

CONQUERING Sjögren's

July/August 2020



Inside this Issue

Genetics of Sjögren's

Clinician's Corner

The Lip Biopsy

How Sjögren's is Diagnosed

All About Clinical Trials



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Table of Contents

Genetics of Sjögren's	3
Clinician's Corner: Genetics and Sjögren's	5
The Lip Biopsy	7
How Sjögren's is Diagnosed	10
All About Clinical Trials	11
You Stood Up	13
Virtual Event Calendar	16
Sjögren's Foundation in Action	17
In Memoriam / In Honor	19

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Genetics of Sjögren's



by *Kandice L. Tessneer, PhD* and *Christopher J. Lessard, PhD*
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Introduction

Scientists and clinicians have made significant advances towards understanding the heritability of Sjögren's during the past three decades. However, to appreciate the significance of these findings, we must first understand the complexity of the human genome. Our genome is a tightly regulated, complex structure composed of DNA that is organized and compacted by specific proteins. This organization allows the genome to function in a coordinated way within the confined space of a three-dimensional nucleus.

DNA contains two different types of "code" that dictate who we are as an individual, a population, and a species. Protein-coding genes make up 2-3% of the DNA in the human genome's 3.8 billion bases. The approximately 20,000 proteins encoded by the human genome are the building blocks and engine of the cell. A change in the DNA sequence that encodes for a specific protein can, sometimes, modify protein function and result in monogenic diseases such as cystic fibrosis and sickle cell anemia.

The remaining 97-98% of the genome is non-protein-coding. While once thought of as "junk DNA," the majority of non-protein-coding DNA is now recognized as having biological function. These non-protein-coding regions are usually comprised of regulatory elements that determine whether and/or how much of a specific protein-coding gene transcript is expressed in specific cell types and in response to different environmental conditions. For example, it is critical that the expression of proteins that are responsible for immune cell activation are rapidly increased in response to viral or bacterial infections. Yet, it is equally as

important to suppress the expression of these proteins in the absence of or after resolving infection to prevent chronic inflammation and subsequent tissue damage. Scientists now know that variations in the DNA sequence (single nucleotide polymorphisms (SNPs); pronounced "snips") can influence the function of these regulatory regions. In some cases, SNPs increase disease risk by altering the transcription of genes, and therefore the expression of proteins involved in normal immune response to pathogens.

Like many complex genetic diseases, Sjögren's is driven by the cumulative effects of 100s of genetic risk variants, i.e. SNPs, scattered throughout the genome. Since most of the variants that increase risk for genetically complex diseases like Sjögren's are located in the 97-98% of the human genome that is non-protein-coding, interpreting the impact of each risk variant on disease is challenging. Especially since we also know that genetic predisposition alone is not enough to result in Sjögren's. Environmental triggers, such as exposure to viral infection, are thought to be needed. In a genetically predisposed person, environmental triggers are thought to initiate an immune response that cannot be controlled, resulting in chronic inflammation and loss of self-tolerance. In order to identify the regions of the human genome that increase risk for Sjögren's, researchers need to compare SNPs between 1,000s of Sjögren's patients and 10,000s of controls. Once identified, further work is needed to understand how these variants influence disease. The functional characterization of variants takes a significant amount of time and resources and

continued page 4 ▼

“Genetics of Sjögren’s” *continued from page 3* ▼

has, therefore, become a significant bottleneck in ongoing research. Despite these challenges, researchers and clinicians from around the world have worked together to make significant progress on our understanding of the heritable risk of Sjögren’s.

Historical Studies on Sjögren’s Genetics

The heritability, and thus the genetic susceptibility, of Sjögren’s was supported by early studies reporting increased prevalence among twin pairs and families, as well as females compared to males, and specific ethnicities. Genetic susceptibility was not, however, empirically supported until studies investigating the potential role of single, suspected genetic regions in small populations of Sjögren’s patients and controls were conducted. The HLA region was among the first identified susceptibility regions associated with Sjögren’s. The HLA association is, by far, statistically the strongest association and encompasses the largest region. It contains hundreds of genes involved in immune system regulation, but has a complex genomic architecture that has complicated researchers’ abilities to determine exactly which gene(s) confer risk. Some of the earliest work in Sjögren’s genetics showed that specific variants in the HLA class II region are associated with the production of anti-Ro autoantibodies.

