

# CONQUERING Sjögren's

November/December 2020

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# Uncertainty and Sjögren's

*Living with the current uncertainty during a pandemic*



by Teri Rumpf, PhD

**W**e can't predict what is to come. Two years ago, when I wrote about living with a chronic illness, I said that in addition to being fatigued, having Sjögren's meant living a life of increased uncertainty. In 2018, I was referring to the uncertainty of having a disease that often makes you look better than you feel; and allows you to be functional (or relatively so) one day, and completely incapable of doing anything the next. It was the uncertainty of living with a disease that made it difficult to plan; one that affected every aspect of life. For me, the uncertainty and the vicissitudes of Sjögren's generated anxiety that I could not escape, but that gradually, over many years, I became accustomed to and learned to live with. It was what people call a "new normal," better at times, worse at others. It was reality but I wanted the old normal back. Little could I, or anyone else, know what the future would bring. Fast forward to 2020. No one (except perhaps a handful of scientists) could have predicted the coronavirus (Covid-19) pandemic sweeping our country and our world. What we face now gives uncertainty a new and entirely different level of meaning.

How anyone reacts depends on who they are, where they live, how high the numbers are in their town, state or part of the country. It depends on their age, state of health, the severity of their Sjögren's; whether they have children in school, or just whatever is on the morning news. It's also a function of the circumstances their life, finances, how they deal with doubt, how vulnerable they feel, who is there to support them. Some of us are leading practically normal lives while other lives have been changed or broken apart in the most fundamental ways. The threat of a

viral illness that may be mild or fatal breaks up our routine, our sense of security and safety, our ability to lead life as we knew it. Much has changed in a short time. For some, everything has changed. And for all of us, the level of threat and uncertainty can change at any moment, with any new piece of information.

Uncertainty causes stress. Stress can be mild or overwhelming, occasionally present or always there. It can be incapacitating or motivating. It affects us in ways that are obvious and ways that we are unaware of. Sometimes we can ignore it, sometimes we can't. Stress disrupts our sleep, our routines, our sense of who and where we are in the world. It increases anxiety and depression. Stress affects the way we feel both physically and emotionally, the way we eat, sleep and interact with others, the way we think. The simplest things become weighty matters with no absolute answers. Do I go to the store? Can we eat in a restaurant if we are outside? Inside? Can I get takeout? Do we send our children to school? Do we see our parents, our grandparents? Is it safe? Can we go to a park, a friend's house? If I send the children to school, will they bring the virus home? Am I more vulnerable because I have Sjögren's? Do I feel more vulnerable because I have Sjögren's? If I start to feel unwell is it Sjögren's or the beginning of Covid-19, or something else completely? Am I having a flare? More than ever, it's important to know what your baseline is and how it varies.

Our responses also change. A crisis is usually defined as something finite and short term. We respond to a crisis with a heightened stress response, but a pandemic is likely to last for an uncertain and unspecified

*continued page 4* ▼

### “Uncertainty & Sjögren’s” *continued from page 3* ▼

period of time. At the beginning we may have responded with caution that is difficult to sustain as time goes on. Now, eight months after the pandemic started our behaviors may begin to change. We are tired of the extreme caution, many of us want to live, to go back to the way things were, even just a little. Even one small thing that makes us feel a little more like ourselves. But seeing the grandchildren or going to a restaurant is not the same. It is not without risk. We may do these things, but they may have a different feel, an element of added stress. We have adapted to having a chronic illness, now we are forced to adapt again.

“I don’t expect to survive this,” a friend with Sjögren’s confided recently, and I thought she was brave to voice her fears so bluntly. The pandemic allows us to say what is on our minds. Another Sjögren’s friend said, “I expect I’ll live through this, but I’m not sure I want to,” referring to the state of the world. A good relationship helps offset stress. Feeling trapped makes it worse. Support makes things better. Instrumental support may come in the form of help with cooking, cleaning, going to the store, buying food, carrying a heavy package. It gives us the feeling that there are people around who will help us. Emotional support allows us to share the most vulnerable parts of ourselves with someone

else. Just as other people’s responses can either help or hinder our ability to cope with the vicissitudes of Sjögren’s, they can help or hinder coping with a pandemic. In a relationship, each partner may handle uncertainty differently. While some of us live alone, some of us have never lived so intensely with their partner or significant other. Nor does living alone have to be synonymous with being isolated. You can be isolated on your own or in a relationship. Uncertainty and doubt are with us, if not about today, about tomorrow.

So when asked to write this article, and asked to write about ways of coping with the current state of the world, my first response was to laugh. I was afraid that if I started to write I would be overwhelmed. It seemed a real possibility. Then I started looking at the people around me and what was helping them cope. I thought about who was doing well and why. Some things emerged. I’ll share them but with the caveat that they are meant only as suggestions and observations, one size does not fit all:

- 1) Control what is controllable. There are choices to be made about even the simplest things. You can only do the best with the information you have at any given time.
- 2) Stick to a routine whenever possible. It provides

*continued page 6* ▼

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# Sjögren's Foundation Announces New Research Grants

The Sjögren's Foundation is excited to announce the selection of three research grant recipients for the new fiscal year – the second group under the Foundation's revamped grant program. This new program offers two distinct grant types, the Sjögren's Foundation High Impact Research Grant at \$75,000 and the Sjögren's Foundation Pilot Research Grant at \$25,000.

