

Letter From Our CEO



Dear SSF Members:

This is the time of the year that I always give thanks to all those who have helped the Sjögren's Syndrome Foundation and reflect back on our many accomplishments.

As you all know, the SSF was founded 30 years ago by a patient for patients. I have always said since joining as CEO, I would never take away the focus from patients. My mother having Sjögren's allows me to see firsthand how this disease can affect a family and a patient's life. She is fortunately healthy but we all live with the concern that it could change at any time. And that is why I fight on a daily basis to make the lives for all Sjögren's patients better.

This past year, we saw many amazing accomplishments and advancements. In this issue, you will be able to read about the latest research award recipients and a major breakthrough

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13 Types of Fatigue

by Teri Rumpf, Ph.D.

This is a revival of an essay I wrote ten years ago, originally entitled *11 Types of Fatigue*. I've been asked by the Sjögren's Syndrome Foundation to give it new life. I thank them for the opportunity and that in the ten years that have passed since the original essay, there is an increased acknowledgment of fatigue as a major factor in Sjögren's. I've decided to add two new types of fatigue to the list, which is by no means meant to be exhaustive.

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 only good 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 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.

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

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in Sjögren's research and the link to Sjögren's genes. All of this shows that your support is helping us make a huge difference in how Sjögren's is viewed by researchers and healthcare professionals.

I am very proud that Sjögren's is starting to gain national and international prominence at scientific meetings and medical conventions. The Foundation is being asked to present at more healthcare professional conferences than ever before and this is all thanks to our amazing group of physicians and healthcare professionals who volunteer their time to prepare presentations and apply to speak at these various conferences.

In addition, our Awareness Ambassador program continues to exceed our expectations. This past year, we added another 135 Awareness Ambassadors to our cadre of volunteers, bringing our total to 463. These Ambassadors go into their communities and to their local healthcare providers with information and educational materials to educate them about Sjögren's. We also want to thank the Carroll Petrie Foundation for serving as the presenting sponsor of our Awareness Ambassador program. Without our Ambassadors, we would not be able to grow as fast as we have.

In addition to our awareness initiatives, patient services continue to be a main focus of the SSF. With more people being diagnosed every day, the SSF received over 12,000 calls this past year from concerned patients and their families about their diagnosis. We are proud to say that we are able to offer them comfort and support, along with education about Sjögren's. We also held over 220 support group meetings this year in the United States, thanks to the 65 support group leaders who coordinate our meetings. Our Sjögren's Blog has thousands of followers and the SSF achieved a major milestone by now having over 11,000 people following us on Facebook. These followers now receive regular communication from the SSF including Sjögren's tips and motivation as well as the ability to connect them with other Sjögren's patients.

And finally, the SSF has been working hard to achieve our *5-Year Breakthrough Goal* of "shortening the time to diagnose Sjögren's by 50% in the next 5 years." We already know that it currently takes 4.7 years to diagnose Sjögren's and we are hoping that with an emphasis on increasing awareness and having our current Sjögren's patients serve as catalysts for conversations about Sjögren's, we will see this diagnosis time decreased to close to 2 years.

So on behalf of the SSF and our volunteer Board of Directors, I thank each of you for carrying the Sjögren's torch, for sharing your story, for donating and for supporting our initiatives. Without you, we would not be able to share such amazing successes and achieve our ultimate goal of making Sjögren's a household name!

Sincerely,

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I used artificial tears often, like when at lunch with friends.

So I saw my doctor—after all, these are my eyes.

And she said I have a disease.

My eye doctor said I have reduced tear production caused by inflammation due to a disease called Chronic Dry Eye. That's a big deal.

She told me I can use artificial tears for temporary relief. But to make more of my own tears, she prescribed RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05% for continued use, twice a day in each eye, 12 hours apart, every day.

Approved Use

RESTASIS® Ophthalmic Emulsion helps increase your eyes' natural ability to produce tears, which may be reduced by inflammation due to Chronic Dry Eye. RESTASIS® did not increase tear production in patients using anti-inflammatory eye drops or tear duct plugs.

Important Safety Information

Do not use RESTASIS® Ophthalmic Emulsion if you are allergic to any of the ingredients. To help avoid eye injury and contamination, do not touch the vial tip to your eye or other surfaces. RESTASIS® should not be used while wearing contact lenses. If contact lenses are worn, they should be removed prior to the use.

