Q Should I take the H1N1 Flu vaccine?

A The Sjögren’s Syndrome Foundation feels it is too early to respond in any official capacity to the question about whether Sjögren’s patients should receive the H1N1 “swine flu” vaccine. The vaccine is still being tested and is expected to be available in the fall, so we will all learn more in the near future. The SSF recommends that patients consult with their doctors and frequently check the CDC H1N1 page (http://www.cdc.gov/H1N1FLU/) which is updated weekly with the latest information.

The SSF also reminds patients to consider receiving the standard flu vaccine (“flu shot”) that is currently available from their physician or pharmacist. For those under Medicare Part B, the standard flu shot is fully covered by Medicare once a year during the fall or winter.

Elaine Alexander, MD, PhD
Chair of the SSF’s Medical and Scientific Advisory Board

Q Should a younger Sjögren’s patient opt for more aggressive treatments of Sjögren’s?

A When it comes to treating Sjögren’s, I like to think about the concept of disease and dis-ease. We can treat the disease (medications such as plaquenil, methotrexate, imuran, rituxan, etc.) and we can treat the dis-ease (medications such as evoxac, biotene products, tylenol, etc.)

The organ systems that are involved and the general health of the person are the primary determinants of which medications should be used. So, for example, if a person has fatigue and aches and pains, plaquenil may be a good medication, but if he or she has interstitial lung disease, imuran or other immunosuppressants may be helpful. The more aggressive treatments are meant for more systemic disease with vital organ system involvement.

A younger person may have fewer co-morbid conditions, such as hypertension, diabetes, heart disease, but has the potential for more time to develop more complications from his or her Sjögren’s. For a younger person I recommend aggressive management and follow-up. This concept is different somewhat than aggressive treatment. Aggressive management means frequent follow-up visits with a physician knowledgeable in following patients with Sjögren’s and consulting with this physician about appropriate treatment of the disease.

Daniel Small, MD

Q I enjoy having a glass of wine with my husband most evenings. Could this cause any problems for my Sjögren’s?

A There are several major reasons not to use alcohol when a person has Sjögren’s. The first is if the person is taking methotrexate for treatment of Sjögren’s, as the combination of methotrexate and moderate alcohol ingestion is associated with an increased risk for liver function abnormalities and cirrhosis of the liver.

The second is if a person with Sjögren’s has evidence of liver function abnormalities. Many patients can develop
Q I frequently experience an intensely painful burning and pin-prick sensation on my tongue. Is this related to Sjögren’s? Is there any treatment?

A A burning sensation is a common oral complication of Sjögren’s syndrome. The cause of a burning sensation/pin-prick sensation is frequently related to decreased salivary flow associated with Sjögren’s. Lower salivary flow will lead to decreased lubrication and subsequently more mucosal (i.e. tissues in mouth such as cheeks, gums and tongue) irritation and burning – especially with the tongue. As saliva has natural properties to fight fungal/yeast infections, a decrease in salivary flow can also lead to an increased mild liver inflammation associated with their Sjögren’s. There are also significant associations between primary biliary cirrhosis, sclerosing cholangitis, and motility disturbances of the biliary system and pancreas. If any of these problems are present, alcohol ingestion may worsen liver function.

The third reason is that alcohol can have adverse effects on the central and peripheral nervous system, so patients with Sjögren’s who have cognitive dysfunction (memory disturbances) or peripheral neuropathy should avoid alcohol.

Although excessive alcohol consumption has adverse health effects, epidemiological studies have demonstrated that moderate consumption of alcohol and wine is associated with a decrease in death due to cardiovascular events. However, confusing this data is that the average moderate wine drinker is more likely to exercise more, to be more health conscious, and to be of a higher educational and socioeconomic class.

A chemical in red wine called resveratrol has been shown to have both cardioprotective and other protective effects in animal studies. Resveratrol is produced naturally by the skins of grapes in response to fungal infection, including exposure to yeast during fermentation. White wine has lower levels of this compound. Other beneficial compounds in wine include polyphenols, antioxidants and bioflavinoids.

Sulfites are present in all wines and are formed as a natural product of the fermentation process, and many wine producers add sulfur dioxide in order to help preserve wine. Sulfur dioxide is also added to foods such as dried fruits. The level of sulfites in wines and other foods varies. Sulphites in wine may cause some people with Sjögren’s, particularly those with asthma or reactive airway disease, to have adverse reactions.