Because Sjögren’s has several disease traits that overlap with other related autoimmune diseases, researchers have focused on evaluating genes that were identified as susceptibility regions in large population-based studies of related autoimmune diseases such as systemic lupus erythematosus (i.e. lupus) and rheumatoid arthritis (RA). Some of the more promising early studies of Sjögren’s genetics evaluated IRF5 and STAT4, which were first described in lupus and RA, respectively. IRF5 and STAT4 encode important regulators of the proinflammatory interferon signaling pathway involved in the immune response against viral infection. Chronic, elevated activation of a large number of genes involved in interferon signaling have been reported in the salivary glands and peripheral blood of Sjögren’s using technologies that study gene expression (gene transcripts that are later translated into protein), and are correlated with two important autoantibodies in Sjögren’s, anti-Ro and anti-La. The role of the interferon pathway (both Type I and II) has been strengthened through more recent studies.

Recent Advances in Sjögren’s Genetics

Completion of the first draft of the human genome, published in 2000, and the advent of genome wide association studies (GWAS) in the mid 2000s revolu-

continued page 6 ▼

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Clinician's Corner: Genetics and Sjögren's



by Nancy Carteron, MD, FACR
Rheumatologist, University of California,
Berkeley and San Francisco Sjögren's
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Does Sjögren's run in families?

Sjögren's, like most autoimmune diseases, can run in families. The clinical risk data is limited in Sjögren's, but data is needed and would be helpful to patients and clinicians advising patients and their families. Like most autoimmune diseases genetic risk factors account for roughly 30% of the overall risk of developing Sjögren's, along with environmental and gender factors, and a triggering event, for example a virus. Factors involved in gene regulation also play a role in developing the disease, referred to as Epigenetic factors. The specific genes that confer risk in Sjögren's vary by population. Genome Wide Association studies have been performed on patients of European, Han Chinese, and Asian descent. There are some similarities, but many differences. Therefore, it is important to interpret the published data that we do have in the context of the population and geography of where the study was performed. The data may or may not be relevant to your family. Even less is known about the familial risk of Sjögren's in the setting of another autoimmune disease.

Both the Innate immune response, immediate to ward off an infection, and the Adaptive immune response, which in long-lasting (memory) and highly specific, are reflected in the Sjögren's specific genes identified to date. Immune response genes have the highest density on the X-chromosome. Since females carry 2 copies of the X-chromosome (XX) compared to the one copy in males (XY), females may be more susceptible to immune dysregulation. Also, Sjögren's patients may have fragments of virus incorporated in their genome, retroviral long interspersed nuclear ele-

ment 1, which can activate the Innate immune system leading to increased Interferon production (Type 1 INF) which can fuel inflammation and autoimmunity.

Further research on the genetics and immune responses in Sjögren's will lead to understanding the immune dysregulation that occurs in the disease, and guide strategies to regain balance in the immune system.

If my family member has Sjögren's, should I get tested?

Not under most circumstances. Testing should be driven by the presence of symptoms that suggest an autoimmune disease, like Sjögren's. However, if a family member has symptoms such as, joint pain, severe fatigue, dry eye, dry mouth, vaginal dryness, nerve pain, etc. the possibility of Sjögren's should be considered, and appropriate consultation and testing performed. The presence of Interstitial Lung Disease (ILD), mucosal associated lymphoid tissue (MALT) Lymphoma, or Primary Biliary Cholangitis (PBC) in the family member should raise suspicion for Sjögren's if any of the wide range of possible Sjögren's symptoms are present.

The one situation where a female family member of a Sjögren's patient might seek testing is prior to pregnancy to screen for the presence of the SSA (Ro) and/or SSB (La) autoantibody. These autoantibodies are associated with neonatal lupus and fetal heart block, and preventive strategies can minimize risk. However, there are no studies that assess the risk/benefit of performing these screening tests on family members of a Sjögren's patient. Individual cases should be discussed with a treating physician, rheumatologist, and/or possibly a high-risk fetal medicine specialist. ■

“Genetics of Sjögren’s” *continued from page 4* ▼

tionized researchers’ abilities to investigate genetic susceptibility in complex human diseases. GWAS are large-scale genetic studies that use glass slides containing DNA fragments that can evaluate at least 100,000 SNPs from thousands of patients and controls in a single experiment. We inherit one copy of every SNP from each of our parents and, together, they are called a genotype. To identify regions in the genome that increase risk for Sjögren’s, researchers compare the frequencies of each genotype found in a large number of Sjögren’s cases to the frequencies found in controls. Because a single GWAS often evaluates 100,000s of SNPs, it is important that each reach a statistical threshold that is much more stringent than most other scientific studies. Therefore, geneticists have established what is called the genome-wide significance threshold where the p-value (measure of significance) must be less than 5×10^{-8} . To achieve this level of statistical significance, many 1000s of patients and controls are needed. To date, several GWAS have been performed in related autoimmune diseases like lupus and RA; identifying hundreds of regions associated with increased risk of disease.

