

# CONQUERING Sjögren's

May/June 2020



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# WHAT YOU NEED TO KNOW:

## *The Coronavirus /Covid-19 and Sjögren's*

The Sjögren's Foundation is continuously working on ensuring that Sjögren's patients have the support and guidance they need during this challenging time. We hope the answers to these frequently asked questions will help give you a little more understanding and knowledge about Sjögren's and Covid-19.

### *What is Covid-19?*

Covid-19 is caused by a coronavirus called SARS-CoV-2. Coronaviruses are a large family of viruses that are common in people. However, Covid-19 is caused by a novel or new coronavirus, that has not been previously identified. The fact that Covid-19 is a new/novel strain allows it to spread more quickly among communities.

Common symptoms include fever, cough, and shortness of breath. If you have any of these symptoms, you should CALL your doctor, local hospital or health clinic for advice and how best to be tested.

### *Are patients with Sjögren's immunocompromised/immunosuppressed?*

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

Please note that hydroxychloroquine (Plaquenil) does NOT suppress your immune system and does not increase any risk for a more serious illness from Covid-19. However, all Sjögren's patients should still be diligent and be tested if symptoms become present.

### *What is an immunosuppressant?*

Immunosuppressants are a class of drugs that interfere with the function of cells composing the immune

system. Drugs used in the chemotherapy of malignant disease and in the prevention of transplant rejection are generally immunosuppressive and occasionally are used to treat severe autoimmune disease.

Examples of immunosuppressants that Sjögren's patients sometimes take include prednisone, methylprednisolone, Imuran, azathioprine, methotrexate, leflunomide, Arava, CellCept, mycophenolate, Rituxan, cyclophosphamide. If you take one of these drugs, your immune system is being suppressed and you should take extra precautions in preventing contracting Covid-19.

### *What type of drug is hydroxychloroquine/Plaquenil?*

Hydroxychloroquine (HCQ) is an immunomodulatory drug. While this category of drugs includes immunosuppressants, it also includes therapies that are not classified as such, including HCQ. Instead of suppressing the immune system, HCQ alters the way the immune system works. The drug reduces levels of type-1 interferon (IFN) and reduces interferon-stimulated gene expression (ISG). As such, it improves the way Sjögren's patients' immune system works and thereby improves Sjögren's symptoms. Other drugs such as corticosteroids work by suppressing an over-reactive immune system, but this is not the mode of action of HCQ. The FDA is looking into clinical trials with HCQ to see if it may improve the outcomes of people who are infected with the coronavirus that causes Covid-19.

### *What precautionary steps can you take?*

The Foundation is encouraging all patients to consider taking all necessary precautions as outlined by

### **“Covid-19”** *continued from page 3* ▼

the Centers for Disease Control and Prevention (CDC) to reduce your exposure. These precautions include:

- Wash your hands often with soap and water for at least 20 seconds
- Cover your cough/sneeze with a tissue or your elbow. Throw used tissues in trash
- Avoid touching your eyes, nose, and mouth with unwashed hands
- Wash hands each time before applying eye drops, dry mouth or dry skin products
- Avoid touching public surfaces
- Clean and disinfect frequently touched objects and surfaces
- Stay home when you are sick
- Avoid people who seem visibly sick
- Practice Social Distancing - Keep 6 feet between yourself and other people and stay home whenever possible
- Wear a cloth face covering when outside of your home in a community setting

### ***How can you help build your immune system?***

Working to make sure you are as healthy as possible is always good, especially in times when viruses are circulating in communities. Below are some healthy ways to build your immune system.

- Avoid smoking
- Include fruits and vegetables in your diet everyday
- Exercise regularly
- Maintain a healthy weight
- If you drink alcohol, drink only in moderation
- Get plenty of sleep to help recharge your immune system
- Talk with your healthcare professional about taking Vitamin C & Vitamin D supplements

### ***Should you cancel doctor appointments?***

Staying on top of your healthcare appointments is always important. We suggest you reach out to your providers in advance to discuss whether or not you should go into the office or if telehealth visits are an option for you.

### **Dental Appointments**

To prevent tooth decay during this time, maintain your daily routine of brushing and flossing your teeth and once daily use of a topical fluoride prior to going to bed. During the Covid-19 pandemic, the sale of comfort foods such as popcorn, pretzels and potato

chips has increased. Frequent consumption of carbohydrate or sugar containing snacks between meals is known to increase caries. So, if you must snack, do not let the snack debris sit on your teeth. Do not continuously sip on sugar containing or carbonated beverages throughout the day. Rinse out your mouth with water or mouthwash as soon as possible to get rid of the snack debris and help neutralize acid pH from beverages other than water and plain tea.

In summary: maintain meticulous oral hygiene, limit snacking and use a topical fluoride. Your dentist is likely available by phone or teleconference should there be specific individual concerns.

### **Eyecare Appointments**

There has been concern about missing eye exam appointments for evaluating retinal toxicity while on hydroxychloroquine. Some eye care provider offices are open to check on this however if your eye doctor is not open, a few months delay in your exam should not put you at risk for problems. Consider rescheduling your appointment by calling your eye care provider now to get an appointment booked for the future. Also, if you see any signs of any eye issues that concern you, reach out to your eye care provider who may be able to speak with you over the phone or have you come in for an emergency appointment if they feel it is necessary.

