

The moisture Seekers



Volume 28, Issue 4

April 2010

What can I do to protect my teeth?

information

you requested



It is a well-known fact that Sjögren's syndrome causes permanent and irreversible damage to the saliva-producing glands resulting in a loss of saliva (dry mouth) which reduces the natural protective functions of saliva, increasing the risk for dental caries (cavities), plaque, and gingivitis. Saliva plays a critical role in the maintenance of oral and dental health. Human saliva is composed of 98% water, while the other 2% consists of electrolytes, mucus, antibacterial compounds, and various enzymes. The enzymes in saliva break down some of the starch and fat present in food as part of the digestive process and also break down food caught in the teeth, protecting them from bacteria that cause decay. Furthermore, saliva lubricates and protects the teeth, the tongue, and the tender tissues inside the mouth.

In the absence of the protective factors of saliva, compliance to a strict oral hygiene regimen and regular professional dental care is essential for

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Q *What are some tips you have as a Sjögren's patient for fighting fatigue?*

A Fatigue is one of the most difficult symptoms of Sjögren's syndrome for most patients to deal with. Some things I find helpful in beating the fatigue are:

1. Planning my activities – I make sure not to over plan. If I have an activity in the morning and evening, I make sure I have some down time in between to rest. Sometimes there will be an all-day event, and I plan to leave the next day open so I can crash if I need to.
2. Sleeping – I try to keep my sleep schedule consistent, going to bed at the same time and waking at the same time. This isn't always easy since I have difficulty falling asleep and I get up through the night to use the bathroom. Try to figure how many hours of sleep you need to feel your best and plan to sleep that long. I need ten hours; eight is just not enough.
3. Traveling – Traveling really exhausts me. If I'm driving, I plan my trip when I get up in the morning or after a rest period. I also plan to travel during off-peak hours so I don't have to deal with a lot of

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On Your Mind
Patients speak on coping with the realities of Sjögren's syndrome.

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traffic. When I fly, I always try to get a direct flight. I'll travel to a larger city and stay overnight so I can wake up fresh and don't have to drive to the airport and then fly in the same day.

- Pushing through fatigue – Sometimes I am just tired no matter what. On those days I push myself to get going, try and take a walk for 20 -30 minutes, or resort to a caffeine boost! Some days nothing works and I just need to sleep and let my body recoup. Give in to those days as long as they don't occur too often.

*Lynn Petrucci, RN
Mechanicsburg, Pennsylvania*

Q *What are some of the ways that you cope with Brain Fog?*

A My computer is my brain! As a Foundation volunteer, I keep track of who I have contacted and what people are doing by documenting everything as I am doing. This way I have a reference... I know exactly what I did and who I called on what date and what was said.

I write down every doctor appointment, any dates and times of occurrences on the master calendar hanging in my kitchen, including all birthdays, anniversaries, etc. I write all birthdays and anniversaries in red at the bottom of the calendar day so I know that it is not an appointment that I have to go to. I keep it in my kitchen as it is easily accessed when I might need to refer to it while on the phone.

I match a calendar kept in my purse to the master calendar that I keep in my kitchen. This way, I can keep track of all of my appointments and know just exactly if I am available at any certain time-frame.

It is so hard for others to understand my brain fog. It is frustrating to me because I was never like this before and Sjögren's has surely affected my life.

*Maurine Daniels
Centennial, Colorado*



**Do we have
your e-mail
address?**

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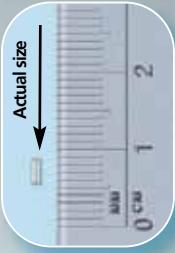
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LACRISERT® is contraindicated in patients who are hypersensitive to hydroxypropyl cellulose. The following adverse reactions have been reported in patients treated with LACRISERT® but were, in most instances, mild and temporary: blurring of vision,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

Please see brief summary of Prescribing Information on adjacent page.