Unfortunately, GWAS in Sjögren’s have lagged far behind, in part due to limited cohorts with the 1000s of well-characterized Sjögren’s patients needed for these studies. In 2010, our research team at the Oklahoma Medical Research Foundation established the Sjögren’s Genetics Network (SGENE), a large international collaboration of investigators from the United States, Norway, Sweden, Netherlands, Germany, Australia, France, Italy, Belgium, Spain, Greece, Colombia, and the United Kingdom, to help enable the large case-control studies needed in Sjögren’s. With the help of our national and international partners, we continue to build our cohorts of carefully characterized and genotyped Sjögren’s patients for genetic studies.

In 2013, we published the first large-scale genetic study of Sjögren’s in patients of European ancestry. Our study replicated the previously implicated HLA, IRF5 and STAT4 regions, and identified four new genetic regions of Sjögren’s susceptibility: IL12A, FAM167A-BLK, DDX6-CXCR5, and TNIP1. At the same time, a GWAS of Sjögren’s patients of Chinese ancestry reported association with GTF2I and, later, IKZF1. More recent work has found that the GTF2I association is common with lupus and impacts the gene NCF1. Further work by our group has also established a well-known interferon-induced gene, OAS1. The risk variants in OAS1 cause an alternate version of the protein to be made that is thought to be less enzymatically active.

In June 2020, we revealed the first GWAS of Sjögren’s patients from European ancestry at the annual European League Against Rheumatism (EULAR) Conference. It was done in collaboration with our international SGENE partners, and in thanks to the more than 3,500 Sjögren’s patients and 23,000 controls that graciously participated in the study. Our new GWAS study has doubled the current list of Sjögren’s susceptibility regions from 10 to 20 including: NAB1, MIR146A-PTTG1, XKR6, MAPT-CRHR1, RPTOR-CHMP6-BAIAP2, TYK2, SYNGR1, CD247, PRDM1-ATG5 and TNFAIP3. Many of these genes are known to regulate the immune system, and have been associated with increased risk of related autoimmune diseases. For example, IL12A is one of two subunits of two different circulating cytokines that activate the interferon signaling pathway. In contrast, TNFAIP3 and TNIP1 are critical negative regulators of the proinflammatory NF- κ B signaling pathway. Loss of TNFAIP3 and TNIP1 have been linked with chronic inflammation and autoimmunity in several disease models.

In addition to genetic risk, GWAS studies have the potential to identify new targets for future therapeutic studies. TYK2 activates innate and adaptive immune cells in response to pro-inflammatory stimulation. Studies have also shown that a protein-coding variant deactivates TYK2 and is protective against severe lupus, RA, psoriasis, Crohn’s disease, ulcerative colitis, and multiple sclerosis. Interestingly, promising pre-clinical trials have reported that a TYK2 inhibitor, BMS-986165, effectively reduces chronic inflammatory responses and prevents the development of autoimmunity in mouse models of lupus and in phase II clinical trials on psoriasis. Given that our latest GWAS identified TYK2 as a new susceptibility gene for Sjögren’s, it is tempting to speculate whether TYK2 inhibitors might also be a potential treatment for Sjögren’s, as the same protein coding variant is among the variants we identified to be associated with Sjögren’s susceptibility. However, before this hypothesis can be tested, researchers must first determine if and how the SNPs carried on the TYK2 region alter TYK2 expression or function in Sjögren’s. In this lies the limitations of GWAS. Population-based GWAS identify genomic regions that are statistically associated with disease susceptibility, but do not provide any insights into how those genetic associations function to influence disease. Functional studies in both immune cells and animal models are necessary to determine how specific genetic mutations influence immune function before ideas of potential therapeutic studies can even be entertained.

The Lip Biopsy It's not as bad as it sounds

by Vidya Sankar, DMD, MHS, Tufts University, Associate Professor,
Director, Division of Oral Medicine, Department of Diagnostic Sciences

Because the clinical presentation of Sjögren's varies a great deal and there is no ONE test that can diagnose the disease, multiple tests are used in the diagnosis of Sjögren's. These include tests measuring salivary and lacrimal gland function (salivary and tear flow rates), but low flow rates can also be caused by medications, other systemic illnesses, caffeine intake, the time of day the tests are obtained, as well as states of dehydration. Blood test such as anti-SSA autoantibodies, are positive in only 30-70% of Sjögren's patients and are not considered totally specific to the disease since they are found in 30% of lupus patients. When the diagnosis is not clear, tissue studies (biopsies) such as the salivary gland biopsy (either parotid gland or minor salivary glands) are extremely helpful in diagnosing the disease. The biopsy looks for signs of inflammation and cells that respond to inflammation that build up within the exocrine glands (salivary and lacrimal). As inflammation increases, it obliterates and destroys normal functioning gland tissue. If the tissue cannot function or is destroyed, saliva and tears cannot be produced. Biopsies may also be a useful tool in assessing patient's responses to treatment. Many research studies look for changes in the minor salivary glands such as a reduction in inflammation to determine if the medication is working.

