

Updates Slated for ICD-10 Code for Sjögren's!

It is with great excitement to announce that the Sjögren's Foundation (SF), in partnership with the American College of Rheumatology (ACR), has led a successful effort to revise the U.S. ICD-10 code for Sjögren's – a major victory for the Sjögren's community. These changes are expected to be folded into the ICD-11 code for international use.

This initiative, which began in 2017, was undertaken with the recognition that the existing ICD-10 (International Statistical Classification of Diseases and Related Health Problems, 10th revision) code for Sjögren's (M35.0, Sicca syndrome [Sjögren]) does not represent the disease and contributes to misinformation and confusion. Changes to the code, which are mentioned in detail later in this article, will benefit providers, investigators, researchers, insurers, and, of course, patients, and address key complications of Sjögren's that were not included in the current code.

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Sjögren's and Thyroid Disease

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Sjögren's is a chronic autoimmune disease which may predispose an individual to other autoimmune diseases. One of the most common autoimmune diseases is thyroid disease. It is not surprising therefore, that for many years, Sjögren's has been associated with thyroid disease. There have been various studies over the years investigating this association but a recent combined assessment of previous studies not only confirmed the association of Sjögren's with autoimmune thyroid disease but also showed an association with non-autoimmune thyroid disease, including thyroid nodules and thyroid cancer. The reason for the non-autoimmune thyroid disease association in Sjögren's is not completely understood, but it could be due to similarities in the tissues that are affected by Sjögren's (salivary and lacrimal

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glands), and the thyroid gland. This combined study demonstrated that the risk for thyroid disease in patients with Sjögren’s was significantly higher than in those who do not suffer from Sjögren’s, up to four times higher.

To understand disorders that affect thyroid function it is important to have a basic understanding of the physiologic mechanisms that are used by the body to produce thyroid hormone. The hypothalamus is a small but important part of the brain that is responsible, among other things, for temperature and hormone regulation. The hypothalamus works in conjunction with the pituitary gland, located at the lower part of the brain, to communicate with many other glands/organs in the body to carry out various functions. Some, but not all, of the pituitary’s functions include communicating with the thyroid gland, adrenal glands, ovaries, testes, and even the kidneys to balance and maintain the level of hormones produced by the various glands with which it communicates.

When the hypothalamus senses that more thyroid hormone is needed, it signals the pituitary gland to produce thyroid-stimulating hormone (TSH). TSH is a hormone that travels through the bloodstream to the thyroid gland and has been aptly named for its function is to stimulate thyroid hormone production in the thyroid gland. The production of thyroid hormone is controlled very closely through a negative feedback loop (kind of like a thermostat) of thyroid hormone. When the thyroid hormone level begins to drop it is sensed by the hypothalamus which stimulates the pituitary to produce TSH which, in turn, stimulates the thyroid gland to produce more thyroid hormone. In times of excess thyroid hormone, the stimulation from the hypothalamus to the pituitary and subsequently to the thyroid gland is suppressed. Therefore, when an individual has a disease state that causes low thyroid hormone production from the thyroid gland (such as autoimmune destruction of the thyroid gland as seen in Hashimoto’s thyroiditis) the pattern that one would see on thyroid testing would be a low thyroid hormone level with an elevated TSH. This pattern indicates that the pituitary is trying to produce more thyroid hormone, but the thyroid is not capable of producing enough for the body’s needs.

Hypothyroidism is defined as having a below normal thyroid level in the body and, as was mentioned above, the most common cause of hypothyroidism in the United States is chronic autoimmune thyroiditis (Hashimoto’s thyroiditis). According to a United

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States National Health and Nutrition Examination Survey, overt hypothyroidism was present in 0.3% of individuals and 4.3% had a milder form of hypothyroidism called subclinical hypothyroidism. Thyroid hormone influences almost every tissue in the body. It is critical to have a normal thyroid level for your body to function properly.

Due to the broad effects of thyroid hormone in the body the signs and symptoms of hypothyroidism are subtle and varied. Some of these symptoms include: dry skin, cold sensitivity, fatigue, muscle cramps, voice change, constipation, or heavier than usual menstrual periods. Unfortunately, these symptoms are notoriously nonspecific, meaning that they are not only seen in hypothyroidism, but can be seen for many other reasons and in many other diseases. This is particularly true with autoimmune diseases such as Sjögren's because many of the symptoms seen in autoimmune diseases overlap with the symptoms of hypothyroidism.

Hypothyroidism can be divided into two distinct forms: Subclinical and overt hypothyroidism.

The first and earlier form of hypothyroidism is called subclinical hypothyroidism because it is generally asymptomatic. It is characterized by a normal thyroid hormone level but with an increase of thyroid stimulation by the pituitary gland (elevated TSH). This elevated TSH with normal thyroid hormone indicates that the pituitary is having to stimulate the thyroid gland more than usual but that the thyroid hormone level is being maintained by the increased thyroid stimulation. At this stage, thyroid function can return to normal by itself. Those with subclinical hypothyroidism or Hashimoto's disease are at higher risk of developing overt hypothyroidism over time. Therefore, when an individual is found to have subclinical hypothyroidism or have antibodies consistent with Hashimoto's disease, they should be monitored periodically with repeat thyroid testing (every 12 months, sooner if significant symptoms appear) to assure that overt hypothyroidism has not developed.

The second form is overt hypothyroidism, which is characterized by a truly low level of thyroid hormone in the body along with an attempted increase of thyroid stimulation to make up for the low hormone by the pituitary gland (elevated

TSH). At this point, enough thyroid tissue has been destroyed to make the damage permanent. The treatment of overt hypothyroidism is thyroid hormone replacement.

The diagnosis of autoimmune thyroid disease is established through testing for certain antibodies against specific thyroid tissue or enzyme markers. As is true of many autoimmune diseases, having the antibodies alone does not always lead to overt symptoms, but we know that those individuals who develop antibodies to the thyroid gland are at higher risk for developing frank hyperthyroidism or hypothyroidism over time. The most common form of autoimmune thyroid disease is chronic autoimmune thyroiditis or Hashimoto's disease. Individuals that have Hashimoto's disease can experience transient levels of hyperthyroidism as they develop inflammation of the thyroid gland and thyroid destruction releases excess thyroid hormone into the body. Over time though, the natural progression of Hashimoto's disease generally

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‡In people with dry mouth who use 2 discs while sleeping and 4 more during the day.

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Rationale for this Initiative

The current code uses “Sicca syndrome” and “Sjögren’s” synonymously. While at one point this may have been a prevailing thought, we know that using these terms interchangeably is inaccurate for a variety of reasons.

Sicca is a symptom and not a disease, while Sjögren’s is a distinct systemic autoimmune, rheumatic disease that can affect multiple organs and body systems. Dryness certainly occurs in Sjögren’s, but dryness alone does not represent the disease and the many other symptoms involved. Furthermore, sicca includes many non-Sjögren’s patients who may have dryness symptoms for numerous reasons, including radiation for head and neck cancers, graft-versus-host disease and as a side effect of certain medications.