### ***What should you tell your doctors about Sjögren's if you are diagnosed with Covid-19?***

If you should contract Covid-19, there are things you will want to do to alert your healthcare team about your Sjögren's.

Be prepared with the following:

- A list of your medications to provide to your healthcare team. It is important to let them know which medications you are already taking, especially is taking immunosuppressant's or hydroxychloroquine/Plaquenil.
- Information for your team of any reactions you have had to medications in the past, especially hydroxychloroquine/Plaquenil.
- Remind them of the lung complications that can occur with Sjögren's. You can provide them with the pulmonary patient education sheet available on our website.
- Visit the Foundation's website to print out our hospital tips education sheet to give to your medical team in case you need surgery.

**Please check the CDC and the Foundation's website for any updates. ■**

# Ask the Sjögren's Foundation Board of Directors – Part 2



The Sjögren's Foundation Board of Directors is comprised of healthcare professionals, patients/family members of patients and pertinent professionals in the field, who volunteer their time to help lead the Foundation so we can fulfill our mission.

These dedicated individuals are responsible for setting our goals and priorities, overseeing policies, implementing our strategic plan, while also ensuring we raise the crucial funds we need to accomplish our mission. Together, the Foundation's staff and Board work to make the biggest impact and help all patients.

In this special Part 2 installment of "Ask the Board," we want you to get to know these devoted volunteers by having them answer your questions.

**Q** *I'm finding it more difficult to wear contacts because of my dry eye. What options are available to Sjögren's patients besides glasses?*

*Dr. Jason Nichols, OD  
Sjögren's Foundation Board Member*

**A** Many patients with Sjögren's suffer from dry eye, which can make contact lens wear challenging. The burdensome symptoms such as eye dryness, grittiness, or burning are typically a result of a reduced ability of the tear glands to produce tears in the normal way, in addition to buildup of inflammation of the ocular surface and associated structures, like the meibomian glands. While many patients can still wear contact lenses comfortably and safely with Sjögren's, others may find it challenging. Therefore, it is important that each individual work with their eyecare provider to determine the suitability of contact lens wear.

There are several steps or considerations that might prove beneficial for continued contact lens wear. First, the eyecare practitioner may need to use treatments to treat any underlying dry eye to first get it under control. These may include things like artificial tears or prescription medications, usually anti-inflammatory, used to treat dry eye disease. In addition, the doctor might also recommend in-office or at-home management options for meibomian gland dysfunction and evaporative dry eye. Depending on the severity of the condition, the practitioner may then proceed with contact lens fitting.

There are many different types of contact lenses, including soft and hard (or rigid) lenses, and either may be an option depending on each patient's individual situation. Among soft lenses, there are different types of materials and designs that can

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be fitted, and some may be more comfortable than others. Some patients are fitted with a rigid lens that is called a “scleral contact lens,” which are larger diameters. Specially fitted lenses are used to help keep the ocular surface moist and protected. Many patients with Sjögren’s find incredible relief from scleral contact lenses. It is important that all contact lens wearers also have current and up-to-date pair of spectacles that can be used intermittently with contact lenses, at their doctor’s specific recommendation.

**Q** *How have you brought Sjögren’s awareness into your everyday life?*

*Cynthia Lopynski  
Sjögren’s Foundation Board Member, Sjögren’s patient*

**A** For me, the key to raising awareness of Sjögren’s in my everyday life has simply been to talk openly about the disease any chance I get. Sjögren’s is not who I am but it is an important aspect of how I live my life. If I have to turn down an invitation to do something because I am having a flare up, I tell people. It is easy for my friends and co-workers to forget I have an illness because the limitations aren’t always apparent. Being honest about those limitations reminds people that this is a serious, chronic illness and not “just dry eye and dry mouth.”

I also raise awareness by making connections. Whenever I get the opportunity to connect with other autoimmune sufferers, I open up about my challenges. As a life coach and a congregational care minister, it is not unusual for me to find myself in conversations with someone who has an autoimmune condition. As we dig into the struggles of a chronic illness, if the opportunity presents itself, I will share that I also have an autoimmune condition. Their response is pretty consistent, “What’s Sjögren’s?” This opens the door for me to explain the illness but also helps them see that I understand and very much relate to their challenges.

The other way I raise awareness is through the Sjögren’s Foundation. For many years my family has participated in the Walk for Sjögren’s and the Sips for Sjögren’s events. These fundraising efforts are a great way for me and my family to tell people about the disease. For someone who doesn’t like a lot of attention, talking about the work of the Foundation is a great way for me to raise awareness without it being about me. It is also a great way to get family and friends to reach into their circles of influence and talk about the disease on my behalf.

I have also raised awareness by serving as an Awareness Ambassador for the Foundation. In this role, I take information to various physicians, dentists, gynecologists, rheumatologist about Sjögren’s and the work of the Foundation. I love this work because the more doctors know and understand the disease, the quicker patients will be diagnosed!

I also tell people any chance I get that I am a member of the Board. Sharing this role gives me the opportunity to talk about the great work that is being done by the Foundation. It is another opportunity to talk about the disease and its impact without it being about me.

So bottom line, for me, raising awareness is about being open and vulnerable about the disease and my own limitations and talking about the work of the Sjögren’s Foundation.

