

The Moisture Seekers



www.sjogrens.org

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June 2010



Sjögren's Syndrome Foundation Leadership Awards

Healthcare Professional Leadership Award – Troy E. Daniels, DDS, MS

Dr. Daniels first began volunteering for the Sjögren's Syndrome Foundation in 1984. Since then, he has continuously stepped up to support the Foundation by authoring articles, answering questions for our newsletters, speaking at SSF conferences as well as representing Sjögren's on multiple national and international task forces.

In 2003, Dr. Daniels was awarded, as Co-Principal Investigator, the first-ever Sjögren's Registry (SICCA), a \$12 million dollar international project funded by the National Institutes of Health. The original five-year award has since been extended to ten years and expanded to include nine sites around the world, including three in the United States. This registry will change the face of Sjögren's worldwide by dramatically increasing our knowledge about Sjögren's, encouraging more researchers to focus on this disease, and providing a wealth of data and tissue samples for researchers to analyze for years to come.

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Information You Requested

This edition of Information You Requested comes straight from the National Patient Conference. The following are actual questions-and-answers asked by attendees during the question-and-answer sessions and answered by the doctors.

Some of these talks are available for purchase as audio CDs. See page 8 of this issue for the complete listing of talks available and audio CD order form.



Q *I've seen some products that are called dissipating preservatives. I wanted to know what you think of those.*

A Preservative-free drops are good, though some people are concerned because patients go through them faster and the cost is higher, so dissipating preservative drops could be appealing. Most dissipating preservatives work by being activated by exposure to ultraviolet light. The moment that drop comes out it instantly dissipates because the UV breaks down the preservative, so there is legitimacy to the claim that the preservatives break down before they have a chance to dwell on the surface of the eye and cause possible reactions. I think it's something you can

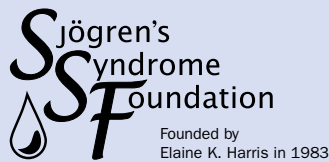
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This December, Dr. Daniels will celebrate his 40th year in Sjögren's work, creating an ideal opportunity to recognize him with our Healthcare Professional Leadership Award. Dr. Daniels currently serves on the SSF Board of Directors and our Medical & Scientific Advisory Board. In 2009, Dr. Daniels accepted Co-Chairmanship of our Clinical Practice Guidelines Oral Section, a new initiative by the Foundation to create treatment guidelines that will improve the quality of care for Sjögren's patients.

Dr. Daniels' commitment and dedication to Sjögren's is seen not only by his list of publications, career achievements and service but especially by his compassion and deep concern for Sjögren's patients worldwide.

Volunteer Leadership Award – Irma Rodriguez & Fred Fernandez



photo by Arthur Johnson

Irma Rodriguez and Fred Fernandez are an inspiring couple. When faced with Irma's diagnosis of Sjögren's, they did not let it stop them from volunteering their time, energy and talents, putting them to use in making a difference for all Sjögren's patients.

Irma, an executive with Coca-Cola, and Fred, a retired UPS executive, began volunteering with the Sjögren's Syndrome Foundation after attending our 2005 National Patient Conference in San Francisco. Together, they have worked with the Foundation and the Atlanta support group to strengthen the local group by leading the effort to survey the Atlanta membership to help increase involvement and active participation.

Over the past three years, Irma and Fred have co-chaired and helped plan and organize the first-ever Atlanta fundraising event for Sjögren's – *Sip for Sjögren's* Fine Water Tasting. Under their leadership, this event quickly became, financially, the most successful *Sip for Sjögren's* event in the country. Fred and Irma's foundation also became Atlanta's first presenting sponsor of the Atlanta *Sip for Sjögren's* event and has been the presenting sponsor each year. They have worked to help establish our *Sip for Sjögren's* volunteer committee and to help set the agenda for that committee. Under their leadership, the Atlanta *Sip for Sjögren's* event has raised nearly \$100,000 for Sjögren's research and education.

