

# 15 Types of Sjögren's Fatigue

Teri Rumpf, Ph.D.

This is the second revival of an essay I wrote fifteen years ago, originally entitled, *11 Types of Fatigue*. Once again, I've been asked by the Sjögren's Foundation to give it new life. I thank them for the opportunity and hope that in the fifteen years that have passed since the original essay, there is increased acknowledgment of fatigue as a major factor in Sjögren's and a growing knowledge that Sjögren's is a systemic disease. My list of fatigue now numbers fifteen different subtypes. It is by no means meant to be exhaustive... the bulk of the article remains the same as it did in both 2003 and 2013.

A quick update: The friend mentioned below was my first friend with Sjögren's and as such, has always been very special to me. We still speak in a kind of shorthand, as I do with most if not all of my Sjögren's friends. The friends I have made over the years are the best outcome of this disease. As a group, we understand what it means to

say that we are "fine." We know that when we say we are "tired," it means really tired, i.e. that something is going on, something out of the ordinary, beyond the everyday feelings of fatigue. "How are you?" is not a question in our general culture. It is a greeting. As such, it deserves a real answer only in those circumstances where there is an understanding that the person asking truly wants to know.

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Evolution of The Moisture Seekers newsletter from left to right: 1984, 1990, 1998, 2002 and 2009

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Founded by  
Elaine K. Harris in 1983

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For those of you who haven't seen it, here is most of the original article with a few additions and revisions:

“How are you?” I asked a friend who has Sjögren's. “Tired,” she said, “how are you?” “Tired,” I replied, knowing we understood each other. We were talking about a special brand of fatigue. Later that day, a friend who did not have Sjögren's asked me the same question. “How are you?” she said. “Fine” I responded, thinking it was the simpler way to answer a basically rhetorical question.

Not everyone with Sjögren's suffers from fatigue, but many of us do. According to the 2016 Living with Sjögren's survey done by the SSF, fatigue was the third most prevalent and disabling symptom of Sjögren's. For me, fatigue has been a problem more disabling than dry eyes or dry mouth. I long for normal energy and the ability to sustain activity, any activity. I long for the kind of fatigue that gets better with a good night's sleep. I want to be able to do things spontaneously. I wish I did not have to pace myself or plan rest stops. I wish that I could just get up and go, but, reluctantly and somewhat resentfully, I know that fatigue is a permanent part of my life. Having decided that if you must live in a particular landscape, you should learn the subtleties of the territory. I've come up with the following subtypes. Your experience may vary:

#### Basic fatigue

This is the inherent fatigue that I attribute to the inflammatory, autoimmune nature of Sjögren's. It's with me all the time. It differs from normal fatigue in that you don't have to do anything to deserve it. It can vary from day to day but is always there. For me, there appears to be a correlation between this kind of fatigue and sed rate (ESR). When one goes up, so does the other. I don't know how often this phenomenon occurs. I could also call this my base-

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#### Correction: Pregnancy in Sjögren's

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Nancy Carteron, MD, FACP

Under the congenital heart block (CHB) sub-heading, weekly Doppler fetal echocardiogram surveillance was suggested between 18 and 20 weeks, however, the suggestion was intended to be between 18 and 24 weeks. It is important to note, however, that the monitoring recommendations are evolving, and that broader ranges have been suggested by the American Heart Association (between 16 and 28 weeks) as well as Jill Buyon, MD (between 18 and 26 weeks) during her presentation at the 2018 American College of Rheumatology State-of-the-Art Clinical Symposium on neonatal lupus.

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# The Sjögren's Syndrome Foundation – 35 Years Later

## 35<sup>th</sup> Anniversary

Steven Taylor



Steven Taylor, CEO SSF

As we celebrate the SSF's 35<sup>th</sup> Anniversary this month, I want to say thank you to Elaine K. Harris for having founded the SSF back in 1983. She had incredible foresight and vision to start an organization that still stands strong today!

Today, in her 90s, Elaine still remains an important force in the eyes of the SSF. Her mantra of “founded by a patient, for patients” remains the center of what we do. The SSF staff and our hundreds of volunteers, work hard to ensure that the patient voice is never lost in our discussions nor plans. And our accomplishments speak volumes for how we are changing Sjögren's for our patients.

Since our 30th anniversary, the SSF has seen great strides in producing results that will help Sjögren's patients. We are working diligently on the development of new therapeutics to treat Sjögren's as well as we have

launched and published the first-ever Clinical Practice Guidelines in Sjögren's! These guidelines are starting to provide a roadmap for physicians and dentists to use when treating their patients. And we have already begun phase 2 of these guidelines to expand into areas like the treatment of pulmonary complications, neuropathies and lymphoma – just to name a few!

And probably one of the biggest accomplishments in the past 5 years, is the SSF's achievement of our 5-Year Breakthrough Goal –to reduce the time to diagnose Sjögren's by 50%! When we set that goal in 2012, it took nearly 6 years to receive a proper diagnosis, and I am proud to say that, in 2017, we were able to announce that we exceeded our goal and we have reduced that time to 2.8 years!

