Neither is good for my physical or mental health.

Over the years, I have learned that I need to have a daily (or every-other-day) practice of the tools that work for me. If I don't, stress hormones will flood my body causing anxiety. If I don't listen to the early signs of this change, I can cause physical harm (having a Sjögren's flare) and mental harm (increased anxiety). Keeping current with my practice is far easier than dealing with the repercussions, yet, it seems I have slipped and need to re-engage! This fall, I experienced two significant flares and I have passed the early warning signs. If I don't re-engage now, I will reduce my resilience for upcoming stressful events (which can cause more flares and can lead me into depression). It's time to action.

Practicing Stress Management

I have several favorite stress management tools that I use. In this edition of *Conquering Sjögren's*, we highlight Dr. Donald Thomas' Fall Focus presentation on stress management and why it is important for our physical and mental health. He shared a number of tools including my favorites that I have practiced over the years:

- **Deep breathing.**
- **Meditation.** Guided body scan and/or quiet focus to still the mind.

- **Mindfulness exercises.** Be intensely aware of your surroundings, including thoughts and feelings from others and from yourself... without judgement.
- **Yoga.** Gentle Yoga, Hatha Yoga, Yoga Nidra. (Yoga Nidra is comfortably lying on your back on the floor with a pillow and props supporting you.)

My optimal routine: I use deep breathing during the day, especially when I'm very busy at work or preparing for meetings. Meditating every day for at least 15 minutes is critical for stress reduction and resilience to handle future stress events (practicing 10 minutes in the morning and 10 minutes at 3pm is my best formula). For mindfulness, I pay close attention to my surroundings, and I work hard on reducing judgement (especially on myself). When I practice yoga every day, I am at my best (but every other day will do the trick).

Building Resilience with a Positive Mindset

Building resilience is a practice that goes hand-in-hand with stress management. Over the years, I have found that setting positive intentions for the day and focusing on my mindset has helped not only with stress management and resilience, but I become happier and kinder to others. My key areas of focus are

- Gratitude
- Intention
- Compassion (for self and for others)
- Inspiration
- Self-reflection

Living with Sjögren's is hard... and life happens. But I want to do what I can to manage it physically and mentally. I have been off my stress management and mindset game for a while now and I am feeling it. So, I'm starting the New Year by journaling every day using the guide I created (and we've included in this edition) titled, *Resilient Mindset Journal*, on page 9.

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“Mindset” *continued from page 7* ▼

When I start this process, I always need to remind myself of a few things:

1. Small steps matter and can lead to big leaps. Write down what I can improve on or positively focus on today. If there is a goal attached to an item, take the step toward it that I can achieve that day (I am notorious for stepping into over-achiever mode, which will defeat the experience).
2. Make each day of journaling different. I may be grateful for similar things, but what is my special focus on that item on this day? This helps me to truly be in touch with myself each day and not get into a routine of just writing down the same thing to fill out the page (which I have done when I’m very busy, but it defeats the purpose).

3. No judgement, especially on myself. This is a positive mindset journal, so I want to stay positive, especially on self-reflection. Telling myself, “I’m glad I achieved X, but it could have been better if I achieved Y” does not feed my soul positively. That self judgement keeps a negative loop spinning in my mind.

So, won’t you join me? We can go on this journey together! Select a stress management tool (or two). Make some copies of the *Resilient Mindset Journal* and try using these tools for 30 days to see how you feel.

I strongly believe that the actions we take to reduce stress and build resilience makes us stronger physically, cognitively, spiritually, and emotionally. This is a great way to start the New Year! ■

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Do we have your current e-mail address?

If you want to receive all the latest updates from the Sjögren’s Foundation, then you should make sure we have your most up-to-date e-mail address! The Foundation is starting to share more information via e-mail, from news about the Foundation and Sjögren’s, to information about the latest treatments and medicines, to local Support Group updates and more. So contact us at info@sjogrens.org to be certain we have your latest e-mail address in our database, and then keep an eye on your Inbox for Sjögren’s news.

