The Moisture Seekers

Sjögren's Syndrome Foundation

www.sjogrens.org

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LETTER FROM SSF CEO STEVEN TAYLOR

As 2012 comes to an end, I thought I'd take a moment to share with you some major milestones that the Sjögren's Syndrome Foundation (SSF) achieved this past year. From the launching of new awareness programs and expansion of professional awareness initiatives to welcoming new supporters as well as continuing our funding of Sjögren's research – the SSF continues to keep up the momentum toward making Sjögren's better known in both the general public and the healthcare communities!

Here are a few of the highlights from 2012:

- In January 2012, the SSF Board of Directors announced our new aggressive 5-*Year Breakthrough Goal* "to shorten the time to diagnose Sjögren's by 50% in 5 years." This initiative has seen incredible growth since its launch. We have increased the number of volunteer Awareness Ambassadors who have helped the SSF raise awareness in their communities by distributing SSF materials, speaking at local health fairs and talking to local media. We also attended four major healthcare professional conferences in 2012 to meet with physicians in various specialties to ensure that they are recognizing the symptoms of Sjögren's while helping to speed up the diagnosis.

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When the Weather Gets Cold: Winter Health Problems

This article is reprinted from NIH News in Health

Bright blue skies, blankets of snow, crisp days and cozy nights by a crackling fire. For many people, winter is a welcome time of year. But for people with certain diseases like arthritis, it can be a pain—literally. While cold weather doesn't cause arthritis or most other conditions that get worse when temperatures drop, it can cause problems for people who have them. If you've got one of these conditions, here's what you need to know to survive winter's chill.

"Weather affects different people differently," Dr. Mark Gourley of NIH says. "Some people actually prefer cold

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weather, but many people with rheumatoid arthritis or lupus will be more stiff in the morning. It can take them longer to get up and loosen their joints and get going."

There's very little research showing that cold weather directly causes arthritis or alters its course. So why does the cold seem to make arthritis feel worse?

As the weather changes, so can the pressure in your joints. If you think of the tissues surrounding the joint as a balloon, Gourley explains, the balloon around the joint will expand a little when air pressure is low. The expanding tissues put pressure on the joint. People can actually feel changes in air pressure in their joints, which is why some people say they can predict the weather by the pain in their joints.

"Do what you can to keep warm," Gourley says. "Bundle up from head to toe in several layers, preheat the car before getting into it and make sure your home or apartment is kept warm." Other suggestions: Sleep under an electric blanket, warm clothing in the dryer before dressing and drink warm or hot drinks, such as coffee, tea or hot chocolate.

It's also important to keep moving, Gourley says. Try exercising the affected joints before going out in the cold weather. It also helps to maintain a regular exercise program year round. Exercise will not only loosen stiff joints, but will help prevent winter weight gain that puts more stress on painful joints.

Joint stiffness isn't the only problem low temperatures can cause. Raynaud's disease is a condition in which the blood vessels quickly narrow, reducing the flow of blood and causing the skin on the fingers, toes and even the nose to temporarily turn white, then bluish. As blood flow returns, the skin turns red and becomes painful. In rare severe cases, Raynaud's can cause skin sores or tissue death (gangrene) at the tips of the fingers and toes.

As with arthritis, the best advice for people with Raynaud's is to keep warm. "Wear mittens as opposed to gloves," Gourley advises. That way, the fingers can help keep each other warm.

Sjögren's syndrome is another condition that can get worse in colder weather. In Sjögren's syndrome, the immune system attacks the body's moisture-producing glands, leading to dryness of the eyes, mouth and other tissues. Cool, dry weather can exacerbate the situation.

People with Sjögren's syndrome need to add moisture back into the environment when the air is dry. Run a humidifier to raise the humidity level in your home and use lotions after bathing to keep skin moist. Use artificial tears for dry eyes and keep a water bottle on hand to sip to relieve dry mouth. Be careful about using mouthwashes with alcohol or over-the-counter cold remedies, either of which can worsen dryness.

Many prescription medications, including antidepressants and high blood pressure medications, can also cause dry mouth. If you're taking these medications and having trouble with dry tissues, ask your doctor about the

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"Letter from CEO" continued from page 1 ▼

Now, the one question I receive from patients already diagnosed is "What is in it for me? I am already diagnosed, so how will this help me live with Sjögren's?" My answer is simple – just imagine if more people know about Sjögren's. If we are able to shorten the time to diagnosis, it will mean that more physicans and dentists know about Sjögren's and, thus, will appreciate the disease and take it as seriously as they should. This, in turn, will mean that more healthcare providers will see patients in their practices which will motivate them to learn more about Sjögren's and how to treat it. Right now, we estimate there are three million Americans yet to be diagnosed and we need to help them get a proper diagnosis! When we are four million strong, there will be no stopping the SSF and no stopping us from getting more treatments and more recognition from every specialty!