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those suffering from Sjögren's syndrome. If health and conditions permit, medications (pilocarpine, cevimeline) are titrated to a maximum dose to stimulate salivary glands and increase salivary production. Unfortunately, that is not enough. Meticulous care is necessary to prevent the development of cavities and can be accomplished with the following recommendations:

- Frequent flossing and brushing of both teeth and tongue, preferably with a mechanical toothbrush such as Sonicare® or Oral B Sonic®, has shown that stimulating the tongue and the roof of the mouth simultaneously results in impulses to all residual salivary tissue in the oral and pharyngeal regions, causing salivation through sonic



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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 JL, 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: Atton 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.

vibrations. In conjunction with frequent flossing, these vibrations efficiently remove bacteria and food particles.

- Chewing xylitol-containing gum also can stimulate salivary production and reduce the development of caries.
- It is also recommended that the frequency of eating or snacking be limited to avoid further risk. Rinsing the mouth after each meal with water, milk or low-fluoride-containing rinses reduces the amount of bacteria in the mouth.
- Prescription strength toothpaste (e.g. Prevident 5000, SF 5000) is strongly advised and must be applied (not rinsed) especially before going to bed.
- Additionally, applications of remineralizing solutions and pastes (e.g. Caphosol, Renew, MI Paste, Oravive, etc.) strengthen teeth and provide further protection from decay.
- Regular dental visits every three months with the application of a high-fluoride-containing varnish (e.g. Vanish, Enamel Pro, Duraphat) are necessary for additional protective benefits.

Despite the oral challenges faced by those suffering from Sjögren's syndrome, adherence to the above recommendations have proven to be beneficial in the fight against dental caries.

Mabi L. Singh, DMD, MS and Athena S Papas, DMD, PhD
Tufts University School of Dental Medicine

Q How effective are saliva substitutes?

A Treatment strategies for xerostomia can be categorized as the following:

1. Mechanical/taste stimulants (chewing gum or sucking on lozenges),
2. Topical (saliva substitutes and mouth rinses) and
3. Systemic (e.g. pilocarpine or cevimeline).

To determine the best management approach for xerostomia complaints and for the prevention of oral complications from low salivary flow, the level of residual salivary flow can be helpful. The amount of residual flow is established by comparing the unstimulated versus the stimulated salivary flow. If there is decreased saliva but significantly more stimulated compared to unstimulated salivary flow, then treatment of dry mouth

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Enjoy the April Awareness issue of The Moisture Seekers!

by Steven Taylor, CEO

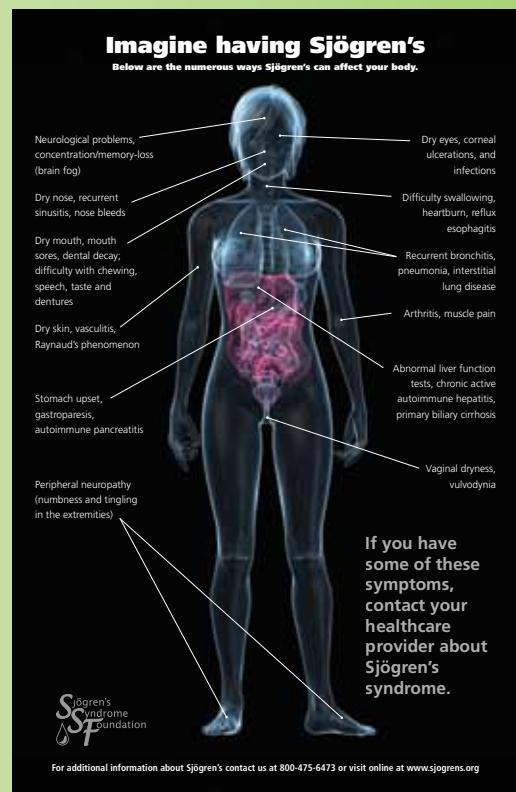
This issue is usually our most sought after issue because for the past five years the April issue has been filled with just Questions and Answers about all different issues surrounding Sjögren's and/or the Foundation. It is also our issue where we highlight Sjögren's Syndrome Awareness Month.

To give you a little background, in 1998, Congresswoman Louise Slaughter from New York, encouraged by the staff and volunteers of the Sjögren's Syndrome Foundation, read into the Congressional Record that April is Sjögren's Awareness Month. And today it is still celebrated.

Rest assured the Foundation works year round on awareness activities, but April is our biggest month to ask all of you to Stand Up for Sjögren's! We ask you to take part in two very important campaigns each April.