The most common side effect is a temporary burning sensation. Other side effects include eye redness, discharge, watery eyes, eye pain, foreign body sensation, itching, stinging, and blurred vision.

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Please see next page for the Brief Summary of the full Product Information.

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BRIEF SUMMARY—PLEASE SEE THE RESTASIS® PACKAGE INSERT FOR FULL PRESCRIBING INFORMATION.

INDICATIONS AND USAGE

RESTASIS® ophthalmic emulsion is indicated to increase tear production in patients whose tear production is presumed to be suppressed due to ocular inflammation associated with keratoconjunctivitis sicca. Increased tear production was not seen in patients currently taking topical anti-inflammatory drugs or using punctal plugs.

CONTRAINDICATIONS

RESTASIS® is contraindicated in patients with known or suspected hypersensitivity to any of the ingredients in the formulation.

WARNINGS AND PRECAUTIONS

Potential for Eye Injury and Contamination

To avoid the potential for eye injury and contamination, be careful not to touch the vial tip to your eye or other surfaces.

Use with Contact Lenses

RESTASIS® should not be administered while wearing contact lenses. Patients with decreased tear production typically should not wear contact lenses. If contact lenses are worn, they should be removed prior to the administration of the emulsion. Lenses may be reinserted 15 minutes following administration of **RESTASIS®** ophthalmic emulsion.

ADVERSE REACTIONS

Clinical Trials Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in practice.

In clinical trials, the most common adverse reaction following the use of **RESTASIS®** was ocular burning (17%).

Other reactions reported in 1% to 5% of patients included conjunctival hyperemia, discharge, epiphora, eye pain, foreign body sensation, pruritus, stinging, and visual disturbance (most often blurring).

Post-marketing Experience

The following adverse reactions have been identified during post approval use of **RESTASIS®**. Because these reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

Reported reactions have included: hypersensitivity (including eye swelling, urticaria, rare cases of severe angioedema, face swelling, tongue swelling, pharyngeal edema, and dyspnea); and superficial injury of the eye (from the vial tip touching the eye during administration).

USE IN SPECIFIC POPULATIONS

Pregnancy

Teratogenic Effects: Pregnancy Category C

Adverse effects were seen in reproduction studies in rats and rabbits only at dose levels toxic to dams. At toxic doses (rats at 30 mg/kg/day and rabbits at 100 mg/kg/day), cyclosporine oral solution, USP, was embryo- and fetotoxic as indicated by increased pre- and postnatal mortality and reduced fetal weight together with related skeletal retardations. These doses are 5,000 and 32,000 times greater (normalized to body surface area), respectively, than the daily human dose of one drop (approximately 28 mcL) of 0.05% **RESTASIS®** twice daily into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed. No evidence of embryofetal toxicity was observed in rats or rabbits receiving cyclosporine at oral doses up to 17 mg/kg/day or 30 mg/kg/day, respectively, during organogenesis. These doses in rats and rabbits are approximately 3,000 and 10,000 times greater (normalized to body surface area), respectively, than the daily human dose.

Offspring of rats receiving a 45 mg/kg/day oral dose of cyclosporine from Day 15 of pregnancy until Day 21 postpartum, a maternally toxic level, exhibited an increase in postnatal mortality; this dose is 7,000 times greater than the daily human topical dose (0.001 mg/kg/day) normalized to body surface area assuming that the entire dose is absorbed. No adverse events were observed at oral doses up to 15 mg/kg/day (2,000 times greater than the daily human dose).

There are no adequate and well-controlled studies of **RESTASIS®** in pregnant women. **RESTASIS®** should be administered to a pregnant woman only if clearly needed.

Nursing Mothers

Cyclosporine is known to be excreted in human milk following systemic administration, but excretion in human milk after topical treatment has not been investigated. Although blood concentrations are undetectable after topical administration of **RESTASIS®** ophthalmic emulsion, caution should be exercised when **RESTASIS®** is administered to a nursing woman.

Pediatric Use

The safety and efficacy of **RESTASIS®** ophthalmic emulsion have not been established in pediatric patients below the age of 16.

Geriatric Use

No overall difference in safety or effectiveness has been observed between elderly and younger patients.