But what I am most excited by, is that since we were founded in 1983, Sjögren's is finally receiving the recognition and appreciation it deserves. Although not to the level we need it to be, we are seeing more and more physicians step up to learn about Sjögren's, while more and more families of patients are starting to get involved with the SSF. We are also seeing more interest from pharmaceutical companies than ever before, all interested in helping us to find a new treatment to help our patients! A treatment that will help fight the entire disease, not just one symptom.

And most importantly, at the end of the day, the SSF is helping patients. We are helping patients connect with other patients, we are helping to educate patients and their families and we are getting patients the proper care they deserve!

As the CEO of the SSF for the past 15 years, it has been an honor that you have trusted me with your personal stories and hopes for the future. And as a son of a Sjögren's patient, I stand alongside my mother, Elaine Harris and the thousands of Sjögren's patients I have personally met, when I say, the SSF was founded by a patient, for patients! And I promise you – we always remember that!

Happy Anniversary SSF! Here is to another 35 years!

Steven Taylor

Chief Executive Officer

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### “Fatigue” continued from page 2 ▼

line fatigue, which fluctuates and gets better or worse. All of the following are superimposed on this basic fatigue.

#### Rebound fatigue

If I push myself too far and ignore the cues my body is sending me to stop and rest, my body will fight back. When I do more than I should, the result is an immobilizing fatigue. It comes on after the fact, i.e., do too much one day and feel it the next. If I push myself today, I very likely will have to cancel everything tomorrow. An extended period of doing more than I should will almost certainly cause a flare.

#### Sudden fatigue

This ‘crumple and fold’ phenomenon makes me resemble a piece of laundry. It comes on suddenly, and I have to stop whatever I’m doing and just sit down (as soon as I can). It can happen anywhere, at any time. It is the kind of fatigue that makes me shut off the computer in mid-sentence. It is visible to those who are observant and know what to look for, even though I make gargantuan efforts to disguise the fact that it is happening.

#### Weather related fatigue

Not everyone has this particular talent, but I can tell that the barometric pressure is dropping while the sky remains blue and cloudless. I feel a sweeping wave, a malaise, that sometimes lifts just after the rain or snow has started. Likewise, I know when a weather front is moving away, even while torrents of water are falling from the sky. I feel a lightening in my body and begin to have more energy. This kind of fatigue is accompanied by an increase in muscle aches and joint pain.

#### Molten lead phenomenon

This fatigue is present when I open my eyes in the morning and know that it is going to be a particularly bad day. It feels as if someone has poured molten lead in my head and on all my limbs while I slept. My muscles and joints hurt and doing anything is like walking with heavy weights. It is often associated with increased symptoms of fibromyalgia and sometimes helped by heat and massage.

#### Tired-wired

Tired-wired is a feeling that comes from certain medications, such as prednisone, too much caffeine, or too much excitement or perhaps it is just a function of Sjögren’s. My body is tired, but my mind wants to keep going and won’t let my body rest.

#### Flare-related fatigue

Flare-related fatigue is an unpredictable state of increased fatigue that can last for days or weeks. It may be caused by an increase in disease activity or an undetected infection. If the latter, it either resolves on its own, or eventually presents other signs and symptoms that can be diagnosed. Additional rest is essential to deal with this kind of fatigue, but rest alone will not necessarily improve it or make it go away. Once a flare begins, it is impossible to predict where it will go or how long it will last.

#### Fatigue related to other physical causes

Fatigue related to other physical causes, such as thyroid problems or anemia or other diseases superimposed on Sjögren’s. This kind of fatigue makes you feel that you are climbing a steep hill when you are

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# SSF in Action!

## SSF at the 14<sup>th</sup> International Symposium on Sjögren’s Syndrome



The SSF was excited to participate in the 14<sup>th</sup> International Symposium on Sjögren’s Syndrome (ISSS), which took place April 18-21, 2018, in Washington, DC. In all, more than 350 attendees from the US and abroad participated in the event, which featured more than 30 oral presentations and nearly 200 scientific posters on a wide array of Sjögren’s-related topics. The symposium, themed, “Paths to Precision Diagnosis and Therapy,” was held with the primary objective of fostering successful drug development and clinical trial design for Sjögren’s.

Beyond attending sessions and networking with attendees, below are some of the ways the SSF was involved with this event:



From left to right: Katherine Hammitt, MA, Theresa Lawrence Ford, MD; Raphaela Seror, MD; and Steven Taylor, MBA, SSF CEO.

#### Event Support / Exhibits

The Foundation was honored to provide monetary support for the conference, which was used for travel grants to help offset the costs for trainees to attend the event. Additionally, the SSF had an exhibit booth

which provided attendees with free resources as well as opportunities to interact with staff to learn more about the Foundation and how to get involved. The SSF also coordinated our neighbor exhibit for the HarmonicSS project, which was staffed by international patient representatives.



