

# CONQUERING Sjögren's

September/October 2020



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

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# Coping with Stress and Anxiety



*Darlene F. Cross, MS*

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*Author **A New Normal: Learning to Live With Grief and Loss** (2010, 2017)*

*Author **Reinventing Normal: How Choice and Change Shape Our Lives** (2013)*

**W**hy on earth would any of us want to read one more thing about stress and anxiety right now? How about the fact we are dealing with stress and anxiety at an unprecedented level and duration that challenges the very meaning of the words? What does coping even mean?

Coping, simply put, means solving a problem or problems. There are certainly many ways to do this, but how you begin can make a big difference in how successful you are with your process and the outcome. The most common mistake in problem solving is when people start working to resolve the problem before it is clearly defined. Often this is the result of communication gone awry, easy to do when emotions take over.

If you find yourself getting caught in the trap of solving a problem before defining it, stop, slow down, back up, start over. Be clear about exactly what the problem is you are trying to solve, or cope with, maybe even write it down. It is easy to get off track and not even know it. For example, you and your loved one may disagree vehemently about the current state of politics and engage in frequent fights. Is the problem that you and your loved one disagree about politics? No. The problem is that you love this person, the relationship is important to you and you do not want to lose it. Resolution here likely looks very differently from one scenario to the other.

The next step in problem solving is to figure out what is about you—the things you have the power to influence, and what is not about you—the things you do not have the power to influence. You may or may not be able to have an impact on your loved one's political leanings, but you cannot follow her into the voting booth. If she does change her mind and it

happens to meet your desires, that decision was hers. As those who follow the 12-Step recovery program understand well, knowing the difference can be pivotal.

Stress, in and of itself is a normal part of everyday life that affects all of us. It can tag along like a friend or it can be a nagging bully. Chronic, sustained stress will take a toll if warnings are not heeded. The first step to de-stressing is committing to self-care at least a little and maybe a lot.

Those of us who live with autoimmune disease(s) tend to have a great appreciation for the power of self-care, both proactive and reactive. We tend to be highly knowledgeable about the endless list of options from which we can choose including meditation, yoga, naps, support systems, ongoing education, journaling, continuing education, diet, and more.

Over time we learn what works for us, what does not work, and how things can change from one day to the next, from better to worse and vice versa. Even with this impressive base of knowledge and understanding, current events that have changed the very way we live and work and with no end in sight are causing stress in ways we never imagined. More than ever before, focusing on what works and doing more of it, and focusing on what does not work and dumping it, it is critical. Consciously choosing to live in the present is a powerful tool that can quickly bring us back to reality when the outside world seems anything but real. My own example right now is if I focus on the news, I feel overwhelmed, discouraged, afraid for my family, and betrayed. The world is making me sick! If I flip the switch to now, to my reality, what I can control, the picture is completely different. My reality is my dogs

*continued page 4 ▼*

**“Coping with Stress”** *continued from page 3* ▼

have dragged out every toy in the toy bin and left them for me to pick up as they are now tired and need a nap. My reality is that I have a cup of my favorite tea in a new mug I treated myself with that I really like. My reality is I need to vacuum but not happening right now. Best of all is my precious reality is that my family is all safe and healthy, and so am I.

Anxiety is another beast. It is our fight or flight mechanism. It can last a short time or hang around entirely too long. It can be a little or it can be a lot. A little can be taking a test or running a sprint, but a lot can be a full-blown anxiety disorder maybe including panic attacks that can be so severe they take many to the hospital fearing a heart attack and death.

Anxiety comes with purpose and varying degrees of intensity. To understand these variances, imagine being chased down the street by a bear. Anxiety kicks in chemicals in our brains and bodies that help us run faster and farther, entirely determined to help us stay alive. Now, suppose you are running down the street afraid of a bear chasing you but there is no bear anywhere around. Your fear causes your heart to race, adrenaline to kick in, you are certain you are going to die even though you know in reality there is no bear. This is what an anxiety disorder is like.

Coronavirus/Covid-19 has taken anxiety and stress to a new extreme. Everything looks pretty much the same, but nothing is. There really are bears in the form of a virus around every corner waiting to attack you, but you cannot see them. We humans are communal beings and thrive on interaction, only now we are isolated and bumping elbows at a distance instead of shaking hands or hugging. We look to “experts” for answers but struggle to know who to believe.

We can listen to endless predictions of when this way of life will end so we can go back to “normal,” but the reality is that no one knows for sure. This uncertainty keeps all of us on high alert too much and too often, wreaking havoc on physical well-being, especially for those battling to regulate autoimmune systems operating with their own agendas. Feeling uncertain in uncertain times is normal, or as we say in the mental health world a normal reaction to an abnormal situation.