NONCLINICAL TOXICOLOGY

Carcinogenesis, Mutagenesis, Impairment of Fertility

Carcinogenesis: Systemic carcinogenicity studies were carried out in male and female mice and rats. In the 78-week oral (diet) mouse study, at doses of 1, 4, and 16 mg/kg/day, evidence of a statistically significant trend was found for lymphocytic lymphomas in females, and the incidence of hepatocellular carcinomas in mid-dose males significantly exceeded the control value.

In the 24-month oral (diet) rat study, conducted at 0.5, 2, and 8 mg/kg/day, pancreatic islet cell adenomas significantly exceeded the control rate in the low dose level. The hepatocellular carcinomas and pancreatic islet cell adenomas were not dose related. The low doses in mice and rats are approximately 80 times greater (normalized to body surface area) than the daily human dose of one drop (approximately 28 mcL) of 0.05% **RESTASIS®** twice daily into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed.

Mutagenesis: Cyclosporine has not been found to be mutagenic/genotoxic in the Ames Test, the V79-HGPRT Test, the micronucleus test in mice and Chinese hamsters, the chromosome-aberration tests in Chinese hamster bone-marrow, the mouse dominant lethal assay, and the DNA-repair test in sperm from treated mice. A study analyzing sister chromatid exchange (SCE) induction by cyclosporine using human lymphocytes *in vitro* gave indication of a positive effect (i.e., induction of SCE).

Impairment of Fertility: No impairment in fertility was demonstrated in studies in male and female rats receiving oral doses of cyclosporine up to 15 mg/kg/day (approximately 2,000 times the human daily dose of 0.001 mg/kg/day normalized to body surface area) for 9 weeks (male) and 2 weeks (female) prior to mating.

PATIENT COUNSELING INFORMATION

Handling the Container

Advise patients to not allow the tip of the vial to touch the eye or any surface, as this may contaminate the emulsion. To avoid the potential for injury to the eye, advise patients to not touch the vial tip to their eye.

Use with Contact Lenses

RESTASIS® should not be administered while wearing contact lenses. Patients with decreased tear production typically should not wear contact lenses. Advise patients that if contact lenses are worn, they should be removed prior to the administration of the emulsion. Lenses may be reinserted 15 minutes following administration of **RESTASIS®** ophthalmic emulsion.

Administration

Advise patients that the emulsion from one individual single-use vial is to be used immediately after opening for administration to one or both eyes, and the remaining contents should be discarded immediately after administration.

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Announcing the SSF's Newest Research Grantees

The Sjögren's Syndrome Foundation is pleased to announce our newest research grant recipients. The number of researchers proposing new projects in Sjögren's continues to increase annually, and the caliber of proposals was exceptionally high this year. The SSF Research Review Committee placed a priority on the following three specific areas when reviewing this year's grants:

- **Innovation**, which is critical for finding new approaches to treatment.
- **Novel diagnostics**, which is important for helping reach the SSF 5-Year *Breakthrough Goal* of reducing the time to diagnosis by 50% in 5 years and for improving clinical trial designs.
- **Junior investigators**, to encourage new researchers to focus their careers on discovering breakthroughs in Sjögren's.

While it was not required that selected recipients meet all of the criteria, these areas served as a guide for ranking the numerous high quality applications received.

With the above criteria in mind, the review committee set out on the arduous task of determining which of the over two dozen exceptional applications received would be funded. "With so many talented researchers, it becomes very difficult to choose which ones will, and which ones, unfortunately, will not receive funding, we encourage all of our readers to consider donating to Sjögren's research. Your giving in this area is critical to our current and future patients as well to keeping investigators in the field," said Denise Faustman, MD, PhD, SSF Medical and Scientific Advisory Board Chair.

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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 a 2012 survey done by the SSF, fatigue was the third most prevalent and disabling symptom of Sjögren's. Fatigue has been a problem more disabling than dry eyes or dry mouth for me. 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 baseline 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 induced by other physical conditions

Fatigue related to other physical causes, such as thyroid problems or anemia superimposed on Sjögren's. This kind of fatigue makes you feel that you are climbing a steep hill when you are really walking on level ground. It resolves once the underlying organic condition is

continued page 8 ▼

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1. DEWS Report, The Ocular Surface, April 2007; 5(2): 69-204



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"13 Types of Fatigue" continued from page 6 ▼

diagnosed and treated. Thyroid problems and anemia are both common among Sjögren's patients, but many other kinds of fatigue may be superimposed.

Fatigue that impairs concentration

Fatigue that impairs concentration precludes thought, 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.