Further justification can be found when looking at classification criteria. Sjögren’s classification criteria has never used either “sicca” nor “sicca syndrome,” and no criteria exist for “sicca syndrome.” Using the 2002 American European Consensus Criteria (AECC) and the 2016 ACR-EULAR criteria as examples, we can see that these criteria rely primarily on serology and biopsy, and in no way indicate that Sjögren’s be defined by sicca.

The current ICD-10 code creates confusion, contributes to misinformation and is potentially detrimental to patients, whose diagnosis carries an incorrect label, which can influence subsequent difficulty with insurance reimbursement, clinicians, who may be unsure of how to best code the disease, study investigators and researchers, who may have trouble accurately identifying Sjögren’s patients for clinical trials and data acquisition, and insurers, who grapple with inaccuracy, which can influence reimbursement to both patients and providers.

What’s Changing?

The following changes are slated to take effect in October 2020:

TABULAR MODIFICATIONS

M35 Other systemic involvement of connective tissue

Revise	M35.0	Sicca syndrome [Sjögren] <u>Sjögren syndrome</u>
Add		Sicca syndrome
Add		Excludes1: Dry mouth, unspecified (R68.2)
Revise	M35.00	Sicca <u>Sjögren</u> syndrome, unspecified
Revise	M35.01	Sicca <u>Sjögren</u> syndrome with keratoconjunctivitis
Revise	M35.02	Sicca <u>Sjögren</u> syndrome with lung involvement
Revise	M35.03	Sicca <u>Sjögren</u> syndrome with myopathy
Revise	M35.04	Sicca <u>Sjögren</u> syndrome with tubulo-interstitial nephropathy
New code	M35.05	<u>Sjögren</u> syndrome with inflammatory arthritis
New code	M35.06	<u>Sjögren</u> syndrome with peripheral nervous system involvement
New code	M35.07	<u>Sjögren</u> syndrome with central nervous system involvement
New code	M35.08	<u>Sjögren</u> syndrome with gastrointestinal involvement
New code	M35.0A	<u>Sjögren</u> syndrome with glomerular disease
New code	M35.0B	<u>Sjögren</u> syndrome with vasculitis
New code	M35.0C	<u>Sjögren</u> syndrome with dental involvement
Revise	M35.09	Sicca <u>Sjögren</u> syndrome with other organ involvement

It is important to note that patients with symptoms of dryness who cannot definitively be linked to Sjögren’s, can still be designated under the Symptoms section of the ICD code.

The Process

From the onset, those involved knew this would be no small task. However, the importance of this initiative helped motivate a team of multi-disciplinary experts, represented by a non-profit, professional society, academia, industry, rheumatology, pediatric rheumatology, primary care, neurology, gastroenterology, pulmonology, nephrology, oncol-

ogy, ophthalmology and oral medicine, to convene and collaborate on the best course forward.

After a series of meetings and discussions, a proposal was submitted to the ICD-10 Coordination and Maintenance Committee (C&M), a federal interdepartmental committee comprised of representatives from the Centers for Medicare and Medicaid Services (CMS) and the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS), with suggestions for modifications to the code for Sjögren's.

Excitingly, the proposal was accepted for presentation at the Fall C&M meeting taking place near Baltimore, MD, in September 2018. Here, Dr. Alan Baer represented the SF, ACR and the multi-disciplinary team who informed the proposal by expertly explaining the rationale for why changes to the Sjögren's code are needed. Dr. Baer's presentation was followed by a presentation by a CDC representative detailing the specific tabular changes that were being requested.

A period for public comment took place in the subsequent months after the meeting, during which few questions were raised. However, as the group learned, because questions had been raised, the proposed changes would need to be revised to address the questions and the proposal presented at the Spring C&M meeting in March 2019.

This time, only a CDC representative was needed for the presentation of the proposal, and Kathy Hammitt, Vice President of Medical and Scientific Affairs, was on hand to provide perspective on the few questions that were raised. An additional public comment period was then held but resulted in no major issues being put forth.

A Team Effort

This effort was no-doubt strengthened by the multidisciplinary team who provided their time and expertise in guiding this project. The Sjögren's Foundation is sincerely grateful to the advisory team, who provided integral help throughout the entire process, and would like to recognize and thank the following individuals:

Alan N. Baer, MD: Director, Jerome Greene Sjögren's Syndrome Clinic & Professor of Medicine, Johns Hopkins University School of Medicine (Rheumatology)

Theresa Lawrence Ford, MD: CEO & Medical Director, North Georgia Rheumatology Group (Rheumatology)

Frederick Vivino, MD: Director, Sjögren's Syndrome Center, Perelman School of Medicine at the University of Pennsylvania (Rheumatology)

Nancy Carteron, MD: University of California San Francisco (Rheumatology)

Scott Lieberman, MD: University of Iowa (Pediatric Rheumatology)

Judith Furlong, MD: ProMedica Physicians Family Medicine (Primary Care)

Julius Birnbaum, MD: Co-director, Jerome Greene Sjögren's Syndrome Clinic, Johns Hopkins University School of Medicine (Neurology)

Augustine Lee, MD: Mayo Clinic, Jacksonville, FL (Pulmonology)

Marie Hogan, MD: Mayo Clinic, Rochester, MN (Nephrology)

Lance Forstot, MD: Corneal Consultants of Colorado (Ophthalmology)

Vidya Sankar, DMD: Brigham and Women's Hospital (Oral Medicine)

Richard Ambinder, MD, PhD: Johns Hopkins University School of Medicine (Oncology)

Katerina Shetler, MD: Palo Alto Medical Foundation (Gastroenterology)

Jo Annah Jensen: Novartis (Industry)

Steven Taylor: Sjögren's Syndrome Foundation

Kathy Hammitt: Sjögren's Syndrome Foundation

Antanya Chung: American College of Rheumatology

A special thank you to Alan Baer, MD, for presenting, in-person, at CMS headquarters during the ICD-10 Coordination and Maintenance Committee meeting in September 2018. Dr. Baer's presence and presentation very eloquently made a case for the proposed changes and helped set us apart by being one of the only presenters outside of CMS and CDC staff during the event.

The SF would also like to recognize Antanya Chung and the American College of Rheumatology for their support and collaboration on this important initiative. ■

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leads to enough destruction of the thyroid gland and decreased function that individuals eventually develop hypothyroidism (low thyroid hormone levels). This is the most common form of thyroid disease seen in those who suffer with Sjögren’s.

Thyroid nodules are extremely common, but even more so in people with Sjögren’s. Thyroid nodules are almost always benign, but can be big enough to cause symptoms. A small number of nodules can be malignant, and, although thyroid cancer is usually nonaggressive and slow growing, problems can occur due to its location in the neck close to arteries, nerves and the windpipe. It is important to check for thyroid nodules if there are any neck masses felt in the neck, any voice changes or any change in swallowing. Evaluation is usually done with a thyroid ultrasound, which is safe and painless. Suspicious nodules may need a biopsy.