Just like all information you give the Foundation, your e-mail address will remain private and will never be given or sold to an outside organization.



Resilient Mindset Journal

Every morning, complete steps 1-4 with thought and intention. Before going to bed, complete step 5.

Date: _____

1 Write down 3 things for which you are grateful.

2 Think of someone you love and for whom you feel compassion and say:

May [name] be filled with love and compassion.
May [name] be safe from inner and outer dangers.
May [name] be healthy in body and mind.
May [name] be at ease and happy.

Deeply experience those feelings and turn them to yourself and say:

May I be filled with love and compassion.
May I be safe from inner and outer dangers.
May I be healthy in body and mind.
May I be at ease and happy.

3 Write down a personal strength or value and how you can put it into action today.

4 What is your inspiration for today? What feeling of purpose can you bring to the day?

5 Ask Yourself: What big wins did I have today? What personal insights and learnings did I gain today? How can I apply these learnings in the future?



Team Sjögren's

Congratulations Team Sjögren's Runners and Walkers!

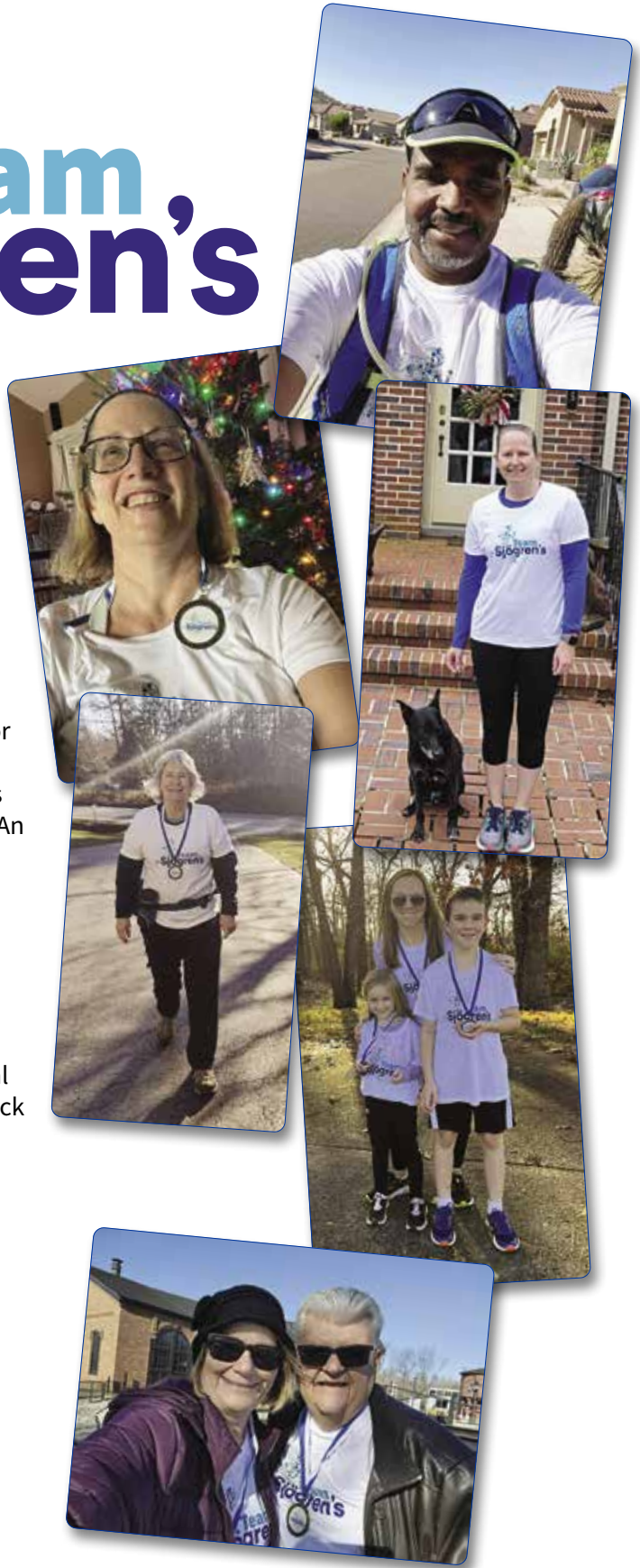
38 Team Sjögren's members committed to fundraise and train for a virtual 5K, 10K, or Half-Marathon over Thanksgiving weekend. Representing 17 different states, these runners raced in their hometowns and raised nearly \$8,000. An inspiring 24 team members were Sjögren's patients. Other members of the team ran as husbands, sons, daughters, grandchildren, sisters, and friends of patients, with the youngest runner being six years old.