First is our Friends Helping Friends campaign. This annual campaign is designed for you to mail letters to your friends and family in an effort to educate them about Sjögren's. We mail each of you five letters for you to send out. However, we encourage you to make additional copies and mail to as many people as you would like. This year's letters, which you already will have received by the time you see this newsletter, are aimed at the more serious side of Sjögren's. We hope that by doing this, your friends and family will understand how complicated Sjögren's can be.

Second is our 2010 Awareness campaign, called *Imagine*. This campaign is aimed at helping others understand what it is like to suffer from Sjögren's. Our entire campaign is focused around the various symptoms, complications and fears that Sjögren's patients live with after a diagnosis. In the *Imagine* packet,



Our Awareness Campaign Poster.

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should focus on mechanical/taste stimulants and systemic treatments, with additional topical therapies as needed and/or tolerated. On the other hand, if there is decreased salivary flow, with no difference in the unstimulated and stimulated salivary flow, techniques to stimulate flow will be of limited value (i.e. mechanical/taste stimulants and systemic), and use of topical therapies needs to be considered.

Commercially available saliva substitutes often contain thickening agents such as carboxymethyl cellulose, mucin or xanthan gum. Recently, saliva substitutes based upon polymer chemistry have been developed. More gel-type (vs. liquid-type) saliva substitutes have also been developed.

There is clearly a role for the use of saliva replacements, particularly in individuals who have no residual salivary gland function. Preferences for these different saliva substitutes are quite variable from patient to patient; therefore, trying the different substitutes is often the best approach to determine individual preference. Some patients will object to the taste or inconvenience of using artificial saliva frequently during the day and will often return to use of water. Other patients have also reported burning associated with the use of saliva substitutes.

In summary, saliva substitutes are safe and have been found to be beneficial in some patients. Tolerability and efficacy are different for each patient; therefore, different types of saliva substitutes should be tried to select if this is an effective approach for the management of xerostomia.

Michael Brennan, DDS, MHS

Q *What basic treatments are available for chronic vaginal yeast infections when basic over-the-counter medications don't seem to be working?*

A Vaginal yeast infections occur when there is a change in the vaginal environment. This can occur in a variety of situations such as during pregnancy, oral contraceptive pill use, antibiotic use or medical conditions associated with immune system problems. Routine hygienic measures such as douching or wearing synthetic undergarments may also put one at risk of developing chronic yeast infections. Other common causes for chronic yeast infection include inadequate treatment or lack of adherence to treatment, widespread use of OTC medication leading to resistant infection, recurrent short courses of antibiotics and long-term use of antifungals.

Over-the-counter (OTC) antifungal treatments for vaginal yeast infections have enabled women to treat themselves when they have symptoms of itching and cheesy vaginal discharge and the signs of redness and swelling of the vulva. The currently available OTC medication includes topical creams and vaginal suppositories. Examples of OTC preparations available include Clotrimazole 1% cream, Butoconazole 1% and 2% cream, Miconazole 1% and 2% cream, Terconazole 6.5% ointment or Miconazole 200mg, Terconazole 80mg or Clotrimazole 100mg vaginal suppositories.

When vaginal yeast infections occur four or more times a year, they are considered chronic. If symptoms are chronic, women should see their physician to confirm the diagnosis and determine that their symptoms are, in fact, caused by a yeast infection. The physician can also determine whether the yeast is resistant to the medication they have been using for treatment. One type of yeast infection which is increasingly resistant to Miconazole and other Imidazoles is *Candida glabrata*. *C. glabrata* is best treated with Terconazole ointment.

If a woman has burning or pain shortly after the treatment is applied, she may be experiencing irritation to the topical agent and, in some cases, may have developed an allergy to an ingredient. In this circumstance, it is also reasonable for her to see her doctor, so that an oral treatment can be used.

Options for oral antifungal therapy include fluconazole (Diflucan) 150mg, Itraconazole 100mg or Ketoconazole 200mg. Systemic therapy is sometimes associated with side effects including nausea, vomiting and stomach pain as well as allergic reactions.

The courses of these treatments vary from a single dose to a week-long treatment. Most uncomplicated yeast infections respond well to 3-7 days oral or topical antifungal treatment, while recurrent. Chronic infections are usually treated with once-daily or once-weekly dosing for 2 to 4 months or a lower prophylactic dose weekly or monthly for up to 6 months.