Additionally, the Foundation has provided no-cost extensions to our current grantees to allow for extra time given the current public health crisis and the resulting barriers to work that many have experienced.

Visit [www.sjogrens.org](http://www.sjogrens.org) to learn more about the Foundation's research grant opportunities.

## High Impact Research Grant Recipients

### Seunghae Cha, DDS, PhD

University of Florida College of Dentistry  
Gainesville, FL

#### Project Title

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

#### Abstract

Our interdisciplinary assessments of recurrent salivary gland swelling in children have discovered a rare cohort of pediatric Sjögren's (Juvenile SS/JSS) at our institute. The prevalence and the natural history of JSS is completely unknown. JSS is commonly misdiagnosed as infection of the salivary glands, as recurrent glandular swelling frequently occurs in JSS without the hallmarks of SS. This application will uncover the gene signatures of JSS immune cells with high-throughput sequencing. Our preliminary data

suggest that mitochondrial RNA may elicit the inflammatory signature in monocyte. We will determine how such altered gene signature of JSS monocyte in the blood affects immune cell phenotype in the target tissue. We hypothesize that robust inflammation in recurrent parotitis of JSS presents more distinct mitochondrial RNA dysregulation compared to JSS without recurrent parotitis or adult Sjögren's. Our ultimate goal is to establish the scientific foundation for JSS diagnostic criteria and targeted therapeutic interventions.



### David T. Wong, DMD, DMSc

University of California, Los Angeles, Los Angeles, CA

#### Project Title

*EFIRM Liquid Biopsy for Early Detection of Sjögren's Syndrome and Sicca Patients*

#### Abstract

There is no early detection for Sjögren's and its precursor sicca. The ability to detect Sjögren's early, can improve quality of life, develop treatment modalities and early detection of lymphoma development in these patients. Early detection of sicca may eventually allow intervention of progression to full blown disease of Sjögren's. We have developed an electrochemical assay, EFIRM, that can measure the pathognomonic autoantibodies of Sjögren's, Ro and La for the first time robustly and quantitatively in saliva of Sjögren's and sicca patients. This Sjögren's Foundation High Impact Research Grant is to test the hypothesis that salivary IgA, not IgG, to Ro and La are associated with salivary gland tissue destruction as reflected by focal

## “Uncertainty & Sjögren’s” *continued from page 4* ▼

some sense of normalcy. Structure your day in a way that suits you and fits around the constraints you have. For example, if you have children, but need to get some work done, get up early if you are a morning person, work after they are in bed if you aren’t. If you have a partner who also works, divide up the day as best you can so that each of you has some time to get things done.

- 3) Simplify. A friend gave me some advice I found very helpful for those times I wasn’t able or didn’t feel like doing very much. She said, “I try to do one thing a day that’s useful or necessary and if I can cross that off my list, I feel I’ve accomplished something.” Only one thing. If you don’t feel up to getting something more done, you can always try again when you do. Put aside the “should.” There are always things that should be done. There are some things you have to get done, but if others are not essential, they can wait until you feel up to it.
- 4) Break things down into small components, the smallest possible components. That way, if you can’t do all of it, you can do some of whatever you need to do. This is a Sjögren’s strategy I learned long ago, when having the energy for some significant project didn’t exist but having enough to fulfill a portion of it did.
- 5) Find something that interests you, or gives you pleasure and try to do it on a daily basis. Even if only for a few minutes. Bake if you like to, knit, cook or garden, or exercise. Move when you can. I know someone who doesn’t want to go out, but she puts on music and walks around her house for twenty minutes. She feels better after. I’ve had a lifelong photography hobby. Since I’m not going anywhere to take photos, I “meet” with two friends online every morning. We choose a theme for the week and we share photos we’ve taken in the past. It allows us to relive the places we’ve been, and it gives us a chance to talk about more than the photos. Oddly enough, it allows us to be future oriented. We invariably think about the places we’d like to go in the future.
- 6) Connect with others. Or multiple people. Each person will take you out of yourself in a different way. It very much helps to find someone with whom you can share your feelings. Now may not be the time to broaden your support system, but it may be the time to reconnect with people. If you enlarge your support