Disorders associated with hypothyroidism?

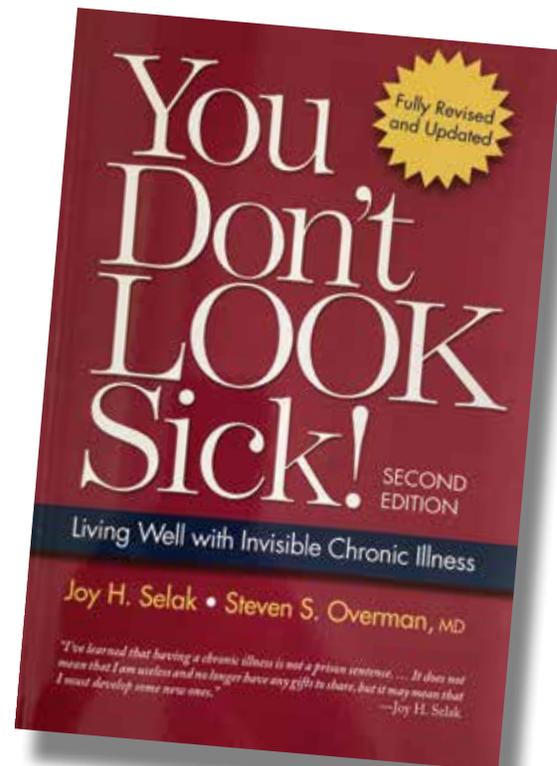
There are many disorders that have been associated with the development of hypothyroidism and many of these are other autoimmune disorders such as Sjögren’s, type 1 diabetes, pernicious anemia, adrenal insufficiency, myasthenia gravis, celiac disease, rheumatoid arthritis, and systemic lupus erythematosus.

In summary, Sjögren’s has been associated with many forms of thyroid disease. The most common manifestation is chronic autoimmune thyroiditis or Hashimoto’s disease which can lead to hypothyroidism. Various studies have shown a risk of some form of thyroid disease of up to 70% in people with Sjögren’s. Therefore, measuring thyroid levels is recommended at diagnosis, and then periodically thereafter. Any new neck masses or any change in voice or swallowing may indicate thyroid nodules and may need evaluation.

There is no cure for autoimmune thyroid disease, but it can be easily diagnosed. Once identified, surveillance is important so that proper therapy can be initiated if needed, which will result in an improvement in overall health and quality of life. ■

You Don’t Look Sick Second Edition

by Joy H. Selak & Steven S. Overman MD

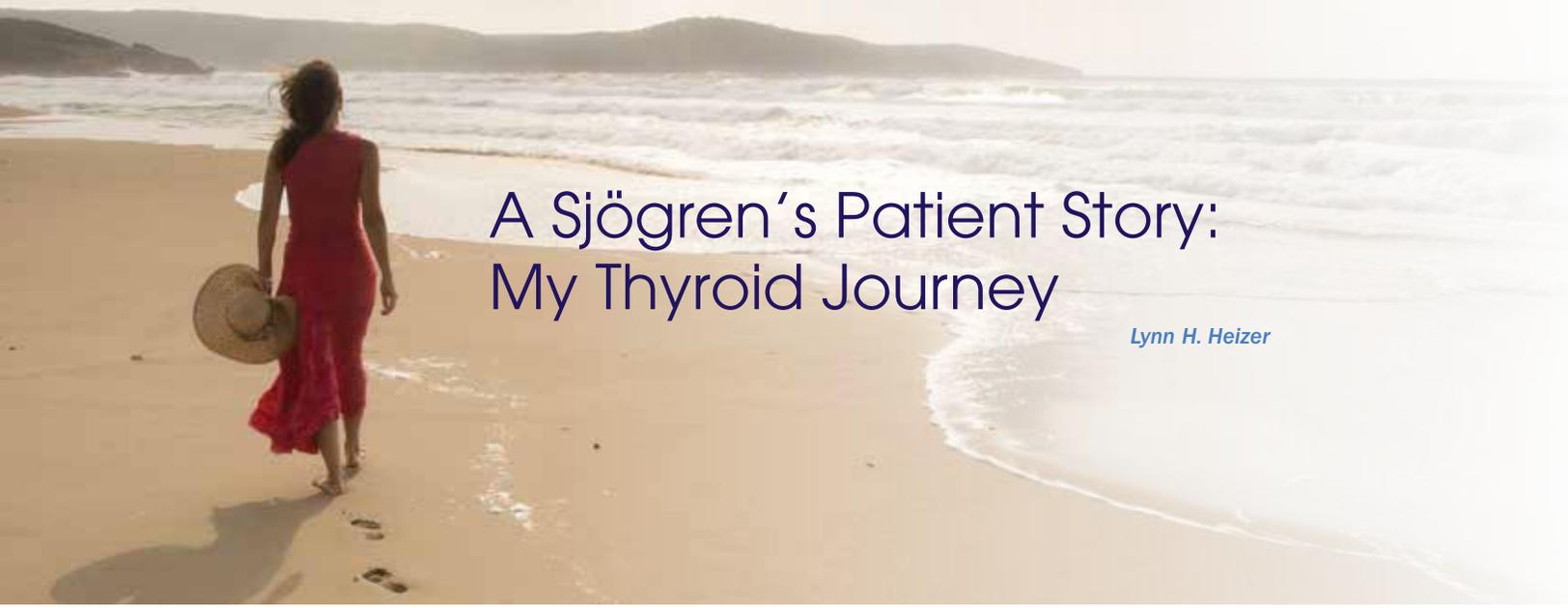


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This book is designed for people at all stages of the chronic illness journey and is also illuminating for caregivers and loved ones. The book may be purchased online at: www.sjogrens.org/ssfstore or by contacting the Sjögren’s Syndrome Foundation office at (800) 475-6473.



A Sjögren's Patient Story: My Thyroid Journey

Lynn H. Heizer

When were you diagnosed with Sjögren's?

I was 48 years old when I was diagnosed with Sjögren's. I had been struggling with joint pain (hips, shoulders, elbows, knees, neck) for 4-5 years. I was playing competitive tennis and just thought my pain was a result of getting older and playing an aggressive sport. Physical therapy and cortisone shots were common for me. In the Fall of 2009, I experienced some very stressful events in my life over a three-month period that led to quite a bit of travel. During that time my eyes had become so dry they literally started bleeding. I wear contacts (when I can), and at the time I had bloody red circles around both irises. I made an appointment with an ophthalmologist. He took one look at my eyes and said, "So, tell me, how have you been feeling lately, any other issues?" Of course I mentioned, my joint pain, and said that I was tired from lots of travel. His reply was astounding, "You need to book an appointment with a rheumatologist, I'm pretty sure you have Sjögren's." Sure enough, within a week or two, the antibodies in my blood work confirmed this diagnosis. I found a wonderful rheumatologist and began Plaquinil (200 milligrams).