In addition, Fred and Irma both volunteer at our National Patient Conferences and Patient Seminars. Fred also serves on the Sjögren's Syndrome Foundation Board of Directors as well as other national SSF

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committees, while Irma continues to make introductions of the SSF to national corporations in the hope of expanding the visibility of Sjögren's and the work of the Foundation.

The SSF is grateful to Fred and Irma for their support and for their work, leadership and dedication to making a difference on behalf of all Sjögren's patients.

Awareness Award – Kim Gross



Kim Gross, SSF's Albany, New York Support Group Leader, has made it her mission to adopt the SSF's top goal of increasing awareness of Sjögren's. She has worked tirelessly both in Upstate New York as well as around the country and has taken on this task in spite of dealing with her own Sjögren's while raising two young children.

If Kim is not organizing her upcoming Sjögren's Support Group meeting or serving on the Albany *Sip for Sjögren's* Committee, she is most likely assisting the SSF by telling her story to journalists, reporters and/or authors. Kim has taken part in focus groups helping educate corporations as well as others to understand the implications of Sjögren's while also sharing her story with countless publications and media outlets. Most notably, her personal story was highlighted in the March 2010 issue of *Ladies Home Journal*.

Kim also has helped raise awareness by coming up with creative ideas that other SSF volunteers might emulate. For example, this past month, Kim held a bake sale at her children's school to raise funds for the SSF, but even more exciting, she had the school send a flyer home with all 400 students promoting the Sjögren's Syndrome Foundation. When Kim was asked about her luck in getting the school to support this project, she said "I just asked." Well spoken by a person who knows all about increasing awareness.

Awareness Award – Ken & Anne Economou

Ken and Anne Economou are a perfect example of how to "Stand Up for Sjögren's." After seeing the SSF's promotion for the 2009 *Team Sjögren's* Marathon Training Program and, despite Anne having Sjögren's, they decided they wanted to make a difference and take on the challenge.

Choosing to participate in the April 2009 Country Music Marathon in Nashville, Tennessee, Ken signed

up for the full marathon (26.2 miles) and Anne for the half-marathon (13.1 miles). They began their training



as well as fundraising for *Team Sjögren's* and were surprised at what they found – overly generous and supportive friends and family. Together, Ken and Anne raised an outstanding \$15,000 for *Team Sjögren's*, far exceeding their goal! Even more impressive, after training for a few weeks, Anne decided to do the entire full marathon – all 26.2 miles!

What makes Ken and Anne most unique, however, is their enthusiasm and belief in others. Over the four months of training, Ken and Anne were able to join with their fellow *Team Sjögren's* members on conference calls, and it soon became apparent that Ken and Anne would become friends and motivators to all of them. Their warmth and compassion was seen throughout their marathon training program and continues today as they help the SSF motivate our newest *Team Sjögren's* recruits for the upcoming 2010 Nashville Country Music Marathon.

As alumni of *Team Sjögren's*, Ken and Anne continue to "Stand Up for Sjögren's," and we are proud to have them standing with us!

Awareness Award – The Satterwhite Family



The Satterwhite family's contribution to the Sjögren's Syndrome Foundation goes far beyond their fundraising ability. Not only does this family support their daughter and sister Kim, who battles Sjögren's, but

they also help to raise over \$15,000 each year through the San Antonio *Sip for Sjögren's* event.

Three years ago, Kim Satterwhite, a young Sjögren's patient, began the crusade to increase awareness for Sjögren's by starting the first San Antonio *Sip for Sjögren's* event. Little did she know that her efforts would become a family affair. Soon after she agreed to help lead the event, her mother Trudy and her sister Melissa immediately jumped in to help. Today, along with friends and a few fellow Sjögren's patients, the Satterwhite family continues to lead the event by

"Information You Requested" continued from page 1 ▼

certainly try and see how you do with it as an alternative or adjunct to using the preservative-free lubricated eye drops.