You have two pairs of major salivary glands, the parotid (in front of the ears/cheek region) and submandibular (below the jaws/neck region) glands. Combined, these salivary glands produce about 90% of your saliva. In addition to those major salivary glands, there are about 750 minor salivary glands distributed throughout the mouth. They can be found just about anywhere within the oral cavity but are abundant inside the lips, cheeks and on the palate (roof of the mouth). Although there are so many of these minor glands, they only produce about 10% of total saliva. Biopsy of the major salivary glands, such

as the parotid gland, can be tricky due to the location of nerves and blood vessels within and throughout the glands as well as cosmetic concerns (biopsies are done through the skin of the face/neck). While the same pathological findings are seen in the lacrimal glands, their proximity to the eye makes it impractical to biopsy these glands. The minor salivary glands are very easy to access as they are abundant along the inside of the lower lip, and the biopsy is done within the mouth, so esthetics are not an issue. For these reasons, the minor salivary glands are frequently selected for biopsy.

The minor gland biopsy can be done in an outpatient setting under local anesthesia (xylocaine) administered directly to the area being biopsied. A small incision is made, less than ½ an inch long, and around 4 of these glands (that are about the size of a pepper corn) are removed. The site is usually closed with a couple stitches and the procedure is over within 10-15 minutes. Patients are free to resume routine activities immediately but are cautioned about eating/chewing since they might bite their lip and not be aware of it due to the numbness. The numbness usually lasts for a couple hours. Once the anesthesia wears off, routine over the counter pain medications such as ibuprofen or acetaminophen are sufficient to manage the post-operative pain. The biopsy site heals quickly with little to no scarring. If scars do develop, they are inside of the mouth so it is of little to no esthetic concern. Side effects include minimal post-operative bleeding, which is usually controlled by the stitches, as well as placing gauze pads with a little pressure. The bleeding typically lasts for a few minutes up to an hour. Swelling can occur- reaching its peak 2-3 days after the procedure and then resolves. Infections are rare. Of course, there might be some side effects like prolonged numbness or tingling in the area biopsied. This has been reported in about

“Genetics of Sjögren’s” *continued from page 6* ▼

Where do we go from here?

Even with the progress made to date, the field of Sjögren’s genetics is behind other related diseases, such as lupus and RA; each of which have more than 100 convincingly associated distinct regions. The international Sjögren’s research community is making significant advances towards understanding why and how this complex disease develops. Genetic studies like ours provide important milestones in this journey by defining new genetic susceptibilities that can eventually be used to implement early identification and intervention strategies. Given that autoimmune diseases like Sjögren’s likely develop when an environmental exposure triggers dysregulated immune pathways in genetically susceptible individuals, it would be advantageous to be able to identify susceptible individuals before disease onset.

Cumulative genetic risk scores have been used, with some success, to predict susceptibility of specific lupus clinical features, where more than 120 genetic risk associations are defined. Although our recent GWAS study doubled the genetic associations for Sjögren’s, it is important to note that there are likely dozens, if not hundreds more genetic associations that have not yet been identified. In order to make cumulative

genetic risk scores and other similar approaches feasible in the future, researchers will need to significantly increase the number of known risk genes.

Defining the complete scope of the genetic susceptibility for Sjögren’s is going to require many more studies like our GWAS using genotyping data from many more individuals from different ancestries. Researchers have learned that genetic susceptibility often changes depending on the ancestry or race of the study population. To this end, we have been working to expand our SGENE collaboration of investigators to include researchers from Mexico, Greece, Italy, the Netherlands, as well as additional sites in the United States, Norway, Sweden and United Kingdom. Our next goal is to increase the number of Sjögren’s patients in our next GWAS to more than 10,000.

To fill the critical gaps in ongoing Sjögren’s research on genetic susceptibility in the future, researchers need the support of Sjögren’s patients, their families and communities. If you would like to help support research on Sjögren’s, we strongly encourage you to visit with your physician about local opportunities. If you would like a more comprehensive review of Sjögren’s Genetics, we recommend this recent review written by one of our SGENE collaborators: Imgenberg-Kreuz, et al. *Rheumatology*, 2019; key330. <https://doi.org/10.1093/rheumatology/key330>. ■



Do we have your current e-mail address?