And two new ones:

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.

Chronic Illness Fatigue

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.

It's difficult to explain the unnatural quality and intensity of this 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 is pervasive. It 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. ■

Suggested reading: *The Sjögren's Syndrome Survival Guide*, by Terri Rumpf, PhD, author of 13 Types of Fatigue article, and Katherine Moreland Hammitt, SSF Vice President of Research, this SSF best seller is often referred to as a "support group in a book" and is available for purchase from the SSF. See order form on page 15.

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Dr. & Mrs. Mark Rodman

Mr. Scott & Dr. Carrie Rodman

Ms. Leslie Salomon

Mrs. Marlene Simon

Mr. Mark Simon

Ms. Robin Stall

Mr. & Mrs. Richard Stromberg

Mr. & Mrs. Jeffrey Stromberg

Linda & Michael Tender

Ms. Ramona Rantala, Eric & Michael

In Memory of Nancy Butler Kipp
Tom & Pam Fife

Kimberly Plummer, Rhonda

Berry, Shirlee Rodriguez &

Cheryl Patrick-Blow

In Memory of Robert E. Keith
Susan Rawlston

In Memory of Sara Savoy
Honeywell CBM HUMS
Rance Myers

In Memory of Connie Larson
The Family and Friends
of Connie Larson

**In Memory of
Gary Lynn & Carol Grace Carter**
The Inside Sales Team



in honor

In Honor of Carol Gerrish
Lauren Gerrish

In Honor of Steven Taylor
Elaine and Herb Harris

In Honor of Valerie Bowles
Nancy Hubbell

In Honor of Jo Weaver
Tedi Schilling- Flathead Valley Sjogrens Support Group

Sjögren's Syndrome Foundation
Legacy of Hope



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.

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XyliMelts time-release oral adhering discs provide dry mouth relief day and night, even while sleeping when dry mouth is worst.

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Winter

Breakthrough Bullet:

SSF Research Grantees

Find Six New Genes

Associated with Sjögren's

50%
in 5 years
Sjögren's
syndrome
FOUNDATION

When Elaine Harris founded the Sjögren's Syndrome Foundation 30 years ago, she saw the value of providing research funding as part of the SSF's mission. Today, we're proud that many past research recipients have gone on to become field experts, often receiving additional funding from other organizations to further their studies. This is why the SSF is excited that two of our own researchers had a major breakthrough this fall when they identified six new Sjögren's-related genes from the first genome-wide study of Sjögren's.*

This study was completed by the Sjögren's Genetics Network, SGENE, a group of international researchers led by scientists at the Oklahoma Medical Research Foundation, OMRF, including two SSF Research Grantees: Dr. Kathy Sivils (Moser), 2011 SSF Research Grant Recipient, and Dr. Christopher Lessard, 2013 SSF Research Grant Recipient. (Read more about his project on page 12.)

"I can't begin to explain how much of a difference the SSF grant made to this work. And this is just a milestone in the beginning of our journey to understand the genetic causes of Sjögren's. I know it's a long way off, but I hope

* Funding for the project was provided by grants from the Sjögren's Syndrome Foundation and No. P50 AR0608040 from the National Institute of Arthritis and Musculoskeletal and Skin Diseases, 5R01 DE015223, 1R01 DE018209-02 and 5R01 DE018209 from the National Institute of Dental and Craniofacial Research, 5U19 AI082714 from the National Institute of Allergy and Infectious Diseases, part of the National Institutes of Health.

"Research Grants" continued from page 5 ▼

This year's newest research grantees are:



Ana Paolo Cotrim, DDS, MSc, PhD – Molecular Physiology Branch, Sjögren's Syndrome and Salivary Gland Translational Unit, National Institute of Dental and Craniofacial Research (NIDCR), National Institutes of Health (NIH), Bethesda, Maryland

Immune-phenotyping and iPSC-related Disease Modeling in Sjögren's Syndrome

Dr. Cotrim was awarded the first year of a potential two-year SSF grant. SSF research reviewers commented that this research "has the potential to create a very valuable collection of Sjögren's subjects that will serve as a resource for learning a lot more about Sjögren's." Adding, "This is an interesting and novel project. It has the possibility of making an important impact on the understanding of the pathophysiology of Sjögren's."