There is good news! We are not helpless, even if may feel like it at times. Here are some ways that can help:

- Start by examining your coping skills. How are you doing? Give yourself a grade. Set a goal for a way you can improve and write a follow-up date on your calendar. Give at least equal time to the things you are doing well and make certain you give yourself credit for them.

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# Vitamin D, Sjögren's and Coronavirus

Jeffrey W. Wilson, M.D.

## Glossary

- Bisphosphonate treatment – Drugs to help slow down osteoporosis, strengthen bones
- Cytokine storm – Severe immune reaction in which excess cytokines are released into the blood too quickly
- Hydroxychloroquine – Immunosuppressive antimalarial drug used in a range of diseases, including Sjögren's
- Hypercalcemia – High levels of calcium in the blood
- Hypercoagulable – Increased tendency for blood clotting
- IU – International Unit; a unit of measure commonly used for vitamins
- Osteomalacia – Softening of the bones
- Osteoporosis – Weakening or “brittleness” of the bones
- Transglutaminase IgA – A biomarker most commonly used in diagnosing celiac disease

### Background

Until 2003, at the Lynchburg Rheumatology Clinic, vitamin D deficiency was associated with metabolic bone disorders; osteomalacia in adults or rickets in children. The accepted normal range for 25-hydroxyvitamin D was 8 to 50 ng/ml (nanograms (ng) per millilitre (mL)). With the introduction of bisphosphonate treatment for osteoporosis, there was interest in the role of vitamin D as part of the osteoporosis treatment regimen.

But the article in 2003 by Plotnikoff and Quigley, relating musculoskeletal pain to “hypovitaminosis D,” stimulated great interest for looking at vitamin D levels in all our rheumatology patients. Was low vitamin D associated with fibromyalgia or other causes of musculoskeletal pain? Using new accepted normal levels for 25-hydroxyvitamin D of 32 to 100 ng/ml, low vitamin D levels were found in over 70% of our patients. The following case demonstrates the importance of monitoring yearly vitamin D levels in Sjögren's patients.

### Case study

A 56-year-old, white, married, female was followed over 10 years for Sjögren's. The 25-hydroxyvitamin D levels in 2003 (43 ng/ml) and 2004 (37 ng/ml) were normal. In 2005 her level was less than 4 ng/ml. For over 25 years the patient carried the diagnosis of irritable bowel syndrome (IBS). Subsequent testing included a tissue transglutaminase IgA level of more than 250 U (normal 0 to 30 U), and a small bowel biopsy confirmed the diagnosis of celiac disease. Her clinical symptoms of IBS resolved with the usual dietary modifications for celiac disease.

*continued page 6* ▼

### “Coping with Stress” *continued from page 4* ▼

- Ask yourself what is about you and what is not about you. Do your best to focus on the things you can control and let go of those you cannot.
- Commit to self-care, whatever that means to you. Know that self-care and selfish are not remotely the same thing. Self-care is the most loving thing you can do for your loved ones.
- Work to understand if your stress and anxiety are in balance to reactions to current events versus whether your response has reached a level that may require help from a professional to prevent further escalation.
- Take what I call your Early Warning System very seriously. A perfect example is I have heard several people in and out of my practice complain about getting cold sores recently and for the first time in years. That is a perfect message from an immune system saying TOO MUCH. If you have not had your shingles vaccinations, now may be the perfect time to do it.
- If your mental battery light comes on saying you are nearly empty, pay attention as you would with your car if the Engine light came on. A restorative nap can do wonders and will not cost you a dime.
- If you are feeling isolated and needing human company, forget texts and emails and call someone you know who is immune compromised. On the list of isolated people, you will find us at the top. Your call may be the best thing that happened to both of us that day.
- Pay attention to anything good that has come about in your life as a result of Covid-19. I have heard of families having dinner together, some for the first time. I know of marriages where conflict resolution became a new priority and old issues were put to rest because there was nowhere to run from problems with everyone stuck at home. Another example is a man with an autoimmune disease who had accepted a bigger job at work but found his symptoms increasing at an unprecedented rate, so choosing quality of life over status he resigned from the job.
- Pay attention to anything not so good in your life that has risen to your attention. It may be time to discard old habits, toxic relationships, or clean out the attic—literally or metaphorically.
- Find SOMETHING to get excited about, no matter how small or what anyone else thinks. We all need a reason to get out of bed in the morning, now more than ever.
- Finally, my forever soap-box speech, during difficult or uncertain times, be careful driving when you may be at your most distracted. Also consider getting a pill counter so you do not take too many or too few of your medications. It is too easy at times like this to find your hairbrush in the refrigerator, another Early Warning Signal.