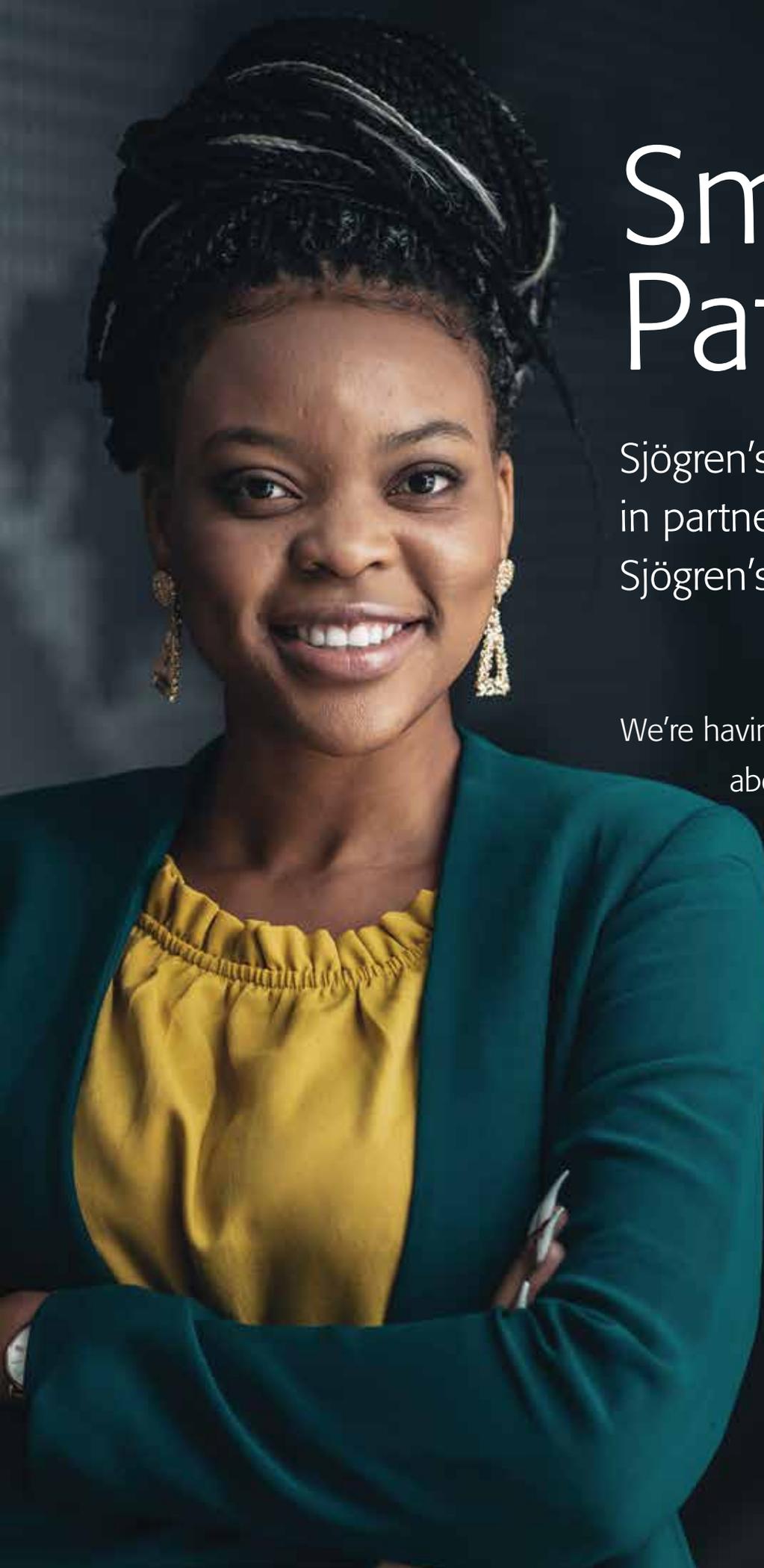
system you may find that different people offer different kinds of support.

- 7) Avoid people who are toxic to you. People who are constantly harsh and critical are not helpful in this climate.
- 8) Be kind to yourself and others. Kindness means everything when times are difficult. If you can help someone, you will find it easier to let him or her help you should you need it. Little acts of kindness will enable all of us get through this. If you can help someone in any way, now is the time.
- 9) Escapism isn’t all bad. Books, puzzles, movies, Netflix, whatever works.
- 10) Live one day at a time. We know what today is, tomorrow is unknown and therefore, uncertain. I use this quote from Ralph Waldo Emerson: “Finish each day and be done with it. You have done what you could; some blunders and absurdities have crept in: forget them as soon as you can.” If you do the best you can at any given moment, that’s all you can do.

Remember that these are truly stressful times. That’s reality. I’ve always hated it when someone (usually an older, male physician) advised me to “avoid stress.” I wondered if they did that in their own lives, if their lives were stress free. Reading descriptions of people who have been living with the “long haul” effects of Covid-19 reminds me of hearing about Sjögren’s. These were normal, healthy people who didn’t ask for a disease. In many cases, they encounter similar responses of disbelief and experience the kind of anxiety and depression that accompany an indeterminate illness. So rather than “avoid stress,” I offer two options: shut it down if possible, stay focused and in the reality of the moment, and distract yourself with something if you can. Put a little pleasure in each day. Deal with what you can; or, if that isn’t possible find something or someone that helps. Don’t wait till it’s completely overwhelming. We all need to get through this, while living with Sjögren’s. There are going to be good and bad days. If today is not a good day, may tomorrow be a better one. We don’t know how long this will last, but it’s likely to be a marathon, not a sprint.

Please visit [www.sjogrens.org](http://www.sjogrens.org) to view the Sjögren’s Foundation response to the pandemic and Covid-19 patient resources. ■

*Teri Rumpf, PhD co-authored The Sjögren’s Syndrome Survival Guide with Kathy Hammitt, Sjögren’s Foundation Vice President of Medical & Scientific Affairs*



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**“Research Grants”** *continued from page 5* ▼

score. Furthermore, the monomeric versus polymeric forms of salivary IgA1 to Ro can discriminate sicca from Sjögren’s patients using saliva samples.