Congratulations to all our Team Sjögren's runners and thank you for stepping up in honor of all Sjögren's patients!

Team Sjögren's is getting ready for our next virtual race, which will be held in June, before we come back for a LIVE event in early 2024. Follow our program and we will prepare you to walk or run either a 5K, 10K, or Half-Marathon this spring.

Even if you have never run or walked such a distance, the staff and our team trainer will help guide you through the entire process and ensure you are ready to participate! With no fundraising requirement, we encourage you to try something new and join our team this New Year.

To learn more about our upcoming virtual race, please contact Kalla Ford, Team Coordinator, at kford@sjogrens.org. ■



Team Sjögren's runs in honor of all Sjögren's patients...

WE ARE TEAM SJÖGREN'S!

Recap of Major Meetings: Sjögren's at ACR Convergence 2022 and the International Symposium on the Autonomic Nervous System

After a few years of virtual sessions, the American College of Rheumatology's (ACR) Convergence returned as an in-person meeting for 2022, held in Philadelphia from November 11-14. This is a premier meeting for the rheumatology community and attracts a global audience of rheumatologists, pharmaceutical companies, patient advocacy groups and more. The meeting features cutting-edge and timely topics on all aspects related to rheumatology, including the prevention, diagnosis and treatment of the range of rheumatic diseases.

For the Foundation, this event represents one of the greatest opportunities to educate the rheumatology community on the complexities of Sjögren's, and Foundation staff were excited to attend this year's meeting to engage with the broader community and learn of the most recent happenings in Sjögren's.

What follows is a summary of how Sjögren's was represented at ACR Convergence 2022 and how the Foundation and our collaborators were involved.

Sjögren's-Focused Learning Opportunities

Sessions on Sjögren's

On Saturday, November 12, Alan Baer, MD, and Sara McCoy, MD, PhD, moderated a session on the recognition, prevention and management of oral dryness complications. Here, attendees learned how to recognize dry mouth through history and exam findings, the most effective methods to prevent tooth decay and loss among patients with dry mouth, and how to treat other common complications of dry mouth. Session speakers included Mike Brennan, DDS, who spoke on the diagnosis of dry mouth in clinical practice, Athena Papas, DDS, PhD, who spoke on the prevention of complications related to dry mouth, and Leslie Laing Gibbard, DDS, PhD, who spoke on how to manage the complications of dry mouth.

At the start of Sunday, November 13, a session on novel imaging and therapeutics for Sjögren's was held.

Moderated by Chadwick Johr, MD, and Eugene Kissin, MD, this session focused on identifying therapeutics to effectively manage Sjögren's patients and included a discussion on cutting edge imaging approaches and latest techniques to accurately diagnose patients with Sjögren's. This session featured presentations by Alan Baer, MD, Alojzija Hocevar, MD, and George A.W. Bruyn, MD, PhD. Dr. Baer shared insight into why drug treatments fail in Sjögren's by looking at the known mechanisms of the disease, Dr. Hocevar discussed new imaging techniques to diagnose Sjögren's, and Dr. Bruyn focused on updating the crowd on the current state of clinical trials in Sjögren's.

Sunday evening, a session featuring a select number of oral abstract presentations was held and moderated by Gaetane Nocturne, MD, PhD, and Matthew Basiaga, MD, DO, RhMSUS.

