

The Moisture Seekers



www.sjogrens.org

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Sjögren's Diagnosis and Challenges

by Daniel Small, MD, Rheumatologist, Sarasota Arthritis Center

Currently there is no simple diagnostic test for Sjögren's, nor are there universally accepted diagnostic and classification criteria. However, those physicians skilled in caring for patients with Sjögren's know that early and accurate diagnosis in the hands of such a physician can greatly benefit a patient with Sjögren's syndrome.

The hallmark clinical findings are dryness of the eyes and mouth and, often, dryness of the nose, throat, vagina, and skin. Many other organ systems may show evidence of dysfunction. The syndrome may develop alone (primary Sjögren's) or in association with almost any of the rheumatic or autoimmune diseases (secondary Sjögren's). Chronic immune system stimulation plays a central role in the pathogenesis of Sjögren's. This chronic immune stimulation is manifested by hyperreactivity of B-cells expressed by increased antibody production and the presence of lymphoplasmacytic infiltrates in the affected glands and organs.

continued page 2 ▼



Preparing for a New Doctor Visit

by Sara Sise, Sjögren's patient and SSF Board of Directors Member

When meeting a physician for the first time, it's imperative to come prepared. Prior to my first visit, I write out my objectives for that appointment. My initial goals are often quite simple. Primarily, I want to determine if a successful working relationship with the practitioner can be achieved. Medical care of a chronic illness, in my opinion, is a journey that requires a trusting partnership. Unfortunately, many primary care physicians have had little experience with Sjögren's. Therefore, it is part of my responsibility to provide them with updated information on our illness.

Listening carefully to answers to questions such as *How many patients have you treated with Sjögren's?* or *Are you interested in receiving professional educational information regarding Sjögren's treatment, research and management?*

continued page 6 ▼

In This Issue

5 Q&A Board of Directors

9 I Stood Up

10 In Memory and In Honor

13 Information You Requested



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"Sjögren's Diagnosis" continued from page 1 ▼

The trigger and the processes that perpetuate the infiltration of lymphocytes and production of increased antibodies are not known. Though a genetic predisposition has been suggested by a number of studies, no clear-cut identifiable gene that can be tested for has been found to be associated with Sjögren's. A variety of viruses have been looked at, but none have been clearly identifiable in the pathogenesis of this disease. Alterations of the number and kinds of cytokines that immune cells produce have been looked at as well, but no pattern is clearly associated with Sjögren's.

There are non-organ-specific antibodies that are found in both primary and secondary Sjögren's (anti-Ro/SSA and anti-La/SSB) that have clinical significance and are used in the diagnostic criteria for Sjögren's. Organ-specific antibodies have been found (antibodies against carbonic anhydrase, alpha-fodrin, proteasomal subunits, and M3 muscarinic receptors) but these currently are not being included in any of the criteria for diagnosis of Sjögren's.

Why is it important for there to be consistent criteria for the diagnosis of Sjögren's syndrome? Since the cause of Sjögren's is unknown, for physicians to properly treat patients with Sjögren's, we need to have data on how patients with this disease will respond to a specific treatment. To date there are very few clinical studies showing a particular therapy is efficacious for Sjögren's patients. One of the problems is the lack of universally acceptable diagnostic criteria.

There has been an evolution in the criteria for making the diagnosis of Sjögren's. The universally accepted gold standard in helping with the diagnosis is the labial gland biopsy showing a characteristic infiltrate of lymphocytes and plasma cells in aggregates (foci) throughout the salivary glands. The problem has been that similar infiltrates can be seen with HIV, hepatitis C, sarcoidosis, and lymphoma. So although the finding of lymphocytic infiltrates is essential in making the diagnosis of Sjögren's, it is not specific for Sjögren's. In the past 30 years there have been multiple attempts to establish a set of diagnostic and classification criteria. European Study Group criteria allowed Sjögren's to be diagnosed on the basis of symptoms and signs of dry mouth and dry eyes. Labial gland biopsy findings and the presence of autoantibodies were among the criteria but were not required for the diagnosis. In contrast, the more stringent San Diego criteria required evidence of autoantibodies or the characteristic pathology. The Europe Study Group criteria were criticized for including a group of non-Sjögren's patients without immunologically active disease. The Sjögren's Syndrome Foundation organized and sponsored meetings between the European and American group, and a revised European criterion was proposed by the American-European Consensus Group. This criterion is very important for defining a group of patients with Sjögren's that could be included in studies for the purpose of looking at pathogenesis,

continued page 8 ▼

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**Alison Tendler MD,
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Dr Tendler is an actual patient and is compensated for appearing in this advertisement.