Lay Abstract

Sjögren's is an autoimmune disease in which the body's defense system attacks moisture producing glands, causing dry eyes and dry mouth. Many factors contribute to the development of Sjögren's, including genetics. In some patients with Sjögren's the immune system attacks blood vessels (vasculitis) and lymphomas (cancer of the immune-system) are more frequent. Stem cells are unique unspecialized cells that can become several different cell types. When stem cells are created artificially from adult cells, it's called Induced Pluripotent Stem Cells (iPSC).

The goal of this proposal is to analyze the immune system and to generate iPSC from Sjögren's patients. We will characterize the iPSC and use these cells to generate Sjögren's specific endothelial (blood vessel) cells, to study the relationship between the immune system and vasculature. Explaining if Sjögren's vascular cells are genetically more vulnerable to immune cells. This will help understand the disease and may lead to new therapies and cure.



Christopher Lessard, PhD – Oklahoma Medical Research Foundation (OMRF) Arthritis and Clinical Immunology Program, Oklahoma City, Oklahoma

Validation and Characterization of Long Non-coding RNAs in Sjögren's Syndrome

Dr. Lessard was awarded the first year of a potential SSF two-year grant. The committee noted the following regarding Dr. Lessard's proposed research, "This is a young investigator who seems devoted to Sjögren's. He's tackling new projects and new ideas and furthermore is doing the project in humans!" Another committee member commented, "Highly interesting approach to understanding genetic aspects of Sjögren's. His project could eventually lead to a novel diagnostic."

Lay Abstract

The human genome contains ~22,000 genes that are expressed as the result of very complex mechanisms involving both proteins and thousands of non-coding regulatory RNA molecules. Recent work by the ENCODE project has found that ~80% of the human genome is functional and actively transcribed into RNA, but only 3-5% contains sequences that code for proteins. Our preliminary studies have found active regions of the genome that do not code for proteins, called long non-coding RNAs (lncRNAs), which are dysregulated and may contribute to the risk of developing Sjögren's. Their precise function is currently unexplored. In other diseases, including breast and prostate cancers, lncRNAs have been shown to be important diagnostic markers and potential targets for therapeutic interventions.

The goal of this project is to characterize the lncRNAs that are implicated in Sjögren's and to evaluate their potential as diagnostic markers and therapeutic targets.



Klaas Max, PhD – Rockefeller University, New York, New York
Sjögren's Antigens and Their Role in Stress Granule Formation, Apoptosis, RNA-release and

Their Contribution Towards Autoimmunity

Dr. Max was awarded the first year of a potential SSF

two-year grant. The committee noted the following regarding his proposed research, "An excellent application by a very talented young investigator. Dr. Max has an excellent track record for publications. He has established excellent collaborations for the project to move forward." Adding, "this program is very worthwhile and ambitious!"

Lay Abstract

Proteins of complexes from the cells nucleus, (NP), are the main group of Sjögren's autoantigens and play important roles in biogenesis and quality control processes. Stress conditions cause impairment of these functions, and let Sjögren's NP travel into stress granules, a step which may influence their release from cells, and their potential to become antigens. This project aims to identify binding partners, which influence the localization of Sjögren's NP and could contribute towards autoimmunity.

We will identify Sjögren's NP binding partners under stressed and unstressed conditions in patients and in healthy controls using blood samples, develop methods to isolate and characterize stress granules, and study their formation and disassembly in cells. Once established, we will try to identify which components that contributes to immune stimulation.

Our approaches potentially allow to detect genetic changes in patients, which may provide a better understanding of autoimmunity and an improve diagnosis of Sjögren's.

Grant Renewals

In addition to our new awardees, the SSF also renewed the following 2012 Research Awards for these researchers to finish the second year of their projects:

continued page 14 ▼

"Around-the-Clock Relief From Dry Mouth"



Lozenges, Sprays & Gel

Designed to meet the needs of Sjögren's patients

Now available at your local
Independent Pharmacy

 Proudly Made in the U.S.A.
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Do we have your e-mail address?

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

Just like all information you give the Foundation, your e-mail address will remain private and will never be given or sold to an outside organization.

"Breakthrough Bullet" continued from page 5 ▼

In addition to the previously known HLA Sjögren's related gene, the international research team, led by Dr. Sivils, found the following disease-related genes:

BLK is a B-cell gene which might account for increased numbers of antibodies.