How did you notice your Sjögren's becoming more extreme and what steps did you take to try and get relief, especially for your extreme fatigue?

The year I was diagnosed, I broke my ankle playing tennis. I felt like my brain wanted me to move but I could not pick up my feet and make them move on the court anymore. I felt like I literally had concrete attached to my feet. My

competitive tennis came to an end. Over the course of the next three years after my diagnosis, I struggled more and more with my energy level, my muscles quivered, my joints hurt, and I had shooting pains in my feet and hands. I also began to have digestive issues that woke me up every night and I began to have difficulty swallowing. I had been diagnosed with Hashimoto's when I was 30, and of course my doctors were checking my TSH, which they always said, was "normal." So, we attributed my symptoms to Sjögren's, and my rheumatologist increased my Plaquinil gradually to 600 milligrams daily. I was now seeing an ophthalmologist 3 times a year to monitor my retina. Additionally, I was seeing gastrointestinal doctors for motility and gallbladder assessments for digestive pain, still seeing physical therapists, and now getting myofascial treatments 3 times a week for connective tissue pain management.

Year 2 after my diagnosis, we decided that we had to sell our home of 18 years, as I could not climb the stairs anymore. I slept deeply each night, but never had the kind of restorative sleep that made you feel rested the next day. I felt like I had the flu all of the time, often feeling in the mornings that my arms and legs had been strapped to the bed with weights overnight. I remember reading *The Moisture Seekers* newsletter article called: "11 Types of Sjögren's Fatigue." I had them all! Many doctors said I was just getting older, but to me it seemed my Sjögren's had advanced very quickly. I dropped out of most activities and carefully selected one or two things each day that were most important to accomplish.

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Year 4 after my diagnosis, I was 52 and going through menopause, my annual TSH test for thyroid came back abnormal. It was very high, and my doctors recommended I see an endocrinologist for a full work up. I did, and was told that I needed to increase my Synthroid (T4), and that I should be fine. Apparently, the other numbers in my thyroid panel were fine. (I never saw the results). Over the next year or so I began to feel a bit better, but was only about 65% of normal. I still felt like I had the flu all of the time.

Years 5 and 6 after my diagnosis, I was still having fatigue, joint pain, swallowing problems, digestive issues, brain fog, infections, and I began passing out on overnight flights. This last part was very scary, and I began a full round of pulmonary testing. We couldn't find any answers, and all of my doctors assumed that since my TSH was now “normal” or even on the low side that my issues must be Sjögren's related. My blood pressure was always low (97/52) which worried me, but doctors and nurses always complemented me on my good heart health and said I must exercise a lot. I would always mention that I rarely exercised. My rheumatologist encouraged me to go on stronger immune suppressants, but I was afraid of suppressing my immune system even further. I had been seeing my General Practitioner (GP) and Urologist regularly for frequent infections. As a result of so many infections, I became allergic to two common antibiotics, and at this point I was using inhalers regularly.

I grieved deeply over the loss of the life I previously had. I had to accept this lifelong diagnosis, but I still felt there must be something I could do to find relief. Thanks to *The Moisture Seekers*, I began reading numerous books on immune system support which gave me concrete things to slowly address. I removed all of my silver fillings (I had many) to eliminate mercury in my body. I began restorative yoga twice per week. I slept 10 hours a day, but still felt like I had the flu all of the time. My vitamin D was very low, so I began supplementing. I read that probiotics and magnesium could help with my digestive issues; so, I religiously began taking these daily supplements.

My ophthalmologist recommended daily Restasis drops and Krill Oil supplements, saying that there was research showing that Krill Oil was the best of the omega-3s for the eyes. I saw the benefit of each change in my lifestyle, but I still felt worn out all of the time. I never felt rested and re-stored, just exhausted.

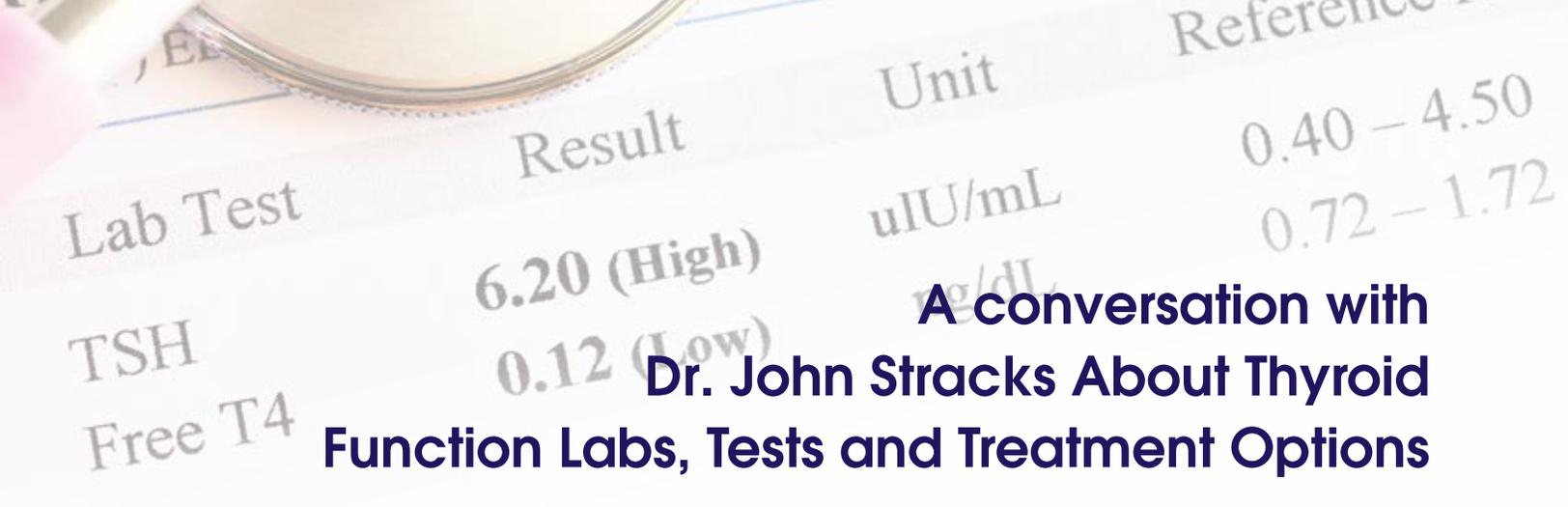
How did you find out about checking your Free T3 levels and what was explained in that process?