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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.

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WARNING

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PRECAUTIONS

General: For ophthalmic use only.

Information for Patients:

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.

Do not allow the tip of the vial to touch the eye or any surface, as this may contaminate the emulsion.

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.

Carcinogenesis, Mutagenesis, and Impairment of Fertility:

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 1000 and 500 times greater, respectively, than the daily human dose of one drop (28 µL) of 0.05% RESTASIS[®] BID into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed.

Cyclosporine has not been found 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).

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 15,000 times the human daily dose of 0.001 mg/kg/day) for 9 weeks (male) and 2 weeks (female) prior to mating.

Pregnancy-Teratogenic effects:

Pregnancy category C.

Teratogenic effects: No evidence of teratogenicity was observed in rats or rabbits receiving oral doses of cyclosporine up to 300 mg/kg/day during organogenesis. These doses in rats and rabbits are approximately 300,000 times greater than the daily human dose of one drop (28 µL) 0.05% RESTASIS[®] BID into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed.

Non-Teratogenic effects: 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 30,000 and 100,000 times greater, respectively than the daily human dose of one-drop (28 µL) of 0.05% RESTASIS[®] BID 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 17,000 and 30,000 times greater, 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 post partum, a maternally toxic level, exhibited an increase in postnatal mortality; this dose is 45,000 times greater than the daily human topical dose, 0.001 mg/kg/day, assuming that the entire dose is absorbed. No adverse events were observed at oral doses up to 15 mg/kg/day (15,000 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.

ADVERSE REACTIONS

The most common adverse event following the use of RESTASIS[®] was ocular burning (17%).

Other events 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).

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Based on package insert 71876US10U Revised January 2008

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Board of Directors Q&A

A Path to the Board of Directors

The SSF Board of Directors is responsible for determining the Foundation's mission, approving goals and priorities, setting policies and helping to plan for the Foundation's future. The Board of Directors consists of a variety of medical and dental professionals, Sjögren's patients and patient family members, all working together to forward the mission of the SSF.

But what qualifies someone to be a member of the Board of Directors? We thought we would follow the path of two of our newest members: long-time patient Pamela Brown and Sjögren's researcher Denise Faustman, MD, PhD.

Tell us a little about yourselves.

Pamela Brown:

I grew up in Nashville, Illinois, and graduated from Concordia Teachers College in River Forest, Illinois, with a degree in elementary education. After teaching for several years in Indianapolis, I moved to Atlanta where I met my husband, Harold.

I worked for the federal government then but quit to stay home with our son after he was born. For the past 21 years, until retiring this February, I have worked at Gwinnett County Public Schools as an administrative assistant in the Special Education Department. Our son and daughter are both married, and we have four grandchildren. I am looking forward to the next phase of my life where I plan to try new things and do things I enjoy.

Denise Faustman: I have an MD and PhD. I originally thought I wanted to be a clinician, so I trained in medicine and endocrinology only to find out that, when I had all that clinical training complete, I was



Denise Faustman, MD, PhD



Pamela Brown

bored with clinical practice. I felt as a pure MD I was not making an impact on people, merely telling people the same message over-and-over again. I think I can now accomplish more in my life by doing research in Sjögren's and moving it forward as clinical trials.

How did you get involved with Sjögren's?

Pamela Brown: I was diagnosed with Sjögren's approximately 25 years ago when my parotid glands became so swollen I couldn't eat. I was fortunate to be diagnosed within just a few months, as opposed to years. I first learned of the Sjögren's Syndrome Foundation from my rheumatologist. Elaine Harris had started the Foundation less than a year earlier, and I quickly joined so I could learn as much as possible about the disease. (This was, of course, long before the days of the Internet and search engines.) I became a member of a local support group, and within a couple of years became the leader.

continued page 12 ▼

"Be Prepared" continued from page 1 ▼

will provide useful information for making this decision. If a practitioner is not open to learning about Sjögren's, then I know immediately that this relationship isn't a good fit. While this can be discouraging to realize, it is far more challenging to try to work with a physician who is not willing to learn about our complex syndrome.