IRF5 & STAT4 which are "master regulators" that activate cells during an immune response CXCR5 directs traffic for lymphocytes and may help explain why immune cells target moisture-producing glands TNIP1 is a binding partner with another autoimmune disease-related gene, TNFAIP3, which "cuts the brakes" on the immune system.

IL12A is one subunit of a protein that acts as a messenger between cells and modulates immune responses.

*This work appears in the journal "Nature Genetics"

these discoveries will open the door for researchers to find therapeutics that work at the genetic level to stop the disease," said Dr. Sivils.

Currently, the only treatment for Sjögren's is to target its symptoms. Although this is only a very initial first step to unlocking the mystery of Sjögren's, this finding gives hope for future studies to investigate the disease's potential causes, progressions and additional treatments at a new genetic level. "Now that we've identified these genes, we can dig down and start to understand how these genetic variants alter normal functions of the immune system," said Dr. Lessard.

It's because of the generous support of our patients and friends that the SSF is able to award grants to talented researchers like Dr. Sivils and Dr. Lessard, who bring novel approaches to Sjögren's research. "I am proud that we were able to provide support for this groundbreaking research and look forward to future Sjögren's breakthroughs," said Steven Taylor, SSF CEO. The SSF will continue to update you on exciting discoveries from current Sjögren's research. We hope you will consider donating to the SSF Research Program to keep novel research like this fully funded. ■

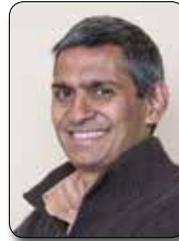
"Research Grantees" continued from page 13 ▼



Karsten Gronert, PhD –
School of Optometry, Vision Science,
Berkeley, California
Amplification of Intrinsic and Protective Ocular Surface Lipid Circuits as Novel Treatment Targets.



Maria Kukuruzinska, PhD –
Department of Molecular & Cell Biology,
Boston University, Boston, Massachusetts
Functional Role of the Hippo pathway in Sjögren's syndrome.



Seshagiri Rao Nandula, PhD –
School of Dentistry, University of Minnesota,
Minneapolis, Minnesota
Role of type 1 interferon signaling in the development of Sjögren's syndrome.

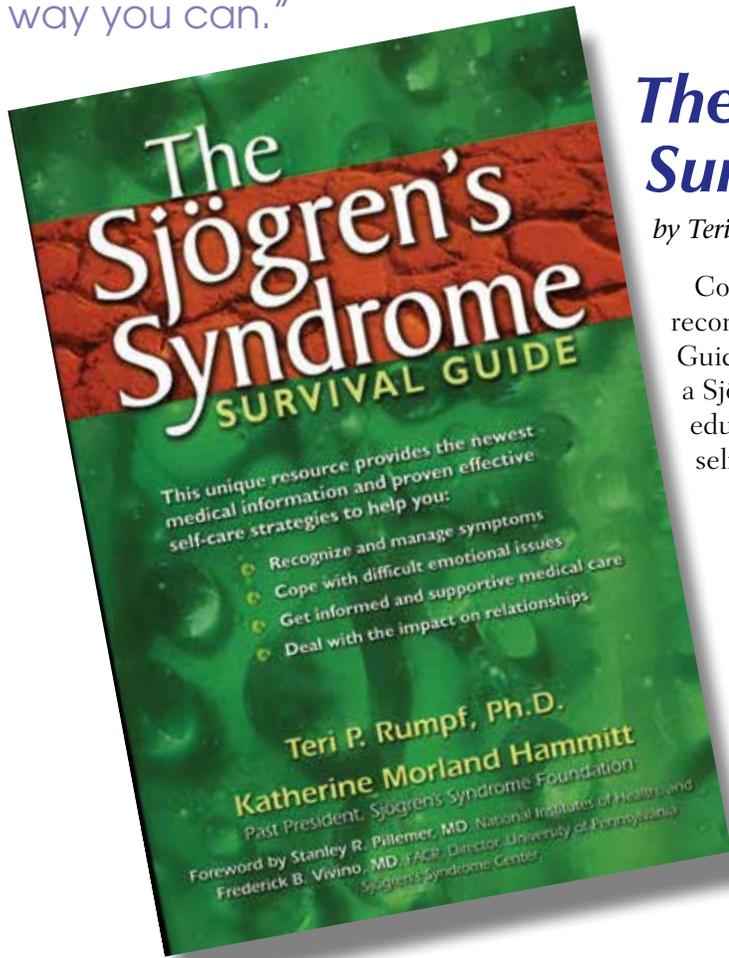
Please visit www.sjogrens.org to read more about these awards on our research section.