- In the Spring of 2012, the SSF awarded nearly $300,000 to fund a broad range of Sjögren's research projects, specifically awarding six (6) Innovative Research Grants. All of these grants will help further our understanding of what is causing Sjögren's and how we can better treat the disease. Without research, we will never find answers and that is why we need to continue to be the leading non-profit organization funding Sjögren's research. Since 2006, the SSF has awarded over $1.5 million to Sjögren's research and we have gained great insight into the disease with our funding. Many of our researchers have continued on to receive large grants from the National Institutes of Health as well as opened full research labs focused only on Sjögren's. In addition, we are also proud to say that some of our researchers have even partnered with clinicians to open Sjögren's clinics to treat patients while also gaining additional research insight into the disease.

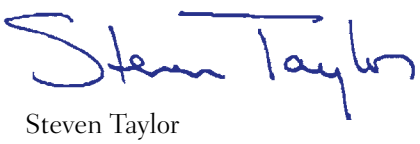
- Patient education also was a major focus in 2012 as we continued to offer 11 issues of *The Moisture Seekers* newsletter, increased the number of patient fact sheets available on our website to 26 as well as held our annual National Patient Conference this past April in San Diego, California. We continue to manage 65 support groups in the United States and serve as the lead mentor to 17 international Sjögren's groups. Education of patients and their families is a cornerstone of the SSF and we are proud of what we are able to offer for both newly diagnosed patients and those who received a diagnosis many years ago.

- After years of working with various pharmaceutical companies and educating them about Sjögren's and the need for new therapeutics, the SSF is proud to announce that three (3) pharmaceutical companies planned to launch clinical trials in 2012. All three companies have compounds that have potential for treating systemic features of Sjögren's and we are excited to see the outcome of these early clinical trials. The SSF will continue to partner with these companies and is looking for new ones to expand options for patients. If you receive a mailing from the SSF about a clinical trial in your area, I encourage you to call and learn more about the trial. Your phone calls will show the sponsoring company that there is an interest and need for Sjögren's therapy! So watch for a mailing from us when a clinical trial is in your area!

- The SSF has also made great strides in the continued development of the first-ever Clinical Practice Guidelines for how to treat, manage and monitor Sjögren's. The SSF launched this initiative in 2010 and, thanks to an amazing group of over 40 volunteer physicians and dentists, we are getting closer to publishing our first set of recommendations. We are proud to have such organizations as the American College of Rheumatology and the American Dental Association ready to review and approve our guidelines with a goal of disseminating them in 2013. These guidelines will be publicly available and we will keep all of you informed when that happens.

These are just a few of the milestones that we saw in 2012. Sincere thanks to the hundreds of volunteers nationwide who help the SSF with our programs and initiatives. Thanks to each one of you for stepping up and helping us change the face of Sjögren's. The staff and I are truly grateful for all you do but, most importantly, Sjögren's patients are thankful that you help put a face and a voice to a disease that deserves more attention! I would be remiss if I didn't ask all of you to consider volunteering in some aspect to help the SSF. Watch our newsletters and our emails for more information about how you can get involved in 2013!

With heartfelt gratitude,



Steven Taylor
Chief Executive Officer

During this festive time of the year, help us continue to be a light of hope for millions of Sjögren's syndrome sufferers.

When making a donation this holiday season, consider restricting your gift to research so that we can once again increase our financial commitment to awarding more research grants in 2013 than ever before.

Each year our research committee has to turn away promising Sjögren's research grant applications because of lack of funding. We want to ensure that we fund as many grants as possible, and with your support we can do that.

For those who have made a research gift this past year, we thank you for your continued support. Each and every gift helps us reach our goal. Please also remember, you can always ask others to make a research donation as well. Family and friends may consider supporting an organization that is important to you – you just have to ask them.

Together we all can make a difference!

❑ Enclosed is my gift of $ _____ to support the Foundation's 2013 initiatives and programs.

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"Research Awards" continued from page 2 ▼

possibility of changing your medication or combating dryness with other treatments. In more severe cases, your doctor may prescribe a medication to increase saliva flow or recommend a simple medical procedure to block the drainage of tears out of your eyes, leaving more natural tears in the eyes to moisten and lubricate them.

Osteoporosis—in which the bones become porous and prone to fracture—may not itself worsen with cold. However, icy steps and walkways in the wintertime can present a particular danger to people whose bones are fragile. Slipping and falling can cause painful fractures that can be slow to heal and even disabling.

