

The Moisture Seekers



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Sjögren's Receives Increased Attention at ACR

by Katherine Morland Hammitt, MA, SSF Vice President of Research

Sjögren's was highlighted more than ever before at the American College of Rheumatology (ACR) annual meeting held in November 2012 in Washington, D.C. "We are pleased that our relationship with the ACR continues to grow, increasing opportunities to educate rheumatologists and encourage researchers in Sjögren's," says Steven Taylor, SSF CEO. Sessions on Sjögren's at ACR included:

- The Foundation-led presentation on the SSF Clinical Practice Guidelines initiative with Moderator Frederick Vivino, MD, and presenters Steven Carsons, MD, and Ann Parke, MD. Speakers discussed the rigorous process underway as the Foundation has been tackling key clinical questions in the management and treatment of Sjögren's.

- A presentation on the 2012 ACR Classification Criteria for Sjögren's moderated by Lindsey Criswell, MD, MPH, Dsc, with Stephen Shiboski, PhD, presenting.
- An SSF-hosted discussion meeting entitled "Criteria in Sjögren's – Steps Forward" and chaired by Caroline Shiboski, DDS, PhD, and Xavier Mariette, MD. While the American European Consensus Group criteria has been in wide use by investigators worldwide since 2002, ACR recently provided tentative endorsement of new criteria developed by the Sjögren's International Collaborative Clinical Alliance (SICCA) Registry and published in 2012. The international community came together to discuss ways to ensure international collaboration as criteria is validated and refined.

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Laughter is the Best Medicine

The Health Benefits of Humor and Laughter

by Melinda Smith, MA, Gina Kemp, MA, and Jeanne Segal, PhD

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Humor is infectious. The sound of roaring laughter is far more contagious than any cough, snuffle, or sneeze. When laughter is shared, it binds people together and increases happiness and intimacy. Laughter also triggers healthy physical changes in the body. Humor and laughter strengthen your immune system, boost your energy, diminish pain, and protect you from the damaging effects of stress. Best of all, this priceless medicine is fun, free, and easy to use

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- The SSF luncheon meeting on Novel Diagnostics that packed in more attendees than at any previous meeting. The SSF is encouraging the development of a new diagnostic test for Sjögren's that will be simpler, less expensive, less invasive, and make diagnosis much easier in Sjögren's.
- The Sjögren's Syndrome Study Group led by Jacques-Eric Gottenberg, MD. The study group covered "From Pathogenesis to New Therapeutic Perspectives of Primary Sjögren's Syndrome."
- Two "Meet the Professor" sessions on "Controversies in Sjögren's" led by Alan Baer, MD.
- A Curbside Consult on "Sjögren's Syndrome: Challenges in Clinical Practice" led by Frederick Vivino, MD.
- Two oral poster sessions and a poster tour on Sjögren's. The number of abstracts on Sjögren's submitted to ACR tripled and the number accepted nearly doubled to 76 this year. Oral presentation sessions on selected abstracts doubled to two with one on clinical aspects of Sjögren's moderated by E. William St.Clair, MD, and Athanasios G. Tzioufas, MD, and a second session on Pathogenesis and Sjögren's moderated by Xavier Mariette, MD, PhD, and Lindsey A. Criswell, MD, MPH, Dsc. In addition, a Poster Tour in Sjögren's was scheduled and led by Jacques-Eric Gottenberg, MD.
- An announcement of the SSF Outstanding Abstract Awards at ACR. This year's winner was Hongen Yin, MD, PhD, of the National Institute of Dental and Craniofacial Research (NIDCR), National Institutes of Health (NIH), Bethesda, Maryland. Dr. Yin presented on a novel gene linked with glandular dysfunction in Sjögren's. Chang-Fu Kuo, MD, at the University of Nottingham, United Kingdom and Chang Gung Memorial Hospital in Taiwan, was awarded an Honorable Mention. Dr. Kuo looked at the incidence of Sjögren's in families and found that siblings of those with Sjögren's were more likely to develop the disease than those without at a relative risk (probability) of 15.5 and heritability overall was at a lower but positive 0.54 risk. ■



Walking to raise awareness and understanding. Let's all take a step to a better tomorrow.

Contact Sjögren's Syndrome Foundation at 800-475-6473 and get information on hosting your own Walkabout.

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You see dry eyes that need artificial tears.

But what you *don't* see could be a type of Chronic Dry Eye disease.