Stephen Cohen, OD from his talk Dry Eye & Sjögren's

Q *You had mentioned that dry eyes feel best in the morning because they have been closed all night. Well, I'm the opposite – at night, when my eyes are closed, if I don't use lubricants, my eyes feel awful in the morning. Why could that be?*



Stephen Cohen, OD

A There are certain conditions that can get worse during the night with the eye in a closed state. For example, if you have blepharitis, which is caused by a common skin bacteria called "staph epidermidis," the waste products of the staph are very irritating. But with your eye closed that staph toxin is lying there all night. If I have a patient who wakes up with really irritated eyes, one of the first things I want to look at is untreated blepharitis. Another possible cause is called "recurrent corneal erosion." Think about pulling a scab off all the time. It starts to heal and you pull the scab off. If the surface of the eye gets irritated through dryness and adherence to the back of the lid, or through an injury, that tissue needs to heal. The good news is it heals very quickly. The bad news is it hurts a lot as I'm sure you've found. So it heals quickly but it doesn't necessarily an-

chor itself. That thin, outer layer of the cornea doesn't anchor itself to the eye very fast, so you run the risk of re-irritating your eye even after you are feeling better. And when you do that over-and-over, it is called "recurrent corneal erosion." You are basically tearing off the outer layer of the front of your eye. Classic sign is you wake up, you open your eyes and it hurts. Using ointments at night helps. Using an antibiotic ointment would help if you have blepharitis as well because it would treat that and give your eye a little more coating.

If you have severe dry eyes and you find you have trouble opening your eyes in the morning because your lid is sticking, try to keep your eyes closed when you wake up and take the heels of your hands and gently massage your lids. What it will do is break any of those adhesions that may be there and it stimulates a little tear production so that you can actually open up your eye safely. But if you wake up and open up your eyes right away, you run the risk of – ouch – pulling that adhesion off, again, like pulling a scab off of a wound.

Stephen Cohen, OD from his talk Dry Eye & Sjögren's

Q *I've been told I am a model responder to Restasis. Is the quality of the tear as good as a natural tear?*

A Restasis has anti-inflammatory abilities, and what is believed is that a lot of dry eyes are considered an inflammatory condition. So the tear glands, which are located right underneath the bones above our eyebrows, often get inflamed and don't produce the tears properly. It has been found that Restasis reduces that inflammation and allows the glands to work more properly. So when you produce tears, if you're the model Restasis patient, you are producing good quality tears.

Stephen Cohen, OD from his talk Dry Eye & Sjögren's

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"SSF Leadership Awards" continued from page 3 ▼

recruiting local sponsors and soliciting silent auction items as well as helping with logistics of the event.

Over the past three years, the event has raised over \$40,000 for Sjögren's research and continues to increase the number of attendees. The Satterwhite family pulls out all the stops to ensure the event is well attended by calling on friends and extended family from their professional and personal lives. Even Kim's extended family, the staff and parents of Stone Oak

Elementary School where Kim serves as a first-grade Teacher, help to ensure that the *Sip for Sjögren's* event is a great success.

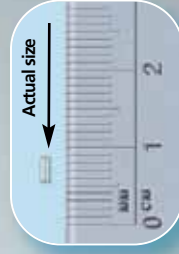
To meet the Satterwhite family is to love them. They exude warmth and compassion, and it is no surprise that they have such a wonderful following in San Antonio. The SSF is proud to have them as members of our extended family. ■

If you drop artificial tears ≥ 4 times a day, give yourself

More Freedom to Go DROPLESS

LACRISERT®: All-day dry eye relief in a single daily dose*

- **Significant improvement** in symptoms, signs, and activities of daily living^{1,2†}
- **Dissolves comfortably** in the eye to begin all-day relief—like a s low-release artificial tear^{2,3}
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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.