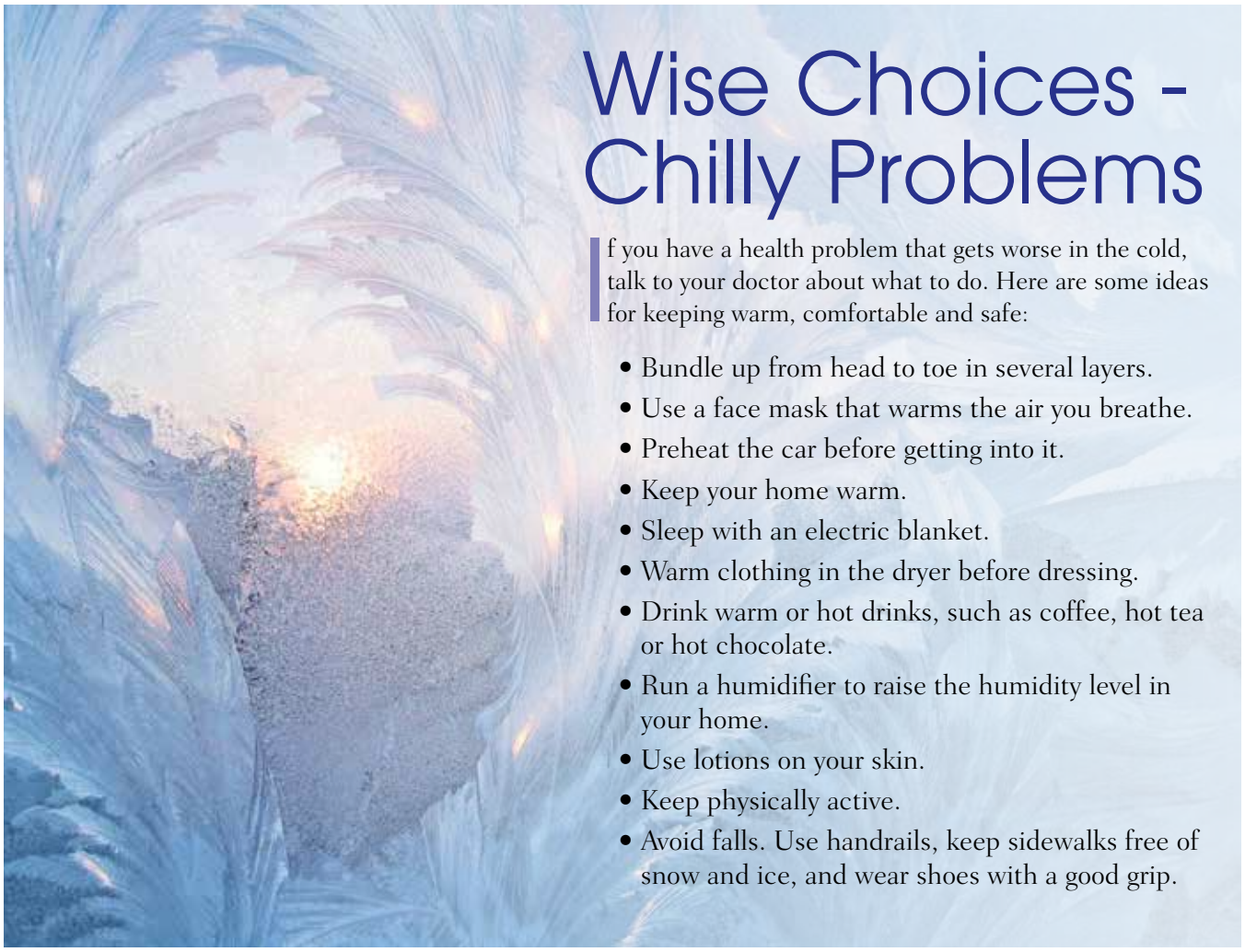
If you have osteoporosis, in addition to following the treatment plan your doctor prescribes, it's important to take measures to reduce your risk of falling. Make sure you have handrails on your porch, keep sidewalks free of snow and ice, and avoid wearing shoes with slippery soles. If you take medications that affect your balance or stability, ask your doctor about the possibility of changing medications, or at least the timing of medications so that they're less likely to interfere with daytime activities.

Cold weather may also affect people with certain lung diseases. For example, asthma can be triggered in some people by physical activity in cold weather. Rheumatoid lung disease, caused by the same immune response that affects the joints of people with rheumatoid arthritis, is characterized by shortness of breath, cough, chest pain and fever. For people with rheumatoid lung disease, winter air can aggravate problems breathing.

"If you have marginal breathing capacity and you compromise that in any way," Gourley says, "cold winter air can make breathing worse."

If you have difficulty breathing, try a face mask when you need to go out in the cold. Such masks, which can be found at many outdoor and sporting goods stores, cover your mouth and use the heat from your own breathing to warm the air before it enters your lungs.