Since each person with Sjögren’s has unique signs and symptoms, and the treatment will vary from person to person, the best thing to do is to ask your physician if regular moderate wine ingestion is appropriate for you.
How do I list the Sjögren’s Syndrome Foundation in my will?

Each year, the Sjögren’s Syndrome Foundation benefits from patients and/or their loved ones remembering the SSF in their wills. To take part and leave your legacy, all you need to do is ask your lawyer to add the SSF to your will by using the Foundation’s name, address and Tax ID#. (provided below). You can work with your lawyer and financial advisor to decide how best to leave your legacy. You can restrict your bequest to research or leave it for basic support of the Foundation’s education and awareness initiatives. By remembering the SSF in your will, you will be leaving a legacy for years to come as your support will help future Sjögren’s patients.

If you have questions, or if your attorney would like to learn more, please contact me by phone at 301-530-4420 ext. 211.

Here is how to list the SSF:

Sjögren’s Syndrome Foundation, Inc.
6707 Democracy Blvd
Suite 325
Bethesda, Maryland 20817
301-530-4420
Tax ID #11-2779073

Steven Taylor, CEO

How can I start a fundraiser in my area?

First, consider what type of fundraiser you would like to coordinate.

Would you like to…

• Organize a Sip for Sjögren’s event
• Organize a Walkabout
• Host a Dinner/Silent Auction
• Coordinate a “Dress Down Day” at your place of employment
• Hold a community garage sale and/or bake sale
• Invite a few friends for a “Sjögren’s Tea”

• Create your own email fundraising campaign
• Do you have another idea?

Once you decide what type of event you would like to coordinate, contact the Foundation. We can offer advice, ideas and ways to save time so that you can focus on your overall goal of raising funds while also raising awareness for Sjögren’s.

To start today, contact me at 800-475-6473 ext 212, or send me an email at sdefruscio@sjogrens.org.

Remember whatever activity you choose, you will be helping to make a difference!

Sheriese DeFruscio, Vice President of Development

How do I log in to the Member Community on sjogrens.org?

All members of the Sjögren’s Syndrome Foundation have access to the member section of our website, sjogrens.org, as well as the ability to buy books and audio CDs with their member discount at our SSF Store.

The Member Community contains a lot of great information including the latest issue of The Moisture Seekers, an archive of every issue dating back to January 2008, an archive of all the Information You Requested questions and answers published in the newsletter over the last few years, and an updated version of our Product Directory. But to access all of this information, and to receive discounts at the SSF Store, you will need to log in to our website.

When your registration is processed by the Sjögren’s Syndrome Foundation, you should receive an email from our website notifying you of your username and password.

If you have this email, just visit our Member Community at http://www.sjogrens.org/home/member-community. You will be prompted to enter a username and password and you can use the information provided in the email.

If you never received this email, or cannot find it, just send an email to us at info@sjogrens.org requesting your login information, and we will send it to you within 24 hours.

Adam Gerard, Vice President of Operations
risk of oral fungal infections. An active oral fungal infection can manifest as mucosal burning. Other causes of oral burning may be related to vitamin deficiencies, oral allergies or autoimmune related oral lesions.

Successful treatment of oral burning requires the correct diagnosis of the underlying cause of the burning. Increasing salivary flow will benefit burning from poor lubrication, and appropriate antifungal therapy will provide relief for an active fungal infection. Appropriate management can also be provided to supplement vitamins, eliminate allergens or treatment of autoimmune oral lesions.

**Can NSAIDs (e.g. Ibuprofen) be dangerous for Sjögren’s patients?**

**A** Generally, no. NSAIDs (non-steroidal anti-inflammatory drugs) are commonly used for pain and inflammation. They are available without a prescription (Ibuprofen: Motrin®, Naproxen: Aleve®) or with a prescription (Celecoxib: Celebrex®, Meloxicam: Mobic®). Over 20 different NSAIDs (COX I and COX II types) are available. As with all medications, some people may experience side effects. Possible side effects of NSAIDs include stomach pain/ulcers/nausea; kidney and liver inflammation/decreased function; elevated blood potassium; elevated blood pressure; fluid retention (swollen ankles); easy bruising; some increased risk of heart attack; worsening of asthma; rarely, brain inflammation (aseptic meningitis). The most common by far are GI side effects. As with most medications, the potential benefits and risks must be considered. Lower doses and less frequent use will lessen the risk.