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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*Some patients may require twice-daily use for optimal results.¹

†Multicenter, 2-visit, 4-week, single-arm study conducted in moderate to severe Dry Eye patients who had previously been using AIs (N=520). Results are based on 418 patients who completed the study.


LACRISERT®
(hydroxypropyl cellulose ophthalmic insert)

"Information You Requested" continued from page 4 ▼

Q What makes saliva substitutes different from water?

A For saliva substitution, a lot of people just use frequent sips of water – it's readily available and it's inexpensive. But water is not saliva. You can actually take sips of water too often and end up removing the mucus film that forms on the mucosa. This would actually increase your symptoms of dry mouth. So it's important to not just sip water every few minutes.

There are many saliva substitutes available. There are over-the-counter preparations, and they may be helpful next to the telephone or when traveling or at your bed-



Troy E. Daniels, DDS, MS

side. They are useful but with some limited expectations. Basically, the saliva substitutes are water plus something else. Most saliva substitutes have carboxymethylcellulose (CMC) to make them a little thicker. Some have CMC with mucopolysaccharide. There are also glycerine polymer-based gels that come in a tube like toothpaste, and for patients with very severe

dry mouth this could be the most effective. However, patients who are making some saliva would not like using it.

Really, you are going to have to shop among the many options and find what works best for you at this stage in your condition. There isn't a single recommendation that can be made. You really do need to shop around.

Some products come in sprays that people find convenient. Other additional components that are useful are xylitol because it inhibits one of the bad bugs called "mutans streptococci." However, the pH of the spray must be neutral. And do not use substitutes if they contain fluoride. It's a very hard way to control your systemic fluoride intake and it is not useful in that particular medium.

And, of course, no saliva substitutes truly replace the functional properties of saliva.

Troy E. Daniels, DDS, MS from his talk

The Importance of Saliva: Dry Mouth and Sjögren's

Q I have trouble sleeping through the night with my dry mouth. Do you have any tips?

A Nocturia is a common cause of sleep disruption for patients with chronic salivary dry mouth. And often it is due to ongoing water consumption right up to bed time. If this is the case, you are going to bed with the potential to produce a lot of urine. After falling asleep, about two hours later, that is what wakes you up. Then, while you are up and you are in the bathroom you get a glass of water. And, guess what, two hours later you're back there, then you get another glass of water, and so on, and then the alarm clock goes off and you don't feel great. This is preventable. Basically, don't swallow any fluids one to two hours before going to sleep. And if you awake from sleep, only use a low volume saliva substitute – don't drink a partial glass of water.

Troy E. Daniels, DDS, MS from his talk

The Importance of Saliva: Dry Mouth and Sjögren's

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LACRISERT® (hydroxypropyl cellulose) OPTHALMIC INSERT

DESCRIPTION

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

Each LACRISERT is 5 mg of hydroxypropyl cellulose. LACRISERT contains no preservatives or other ingredients. It is about 1.27 mm in diameter by about 3.5 mm long. LACRISERT is supplied in packages of 60 units, together with illustrated instructions and a special applicator for removing LACRISERT from the unit dose blister and inserting it into the eye.

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.

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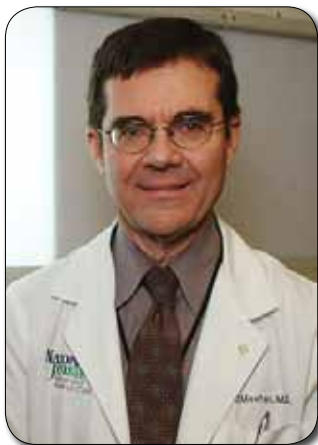
References: Kuffler BH; for the LAC-07-01 Study Group. Lacrisert (hydroxypropyl cellulose ophthalmic inserts) significantly improves symptoms of dry eye syndrome (DES) and patient quality of life. Poster presented at: Association for Research in Vision and Ophthalmology (ARVO) 2009 Annual Meeting; May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

Q *I put Vaseline in my nostrils because my nose is so dry, but I recently read that the Vaseline can end up in my lungs. Is this true?*

A Our ENT physicians do not like Vaseline in the nose specifically because of this issue. So they recommend that people use Ocean spray frequently and put the normal saline back in there. Generally, they think Vaseline is toxic to the lung if you inhale it.