If you have symptoms brought on by cold weather, be sure to mention them to your doctor. ■



Wise Choices - Chilly Problems

If you have a health problem that gets worse in the cold, talk to your doctor about what to do. Here are some ideas for keeping warm, comfortable and safe:

- Bundle up from head to toe in several layers.
- Use a face mask that warms the air you breathe.
- Preheat the car before getting into it.
- Keep your home warm.
- Sleep with an electric blanket.
- Warm clothing in the dryer before dressing.
- Drink warm or hot drinks, such as coffee, hot tea or hot chocolate.
- Run a humidifier to raise the humidity level in your home.
- Use lotions on your skin.
- Keep physically active.
- Avoid falls. Use handrails, keep sidewalks free of snow and ice, and wear shoes with a good grip.

Bloomberg School Graduate Receives Fulbright Grant

Reprinted with permission from the Johns Hopkins Bloomberg School of Public Health, Public Health News Center, May 30, 2012.

The prestigious Fulbright Program recently awarded a grant to Bloomberg School graduate Jessica Brandt to conduct research on Sjögren's syndrome, a chronic autoimmune disorder that affects nine times as many women as it does men.

Sjögren's syndrome causes the human immune system to turn on itself, most notably in the exocrine glands that produce tears and saliva. Patients with the disease develop clinical dry mouth and eyes, but also risk organ dysfunction and lymphoma. It is a disease that affects approximately 4 million Americans every year, most of them women.

"Presently, the underlying reasons for this sex difference are incompletely understood but constitute a promising area of research within the autoimmunity field," said Brandt in her research proposal to the Fulbright Program.

To conduct her research, Brandt will travel to Italy to work with the Rheumatology Unit at Sapienza University of Rome. Her work to identify the reasons for the sex difference between male and female patients will add to the work already being done there on Sjögren's syndrome. Results could lead to improved treatment of the disease for both men and women.

Brandt's interest in the field of immunology stems from her work with DeLisa Fairweather, PhD, assistant professor in the Bloomberg School's Department of Environmental Health Sciences. It was during that time that Brandt learned prevalence is higher among one gender group for many autoimmune disorders.

The U.S. Congress established the Fulbright Program in 1946 to "foster mutual understanding among nations through educational and cultural exchanges." The program offers grants to study, teach and conduct research in foreign countries.

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I Stood Up...

Drs. Shen and Patel and the Phoenix Walkabout Team

Dr. Joanne Shen and Dr. Dave Patel of the Ophthalmology Clinic at Mayo Clinic Arizona decided that they wanted to do something to honor all the Sjögren's patients they treat. Over the past three years, Dr. Shen and Dr. Patel have stood up and organized a Mayo Clinic Staff Team for the annual Phoenix area *Sjögren's Walkabout*.

In addition to recruiting staff to participate in the *Walkabout*, the Mayo Clinic also sponsors the event while also donating $25 for each Mayo staff member who attends the *Walkabout*. To encourage participation from all Mayo Departments, Administrator Nita Sharma and Nurse Manager Mary Lynn Kodrich generously donate their time to help by setting up sign-up tables and sharing information about Sjögren's in the cafeteria a few weeks before the event. They are not only recruiting teammates but they are also increasing Sjögren's awareness! This is a great example of helping the Sjögren's Syndrome Foundation while also encouraging employee participation in a community event. What a great way to bring together staff from all over the Mayo while building employee morale and supporting their community!

Just this year, the Ophthalmology Department of the Mayo Clinic Arizona successfully recruited 19 team members to participate in the Phoenix Area *Walkabout,* raising over $600. Since Dr. Shen and Dr. Patel started this effort, the Mayo Clinic has raised nearly $2,500 for the Sjögren's Syndrome Foundation.

Thanks to all of the staff and participants at the Mayo Clinic Arizona for *Standing Up For Sjögren's*!

How will you Stand Up?

Consider taking part in your local Sjögren's *Walkabout* by recruiting a team to walk with you.

1. Start by asking your (or have someone you know ask their) Manager/ HR Director for permission to organize a workplace Sjögren's awareness/fundraising campaign.
2. Ask your co-workers to learn about Sjögren's and make a donation.
3. Remember that many companies offer a company match for any donation made to a non-profit organization so remind your walkers to see if their company will match their donation. If your company doesn't have a formal matching gift program, ask your company if they would give your team a donation to jump start your effort.

If you don't have a Sjögren's *Walkabout* in your area, consider starting one by contacting Ben Basloe at the Sjögren's Syndrome Foundation at 1-800-475-6473 ext. 207. ■

Q&A

Ava J. Wu, DDS

Q My parotid glands swell and are painful; however, there is no drainage and the doctor said they were not infected. How can they be treated? Can a reoccurrence be prevented?