Year 7 after my diagnosis, and endless doctor's appointments and advanced tests, I had to switch to a new General Practitioner (GP), because my GP moved out of state. I shared my labs, test results, and my Sjögren's journey on my first appointment with my new doctor who listened carefully and then wanted to do a couple of blood tests. One of those tests was my TSH, but she also included my Total T3 and Free T3. This was the first I had heard of these other two thyroid tests. When I met with her again, she said that both my Total T3 and Free T3 were on the low side of normal and that she has learned in her practice that most people (especially women) feel best if their Free T3 is in the UPPER 25% of the normal range. I have since learned that the “normal range” for Free T3 has changed over the years. It used to be (2.1 -4.4 pg/ml) and now the normal range is (2.5-4.5 pg/ml). She said that my TSH was slightly below normal so she did not want to increase my Synthroid (T4). She just wanted to give me T3. This was in the form of an inexpensive pill called Cytomel. It has a short active life span which is why you need it daily. Within 5 days I started feeling much better, and over the course of the next month I couldn't believe the change in my energy level as I now had energy to get thru the day. I felt rested for the first time in 7 years!

What were your first steps in starting treatment?

Within days I was feeling more energetic. I woke up in the mornings feeling rested and re-stored. I began being more active and engaging in life again. I still had to monitor my activity, espe-

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A conversation with Dr. John Stracks About Thyroid Function Labs, Tests and Treatment Options

What labs are drawn to test thyroid levels and what are you looking for?

I find that a TSH, free T4, free T3, total T4, total T3, reverse T3, TPO antibodies, and anti-thyroglobulin antibodies labs give the information needed. Each lab provides your doctor with a piece of information, between all these labs, your doctor will get a 360-degree picture of what's going on with your thyroid.

What are Free T-3 levels?

There are two thyroid hormones in the body, Thyroid 4 (T4) and Thyroid 3 (T3). T4 is a storage form of the hormone and T3 is the active form of the hormone. Everyone needs plenty of the active form to get the full benefit of thyroid hormone treatment, but not everyone is great, genetically speaking, at manufacturing T3. For patients with thyroid disease who aren't feeling well, a simple blood test can tell if low T3 levels are present and causing someone to not feel well.

What treatments are available for patients and when should they start to see results?

For patients with low T3 levels, the usual thyroid medication, levothyroxine, may not be a great option since it only contains T4. Instead, they may benefit from a combination of levothyroxine and liothyronine (T3). This often increases T3 levels and decreases symptoms. Natural Desiccated Thyroid (NDT) medication is also an option. This medication is made from the thyroid glands of pigs and has a fixed ratio of T4 and T3 and works quite well for a number of people.

What is Cytomel and are there any side effects I should be aware of?

Cytomel is a brand of liothyronine (T3) as mentioned above. Side effects include feeling

anxious, jittery, having a rapid heart rate, heart palpitations, sweating, or panic attacks. If these occur (which they do, but quite rarely), it's almost always a sign that the dose of medication is too high. For that reason, I start people off on low doses of the medication and increase very slowly over time, looking to minimize and/or eliminate any side effects.

How often do you check labs?

Remember the labs give some information, but you give your doctor more information. Thus, at your first follow-up appointment, be prepared to talk with your doctor and share how you are doing on the medication(s) that you are taking. This information will help your doctor make a decision about the best next course of action. From there, your doctor may adjust your medication and see how you do. While looking for the best dose of thyroid medication for you, your doctor may run labs every 3–6 months. Once you're on a stable dose of medication, your doctor may decide to order labs once per year.

Are there any additional complications I should be aware of when looking at thyroid treatments?

Studies show about 20% of the population has a genetic profile that makes it hard to turn T4 into T3. Using T3 medication gets around this genetic block, so it can be quite effective, is safe, and is evidence based. Anyone who is taking standard thyroid medication such as Synthroid, Levoxyl, Tirosint, or Levothyroxine, and isn't feeling great should investigate getting a full lab panel done and using a form of T3 based medication if they find that their T3 levels are low. ■

Dr. John Stracks is an Integrative Family Physician and an Assistant Clinical Professor of Family Medicine at Northwestern University

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cially since I felt like doing so much more. Unfortunately, I ran into a complication that required much determination and persistence. I mention it now, as I want others to have encouragement to continue looking for a solution even if they hit a snag. After 6 weeks on the Cytomel (10mcg), I began having daily headaches. I have always been prone to migraines, but the pain and nausea of daily headaches was something I could not tolerate. My new GP worked with me as we tried special compounding of the Cytomel in case I was allergic to some of the fillers etc., but nothing worked. I was particularly frustrated, as I realized I had to stop taking this medication which had given me my life back. I began reading furiously about T3 alternatives and was willing to try anything. I was thrilled to learn that there were alternative medications and I began searching for integrated medicine physicians in my area. I found that Northwestern University Hospital had an Integrated Medicine Practice and that there was a doctor on staff focusing on endocrinology.

When did you notice this treatment was working for you?

It took me a rather difficult year working closely with this new integrated physician to transfer over from the Synthroid (T4), that I had been taking for decades, to this new medication (a natural medication, T4 and T3 together, made from desiccated pig thyroid, called Nature Throid). Every couple of months my blood was tested; and slowly, I began to feel better and better - the extreme fatigue was gone and no headaches! I have now been on this medication 100% for over 2 years and my joint pain, muscle pain, and shooting pains in my feet and hands have abated. The dryness and difficulty swallowing is much more manageable, and amazingly, the nightly burning and bloating in my stomach has completely disappeared. Additionally, my blood pressure has risen to a normal 114/70 and I am no longer passing out on flights. I love the fact that I am able to exercise again which is impossible to do when you feel like you have the flu. My heart, lungs, muscles and bones are all getting stronger each day

not weaker as they had been doing for the past 7 years. Amazingly, I was slowly able to back off my high dosage of Plaquinil and have now been 100% off of it for 9 months with no increase in symptoms. I also no longer need an inhaler and I have not had an infection for 2 years!

What advice would you have for other patients looking for answers for their extreme fatigue and considering this as an option?

It is scary when you feel that your life has suddenly stopped and each day feels like you have to physically climb a mountain just to get through the day. To your family, friends, and doctors you look healthy, but you know something is wrong. There are many causes of this type of fatigue, but I have learned that a simple series of tests (TSH, TT4, Free T4, TT3, Free T3, Reverse T3 and 2 antibodies tests) can possibly provide a clue. Ask to see all of your tests results, and if you find that your Free T3 is not in the upper 25% of the normal range, then I encourage you to discuss this as a possible cause of fatigue with your doctor. I have learned that the normal ranges are simply guidelines and actually keep changing. Just because your test results fall in the “normal” range does not mean they are OPTIMAL for you. I encourage you and all of the doctors you work with to strive to find your OPTIMAL levels.

Is there any additional information you'd like to share?

As with any medication, there are possible side effects of Cytomel that you will need to monitor carefully, namely that it can cause atrial fibrillation and a racing heart (especially if you drink caffeine), so you need to work carefully with your doctor. Additionally, there is quite a bit of controversy surrounding the treatment of the thyroid. (*Noted below). Nonetheless, I encourage all patients suffering from the debilitating aspects of fatigue to find a doctor that is open to this option, one who is willing to listen to symptoms and study ALL test and lab results to work together to see if the addition of a small amount of T3 might help alleviate fatigue. It won't be right for everyone, that is for sure, but if this turns out to be an

SSF in Action!