*Yesterday I was clever and wanted to change the world. Today I am wise, so I am changing myself. — Rumi* ■

### “Vitamin D” *continued from page 5* ▼

This case reminds us that the vitamin D level should be checked at least yearly. When low levels are discovered after prior normal levels, it may be a clue to the onset of disorders seen more frequently in Sjögren’s patients, such as celiac disease or primary biliary cirrhosis. It also is a reminder to remain vigilant, especially in Sjögren’s patients, for other autoimmune diseases developing such as hypothyroidism or B12 deficiency.

Michael Holick raised the general awareness of vitamin D insufficiency in 2006. Over the next decade, vitamin D was touted as a panacea for cardiovascular disease, cancer, diabetes, falls in the elderly, neurologic diseases like multiple sclerosis, and autoimmune diseases. Studies over the last five years have not shown beneficial effects in preventing cardiovascular disease, cancer, or falls in the elderly, but confirmed vitamin D’s role in protecting against osteoporosis.

#### General information

Vitamin D is unique in being produced by the skin’s exposure to the sun. “Vitamin” is derived from “vital amine” implying something coming from exogenous

sources; not manufactured by our bodies. The increased frequency of vitamin D insufficiency relates partly to success of sunscreens, less outdoor exposure for children playing indoors, the anti-sun exposure skin cancer-melanoma education by dermatology, and something I suspect; with aging, our skin no longer manufactures adequate vitamin D on sun exposure. For years, in the office, I would see retired, elderly white male patients who never learned about sunscreens, never used them, were playing golf three times a week in the summer and looked like red lobsters. They could not have had more sun exposure. Yet, on testing, they had deficient or insufficient vitamin D levels.

An antimicrobial effect of vitamin D is suggested by the history of tuberculosis (TB) sanatoriums in the early 1900’s, before anti-TB meds existed. Improvement of patients may have been partly due to sun exposure boosting vitamin D levels. An unintended experiment was the failure of a TB sanatorium in Mammoth Cave where, of course, there was no sun exposure.

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# 2020 VIRTUAL National Patient Conference

## Conference Highlights

On June 26<sup>th</sup> and 27<sup>th</sup>, over 800 people from across the world joined the first-ever Sjögren's Foundation virtual National Patient Conference, "Coming Together to Conquer Sjögren's." Although this annual Conference looked a little different this year, thanks to technology and the dedication of both medical experts and patients, we were able to join as a community to learn and share.

During the midst of a pandemic, the Foundation's staff and volunteers worked quickly to transition our Conference to a virtual platform that conveyed both a professional and intimate feel to the event. The Foundation knows that not everyone can travel to one of our educational seminars, which is why we were so excited that this year we welcomed registrants from 47 states and 17 countries!

Our educational Conferences are designed to help patients take control of their health and gain a better understanding of their disease. The 2020 program catered to both newly diagnosed patients and longtime members. During the two-day program, the audience enjoyed informative lectures by expert speakers from around the country. This year's presentation topics included:

- **Sjögren's: An Overview** by Nancy Carteron, MD
- **Pediatric Sjögren's** by Scott M. Lieberman, MD, PhD
- **Conquering Sjögren's: What's Next?** by Steven Taylor, Sjögren's Foundation President and CEO
- **Oral Manifestations of Sjögren's** by Ava J. Wu, DDS
- **Product Showcase and Conference Day Wrap-Up** by Susan Barajas, Sjögren's Foundation Board Member and Support Group Leader

- **Sjögren's and Dry Eyes: What's New?** by Stephen Cohen, OD
- **Integrative Medicine: A Role for Treatment in Sjögren's** by William Mitchell, ND
- **Sjögren's Research Update** by Kathy Sivils, PhD, and Kathy Hammitt, MA, Sjögren's Foundation Vice President of Medical & Scientific Affairs
- **How Coaching Can Help You Live Your Best Life** by Janet Church, Sjögren's Foundation Board Chair
- **Autonomic Nervous System Involvement and POTS** by Brent P. Goodman, MD

In addition to the ten informative lectures that the audience enjoyed, the Conference also included seven fun, interactive 10-minute sessions called "Exploring Sjögren's" that were held between lectures. Some of these segments were interviews with sponsors and other segments were opportunities for the Foundation to learn from the attendees by using an online polling feature and chat box!