From left to right: Nancy Carteron, MD; Katherine Hammitt, MA, SSF VP of Medical & Scientific Affairs; and Theresa Lawrence Ford, MD

#### Presentations

Over the course of the event, the SSF was involved with two panel presentations and presented four posters. On day one, Steven Taylor moderated, and Kathy Hammitt participated in, a panel session entitled, “The Perspective of Those Affected by Sjögren’s Syndrome.” Joining them for this discussion were patient representatives from both England and the Netherlands. Steven Taylor also participated in a panel presentation on HarmonicSS, in which he, project leadership and patient representatives spoke about the great potential for this collaborative effort.

Each of the SSF’s four selected posters were presented during three designated sessions on Friday,

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really walking on level ground. It may resolve once the underlying organic condition is diagnosed and treated. Thyroid problems and anemia are both common among Sjögren's patients, but many other kinds of fatigue may be superimposed. Sjögren's and fibromyalgia often co-exist, such that it is difficult to separate one from the other.

*Fatigue impairs concentration*

Fatigue impairs concentration, precludes thought, and makes me too tired to talk, think or read. Fatigue robs me of memory and encloses me in a fog of cotton wool so thick I can't find my way out until the fog miraculously lifts. For me, brain fog goes hand-in-hand with other kinds of pernicious fatigue.

*Stress, distress, anxiety or depression*

Stress, distress, anxiety or depression all can create a leaden kind of emotional fatigue that can be as exhausting as one due to physical causes. Although some people do not associate their increased fatigue with emotional states, many are aware of the effects of increased anxiety and depression, even if they cannot control what they feel. Intense emotion is very draining. Stress, anxiety and depression all are known to disrupt sleep.

*Fatigue that comes from not sleeping well*

Some people with Sjögren's have trouble both getting to sleep and staying asleep. Some wake up in the morning feeling as if they had never slept at all. Many aspects of Sjögren's affect sleep: being too dry, in too much pain or malaise; multiple trips to the bathroom, the need for water or to put in eye ointment all deter a good sleep. Lack of restorative sleep increases fatigue. Fibromyalgia worsens when you don't get a good night's sleep. Chronic pain increases fatigue.

*Fatigue that comes with normal aging*

I'm old enough for Medicare now and my friends are more tired too, although they seem to be able to do two or three or even four times what I can do on any given day. In fact, the gap between what they can do and what I can do just seems to be growing, despite my best efforts. It's been a long time since I tried to keep up, but it still hurts that I can't.

*Fatigue that comes from a chronic illness that just won't quit*

We've all heard the expression "sick and tired of being sick and tired" and that phrase truly captures what many of us feel. I would take it one step further. There's

a fatigue that comes with the uncertainty of a chronic disease. It's a debilitating fatigue born of never knowing what will come next. The chronicity of Sjögren's can wear me down and I have to make special attempts not to let it. When these attempts don't work, I wait a while and try to find something else that distracts me from my illness.

And two new ones:

*Fatigue that comes from trying to keep up with family and friends who don't have a chronic illness*

As much as I try, it just isn't possible to keep up. I'm on a schedule that's all my own, and as much as I fight it, it separates me from the people I love. I'm willing to compromise to do things their way, but my body won't cooperate.

## Doctor Fatigue

I get very tired of spending my time in waiting rooms, having lab tests, and going to doctors. I don't understand why I didn't say this before. I'm sure it's self-explanatory. Enough said.

It's difficult to explain the unnatural quality and intensity of Sjögren's fatigue to someone whose only experience has been with what is normal. We're not talking about the same stuff. It's apples and artichokes. Sjögren's fatigue assaults everything I do. There isn't a part of my life that hasn't been touched by it. It is there even on my happiest days.

Because people don't understand, it's often misinterpreted. "Is it depression?" a health care professional who didn't know much about Sjögren's asked me. I tensed. Was he saying it was all in my head? I began to get angry but then gave him the benefit of the doubt. I put my first reaction aside and decided he was trying to understand. I was relating something outside his frame of reference, and he was attempting to find a point with which he could identify.

When you describe Sjögren's fatigue to someone who has never experienced it, you are asking him or her to think outside the box. You want them to understand an experience that is common to those who have Sjögren's and many other autoimmune diseases but rare otherwise. Perhaps their first reaction will be negation or denial. While it's always difficult to encounter expressions of disbelief, it is not uncommon. I tried to see it as an opportunity to educate.