SSF's Makara Presents at NIAMS Outreach and Education Day



On October 16, 2019, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Coalition held their biennial Outreach and Education Day in Bethesda, MD. This full-day event serves as a forum for coalition members to connect and share best practices on the importance of connecting science to the public while gaining a better understanding of how NIAMS and the National Institutes of Health (NIH) function. This event also provides attendees with the opportunity to hear about the latest research advances and related developments from NIAMS staff and is a chance to foster dialogue on the future path and directions of NIAMS-funded research.

As part of the event, the SSF's Matt Makara, MPH, who serves as the foundation's director of research and scientific affairs, presented during one of the afternoon sessions, "Clinical Trials: How to Educate Patients and Providers," as well as a poster session in which he shared information on some of the initiatives that are currently in the works related to clinical trials, biomarkers and education.

The panel presentation featured three speakers

providing different perspectives on best practices related to clinical trial education and awareness. First, Anna Fine, PharmD, discussed clinical trials from the NIH perspective and spoke on the redesign of clinical trials. gov and how best to use this resource. Next, Makara provided insight into the SSF's Clinical Trials Consortium and one of the initiatives that's been led by this group, the Sjögren's Training and Education Platform (STEP). These two topics were chosen with the thought that the processes, barriers

and successes of these initiatives could help other, similar, organizations replicate these efforts to advance clinical trials in their given fields. The final speaker of the session was Jennifer Gordon, PhD, who was attending as a representative of the Vasculitis Foundation, provided a patient's perspective on being involved with a clinical trial. Dr. Gordon provided details of her journey to diagnosis and her experience being involved with a large trial within her disease area.

Following the panel sessions and presentations, attendees were invited to the poster room, where around a dozen organizations, including the SSF,



**National Institute of
Arthritis and Musculoskeletal
and Skin Diseases**

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases.

“Journey” continued from page 10 ▼

answer for you, a whole host of painful symptoms, doctor’s appointments, and expensive tests just might decrease or even disappear.

And, finally, never give up. Try to be your healthiest each day. Continue to educate yourself and learn about your body, be protective of your rest, pace yourself, and be your own best advocate. ■

** Integrative physicians also believe that the true measure of a person’s thyroid health is the number of active hormones circulating in the blood (free T4 and free T3) and not TSH. They argue that TSH is an inexact value given that it can lie within the normal range with Hashimoto’s disease and that free T3*

offers a “real-time” snapshot of thyroid function. For these practitioners, a low free T3 is considered justification for thyroid hormone replacement therapy.

By contrast, many conventional doctors will not test T3 given that there is no direct association between T3 levels and the risk of overt hypothyroidism. Moreover, the T3 replacement drug Cytomel (liothyronine) is not even endorsed for the treatment of hypothyroidism due to the risk of reactive hyperthyroidism, minimizing the value of T3 in directing thyroid treatment.

Shomon, M. (2019) Understanding Your Thyroid Blood Test Results Retrieved from: <https://www.verywellhealth.com/interpret-your-thyroid-test-results-3231840#controversies>

Smart Patients

Sjögren’s Community
in partnership with the
Sjögren’s Syndrome
Foundation

We’re having honest conversations
about Sjögren’s and our health. Join
SSF members in our online community:
smartpatients.com/ssf





You Stood Up!

Attention AMAZON Shoppers

amazon.com[®]

Did you know that when you shop on Amazon you can choose to have a percentage of your purchase donated to the Sjögren's Syndrome Foundation?

Alan does! Every time he shops on Amazon, he chooses to donate to the Sjögren's Syndrome Foundation. Alan is a frequent Amazon shopper purchasing items for his office as well as home.

Over the past several years the SSF has received \$16,730.55 simply because smile.amazon shoppers chose to create an account to support the SSF when they shop using smile.amazon.com!

This is a simple way that you and your friends and family can help to support the SSF!

All you need to do is sign-up and visit smile.amazon on computer and/or downloaded the smile.amazon app on your phone. If you already have an account, open your Account & Lists page and select Your AmazonSmile it is easy to

do! Once you set up your account and select the Sjögren's Syndrome Foundation as the charitable organization that you would like to support you will be giving .05% of every purchase to the SSF.

The prices are the same and there is no additional charge for any of the items purchased using the link. And you even can use this as an Amazon Prime member!

The SSF thanks Alan for standing up and making a difference as well as everyone who has selected to support the Sjögren's Syndrome Foundation as their charity of choice on AmazonSmile!

Here is how you can set up your dashboard and do the same!

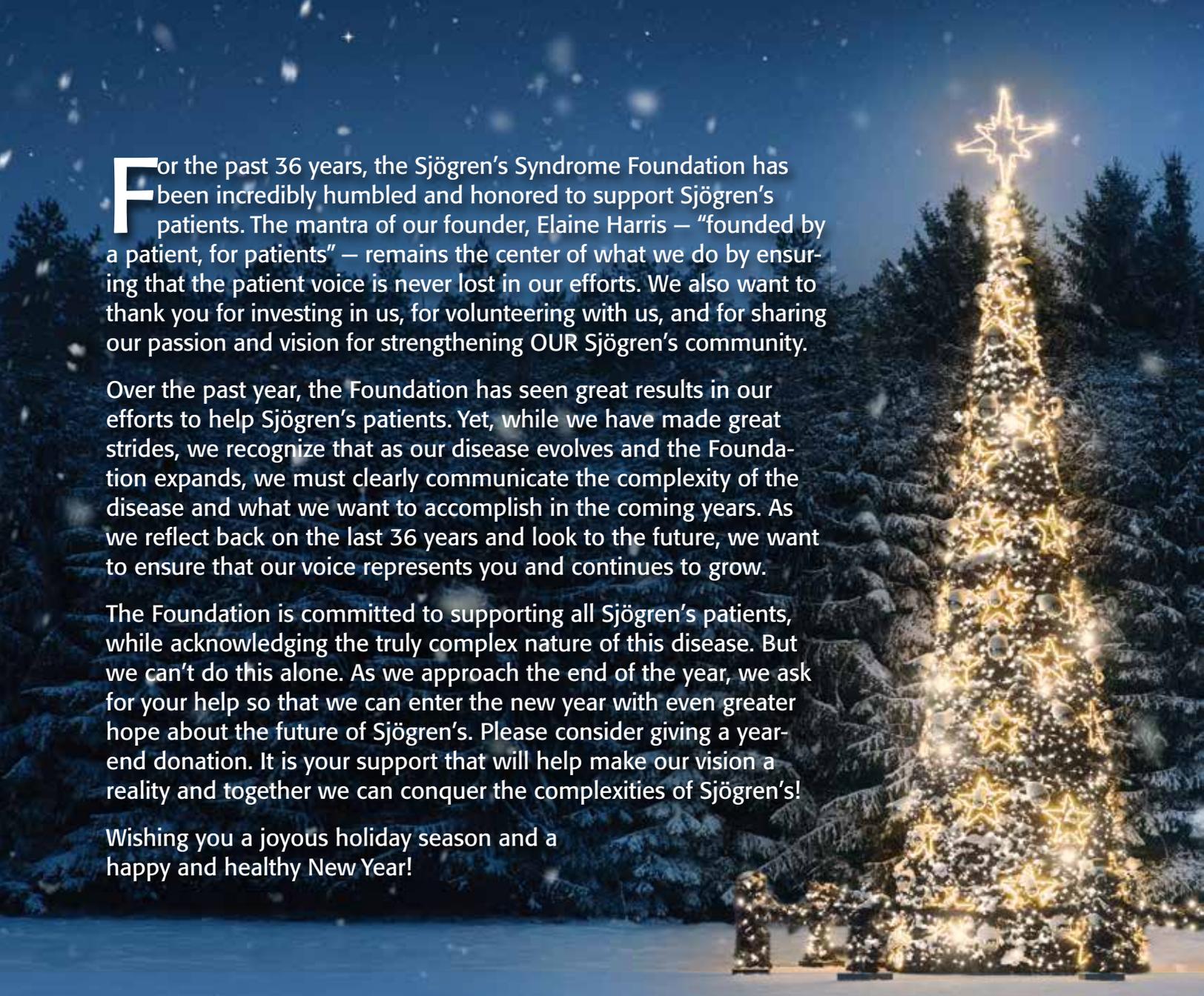
To shop at AmazonSmile simply go to smile.amazon.com from the web browser on your computer or mobile device. You may also want to add a bookmark to smile.amazon.com so you can just click and easily access your shopping page. ■