**Q** *As a pediatric rheumatologist, is it more difficult to diagnose children with Sjögren’s?*

*Scott Lieberman, MD  
Sjögren’s Foundation Board Member*

**A** The simple answer is “yes!” And, there are several reasons. Diagnosis of Sjögren’s in general is often not straight forward (even in adults) since no individual tests can tell us 100% yes or no when we are considering the diagnosis of Sjögren’s. So, we rely on a collection of tests including blood tests, imaging tests, functional tests, and biopsies. Many of these tests are trickier to do in children, especially those young children that may have trouble sitting still for these tests to be performed. Getting all the right testing done can be tricky. But, even if testing can be performed, we do not have well-established child-specific normal values. While any results that meet the adult definitions of abnormal are likely also reliably abnormal in children, we have found that at least some tests in children may be abnormal even when the results are “normal” by adult standards. One example is the degree of inflammation in minor salivary glands when evaluated after a lip biopsy. The definition of abnormal (and, thus, consistent with Sjögren’s) in adults was defined in part by the finding that some inflammation may be present in healthy adults who do not have a diagnosis of Sjögren’s. In children, though, we have found that inflammation was almost non-existent in biopsy samples from children who did not have Sjögren’s. So, in my experience, any degree of the characteristic inflammation on

these biopsies may be abnormal and suggestive of Sjögren's in a child. But additional study is necessary to better define a specific cut-off to use as abnormal when considering Sjögren's in a child.

Similar to the lack of well-defined child-specific normal and abnormal values for various Sjögren's-related tests, we have also not formally established a set of criteria that must be met for the diagnosis of Sjögren's to be made. Again, if a child has abnormal tests and meets criteria defined for Sjögren's in adults, then the diagnosis is clear. But many children do not meet such criteria making the diagnosis less clear. This may, in part, be related to children being at an earlier stage of the disease process such that they do not yet have the objective gland dysfunction and associated dryness that tends to occur years after the autoimmunity begins. With no abnormal tests related to dryness, we are left with blood tests, imaging tests, and lip biopsies to help us determine if a child has Sjögren's. Of these, blood tests are well-defined and determining positive and negative is well-established. But, these tests for Sjögren's-associated autoantibodies (typically, SS-A/Ro or SS-B/La antibodies) may not always be present. In adults, up to 40% of individuals may not have an abnormal Sjögren's antibody tests. Presumably, a similarly

high percentage of children with Sjögren's may also lack this abnormal test making the diagnosis more challenging. Imaging studies (including MRI or ultrasound) can be performed to detect inflammation of saliva- or tear-producing glands, but exactly what is needed for these tests to suggest Sjögren's (versus some other cause of inflammation) is not well-defined. Still, imaging tests are non-invasive and can give us helpful information to add to the consideration of making the diagnosis. But alone, an abnormal imaging test is not enough to make the diagnosis. This leaves the lip biopsy, but how often this test is diagnostic in children is not clear largely due to the lack of child-specific abnormal definition as discussed above.

Together these issues often make diagnosis of Sjögren's in a child more challenging. But, the first step is actually thinking about Sjögren's as a possible diagnosis. We need a high index of suspicion and should consider whether this diagnosis is worth pursuing in nearly all children presenting to a pediatric rheumatologist's office. After all, children with Sjögren's may present to a pediatric rheumatologist's office with symptoms suggestive of Sjögren's (salivary gland swelling, dryness) or with other, less

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**“Ask the Board”** *continued from page 7* ▼

specific symptoms (joint pain with or without arthritis, fatigue, nonspecific musculoskeletal pain, or symptoms that may be mistaken for lupus or other rheumatic diseases). Hopefully, though, with ongoing efforts to better understand this disease in children we will be able to make the diagnosis and, eventually, will be able to stop the autoimmune process to prevent the progression over time.

**Q** *As a parent to a child with Sjögren’s, what advice do you have for other parents?*

*Monica McGill, EdD  
Sjögren’s Foundation Board Treasurer,  
Parent of a Sjögren’s patient*

**A**s it turns out, and many of you may be able to relate, my daughter wasn’t diagnosed with Sjögren’s until she was 19. Once we began to understand what Sjögren’s is, it put many of her symptoms from the previous decade in perspective. She suffered for years because we did not know her health problems were due to an autoimmune disease.

Many healthcare providers need more knowledge about Sjögren’s to prevent patients from being prescribed the wrong treatments, like unnecessary oral surgery in my daughter’s case. Because of this, I am a big proponent of parents investigating “the unusual.” If something doesn’t seem right, it’s okay to pursue that with other physicians until you find healthcare providers that take these out-of-the-ordinary symptoms seriously and thoroughly investigate.

Adults with Sjögren’s struggle to find physicians that understand the complexity of the disease. Finding the proper healthcare team for your child will take even more time and patience because the condition is so rare (or misdiagnosed) among children. Even after finding your team, little is known yet about the best treatments.

At the same time, though, your child is suffering. As a parent or guardian, there is nothing more that you want to do except to take that suffering away right now. There are two distinct journeys happening—your child’s and yours. As a caretaker, your journey involves caring for your child. But, as many caretakers have learned, the emotional stress and mental anguish of watching your child suffer is real.