First, Blake Warner, PhD, MPH, DDS, shared findings from his work on identifying pathogenic drivers to Sjögren's using single cell and spatial transcriptomics. Dr. Warner shared that approaches using single cell multiomics and spatial transcriptomics facilitate the dis-entanglement of the complex disease-dependent tissue disorganization, cellular compositional alterations, and transcriptional cellular states in the salivary glands of Sjögren's patients. The second presenter, Saba Nayar, PhD, spoke on her work to identify the unique biological profiles of germinal centers within tertiary lymphoid structures in the salivary glands of Sjögren's patients. Using transcriptomic analysis, Dr. Nayar and colleagues have revealed 3,863 significantly differentially expressed genes in salivary gland tertiary lymphoid structures. Next, Marie Dulin, MD, spoke on the utility of BAFF-var as a new predisposing factor for Sjögren's and the impact on disease activity. An increased prevalence of BAFF-var was found in Sjögren's patients when compared to the general population. Lastly for this session,

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“Recap” *continued from page 11* ▼

Raphaele Seror, MD, PhD, discussed the Sjögren Tool for Assessing Response (STAR). In her work, Dr. Seror reanalyzed 9 Sjögren’s trials using STAR to assess baseline activity and overall response rates, and has found that STAR, and CRESS, saw a consistent response across most trials.

The last Sjögren’s-specific session took place on Monday morning and focused on the unmet needs related to recognizing, preventing and managing Sjögren’s. Moderated by Lisa Christopher-Stine, MD, MPH, and Blake Warner, PhD, MPH, DDS, the objectives of this session were to delineate novel treatments for common complications of dry mouth, to discuss updates on the pathophysiology of salivary gland hypofunction and manifestations of lymphoma in Sjögren’s, and to describe the evaluation of lung and renal complications in Sjögren’s. Alen Zabotti, MD, began the session with a description of the glandular pathology of the disease, followed by a rheumatological perspective on pulmonary and renal manifestations presented by Sara McCoy, MD, PhD, and lastly, a description of tips and best practices for the management of dryness by Leslie P. Laing Gibbard, PHD, DDS.

Foundation Luncheon

Though not officially part of ACR Convergence, the Foundation held its annual Luncheon on Sunday, November 13th, for those attending the conference in Philadelphia. This invite-only event included rheumatologists as well as a range of other medical specialists, researchers, industry partners and patients.

The Foundation’s Kathy Hammitt and Janet Church began the meeting with an introduction of what would be discussed as well as important updates on Foundation programs, including highlights from the 2021 *Living with Sjögren’s* patient survey to emphasize the severity of the patient experience.

This year’s theme was “Breaking the Barriers to Clinical Trials in Sjögren’s,” and the event was moderated by Alan Baer, MD, Chair of the Sjögren’s Foundation Medical and Scientific Advisory Council and Director of the Sjögren’s Clinic at Johns Hopkins University.

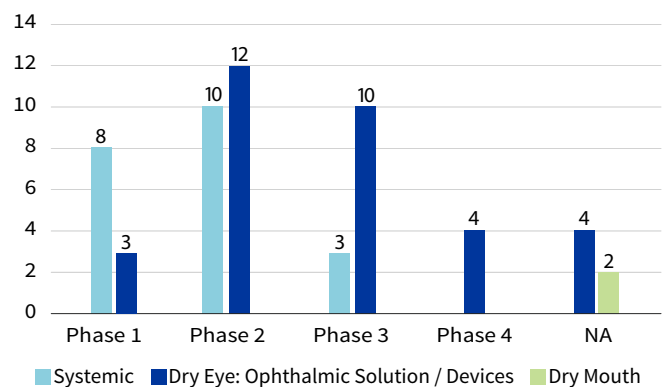
In addition to moderating, Dr. Baer shared an important update on the international nomenclature initiative on Sjögren’s. Here, Dr. Baer discussed the process and methodology as well as examples of prior name changes in other diseases to help set a precedent for what may come of this work. Key next steps in the initiative include fine-tuning survey questions based on the initial response, engaging in a second round of Delphi voting for both patients and clinicians, subsequently analyzing the results and preparing the findings for publication.