On behalf of the Research Committee and our research grantees, we'd also like to recognize the Galewood Family Foundation and the Bannon-Humphery Foundation for their continued support of the SSF's Research Program. ■

Did you notice our extended issue?

The Sjögren's Syndrome Foundation is now combining our November and December issue of *The Moisture Seekers*. This extended issue has more pages to provide all the great information while cutting down on mailings you receive each year during this busy time of year. We hope you enjoy this new November/ December issue and have a joyful holiday season and healthy New Year. ■

“No one grew up with plans to have a chronic disease. It just happens. Once it does, you have to do everything possible to live in the best way you can.”



The Sjögren's Syndrome Survival Guide

by Teri P. Rumpf, PhD and Katherine Morland Hammitt

Continually one of our best selling and most highly recommended books. The Sjögren's Syndrome Survival Guide is written together by a clinical psychologist and a Sjögren's patient, this unique resource provides both educational medical information and proven effective self-care strategies to help you:

- Recognize and manage symptoms
- Cope with difficult emotional issues
- Obtain informed and supportive medical care
- Deal with the impact on relationships

The Survival Guide is a wonderful resource in a highly readable format addressing all aspects of Sjögren's. It includes clear and practical advice to allow people to take control of this disease and enjoy enormous improvements in their quality of life.

This book can be purchased using the order form below, online at www.sjogrens.org or by contacting the Sjögren's Syndrome Foundation office at 800-475-6473.

	Non-Member Price	Member Price	Qty	Amount
The Sjögren's Syndrome Survival Guide by Teri P. Rumpf, PhD and Katherine Morland Hammit	\$15.00	\$13.00		
<i>Maryland Residents add 6% sales tax</i>				
Shipping and Handling:	US 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			
Total Amount				

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



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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 _____ Security Code _____ Signature _____

We here at the Sjögren's Syndrome Foundation would like to thank you for your continued support and dedication to the fight against Sjögren's. As we celebrate our 30th anniversary, we are incredibly grateful to have had such long-term success. But we share this success with YOU! Your generosity and support has helped get us to this point, making our achievements possible.

While we have made great strides in the world of Sjögren's, unfortunately there is more work to be done. As a loyal supporter, you know our track record of supporting Sjögren's patients, increasing public and professional awareness and furthering Sjögren's research. Now, as 2013 comes to a close, your support is needed more than ever. We ask that you consider giving a year-end donation this holiday season.

As we celebrate increased recognition of Sjögren's, advancements in research, new diagnostics and more patients being diagnosed faster, we also prepare ourselves for the challenges ahead, and these demands on the SSF are even greater. Your support is truly integral to the work we do.

Please don't miss this opportunity to help fulfill our holiday wish: a world where patients are diagnosed quicker, have better treatments available and Sjögren's is widely recognized.

Wishing you a joyous holiday season and happy 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

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Team Sjögren's Celebration and Family Picnic!



Lauren and her cousin Taylor helping at the Team Sjögren's 4th of July Lemonade Stand

I Stood Up...

Team Sjögren's California Kids Stand Up for Sjögren's!

Team Sjögren's California has turned their event into a family affair.

When Estrella, new mom and Sjögren's patient, first started the Team Sjögren's California group to run in their local 6 miles Wharf to Wharf race she enlisted the help of other mothers in her community. Four years later, Team Sjögren's California has grown into one of the Foundation's largest fundraising events with the "Team Sjögren's Kids" leading the way!

Lauren and Jasmine, daughters of Dr. Ava Wu and Dr. Lawrence Yee, and their cousin Taylor hosted awareness events as part of their school's community service program, and joined their whole family at the race for their fourth consecutive year. The girls also baking homemade treats for the Team's 4th of July Lemonade Sale, where Anderson (5), the son of Estrella her husband Jerry, helped work the stand!

Anderson, who has been a part of the event since the beginning, is looking forward to running in his first Wharf to Wharf next year in 2014. A big part of his motivation was Francesca (7), the daughter of fourth year teammate Karen, who was super excited to run in the race for her first time!

In addition to selling baked goods and lemonade to raise funds for their Team, many of the kids attended the race and cheered on all the runners. Max (6) and his mom, Alex, are both Team veterans whose smiling faces are staples at Team Sjögren's California fundraising events.