Secondly, before an appointment, I gather three pieces of information:

- Copies of my last few lab and test results.
- A typed list of my current medications/supplements with dosages.
- A typed list of significant medical conditions/injuries with corresponding dates and treatments (the last two are kept as easily updated documents on my computer).

Providing my new practitioner with these lists helps expedite my appointment and serves as an indicator that I am serious about taking an active roll in managing my health.

Depending on the situation, I also have brought a copy of *The Sjögren's Syndrome Handbook* to give to the physician along with a copy of *The Sjögren's Quarterly* which I offer to have sent to them. I explain that a great deal more has been learned about Sjögren's in the last 5-10 years, including the fact that many patients experience more systemic disease involvement than previously understood (many doctors still only relate dry eyes and dry mouth with Sjögren's). I also inform them that while significant medical ground has been gained, it still takes, on average, seven years to diagnose Sjögren's. This is a mind-numbing statistic considering it is the second-most-common autoimmune disease, affecting nearly four million Americans.

Bringing a medical history binder to my appointments also has been extremely helpful. I use a large three-ring binder divided by medical specialty (including copies of office visit records), lab results, testing results, new treatment information, medication records, and notes. Because my binder is ridiculously thick, I keep it in my tote bag, out of sight, until I need to reference something. Several times I was able to provide missing lab results which provided the basis for immediate changes in treatment.

The last matter of business for my new doctor visit is the establishment of clear guidelines regarding medical management and communication procedures. Understanding medical management means clarifying what things I will see this doctor for and what conditions will predicate a visit to a different member of my "medical team." I also work with my practitioner to determine who will be the "chief navigator of my ship." This may sound simple as I imagine it is widely understood that a rheumatologist would always function as a Sjögren's patient's main physician. However, depending on a number of factors, including insurance coverage, appointment availability, geography and perhaps even a practitioner's interest in managing a patient with Sjögren's, that question can have a myriad of answers. I also discuss how various physicians communicate my care to one another, so that my main physician will have a complete picture of my health. Furthermore, understanding the new physician's office procedures for sick or same-day visits, medication refills and how often I should be seen for follow-up care are good questions to have answered on your first visit.

Establishing a successful relationship with a physician is like establishing a relationship with a friend. It requires understanding, patience, effective communication and a sense of humor. ■



Ruth Strickland Price

Leaving a Legacy of Hope

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.

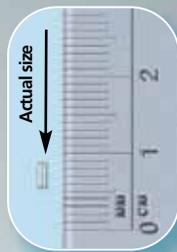
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LACRISERT® is contraindicated in patients who are hypersensitive to hydroxypropyl cellulose. The following adverse reactions have been reported in patients treated with LACRISERT® but were, in most instances, mild and temporary: blurring of vision, eye discomfort or irritation, matting or stickiness of eyelashes and red eyes. If improperly placed, LACRISERT® may result in corneal abrasion.

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"Sjögren's Diagnosis" continued from page 2 ▼

disease course, and response to treatment. However, on a day-to-day basis, a practicing physician encounters patients with Sjögren's who need care but may not fit the American-European Consensus Criteria.

First let's look at the criteria. In order to meet them, a patient must have four positive out of the following six, as long as the labial gland biopsy and the autoantibodies are not both negative, and none of the exclusions may apply.

The American-European Consensus Criteria

- Subjective dry eyes (my eyes are dry, feel gritty and I have difficulty making tears)

- Objective dry eyes (positive Schirmer's test, positive Rose-Bengal staining)
- Subjective dry mouth (my mouth is dry; I have altered taste and dysesthesias)
- Objective dry mouth (decreased salivary flow tests, positive sialography)
- Positive autoantibodies (SSA, SSB antibodies)
- Positive labial gland biopsy
- Exclusions: anti-cholinergic drugs, HIV, Hepatitis C, lymphoma, sarcoidosis, radiation therapy

I would like to tell you about some of the problems with using the American-European criteria for making the diagnosis in clinical practice. We know that many patients have the disease for many years before it is properly diagnosed. I have a patient in my practice who has Sjögren's, but she came to me many years after she had symptoms and was not treated aggressively during that time. About five years ago she was diagnosed as having a B-cell lymphoma and was successfully treated by a local oncologist. By the time she saw me, she clearly had had manifestations of Sjögren's for many years, but because her lymphoma was diagnosed first, she was excluded by the American-European Consensus due to her lymphoma history. Sjögren's is strongly associated with B-cell lymphoma. It is more likely to occur in patients who are SSA positive and have hypergammaglobulinemia, as my patient did.