A In order to treat your salivary gland swellings, it would be helpful to have additional information and testing to determine the cause and to subsequently make a statement as to the possibility of recurrence. For example:

When does the pain occur? Infectious and inflammatory disorders often are associated with constant pain. Obstructive disorders are usually only associated with pain right before or during eating, unless an associated inflammation or infection occurs and then the pain may be constant. Benign neoplastic disorders are usually painless, unless they impinge on a nerve or impinge on a salivary duct, causing obstruction-related pain. Malignancies of the salivary gland may cause pain when they are in the advanced stage.

Does the salivary gland swelling change in size? Intermittent obstruction of the salivary ducts will cause variations in the size of the mass, whereas neoplastic or cancerous processes will only progressively enlarge over time. Swelling after eating suggests duct obstruction with a stone, mucous plug or duct stricture.

How long have the salivary gland swellings been present? Development over the course of hours suggests an obstructive or infectious (i.e., bacterial or viral) disorder. A slow-growing swelling over months or years suggests an infiltrative or neoplastic disorder.

What is your general health? Infections of the salivary gland are seen in debilitated, poorly hydrated individuals with poor oral hygiene. Patients with Sjögren's syndrome (SS) who have low salivary flow, poor oral hygiene and poor hydration would be considered to be at risk for salivary gland infections. Uncontrolled alcoholism, diabetes, liver disease, or malnutrition may further affect the ability of the body to fight infection.

Does the swelling occur just in the parotid glands, or are the submandibular/sublingual glands affected as well? Multiple gland involvement suggests a systemic illness such as Sjögren's syndrome. Involvement of a single gland would lean the clinician toward thinking about the possibility of a neoplasm.

Do the salivary glands present as a diffuse increase in size or does the swelling manifest as a nodule or mass within the gland? A diffuse swelling suggests an inflammatory process that can occur as the result of an obstruction (kink in the duct, mucous plug), infection (bacterial, viral), or Sjögren's syndrome. A distinct mass within the salivary gland suggests a neoplasm or granulomatous inflammation (sarcoidosis). A smooth, mobile, well-defined mass within the salivary gland suggests a benign lesion or a lymph nodule. A non-movable mass that is irregular in size suggests a malignant mass. If the facial nerve is involved (droopy lip and face on one side), then the index of suspicion for a malignancy is increased.

Is a salivary stone present? Stones typically occur more often in the submandibular gland. It is also uncommon for stones to be present in more than one gland. Occasionally, large stones of the submandibular gland may be palpated by the examiner.

What is the quality of the fluid expressed from the salivary gland orifice? In the setting of an infection of the salivary gland it is possible to have no drainage from the gland if an obstruction is involved. During a viral infection of the parotid gland, the draining saliva will be clear, but the duct orifice may be swollen and red.

The major causes of salivary gland swelling are obstruction, infection, tumor/neoplasm and inflammation. From the information provided, I will assume that a viral or bacterial infection is not the cause of your swelling. A tumor/neoplasm is usually a unilateral event in the salivary glands (i.e., one parotid gland or the other) so tumor/neoplasm will be omitted as a potential cause of your problem. I will also assume that your doctor was not able to palpate any solid masses within your parotid glands and ruled out the possibility of involvement of the temperomandibular joints. That leaves us with the possibilities of obstruction and inflammation, which I will discuss in further detail.

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Obstruction of the salivary gland refers to the idea that there is a blockage of salivary flow through the salivary ductal system that carries the saliva from your salivary gland to your mouth. This causes the saliva to back up within the duct system and is associated with the typical sharp pain or pressure that occurs just prior to or with eating. The duct circumference may be stretched, causing irritation in the area as the saliva backs up with nowhere to go; hence, the pain. The pain is diminished and the swelling is significantly to completely resolved if the saliva is allowed to pass by the obstruction, releasing the built-up pressure. Chronic obstruction of the salivary gland ducts, especially in the setting of low salivary flow, can predispose an individual to recurrent bacterial infections and associated chronic inflammation. The obstruction may be caused by salivary stones, inspissated mucous and/or debris, anatomical strictures within the duct, and occasionally from external pressure on the duct (i.e., tumor).

An ultrasound of your salivary glands would be a relatively inexpensive method to look for the presence of salivary stones or prominent duct dilations (sialectasia). If the deep lobe of the parotid gland (not easily visualized with ultrasound) is involved, then a CT may be indicated. If a salivary stone is present, then it may be removed by sialoendoscopy or surgery. If kinks are present in the duct system, new technology allows the placement of stents to keep the duct open and saliva flowing. Initial management of obstruction of the salivary gland includes gentle massage of the salivary gland or "milking" action to try to push saliva past the obstruction, allowing the pressure/swelling to resolve. A mucolytic agent may be used for 5-10 days in an attempt to thin the saliva or decrease the size of a mucous plug, allowing easier passage of the saliva through the ductal system. Methods to increase salivary flow through the salivary ductal system, which may then have a cleansing effect, include staying hydrated by drinking plenty of water, application of warm compresses to the cheek area, and sucking on sugar-free hard candies to encourage flow. Ibuprofen may be used to manage pain and attempt to decrease associated inflammation. A medication to increase salivary flow would not be indicated in the "acute" swelling state.