"No," I said to the doctor who asked about depression, "think of it as a never-ending flu that varies in intensity but never goes away." He grimaced. ■

### About the Author: Teri P. Rumpf, Ph.D.

Sometimes words come with difficulty, but not on the day I wrote the original version of this essay. I wrote it because I was frustrated and tired of being tired and the words just poured out. I'd had enough of people not understanding that it was possible to look, but not feel, normal, and I'd had enough of people thinking that just because Sjögren's was a disease they had never heard of, they could discount it. The original article probably took fifteen minutes to write and fifteen minutes to revise. I never dreamed that fifteen years later, I would be working on yet another revision, but it's not just me that I'm describing. Fatigue is a factor that shapes people's lives. There are days when, like a cloud, it lifts, at least momentarily. On those days, I rush about to get things done. On other days, I give in. I cave. I hate the fact that I cannot push through and do things anyway. My "normal" friends have an elasticity and an ability to recover when they are tired that I don't have. My fatigue separates me from my friends and family. Over the years, they have come to accept the fact that I may or may not be joining them. A fatigue like that makes it hard to plan.

I think I was a tired child. I never understood how the people around me could do everything that they did. Looking back, I'm amazed that I accomplished what I did. On the first day of graduate school in clinical psychology, the first lecturer used these exact words to describe the self: "The self", he said, "is a physical self". An odd way to begin a program that would focus on human emotions and behavior, I thought, but he was right. We are bound by the constraints of our bodies.

It's hard living with a disease that is unfamiliar, to the public at large and even to many physicians, including rheumatologists. The concept of Sjögren's as a systemic disease, not just dry eyes and dry mouth, is finally making headway. What living with Sjögren's has meant for me, in addition to being fatigued, is a dramatic increase in uncertainty and a reality that has been difficult for family and friends to comprehend. "Life is uncertain", I'm sure many of them would say. True enough, but even more so with a chronic disease that can make you feel sicker than you appear. I never really know whether I'll be able to keep the plans I make. When I was younger, I wondered what would happen next, what would go wrong. The things I worried about didn't necessarily happen, and the things that weren't even on my radar did. The uncertainty became the source of anxiety. If I couldn't escape it, I could attempt to cushion it. When family and friends failed to understand, I tried to surround myself with people who did, both in my choice of physicians and friends. Through Sjögren's I have made lifelong friends, and I hope that watching my struggles has taught others something, not only about the illness, but about what it means to have to live with something uncertain, unexpected and unwanted. I have learned to accept people who don't get it, but my enduring appreciation and gratitude go to those who do.

After almost three decades of Sjögren's, I can say this: although I have not had the life I might have had without Sjögren's, I have had a full life and that is what is important. From this vantage point, I offer the following words of advice: it won't be easy, this is a disease that gets in your way; there will be ups and downs, but live the finest life you can, and if anyone thinks they know how you could improve on life with an uncertain, unpredictable chronic disease, just tell them "I'm doing the best that I can." And leave it at that. ■




  
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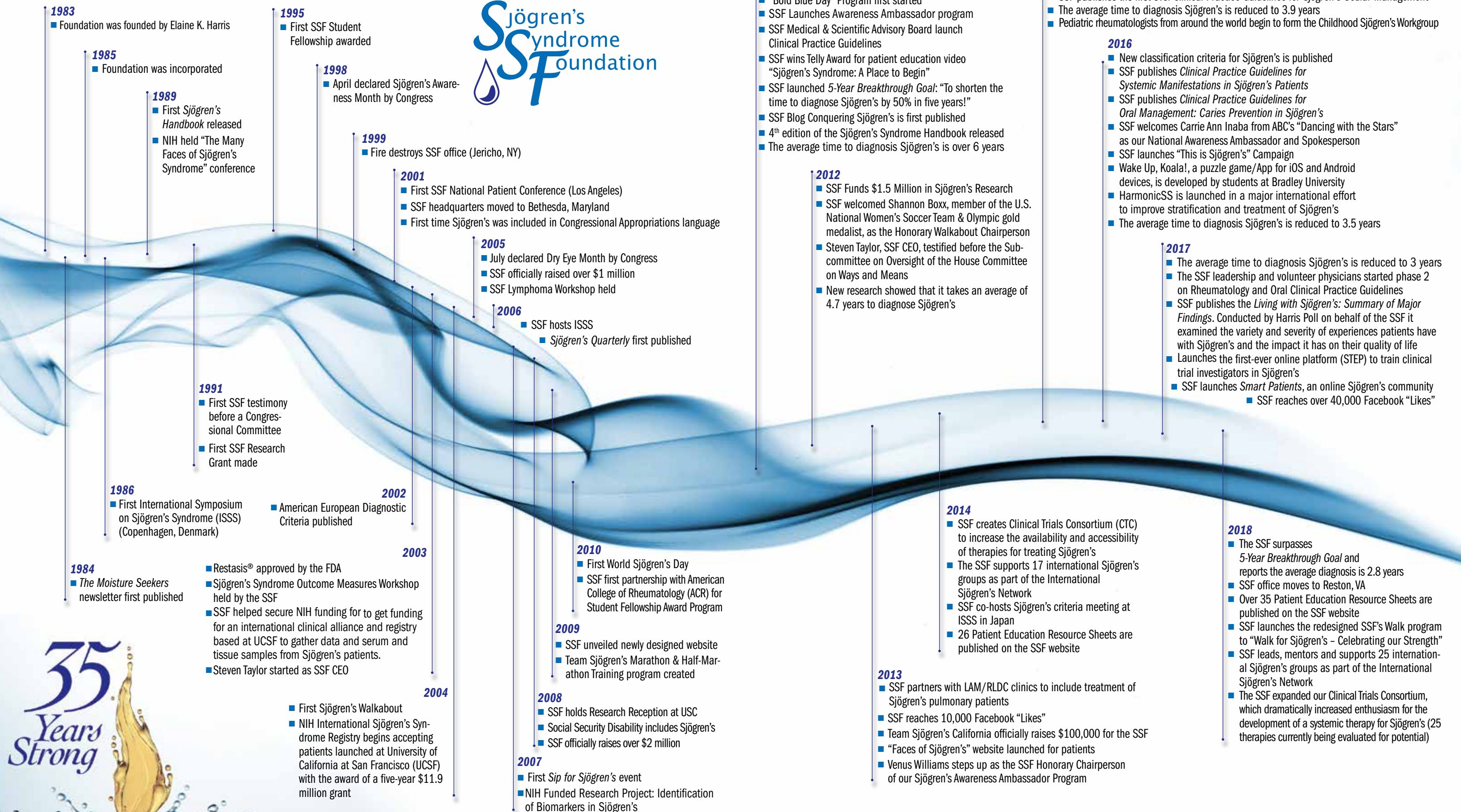
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# Sjögren's Syndrome Foundation Timeline 1983 – 2018