**Pilot Research Grant Recipient**



**Sharmila Masli, PhD**  
*Boston University, Needham, MA*

**Project Title**  
*Tear biomarkers for differential diagnosis of Sjögren’s vs. non-Sjögren’s dry eye*

**Abstract**

Sicca symptoms associated with Sjögren’s include dryness of the mouth and eyes. Several non-Sjögren’s conditions also result in dry eyes. However, at present no clinical tests available to eye doctors successfully distinguish Sjögren’s related dry eye. This issue adds to the current delay experienced by Sjögren’s patients in receiving accurate diagnosis and consequential prolonged suffering. Many complications involving several organs are possible in Sjögren’s, including cancer, making early diagnosis critical. In fact, when patients with clinically significant dry eye were screened for Sjögren’s, over 30% were newly diagnosed with Sjögren’s. Therefore, the ability to identify Sjögren’s-related dry eye can facilitate earlier diagnosis of Sjögren’s. This study proposes to identify tear components that differentiate Sjögren’s vs. non-Sjögren’s dry eye. Such tear components can form the basis for a diagnostic test that helps clinicians detect Sjögren’s earlier and manage treatment effectively to prevent development of serious complications.

## Extended Research Grants

**Kimberly Jasmer McDonald, PhD**

*Postdoctoral Fellow, University of Missouri, Dept. of Biochemistry, Columbia, MO*

**Project Title**

*P2Y<sub>2</sub> Receptor as Therapeutic Target in Sjögren’s Syndrome Mouse Model*

**Description**

It is the goal of this proposal to elucidate the role P2Y<sub>2</sub>R plays in infiltrating SMG B cell function and evaluate P2Y<sub>2</sub>R as a novel therapeutic target for the treatment of Sjögren’s.

**Melodie Lynn Well, PhD**

*Assistant Professor, University of Utah, School of Dentistry, Salt Lake City, UT*

**Project Title**

*The Impact of a Global Increase in Hepatitis Delta Virus (HDV) Exposure on the Incidence of Sjögren’s Syndrome Diagnosis*

**Description**

We hypothesize that this increase in global HDV exposure may lead to increased Sjögren’s development in susceptible populations. This discovery in connection with the novel HDV profile observed in Sjögren’s patients is highly innovative and warrants immediate investigation. Therefore, we have designed two studies to perform cross-correlative analysis between HDV and Sjögren’s diagnoses within the Utah population. These studies will provide the foundation for advancement to clinical trials.

**Yee Ling Wu, PhD**

*Assistant Professor, Loyola University Chicago, Dept. of Microbiology and Immunology, Maywood, IL*

**Project Title**

*Genetic and Phenotypic Polymorphisms of Complement C4 in the Pathogenesis of Sjögren’s Syndrome*

**Description**

We hypothesize that C4 genetic and protein polymorphisms are engaged in disease predisposition and in modulating the clinical presentation of Sjögren’s. We will analyze patient samples using accurate molecular assays for determining C4 gene copy numbers, immunoassays for activated complement protein products and transcriptomic analyses to 1) determine the cause of low C4 in Sjögren’s, and 2) evaluate the utility of combining genetic stratification of C4 and new protein markers in the diagnosis and management of Sjögren’s.

**Emily Anne Lanzel, DDS, MS**

*Visiting Assistant Professor, University of Iowa, College of Dentistry*

**Project Title**

*Salivary Biomarkers for Diagnosis of Childhood Sjögren’s Syndrome*

**Description**

The objective of this study is to identify reliable diagnostic biomarkers that may be used to diagnose childhood Sjögren’s. We hypothesize that chemokines, cytokines, and biomarkers associated with the presence of CD4+ T cell, CD8+ T cell, and B cell infiltration in the salivary glands of children with Sjögren’s should be detectable in their saliva.

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# Clinician's Corner:

## Fatigue Fighters



*Frederick B. Vivino, MD, MS, FACR  
University of Pennsylvania, Division of  
Rheumatology, Penn Sjögren's Syndrome  
Center, Philadelphia*



*Fatigue is one of the most prevalent and disabling symptoms of Sjögren's. Here are some tips that can help you cope with this problem:*

- Work with your doctor to find a specific cause and treatment for your fatigue. Possible causes may include systemic inflammation, poor sleep, fibromyalgia, depression, hypothyroidism, anemia, muscle inflammation, vitamin deficiencies or side-effects of medications.
- Know your limits and pace yourself. Plan to do no more than one activity on your bad days. Try to do more on your good days, but don't overdo it!
- Listen to your body and plan to take a 20-minute time-out every few hours to help you get through your day. Educate your friends and family about what you are going through and how the fatigue in Sjögren's can come and go.
- Develop a support system to help you with tasks. Ask friends and family members to be prepared to do one or two chores for you on your fatigue days. Give them specific instructions in advance and be reasonable with your expectations.
- Get at least eight hours of sleep every night. If you wake up at night, plan extra time for sleep.
- Get your body moving every day! This may help not only your fatigue but also your chronic pain, poor sleep and depression. Start with five minutes of aerobic exercise daily (e.g. walking, biking, running, elliptical, treadmill) and increase the duration by an additional two-to-three minutes every 2-4 weeks up to a maximum of 25 minutes daily. If you have a heart or lung condition, consult your doctor first.
- Identify the major stressors in your life, and work with a mental health professional or your support system to minimize their impact.
- If you are still employed, ask your employer for accommodations because you have a medical condition. Try to work from home if possible, to gain more flexibility with your work routine. Check the following resources (search "chronic fatigue") to get more information on work accommodations and/or career options:
  - Disability and Business Technical Assistance Center at [www.dbtac.vcu.edu](http://www.dbtac.vcu.edu).
  - Job Accommodation Network at [www.jan.wvu.edu](http://www.jan.wvu.edu).