To begin the discussion on clinical trials, Kathy Hammitt shared some of the promising aspects that have been recognized, including the sheer increase in number of trials currently taking place (Fig. 1). Expanding on this, Hammitt shared insight into all of the different pathways that are currently being investigated for a potential Sjögren’s therapy.

Setting the stage to discuss the barriers for clinical trials, a conversation led by Daniel J. Wallace, MD, Chair, Sjögren’s Foundation Clinical Trails Consortium, Associate Director, Rheumatology Fellowship Program, Cedars-Sinai, Professor of Medicine, David Geffen School of Medicine, UCLA, Hammitt led a brief discussion on what’s currently being used as clinical trial endpoints in Sjögren’s therapies. From here, Dr. Wallace led a lengthy discussion, with significant audience feedback, on the current barriers to Sjögren’s trials and what can be done to alleviate them. Notably, some of the barriers included the limited pool of patients available due to strict disease criteria and the occurrence of multiple trials at the same time, which further reduces the pool of available patients for any one trial. Other barriers discussed on the day included insufficient staff or incentives to coordinate and participate in trials as a principal investigator, lack of accessibility to infusion sites, if needed, and difficulties in obtaining a reliable salivary gland biopsy from patients.

Following the event, attendees were invited to share additional feedback by way of a brief survey, which will inform the continuation of this important discussion on how the Sjögren’s community can achieve better trials and outcomes.

Fig. 1: Current Clinical Trials in Sjögren’s



Foundation Booth

Lastly, the Foundation was excited to debut an updated and redesigned booth structure in this year’s exhibit hall. As in years past, Foundation staff shared a wide variety of materials, including clinical practice guidelines and the new edition of the *Sjögren’s Book*.

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Sjögren's Foundation Outstanding Abstract Awards at ACR 2022

The Sjögren's Foundation was delighted to once again have the opportunity to recognize a young investigator for their exceptional research in Sjögren's. This year's winner of the Foundation's Outstanding Abstract Award was Xiaomei Shan PhD(c), a doctoral candidate at the University of Erlangen, in Erlangen, Germany. Her winning abstract was titled, *Early Histopathological Changes of the Salivary Glands Associated with the Development of Sjögren's*.

The objective of this work was to evaluate the early epithelial changes induced by the stimulation of salivary secretion under the action of specific beta-adrenergic agonists. Using a mouse model, Shan and colleagues found that beta adrenergic stimulation of hypercalcemic mice caused cellular swelling and an absolute loss of epithelial nuclei of the mucous acini of the submandibular glands that persisted until the end of the recovery phase. They also found that the ribosomal protein S6 is part of the translation machinery and is activated by phosphorylation via the mTOR pathway and that TGF- β is a potent inhibitor of the mTOR pathway.

Shan and colleagues concluded that subtle damage of salivary epithelial cells concur in the activation of the mTOR pathway, which is involved in the regulation of cell size, growth, proliferation and autophagy. These early changes in the mucous acini are sufficient to initiate B cell infiltration and autoantibody response conditioning the appearance of Sjögren's-like manifestations in the mouse model being used.

Though unable to attend in-person, Shan was recognized for her work at the Foundation's luncheon held on Sunday, November 13, 2022.

The Sjögren's Foundation's Outstanding Abstract Award is designed to recognize exceptional research efforts in the field of Sjögren's and encourage new or early-stage investigators to continue to focus on



Xiaomei Shan PhD(c)

Sjögren's throughout their career. The Foundation is grateful for the distinguished panel of professionals who reviewed and provided feedback on this year's abstracts. In all, there were more than 50 eligible abstracts for review. The Foundation would also like to congratulate all authors who had their work accepted at this year's meeting.