Even though this year's Conference was virtual, we understand that not everyone was able to join us that weekend, which is why we are offering seven of the most popular talks in a downloadable video format with the follow-along PowerPoint presentation printouts. These video downloads are an excellent way to have a permanent resource with some of the most vital information available to Sjögren's patients. Purchase just the talks you want to watch or purchase the entire set! Learn how to order your copies today on page 17.

“2020 Virtual NPC” continued from page 7 ▼

# National Patient Conference Testimonials

“I want to say a huge THANK YOU to everyone at the Sjögren’s Foundation for the Conference. It was absolutely wonderful! I learned so much and felt that although we were all in our own homes, we were very much together.” – **Carolyn W.**

“Wow!!!! What awesome presentations! Thank you.” – **Kathe M.**

“It was so well done. It was the best teleconference I have ever attended! Thank you so much. You [Steven Taylor] and Janet [Church] really touched my husband and I with your knowledge and heartfelt presentations at the Conference. Thank you so much! God bless.”

– **Reverend Craig P. and Dr. Marcia P.**

“FANTASTIC! Thank you for everything. It is an A+ event!” – **Carol C.**

“Congratulations for pulling together such a wonderful virtual Conference! I would not have been able to get to the Conference this year in any case, so I was actually thrilled that it ended up online. The presentations were great although occasionally a bit like drinking from a firehose — so much to absorb in so little time that I needed to see it all again... and again!” – **Laura R.**

“I always wanted to go to your Conference. Well done!” – **Maebh G. from Dublin, Ireland**

“Thank you for providing an OUTSTANDING Conference! I never knew there was so much help. I heard so many things that validate what I’m going through and was greatly encouraging. Thank you for all that you are doing!” – **Lyn F.**

“I want to thank you for a great Conference. I enjoyed the speakers and the topics presented. The Sjögren’s Foundation should be proud of their first virtual Conference.” – **Karen M.**

“I want to thank all of you for a truly wonderful event. I have probably been to at least six in-person Sjögren’s National Patient Conferences and I think this may have been the best. Thank you, thank you, thank you!” – **Mary K.**

“This was honestly the best virtual Conference I’ve ever attended. Thanks again for a great experience and keep up the great work. Finding you guys and the patient community has made me feel less alone in this path of life.” – **Julie B.**

 **Sjögren's**  
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# The Sun and Sjögren's

Sjögren's patients, and those suffering from autoimmune disease in general, need to be cautious about their time in the sun. Ultraviolet (UV) radiation emitted from the sun and other light sources (such as some fluorescent lights) can alter immune function and lead to an autoimmune response in the body and skin.

In response to the sun, Sjögren's patients can experience skin rashes, ocular sensitivity, pain, and disease flares. Sun sensitivity with Sjögren's is associated with the autoantibody SSA/or Ro. Remember to protect yourself from the sun all year-round.

*"Vitamin D" continued from page 6 ▼*

## *Coronavirus/ Covid-19, hydroxychloroquine and vitamin D*

One of the first controversial ideas that arose as part of the Covid-19 pandemic was the use of hydroxychloroquine (Plaquenil/HCQ) as a treatment for active infection or as a preventive medication. Studies so far have shown no benefit. Instead, many of our rheumatology patients had trouble obtaining their prescribed hydroxychloroquine; scarce due to the increased demand.

The action of hydroxychloroquine has never been clearly identified as a remittive agent or perhaps as an immune modulator like vitamin D. Retrospective analysis of the Covid-19 experience in our rheumatology patients already on hydroxychloroquine will be of interest in finding out if the medication had a role in preventing initial infection or if hydroxychloroquine decreased morbidity and mortality of infected patients.

An article by WebMD, May 18, 2020, reviewed reports from different countries around the world of increased morbidity and mortality in patients of all races associated with low vitamin D levels. The role of vitamin D in immune modulation is considered. While we do not want our immune system suppressed, failing to react to acute infection, we likewise do not want an over-reactive immune response resulting in hyper-inflammatory manifestations such as cytokine

storm, which may harm the patient. Hopefully, vitamin D supplementation will modulate the immune system helping resist infection initially or decreasing the autoimmune induced reactions associated with greater morbidity and mortality.

Vitamin D deficiency is very common in African American blacks and other dark-skinned people. The melanin in the skin acts as a natural sun block. For over twenty years, the majority of black patients seen at the Lynchburg Rheumatology Clinic were found to have low levels of vitamin D. Normal levels of vitamin D, measured by 25-hydroxyvitamin D blood tests, are greater than 30 ng/ml; vitamin insufficiency ranges from 21 to 29 ng/ml; and levels less than 20 ng/ml indicate deficiency of vitamin D. Extremely low levels (less than 10 ng/ml) were often seen in patients with autoimmune disorders like Sjögren's and lupus. Pharmacogenetics relate to inherited tendency to these extremely low vitamin D levels and to family histories of connective tissue and other autoimmune diseases.