**“Research Grants”** *continued from page 8* ▼

**Kristi Ann Koelsch, PhD**

*Assistant Professor of Research, Dept. of Medicine, College of Medicine, University of Oklahoma Health Sciences Center*

**Project Title**

*Salivary Anti-Ro Defines a New Phenotype of Sjögren’s Syndrome*

**Description**

Sjögren’s is characterized by a lymphocytic infiltration of the salivary glands as well as anti-Ro (or SSA) in the serum. Neither research classification nor clinical diagnosis can be made without at least one of these two features, we have studied subjects attending a comprehensive sicca evaluation clinic who had dry eyes, dry mouth, objective findings of lacrimal and salivary gland dysfunction but no serum auto-antibodies and no focal lymphocytic infiltration. In a substantial subset of these subjects we find anti-Ro in the saliva. Some subjects have both IgA and IgG anti-Ro, while others have only IgA anti-Ro. This project will fully characterize this group of patients, who may represent a previously unrecognized phenotype of Sjögren’s, or an intermediate stage from which some will develop classical Sjögren’s ■

**Sjögren’s Foundation Outstanding Abstract Award at ACR 2020**



The Sjögren’s Foundation is delighted to recognize Sherri Longobardi as the 2020 winner of the Sjögren’s Foundation Outstanding Abstract Award at the American College of Rheumatology’s Annual Meeting.

Ms. Longobardi, who works out of the University of Oklahoma Health Sciences

Center and the Oklahoma Medical Research Foundation, received the award for her abstract titled, “Novel Shared Antibody Specificities in Ro Antibody Negative Sjögren’s Syndrome.” Conclusions from this work revealed a set of eight novel antigens, which were bound by plasma IgG in both Ro positive and Ro negative Sjögren’s patients. Notably, these antigens may be useful for diagnosing Sjögren’s without a lip biopsy.

The Sjögren’s Foundation 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 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. ■

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**\$3.7M NIH Grant to Support Genetics and Sjögren’s Research**



The Sjögren’s Foundation would like to congratulate Dr. Christopher Lessard, PhD, and his team at Oklahoma Medical Research Foundation (OMRF) on being awarded a \$3.7 million grant to study which genes are associated with Sjögren’s!

Dr. Lessard is a friend of the Sjögren’s Foundation and a former research grant recipient. The Foundation strives to foster research that will have the greatest potential impact and we are truly proud of the continued work of Dr. Lessard and the OMRF team. ■



# Sjögren's and Gastrointestinal Complications

by Nancy Carteron, MD, FACR

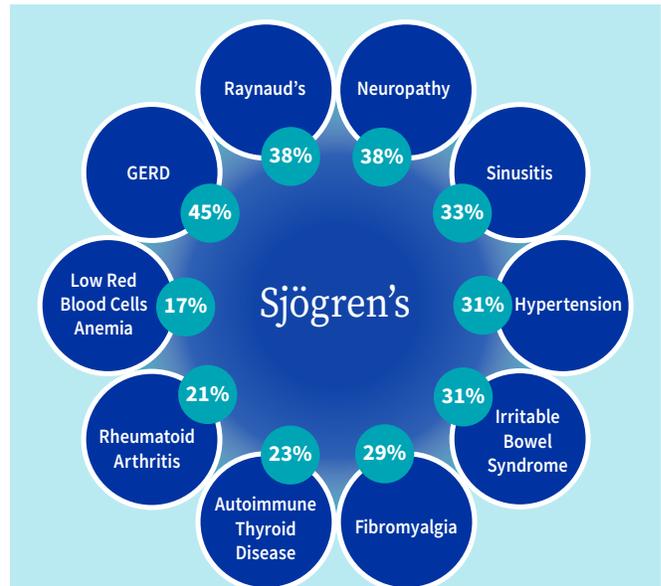
The gastrointestinal (GI) tract is an internal mucosal surface, rich in immune system cells/antibodies and nerves, whose main function is to digest food and absorb nutrients for optimal health. Enjoying food and sharing meals is an important part of every society, but for many with Sjögren's, it is a major challenge.

## Tips for managing GI symptoms in Sjögren's:

- Swallowing problems may be related to esophagus muscle inflammation (myositis), dryness, or nerve dysfunction. To help, chew as well as possible and try soft foods, olive oil, and coconut water.
- Gastroesophageal Reflux Disease (GERD) is more common and due to decreased Lower Esophageal Sphincter tone (60% vs 20% normal). Avoid reclining after a meal; various anti-acids are available. See tips for reflux in the Patient Education Sheet, "Reflux and Your Throat," on page 12.
- Gastroparesis (delayed gastric emptying) occurs in Sjögren's (30-70%), and, similar to diabetes, causes upper abdominal pain/fullness/nausea.
- Gastric parietal cells can be destroyed leading to B12 deficiency. If a H pylori bacterial infection is present, it can be treated.
- Small intestine immune attack (Celiac) or bacterial overgrowth can result in abdominal pain, cramping, bloating. Try a wheat/gluten free diet, or other food group elimination diets. Most nutrients are absorbed here. Be aware, MALT (mucosal associated lymphoma) can occur.
- The large intestine is where liquid is reabsorbed. Constipation and diarrhea can occur with Sjögren's. To help, increase vegetables and try magnesium supplement for constipation.
- The pancreas, which releases digestive enzymes, can have low-level inflammation (20-

40%) in Sjögren's. Here, a pancreatic enzyme trial is an option.