“SSF in Action” continued from page 5 ▼

April 20, 2018. During these times, attendees were free, and encouraged, to visit the posters and learn more from the authors about their work.

Three of the four SSF posters provided information on the efforts of Phase 2 of the Foundation’s initiative to develop clinical practice guidelines for Sjögren’s. Posters on guideline development on the following topics were included: neurological involvement in Sjögren’s; oral manifestations in Sjögren’s, including mucosal management and treatment and the use of secretagogues in Sjögren’s, and; pulmonary involvement in Sjögren’s. These posters provided both reasoning for why the topics had been selected as well as the progress that’s been made up to the time of presentation.



Meetings

The SSF took advantage of the many international Sjögren’s experts and patients being together in one place and led two meetings during the ISSS. First, a meeting of the International Sjögren’s Network took place on Friday, April 20, 2018, which included more than 20 attendees from around the world who took the time to discuss group activities and ways in which the group can continue to strengthen and grow.

Second, at the conclusion of the ISSS, the SSF held a meeting of the Clinical Trials Consortium Steering Committee in which the attendees received updates on a variety of important SSF-led initiatives.

There were a lot of great things to take from this event and we’re now looking forward to the next ISSS, which will take place in Rome, Italy, in 2021. ■

Standing with SSF and HarmonicSS posters from left to right: Ana Viera, Portugal; Alice Espinoza, France; and Joyce Koelewijn-Tukker, Netherlands.

# Celebrating 35 Years in the Fight Against Sjögrens!

After being diagnosed with Sjögren’s in 1983, Elaine Harris was frustrated that it took so long to identify the symptoms she was experiencing and discouraged by the lack of information that existed about the disease. Determined initially to simply meet other patients and start a support group, Elaine ended up achieving so much more.

35 years later, the mission and core values of the Sjögren’s Syndrome Foundation (SSF) remain the same while we have also grown into a multi-faceted organization that has expanded its outreach, increased its funding for research and education, and has significantly improved awareness about this complex disease.

The reason for the SSF’s longevity, growth and continued achievements are because of the contributions of countless dedicated volunteers, board members, generous donors and other supporters. It has been your ideas and input, your questions and your appetite for answers and information that have helped to shape who we are today. In 2018, we remain the only national non-profit organization dedicated to conquering

Sjögren’s. Additionally, the SSF is extremely honored to serve as the voice for all Sjögren’s patients. Our initiatives, programs and overall efforts are first and foremost started, advanced and expanded with the Sjögren’s patient in mind.

The SSF’s goal is to alleviate patients’ concerns and provide them with a sense of hope. With so many people living in trepidation of their disease progressing, we want to make a difference for patients and to provide them with a sense of hope now and for the future. Hope that patients are diagnosed sooner; receive the best possible treatment they need and deserve; and are able to improve their quality of life.

It is truly remarkable how far the Foundation has come in the past 35 years and how many people have been helped but just imagine how much more can be accomplished in the years to come.

Help us celebrate our accomplishments and continue on our journey of conquering Sjögren’s by donating in honor of our 35<sup>th</sup> Anniversary below.