There is one area where those with Sjögren’s may be at greater risk than those without the disease – GI side effects. Those without Sjögren’s have around a 10-20% risk of stomach pain, while those with Sjögren’s have about a 15% risk. Possible reasons for this increased risk include the following. Some people with Sjögren’s have atrophic gastritis (“aged stomach cells”), which leaves them vulnerable to acid medications like NSAIDs. Some have antibodies that attack their stomach cells (parietal cell and gastric cell antibodies). They also may have GI motility problems, which increase exposure time to medications. These can lead to an increased risk of stomach and esophagus irritation. Knowing the potential side effects and working closely with your physicians can avoid most problems!

**Are there any hypotheses as to what causes Sjögren’s?**

**A** Sjögren’s is considered a “complex” disorder in that it is not believed to have a single cause. That is characteristic of a syndrome; it is a collection of symptoms which are recognized as a particular condition. It is most likely that a number of individual factors, genetic and others, when they occur together, lead to the condition diagnosed as Sjögren’s syndrome. It is the combination of factors which is responsible for the signs and symptoms of Sjögren’s, not any one cause. This is why Sjögren’s syndrome may appear differently in different people – varying combinations of these factors will have diverse expression depending on the individual and the extent of involvement.

It is clear that Sjögren’s syndrome has a genetic component. This has been shown using genomic analysis, a way of studying the DNA of an individual. Looking in blood and in saliva, researchers have found specific patterns, termed a “DNA signature,” which occur with greater frequency in Sjögren’s syndrome than in non-affected individuals. A single specific genomic alteration has not been found – and is unlikely to be found – but a common pattern of autoimmunity has been seen. This is also why autoimmune conditions, including Sjögren’s, often occur in several family members.

It is likely that other factors in the setting of this genetic background are responsible for the clinical expression of Sjögren’s. Among the factors which have been investigated are viruses, nutrition and stress (physiological and psychological). It is important to re-emphasize that no single factor has been shown to be a “cause” of Sjögren’s but that any of these may contribute to its development and progression.
For patients with Sjögren’s syndrome,

**Dry mouth is no piece of cake.**

Are you one of the 2-4 million patients with Sjögren’s syndrome? If you have experienced dry-mouth symptoms, then you know how difficult it can be to eat, chew and swallow food. But does your healthcare provider understand?

In the past, you may have tried to explain the uncomfortable feeling of your dry-mouth symptoms to your healthcare provider. Maybe it’s time to talk to him or her again.

Ask your healthcare provider about EVOXAC, a prescription treatment option for dry-mouth symptoms associated with Sjögren’s syndrome that works by stimulating the production of your body’s own natural saliva.

Visit DiscoverEVOXAC.com for a list of questions to take to your healthcare provider.

---

**IMPORTANT SAFETY INFORMATION ABOUT EVOXAC (cevimeline HCl)**

**What is EVOXAC?**

EVOXAC (cevimeline hydrochloride) is a prescription medicine used to treat symptoms of dry mouth in patients with Sjögren’s syndrome.

**Who Should Not Take EVOXAC?**

You should not take EVOXAC if you have uncontrolled asthma, allergies to EVOXAC, or a condition affecting the contraction of your pupil, such as narrow-angle (angle-closure) glaucoma or inflammation of the iris.

**What should I tell my Healthcare Provider?**

Tell your healthcare provider if you have any of the following conditions:

- History of heart disease
- Controlled asthma
- Chronic bronchitis
- Chronic obstructive pulmonary disease (COPD)
- History of kidney stones
- History of gallbladder stones
- Tell your healthcare provider if you are trying to become pregnant, are already pregnant, or are breastfeeding.
- Tell your healthcare provider about all medications that you are taking, including those you take without a prescription. It is particularly important to tell your healthcare provider if you are taking any heart medications, especially “beta-blockers”.
- If you are older than 65, your healthcare provider may want to monitor you more closely.

**General Precautions with EVOXAC**

- When taking EVOXAC, use caution when driving at night or performing other hazardous activities in reduced lighting because EVOXAC may cause blurred vision or changes in depth perception.
- If you sweat excessively while taking EVOXAC, drink extra water and tell your healthcare provider, as dehydration may develop.
- The safety and effectiveness of EVOXAC in patients under 18 years of age have not been established.

**What are some possible side effects of EVOXAC?**

- In clinical trials, the most commonly reported side effects were excessive sweating, headache, nausea, sinus infection, upper respiratory infections, running nose, and diarrhea.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.FDA.gov/medwatch, or call 1-800-FDA-1088.