*While you help your child with their journey, what can you do to ensure that you maintain the capacity to fully support your child?*

Find your support group. Finding your own small team of supporters to help you manage the stress and

emotions of caretaking can be very powerful. This can range from therapy from a trained professional, to close friends and family who can empathize and give a helping hand when needed, or even to journaling your thoughts and feelings. These can help you recognize the symptoms of stress or even depression, which then can allow you to find positive ways to cope.

Take time for yourself. No matter your situation, it is important to step away when needed without feeling guilty. Chances are you have other demands on your time, whether it is work, other children, aging parents, or more. Recharging your own batteries is essential. Taking the time to “recharge” can consist of physical activities like going to the gym or taking a nature walk, or it can be more mental exercises like meditation or yoga.

Advocate. I feel better through volunteering with the Sjögren’s Foundation. It’s empowering to know that I’m contributing in some small way to help find better treatments and (one day hopefully!) a cure. The Foundation is small but mighty, with a team that is passionate about making life better for my daughter and the many others who suffer. Simply sharing Sjögren’s research with your child’s healthcare providers can help replace feelings of helplessness with hope.

The Sjögren’s Foundation has recognized the need for more education, advocacy, and support for parents and guardians of children with Sjögren’s, including a new support group. If you would like more information, please feel free to reach out to Foundation at [info@sjogrens.org](mailto:info@sjogrens.org).

**Q** *I’ve been suffering with a terrible white dry cracked tongue for the last two months. I’ve been tested and it’s not thrush. Is this common with Sjögren’s and are there any medications to help manage this symptom?*

*Ava Wu, DDS  
Sjögren’s Foundation Board Member*

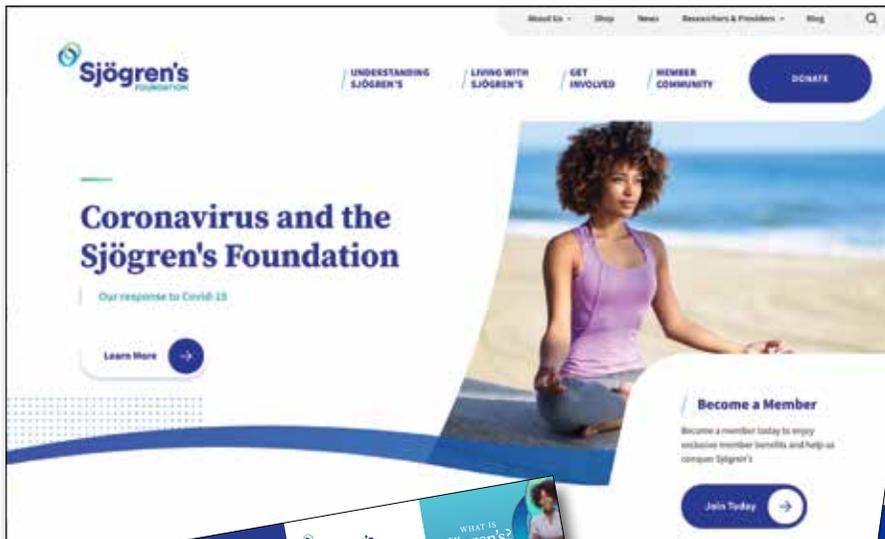
**A**A dry cracked tongue is common in Sjögren’s patients that have the lowest salivary flow rates. A dry tongue is like having dry skin. One wants to keep it moisturized to the best of one’s ability for greatest comfort. Hydration levels are definitely important. Sipping water throughout the day, adding an oil to ingested water, artificial salivas, chewing/sucking on sugar free gum/hard candies, and medication (Salagen® Evoxac®) may be used to stimulate additional saliva for mechanical cleansing and moisturization. Sometimes food and debris can be trapped

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# Have you seen our new look?

The Sjögren's Foundation has officially changed our name, our logo, our look and our website! The Foundation has dropped the word "syndrome" from our name and literature, and after a year-long project working alongside our Board of Directors, Medical & Scientific Advisors, patients and volunteers, we are excited to share with you our new materials and newly designed and rebranded website - [www.sjogrens.org](http://www.sjogrens.org).



**“Ask the Board”** *continued from page 8* ▼

in deep cracks of the tongue and cause irritation. In this case, gentle brushing with a soft toothbrush and frequent rinsing can be helpful.

Two interesting mechanisms that have received little attention with regard to oral dryness address how additional saliva can unknowingly be removed from the mouth: evaporation and absorption of water through the oral mucosa. The clinical implication of the evaporative process is most profound for mouth breathers during exercise and those unconsciously breathing through the mouth. The significance of this observation would be to try to minimize the amount of evaporative fluid by choosing to breathe through one’s nose with the lips firmly sealed. Not all persons are able to breathe through their nose, in which case one would think about trying to create an oral moisture chamber by covering your mouth with a hand, a mask, a scarf or similar item during breathing to prevent moisture loss through the mouth. The use of a humidifier puts more water in the air. Many of my patients find it helpful to add a bit of olive oil to their water, use oil straight as an oral moisturizer, or include milk into tea/coffee to add fat. This may be the result of the fat/oil acting as a barrier to saliva from being reabsorbed through the mucosa.