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## Interview with Elaine K. Harris, SSF Founder

Steven Taylor and Elaine Harris at the SSF 30<sup>th</sup> Anniversary Celebration in 2013

Like many newly diagnosed patients, Elaine K. Harris was frustrated with the lack of information available about her disease. Without a Foundation or the internet, Elaine was only able to find two patient fact sheets that mentioned the disease. Determined to take control of her health and learn more about her symptoms, Elaine used her past community involvement to start a local support group with only one other Sjögren's patient that she met, the secretary of her doctor. She then slowly grew that support group into the Sjögren's Syndrome Foundation (SSF).

Today, the Foundation serves thousands of patients and has grown into a powerhouse organization, breaking down barriers worldwide in the field of Sjögren's. The many achievements that the SSF has seen in the last 35 years is because of the hundreds of volunteers and members across the country. Although none of what we have today would be possible if it wasn't for Elaine turning her frustration into a source of hope for all patients.

This August, Elaine Harris and Janet Church, the new Chairman of the SSF Board of Directors, had the opportunity to meet and discussed the past, present and future of the Foundation. Below are excerpts from their interview.

### What was your key motivation as to why you started the Foundation?

I wanted more people to know about Sjögren's, to be able to talk to other patients and have more doctors interested in it.

### How do you think the Foundation is doing today?

I think the Foundation is doing superbly.

### What was the primary focus of the SSF in its earliest days?

There was a need for doctors who could recognize the discrete manifestations as possibly related symptoms. We wanted to develop and distribute patient-oriented literature that would also help doctors communicate with each other regarding the patient's needs and proposed treatment.

We also saw a great need for promoting public awareness about Sjögren's and getting more physicians interested so that they would focus on developing treatments, bringing relief to patients.

### How did the newsletter receive the name, The Moisture Seekers?

Name recognition is a challenge with Sjögren's. It's a disease name that people cannot easily pronounce or spell. We reasoned that since we were looking for moisture for the many organs in our body, naming our group *The Moisture Seekers* made sense.

When we were ready to incorporate as an official "not-for-profit organization," our lawyer suggested it would be best to name the organization after the disease. We decided to become the "Sjögren's Syndrome Foundation" but I didn't want to let the name *The Moisture Seekers* go and retained it for the newsletter.

### Why do you think it's important for patients to add their voice to the SSF?

The squeaky wheel gets oiled. Sjögren's patients take time and doctors are often limited with time. This is why it's so important to learn from doctors through the SSF newsletter, local support group meetings and the National Patient Conferences.

It is also important to help educate your doctor and not be bashful when talking about your disease. You

have to spread the word and keep trying for those who are living with debilitating manifestations and find it difficult to function.

### What is the best advice that you would give to a new diagnosed patient?

Meet other Sjögren's patients. Patients will talk to each other about some of their problems that they are reluctant to bring up to doctors.

Find a doctor who is informed about the many manifestations of Sjögren's or one who will work with you and is interested in learning. Someone who will listen to your problems, communicate with the other specialists treating you, and keep up with the new medications being developed to treat the disease.

### What advice would you like to share with all patients?

Be open about your Sjögren's and never stop reaching!

### What is the biggest transformation between the early years of the SSF to now?

Growth in the pharmaceutical industry. Today it seems possible that there's a pot of gold to be found! ■



Elaine K. Harris (center)



Elaine Harris at the 2016 New York City Sip for Sjögren's Event



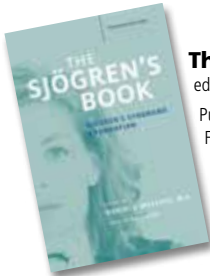
Janet E. Church  
Chairman Sjögren's Syndrome  
Foundation Board of Directors

Janet Church has served as a member of the Board of Directors for six years and throughout that time has offered her expertise as an entrepreneur, tech-industry veteran and a Sjögren's patient, a key member and volunteer of the foundation. We are honored to have Janet as the new Chairman of the Sjögren's Syndrome Foundation Board of Directors.

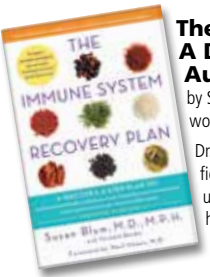
"It was a joy to talk to the woman who has been carrying the patient flag for all of us for the past 35 years. As the new SSF Chairperson and having been diagnosed with Sjögren's for 12 years, I look forward to the many direct patient-to-patient conversations we will have in the upcoming years and promise to do my best to carry the flag!