Please see a brief summary of Important Information for EVOXAC on the next page.
In addition, the following adverse events (AEs) (incidence) were reported in the Slentzer’s clinical trials:

<table>
<thead>
<tr>
<th>Adverse Event</th>
<th>Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>11.6%</td>
</tr>
<tr>
<td>Syncope</td>
<td>10.2%</td>
</tr>
<tr>
<td>Urticaria</td>
<td>7.8%</td>
</tr>
<tr>
<td>Infusion reaction</td>
<td>6.3%</td>
</tr>
<tr>
<td>Malaise</td>
<td>5.1%</td>
</tr>
<tr>
<td>Nausea</td>
<td>4.5%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>3.9%</td>
</tr>
<tr>
<td>Chills</td>
<td>2.4%</td>
</tr>
<tr>
<td>Fever</td>
<td>1.5%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>1.4%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>1.2%</td>
</tr>
<tr>
<td>Infusion site reaction</td>
<td>1.0%</td>
</tr>
<tr>
<td>Infection</td>
<td>1.0%</td>
</tr>
</tbody>
</table>

The following adverse events were reported in at least 1% of patients:

<table>
<thead>
<tr>
<th>Adverse Event</th>
<th>Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>10.2%</td>
</tr>
<tr>
<td>Syncope</td>
<td>7.8%</td>
</tr>
<tr>
<td>Urticaria</td>
<td>6.3%</td>
</tr>
<tr>
<td>Infusion reaction</td>
<td>5.1%</td>
</tr>
<tr>
<td>Malaise</td>
<td>4.5%</td>
</tr>
<tr>
<td>Nausea</td>
<td>3.9%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>2.4%</td>
</tr>
<tr>
<td>Chills</td>
<td>1.5%</td>
</tr>
<tr>
<td>Fever</td>
<td>1.2%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>1.0%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>1.0%</td>
</tr>
<tr>
<td>Infusion site reaction</td>
<td>0.8%</td>
</tr>
</tbody>
</table>

The following adverse events were reported in at least 10% of patients:

<table>
<thead>
<tr>
<th>Adverse Event</th>
<th>Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>20.1%</td>
</tr>
<tr>
<td>Syncope</td>
<td>10.4%</td>
</tr>
<tr>
<td>Malaise</td>
<td>9.5%</td>
</tr>
<tr>
<td>Infusion reaction</td>
<td>7.8%</td>
</tr>
<tr>
<td>Malaise</td>
<td>6.3%</td>
</tr>
<tr>
<td>Nausea</td>
<td>3.9%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>2.4%</td>
</tr>
<tr>
<td>Chills</td>
<td>1.2%</td>
</tr>
<tr>
<td>Fever</td>
<td>1.0%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>1.0%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>0.8%</td>
</tr>
</tbody>
</table>

The following adverse events were reported in at least 10% of patients:

<table>
<thead>
<tr>
<th>Adverse Event</th>
<th>Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>19.0%</td>
</tr>
<tr>
<td>Syncope</td>
<td>10.4%</td>
</tr>
<tr>
<td>Malaise</td>
<td>7.8%</td>
</tr>
<tr>
<td>Infusion reaction</td>
<td>6.3%</td>
</tr>
<tr>
<td>Malaise</td>
<td>5.1%</td>
</tr>
<tr>
<td>Nausea</td>
<td>3.9%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>2.4%</td>
</tr>
<tr>
<td>Chills</td>
<td>1.2%</td>
</tr>
<tr>
<td>Fever</td>
<td>1.0%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>1.0%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>0.8%</td>
</tr>
</tbody>
</table>

The following adverse events were reported in at least 5% of patients:

<table>
<thead>
<tr>
<th>Adverse Event</th>
<th>Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>19.0%</td>
</tr>
<tr>
<td>Syncope</td>
<td>10.4%</td>
</tr>
<tr>
<td>Malaise</td>
<td>7.8%</td>
</tr>
<tr>
<td>Infusion reaction</td>
<td>6.3%</td>
</tr>
<tr>
<td>Malaise</td>
<td>5.1%</td>
</tr>
<tr>
<td>Nausea</td>
<td>3.9%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>2.4%</td>
</tr>
<tr>
<td>Chills</td>
<td>1.2%</td>
</tr>
<tr>
<td>Fever</td>
<td>1.0%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>1.0%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>0.8%</td>
</tr>
</tbody>
</table>

The following adverse events were reported in at least 5% of patients:

<table>
<thead>
<tr>
<th>Adverse Event</th>
<th>Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>19.0%</td>
</tr>
<tr>
<td>Syncope</td>
<td>10.4%</td>
</tr>
<tr>
<td>Malaise</td>
<td>7.8%</td>
</tr>
<tr>
<td>Infusion reaction</td>
<td>6.3%</td>
</tr>
<tr>
<td>Malaise</td>
<td>5.1%</td>
</tr>
<tr>
<td>Nausea</td>
<td>3.9%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>2.4%</td>
</tr>
<tr>
<td>Chills</td>
<td>1.2%</td>
</tr>
<tr>
<td>Fever</td>
<td>1.0%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>1.0%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>0.8%</td>
</tr>
</tbody>
</table>
Dietary supplements were defined in a law passed by Congress in 1994 called the Dietary Supplement Health and Education Act (DSHEA). According to DSHEA, a dietary supplement is a product that:

- Is intended to supplement the diet
- Contains one or more dietary ingredients (including vitamins, minerals, herbs or other botanicals, amino acids, and certain other substances) or their constituents
- Is intended to be taken by mouth, in forms such as tablet, capsule, powder, softgel, gelcap, or liquid
- Is labeled as being a dietary supplement

Research has shown that some uses of dietary supplements are effective in preventing or treating diseases. For example, scientists have found that folic acid (a vitamin) prevents certain birth defects, and a regimen of vitamins and zinc can slow the progression of the age-related eye disease macular degeneration. Also, calcium and vitamin D supplements can be helpful in preventing and treating bone loss and osteoporosis (thinning of bone tissue).

Research has also produced some promising results suggesting that other dietary supplements may be helpful for other health conditions (e.g., omega-3 fatty acids for coronary disease), but in most cases, additional research is needed before firm conclusions can be drawn.

Federal Regulation of Dietary Supplements

The Federal Government regulates dietary supplements through the U.S. Food and Drug Administration (FDA). The regulations for dietary supplements are not the same as those for prescription or over-the-counter drugs. In general, the regulations for dietary supplements are less strict.

- A manufacturer does not have to prove the safety and effectiveness of a dietary supplement before it is marketed. A manufacturer is permitted to say that a dietary supplement addresses a nutrient deficiency, supports health, or is linked to a particular body function (e.g., immunity), if there is research to support the claim. Such a claim must be followed by the words "This statement has not been evaluated..."
With continuing research, we should be able to identify individuals at risk of developing an autoimmune condition based on genomic and proteomic analysis. As further contributing factors are recognized and increased details about the pathological mechanisms of Sjögren's syndrome are elucidated, it should be possible to intervene early to prevent development of the disorder or minimize its impact.

Philip Fox, DDS

Q What are the long-term effects of the use of Plaquenil?

A Plaquenil® (hydroxychloroquine) is an immunomodulating drug that was originally FDA approved for malaria but is now more widely used to treat people with various autoimmune diseases including systemic lupus, rheumatoid arthritis and Sjögren’s. In Sjögren’s syndrome it may improve various signs and symptoms including fatigue, joint and muscle pain, skin rashes and swollen glands. It is considered the safest of all immunosuppressive drugs and generally is well-tolerated in long-term use. However, patients who have rare hematologic diseases such as glucose 6 phosphate dehydrogenase (G6 PD) deficiency or porphyria should avoid this drug. As with any drug, side effects may occur. Short-term side effects may include nausea, vomiting, diarrhea, skin rashes and headaches. The side effects can sometimes be alleviated by switching from the generic form to the branded product or vice-versa. Long-term side effects may include myopathies (muscle weakness) or retinal toxicity. Both problems are rare but serious. Muscle weakness can be monitored by measuring strength and the muscle enzymes (CPK, aldolase) in the blood. For the eyes, prior to starting this medication, a thorough baseline eye exam is recommended including screening for abnormalities of the macula (back of the eye), red/green color vision and visual fields. The eye examination should be repeated yearly or as often as recommended by your eye doctor. Long-term eye and muscle side effects, if caught early, may be reversible.

Frederick B. Vivino, MD, FACR

Q Is Sjögren’s Syndrome hereditary?

A Hereditary diseases are those that tend to “run in families.” Although environmental factors may play a role, hereditary diseases are typically thought, due to genetic factors, passed from generation to generation. In Sjögren’s syndrome, the answer is yes, there is certainly a genetic component that determines whether a person will develop the disease. The next most important questions become

1) Which specific genetic factors are important in SS?
2) To what degree do they influence the disease?
3) How do these factors act biologically to result in the clinical problems experienced by patients?