You may have reduced tear production caused by inflammation due to a disease called Chronic Dry Eye. Even close up, you won't see this kind of inflammation. You can use artificial tears for temporary relief. But to help you make more of your own tears, your eye doctor may prescribe RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05%.

With continued use, twice a day every day, approximately 12 hours apart, RESTASIS® helps increase your eyes' natural ability to produce tears, which may be reduced by inflammation due to Chronic Dry Eye. RESTASIS® Ophthalmic Emulsion did not increase tear production in patients using anti-inflammatory eye drops or tear duct plugs.

Important Safety Information: RESTASIS® Ophthalmic Emulsion should not be used by patients with active eye infections and has not been studied in patients with a history of herpes viral infections of the eye. RESTASIS® should not be used while wearing contact lenses. If contact lenses are worn, they should be removed prior to use. The most common side effect is a temporary burning sensation. Other side effects include eye redness, discharge, watery eyes, eye pain, foreign body sensation, itching, stinging, and blurred vision.

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 next page for the Brief Summary of the full Product Information.

"This type of Chronic Dry Eye disease causes inflammation that reduces your ability to make tears. Your doctor may prescribe RESTASIS® Ophthalmic Emulsion. It's what I use myself."

— Alison Tendler MD,
RESTASIS® User, Eye Doctor

Individual results may vary.



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Dr. Tendler is an actual patient and is compensated for appearing in this advertisement.



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INDICATIONS AND USAGE

RESTASIS® ophthalmic emulsion is indicated to increase tear production in patients whose tear production is presumed to be suppressed due to ocular inflammation associated with keratoconjunctivitis sicca. Increased tear production was not seen in patients currently taking topical anti-inflammatory drugs or using punctal plugs.

CONTRAINDICATIONS

RESTASIS® is contraindicated in patients with active ocular infections and in patients with known or suspected hypersensitivity to any of the ingredients in the formulation.

WARNING

RESTASIS® ophthalmic emulsion has not been studied in patients with a history of herpes keratitis.

PRECAUTIONS

General: For ophthalmic use only.

Information for Patients

The emulsion from one individual single-use vial is to be used immediately after opening for administration to one or both eyes, and the remaining contents should be discarded immediately after administration.

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

RESTASIS® should not be administered while wearing contact lenses. Patients with decreased tear production typically should not wear contact lenses. If contact lenses are worn, they should be removed prior to the administration of the emulsion. Lenses may be reinserted 15 minutes following administration of RESTASIS® ophthalmic emulsion.

Carcinogenesis, Mutagenesis, and Impairment of Fertility

Systemic carcinogenicity studies were carried out in male and female mice and rats. In the 78-week oral (diet) mouse study, at doses of 1, 4, and 16 mg/kg/day, evidence of a statistically significant trend was found for lymphocytic lymphomas in females, and the incidence of hepatocellular carcinomas in mid-dose males significantly exceeded the control value.

In the 24-month oral (diet) rat study, conducted at 0.5, 2, and 8 mg/kg/day, pancreatic islet cell adenomas significantly exceeded the control rate in the low dose level. The hepatocellular carcinomas and pancreatic islet cell adenomas were not dose related. The low doses in mice and rats are approximately 1000 and 500 times greater, respectively, than the daily human dose of one drop (28 µL) of 0.05% RESTASIS® BID into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed.

Cyclosporine has not been found mutagenic/genotoxic in the Ames Test, the V79-HGPRT Test, the micronucleus test in mice and Chinese hamsters, the chromosome-aberration tests in Chinese hamster bone-marrow, the mouse dominant lethal assay, and the DNA-repair test in sperm from treated mice. A study analyzing sister chromatid exchange (SCE) induction by cyclosporine using human lymphocytes *in vitro* gave indication of a positive effect (i.e., induction of SCE).

No impairment in fertility was demonstrated in studies in male and female rats receiving oral doses of cyclosporine up to 15 mg/kg/day (approximately 15,000 times the human daily dose of 0.001 mg/kg/day) for 9 weeks (male) and 2 weeks (female) prior to mating.

Pregnancy-Teratogenic Effects

Pregnancy category C.

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

Non-Teratogenic Effects: Adverse effects were seen in reproduction studies in rats and rabbits only at dose levels toxic to dams. At toxic doses (rats at 30 mg/kg/day and rabbits at 100 mg/kg/day), cyclosporine oral solution, USP, was embryo- and fetotoxic as indicated by increased pre- and postnatal mortality and reduced fetal weight together with related skeletal retardations. These doses are 30,000 and 100,000 times greater, respectively than the daily human dose of one-drop (28 µL) of 0.05% RESTASIS® BID into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed. No evidence of embryofetal toxicity was observed in rats or rabbits receiving cyclosporine at oral doses up to 17 mg/kg/day or 30 mg/kg/day, respectively, during organogenesis. These doses in rats and rabbits are approximately 17,000 and 30,000 times greater, respectively, than the daily human dose.