For me, I felt that getting involved with the Foundation was a way that I could help myself the most. I feel that it is better to Stay Active, Stay Informed and Attempt to Do Something, than to not do something. I am inspired by all that the SSF has accomplished and I am personally excited, as well as honored, to be leading us over the next two years." ■

# 35<sup>th</sup> Anniversary Special Top 5 SSF Resources



**The Sjögren's Syndrome Handbook**  
edited by Daniel J. Wallace, MD  
Published in conjunction with the Sjögren's Syndrome Foundation in 2011, this edition of the Sjögren's Syndrome Handbook is completely revised and expanded from the Third Edition, with new articles and the latest information on Sjögren's.  
**Member Price: \$28**      Non-Member Price: \$32



**The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease**  
by Susan Blum, MD, MPH (Author), Mark Hyman, MD (Foreword), Michele Bender (Contributor)  
Dr. Susan Blum, one of the most sought-after experts in the field of functional medicine, shares the four-step program she used to treat her own serious autoimmune condition and help countless patients reverse their symptoms, heal their immune systems, and prevent future illness.  
**Member Price: \$22**      Non-Member Price: \$25



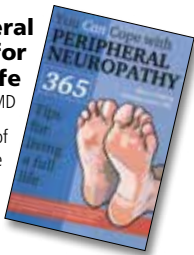
**The Sjögren's Syndrome Survival Guide**  
by Teri P. Rumpf, PhD and Katherine Morland Hammitt (VP of Medical & Scientific Affairs)  
Often referred to as a support group in a book, this is a complete resource for Sjögren's sufferers, providing the newest medical information, research results, and treatment methods available, as well as the most effective and practical self-help strategies.  
**Member Price: \$17**      Non-Member Price: \$20



**You Can Cope With Peripheral Neuropathy: 365 Tips for Living a Full Life**  
by Mims Cushing and Norman Latov, MD

You Can Cope With Peripheral Neuropathy is a compendium of tips, techniques, and life-task shortcuts that will help everyone who lives with this painful condition.

**Member Price: \$16**      Non-Member Price: \$19



**Set of 7 Audio CDs**  
from the 2018 SSF National Patient Conference  
**Member Price: \$100**

These books can be purchased using the order form below, online at [www.sjogrens.org/ssfstore](http://www.sjogrens.org/ssfstore) or by contacting the Sjögren's Syndrome Foundation office at 800-475-6473.

	Non-Member Price	Member Price	Qty	Amount
<b>The Sjögren's Book, 4th Edition:</b> <i>by Daniel J. Wallace, MD</i>	\$32.00	\$28.00		
<b>The Sjögren's Syndrome Survival Guide:</b> <i>by Teri P. Rumpf, PhD and Katherine Morland Hammitt</i>	\$20.00	\$17.00		
<b>The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease:</b> <i>by Susan Blum, MD, MPH (Author), Mark Hyman, MD (Foreword), Michele Bender (Contributor)</i>	\$25.00	\$22.00		
<b>You Can Cope With Peripheral Neuropathy: 365 Tips for Living a Full Life:</b> <i>by Mims Cushing and Norman Latov, MD</i>	\$19.00	\$16.00		
<b>Set of 7 Audio CDs from the NPC 2018</b>	n/a	\$100.00		
<b>Shipping and Handling:</b>	U.S. Mail: \$5 for first item + \$3 for each additional item Canada: \$14 for first item + \$3 for each additional item Overseas: \$22 for first item + \$3 for each additional item			
<b>Total Amount</b>				

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 \_\_\_\_\_

## in memoriam

**In Memory of Adam Weinstein**  
Ellen and Jerry Reibstein  
**In Memory of Barbara Reilly McFadden**  
Paula and Michael Kelly  
James and Caryn Kinzig  
The Neill Family  
John and Liz Kramer  
Frank Byrne  
**In Memory of Christine Beth Barnes**  
Nancy and Mike Thompson  
**In Memory of Deborah Bales Magill**  
Nana's Grandkids care of Barbara Wofford Kanwat  
John Magill  
Mrs. Michele LaFrage Peter  
**In Memory of Elizabeth "Loretta" Landry**  
Judy A. Dalferes  
**In Memory of Frances Eve Lee**  
Norm and Mela Kolpin  
**In Memory of Helen A Kinlan**  
Jefferey and Kimberly Shouse  
**In Memory of Herbert Fineman**  
Ellen and Jerry Reibstein

**In Memory of Jeri-Ann Dolch**  
Jim and Laura Lee  
**In Memory of Judy Davenport Johnston**  
Diana and David Salter  
Matt and Karen Winslow  
Deborah and Alan Lewis  
Russell Sloan  
**In Memory of Mattie Watson**  
Tommy, Liz, JT and Stacey Adkins  
**In Memory of Mauri Gibson**  
Larry and Dawn Koepfer  
Paul and Natalie Arnold  
Tom Bryson  
The Cravens Family  
Namita Dhawan  
Kathi Kerr-Zurubi  
Mike and Gerry Tinnan  
Mark and Ranae Salem  
Lark and Pete Turner  
Marc and Karen Gleason  
Rita Knepper  
Joseph and Darcy Piche  
Tony Gibson