The underlying genetic causes of Sjögren’s are complex. Genetics not only play a role in influencing who
Once-daily,* preservative-free LACRISERT®
Extends tear life for all-day lubrication and protection

▶ Unlike artificial tears, LACRISERT® works continuously to stabilize and thicken tears for all-day relief.
▶ LACRISERT® begins to gently dissolve and lubricate within minutes.

69% of Sjögren’s syndrome patients in a clinical study preferred LACRISERT® over artificial tears due to increased comfort†

Most adverse reactions were mild and transient and included transient blurring of vision, ocular discomfort or irritation, matting or stickiness of eyelashes, photophobia, hypersensitivity, edema of the eyelids, and hyperemia. LACRISERT® is contraindicated in patients who are hypersensitive to hydroxypropyl cellulose. If improperly placed, LACRISERT® may result in corneal abrasion.

*Some patients may require the flexibility of twice-daily dosing for optimal results.
†In a 2-phase study of patients with dry eye: phase 1 was a 6-month, comparative, randomized, crossover study in 40 patients (37 with Sjögren’s syndrome); phase 2 was an open-label, follow-up study in 37 patients for 2 months to 18 months.


For more information, visit www.LACRISERT.com or call 1-877-ATON-549.
Please see brief summary of Prescribing Information on adjacent page.
The Sjögren’s Syndrome Foundation would like to thank Kathleen A. Arntsen, President and CEO of the Lupus Foundation of Mid and Northern New York, Inc., for her piece, “Participating in Clinical Trials,” published in the Summer 2009 issue of The Moisture Seekers. Not only is Kathleen a lupus and Sjögren’s patient, but she is a strong patient advocate who has worked tirelessly for nearly thirty years on behalf of autoimmune disease patients.

“Information You Requested” continued from page 8

develops Sjögren’s, but also which specific symptoms and features of Sjögren’s a person might develop. We have a few candidates, but have not yet firmly identified which specific genetic factors, or genes, cause Sjögren’s. Humans carry about 21,000 different genes, each of which provide “instructions” for how our bodies work and control a wide variety of traits such as eye color, height, and how our immune systems function. For diseases that are obviously hereditary, such as Huntington’s disease, cystic fibrosis, or sickle cell anemia, the underlying genetics are relatively simple, where mutations or variations in a single gene cause the disease. In Sjögren’s, there may be dozens that act together or in various combinations that lead to disease. We have much work to do to test all 21,000 genes, identify which specific ones are important in Sjögren’s, and then understand how they act differently in patients and healthy individuals.

Because of the complexities involved in the genetics of Sjögren’s, the degree to which genetic factors play a role varies among different families. In perhaps 30% or more cases, several members within a family may have Sjögren’s or other autoimmune problems that are obviously related to Sjögren’s. In these cases, the genetic component may have a stronger influence — either more genes are involved or the genetic factors have a large biological effect on the disease manifestations. In most families, only one person has Sjögren’s and a genetic component to Sjögren’s may not be obvious at all, but is very likely to still be important. In fact, genetics does play a role to some extent in essentially all diseases to varying degrees. The specific genetic factors that increase risk for developing Sjögren’s are not likely to be the same for all patients.

Over the last decade or so, advances in our understanding of how genetic factors operate in many diseases has been considered revolutionary. For example, we have now identified over 30 genes that are important risk factors in lupus and believe many more will be identified in the near future. Some of these genes are also important in other autoimmune disorders. These genetic studies are providing critical insight into what causes lupus. Similar studies in Sjögren’s will go a very long ways towards helping understand the root causes and are now underway with the hope that this new knowledge will bring forth new opportunities for improving diagnostic and therapeutic approaches in Sjögren’s.

Kathy Moser, PhD

**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, hyperemia, 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.
by the Food and Drug Administration. This product is not intended to diagnose, treat, cure, or prevent any disease.”

- Manufacturers are expected to follow certain “good manufacturing practices” (GMPs) to ensure that dietary supplements are processed consistently and meet quality standards. Requirements for GMPs went into effect in 2008 for large manufacturers and are being phased in for small manufacturers through 2010.

- Once a dietary supplement is on the market, the FDA monitors safety. If it finds a product to be unsafe, it can take action against the manufacturer and/or distributor, and may issue a warning or require that the product be removed from the marketplace.

Also, once a dietary supplement is on the market, the FDA monitors product information, such as label claims and package inserts. The Federal Trade Commission (FTC) is responsible for regulating product advertising; it requires that all information be truthful and not misleading.