Offspring of rats receiving a 45 mg/kg/day oral dose of cyclosporine from Day 15 of pregnancy until Day 21 post partum, a maternally toxic level, exhibited an increase in postnatal mortality; this dose is 45,000 times greater than the daily human topical dose, 0.001 mg/kg/day, assuming that the entire dose is absorbed. No adverse events were observed at oral doses up to 15 mg/kg/day (15,000 times greater than the daily human dose).

There are no adequate and well-controlled studies of RESTASIS® in pregnant women. RESTASIS® should be administered to a pregnant woman only if clearly needed.

Nursing Mothers

Cyclosporine is known to be excreted in human milk following systemic administration but excretion in human milk after topical treatment has not been investigated. Although blood concentrations are undetectable after topical administration of RESTASIS® ophthalmic emulsion, caution should be exercised when RESTASIS® is administered to a nursing woman.

Pediatric Use

The safety and efficacy of RESTASIS® ophthalmic emulsion have not been established in pediatric patients below the age of 16.

Geriatric Use

No overall difference in safety or effectiveness has been observed between elderly and younger patients.

ADVERSE REACTIONS

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

Other events reported in 1% to 5% of patients included conjunctival hyperemia, discharge, epiphora, eye pain, foreign body sensation, pruritus, stinging, and visual disturbance (most often blurring).

Rx Only



Based on package insert 71876US14B Revised February 2010

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U.S. Patent 5,474,979

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"Laughter" continued from page 1 ▼

Laughter is strong medicine for mind and body

"Your sense of humor is one of the most powerful tools you have to make certain that your daily mood and emotional state support good health." ~ Paul E. McGhee, PhD.

Laughter is a powerful antidote to stress, pain, and conflict. Nothing works faster or more dependably to bring your mind and body back into balance than a good laugh. Humor lightens your burdens, inspires hopes, connects you to others, and keeps you grounded, focused, and alert.

With so much power to heal and renew, the ability to laugh easily and frequently is a tremendous resource for surmounting problems, enhancing your relationships, and supporting both physical and emotional health.

Laughter is good for your health

- **Laughter relaxes the whole body.** A good, hearty laugh relieves physical tension and stress, leaving your muscles relaxed for up to 45 minutes after.
- **Laughter boosts the immune system.** Laughter decreases stress hormones and increases immune cells and infection-fighting antibodies, thus improving your resistance to disease.
- **Laughter triggers the release of endorphins,** the body's natural feel-good chemicals. Endorphins promote an overall sense of well-being and can even temporarily relieve pain.
- **Laughter protects the heart.** Laughter improves the function of blood vessels and increases blood flow, which can help protect you against a heart attack and other cardiovascular problems.

The Benefits of Laughter

Physical Health Benefits:

- Boosts immunity
- Lowers stress hormones
- Decreases pain
- Relaxes your muscles
- Prevents heart disease

Mental Health Benefits:

- Adds joy and zest to life
- Eases anxiety and fear
- Relieves stress
- Improves mood
- Enhances resilience

Social Benefits:

- Strengthens relationships
- Attracts others to us
- Enhances teamwork
- Helps defuse conflict
- Promotes group bonding

Laughter and humor help you stay emotionally healthy

Laughter makes you feel good. And the good feeling that you get when you laugh remains with you even after the laughter subsides. Humor helps you keep a positive, optimistic outlook through difficult situations, disappointments, and loss.

More than just a respite from sadness and pain, laughter gives you the courage and strength to find new sources of meaning and hope. Even in the most difficult of times, a laugh—or even simply a smile—can go a long way toward making you feel better. And laughter really is contagious—just hearing laughter primes your brain and readies you to smile and join in the fun.

The link between laughter and mental health

- Laughter dissolves distressing emotions. You can't feel anxious, angry, or sad when you're laughing.
- Laughter helps you relax and recharge. It reduces stress and increases energy, enabling you to stay focused and accomplish more.
- Humor shifts perspective, allowing you to see situations in a more realistic, less threatening light. A humorous perspective creates psychological distance, which can help you avoid feeling overwhelmed.