2020 is a Year of Change at the Sjögren's Foundation

We are excited and can't wait for you to see our new look coming soon!

Watch your mailbox this January for your issue of the new Sjögren's Foundation Member Publication!

Highlights include a new look, new name with additional content spread among 6 expanded issues.



For the past 36 years, the Sjögren's Syndrome Foundation has been incredibly humbled and honored to support Sjögren's patients. The mantra of our founder, Elaine Harris – "founded by a patient, for patients" – remains the center of what we do by ensuring that the patient voice is never lost in our efforts. We also want to thank you for investing in us, for volunteering with us, and for sharing our passion and vision for strengthening OUR Sjögren's community.

Over the past year, the Foundation has seen great results in our efforts to help Sjögren's patients. Yet, while we have made great strides, we recognize that as our disease evolves and the Foundation expands, we must clearly communicate the complexity of the disease and what we want to accomplish in the coming years. As we reflect back on the last 36 years and look to the future, we want to ensure that our voice represents you and continues to grow.

The Foundation is committed to supporting all Sjögren's patients, while acknowledging the truly complex nature of this disease. But we can't do this alone. As we approach the end of the year, we ask for your help so that we can enter the new year with even greater hope about the future of Sjögren's. Please consider giving a year-end donation. It is your support that will help make our vision a reality and together we can conquer the complexities of Sjögren's!

Wishing you a joyous holiday season and a happy and healthy New Year!

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

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

Mail to SSF, BB&T Bank · PO Box 890612 · Charlotte, NC 28289-0612 or Fax to: 301-530-4415

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____ E-mail _____

Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) **payable to SSF.**

MasterCard VISA Discover AmEx Card Number _____ Exp. Date _____

Signature _____ CC Security Code _____



How Your Support is Making a Difference!

2019 was an exciting year for the Sjögren's Syndrome Foundation (SSF)! Advancements in Sjögren's research and increased awareness for Sjögren's speak to the continuous efforts of the SSF's Board of Directors and staff as well as our Medical and Scientific Advisors and the hundreds of SSF volunteers throughout the country. But the greatest impact is being made by YOU! It is your generosity and continued support that have made our achievements over the past year possible. We are truly grateful for your part in our growth and success.

The SSF was excited to announce that we surpassed our *5-Year Breakthrough Goal*: To shorten the time to diagnose Sjögren's by 50% in 5 years and it now currently takes 2.8 years to receive a proper diagnosis for Sjögren's. While this goal was surpassed and announced in 2018, this transformative achievement has meant an even greater need for the Foundation to increase its efforts and provide valuable patient support, increased awareness and education and guidance for healthcare professionals.

The following is a sampling of some of our work and achievements in 2019 and how your generous donations are making a difference in conquering the complexities of Sjögren's!

Serving as the Voice of All Sjögren's Patients

The SSF is proud that all of our programs and initiatives, are first and foremost developed with the Sjögren's patient in mind. Making sure the patient voice is included in such things as clinical trial design; international research collaborations as well as when we grace the halls of Congress, research institutions and top medical centers.

Getting Closer to Finding New Therapeutics for Sjögren's

The SSF has expanded our efforts and is working with 11 pharmaceutical companies looking to develop potential therapies for Sjögren's. The Clinical Trial Consortium, the SSF's international initiative to increase the availability and accessibility of therapies to treat Sjögren's, continues to evaluate key issues surrounding clinical trials while focusing on the development of better outcome measures in Sjögren's and the discovery of diagnostic and prognostic biomarkers. In addition, in 2019, the SSF designed and launched the first ever online Sjögren's Training and Education Platform (STEP) to be used to train clinical trial investigators.

Expanding the Clinical Practice Guidelines

Phase 2 of the SSF's Clinical Practice Guidelines are well underway. Included in Phase 2 are guidelines for pulmonary complications, central nervous system involvement, peripheral nervous system involvement, lymphoma and vasculitis. These guidelines will significantly increase the guidance offered on management and treatment of Sjögren's and expand the breadth and number of specialists involved who have not traditionally trained and/or involved with the treatment Sjögren's.

Impacting Sjögren's Research

As the premiere funding organization for Sjögren's research, we are extremely proud of the leadership role that we have taken to move Sjögren's research forward and are even more excited about what is yet to come. This past fall, the SSF announced a new funding opportunity for researchers, called the SSF High Impact Research

“SSF in Action” continued from page 11 ▼

had posters featured. Here, Makara spoke with attendees about different initiatives that are currently underway, including additional details on the STEP program and our efforts to educate members and physicians on both the availability and what it means to be involved in a clinical trial. The poster also included information on various initiatives, both domestic and international, related to efforts to identify new biomarkers for Sjögren’s.

Other topics covered throughout the day included overviews of the coalition, NIH and NIAMS, best practices for communicating fund-

ing opportunities, how to amplify the patient voice, integrative approaches to pain management, engaging with underserved and minority audiences and an update on the NIH All of Us initiative. Breakouts by disease group – including systemic rheumatic diseases and skin diseases, muscle and bone diseases and osteoarthritis and orthopedic diseases and disorders – led by NIAMS staff were also included.

The SSF is grateful for the opportunity to participate in this event and would like to thank all of the those from NIAMS and the coalition’s planning committee for their efforts in organizing the event. ■

“Support for the SSF” continued from page 15 ▼

Grant. This grant, is offered at \$75,000 and was awarded for the first time this past Spring. The Foundation also continues to awards SSF Pilot Research Award at \$25,000. In addition to our new 2019 grants, three additional grants were renewed for previous year awardees.