To view the winning abstract, please visit: <https://www.sjogrens.org/researchers-providers/research-grants/other-awards> ■



“Recap” *continued from page 12* ▼

Conference attendees who stopped by the booth were encouraged to attend the upcoming State of Sjögren’s event, sign up for *Sjögren’s Quarterly*, consider becoming involved with Sjögren’s trials and to apply for a research grant.

The Foundation’s booth was a meeting point for many of our colleagues to reconnect after being virtual for the past few years, and an opportunity to expand our professional network with all of the new faces who stopped by.

33rd International Symposium on the Autonomic Nervous System

The Foundation, for the first time, was excited to engage and take part in the 33rd International Symposium on the Autonomic Nervous System, put on by the American Autonomic Society (AAS).

In recent years, dysautonomia in its array of manifestations has become a prominent topic in Sjögren’s, and attending this meeting was an important step in engaging with key specialists, including neurologists and cardiologists, in this area.

Key presentation areas of the conference included non-invasive measures of autonomic dysregulation in



The Foundation’s Lane Destro, PhD, Director of Corporate Partnerships (Right), and Michele Champigny, VP of Patient Education (Left), at the Sjögren’s Foundation Booth in the ACR Expo Hall.

children, postural orthostatic tachycardia syndrome (POTS) and orthostatic intolerance, the pathophysiology and clinical pharmacology of autonomic disorders, autonomic regulation and failure, the autonomic sequelae of COVID-19, sleep and the autonomic nervous system, cognitive function in autonomic disorders, neuromodulation and disease treatment, and practical management issues in POTS.

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“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.

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You Stood Up!

NFL Coach Brings Awareness to Sjögren's During My Cause My Cleats

NFL stars reveal their passions beyond the game and wear their hearts on their feet through My Cause My Cleats.



The National Football League's (NFL) My Cause My Cleats program gives players and coaches the opportunity to highlight a cause that is close to their heart by wearing custom designed cleats. During Week 13, all NFL players and coaches honored their chosen organizations by wearing, and then auctioning, specially designed cleats.

Lunda Wells, tight end coach for the Dallas Cowboys, used his My Cause My Cleats game day shoes to support the Sjögren's Foundation on December 4, 2022. For the second year in a row, Coach Wells designed his cleats in honor his wife, Tiffany, and all Sjögren's patients. His shoes also shared that Sjögren's is serious, systemic and prevalent.

Thank you, Coach Wells, for standing up for all Sjögren's patients and congratulations to the Dallas Cowboys on their win during the My Cause My Cleats game! ■



"Game day shoes in support of my Wife and the Millions of people that live with Sjögren's." -@Lundawells (Lunda Wells on Twitter)

Cleats 2022



Cleats 2021

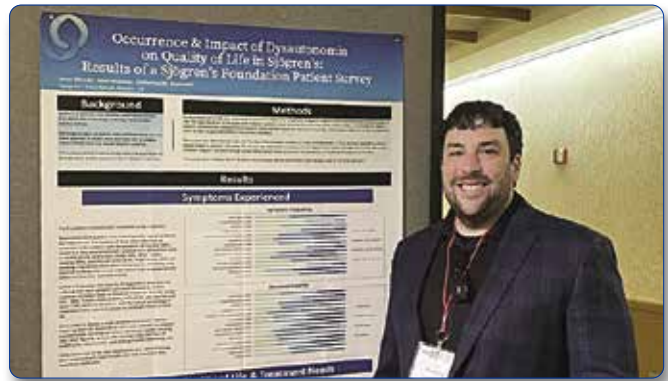


Coach Lunda Wells wearing the cleats at the My Cause My Cleats game.

“Recap” *continued from page 14* ▼

The Foundation was represented by Matt Makara, MPH, Senior Director of Research & Scientific Affairs, who was on site to help raise awareness on Sjögren’s and the Foundation through multiple touchpoints, including a poster and newly designed handout to promote provider and research involvement with the Foundation. This handout, which was delivered to each conference attendee, shared information on research grants, clinical practice guidelines and *Sjögren’s Quarterly* as well as invited them to upcoming meetings and provided insight into why their involvement is important to our community.