The tongue dorsum or top surface of the tongue is covered with papillae, giving it a rough surface. Some of these papillae look like red dots, which contrasts with the thin white coat that often covers the tongue. The papillae can elongate and result in a hairy looking tongue that can be various colors (green, brown, black) including white. The white hairy tongue can be associated with candidiasis, poor dental hygiene, and antibiotic therapy. White hairy tongue is considered a benign condition. Brushing or scraping the tongue will remove the debris caught within the “hairs” and help the papillae return to their normal appearance.

A thickened, white patchy area that cannot be wiped off may be leukoplakia. It may be related to alcohol and tobacco use. This should be evaluated by a health professional.

Lichen planus (LP) can also appear on the tongue in the form of a white lacy pattern or as scattered red ulcerations. The lacy version of this usually does not require treatment, while the red version of LP can be treated with a topical steroid. A biopsy can help if the diagnosis is unclear.

Squamous cell carcinoma (SCC) can appear as a thickening over a white or red base. SCC typically occur on the side of the tongue rather than the top of the tongue. Biopsy is critical to establish a diagnosis.

Single or multiple white ring-shaped lesions with red centers which can move around on the surface of the tongue over a matter of hours is likely a geographic tongue. These lesions may spontaneously disappear and are occasionally painful. These lesions are benign.

Once the major reasons of why a tongue can be white are ruled out (white hairy tongue, leukoplakia, LP, leukoplakia, SCC, geographic tongue), what is left is a dry tongue. Improving the sensation of oral dryness will be a process of trial and error involving strategies to increase moisture to the tongue and the prevention of moisture loss.

## Q *How has being involved in the Foundation helped you with living with the disease?*

*David Schrader*

*Sjögren’s Foundation Board Member, Sjögren’s patient*

**A** The Sjögren’s Foundation has been a great source of information, support and optimism.

Seven years ago, my Sjögren’s diagnosis came with a mix of relief and confusion. Relief that what was going on had a name; confusion because it was unfamiliar to me.

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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](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.

# You Stood Up!

## *Sjögren's Awareness Month*



**T**hank you for supporting Sjögren's Awareness Month and helping hundreds of thousands of people learn about this complex disease.

You are the voice and the face of the Foundation. It is the collection of your experiences that truly portrays this complex disease, which is why the 2020 #ThisIsSjögrens national campaign was created to highlight the many faces of Sjögren's.

Every day in April, the Foundation highlighted a different patient and shared a glimpse into their life living with the disease on our website and social media accounts. Each daily post gave a small insight into *what is Sjögren's* and together they showcased the complexity of the disease.

Thank you to everyone who shared their story and followed our campaign for making this our most successful awareness campaigns to-date!

*Below are five of the Faces shared this year and we hope you will visit [www.sjogrens.org](http://www.sjogrens.org) to view all the stories highlighted during this year's April Awareness Month.*



### **Katie 25 (diagnosed at 20)**

My most difficult Sjögren's symptom that people don't understand is fatigue. It's not being tired. It's your muscles refusing to work, your legs refusing to carry you around and your arms refusing to

be raised up. Some people with Sjögren's will wake up with this fatigue, some develop it after a busy or stressful day, and for others, it hits us like a brick out of nowhere. We aren't being lazy. It can be paralyzing.



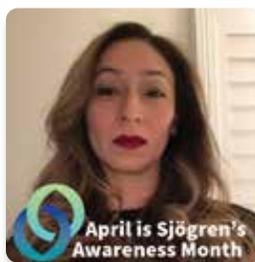
### **Chris 30 (diagnosed at 25)**

Since being diagnosed with Sjögren's, I have learned that there is no right answer for this disease. Just when you think you have a symptom under control, something new pops up that you've never experienced. We are in this together!



### **Inonge 58 (diagnosed at 54)**

My most difficult Sjögren's symptoms are chronic pain, fatigue, brain fog and body swelling. Due to scalp sensitivity, I'm unable to wear a wig and have been forced to accept the new me with alopecia. I have lost a lot because of this disease, which has taught me to focus on the things that really matter.



### **Ana 43 (diagnosed at 23)**

I wish people understood that just because I look "normal," internally, I am fighting a battle with a multi symptom disease. Every day is a struggle to gather energy and live a life, as best as I can.



### **Abby 22 (diagnosed at 22)**

My most difficult Sjögren's symptoms are fatigue, frequent fevers and a painful malar rash on my face. My rheumatologist suggested I try a restrictive autoimmune protocol diet, which helped me learn what foods trigger me and my symptoms. ■



# Resource Order Form

	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		

**Shipping and Handling:** U.S. Mail: \$7 for first item + \$2 for each additional item

**Sub-Total:**

**Membership (new / renewal):** Includes *Conquering Sjögren's* newsletter, member pricing on books and more benefits.

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# Join Team Sjögren's in Chicago!

“Rock the Windy City alongside Iconic City Sights and Stunning Lakefront Views”

**Rock 'n' Roll**  
MARATHON SERIES®

We're looking for runners or walkers to join our Team Sjögren's Training Program for the Rock 'n' Roll series Chicago Half Marathon (13.1 miles) or 12K (7.4 miles) race on July 19<sup>th</sup>. Follow our program and we will prepare you to WALK or RUN in either race, where each turn is filled with the sights and sounds of Chicagoland.