Elderly women in my community often are taking anticholinergic medications for bladder control. These can contribute to dry eyes and dry mouth. In order to qualify for the consensus criteria, these patients have to be tested off of their medication. Otherwise they must be excluded according to the criteria.

There are many patients with hepatitis C who exhibit signs and symptoms of Sjögren's, yet they are excluded by the consensus criteria. Do they have primary or secondary Sjögren's? Since we don't know yet what causes Sjögren's, doesn't this group of patients provide a valuable human model for study?

I have found that there are many clues in a patient's history that can lead to the diagnosis of Sjögren's, sometimes before significant symptomatic sicca (dry eye and dry mouth) symptoms are present. Thyroid disease, esophageal dysfunction, neuropathies, joint pain, hoarseness, recurrent respiratory problems, fatigue, lymph node enlargement, and rashes are all clues to possible systemic problems associated with Sjögren's. A physician who pays attention to these findings, along with the findings of autoantibodies and

continued page 10 ▼

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P H A R M A

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DESCRIPTION

LACRISERT™ Ophthalmic Insert is a sterile, translucent, rod-shaped, water soluble, ophthalmic insert made of hydroxypropyl cellulose, for administration into the inferior cul-de-sac of the eye.

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INDICATIONS AND USAGE

LACRISERT is indicated in patients with moderate to severe dry eye syndromes, including keratoconjunctivitis sicca. LACRISERT is indicated especially in patients who remain symptomatic after an adequate trial of therapy with artificial tear solutions. LACRISERT is also indicated for patients with exposure keratitis, decreased corneal sensitivity, and recurrent corneal erosions.

CONTRAINDICATIONS

LACRISERT is contraindicated in patients who are hypersensitive to hydroxypropyl cellulose.

WARNINGS

Instructions for inserting and removing LACRISERT should be carefully followed.

PRECAUTIONS

General

If improperly placed, LACRISERT may result in corneal abrasion.

Information for Patients

Patients should be advised to follow the instructions for using LACRISERT which accompany the package. Because this product may produce transient blurring of vision, patients should be instructed to exercise caution when operating hazardous machinery or driving a motor vehicle.

Carcinogenesis, Mutagenesis, Impairment of Fertility

Feeding of hydroxypropyl cellulose to rats at levels up to 5% of their diet produced no gross or histopathologic changes or other deleterious effects.

Pediatric Use

Safety and effectiveness in pediatric patients have not been established.

Geriatric Use

No overall differences in safety or effectiveness have been observed between elderly and younger patients.

ADVERSE REACTIONS

The following adverse reactions have been reported in patients treated with LACRISERT, but were in most instances mild and transient: transient blurring of vision, ocular discomfort or irritation, matting or stickiness of eyelashes, photophobia, hypersensitivity, edema of the eyelids, and hyperemia.

DOSAGE AND ADMINISTRATION

One LACRISERT ophthalmic insert in each eye once daily is usually sufficient to relieve the symptoms associated with moderate to severe dry eye syndromes. Individual patients may require more flexibility in the use of LACRISERT; some patients may require twice daily use for optimal results.

Clinical experience with LACRISERT indicates that in some patients several weeks may be required before satisfactory improvement of symptoms is achieved.

Issued June 2007

References: Koffler BH; for the LAC-07-01 Study Group. Lacrisert (hydroxypropyl cellulose ophthalmic inserts) significantly improves symptoms of dry eye syndrome (DES) and patient quality of life. Poster presented at: Association for Research in Vision and Ophthalmology (ARVO) 2009 Annual Meeting; May 3-7, 2009; Orlando, Florida. 2. Katz JI, Kaufman HE, Breslin C, Katz IM. Slow-release artificial tears and the treatment of keratitis sicca. *Ophthalmology*. 1978;85(8):787-793. 3. Lacrisert [package insert]. Lawrenceville, NJ: Aton Pharma, Inc.; 2007. 4. Hill JC. Slow-release artificial tear inserts in the treatment of dry eyes in patients with rheumatoid arthritis. *Br J Ophthalmol*. 1989;73(2):151-154.



I Stood Up...

Ben Dillon
Mesa, Arizona

The Sjögren's Syndrome Foundation's Little Voices national spokesperson, Ben Dillon, from Mesa, Arizona, has once again proven that anyone can *Stand up for Sjögren's*.