It is important to eliminate other causes of vaginitis before attributing symptoms to chronic yeast vaginitis. If chronic yeast infection is diagnosed, treatment may be necessary until a culture is negative.

Pamela Stratton, MD and Suhasini Kaushal, MD

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Ask the Staff



Why did you start a marathon training program when people with Sjögren's can't run?

We understand that some Sjögren's patients are unable to run due to joint issues, and some even have challenges with walking. However, many of our Sjögren's patients still lead active lives that include regular exercise and strength training. Even still, *Team Sjögren's* was not established to necessarily attract Sjögren's patients as participants. Our initial goal was to involve those who love Sjögren's patients – have them step up and take on this challenge in honor of the person they know with Sjögren's.

In the past year, *Team Sjögren's* has raised nearly \$50,000 and completed two marathon training programs – the Nashville Country Music Marathon in April 2009 and San Antonio Rock 'n' Roll Marathon in November 2009. Each training program saw loved ones of Sjögren's patients training and raising funds for Sjögren's research. This is truly wonderful. But possibly even more impressive is that our training program has included numerous Sjögren's patients. And on April 24th, the Foundation will be returning for our second Country Music Marathon with a stronger team than before. We have 16 new trainees joining us, four of whom are Sjögren's patients.

With that said, not all Sjögren's patients can participate in all of our programs. That is why the Foundation has three signature events – *Walkabout*, *Sip for Sjögren's*, and *Team Sjögren's*. Together, each of these events attracts a different group of patients and supporters. As the saying goes, not everything will be your cup of tea, but we hope you will find something you can do to Stand Up for Sjögren's!

*Steven Taylor
SSF Chief Executive Officer*

How can I get more connected with the SSF?

There are numerous ways to be more involved with the Sjögren's Syndrome Foundation:

- Give us your most recent e-mail address. This way you will be sure to receive our monthly updates on Sjögren's and SSF news as well as any other updates sent out to our e-mail list, such as Support Group meetings, events or seminars happening in your area.
- Log in to our Member Community. Make sure you

have the correct login information for our website so you can visit our Member Community at www.sjogrens.org. There you can view both current and archived issues of *The Moisture Seekers*, Information You Requested split up by categories, our full list of brochures and fact sheets, as well as the most up-to-date version of our Product Directory.

- Attend events in your area. From being part of the crowd at a Sjögren's *Walkabout*, to tasting water at a *Sip for Sjögren's*, to volunteering along the marathon route at *Team Sjögren's*, all of our events are great ways to get connected. Not only do they raise vital funds supporting Sjögren's research and education, but they are a great way to raise awareness. And the more attendees we have at events, the more effective they are at raising awareness.
- Go to a Support Group meeting. With over 87 active Support Groups around the country, there is a good chance you can find one in your area. Most Support Groups meet several times a year, offering a wonderful opportunity to talk with other Sjögren's patients, and often hear an expert speak about Sjögren's. Contact the SSF office or visit www.sjogrens.org/supportgroups to learn more.
- Subscribe to the *Sjögren's Quarterly*. This professional journal is written for dentists and physicians, but many Sjögren's patients have become such strong medical advocates that they can learn quite a bit of information from this quarterly journal. Subscriptions are \$18 a year. Contact the Foundation office to learn more.

*Pat Spolyar
Director of Awareness*

How long does it take to put together an issue of The Moisture Seekers?

Planning and publishing *The Moisture Seekers* is an ongoing process. Some issues are in the planning stages months in advance before reaching your mailbox. Our Publication Committee is constantly working on future issues, talking with doctors, finding new articles, and scouring other resources for additional content that we think our readers will find interesting and educational.

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We Stood Up...

The Taylor Family

Sjögren's awareness has become a family affair for Steven Taylor, the CEO of the Sjögren's Syndrome Foundation. Because his mother suffers from this debilitating disease, every member of Steve's family is often involved with Foundation events. From attending Walkabouts or health fairs to his children sharing information on Sjögren's at their school, Steven Taylor's family regularly Stands up for Sjögren's.