**Our Team is always full of walkers and runners – so don't fret if you aren't a runner!**

The Team Sjögren's program takes people from the couch to the course. The Sjögren's Foundation staff and our Team trainer will help guide you through the entire process and ensure you are ready to participate in July! In addition, you will be increasing awareness for Sjögren's, as well as, helping raise crucial funds for Sjögren's research and education.

Voted one of the BibRave Top 20 Half Marathons, the Rock 'n' Roll Chicago Half Marathon is a must-do in 2020! The course takes you on a perfect tour of the Windy City where you will run/walk the Magnificent Mile, through downtown and along Lake Michigan. Whether you choose the Half Marathon or 12K, you will be cheered on by bands, cheerleaders and supportive spectators throughout the route!

The Foundation has a limited number of spots for this epic summer event and we hope you'll be one of them! If you don't feel you can walk or run in this event, do what so many other patients have done and recruit someone else – your husband, wife, sister, cousin, daughter, son or friend – and have them walk or run in your honor.

If you want to receive information about training and joining Team Sjögren's Chicago, please contact Kalla Ford at [kford@sjogrens.org](mailto:kford@sjogrens.org)!

**Team Sjögren's**

**As a Team Sjögren's member, you will receive:**

- World-class training from our Team Trainer
- Leadership and mentorship from past runners and Sjögren's Foundation staff
- Hotel room accommodations in Chicago
- Airfare reimbursement
- An opportunity to join a Team of those wanting to make a difference
- And much much more

**“We Run in Honor of the 4 Million Americans with Sjögren's...  
We Are Team Sjögren's”**

If you want to receive information about training and joining Team Sjögren's Chicago, please contact Kalla Ford at [kford@sjogrens.org](mailto:kford@sjogrens.org)!

**“Ask the Board”** *continued from page 10* ▼

For years, I had been struggling with a range of symptoms (dryness, joint pain, digestive problems, bouts of intense fatigue, brain fog) and been passed from specialist to specialist before seeing a rheumatologist.

Like many people, my Sjögren’s diagnosis sent me reading and researching to learn about the disease and possible treatments. I joined the Foundation as a member and was glad to find credible resources to get educated and empowered to play a more active role in my healthcare.

Living with a chronic, systemic (and often invisible) disease brings physical and emotional components. To help with the emotional reckoning, the Foundation provides ways for patients, caregivers and medical professionals to share their stories, learn from each other and support each other. From other patients’ experience and advice, I was able to accept that life would be different, make a big career change and overcome my anxiety about the complexity and uncertainties.

The way forward became clearer. I became more open to trying new things: nutrition, alternative medicine, meditation. Now I listen much more than I talk, try to focus on things I can do, look for ways to volunteer to help others and give myself permission to say “no” when that’s the best answer. I’ve learned to be grateful for small pleasures like a pain-free day,

a warm cup of tea and a good book.

Last year, Steven Taylor, Sjögren’s Foundation CEO, asked if I would be interested in participating in the project he was undertaking to review and update the Foundation’s branding. This gave me an opportunity to converse with other patients and Foundation staff and share some thoughts from my professional and personal experience. I was really impressed by the process and am excited about the strong new branding.

Following that project, I was pleased to be invited to join the Foundation’s Board of Directors as the first male Sjögren’s patient to serve on the Board. When I attended my first meeting, it was overwhelming and inspiring to meet the staff and Board members who enthusiastically dedicate their time, energy and expertise.

It is a great comfort to know you have a partner in the Foundation. My experience with the Foundation has made me more informed, more appreciative of the battles people are waging, more proactive in my own healthcare and more optimistic for a better future. ■

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 **Sjögren's**  
FOUNDATION

# Sjögren's Foundation In Action!

## *The Foundation's Response to the Hydroxychloroquine/Plaquenil Shortage*



As you may know, early on in the Covid-19 crisis, many patients were unable to fulfill their regular Hydroxychloroquine/Plaquenil (HCQ) medication due to a market shortage. This shortage created incredible stress for our patients and quickly became a top priority for the Sjögren's Foundation to address.

This market shortage was caused by an incredible increase in new prescriptions being written for non-rheumatological patients. The spike first happened on March 19<sup>th</sup>, when the President promoted the use of HCQ in the treatment of Covid-19. Within 24 hours of that first mention, over 32,000 new prescriptions were written for HCQ. This was 46 times the normal rate of new prescriptions. The increase in new prescriptions continued into mid-March, with over 40,000 physicians writing a first-time prescription for hydroxychloroquine.

Since day one, the Foundation knew we had to protect our patients and serve as a loud voice in addressing the shortage of HCQ. As we know, 43% of our patients take HCQ to treat their Sjögren's, along with millions of others that use it for their lupus or rheumatoid arthritis.

We immediately wrote a letter to the U.S. Food and Drug Administration (FDA), to which they were very responsive and ensured us that they were working on the shortage. The FDA started to work with manufacturers to implement a massive ramp-up of production. The FDA assured Steven Taylor, Sjögren's Foundation CEO, that patients should be seeing a release of more supply by mid to late April. The Foundation would specifically like to thank Dr. Janet Woodcock from the FDA for her support and for her representation of autoimmune disease patients during this shortage. As a former rheumatologist, Dr. Woodcock fully understands the needs of Sjögren's patients.