Equipped with knowledge and driven through love for his grandmother, who has Sjögren's, Ben decided that he would once again educate his school's staff and fellow students. That is why this past January, Ben and his mother Pam arranged for him to visit students in elementary classrooms and schools in the Phoenix area to educate them about Sjögren's.

Ben talked about his grandmother's experience of living with Sjögren's and how it can affect the body. He provided coloring pages, which described the symptoms of Sjögren's and explained how those affected have limitations and are not able to live their lives like everyone else.

In addition, thanks to Vimal Patel of Time4Health of Scottsdale, Ben was able to distribute piggy banks to the schools to have his fellow students collect pennies for Sjögren's.

From his presentations to the *Little Voices* coloring pages to the Sjögren's piggy banks, Ben once again *Stood Up For Sjögren's*, helping to increase awareness and make a difference.

Ben then attended the *Phoenix Area Walkabout* along with his new friends from the classrooms and turned in the piggy banks full of the change they collected!

Congratulations, Ben! Thanks for Standing Up and making a difference! ■



Longview Elementary School students present a wagonful of piggy banks to Foundation CEO Steven Taylor at the Phoenix Area Walkabout.



"Sjögren's Diagnosis" continued from page 8 ▼

elevated markers of inflammation such as an elevated sedimentation rate or C-reactive protein, may suspect that the patient has an autoimmune disease or Sjögren's. If the patient has a positive SSA or SSB antibody and the features of the disease, the physician usually will make the diagnosis. If the SSA and SSB antibodies are not present, a labial gland biopsy will be essential to help make the diagnosis.

Making the diagnosis of Sjögren's syndrome is important to allow the physician to offer the patient early therapy that may help the symptoms and delay progression of the disease. The key to the diagnosis is to have an index of suspicion that the condition may be present. If your physician is not familiar with the manifestations of Sjögren's, it is unlikely that he or she will be able to diagnose this disease, especially if the SSA and SSB antibodies are not present or their presence has not been determined due to a lack of laboratory testing. ■



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In Honor of Dr. Gary Foulks

Diane R. Parker

In Honor of Dr. Harry Spiera

Elizabeth Farishian

In Honor of Joseph Galtman's Bar Mitzvah

Deirdre & Stephen Perl-Strock

In Honor of Penny Oliver

Susan Oliver

In Honor of Yvette Gontkovsky's Birthday

Kris, BJ & Miyah Gontkovsky

In Honor of Zachary Borine's Bar Mitzvah

Deirdre & Stephen Perl-Strock



in memoriam

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"Board of Directors Q&A" continued from page 5 ▼

Over the years I have also helped organize and chair several events in the Atlanta area, been a contact person for newly diagnosed patients, manned booths at numerous medical conferences, and become friends with several of the Board Members. I have watched the Foundation evolve into the incredible organization it is today. The dedication of Steve, his staff, and the Board has made such a difference. The amount of information available is amazing and makes it so much easier for patients, physicians and dentists to learn about the disease and its various manifestations. Quite a difference from when I was diagnosed!

Denise Faustman: As my colleagues know, I work on two autoimmune diseases: diabetes and Sjögren's. I always say that I did not find Sjögren's, but Sjögren's keeps finding me. There is more money to work on diabetes but I find the problems of Sjögren's so clinically relevant and the data in a mouse model of Sjögren's so compelling to bring forward to patients. I also think the Sjögren's research community members are so supportive and interactive. It is a pleasure to work in Sjögren's as a researcher and share concepts in such a collegial manner.

In your opinion, where do you see the SSF making the biggest impact for Sjögren's in the next five years?

Pamela Brown: One of the biggest impacts I see will be the increased awareness and education of patients and families, physicians, dentists and legislators. From the perspective of a patient, I am hoping that a huge impact will be made in the area of research funded by grants which will undoubtedly help find new treat-

ments to make our lives more comfortable and possibly find a cause and cure.

Denise Faustman: Money for research! Money for research!

Everyone is so busy these days, so why did you decide to accept a volunteer board position?

Pamela Brown: I actually have more free time now that I am retired, but that really didn't influence my decision to accept the position on the Board as much as one would think. I was quite honored when Steve Taylor (SSF CEO) asked if I would consider being nominated to serve and be a part of such a distinguished group of professionals and patients. As a patient, the work of the SSF is important to me, and if I can make a contribution by being on the Board of Directors, then I consider it a privilege, and it gives me a sense of pride that I am doing something to help myself and others who have the disease.