That involvement continued this past November when Steve, his mother, his twin sons Jack and Owen, and his nephew Jamie, ran in the Troy Turkey Trot in upstate New York. Each family member, proudly wearing *Team Sjögren's* shirts, stood together at the start line prompting many questions on what exactly *Team Sjögren's* is. Even Steve's children were involved, explaining the disease to fellow runners at the starting line.

The awareness raising continued into the race. While running, Steve's mother met a young fellow patient who happened to notice the *Team Sjögren's* shirt. They chatted for a portion of the race and a few weeks later the patient contacted the SSF to join the *Team Sjögren's* Marathon Training Program!

Remember, Standing Up for Sjögren's does not mean you have to organize an event or get an article placed in a newspaper. It can be as simple as wearing your *Team Sjögren's* shirt to walk, to a race, to the gym, or even to the grocery store. Watch the SSF website for offers to purchase *Team Sjögren's* t-shirts as well as awareness static stickers for your car.

Together, with everyone Standing Up, we will start to change the perception of Sjögren's and make it a household name. ■

The Taylor family poses for a photo before the Troy Turkey Trot.

L to R: Jack, Owen, Steven, Cathy, Jamie.



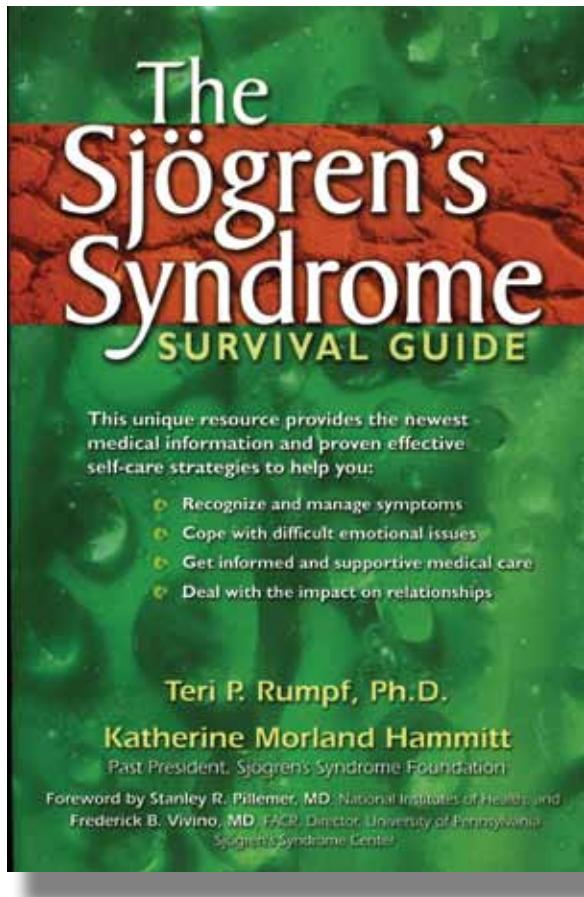
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The Sjögren's Syndrome Survival Guide

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.

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"Information You Requested" continued from page 6 ▼

Q Is it okay for a new mother with Sjögren's to breast-feed?

A Generally, women with Sjögren's can breast-feed. There is passage of protective antibodies that benefit the baby. Autoantibodies can be passed as well, but they will be degraded by the baby and not persist past their normal life span. These autoantibodies do not usually cause problems that we know about. The one exception is the SSB/La antibody could cause neonatal lupus, but this is self-limited if it occurs and is fairly rare.

I am not aware of any evidence that women with Sjögren's who breast-feed harm the baby in any way. In general, though, women with any autoimmune disorder should work with their specialist and OB/high-risk OB team during pregnancy to prevent possible problems.

Nancy Carteron, MD, FACR

Q I sometimes have trouble catching my breath, even at rest. What are the pulmonary complications of Sjögren's? Could my shortness of breath be related to my Sjögren's?

A Shortness of breath, or dyspnea, can result from many pulmonary, cardiac, and even emotional conditions. If you are pretty sure that moments of anxiety and possible hyperventilation are not responsible for your episodes of shortness of breath, then please consult with your doctor or a lung specialist.