The pandemic has also brought attention to the increased cases, hospitalizations, morbidity, and mortality among African Americans. While representing 13.4% of the U.S. population, Black Americans make up 25% of individuals testing positive for Covid-19 and 39% of fatalities. This has been attributed to many factors such as poverty, decreased access to health care,

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## *Clinician's Corner:* Is it recommended that I get the 2020 flu shot if you have Sjögren's?

Mehrnaz Maleki Fischbach, MD

Another flu season is right around the corner. And this year, the world is grappling with Novel Coronavirus (Covid-19) pandemic while we are going to face the flu. As a patient with Sjögren's you are wondering about whether or not you should receive a flu vaccine this year. I do believe it is important to gain some knowledge about the flu.

The estimated mortality of flu death in 2019-2020 season was around 24,000-62,000.

People with flu can spread it to others up to about 6 feet away and should use use masks. The same precautions are needed for Covid-19 prevention. Most experts think that flu viruses spread mainly by droplets made when people with flu cough, sneeze or talk and less commonly from surfaces, which is similar to Covid-19. People with flu are most contagious in the first 3 to 4 days after the illness began. Most healthy adults may be able to infect others beginning one day before symptoms develop and up to 5 to 7 days after becoming sick. Children and some people with weakened immune system may pass the virus for longer than 7 days.

While it's not possible to say with certainty what will happen in the fall and winter, Centers for Disease Control (CDC) believes it's likely that flu viruses and the virus that causes Covid-19 will both be spreading. In this context, getting a flu vaccine will be more important than ever.

Antiviral drugs can lessen symptoms and shorten the time you are sick by 1 or 2 days. They also can prevent serious flu complications, like pneumonia. For people at high risk of serious flu complications, treatment with antiviral drugs can mean the difference between milder or more serious illness possibly resulting in a hospital stay. CDC recommends prompt treatment for people who have influenza infection

or suspected influenza infection and who are at high risk of serious flu complication.

An annual seasonal flu vaccine is the best way to help protect against flu. Vaccination has been shown to have many benefits including reducing the risk of flu illness, hospitalizations and even risk of flu related complications. Flu vaccine causes antibodies to develop in the body about 2 weeks after vaccination. These antibodies provide protection against infection with the viruses that are in the vaccine.

The seasonal flu vaccine protects against the influenza viruses that research indicates will be the most common during the upcoming season. Traditional flu vaccine (called "trivalent" vaccines) are married to protect against three flu viruses and influenza A (H1N1) virus, and influenza A (H3N2) virus, and an influenza B virus. There are also flu vaccines made to protect against four flu viruses (called "quadrivalent" vaccines). These vaccines protect against the same viruses as the trivalent vaccine and an additional B virus. Patients over age 65 need high-dose vaccine.

Annual vaccination against seasonal influenza is recommended for all U.S. persons aged  $\geq 6$  months. Effectiveness of seasonal influenza vaccine varies by season.

A paper by Wahren-Herlenius and colleagues, published in 2017 addressed the effect of H1N1 flu vaccine in patients with Sjögren's. Untreated Sjögren's patients had an exaggerated response with higher IgG levels to H1N1 flu vaccine, hydroxychloroquine treated patients did not show any exaggerated response.

Patients with Covid-19 should delay getting their influenza vaccine, not because of any evidence about how the virus affects vaccination, but in order to en-

**“Vitamin D”** *continued from page 10* ▼

increased exposure related to employment, housing density, and lower vitamin D levels. While these factors merit societal attention and social justice, they will involve long term, slow societal changes, but vitamin D supplementation can be added now for all individuals, as well as African Americans.

**Treatment for vitamin D insufficiency**

Initial therapy depends on the level of vitamin D and family history (pharmacogenetics). I usually begin with prescription D2—50,000 IU weekly for 12 weeks and repeat the 25-hydroxyvitamin D. Final vitamin D replacement regimens are unpredictable. They must be individualized according to follow-up 25-OH Vitamin D levels.

Some patients may maintain normal levels on 50,000 IU of D2 monthly. The most extreme regimen has been 50,000 IU D2 twice a week and 4000 IU D3 daily. Several of my young patients with lupus were on that regimen.