**In Memory of Michael E. Cromar**  
John Maher  
**In Memory of Neil Levine**  
Ellen and Jerry Reibstein  
**In Memory of Luke Taylor**  
Bobette Morgan  
**In Memory of Marcia Lee Arand**  
Financial Center care of Diane Roberts  
**In Memory of Phyllis "Sue" Smith**  
Winona and Merrin Godfrey  
Dave and Barb Douts  
Larry and Connie Folkenroth  
Gene and Jane Snyder  
**In Memory of Sue Henriksen**  
Aaron Henriksen  
**In Memory of Susan, mother of Lynn Spitzer**  
The Haubergers, Sectors and Perlows  
**In Memory of Sylvia Rosen**  
Lockheed Martin BP care of Suzanne Rowan  
**In Memory of Wink Blair Sutz**  
Lois Peach

## in honor

**In Honor of Carol Schlags**  
Cory Schlags  
**In Honor of Debra Heintz**  
Ben & Jerry's Foundation  
**In Honor of Diana Laboy-Rush and Marci Laboy**  
Uncle Adler Manjares  
**In Honor of Dr. Helene Fein**  
Barbara and Terry Bachow  
**In Honor of Genevieve Dayes**  
Angela T Joseph  
**In Honor of Harry Spiera, M.D.**  
Laura Figueiredo  
**In Honor of Joanne Boland**  
Anonymous  
**In Honor of Jonathan Morse**  
Michael and Joan Pokroy  
**In Honor of Leiba Husock**  
Howard Husock and Robin Henschel  
**In Honor of Lynn Sheskey**  
Derek Townsend  
**In Honor of Melissa Schlags**  
Cory Schlags

**In Honor of Robert I. Fox, M.D., Ph.D.**  
The Henry J. Fox Charitable Trust care of  
Leslie Kefauver, Robert Fox and Linda Joy Fox  
**In Honor of Rosanna Suriano**  
Adriana Suriano  
**In Honor of Rosario Solis**  
Rosie Stoleran, Lauren and Stephanie  
**In Honor of Sarah Carlson**  
Susan and Alan Lapp  
**In Honor of Shelley Stewart**  
William and Teresa Schmidt  
**In Honor of Shirley Strickler**  
Natalie Strickler  
**In Honor of Susan Paul-Souza**  
Rita Paul  
**In Honor of Vivian and Kip Kistler**  
Cindy Crawley  
**In Honor of Wendy Kahn Budd**  
Brenda B.K. Kahn  
Sandra Kahn



## TMS Walk Calendar

### Los Angeles Area

**Saturday, October 20, 2018**

La Mirada Community Regional Park

13701 Adelfa Dr, La Mirada, CA 90638

[Events.sjogrens.org/LosAngelesWalk](http://Events.sjogrens.org/LosAngelesWalk)

### Austin Area

**Saturday, November 3, 2018**

Round Rock Premium Outlets

4401 N Interstate Hwy 35, Round Rock,  
TX 78664

[Events.sjogrens.org/AustinWalk](http://Events.sjogrens.org/AustinWalk)







## 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*



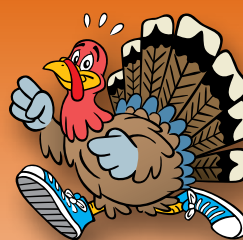
### A Single Kit Includes: \$35

- Team Sjögren's T-shirt, with Turkey Trot logo on the front!
- SSF Awareness Bracelet
- Certificate of Participation
- "What is Sjögren's?" Brochure
- SSF Reusable Shopping Bag
- SSF Pin
- SSF Hat



### T-Shirt: \$20

- Team Sjögren's T-shirt, with Turkey Trot logo on the front!



# Team Sjögren's

## Team Sjögren's Goes Turkey!

This Thanksgiving, we hope you will consider participating in your community Turkey Trot as a member of Team Sjögren's!

What a great way to start your day of giving thanks – by purchasing a Team Sjögren's Turkey Trot Kit and walking or running with others in your area, increasing awareness for Sjögren's and helping raise crucial funds for Sjögren's research.

You can find a local Turkey Trot by visiting [www.active.com](http://www.active.com) or in your local newspaper. If there isn't one in your area, consider creating your own Turkey Trot! Ask family and friends to join you for a morning walk in your neighborhood or at a nearby park on Thanksgiving morning while wearing your Team Sjögren's T-shirts!

Order your Team Sjögren's Turkey Trot Kit by calling 800-475-6473 or online at [www.sjogrens.org](http://www.sjogrens.org).

	Qty.	Size: S-2XL	Total
Team Sjögren's Turkey Trot T-Shirt	\$20 ea.		
Single Person Team Sjögren's Turkey Trot Kit	\$35 ea.		
<b>Shipping and Handling:</b>			
U.S. Mail: \$5 for first item + \$3 for each additional item			
Canada: \$14 for first item + \$3 for each additional item			
Overseas: \$22 for first item + \$3 for each additional item			
<b>Total Amount Due</b>			

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or Fax to: 301-530-4415**

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City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

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☐ MasterCard ☐ VISA ☐ Discover ☐ AmEx Card Number \_\_\_\_\_

Exp. Date \_\_\_\_\_ Security Code \_\_\_\_\_ Signature \_\_\_\_\_