Inflammation of the salivary gland, as noted above, can occur as the result of repeated infections, chronic obstruction of the salivary ducts or the presence of a tumor. In your question, you do not state how long you have had the salivary gland swelling. If the swelling is occurring for the first time and you are in the first week of the process, then I would be less inclined to think that significant damage has occurred and recovery would be possible with accurate diagnosis and management. On the other hand, if this painful process of salivary gland swelling has been going on for months, then a certain chronicity and associated damage would be implied. Twenty-five to 56% of individuals with Sjögren's syndrome

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Recommended by eye doctors, tranquileyes eye hydrating therapy soothe dry, puffy eyes. The included gel packs can be warmed in a microwave and placed inside the goggles to stimulate tear production and the release of beneficial oils from the eyes' meibomian glands, increasing relative humidity and moisture to relieve dry eyes. Or, freeze gel packs to reduce swelling and eye puffiness. The goggle can also be used during sleep, comfortably sheltering the eyes from drafts and light while keeping moisture in.

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Emergency Room Visits and Sjögren's — A Patient Guide

by Lynn Petruzzi, RN, MSN

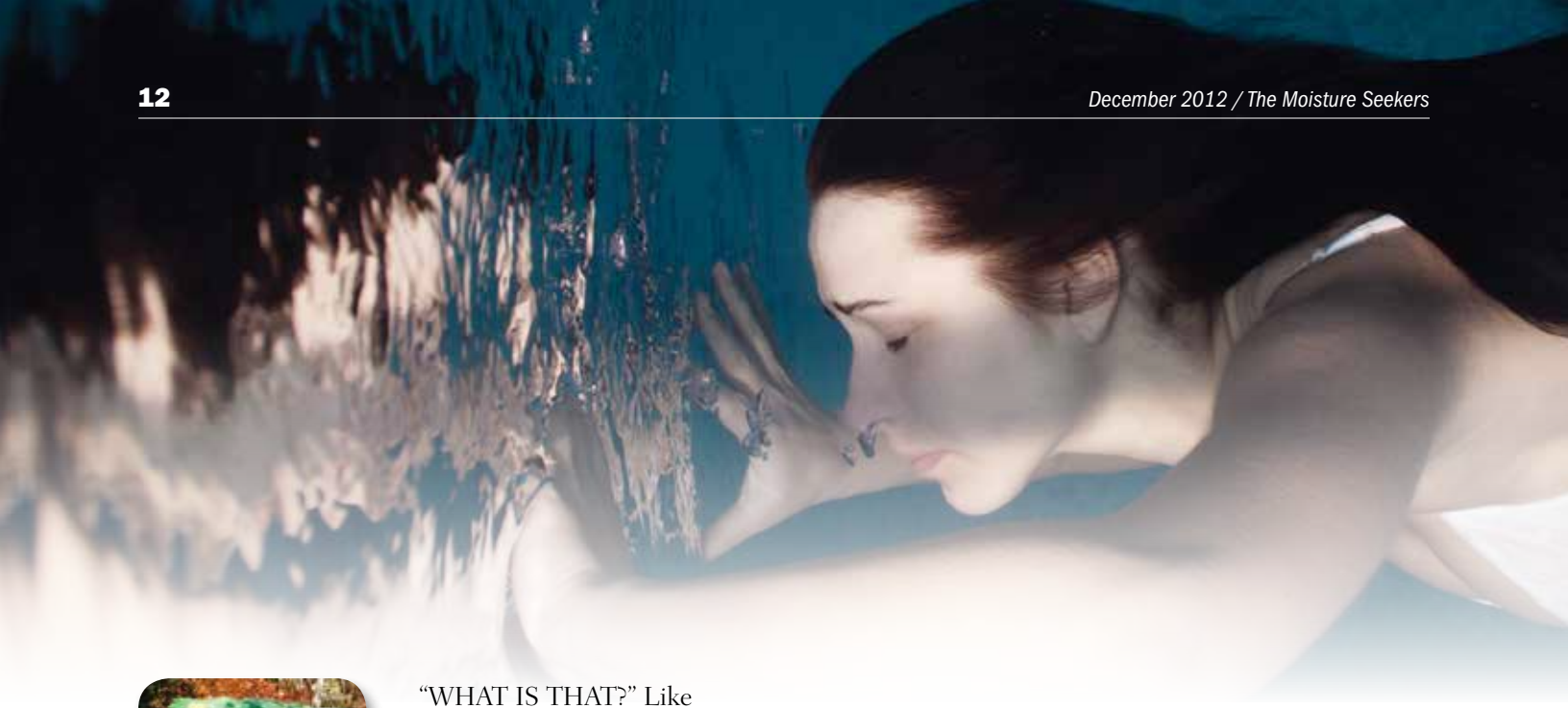
Always go to the emergency room if:

- **You are having chest pain**, even if you think it may be severe GERD or esophageal spasm. It is best to let the experts determine the cause.
- **You have any signs of a stroke** – numbness/tingling or inability to move an extremity, inability to speak, loss of consciousness, visual disturbance or loss of vision.

Additional important information:

- **Do not attempt to drive yourself to the emergency room if the above occur**. It is best to call 911 so your condition can be evaluated by a healthcare professional as soon as possible. If you are alone and able, call a family member or friend to be with you and accompany you to the ER.
- **Remember to bring** your insurance cards, photo ID and a means to pay your co-pay.
- **Take your oral and ocular products and the remainder of your daily medications** with you. Do not take any medications while in the ER or while waiting to be seen without permission from your doctor.
- **Take a copy of your medical history**, medication list and list of your key doctors and their contact information with you.
- **Tell the nurses and doctor that you have Sjögren's**. If they don't know what Sjögren's is, tell them it is a lupus-like disease.
- **If you have problems other than the above**, you may still need to go to the emergency room. Call your doctor's office or the doctor on call after hours and on weekends and report your symptoms. They will help you determine whether an emergency room visit is necessary.
- **Remember** that the most critical patients will be seen first in the emergency room (i.e. chest pain, stroke, trauma), so you may have to wait a considerable amount of time to be taken to a room and be seen by a doctor.
- **Be aware of other care providers in your area to treat non-emergency care needs**. An urgent care center or orthopedic after-hours clinic may be a more timely and cost-effective manner to get your health concerns addressed. Bring the same information you would bring to the emergency room to these facilities.

For more information on Sjögren's syndrome, visit the SSF web site at www.sjogrens.org, call 800-475-6473, email ssf@sjogrens.org or write to the Sjögren's Syndrome Foundation, 6707 Democracy Blvd, Suite 325, Bethesda, MD 20817. ■



"WHAT IS THAT?" Like most, I had no knowledge about Sjögren's until that moment. Now I tell people that Venus Williams and I have something in common and it isn't tennis! Many have heard about Venus' experience with Sjögren's and could relate to my illness through her. After struggling for nine years with a variety of illnesses, I appreciated finally having a diagnosis but was afraid of the unknown.

My main symptoms were not dry mouth and dry eye. I had chronic sinusitis, ear infections, swollen parotid glands and a consistently abnormal white blood count. Four months before being diagnosed, I suffered severe joint pain, stiffness, fatigue and mental fog. I struggled to be productive after 11:00a.m. and finally retired because I felt I wasn't a productive team member anymore and was frustrated. So were the people around me. None of us knew my body was out of balance.

Education is the key to identifying this disease early and getting the needed treatment. I had one doctor tell me I was crazy and needed to see a psychologist, but it was the hodgepodge of illnesses and symptoms associated with Sjögren's. Now, I read books, talk to my doctor, research the Sjögren's Syndrome Foundation's website and talk to anyone who will listen. I went through the denial to acceptance process fairly quickly. I do my best to manage the disease and not let it manage me. Some days are given over to the symptoms, but it beats other alternatives.

My advice is to never give up and only give in when you must. Stay active and enjoy life to its fullest. Identify friends and family who understand your illness and rely on them for support. Life is a journey with many twists and turns – Sjögren's is just one more of them along the way. Lastly, keep faith and hope alive that a cure will be found.

- Nancy

continued page 13 ▼

December

Breakthrough Bullet:

When I was diagnosed with Sjögren's, my first thought was…

50% in 5 years

Sjögren's syndrome FOUNDATION

"Breakthrough" continued from page 12 ▼

Nancy's story is just one of the 15 stories that were previously submitted for a new awareness campaign, *Faces of Sjögren's*.

The Foundation knows how isolating being diagnosed with an invisible illness can be, but you are not alone. There are an estimated four million Americans suffering from Sjögren's, both men and women of different ages and ethnicities, which is why we are launching *Faces of Sjögren's* – to share your stories on our web site.

As a way to help recently diagnosed patients, in addition to helping others find a diagnosis quicker, these stories will help others relate because no patient is alone. Whether you are a patient, doctor, loved one or family member, we want to know your own personal experience with Sjögren's. With your help, we hope this project will help us reach our 5-*Year Breakthrough Goal*!