Richard T. Meehan, MD, FACP, FACC from his talk Lung Complications & Sjögren's

Q *I have become very short of breath when I go upstairs or up inclines to the point that it affects my lifestyle. I have normal pulmonary functions and further testing shows no Sjögren's changes. Is that possible?*



Richard Meehan, MD, FACP, FACC

A Yes. Sometimes when someone is short of breath but normal physiology and the CT scan doesn't explain it, you have to look for alternative causes. That is why a cardiac workup, for example, would be good to make sure there is no pulmonary hypertension or underlying cardiovascular disease. Sometimes it takes a complete exercise test to do that. Is it heart? Lung? Combination? They can figure it out. But this needs

to be evaluated if there is a significant change in your exercise capacity.

Richard T. Meehan, MD, FACP, FACC from his talk Lung Complications & Sjögren's

Q *You emphasize bringing all of your medical information to doctor visits, but most of us have nearly books-upon-books of our medical history. So, in reality, how far back do you think the information should go?*

A That's a good question. You need all your information. However, your doctors probably don't need all your information if they already know you. But for your initial visit, give them everything that you have.

Then, after that, just give your doctors updates – bring anything that has happened in the 2-3 months since your last visit. Now, do doctors look at the information? They do when it is important. But for new patients a doctor cannot read your medical history right there in front of you during your visit – there just is not enough time. But I will read a patient's history at the end of the day after I've seen all my appointments.

Steven R. Weiner, MD, FACP, FACC from his talk The Doctor/Patient Relationship

Q *I've noticed that when I go to a doctor's office with my full medical history, I automatically get discounted as a hypochondriac. What do you suggest I do differently?*



Steven R. Weiner, MD, FACP, FACC

A Relationships are difficult and communication is hard. You need to find the people who work well for you. Sometimes they are not right next door. But you need to find the support personnel that will work for you. If you have the luxury of picking between doctors, that is what you have to do. I moved my offices a few years ago about nine miles away. For some odd reason 20% of my patients did not

want to drive the extra distance. But if I were cutting their hair they would have driven a lot further!

But like anything else you need to find your best support: your best grocery store, your best dry cleaner and your best doctors. You ask your friends, you ask your relatives, you ask everyone you can to try and find those supportive people.

I know that in some health insurance systems your choices are limited. As a result you may have to become far more directive about your care. You may have to gather your information, make it concise, and direct your care as to what you want. I know that may sound absurd.

The more you know about what you have, the better your treatment is. That is where the Sjögren's Syndrome Foundation excels, in educating patients. If you come in and say, "This is my problem and this is what I think I need," your doctor has to respond to it. And

Six of our most popular talks from the 2010 National Patient Conference held in San Francisco, California 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.

Overview of Sjögren's Syndrome – Nancy L. Carteron, MD, FACP: A specialist in rheumatology, autoimmune disease and inflammation, Dr. Carteron is co-author of our best seller, *A Body Out of Balance*. Dr. Carteron presents a comprehensive explanation of the range of symptoms that Sjögren's patients experience, explains their causes, and offers practical tips for managing them.

Dry Eye and Sjögren's – Stephen Cohen, OD: A private practice optometrist in Scottsdale, Arizona, a founding board member of the Arizona Optometric Charitable Foundation and published often in professional journals for optometry and ophthalmology. This esteemed eye care expert will describe the latest methods and treatment options available for managing dry eye.