- Liver – Autoimmune cholangitis (PBC, hallmark mitochondrial Ab) or Hepatitis (smooth muscle Ab) can occur in Sjögren's. Here, the hepatitis C virus should always be excluded.
- For additional help, I recommend a Neurogastroenterology or GI Motility Center as an option for Sjögren's patients with persistent GI problems. ■



## Other Diagnosed Health Conditions

There are many known comorbidities or manifestations of Sjögren's that can occur in conjunction with the disease. *Living with Sjögren's* survey respondents reported having been diagnosed by a health care provider with an average of five other health conditions, including Gastroesophageal Reflux Disease (GERD) (45%), Raynaud's (38%), Neuropathy (38%), Sinusitis (33%), Hypertension (31%), and Irritable Bowel Syndrome (31%).

*The Foundation thanks Soo Kim Abboud, MD for authoring this Patient Education Sheet. Dr. Abboud is an Assistant Professor with the Department of Otolaryngology, Head and Neck Surgery, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania*

While the exact reasons are unknown, many patients with Sjögren's suffer from gastroesophageal reflux disease (GERD). This can cause a wide variety of symptoms that can be mistaken for other conditions. Symptoms may include persistent heartburn and/or regurgitation of acid, stomach pain, hoarseness or voice change, throat pain, sore throat, difficulty swallowing, sensation of having a lump in the throat, frequent throat clearing, and chronic cough (especially at night time or upon awakening).

### **Tips for combating gastroesophageal reflux in the throat:**

- Avoid lying flat during sleep. Elevate the head of your bed using blocks or by placing a Styrofoam wedge under the mattress. Do not rely on pillows as these may only raise the head but not the esophagus.
- Don't gorge yourself at mealtime. Eat smaller, more frequent meals and one large meal.
- Avoid bedtime snacks and eat meals at least three-four hours before lying down.
- Lose any excess weight.
- Avoid spicy, acidic or fatty foods including citrus fruits or juices, tomato-based products, peppermint, chocolate, and alcohol.
- Limit your intake of caffeine including coffee, tea, and colas.
- Stop smoking.
- Don't exercise within one-two hours after eating.
- Promote saliva flow by chewing gum, sucking on lozenges or taking prescription medications such as pilocarpine (Salagen®) and cevimeline (Evoxac®). This can help neutralize stomach acids and neutralize symptoms.
- Consult your doctor if you have heartburn or take antacids more than three times per week. A variety of OTC and prescription medications can help but should only be taken with medical supervision.

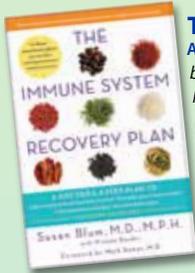
**To view all Sjögren's Foundation Resource Sheets and Brochures scan the code below or got to:**  
**[www.sjogrens.org/understanding-sjogrens/resources/brochures-resource-sheets](http://www.sjogrens.org/understanding-sjogrens/resources/brochures-resource-sheets)**



**For more information on Sjögren's, contact the Sjögren's Foundation at:**  
**10701 Parkridge Blvd., Suite 170, Reston, VA 20191 • (301) 530-4420 • [www.sjogrens.org](http://www.sjogrens.org)**

Clinicians: Please make multiple copies of this Patient Education Sheet and distribute to your patients.

# Top 5 Sjögren's Resources from the Foundation Bookstore



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

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

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

## The Sjögren's Syndrome Survival Guide

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

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

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



## The Sjögren's Book (2011)

edited by Daniel J. Wallace, MD

This hard cover book is written by the foremost medical professionals in the field of Sjögren's. The language is at college level and while the book is medically detailed it is still easy for the lay person to understand

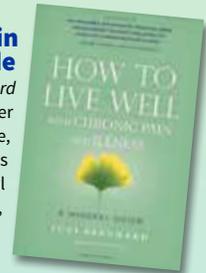
**Member Price: \$28** Non-Member Price: \$32

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

by Toni Bernhard

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

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

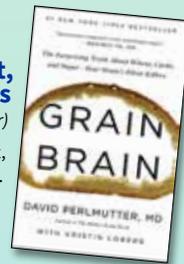


## Grain Brain: The Surprising Truth about Wheat, Carbs, and Sugar - Your Brain's Silent Killers

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.

**Member Price: \$20** Non-Member Price: \$25



	Non-Member	Member	Qty	Amount
<b>The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease</b> by Susan Blum, MD, MPH (Author), Mark Hyman, MD (Foreword), Michele Bender (Contributor)	\$25.00	\$22.00		
<b>The Sjögren's Syndrome Survival Guide</b> by Teri P. Rumpf, PhD and Katherine Morland Hammitt	\$20.00	\$17.00		
<b>The Sjögren's Book (2011)</b> edited by Daniel J. Wallace, MD	\$32.00	\$28.00		
<b>How to Live Well with Chronic Pain and Illness – A Mindful Guide</b> by Toni Bernhard	\$17.00	\$14.00		
<b>Grain Brain: The Surprising Truth about Wheat, Carbs, and Sugar - Your Brain's Silent Killers</b> by David Perlmutter, MD (Author) and Kristin Loberg (Contributor)	\$25.00	\$20.00		
<b>Shipping &amp; Handling</b> U.S. Mail: \$7 for first item + \$2 for each additional item				
<b>Total Amount</b>				

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# We Did It!