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

“Lip Biopsy” *continued from page 7* ▼

5% of patients. A majority of the patients that experience this regain normal sensations within several weeks to months. A number of medications- both prescription and herbal may have an impact on bleeding and ability to heal. Therefore, it is important to tell your doctor about which medications you are taking, so that the appropriate measures can be taken to minimize these events.

Biopsies should be performed by individuals who are familiar with the lip biopsy procedures, this includes Oral Medicine specialists, and certain Oral Surgeons and Otolaryngologists (ENTs). Once the

specimen is obtained, the tissue should be sent to an oral pathologist who are familiar with the specific inflammatory characteristics and patterns associated with Sjögren’s for diagnosis.

The minor gland lip biopsy is a safe procedure and can be instrumental when it comes to diagnosing Sjögren’s and helpful in determining if patients are responding to therapy. Understanding the role of the biopsy in diagnosis and what to expect when undergoing the procedure may help patients seek out qualified individuals when making the determination to have the biopsy. ■

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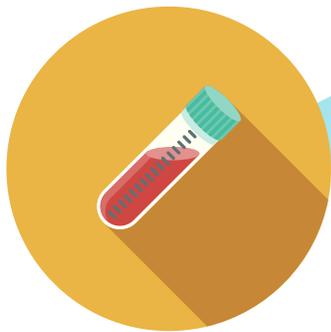
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How is Sjögren's diagnosed?



Unfortunately, there is no single test that will confirm the diagnosis of Sjögren's and thus physicians must conduct a series of tests and ask about symptoms the patient is experiencing.

Physicians will use a number of tests to determine a Sjögren's diagnosis.

Objective tests used in diagnosis include:

Blood tests you may have include:

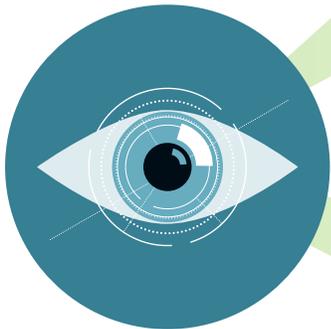
- SS-A (or Ro) and SS-B (or La): Marker antibodies for Sjögren's. 70% of Sjögren's patients are positive for SS-A and 40% are positive for SS-B. Also found in lupus patients.

Eye tests most commonly used include:

- Schirmer test: Measures tear production.
- Rose Bengal and Lissamine Green: Use of dyes to examine the surface of the eye for dry spots.

Dental tests most commonly used include:

- Salivary flow: Measures the amount of saliva produced over a certain period of time.
- Salivary gland biopsy (usually in the lower lip): Confirms lymphocytic infiltration of the minor salivary glands.



Subjective questions used in diagnosis may include:

Ocular Symptoms*

- Do your eyes feel dry?
- How long have you been experiencing dry eye?
- How often do you use artificial tears each day?

Oral Symptoms*

- How long have you had dry mouth?
- Do you experience salivary gland swelling?
- Do you need liquids to swallow food?



**These questions are a sampling of questions a physician may ask a patient.*

In addition to objective and subjective testing, your physician will also take a complete medical history as well as discuss your various symptoms you may be experiencing. Your physician will then consider the results of all these tests and his/her examination to arrive at a final diagnosis.

Further research is being conducted to refine the diagnostic criteria for Sjögren's and to help make diagnosis easier and more accurate. ■



All about Clinical Trials and Sjögren's

by Theresa Lawrence Ford, MD

CEO & Medical Director of North Georgia

Rheumatology Group, PC

Sjögren's Foundation Clinical Trials Consortium (CTC) Chair

A clinical trial is important on so many fronts! It contributes to the advancement of science, our knowledge about Sjögren's and whether specific therapy approaches will work. It provides the participants an opportunity to receive potential benefit from a drug, medical device or procedure or even lifestyle changes such as diet or exercise. In a clinical trial, a new medication or product may be compared to one that is currently available, so we can learn which one works best or which one works better for certain patients. A new medication may be compared to a placebo that has no active ingredient and is sometimes called a sugar pill. Having some patients on the new drug and others on a placebo helps us to know for certain whether the drug works and benefits are not just due to the expectation that you will get better on the new drug. When this new application (medication or product) is first studied, it may not be known whether or not it will help. For that matter, study investigators might not know whether or not it may be harmful or not make any difference at all.

Clinical trials are designed by investigators who have special interests in particular disease states and hope to add medical knowledge relating to the treatment, diagnosis and prevention of diseases. The investigators that conduct the trials attempt to determine if the medication or product works or is effective. They also attempt to determine if there will

be adverse effects associated with the therapeutic intervention. In other words, is it safe for human use? With this knowledge, a determination can be made as to how use of the product may affect the disease state for which it is being studied.