We hope to have even more stories when we officially launch the campaign. Please keep the following guidelines in mind if you'd like to submit your story:

- Stay within 250 words
- Include aspects of how Sjögren's has affected your life and ways you have been able to effectively cope with your symptoms
- Include a few personal words of inspiration
- At the beginning of your story, please complete the following phrase, "When I was diagnosed with Sjögren's, my first thought was…"
- And don't forget to include a picture of you!

Email your story to tms@sjogrens.org with the subject "*Faces of Sjögren's*" or mail it to the Foundation's office at 6707 Democracy Blvd., Ste 325, Bethesda, MD 20817.

Together we will conquer Sjögren's! ■

"Q&A" continued from page 10 ▼

can have chronic inflammation resulting in salivary gland swelling. For most this is an episodic event. The swelling can occur in multiple glands at the same time and may be associated with little or no discomfort. For others, the salivary gland swelling is persistent and close follow-up is necessary because of an increased risk of a transition to lymphoma. In cases where there is chronic inflammation of the salivary gland, it is important to avoid acute flare-ups because of bacterial infection. In the setting of low salivary flow, the oral bacteria have an easier time moving into the ductal system as there is a decreased "washing effect" of saliva flowing through the ducts from the salivary gland. Methods to prevent infection include excellent oral hygiene, hydration, warm compresses and sugar-free lozenges to stimulate salivary flow.

You will note that there is overlap in the symptoms associated with the different causes of salivary gland swelling. Specialized imaging such as an ultrasound, magnetic resonance imaging or CT may be helpful in further delineating your condition if there is no resolution with conservative management. ■

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Call us today for more information.

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Sjögren's Syndrome Foundation

Order these great resources today!

	Non-Member Price	Member Price	Qty	Amount
The Sjögren's Book, Fourth Edition: *edited by Daniel J. Wallace, MD.* The 2011 edition of the Sjögren's handbook has been completely revised and expanded with all new chapters and the latest information on Sjögren's.	$30	$26		
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 Fremes, 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 Balance Within: The Science Connecting Health and Emotions *by Esther M. Sternberg, MD.* 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		
Dancing at the River's Edge: A Patient and her Doctor Negotiate Life with Chronic Illness *by Alida Brill and Michael D. Lockshin, MD.* A dual memoir with a patient and her doctor that offers a powerful and inspirational testimony from either side of the examining table.	$16	$14		
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		
The Woman's Book of Sleep: A Complete Resource Guide *by Amy Wolfson, PhD.* An overview of the latest findings pertinent to women's sleep, and it distills their practical implications in a direct and straightforward style.	$16	$13		
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		
Purchase a full set of last year's *Moisture Seekers* newsletter Volume 29, 2011 (11 issues) as originally published.	$50	$20		
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in memoriam

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In Honor of Abby & Kyle Smith
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In Honor of Cheryl & Brad Smith
Grandma Smith

In Honor of Connie Ellison's 50th Birthday
Judith Grimes

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.

The Moisture Seekers
Sjögren's Syndrome Foundation Inc.
6707 Democracy Blvd., Ste 325
Bethesda, MD 20817
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If you would like to receive this newsletter but are not currently an SSF Member, please contact us! 800-475-6473

SAVE THE DATE!

2013 SSF National Patient Conference

"Discover the Possibilities"

April 12-13, 2013

Hyatt Regency Bethesda
Bethesda, Maryland

As a Sjögren's patient, it's easy to feel confused or overwhelmed by the abundance of information available about the illness and how it affects your body. But here is your opportunity to "Discover the Possibilities" for an educational journey to take control of your health and day-to-day living by learning from the best minds dealing with Sjögren's. This April, join fellow Sjögren's patients and their family members as well as healthcare professionals and other experts who specialize in Sjögren's at the 2013 SSF National Patient Conference in Bethesda, Maryland.

SSF programs are the best Sjögren's patient education opportunities in the country. They have helped thousands gain a better understanding of Sjögren's and will help you, too. This two-day event will feature an array of presentations from the country's leading Sjögren's experts – physicians, dentists, eye care providers, and researchers – who will help you understand how to manage all key aspects of your disease. So this April 12-13, we invite you to join with us and experience a weekend where you will "Discover the Possibilities" for heightening your understanding of Sjögren's at the 2013 National Patient Conference in Bethesda, Maryland!

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

Presentation topics will include:
Overview of Sjögren's Syndrome
Sex and Living with Sjögren's
Biologic Therapies and Sjögren's
Understanding Blood Changes and Test Results
Caregiver/Patient Perspective on Sjögren's
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Dry Eye and Sjögren's
Dry Mouth and Sjögren's
Podiatry Issues and Sjögren's
Hope for the Future: Research Update