To further emphasize this need, the Foundation submitted and was accepted for a poster presentation on the occurrence and impact of dysautonomia in Sjögren’s. During the poster session, attendees had the opportunity to discuss the findings and ask questions about Sjögren’s and, beyond dysautonomia, learn about the broader patient experience as a whole using data from the 2021 *Living with Sjögren’s* patient survey and included information on POTS, GI issues, eye problems, sleep and more.



Matt Makara, MPH, Sr. Director of Research & Scientific Affairs, presents information from the 2021 Living with Sjögren’s patient survey at AAS.

On behalf of the Foundation, we thank the organizers of each of these important meetings and all of our colleagues, domestic and international, for coming together and sharing their work, prioritizing patients, and moving forward with enthusiasm to help improve our understanding of this complex disease and our ability to diagnose, manage and treat Sjögren’s patients everywhere. ■



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





STRONGER THAN SJÖGREN'S

Join a Spring Walk for Sjögren's Event!

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

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

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

Spring 2023 – Walk for Sjögren's Calendar

March

Virtual Southwest Walk for Sjögren's
Saturday, March 11, 2023

Virtual Southeast Walk for Sjögren's
Saturday, March 11, 2023

April

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

May

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

June

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

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

events.sjogrens.org

Congratulations and thank you to our Walk for Sjögren's Stars in 2022! They contributed to the success of a Walk for Sjögren's with their outstanding outreach and by raising \$1,000 or more. View our 2022 Stars and learn more by visiting events.sjogrens.org or click the QR code below.



Awareness never looked so good!



Sjögren's Foundation Water Bottle

Featuring a sleek design, this high-end reusable water bottle was selected specifically for Sjögren's patients. Easy to open and refill, these temperature-controlled bottles are ideal for raising awareness of Sjögren's and keeping you hydrated!

Description

- Holds 16.9 ounces (500ML) of liquid
- Double wall 18/8 stainless steel thermal bottle with copper vacuum insulation
- Threaded insulated lid, and powder coated finish
- Durable, scratch resistant, and smudge-proof with extra grip
- Height: 10.75"
- Width: 2.625"
- Sjögren's Foundation signature color logo imbedded

Member Price \$35

Non-Member Price: \$38

| | Qty. | Total |
|---|----------|-------|
| Sjögren's Foundation Water Bottle | | |
| Member Pricing | \$35 ea. | |
| Non-Member Pricing | \$38 ea. | |
| Sjögren's Foundation Face Masks (2 pack) | | |
| Member Pricing | \$12 ea. | |
| Non-Member Pricing | \$15 ea. | |
| Shipping and Handling: U.S. Mail: \$7 for first item + \$2 for each additional item | | \$7 |
| Total Amount Due | | |

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

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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.

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Exp. Date _____ Security Code _____

Signature _____

Sjögren's Foundation Reusable 3D Cotton Face Masks (2 pack)



Non-medical reusable 3D cotton mask that covers mouth and nose. Masks come in packs of two – one navy face mask and one royal blue.

Multiple layers of fabric made of 95% cotton and 5% spandex for flexibility and comfort with adjustable ear straps and built-in pocket for filter insert (filter not included).

Member Price \$12

Non-Member Price: \$15



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Anthony Abatemarco

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Conquering Sjögren's

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



2023 Virtual National Patient Conference

Conquering Sjögren's Together

Save The Date **April 21 – 22, 2023**

for the 2023 National Patient Conference!

As you begin making plans this New Year, mark your calendars for the 2023 Sjögren's Foundation National Patient Conference! This two-day, virtual event will be held on April 21 and 22, 2023. As in the past, you can expect a fantastic lineup of presenters sharing pertinent Sjögren's information that is designed to help you better understand and manage your symptoms. We look forward to having you join us for this informative educational experience!