In general, clinical studies are important because they add to our medical knowledge and are necessary for regulatory agency approval so the new drug or product can come to market. Importantly, the results of these trials ultimately can make a profound difference in future patient care.

If you are interested in participating in a clinical trial, I recommend that you first talk to your health-care professional. Your provider can make you aware of your particular potential benefits and risks and should be part of your team in helping you decide whether to participate. The Sjögren's Foundation provides a list of clinical trials in Sjögren's, and you can learn more about these trials and how to sign up on page 12. You can also go to www.clinicaltrials.gov to search for additional trials. Currently, about 14 therapies as well as additional products and devices are in clinical trials or are in the planning stages for clinical trials in Sjögren's. This number is higher than ever before and brings hope that treatments that could make a major difference in patients' lives are on the horizon. If you are eligible to participate in a clinical trial, you may be one of the first to benefit from a new treatment. ■

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Clinical Trials in Sjögren's

Clinical trials are a crucial element in medicine and healthcare to help develop drugs that will treat or possibly cure certain diseases. Researchers use clinical trials to test if a drug works, how well it works, how safe it is and how it compares to any currently available treatments.

The Sjögren's Foundation has a section on its website devoted to clinical trials in Sjögren's and a listing of clinical trials that are currently recruiting Sjögren's patients.

To learn more visit:
www.sjogrens.org/living-with-sjogrens/clinical-trials



You Stood Up!

Celebrating Our Strength



Sjögren's Foundation Members Stand Up Around the Country! As the Sjögren's Foundation starts planning for the Fall events, we want to thank everyone who stepped up by supporting one of our events over this past year! Our success is a direct result from you, our amazing volunteers and supporters. Thank you for being a part of our journey to conquer the complexities of Sjögren's, especially in these unprecedented challenging times. The funds you raised allow us to continue providing programs and services, advocating for patients and funding research for the four million people living with Sjögren's. Together we are working to develop new therapeutics to treat this debilitating disease and transform the future for all patients.

Celebrating our Resiliency During These Challenging Times!

To insure everyone's health and safety, we transitioned our Spring live events into virtual ones. Our Sjögren's community still Sjö-ed Up and became even stronger by coming together and staying committed to our cause by participating in our Virtual Walks for Sjögren's.

The events were intimate and very rewarding bringing the Sjögren's community together in the best way possible. Thank you to everyone who joined us so we could continue to raise vital awareness and funds to support our mission and initiatives!

Thanks to the hundreds of patients, family members, friends and healthcare providers who joined us to strengthen the fight against Sjögren's. You raised funds, donated, volunteered and helped us increase awareness by being a part of one of our events. Thanks to all of your support and hard work, we raised over \$165,000 from Foundation Walk Events!

A look back at the 2019-2020 Sjögren's Foundation National Events:

- New Hampshire Walk for Sjögren's, Dorrs Pond at Livingston Park, – October 6, 2019
- Los Angeles Area Walk for Sjögren's and Health Fair, La Mirada, CA – October 19, 2019

- Austin Area Walk for Sjögren's and Health Fair, Austin, TX – November 9, 2019
- Team Sjögren's Goes Turkey, Turkey Trots Nationwide – November 2019
- Team Sjögren's Philadelphia - September 15, 2019
- Phoenix Area Walk for Sjögren's and Health Fair, Phoenix, AZ – February 29, 2020
- Orlando Area Walk for Sjögren's, Orlando, FL – March 14, 2020 – Postponed

Virtual Events:

- DC Metro Area Virtual Walk for Sjögren's – May 16, 2020
- Denver Area Virtual Walk for Sjögren's – May 30, 2020
- Philadelphia Tri-State Area Virtual Walk for Sjögren's – June 13, 2020
- Texas Area Virtual Walk for Sjögren's – June 20, 2020
- National Patient Conference, Virtual – June 26–27, 2020

View the upcoming 2020 Sjögren's Foundation National Event Calendar on page 16.

Participate in one of the Virtual Fall Walk for Sjögren's events.

To learn more visit: events.sjogrens.org



continued page 14 ▼

Thank you for Supporting a 2019-2020 Walk for Sjögren's

We are truly grateful to ALL of our Walk for Sjögren's Sponsors! Thank you! These sponsors demonstrated a commitment to supporting local Sjögren's communities across the country, while also generously impacting the overall success of the Walks.