The Importance of Saliva: Dry Mouth and Sjögren's – Troy E. Daniels, DDS, MS: Professor of Oral Medicine and Oral Pathology at the University of California, San Francisco, Schools of Dentistry and Medicine. Saliva is an essential body fluid for the protection of oral functions, and its value is seldom appreciated until there is not enough. Dr. Daniels will show a lack of saliva can impact your oral health. This enlightening talk will answer your questions about your teeth, gums, saliva, swallowing and more.

CNS Disease in Sjögren's: Update and New Paths Forward – Elaine L. Alexander, MD, PhD: A rheumatologist, immunologist, and former Assistant Professor of Medicine at Johns Hopkins Medical Institutions, and current Chair of the SSF Medical and Scientific Advisory Board. Her research has focused on potential causes and treatment of autoimmune, inflammatory, rheumatologic and neurologic disorders, with a particular emphasis on Sjögren's. Dr. Alexander understands the challenges that may afflict patients with central nervous system complications of Sjögren's and will share insights and strategies with you.

Lung Complications & Sjögren's – Richard T. Meehan, MD, FACP, FRCR: Chief of Rheumatology and Professor of Medicine at National Jewish Health in Denver, Colorado, as well as Co-Director of the Autoimmune Lung Center. Lung complications are sometimes the most misunderstood and life-threatening manifestations of Sjögren's. Dr. Meehan will add to your understanding of the various pulmonary complications and leave you with knowledge to share with your own physician.

Heart Disease: The Impact of Inflammation & Autoimmune Diseases – Debra R. Judelson, MD, FACC, FACP: An internist and cardiologist in private practice in Beverly Hills with the Cardiovascular Medical Group of Southern California and Director of their Women's Heart Institute. Dr. Judelson is a nationally recognized speaker on heart disease and created the first program to educate doctors about heart disease in women with the American Medical Women's Association. Dr. Judelson will cover the risk factors, symptoms and diagnostic tests for heart disease, a critical but often overlooked facet of women's health.

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

	Non-Member Price	Member Price	Qty	Amount
Overview of Sjögren's Syndrome – Nancy L. Carteron, MD, FACP	\$30	\$12		
Dry Eye and Sjögren's – Stephen Cohen, OD	\$30	\$12		
The Importance of Saliva: Dry Mouth and Sjögren's – Troy E. Daniels, DDS, MS	\$30	\$12		
CNS Disease in Sjögren's: Update and New Paths Forward – Elaine L. Alexander, MD, PhD	\$30	\$12		
Lung Complications & Sjögren's – Richard T. Meehan, MD, FACP, FRCR	\$30	\$12		
Heart Disease: The Impact of Inflammation & Autoimmune Diseases – Debra R. Judelson, MD, FACC, FACP	\$30	\$12		
<i>Maryland Residents add 6% sales tax</i>				
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

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City _____ State _____ Zip _____

Telephone _____ E-Mail _____

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☐ MasterCard ☐ VISA ☐ AmEx Card Number _____ Exp. Date _____

Signature _____ CC Security Code _____

Congratulations to Chad Antley, Jennifer Barrett, Gabe Cabrera, Crystal Carr, Gianna Casale, Jodie Hammerberg, Sue Handchetz, William Herndon, Maria LeRose, Penny Martin, Stacey Mize, Tam Ngo, Cathy Reppenhagen, Angel & Paul Schweigert, Ann & Kathy Stanton, Steven Taylor, and Gregory Wuchter for joining *Team Sjögren's* and taking part on April 24th at the Country Music Marathon and Half-Marathon in Nashville, Tennessee. Over the past few months, our team has logged countless training miles, raised funds for Sjögren's research and education and ultimately raised awareness of Sjögren's.

On race day, five members of *Team Sjögren's* set out to run the full marathon (26.2 miles) and fourteen stepped off for the half-marathon (13.1 miles). All fourteen of our half-marathoners finished the full 13.1 miles, but due to severe thunderstorm and tornado warnings in Nashville, our full-marathon runners were forced to abandon the course at mile 22 before fully completing all 26.2 miles.