Sjögren's can cause a variety of changes in the lung, ranging from excessive mucus interfering with air movement through collections of lymphoid tissue narrowing some of the tiny peripheral airways (obstructive bronchiolitis) to a stiffening of the lung by invasion of lymphocytes into the delicate fine structure of the lung (lymphocytic interstitial pneumonia). There are also other pulmonary abnormalities which have been less often associated with Sjögren's, and a pulmonary specialist can help look for these. Most of these problems are readily treatable. If the shortness of breath has been progressive, and especially if it is getting worse rapidly, you should consult your physician without delay, so he or she can evaluate for possible pleural fluid, heart failure, pneumonia, lymphoma, or other high-priority problems.

H. Kenneth Fisher, MD

Q What are some questions I should ask before going on prednisone or other steroid treatments?

A Prednisone and other corticosteroids (especially at higher doses) are among the fastest acting and most potent immunosuppressive therapies available. In Sjögren's these drugs have proven to be useful for management of inflammatory joint and muscle pain, fatigue, swollen glands, and serious internal organ involvement. However, like every therapy, steroids can have both short- and long-term side effects. Therefore, you should ask your physician the following questions in order to better understand the benefits and risks of treatment:

- What symptoms will improve if I decide to take this treatment?
- How long will it take to see a benefit?
- What dose of prednisone will I be taking and is it considered high, medium or low?
- How long will therapy be required?
- What are the most common short-term side effects?
- What side effects should I expect if I need this treatment long-term?
- Can I do anything to prevent side effects?
- How will side effects be monitored?

Frederick B. Vivino, MD, FACR

Q I've heard cleaning your eyelids is important. Why is that? How do you go about cleaning your eyelids and how often do you suggest it be repeated?

A The eyelid margin is a very important contributor to protection of the surface of the eye and stability of the tear film. Lid margin problems occur in two forms that can aggravate dry eye: anterior and posterior.

In patients with Sjögren's not only is there the problem of reduced production of liquid tears, but there is often a problem with obstruction of the glands in the eyelid that secrete lipid onto the tear film to prevent evaporation of the tears. These glands are called meibomian glands and your eye care practitioner may alert you to "meibomian gland dysfunction," which is the obstruction of the openings of the glands at the edge of the eyelid margin just behind the base of the eyelashes. Such obstruction leads to evaporative dry eye which

can aggravate the dry eye situation. Symptoms of the eyelid margin problem, meibomian gland dysfunction, can be irritation with redness of the eyelid margin and, frequently, difficulty reading or working at a computer.

The first step in managing the lid margin is lid hygiene and massage. The attached diagram illustrates the most effective method of massage to the eyelid. Precede the massage with application of warm compresses to the eyelid for at least a minute using a warm washcloth. Some patients will use a bag of rice heated in the microwave oven, but it is important not to use too much heat such that it turns the skin red or, worse yet, burns the skin of the eyelid or face. The heat melts the lipid secretion so that the massage can express the secretion. The massage is done with the flat, pulpy area of the index finger starting at the base of the nose and moving towards the ear. Four or five such swipes to compress the eyelid against the eyeball is usually all that is needed and the pressure should not be so great as to cause discomfort in the eyeball. I recommend to my patients to do the hot compress/massage method twice a day for a week then once a day thereafter. It is important to remember that you are trying to press on the eyelid to squeeze the glands in order to express the secretions.

If the hot compress/massage method does not completely resolve the plugging problem, it is possible to use either topical azithromycin solution (Azasite) once daily for two to four weeks to clear the problem. Some patients require the use of oral medications to treat the problem. Doxycycline by mouth once or twice daily for two months works well, but some patients do not tolerate the doxycycline due to upset stomach. Oral omega-3 essential fatty acids also have been reported to improve the meibomian gland secretion but usually require at least 3000 mg (three pills) per day to be effective.

It is important to remember that there are two types of lid margin problems. The meibomian gland dysfunction (the glands in the posterior eyelid) is the most common problem, but inflammation of the glands at the base of the eyelashes (anterior location in the eyelid) can cause irritation and crusting on the eyelashes. This problem responds best to eyelid wipes, such as Eye-Scrub pads. The daily use of the eyelid wipes helps to clear the crusts but if inflammation and irritation persist, then topically applied antibiotics or antibiotic/steroid combination therapy may be needed. Remember that the eyelid wipes do not control the posterior meibomian gland problem but only the anterior problem.