Denise Faustman: I think the research money the Sjögren's Syndrome Foundation raises and distributes is HIGH IMPACT money. It is money that tests new ideas, and the SSF is open to new ideas to help people. I wanted to give my time to make sure money raised continues to support the innovations that make big changes.

The Sjögren's Syndrome Foundation is honored that so many talented and passionate people have volunteered their valuable time to help the Foundation continue to move forward. A full list of our Board members and officers can be found on page two. We want to thank each of them for their continued support and dedication to the Foundation. ▮

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Are there any contraindications for Sjögren's patients who are thinking of having laparoscopic gastric band surgery or gastric bypass surgery?

Obesity and its complications have become a major health issue in the United States. Bariatric surgery is the term used for surgery that is done to aid in weight loss. The most commonly performed bariatric surgery procedures are laparoscopic adjustable gastric banding (lap banding) and Roux-en-Y gastric bypass.

Lap banding involves the placement of an adjustable band around the opening of the stomach, thereby reducing the effective volume of the stomach and the amount of food that one can eat at a given time. Using a needle to instill fluid into a port in the band, the size of the band can be adjusted, which allows for control of volume of the stomach. Lap banding is a relatively popular choice because the surgery is done

laparoscopically, it is reversible, and the underlying anatomy of the gastrointestinal tract is not changed (that is, no portion of the GI tract is bypassed). The success of a lap band surgery depends on the ability of the individual to adhere to their new dietary regimen. An individual with a lap band who continues to eat a high volume of high-calorie foods will not experience weight loss.

Roux-en-Y gastric bypass is a surgical procedure where, not only is the volume of the stomach reduced, but a large portion of the intestinal tract is surgically bypassed, thus reducing the amount of calories that can be absorbed. This surgery is permanent and can

continued page 15 ▼



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by Rosalind Joffe and Joan Friedlander

Women, Work, and Autoimmune Disease is a book for women who live with chronic illness, encouraging them to stay employed to preserve their independence and sense of self.

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See Resource Order Form on Page 14

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The Sjögren's Syndrome Survival Guide by Teri P. Rumpf, PhD, and Kathy Hammitt. A complete resource for Sjögren's sufferers, providing medical information, research results, and treatment methods as well as the most effective and practical self-help strategies.	\$15	\$13		
A Body Out of Balance by Ruth Femes, MA, and Nancy Carteron, MD, FACR. A Sjögren's patient and a doctor offer their authoritative insight into one of the most common yet most misunderstood autoimmune disorders.	\$13	\$10		
The Autoimmune Connection: Essential Information for Women on Diagnosis, Treatment, and Getting on with Your Life by Rita Baron-Faust and Jill P. Buyon, MD. This book covers the full spectrum of autoimmunity and the myriad ways it influences the lives of women.	\$19	\$15		
The Balance Within: The Science Connecting Health and Emotions by Esther M. Sternberg, MD. Sternberg, a neuroscientist at NIH, writes on the connection between your mind, your emotions and your immune system. This book details how the brain and immune system are connected and how you can harness that connection to fight your sickness.	\$15	\$11		
Women, Work and Autoimmune Disease by Rosalind Joffe and Joan Friedlander. A book for women who live with chronic illness, encouraging them to stay employed to preserve their independence and sense of self.	\$17	\$14		
Chronic Pain For Dummies by Stuart Kassan, MD, et. al. This reassuring, practical guide helps you understand what causes pain and how to manage it with the newest pain-relieving techniques.	\$18	\$15		
Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop by Norman Latov, MD, PhD. Peripheral neuropathy is a widespread disease, yet many people do not even realize they have it. If you experience pain, numbness, or tingling in your feet or other extremities, this book is for you.	\$19	\$16		
You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life by Mims Cushing and Norman Latov, MD. A compendium of tips, techniques, and life-task shortcuts that will help everyone who lives with this painful condition.	\$19	\$16		
Vulvodynia Survival Guide: How to Overcome Painful Vaginal Symptoms & Enjoy an Active Lifestyle by Howard I. Glazer, PhD and Gae Rodke, MD, FACOG. A great resource for anyone experiencing vulvodynia symptoms. This book will help readers identify triggers, reduce symptoms, find medical help, reduce pain, and renew their enjoyment of life.	\$16	\$13		
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The Memory Bible: An Innovative Strategy for Keeping Your Brain Young by Gary Small, MD. This program has helped thousands of people improve their ability to remember everyday issues like where their car is parked as well as more important abilities to think fast and maintain a healthy brain.	\$16	\$13		
I-Can't-Chew Cookbook by J. Randy Wilson. The ultimate cookbook for people with chewing, swallowing and dry-mouth disorders. Inside are 200 soft and tasty recipes and each recipe comes with complete nutritional analysis.	\$16	\$14		
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"Information" continued from page 13 ▼