Sources of Science-Based Information

It is important to look for reliable sources of information on dietary supplements so you can evaluate the claims that are made about them. The most reliable information on dietary supplements is based on the results of rigorous scientific testing.

To get reliable information on a particular dietary supplement:

- Ask your health care providers. Even if they do not know about a specific dietary supplement, they may be able to access the latest medical guidance about its uses and risks.

- Look for scientific research findings on the dietary supplement. The National Center for Complementary and Alternative Medicine (NCCAM) and the Office of Dietary Supplements, both a part of the National Institutes of Health (NIH), as well as other Federal agencies, have free publications, clearinghouses, and information on their Web sites.

Safety Considerations

If you are thinking about or are using a dietary supplement, here are some points to keep in mind.

Tell your health care providers about any complementary and alternative practices you use, including dietary supplements (see nccam.nih.gov/timeto-talk). It is especially important to talk to your health care provider if you are

- Thinking about replacing your regular medication with one or more dietary supplements.

- Taking any medications (whether prescription or over-the-counter), as some dietary supplements have been found to interact with medications.

- Planning to have surgery. Certain dietary supplements may increase the risk of bleeding or affect the response to anesthesia.

- Pregnant or nursing a baby, or are considering giving a child a dietary supplement. Most dietary supplements have not been tested in pregnant women, nursing mothers, or children.

If you are taking a dietary supplement, read the label instructions. Talk to your health care provider if you have any questions, particularly about the best dosage.

Wet Your Whistle!
Proven Effective—Works for Hours

OraMoist is a time-released disc that moistens the mouth for hours. It adheres to the roof of the mouth, then slowly dissolves, stimulating saliva production and lubricating the mouth. It’s sweetened with cavity-fighting xylitol, proven effective, easy to use, and lasts up to 4 hours.

Call for your free trial sample
800-448-1448

www.ora-moist.com

October 2009 / The Moisture Seekers
In Memory of Anna Vancheri
Mr. & Mrs. Richard Panicucci

In Memory of Barbara Davis
Susan Willis

In Memory of Beatrice Liem
Sandy Fukudome

In Memory of Dorothy Wood
Jack & Suzette Mueller

In Memory of Ellamae Skahen
James W. Snider, DDS

In Memory of Jack Eicher
Emil & Jean Simanski

In Memory of John R. Shaw
Staff of Millersville University
Human Resources Office

In Memory of Mary Futak
Mr. & Mrs. Thomas G. Hogan, Jr.
Middletown Senior Citizens Association
SJW Seniors of Knights of Columbus

In Memory of Mary Ruth
Melissa, Scott & Noah Messina
Bruce & Nancy Null
Sandra Watt

In Memory of Merrill Lovik
James & Diane Evenson
Vivian G. Jones

In Memory of William Eugene Cussimanio
Mary Bow
Laurence & Ann Brown
George & Jo Sue Burenhide
Marilyn Cussimanio
Ellis & Thelma Frakes
Betty & Charles Gates
William & Judith Gifford
Lester & Vivian Hess
Ron & Marilyn Hess
Richard Hudson
Richard & Barbara Ingold
Jerri & James Kirby
Mary Ann Kiser
Wendell & Deborah Lentz
Gene Mason
Larry & Sandra Messer
Sandra Messer
Steve & Terry Miller
Betty Miller
Carol Murphy & Family
Joe & Susan Nepote
Helaine Obolsky
Nora Payne
Wendy Schmidt-Strukel
Larry & Linda Spicer
Elaine White
Judy & Jim Zanardi

In Honor of Bobby & Mort Weisenfeld
Bert Cohen

In Honor of Courtney & Robert’s Marriage
Bill & Karen Desberg

In Honor of Harold Brown’s Birthday and Retirement
Pamela Brown

In Honor of Members & Leaders of our Chapter from 1985-2009
San Diego & Imperial Counties Chapter

In Honor of Nancy Korb’s Birthday
Brenda & Rudy

In Honor of Patrice Adcroft
Joan Tramontano

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.
Take back your mouth.

Laugh. Talk. Kiss. Don’t let symptoms of a dry mouth keep you from enjoying life.

Oasis® Moisturizing Mouthwash and Mouth Spray work together as a complete hydrating system to lubricate the inside of your mouth for up to two hours. Together, they provide great-tasting relief whenever symptoms occur, wherever you are.