Since the occurrence of the eyelid margin problems can be so frequent, it is a good idea to practice good eyelid hygiene to prevent as well as treat the meibomian gland dysfunction or lid margin disease.

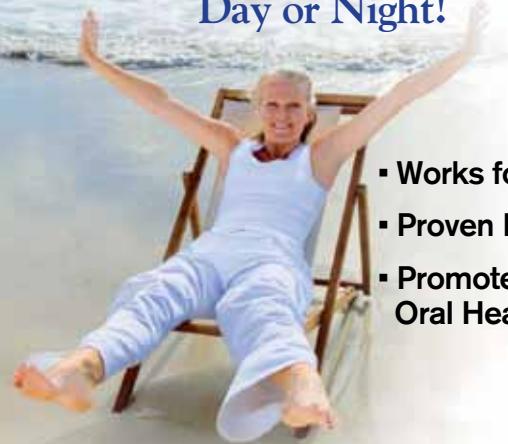
Gary Foulks, MD, FACS

Q *I was diagnosed with Sjögren's six years ago and that is the only autoimmune disease I have. What is the likelihood I will develop another autoimmune disease?*

A As with other autoimmune conditions, patients with primary Sjögren's are more likely to develop other autoimmune diseases than people without autoimmune diseases. Some of the autoimmune diseases associated with primary Sjögren's are Hashimoto's thyroiditis (also known as autoimmune thyroid disease), primary biliary cirrhosis, autoimmune hepatitis, pernicious anemia, celiac disease (sprue), and myasthenia gravis.

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"Information You Requested" continued from page 13 ▼

Hashimoto's thyroiditis is the most common autoimmune disease in patients with Sjögren's syndrome. It is manifested by the presence of antibodies directed against thyroid antigens (anti-thyroglobulin antibodies and anti-TPO antibodies) and patients may have normal (euthyroid), low (hypothyroidism) or high (hyperthyroidism) thyroid function. Most patients are euthyroid, some are hypothyroid and few are hyperthyroid. One study of 479 primary Sjögren's patients found the prevalence of Hashimoto's thyroiditis to be 6.26% compared with 1-2% reported in the general population. Another study found antithyroid antibodies were present in 11% of primary Sjögren's patients and 3% of healthy controls.

The risks of developing the other conditions listed above are not known. As they occur much less frequently in the general population, the risks in primary Sjögren's are, therefore, much lower than the risk of developing autoimmune thyroid disease.

The reason why patients with autoimmune diseases, including Sjögren's, develop other autoimmune diseases is not known. What is suspected is that patients with autoimmune diseases have a propensity towards autoimmunity in general and that this propensity is genetically based. This is supported by the finding of a higher prevalence of autoimmunity and autoimmune diseases (and not necessarily the same disease) in family members (parents, siblings and children) of patients with autoimmune diseases when compared with family members of non-autoimmune controls.

Neil I. Stahl, MD

Q Do men with Sjögren's have different symptoms from women?

A This is an interesting question, because in the past when I have reviewed my patient series for signs and symptoms, I didn't look for specific differences between the sexes. At the time I was interested in whether patients with SS-A and SS-B antibodies differed from those that didn't have these antibodies. So now I need to go back and look at the differences in signs and symptoms based on gender. In reviewing the literature, there are several studies that attempted to answer this question. Some of the studies were small series of patients, and thus could not reliably answer this question. The best study I could find was a fairly recent study that involved 492 Hungarian patients with Sjögren's. The female to male ratio was 7:1. Glandular and extraglan-

dular manifestations and immunoserological parameters were assessed. Vasculitis symptoms and lymph node enlargement were more frequent in men than in women; Raynaud's and thyroiditis were more frequent in women. Anti-SS-A and anti-SS-B were the most frequent autoantibodies and were seen in both genders.¹

Another study from Spain looked at a series of 223 patients with Sjögren's, but only 19 were men. The authors concluded "Except for a lower prevalence of articular involvement, we could not find any notable differences in clinical and immunological characteristics between male and female patients with primary SS."²

Thus, there may be slight differences in the populations of men and women with Sjögren's, but for any one person, it would be difficult to predict future signs and symptoms based on his or her gender.