What was most exciting, however, is that the *Team Sjögren's* presence was known on race day, along with 35,000 others runners in the Country Music Marathon, giving it there all and continuing to help raise awareness for Sjögren's. We are proud of our runners, all the hard work they went through in their training, and all they have done to help raise vital funds and awareness for Sjögren's and the Foundation. Together, our *Team Sjögren's* participants raised over \$30,000 for the Sjögren's Syndrome Foundation!

TEAM SJÖGREN'S 2010 NASHVILLE COUNTRY MUSIC MARATHON



Planning for the next marathons has already begun! Currently we are looking at joining the New Orleans Rock 'n' Roll Marathon on February 13, 2011 and once again returning to the Nashville Country Music Marathon on April 30, 2011. If you or someone you know are interested in training for a marathon or half-marathon to benefit Sjögren's patients, contact Elyse Gorfain at the SSF office at 800-475-6473 x217 or egorfain@sjogrens.org. ■

"Information You Requested" continued from page 7 ▼

sometimes, for doctors, when you're asking a technical question, they are much more comfortable than when it is more generalized. And if your doctor does not respond, you can, in fact, go to your insurance company and say, "This was my problem, this is what happened, and this is the difficulty." And, even in HMOs, your insurance company may redirect you, hoping to find the person who can answer your questions. ■

Steven R. Weiner, MD, FACP, FACR from his talk
The Doctor/Patient Relationship

Remember your loved ones
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in honor

In Honor of Ann M. Baum

Stephen Baum

In Honor of Betty Klein

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Kathleen & Frank Astolfi

Bob & Mary Ziemer

In Honor of Dr. Robert Fox's Birthday

Lillyan Shelton

In Honor of Janna Nemeth

Steve & Michelle Nemeth

In Honor of Kim & Charles Vaughn

Karen Sumers, MD

In Honor of Lori Garrison

Karen Garrison



in memoriam

In Memory of Dianne Blevins

Carole P. Bickert

In Memory of Dr. Darlene Smith

Oma/Corry Bensch

Lucille Brindisi

Caren R. Dickman

Rick, Nita, Rebecca & Erika Duenas

Kate Gervais

Deb & Hank Heilman

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Livingston, Adler, Pulda, Meiklejohn & Kelly PC

Barbara Maddaloni & Chris Bierwagen

In Memory of Darlene Smith

Pat Trionfo & Howie Spitz

In Memory of Elaine Knutsen

June Combella

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Quantum Health
Sjögren's Syndrome Foundation Book Table
Stand Up for Sjögren's
Team Sjögren's



During the National Patient Conference, attendees enjoyed a lively discussion with Sjögren's patients answering questions from other patients on managing day-to-day living with Sjögren's.

Here are a few of those questions and answers.

Q *How do you find balance between acknowledging your illness and not letting it overwhelm or consume you?*

A I think the first thing to recognize is that you are not the diagnosis. So we are all individuals. We are much more than the disease. And that's important not to lose sight of because, of course, we spend so much time focused on our symptoms and complications and focused on finding help and answers.

The second thing that I would say is that even though sometimes it seems like it's the end of your life, it's not. I think one of the best things that ever happened to me when I was first diagnosed was that I met someone who had had Sjögren's for 20 years, and she had been able to have a good family life and children and keep a career going. And I thought, "Oh, thank goodness, because if she can do it, I will find a way to do it."

Our theme here has been to empower yourself. And I think that's really important because the first thing that I found is that I'm much more afraid of something that I don't know. The more I can educate myself, the more I can learn, the more I can learn about my own body, the less scary it is. I think it is really important that all of us come to conferences like this. Educate ourselves through the books, meetings and other offerings from the Foundation. Because that really helps us to be able to approach our disease with much more confidence and really feel like we're much more in control.