## Sjögren's Pulmonary Clinical Practice Guidelines Published

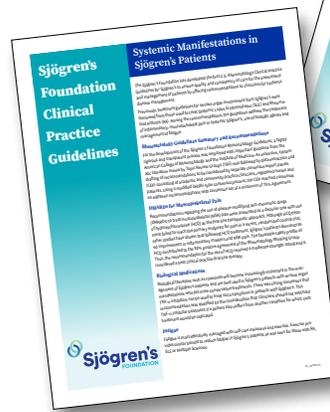
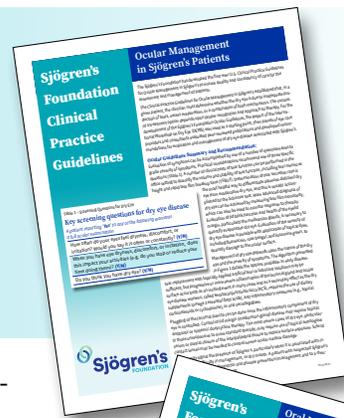
The Sjögren's Foundation is excited to announce the successful publication of our Consensus Guidelines for Evaluation and Management of Pulmonary Disease in Sjögren's in the prestigious medical journal, *CHEST*. This is the culmination of many years of work and is a major step forward for the Sjögren's community.

Watch for your January/February *Conquering Sjögren's* issue to learn more about these guidelines. ■



Go to:  
[www.sjogrens.org/researchers-providers/clinical-practice-guidelines](http://www.sjogrens.org/researchers-providers/clinical-practice-guidelines)

For our current *Clinical Practice Guidelines* or just scan the QR code.



## 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](mailto:info@sjogrens.org) to be certain we have your latest e-mail address in our database, and then keep an eye out in 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.



# Sjögren's Foundation In Action!

## Sjögren's Foundation Coordinates Virtual Booths at Dry Eye and GRYT Health Events



The Foundation's Michele Champigny, Senior Director of Professional Awareness, and Matt Makara, MPH, Director of Research and Scientific Affairs, coordinated and staffed a virtual booth at the Everything Dry Eye Virtual Symposium, organized by the Twin Cities Ocular Surface Disease Symposium and Dry Eye Booth Camp. The symposium offered live, high-quality education for doctors and staff who manage dry eye and ocular surface disease, networking opportunities and a virtual exhibit hall, which included a Sjögren's Foundation booth. Michele and Matt were available during the open exhibit hours on Friday, August 14<sup>th</sup> and Saturday August 15<sup>th</sup> to interact live with attendees – answering questions,

providing resources and fostering new relationships for the Foundation and Sjögren's community. More than 500 attendees visited the virtual booth throughout the event.

Additionally, Michele Champigny and Sjögren's Foundation CEO, Steven Taylor, coordinated a virtual booth for the COVID Advocacy Exchange Resource Fair, a virtual event organized by Bristol Myers Squibb and Gryt Health. This effort was established to promote ongoing communications and resources for the patient advocacy community through the COVID Advocacy Exchange related to issues around the global health crisis. The online platform can be accessed at: [www.covidadvocacyexchange.com/en/](http://www.covidadvocacyexchange.com/en/) ■



Dry Eye Virtual Booth



GRYT Health Booth

# Season of Giving

**F**or so many people, 2020 has been an incredibly challenging year. The Sjögren's Foundation is acutely aware of the impacts the pandemic has had on Sjögren's patient, and we want to reassure you that YOU ARE NOT ALONE! The Sjögren's Foundation is here for you now, more than ever.

The Foundation is so grateful for every volunteer, healthcare professional, and donor, whose support has allowed us to effectively respond to the Covid-19 crisis while at the same time, not letting it impact our valuable work and efforts. We are proud of how we have been able to maintain our momentum and that is in no small part because of YOU!

We have also taken the opportunity to revamp our patient programs and make them even more accessible by increasing outreach and communication. The Foundation is focused on bringing us all together, even when we can't be together.

The pandemic has impacted non-profits in unique ways, but the Sjögren's Foundation remains committed to our mission to conquer the complexities of Sjögren's and to change the future for all Sjögren's patients. If 2020 has taught us anything though, it is that we can't do this alone. As the year comes to a close, we ask you to please consider making a year-end gift. Your generosity will mean continued support for patients and greater hope for the future of Sjögren's.

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



- Enclosed is my gift of \$\_\_\_\_\_ to support the Foundation's initiatives and programs.
- I am interested in learning more about how to make a stock donation.
- Please send me information about listing the Sjögren's Foundation in my will.

***Thank you for your support of the Sjögren's Foundation.***

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# You Stood Up!

## *Sjögren's Foundation Support Group Leaders Go Virtual!*



As we continue to navigate the coronavirus (Covid-19) and focus on the health and safety of patients, many Sjögren's Foundation support groups have moved to a virtual platform. Gia, Susan and Yvonne are all volunteer support group leaders who have begun hosting virtual meetings since the pandemic.