Daniel Small, MD

1. Clin Rheumatol. 2008 Dec;27(12):1479-83. Epub 2008 Jun 14.

2. Scandinavian Journal of Rheumatology, Volume 37, Number 4, July 2008 , pp. 300-305(6) ■

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If you are interested in organizing a Sip for Sjögren's event in your area, please contact Pat Spolyar, Director of Awareness, at 800-475-6473, ext. 221 or pspolyar@sjogrens.org.

"Ask the Staff" continued from page 7 ▼

We take great care to provide you with a high-quality, informative newsletter. Each issue usually starts with finding main articles for each issue and collecting additional content that is pertinent for Sjögren's patients. Additionally, we must confirm which advertisements will appear in each issue, as well as what upcoming Foundation events or conferences will be promoted. From there, the issue is moved on to our graphic designer who creatively organizes the entire issue. Then the editing process begins, moving back and forth among our various reviewers including SSF staff, article authors and our volunteer editor. Finally, the issue is sent off to a print shop that prints, addresses and mails our newsletter all over the world.

From start to finish, that whole process takes over two months.

Adam Gerard
Vice President of Operations

I noticed that the Sjögren's Syndrome Foundation is recognized by the National Health Council as fitting into their Standards of Excellence. Can you tell me more about this?

The Sjögren's Syndrome Foundation is very proud of the work we accomplish and the high standards we hold ourselves to while working towards our mission. As a result, we are extremely excited that the National Health Council continues to recognize the Sjögren's Syndrome Foundation as being in compliance with the Council's Standards of Excellence.

The National Health Council's Standards of Excellence ensure that members of the Council maintain the "highest standards of efficiency, accountability and public stewardship. Organizations meeting the standards have proven themselves worthy of the public's support."

The Standards of Excellence are over 40 specific standards defined by the National Health Council which focus on all aspects of managing a Volunteer Health Agency. These standards are focused on good governance, transparency and ethical practices. Moreover, the Council's standards are more extensive than those of many charity watchdog groups, covering or expanding on such areas as corporate relationships, fundraising standards and operations.

"I am proud the Sjögren's Syndrome Foundation has met all NHC standards. The staff and Board of Directors worked diligently to make this happen and we continue to strive at deserving your support," said Steven Taylor, Chief Executive Officer of the Sjögren's Syndrome Foundation.

The National Health Council is the recognized leader in promoting the health of all people by advancing the voluntary health movement. For more information on the National Health Council and their Standards of Excellence, you can visit them online at <http://www.nationalhealthcouncil.org/pages/standards.php>. ■

Adam Gerard
Vice President of Operations

"April Awareness" continued from page 5 ▼

which you can request from the SSF office, you will see a poster that you can ask to hang up at your physician's office, community center, church, school, library or elsewhere. (Additional posters can be obtained by contacting the Sjögren's Syndrome Foundation office.) This year's kit includes ways to help us increase awareness through physicians' offices and health reporters as well as using your Facebook, Twitter and My Space pages. So I hope you will participate and help us start to get others to *Imagine* a life with Sjögren's.

As you can see, April is always a busy time for the Foundation. We hope you will join with us on these two very important campaigns. Just *Imagine* if every member of the SSF mailed their five letters and hung up just one poster – we would touch nearly 100,000 communities in the United States!

As always, thanks for all you do to help make Sjögren's a household name! ■



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Don't Forget "Friends Helping Friends!"

We hope that you have had a chance to review your *Friends Helping Friends* materials packet that you recently received in the mail. This awareness letter campaign offers you the opportunity to reach out to those you know, inform them about Sjögren's, and request their support. Your decision to participate in this campaign will help to increase awareness nationwide while raising additional funds towards research and education.

This year's campaign theme is "Imagine" and we will be focusing on the numerous complications of Sjögren's to help enlighten your friends and family about the seriousness of the disease.

If you need additional materials, please contact the Foundation office at 800-475-6473 extension 217, and we will be sure to send them to you as soon as possible.

Remember, by participating in *Friends Helping Friends*, you will not only be helping to spread the word about Sjögren's, but you will also be helping to raise crucial funds to support research, education and awareness. I hope you will take our challenge in 2010 and *Stand Up for Sjögren's* by mailing out your 2010 *Friends Helping Friends* letters.