The Foundation also heard from the U.S. President of Novartis Pharmaceuticals, one of the makers of HCQ. They announced that they were increasing production and donating 130 million doses of HCQ to the Covid-19 response, so as to free up other supply for autoimmune disease patients. In addition, thanks to our relationship with Pharmaceutical Researchers & Manufacturers of America (PhRMA), the Foundation was also able to get word to the makers of Plaquenil and other makers of HCQ, to ensure they understand the urgency of the supply shortage.

To continue our advocacy in this area, the Foundation also joined with other organizations, including the American College of Rheumatology, Lupus Foundation and the Arthritis Foundation to reach out to all state governors, insurance commissioners and boards of pharmacy to enlighten them on the shortage issue. The goal was to work towards increasing supply of HCQ, ensure no price gauging happened as well as ensure that refills for current autoimmune patients was a top priority.

Finally, the Foundation reached out to health insurance plans, including Kaiser Permanente in California, that had been denying refills for the drug. The reasoning for denying refills was unacceptable and the Foundation was not going to allow our patients to sacrifice their health or lives so as others could stockpile a medication that had yet to be proven to work in the treatment of Covid-19.

Since then, the Foundation is pleased to announce that the ramping up of production has helped to ease the shortage crisis and has led to our patients being able to get refills. In addition, formal trials and research has proven that HCQ was being prematurely

**“In Action”** *continued from page 15* ▼

promoted and was not working in Covid-19 patients as was first being promoted. All of this has helped to almost fully alleviate the shortage issue.

The Foundation knew that it had to take bold and aggressive moves to address this issue and ensure that our patients’ voices were heard. In all of our work in clinical trials, the Foundation is well aware that the FDA, sponsoring pharmaceutical companies, and the Sjögren’s Foundation are barred from prematurely promoting any findings. In fact, we would all be fined if we mentioned anything about a potential therapy working or not working, before a formal report was filed or trial was finished. This premature promotion

of HCQ before it was fully tested is a prime example of why this rule is in place and why we should not give false hope to patients and possibly cause any undue stress in the healthcare supply chain.

In the end, we hope you know that the Foundation was not going to sit idly by and allow this shortage to affect our patients who are successfully being treated with HCQ. We appreciate you standing by us and for supporting our fight to make sure the Sjögren’s patients were not silenced.

If you are continuing to experience a shortage in your area, please let us know but most importantly, please send an email to the FDA at [DRUGSHORTAGES@fda.hhs.gov](mailto:DRUGSHORTAGES@fda.hhs.gov). ■



*Dr. Harry Spiera; Elaine Harris, Founder of the Sjögren’s Foundation; Steven Taylor, CEO of the Sjögren’s Foundation*

## Remembering Dr. Harry Spiera

### *A True Sjögren’s Champion*

**T**he Sjögren’s Foundation was incredibly saddened to learn of the recent passing of Dr. Harry Spiera. A distinguished and highly regarded rheumatologist, Dr. Spiera was a friend of the Foundation since its inception and beloved by the Sjögren’s patients he cared for during his nearly 60 years in practice.

Dr. Spiera was regularly recognized as one of the top doctors in the New York Metro Area and a leading Sjögren’s expert in the United States. He was part of the Mount Sinai Health System for more than 40 years where he helped begin the Division of Rheumatology at Mount Sinai Hospital and served as its first Chief. Dr. Spiera was also a founding member of the Sjögren’s Foundation, working closely with founder and patient, Elaine Harris. In subsequent years, he remained a loyal friend, contributor, and valuable resource for the Foundation.

Most importantly, Dr. Spiera was a tireless advocate for Sjögren’s and the Sjögren’s patients he served throughout his long and distinguished career. To recognize this, as well as his role in forming the Foundation, we were proud to recognize Dr. Spiera as a “Sjögren’s Foundation Champion” in 2016.

The Foundation was honored to acknowledge and thank Dr. Spiera for his role in forming the organization and his never-ending support of Sjögren’s patients and the Foundation’s efforts. Dr. Spiera’s impact can also be seen in the online tributes posted by his patients since his passing, with many crediting their lives to his care and offering thanks for his endless concern, compassion and kindness.

The Sjögren’s Foundation mourns the loss of a true hero to the Sjögren’s community and sends our deepest condolences to his family, friends and loved ones. ■

# Sjögren's Foundation Events Go Virtual!

**T**he Foundation has been monitoring the Covid-19 outbreak and due to the unpredictable progression of the virus, the Foundation has had to reschedule many of our events. A lot of our spring events have gone virtual, including our 2020 National Patient Conference.

The health and safety of our patients, their families and our volunteers will always come first.

We will continue to evaluate future events as needed. Please visit [www.sjogrens.org](http://www.sjogrens.org) to learn more about rescheduled events and watch for emails with updates about local events.

To learn more about Foundation events, visit [events.sjogrens.org](http://events.sjogrens.org) or contact us at (301) 530-4420 or email [info@sjogrens.org](mailto:info@sjogrens.org).



## Sjögren's Foundation Virtual Event Calendar

To learn more about Walk for Sjögren's events, please visit [events.sjogrens.org](http://events.sjogrens.org) or contact Jessica Levy at (301) 530-4420 ext. 218 or email [jlevy@sjogrens.org](mailto:jlevy@sjogrens.org).