While "going virtual" has its own challenges with many people using online platforms like Zoom for the first time, Gia, Susan and Yvonne each talk about the many highlights of being forced to go virtual. "Some members cannot drive or leave their home for other reasons. Virtual meetings have allowed them to get the support they would otherwise be missing out on," said Gia.

Susan agreed adding, "I've already had one attendee from another state! Many patients have friends across the country through online groups. Virtual support groups allow us to connect and 'meet up' in a positive, educational setting to discuss our disease."

The Foundation knows much can be learned at support group meetings and the importance of not feeling alone. Yvonne urges those who are looking for support to reach out. "Don't isolate. It's so important to connect with others and the technology is not too complicated."

While events and support group meetings continue to look a little different at the Foundation, we encourage you to use these online opportunities to connect with us in new ways. Please visit [www.sjogrens.org](http://www.sjogrens.org) to learn more about Sjögren's Foundation support group meetings, Town Halls and other events. ■

*"The Sjögren's Community is such a wonderful, caring group of people. You will make lasting friendships through involvement with other patients and the Sjögren's Foundation." – Susan*



Gia  
Albany, NY Support  
Group Leader



Susan  
Foothill Communities/  
Inland Empire, CA  
Support Group Leader



Yvonne  
Broward County/ Fort  
Lauderdale, FL Support  
Group Leader



# A Caregiver's Reflection:

## *From a husband of a Sjögren's patient*

*by Jonathan Morse, Sjögren's Foundation Board Member, Husband of a Sjögren's patient*

### *Caring for a Sjögren's patient is demanding.*

I believe that the medical community remains ill-prepared to recognize, address and treat the cascade of complexities attributed to Sjögren's. This on its own presents feelings of loneliness and fear. The need for patience, understanding, acknowledgement and validation are ever-present.

A path to rebuild confidence is relying on the wealth of relevant information available online, for example, [www.sjogrens.org](http://www.sjogrens.org) and the many related sites. Call it the democratization of care, taking matters into your own hands, patients and Caregivers find others sharing familiar tales of their experiences with medications and their on-going search for care.

The role of Caregiver is a delicate balance. The Sjögren's patient has lost so much. The disease has robbed many favorite activities. The disease has turned food and eating to the equivalent of a form of torture. The disease is misunderstood by friends and family, leaving the Sjögren's patient and Caregiver isolated and lacking attention, care and concern. And yet, the Caregiver is in possession of all of this, but also needs to allow the Sjögren's patient to preserve some element of the person that used to be, the person that was previously capable, the person that always did so much.

The Caregiver role is unselfish. And that is no simple statement. The Caregiver needs to take care of themselves because without the Caregiver the Sjögren's patient is truly alone. Caring for a Sjögren's

patient means 'right-sizing' the activity level in all aspects of life. That is, a sensitivity to schedule, to timing, to events, to activity, to food...to life.

All too often, the battle with symptoms of Sjögren's cause the patient and Caregiver to place hope in the next physician appointment. The appointment is not for another six weeks. The disease is crushing now. I am not suggesting cancelling the appointment. I am, however, suggesting alternative care, self-care. For example, I mentioned 'right-sizing,' I would add making the right food choices. And, despite the hammering pressure from medication side effects, despite the debilitating digestive condition and the need to file the head-to-toe pain in a box, find a way to include a regimen of daily exercise.

Sjögren's loss is real. The cascade of complications affecting sight, smell, taste and touch serve as reminders for how much has been taken. Our task as Caregiver remains shining light on all that remains. The things we need in life are simple pleasures, learning new things, seeing new sights, making new acquaintances. 'Right-sizing' makes possible the simple pleasures that bring joy and fulfillment.

The losses endured by Sjögren's patients is depressing, which is a very different statement than Sjögren's patients are depressed. The loneliness of Sjögren's is scary. The unknowns of Sjögren's is not insignificant. The task of the Caregiver is to turn the energy attached to the impact of loss, the feeling of loneliness, the fear of unknown into the possibility of satisfaction through validation and acknowledgement. ■



## IN MEMORIAM

### **In Memory of Barbara Gordon**

Genevieve Dayes

### **In Memory of Barbara Spors**

Irmgard Spors

### **In Memory of Carol Ann Gergel**

James Gergel

### **In Memory of Carolyn Chide**

Nancy Cooper

### **In Memory of Dollie Carpenter**

Jeremy and Leigh Johnson and Family  
Safe Families for Children, Quad Cities

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Amy Anderson

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Alejandra Lenis Munoz

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Jane Stone

### **In Honor of Ray Wick**

Frances Phillips

### **In Honor of Viki Schaub**

Melissa Carter

### **In Honor of Young Ju Park**

Estelle Hahn



### **Are You a Spouse or Partner of Someone Living with Sjögren's?**

The Foundation knows how supporting and/or caring for someone with a chronic illness, like Sjögren's, can be very rewarding but it also has a significant impact on your life, too.

Please contact the Foundation at (301) 530-4420 or send an email to [info@sjogrens.org](mailto:info@sjogrens.org) and sign-up to receive specialized mailings, educational information, and notices about teleconference support group meetings for spouses and partners of Sjögren's patients.



## Conquering Sjögren's

Sjögren's Foundation Inc.  
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