It is also important to surround yourself with people who support and validate you. Most of us have limited energy, so we want to spend that limited time with people who do help empower us and make us feel much better about ourselves.

Katherine Morland Hammitt

Q *Do you feel guilty about the changes you have had to make in your lifestyle and how it affects your family?*

A I think sometimes we can look at the positives, especially with children. Because when I was diagnosed, my daughter was a year-and-a-half old, and then I had a second child a year later. My vision as a parent was, I was going to be out there, I was going to be at every soccer match, I was going to be carpooling all the kids all over the place, I was going to be on all the field trips. And I had to redefine that, first for myself so that I would accept myself. And that that's not the kind of mother that I was going to be even though that's what I had always dreamed I would be and who I wanted to be. And once I was able to accept it in myself, it was much easier for my husband and my children to accept it.

Trying to look more at the positives side, I feel like my children are much more sensitive to people who have any kind of disabilities, and especially disabilities that aren't visible. I'll never forget the day my son came running home from school all excited because he was the only one in the second grade who knew what lupus is. I've found that my children really developed that sensitivity with other children, and so I'm just so proud of them.

Katherine Morland Hammitt

Live, Learn & Share



This October, come to Hartford, Connecticut and take control of your health by learning the most up-to-date information from the brightest minds in Sjögren's syndrome.

Our *Live, Learn & Share* seminars are the best one-day Sjögren's patient seminars in the country. They have helped thousands gain a better understanding of Sjögren's and will help you, too. Our panel of medical experts will address an array of Sjögren's topics; plus, you'll have the rare chance to meet and share tips with fellow Sjögren's patients.

If you want to be your own best advocate by gaining a thorough understanding of all the key aspects of Sjögren's syndrome, then this one-day seminar is for you.



HARTFORD PATIENT SEMINAR SATURDAY, OCTOBER 2, 2010

FEES – Note: Early Bird Deadline is September 8, 2010

SSF Members & Guests
Non-Members

September 8th and before
\$65 per person
\$90 (includes one-year membership)

September 9th and after
\$85 per person
\$110 (includes one-year membership)

- A fee of \$25 will be charged for all seminar registration cancellations. Refund requests must be made by September 8, 2010. After that date, we are sorry but no refunds will be made.
- Dietary Requests: Unfortunately, we cannot accommodate all special dietary requirements. We can accommodate vegetarian or gluten-free dietary requests. If you require a **vegetarian** or **gluten-free** meal option, please contact Stephanie Bonner at the SSF office (800-475-6473 ext. 210) by September 23rd.
- A limited number of rooms are available at the Sheraton Hotel at Bradley International Airport, Windsor Locks, Connecticut 06096, at the SSF rate of \$99 per night plus tax if reservations are made by September 15, 2010. To make room reservations, please call the hotel directly at 1-860-627-5311 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.

Call Today
to reserve your place.
800-475-6473

QUESTIONS? Call 800-475-6473 or visit www.sjogrens.org

"From the Mailbag" continued from page 13 ▼

Q Can you talk about working with your significant other to find a way to get that support you need as a Sjögren's patient?

A I can talk about me and my husband. Often times when faced with a problem, men want to just fix it. Take a pill, have surgery, get cured. And that's how my husband was initially. He just wanted to deal with it very quickly.

The best strategy in educating my husband was to not overwhelm him. Not to tell him everything that

could possibly happen in the future with Sjögren's. And really just deal with one thing at a time. So I would share an e-mail I had received from an online group. Or I would ask him to read an article in *The Moisture Seekers*. And then I would tell him about a medication that I am trying. So we just take it one step at a time to share and educate and to gradually bring him on board to the point now where he tells me what I can and cannot eat, and what I can and cannot do with energy levels. And he did help with the *Sip for Sjögren's* event I organized last year, which was very beneficial.

Mary McNeil




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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.




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