May

**Denver Area Virtual Walk for Sjögren's**  
*Saturday, May 30, 2020*

June

**Philadelphia Tri-State Area Virtual Walk for Sjögren's**  
*Saturday, June 13, 2020*

**Texas Virtual Walk for Sjögren's**  
*Saturday, June 20, 2020*

**2020 Virtual National Patient Conference**  
*Friday and Saturday, June 26-27, 2020*

**[events.sjogrens.org](http://events.sjogrens.org)**

# Are you looking for a meaningful volunteer experience?

*Interested in making a difference in the lives of other Sjögren's patients?*

## ***Join us as a Patient Support Volunteer!***

**P**atient Support Volunteers are seasoned Sjögren's patients who are willing to receive calls from newly diagnosed Sjögren's patients. You will provide them with support and Sjögren's information, especially about day-to-day living, coping strategies and available resources. The Foundation is looking for qualified volunteers throughout the country to be part of our growing network of support!

### ***If you are someone who:***

- Has been diagnosed with Sjögren's for 1 year or more
- Has been a Foundation member for at least 6 months
- Is knowledgeable about Sjögren's and the resources available to newly diagnosed patients
- Is known for being a great listener and having a positive outlook

### ***This could be the perfect volunteer opportunity for you!***

If you are interested in learning more about how to become part of our team of volunteers, contact Kathy Ivory at [kivory@sjogrens.org](mailto:kivory@sjogrens.org) for more information.





## IN MEMORIAM

**In Memory of Camille Silliman**  
Mary-Alice Thompson

**In Memory of Carol Schenkel**  
Mary Shaw

**In Memory of Karen Caron**  
Bedford Girl's Ice Hockey Team  
Suzanne Wetherbee

**In Memory of Cindy Will**  
Ken Gerver

**In Memory of Ellen Kovacevich**  
Eric Nakahara

**In Memory of Fritz Marsa**  
David Marsa

**In Memory of Jacqueline Klein**  
Sandy Barker and Billy Noland  
Jerry and Marolyn Jordan  
Bob Herd  
Lora Summerwill  
Alan and Becky Klein

**In Memory of Jimmy Ford**  
Fred Fernandez and Irma Rodriguez

**In Memory of Joanie Kower**  
Irene Resnick

**In Memory of Maury Young**  
Adam Young

**In Memory of Susan Martin Hansen**  
Bruce Hansen

**In Memory of Pauline McCaffrey**  
Bernice Kirchler  
Cindie Kozeluh  
Jim and Julie Shellard  
Carl and Rosemary Pallasch

**In Memory of LaNell Choden**  
Audrey Choden

**In Memory of Leo Sreebny**  
Evelyn Bromet

**In Memory of Linda Benvenutty**  
Mei Chiang

**In Memory of Maria and Norman Demetrios**  
Eleni Clement

**In Memory of Nancy Gonzalez**  
Manuel Gonzalez

**In Memory of Patricia Kleinedler**  
Anne Kirkland

**In Memory of Patricia Stepalritch**  
Kermit and Naomi Roberts

**In Memory of Robert Ginsberg**  
Adrienne Ginsberg

**In Memory of Elizabeth Reeves**  
Vicki Stewart

**In Memory of Marian Walker**  
Jim and Carol Spencer  
Susan Barajas

**In Memory of Iona Staples**  
Matthew Letson

## IN HONOR

**In Honor of Kathy Heimann**  
Lisa Heimann

**In Honor of Amy Zappia**  
Karen and Stu Troyan

**In Honor of Steven Taylor**  
Eva Plude  
Shari Kafton

**In Honor of Anne Economou**  
Gretchen Shelton

**In Honor of Margaret Avila**  
Ann Makowski

**In Honor of Margaret Burkholder**  
Barbara Cudzik

**In Honor of Jessica Esposito**  
Frank Capiello  
Laurie Gagne

**In Honor of Jessica Levy**  
Joan Billig

**In Honor of Pat Schleicher**  
Kathryn Simonson

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## Conquering Sjögren's

Sjögren's Foundation Inc.  
10701 Parkridge Blvd., Suite 170  
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Phone: (301) 530-4420  
Fax: (301) 530-4415

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

# Celebrating World Sjögren's Day

**O**n July 23<sup>rd</sup>, we hope you will join with the Foundation to celebrate World Sjögren's Day and the birthday of Dr. Henrik Sjögren, the Swedish ophthalmologist who first identified the disease.

In 1929 Dr. Sjögren met a patient who complained of dry eye, dry mouth and joint pain. While each of these symptoms were already well known, it was the combination of them that Dr. Sjögren noticed and decided to investigate.

Dr. Sjögren could have been just an ophthalmologist who happened to meet a patient with dry eye, but his open mind led him to the discovery of an unknown clinical entity. His work not only paved the way for current researchers in the field but has also helped all patients living with this complex disease.

In addition to honoring Dr. Sjögren, World Sjögren's Day gives everyone touched by the disease a vehicle to reach out and educate those close to you about Sjögren's. It is the ideal opportunity for you to have your voice heard and share your story.

Visit [www.sjogrens.org](http://www.sjogrens.org) to learn more about how you can join in the celebration of what would have been Dr. Sjögren's 121<sup>st</sup> birthday.