In hopes of increasing resistance to Covid-19 for anyone not on vitamin D, I recommend 4000 IU D3 daily and a baby aspirin (with respect to hypercoagulable complications reported).

Toxicity from vitamin D supplementation is rare. 50,000 IU of prescription D2 daily for 3 months would

be required. I saw one patient from a nursing home who accidentally was given this regimen by medication error. Her vitamin D level was 141 ng/ml. However, she felt fine, her serum calcium level was normal (hypercalcemia is the best indicator of toxicity) and subsequent bone density was normal.

**Summary**

While vitamin D does not appear to be a panacea, it continues with an important role in metabolic bone diseases such as osteomalacia and osteoporosis. The Covid-19 pandemic reemphasizes the importance of vitamin D as an immune modulator, decreasing infectivity of the virus (incidence of cases) and decreasing morbidity and mortality of infected patients, which are disproportionately high in African Americans. ■

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# Clinical News

## *Findings from a Small Cohort of Rheumatic Disease Patients with Covid-19*

Results of a comparative cohort study between Covid-19 patients (n=104) and rheumatic disease patients with Covid-19 (n=52) found that the group with rheumatic disease was more likely to need mechanical ventilation (48% vs 18%; multivariable OR = 3.11 (95% CI 1.07 to 9.05), though similar clinical features and hospitalization rates were observed (44% vs 40%; p=0.50). Notably, the mortality rate between the two groups in this study were similar, with rheumatic disease patients at 6% and non-rheumatic disease Covid-19 patients at 4% (p=0.69). The authors note that while these findings have important implications for patients with rheumatic disease, further validation is required. Additionally, 75% of the rheumatic disease patients included in this study were on immunosuppressive medications. Patients were identified from a U.S. healthcare system between March 1, 2020, and April 8, 2020.

### **Citation**

D'Silva KM, Serling-Boyd N, Wallwork R, et al. Clinical characteristics and outcomes of patients with coronavirus disease 2019 (COVID-19) and rheumatic disease: a comparative cohort study from a US 'hot spot'. *Annals of the Rheumatic Diseases* Published Online First: 26 May 2020. doi: 10.1136/annrheumdis-2020-217888

### **Sjögren's Foundation Note**

*We wanted to share these findings as they are relevant to Sjögren's and the subscribers of Sjögren's Quarterly. However, the landscape and our understanding of Covid-19 has and continues to evolve, so we'd like to emphasize the authors' statement that further validation is required.*

## *Salivary Gland Biopsy to Assist in Diagnosing Sjögren's in POTS Patients*

Investigators found that positive ANA and skin biopsies for small fiber neuropathy were helpful features in determining if POTS patients should undergo a labial salivary gland biopsy (LSGB) for a histological confirmation of Sjögren's. This study included POTS patients (n=161) who underwent an LSGB followed by a review of their antibody and diagnostic testing results. In all, 11% (n=17) of the POTS patients included in the study had positive biopsy results. Sixty-five percent of the patients in this group were ANA positive. Additionally, associations were found between skin nerve biopsy for small fiber neuropathy and a positive LSGB (p = .046).

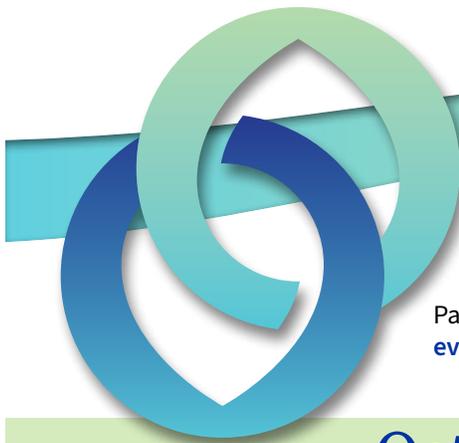
### **Citation**

Pasady SR, Warren CB, Wilson RG. Utility of salivary gland biopsy in diagnosing Sjögren's syndrome in a POTS patient population. *Auton Neurosci*. 2020;227:102694. doi:10.1016/j.autneu.2020.102694

## *Hydroxychloroquine Associated with Improved Quality of Sleep in Sjögren's*

An investigation into the effects of hydroxychloroquine (HCQ) on sleep has shown that long term use of the drug can reduce the risk of sleep disturbances in Sjögren's patients. Sjögren's patients (n=383) were divided into two groups based on the Pittsburgh Sleep Quality Index (PSQI): the good sleep group (GSG) (n=175) and the poor sleep group (PSG) (n=208). No statistical differences were noted at baseline between the GSG and PSG. HCQ use was then identified in both groups (GSG, n=118; PSG, n=112) and identified as being related

*continued page 14 ▼*



## Sjögren's Foundation Virtual Event Calendar

Participate in one of the Fall Walk for Sjögren's events. To learn more visit: [events.sjogrens.org](https://events.sjogrens.org) or contact Jessica Levy at (301) 530-4420 ext. 218.