Below is a list of our Presenting and Major level Walk Sponsors:

New Hampshire Area Walk for Sjögren's and Health Fair

- FitWise Personal Training
- MAI Capital Management
- The Caron Family in Memory of Karen T. Caron

Los Angeles Area Walk for Sjögren's and Health Fair

- Eye Eco

Austin Area Walk for Sjögren's and Health Fair

- Baylor Scott & White Health
- In Balance Chiropractic and Acupuncture

Phoenix Area Walk for Sjögren's and Health Fair

- Doctor My Eyes
- Spinato's Pizzeria and Family Kitchen
- Mayo Clinic
- Gilbert Center for Family Medicine
- Primus Pharmaceuticals

Orlando Area Walk for Sjögren's

- Ledford Wealth Management Group
- BKHM CPA
- Fay Hu, DMD General Dentistry
- Central Florida Pulmonary Group, P. A.
- Orlando Eye Institute & Parbhu Oculofacial Plastic Surgery
- Pillar To Post, The Jeff Mackey Team

DC Metro Area Virtual Walk for Sjögren's

- Arthritis and Rheumatism Associates, P.C.
- Ben and Jerry's Rockville and owners – Marc & Bonnie Sosin

Denver Area Virtual Walk for Sjögren's

- Colorado Eye Consultants
- Colorado Center for Arthritis and Osteoporosis
- Jim and Joan Walsh Foundation
- Anne & Ken Economou

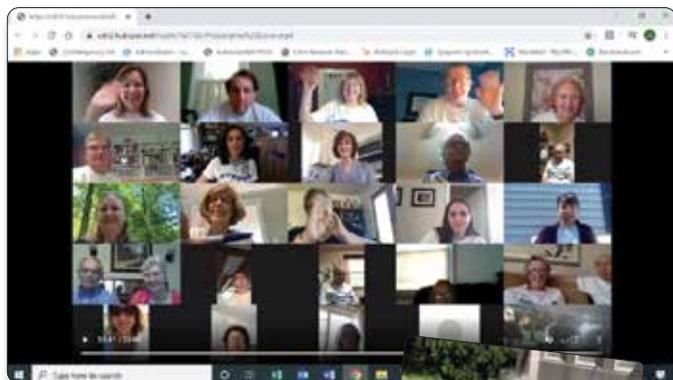
Philadelphia Tri-State Area Virtual Walk for Sjögren's

- The latesta Family

- Leventhal Sutton and Gornstein
- FemmePharma
- The Metal Prep Company, Inc.
- St. Luke United Methodist Church
- Bassett Home Furnishings
- Penn Medicine
- Scheie Eye Institute
- Penn Dry Eye and Ocular Surface Center
- Penn Medicine Valley Forge
- Penn Sjögren's Center and Division of Rheumatology
- The Vivino Family

Texas Virtual Walk for Sjögren's

- The Bromberg Family
- The Rubenstein Family
- Stacie and James Thomas
- Fagadau, Hawk and Swanson, MD (Eye Physicians & Surgeons)





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Remembering Jean Sawyer Kahan

former President of the Sjögren's Foundation

The Foundation is saddened by the passing of Jean Sawyer Kahan, the first President of the Sjögren's Foundation, following founder Elaine K. Harris.

Kahan was an unwavering advocate for patients. Under her leadership, the Sjögren's Foundation Patient Advisory Group to the Board was created to ensure that the patient voice was always heard. Putting patients at the heart of the Foundation



Jean Sawyer Kahan

was a focus carried over from 1941-2020 Elaine Harris and remains a major part of today's mission under current President and CEO, Steven Taylor.

The Foundation remembers a true Sjögren's champion and sends our deepest condolences to her family, friends, and loved ones.



Sjögren's Foundation Virtual Event Calendar

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

October

Los Angeles Area Virtual Walk for Sjögren's
Saturday, October 3, 2020

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

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

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

events.sjogrens.org



Sjögren's Foundation In Action!

Supporting you through Covid-19: Sjögren's Town Hall Meetings

This spring marked unprecedented times for the world as we began to live with coronavirus/ Covid-19. We hope that you saw that the Foundation was here to support you and we will continue to work nonstop to provide the information and resources you need during this difficult time.

Throughout this crisis, the health and safety of our patients, their families and our volunteers continue to be our number one priority. From releasing numerous statements on Covid-19 and Sjögren's, to advocating for your rights during the Hydroxychloroquine/ Plaquenil (HCQ) shortage, we are here to help navigate this with you.

As all of our Foundation local and national events moved to virtual platforms, our goal was to continue to provide both credible information and a connection for patients. This is why in addition to already pre-schedule events, the Foundation developed 22 patient support town hall meetings via ZOOM that focused on connecting with you while helping you learn about techniques and resources to stay well during this time.