Providing Valuable Patient Support & Sjögren’s Education

In April, over 550 people attended the SSF’s National Patient Conference (NPC) in the Boston, MA area. This was the largest attendee turnout ever for a NPC. Another 175 people recently attended a one-day patient conference in Cleveland, OH. The SSF continues to support more than 65 local support groups while also publishing our patient newsletter. In 2019, the SSF also created and launched a new web series on YouTube called *Exploring Sjögren’s*. This documentary style

talk show discusses the various complications of Sjögren’s while also sharing the work being done by the Foundation. Additionally, the SSF’s website, www.sjogrens.org also remains the top source for relevant and valuable Sjögren’s information for patients, their families and healthcare providers.

A New Vision & Mission for the SSF

The SSF also continues to expand our reach and scope, the SSF volunteer Board of Directors established a new Vision Statement for the organization as well as updated our mission to better reflect our efforts and goals. The new vision clearly states what we are already striving to accomplish – “to create a community where patients, healthcare professionals and researchers come together to conquer the complexities of Sjögren’s.” We hope you’ll continue to join with us in 2020 on this very important mission. ■

If you would like to receive information on how you can *Leave a Legacy* to support the Sjögren’s Syndrome Foundation’s critical research initiatives or to support one of our many other programs, please contact Steven Taylor at 800-475-6473.

Sjögren’s Syndrome Foundation
Legacy of Hope

Leave A Legacy – Remember Us in Your Will



SAVE THE DATE

2020 National Patient Conference

April 3 – 4, 2020

Hyatt Regency Phoenix

122 North Second Street, Phoenix, Arizona

This spring we invite you to join with fellow Sjögren's patients, their families, medical experts, and product exhibitors and attend our 2020 National Patient Conference at the Hyatt Regency Phoenix hotel.

Sjögren's is not the same for every person diagnosed, which is why educating yourself on the most up-to-date information and treatment options is so important. Attending the SSF National Patient Conference is one way you can gain information from many different sources while also meeting fellow patients.

This year's Conference will include opportunities to:

- Learn from national Sjögren's experts, researchers and SSF staff
- Find new products and receive free samples in our exhibitor hall
- Share with your fellow patients
- Browse Sjögren's resources at the SSF Book Table

We encourage you to take this opportunity to gain an understanding of all the key aspects of Sjögren's. This two-day educational experience will give you the tools to take control of your health and learn how to manage and understand your Sjögren's symptoms and complications.

Watch for your Conference brochure coming in January or visit www.sjogrens.org to see updated conference information.

Presentation topics will include:

- Sjögren's: An Overview
- Integrative Medicine: A Role for Treatment in Sjögren's
- Oral Manifestations of Sjögren's
- International Sjögren's Research Update
- Autonomic Nervous System Involvement and POTS
- Sjögren's and Dry Eyes: What's New?
- Pediatric Sjögren's
- The State of Sjögren's: Transforming the Future
- "Ask the Doctor" Panel
- And More To Be Announced!





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!

Patient 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 SSF 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 member of the SSF 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 Michele Champigny at mchampigny@sjogrens.org for more information.


in memoriam

In Memory of A.J. Friedman
Elaine and Larry Levin

In Memory of Albert Anctil
Mary Lou Matherwicz
Ruth Barrios
Anctil Family

Betty and Jim Harrison
Arthur and Barbara Parmet

In Memory of Alice Glupe
Kenneth Glupe

In Memory of Bernice Kaplan
Linda J. Griffin

In Memory of Brenda Taylor Skipwith
Jane Johnston

In Memory of Brian Koukoutchos
Dave and Kathy Mount

In Memory of Cheryl Lee Schrum
LaMonica Fine Foods

In Memory of Donna Solk
Elaine and Larry Levin

In Memory of Florence Fox
Mark and Monica Carnesi
Sue and Marc Laufer
Lisa and Steve Marcus
The Ostrelich Family
Maryanne Pitman

In Memory of Kevin Erle Gubbe
Office of Advising and Evaluations, SDSU
Ever Loved

Randi and Don Carl
Tracie A. Paulen

In Memory of Mary Alice Kent Pound
TenderCare Family

In Memory of Nelly B. Thalheimer
Joan Thalheimer

In Memory of Pamela R Morin
John and Elizabeth Jackson

In Memory of Pat Kleinedler
Carolyn Gordon

In Memory of Roger E. Seremula
Julieann Hatam and Kathy Pristash

In Memory of Sandra D. Scheer-Clark
Bette Wigand

Denise Bennett
Brenda Marple

Rudie Eberleim
Crystal Forsyth

Blackhawk Chapter POCI

In Memory of William Emerson Stratton III
Janet M. Thompson


in honor

In Honor of Laura Freeman Edwards
Lynn Colwell

In Honor of Janice Diggins Clark and Hal Clark

Barbara and Neil Barrocas

In Honor of Wendy K Budd
Brenda Kahn

In Honor of Deb and Carl
Virginia and David Todd

In Honor of David J. Markun
Teri P. Rumpf

In Honor of Cathy Taylor Reppenhagen
Marc Snyder



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

The Sjögren's Syndrome Foundation is excited to announce the NEW Spouses and Partners Support Group for husbands, wives, girlfriends, boyfriends, or partners of someone living with Sjögren's. The Foundation knows how supporting and/or caring for someone with a chronic illness, like Sjögren's, can be very rewarding but it also has a significant impact on your life, too.

Please contact the Sjögren's Syndrome Foundation (SSF) at 301-530-4420 Ext. 203 or send an email to ssf@sjogrens.org and sign-up to receive specialized mailings, educational information, and notices about teleconference support group meetings for spouses and partners of Sjögren's patients.

We know you will find the SSF's "Spouses and Partners Support Group" a great way to be a supportive partner as well as an opportunity to connect, exchange helpful information and coping techniques with other life partners of Sjögren's patients – just like you.

Sharing can make a real difference in your life!

Sign up today!

Teleconference Support Group Meetings will start in January 2020!





The Moisture Seekers
Sjögren's Syndrome 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 an SSF Member, please contact us! 800-475-6473

Every Santa has his secret

Shop and support the SSF

Shop for Sjögren's

Shop to benefit the Sjögren's Syndrome Foundation

The Sjögren's Syndrome Foundation has partnered with online retailers who will donate a portion of your purchase to the SSF, so shopping online is now an easy way to contribute to Sjögren's!

Just visit www.sjogrens.org/shopforsjogrens and click through the links provided so that your purchases will benefit the SSF. Once you select the "Sjögren's Syndrome Foundation" as your charity of choice, whenever you return to these retailers and log in, any shopping you do will benefit the SSF. It's that simple!

Some of our partners include:



Amazon is one of the most popular online stores in the world, offering a wide variety of products.



iGive.com offers exclusive deals with over 700 brand name stores you know and love, with a specified percentage of each purchase coming back to the SSF.