### October

**California Virtual Walk for Sjögren's**  
Saturday, October 3, 2020

**New England Virtual Walk for Sjögren's,  
in Memory of Karen T. Caron**  
Saturday, October 3, 2020

**New York State Virtual Walk for Sjögren's**  
Saturday, October 24, 2020

**Pacific Northwest Virtual Walk for Sjögren's**  
Saturday, October 24, 2020

### November

**One-Day Virtual Patient Conference**  
Saturday, November 7, 2020

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### "Clinical News" continued from page 13 ▼

to sleep quality through univariate and multivariate analysis. Investigators reconfigured the groups into HCQ-administered (n=230) and non-administered (n=153) and found that more than half (51.3%) of the patients in the HCQ-administered group had good sleep, while only 37.9% in the non-administered group had good sleep ( $p < 0.05$ ). At follow-up, the HCQ-administered group scored better in both PSQI ( $7.3 \pm 2.1$  vs.  $8.1 \pm 2.4$ ,  $p < 0.05$ ) and ESSPRI ( $4.9 \pm 1.1$  vs.  $5.4 \pm 1.3$ ,  $P < 0.05$ ). ■

### Citation

Guan P, Sun C, Chen Z, Chen J, Ran R. Long-term hydroxychloroquine therapy improves the quality of sleep in patients with primary Sjögren's syndrome: a real-world study [published online ahead of print, 2020 Jul 20]. *Ann Palliat Med.* 2020;apm-20-1380. doi:10.21037/apm-20-1380.



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# You Stood Up!

## Fun Summer Fundraisers



### *“Lemonade for Sale!”*

Even a pandemic couldn't stop Ella from holding her summer lemonade fundraiser to support the Sjögren's Foundation.

Ella, 13, was diagnosed with the disease last year. She and her grandmother, who also has Sjögren's, have been long time supporters of the Foundation. “I want to spread awareness about Sjögren's because it is something most people have never heard of, even though it is one of the most prevalent autoimmune diseases. Sjögren's isn't something only adults get – kids get Sjögren's too,” said Ella.

Ella had been planning to hold a lemonade stand and creatively adapted the time-honored way to raise money to the current Covid-19 protocols. She created a website where customers were able to order and pay online. Then Ella made and delivered fresh home-made lemonade, while wearing a mask and gloves!

Thank you, Ella, for lifting spirits this summer, while also raising awareness of Sjögren's and donating funds to Sjögren's research.

### *“A Celebration for a Great Cause!”*

Every year, Tundra hosts a fundraiser to help celebrate her birthday and give back to a cause that's close to her family. Her decision to support the Sjögren's Foundation this year was easy. Her daughter, Kaitlyn, was recently diagnosed with Sjögren's, six days after 11<sup>th</sup> birthday.

Using the Foundation's Facebook fundraising tool, Tundra set-up a birthday fundraiser and shared the event on her personal page with her family and friends. Tundra and Kaitlyn were able to follow the fundraiser and watch excitedly as donations began pouring in, knowing that 100% of Facebook donations go directly to the Sjögren's Foundation.

Through the fundraiser, this mother-daughter duo helped educate others about the disease and also continue their communication about the complexity of Sjögren's. “Kaitlyn still doesn't understand fully what it means to be diagnosed with Sjögren's but we are



working to educate her so that she is not scared and is able to recognize signs and symptoms. As a parent you never know where or what life will bring your way. What Kaitlyn wishes others knew, is that Sjögren's is a real health issue. She hopes pediatric doctors will continue to do research and be more understanding and compassionate to their patients,” said Tundra.