And joining all of these wonderful kids were two new faces Kristina (9) and her sister Karina (12) who participated with their parents Vonny and Bendik. The girls ran to support their mom who had been recently diagnosed with Sjögren's, and had no problem joining in the festive Team Sjögren's spirit.

Little Voices can make a big difference in fighting this serious disease and the SSF is proud of all the Team Sjögren's California Kids! ■

Francesca (7) ran the whole Six Miles for Sjögren's and Anderson (5) cheered her on



Kristina (9) is showing her Team Sjögren's Spirit! Kristina ran in race with her sister Karina (12) along with their dad and Mom, who has Sjögren's



Sisters Lauren and Jasmine, along with their cousin Taylor



Max (6) and Anderson (5)

SAVE THE DATE!

2014 SSF National Patient Conference

“Solving the Sjögren’s Puzzle”

April 25-26, 2014

Hyatt Regency O’Hare
Chicago (Rosemont, Illinois)

As a Sjögren’s patient, it’s easy to feel confused or overwhelmed by the abundance of information available about the illness and how it affects your body. But here is your opportunity to work on “Solving the Sjögren’s Puzzle,” taking an educational journey to take control of your health and day-to-day living by learning from the best minds dealing with Sjögren’s. This April, join fellow Sjögren’s patients and their family members as well as healthcare professionals and other experts who specialize in Sjögren’s at the 2014 SSF National Patient Conference in Chicago (Rosemont, Illinois).

SSF programs are the best Sjögren’s patient education opportunities in the country. They have helped thousands gain a better understanding of Sjögren’s and will help you, too. This two-day event will feature an array of presentations from the country’s leading Sjögren’s experts – physicians, dentists, eye care providers, and researchers – who will help you understand how to manage all key aspects of your disease.

So this April 25-26, we invite you to join with us and experience a weekend where you will heighten your understanding and work toward “Solving the Sjögren’s Puzzle” at the 2014 National Patient Conference in Chicago (Rosemont, Illinois).

Call 800-475-6473 or visit www.sjogrens.org today to receive the latest information.

Presentation topics will include:

- Overview of Sjögren’s Syndrome
- Pulmonary Issues and Sjögren’s
- Dry Eye / Dry Mouth and Sjögren’s
- What is in the Clinical Trial Pipeline?
- Gastrointestinal Issues and Sjögren’s
- Clinical Practice Guidelines Overview
- Nutrition, Wellness and Autoimmune Disease
- Overlapping Major Connective Tissue Diseases

Holiday Soft Diet Recipe: Creamy Spinach-Onion Casserole

3 packages (10 ounces each) chopped spinach, thawed, well drained

2 cups reduced-fat sour cream

1 envelope (1 ounce) dry onion-soup mix

Combine all ingredients and spoon into greased 1 ½-quart casserole. Bake (covered) at 350 degrees until hot through, about 30 minutes. Makes 6 servings.

Per Serving:

159.7 Calories

10.5g Protein

15.2g Carbohydrate

4.3g Fiber

7.0g Total Fat

4.0g Saturated Fat

26.7mg Cholesterol

581.9mg Sodium

New Advanced Technology from Eye Eco

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3 Easy Steps to Proven Dry Eye Relief

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Enjoy repeated 15 -18 minute warm compresses. Members of the foundation receive 15% off. For more information or to order visit www.eyeeeco.com. Use promotional code 'SSF' to receive 15% discount. Or call toll free 1-888-730-7999.

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If you would like to receive this newsletter but are not currently an SSF Member, please contact us! 800-475-6473

This Season Remember to 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 the value 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. Some of our partners include:

- ◆ **Amazon.com** is one of the most popular online stores in the world, offering a wide variety of products. 8.5% of the value of your purchase is donated back to the Foundation.
- ◆ **Drugstore.com** is a leading online provider of health, beauty, vision, and pharmacy products. The website allows you to shop as if you were at your local drug store, and you can get instant savings while 10% of your purchase benefits the SSF.
- ◆ **Walmart.com** offers access to a wide assortment of products at their everyday low prices, with up to 4% of your purchases being donated to the SSF.
- ◆ **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. Be sure to select "Sjögren's Syndrome Foundation" as your charity of choice. Whenever you return to iGive.com and log in, any shopping you do will benefit the SSF! It's that simple.