Topics of our Town Hall Meetings included:

- Coping with Stress & Anxiety
- Creative Ways to Stay Busy
- Mediation & Your Mindset
- Sjögren's Medical & Scientific Updates
- Exercise Tips for Staying Active at Home
- Spirituality & Stress Relief
- Telehealth 101
- Eating Well & Staying Well
- Sjögren's Product Showcase
- And more!

We want to thank our volunteer speakers and everyone who joined us live on these calls. If you missed one of our calls, you can listen to a free recording of all the completed town hall meetings on the Foundation's website www.sjogrens.org.

As we continue to effectively respond to Covid-19 and maneuver the world's new normal, we understand that things might look a little different for a while. We hope that our strong and continued response to the crisis has helped you while also highlighting our ongoing and unwavering dedication to supporting Sjögren's patients. ■

The Sjögren's Foundation Coronavirus/Covid-19 Resources

The Sjögren's Foundation, in concert with our medical advisors, is continuously monitoring the coronavirus/Covid-19 and what the Foundation should be doing. Our goal is to provide Sjögren's patients the support and guidance needed during this time.

We hope you will visit our website www.sjogrens.org to view all our Covid-19 resources, including a document of frequently asked questions and recommended precautions for patients.

Stay informed. Stay aware. Be your own best medical advocate.

4 issues for just
\$20
for Foundation
members!



To increase professional awareness about Sjögren's, the Foundation publishes the *Sjögren's Quarterly* – a professional resource geared toward medical and dental professionals, clinicians, researchers, and anyone interested in the latest in Sjögren's research findings and treatments.

Although the content is primarily written for a professional audience, *Sjögren's Quarterly* is not just for doctors and researchers. Patients may benefit from the information, too.

If you are interested in subscribing to *Sjögren's Quarterly*, we are offering a special introductory rate of just \$20 for Foundation members. Take charge of your healthcare by keeping on top of all the best medical information available.

Subscribe to *Sjögren's Quarterly* today, and you might just teach your doctor a thing or two about Sjögren's.

	Non-Member Price	Member Price	Qty	Amount
A one-year subscription to the <i>Sjögren's Quarterly</i>	\$50.00	\$20.00		
Total Amount				

Mail to: Sjögren's Foundation Inc., 10701 Parkridge Blvd., Suite 170, Reston, VA 20191
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James Goebel
- In Memory of Bonnie Buckallew**
Tedi Schilling
Georgia Weaver
- In Memory of Debbie Magill**
Barbara Wofford-Kanwat
- In Memory of Dennis Zuchowski**
Bob and Nancy Reid
- In Memory of Dorothy "Dot" Hoffman**
Lisa Stathopoulos
Ruth Ford
Kristin Essay
Charlotte Hoffman
- In Memory of Jamnu Khemani**
Thibault Gournay
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Elizabeth Carter

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Ceil Keim
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Mariann Vandenberg
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Mary Manki
Suzanne Haima
- In Memory of Pamela Morin**
Heather Morin
- In Memory of Phyllis Keesey**
Robert Wright
- In Memory of Steven Taylor's Grandfather Edgar Terry, Sr.**
Ken and Anne Economou

IN HONOR

- In Honor of Alexis Harley**
Dana McCreary
- In Honor of Bobbie Bajda**
Bruce Kravitz
Alan Kravitz
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Mark Earley
- In Honor of Kellee Studdard**
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Judy Pearl
- In Honor of Monica**
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Conquering Sjögren's

Sjögren's Foundation Inc.
10701 Parkridge Blvd., Suite 170
Reston, VA 20191
Phone: (301) 530-4420
Fax: (301) 530-4415

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

Become a Sjögren's Foundation Awareness Ambassador

The Sjögren's Foundation is looking for volunteers to help us raise awareness among the healthcare providers in their community.

Awareness Ambassadors are on the front lines, helping the Foundation achieve their Mission and Vision of providing credible resources and conquering the complexities of Sjögren's through awareness. They do this by implementing the Foundation's campaigns, targeted at educating healthcare professionals in their area about the various manifestations of the disease. Together, these Awareness Ambassadors have reached thousands of healthcare professionals throughout the country, making a tremendous impact on the landscape of Sjögren's in the medical community.

If you are interested in joining the Foundation as an Awareness Ambassador visit our website www.sjogrens.org choose the "Get Involved" tab and click "Volunteer" to find out more details and sign up. Or you can email Michele Champigny at mchampigny@sjogrens.org.

The Foundation's vision is:

"To create a community where patients, healthcare professionals and researchers come together to conquer the complexities of Sjögren's."