Thank you, Tundra and Kaitlyn, for standing up for the Sjögren's community. If you are interested in learning more about hosting your own fundraiser to support the Foundation, please email [info@sjogrens.org](mailto:info@sjogrens.org). ■





	Non-Member	Member	Qty	Amount
<b>The Sjögren's Syndrome Survival Guide</b> 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		
<b>The Sjögren's Book</b> , 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		
<b>The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease</b> 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		
<b>You Don't Look Sick! Living Well with Chronic Invisible Illness</b> 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		
<b>Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop</b> by Norman Latov, MD, PhD. Peripheral neuropathy is a widespread disease, yet many people do not even realize they have it.	\$19	\$16		
<b>You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life</b> 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		
<b>Healing Arthritis: Your 3-Step Guide to Conquering Arthritis Naturally</b> by Susan S. Blum, MD, MPH (Author), Mark Hyman (Foreword).	\$24	\$20		
<b>Tales From the Dry Side</b> by Christine Molloy. Thirteen personal stories behind the autoimmune illness. Sjögren's tales from courageous men and women who share their journey with Sjögren's.	\$16	\$13		
<b>A Body Out of Balance</b> 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		
<b>The Memory Bible: An Innovative Strategy for Keeping Your Brain Young</b> 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		
<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). 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		
<b>How to Live Well with Chronic Pain and Illness – A Mindful Guide</b> by Toni Bernhard. The book addresses challenges created from chronic illness to help readers make peace with a life turned upside down.	\$17	\$14		
<b>Shipping and Handling:</b> U.S. Mail: \$7 for first item + \$2 for each additional item				
<b>Sub-Total:</b>				
<b>Membership (new / renewal):</b> Includes <i>Conquering Sjögren's</i> newsletter, member pricing on books and more benefits.		<b>\$36 each</b>		
<b>Please consider an additional contribution:</b> <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: _____				
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## Available video downloads from the 2020 Virtual National Patient Conference to purchase include:

- **Sjögren's: An Overview** by Nancy Carteron, MD
- **Pediatric Sjögren's** by Scott M. Lieberman, MD, PhD
- **Oral Manifestations of Sjögren's** by Ava J. Wu, DDS
- **Sjögren's and Dry Eyes** by Stephen Cohen, OD
- **Integrative Medicine: A Role for Treatment in Sjögren's** by William Mitchell, ND
- **Autonomic Nervous System Involvement and POTS** by Brent P. Goodman, MD
- **How Coaching Can Help You Live Your Best Life** by Janet Church, Sjögren's Foundation Board Chair

## If you purchase the collection of seven (7) video downloads, also included will be:

- **Sjögren's Foundation Update** by Steven Taylor, Sjögren's Foundation President and CEO
- **Sjögren's Research Update** by Kathy Sivils, PhD and Kathy Hammitt, Vice President of Scientific and Medical Affairs, Sjögren's Foundation

**Member Price: \$20 per video**

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**Collection of all 7 downloads: \$100 member / \$140 non-member**

These video downloads are an excellent way to have a permanent resource with some of the most vital information available to Sjögren's patients. Purchase just the talks you want to hear or purchase the entire set!

If you have any questions or need additional information you can contact the Foundation office at (301) 530-4420.



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

# Team Sjögren's Goes Turkey!

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

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

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



### A Single Kit Includes: \$35

- Team Sjögren's Cotton T-shirt, with Turkey Trot logo on the front!
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Team Sjögren's Turkey Trot T-Shirt	\$20 ea.		
Single Person Team Sjögren's Turkey Trot Kit	\$35 ea.		
<b>Shipping and Handling:</b> U.S. Mail: \$7 for first item + \$2 for each additional item			
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- Check this box if you're interested in learning more about the Team Sjögren's Training program, where you can train for a 5K, 10K or Half-Marathon, or email Kalla at [Kford@sjogrens.org](mailto:Kford@sjogrens.org).



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Pati Biancalana

### **“Flu Shot”** *continued from page 11* ▼

sure others in the healthcare setting are not exposed unnecessarily, CDC officials said on a call with clinicians on Thursday.

Routine vaccination should be deferred for patients with suspected or confirmed Covid-19, regardless of symptoms, and patients should be screened for Covid-19 symptoms before and during the visit. In addition, clinicians should use personal protective equipment (PPE) during vaccination, including masks, eye protection and gloves, when appropriate.

To summarize, I strongly recommend inactivated injectable flu vaccines for Sjögren’s patients but

caution is warranted when considering vaccination in non-treated Sjögren’s patients who have really active disease with multi-organ involvement. It is more important than ever to protect yourself and others from the flu, not only for you and your household, but for the entire community. If you get sick and have to go to the doctor, your chances of being around someone with Covid-19 are much higher. The patients on immunosuppressive medications (like prednisone, methotrexate, azathioprine, mycophenolate mofetil, rituximab) should not receive live attenuated influenza vaccine (the nasal spray flu vaccine).” ■



## Conquering Sjögren's

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# IT'S TIME

## United Way • Combined Federal Campaign • State Payroll Deduction

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

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

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

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

### ***Just think – every dollar counts.***

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

*Remember, the Foundation has received the:*