Get Oasis® and Get Back to Life
- Alcohol and sugar free
- Enamel safe pH
- Mouth Spray sweetened with Xylitol
- Product is intended for temporary relief of minor discomfort and protection of irritated tissues in a sore mouth. If sore mouth symptoms do not improve in 7 days, see your dentist or doctor promptly. Severe or persistent sore throat or sore throat accompanied by high fever, headache, nausea and vomiting may be serious, see your dentist/doctor promptly. Children under 2, consult a dentist or doctor before use.

- The amount of the active ingredient may be higher or lower than the label states. That means you may be taking less—or more—of the dietary supplement than you realize.
- The dietary supplement may be contaminated with other herbs, pesticides, or metals, or even adulterated with unlabeled ingredients such as prescription drugs.


You can also learn more about dietary supplements from NCCAM by viewing the expanded version of this article at nccam.nih.gov/health/supplements/wiseuse.htm. The expanded article includes selected references and additional resources.


Give Us Your Feedback
We’d love to hear from you to help us continue developing new and improved products. We invite you to take a quick survey at OasisDryMouth.com/sjogrensurvey.

Visit OasisDryMouth.com or call 1-888-93-OASIS (1-888-936-2747) for more information and 15% off multi-pack product orders. Use the discount code: oasis-ssg.

Or, purchase Oasis® at local retailers, drugstore.com or Amazon.com.
**2009 SSF National Patient Conference**

**Audio CDs are Now Available!**

Six of our most popular talks from the 2009 National Patient Conference held in Arlington, Virginia, are available for purchase as audio CDs. Each talk is 30-40 minutes long and each CD comes enclosed with the handouts and visual aids used by the presenter. Buy just the talks you want to hear or purchase the whole set! Whether you attended the conference or not, these audio CDs are an excellent way to have a permanent resource with some of the most vital information available to Sjögren’s patients.

These CDs may be purchased using the order form below, online at the SSF Store, or by calling the SSF office at 800-475-6473.

<table>
<thead>
<tr>
<th>Talk Description</th>
<th>Non-Member Price</th>
<th>Member Price</th>
<th>Qty</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dry Eye and Sjögren’s – Gary N. Foulks, MD, FACS</td>
<td>$30</td>
<td>$12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dry Mouth and Sjögren’s – Andres Pinto, DDS, DMD</td>
<td>$30</td>
<td>$12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal Manifestations of Sjögren’s – Matthew Nichols, MD</td>
<td>$30</td>
<td>$12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Managing Patients with Immunosuppressive Treatments – Frederick B. Vivino, MD, FACR</td>
<td>$30</td>
<td>$12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hodgkin’s B Cell Lymphoma and Sjögren’s – Elaine L. Alexander, MD, PhD</td>
<td>$30</td>
<td>$12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurological Manifestations of Sjögren’s – Julius Birnbaum, MD</td>
<td>$20</td>
<td>$12</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Maryland Residents add 6% sales tax

Shipping and Handling: US Mail: $5 for first item + $1 for each additional item
Canada: $8 for first item + $1 for each additional item
Overseas: $18 for first item + $2 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

Name ____________________________________________________________________________
Address __________________________________________________________________________
City ___________________________    State ________    Zip ____________________________
Telephone ____________________    E-Mail __________________________________________________________________________

☐ Enclosed is a check or money order (in US funds only, drawn on a US bank, net of all bank charges) payable to SSF:

☐ MasterCard    ☐ VISA    ☐ AmEx    Card Number ___________________________    Exp. Date _____________

Signature ________________________________________________________________________
The Leader in Dry Mouth

- #1 Dentist Recommended Dry Mouth brand
- Proven to relieve Dry Mouth
- Supplements saliva’s natural defenses

Toothpaste, Mouthwash, Gel, Spray, Gum and more

©2009 GlaxoSmithKline Read and follow label directions.
by Mims Cushing and Norman Latov, MD

Written by both a patient-expert and a doctor, this book is a welcome addition to the information on Peripheral Neuropathy. The book covers such diverse topics as:

- What to ask at doctor appointments
- Making the house easier to navigate with neuropathy
- Where to find a support group
- Using vitamins and herbs for treatment
- Advice for traveling
- And much, much more!

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

About the authors:
Mims Cushing lives with peripheral neuropathy. She has published extensively in magazines and newspapers, including the New York Times.

Dr. Norman Latov is the author of Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won’t Stop (also available for ordering below). He is also the Director of the Peripheral Neuropathy Clinical and Research Center at the Weill Medical College of Cornell University.