be done in either an open or laparoscopic procedure. Weight loss associated with gastric bypass may be slightly higher than that seen with lap banding; however, nutritional deficiencies, due to malabsorption of certain vitamins and nutrients, can be seen in individuals with gastric bypass. Life-long vitamin supplementation may be required.

The safety of bariatric surgery in individuals with Sjögren's syndrome depends on the degree of underlying autoimmune inflammation and whether there are any Sjögren's-related gastrointestinal diseases present. In some individuals with Sjögren's or other autoimmune diseases, dysmotility of the esophagus can be seen, typically presenting as difficulty swallowing.

Reduction in gastric volume through either procedure could exacerbate these symptoms. Some individuals with Sjögren's may have atrophic gastritis, celiac sprue, or liver diseases associated with autoimmune inflammation. These conditions can lead to malabsorption of vitamins and nutrients. Any individual with Sjögren's who has evidence of nutritional deficiencies pre-surgery may not be a good candidate for gastric bypass, which would only worsen those nutritional issues.

Before any bariatric surgery, you should have a thorough discussion with both your physician and your surgeon regarding the risks and benefits of the procedure and how your Sjögren's may affect the outcome.

Matthew Nichols, MD

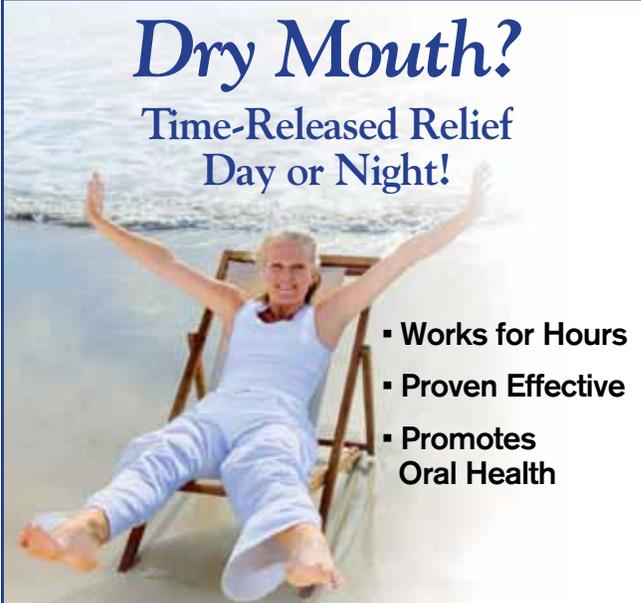


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We Need Your Support For Sjögren's Research!

The Sjögren's Syndrome Foundation is proud of our highly respected Sjögren's Research Program. We have, for the past six years, increased our funding for Sjögren's research every Spring. This year, we are hoping to continue that tradition by offering nearly \$300,000 in research grants to promising Sjögren's projects, but we need your help. Funding is in need to ensure that we reach that goal.

Each year, the Foundation staff and research volunteers work diligently to attract talented and dedicated scientists to our research program. We foster relationships with top researchers in the field of Sjögren's, as well as autoimmune diseases, in hopes they will consider conducting Sjögren's research.

While we have made great progress, we need your help this year to ensure we can fund more research projects than last year. In 2009, we turned away sixteen promising projects due to lack of funding, and 2010 is shaping up to be the same ratio. Every project that is turned away means one less chance for a breakthrough in our fight against Sjögren's syndrome.

Our goal is to increase our research program this year once again but we need your help. We hope you will consider making a donation to the SSF Research Program so that we can ensure more research is done for Sjögren's.

Please use the form below to make your donation or contact the Foundation directly by calling 800-475-6473.

On behalf of Sjögren's patients, thank you for believing in the Sjögren's Research Program! With your support, we will uncover potential therapies for patients as well as unlock the mystery of Sjögren's and find an overall cure.

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