The social benefits of humor and laughter

Humor and playful communication strengthen our relationships by triggering positive feelings and fostering emotional connection. When we laugh with one another, a positive bond is created. This bond acts as a strong buffer against stress, disagreements, and disappointment.

Laughing with others is more powerful than laughing alone

Shared laughter is one of the most effective tools for keeping relationships fresh and exciting. All emotional sharing builds strong and lasting relationship bonds, but sharing laughter and play also adds joy, vitality, and resilience. And humor is a powerful and effective way to heal resentments, disagreements, and hurts. Laughter unites people during difficult times.

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"Laughter" continued from page 5 ▼

Incorporating more humor and play into your daily interactions can improve the quality of your love relationships—as well as your connections with co-workers, family members, and friends. Using humor and laughter in relationships allows you to:

- Be more spontaneous. Humor gets you out of your head and away from your troubles.
- Let go of defensiveness. Laughter helps you forget judgments, criticisms, and doubts.
- Release inhibitions. Your fear of holding back and holding on are set aside.
- Express your true feelings. Deeply felt emotions are allowed to rise to the surface.

Creating opportunities to laugh

- Watch a funny movie or TV show.
- Go to a comedy club.
- Read the funny pages.
- Seek out funny people.
- Share a good joke or a funny story.
- Check out your bookstore's humor section.
- Host game night with friends.
- Play with a pet.
- Go to a "laughter yoga" class.
- Goof around with children.
- Do something silly.
- Make time for fun activities (e.g. bowling, miniature golfing, karaoke).

Bringing more humor and laughter into your life

Laughter is your birthright, a natural part of life that is innate and inborn. Infants begin smiling during the first weeks of life and laugh out loud within months of being born. Even if you did not grow up in a household where laughter was a common sound, you can learn to laugh at any stage of life.

Begin by setting aside special times to seek out humor and laughter, as you might with working out, and build from there. Eventually, you'll want to incorporate humor and laughter into the fabric of your life, finding it naturally in everything you do.

Here are some ways to start:

- **Smile.** Smiling is the beginning of laughter. Like laughter, it's contagious. Pioneers in "laugh therapy," find it's possible to laugh without even experiencing a funny event. The same holds for smiling. When you


look at someone or see something even mildly pleasing, practice smiling.

- **Count your blessings.** Literally make a list. The simple act of considering the good things in your life will distance you from negative thoughts that are a barrier to humor and laughter. When you're in a state of sadness, you have further to travel to get to humor and laughter.
- **When you hear laughter, move toward it.** Sometimes humor and laughter are private, a shared joke among a small group, but usually not. More often, people are very happy to share something funny because it gives them an opportunity to laugh again and feed off the humor you find in it. When you hear laughter, seek it out and ask, "What's funny?"
- **Spend time with fun, playful people.** These are people who laugh easily—both at themselves and at life's absurdities—and who routinely find the humor in everyday events. Their playful point of view and laughter are contagious.
- **Bring humor into conversations.** Ask people, "What's the funniest thing that happened to you today? This week? In your life?"

Want to bring the fun? Get a pet...

Most of us have experienced the joy of playing with a furry friend, and pets are a rewarding way to bring more laughter and joy into your life. But did you know that having a pet is also good for your mental and physical health? Studies show that pets can protect you depression, stress, and even heart disease.

continued page 8 ▼



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I Stood Up...

Team Sjögren's Dynamic Duo!

When our *Team Sjögren's* Marathon Training Program started five years ago – little did we know that it would be such a great success. Together, our 60+ runners have raised an incredible \$200,000 for Sjögren's research, education and awareness while also increasing awareness in their local communities.

Two of the reasons for its resounding success are two women – Kalla Ford and Tara Mardigan!

Kalla Ford started volunteering two years ago as our team trainer after running her first *Team Sjögren's* marathon with us. Kalla originally signed up to run in honor of her mother who has Sjögren's and since then has been an instrumental part of *Team Sjögren's* success. "As a professional fitness trainer and runner herself, Kalla is a perfect match to be our team trainer," said Steven Taylor, SSF Chief Executive Officer. Her commitment to the program is highlighted by the time she gives to coaching the runners and attending conference calls with the entire team – preparing them for one of the most rewarding and life-changing experiences of their lives. Kalla's running and fitness experience coupled with her passion for the fight against Sjögren's is a wonderful example of how you can take what you know and make a difference for the SSF!

Tara Mardigan became involved with *Team Sjögren's* in another way. Steven Taylor, having known her since they were kids, contacted Tara eight years ago to help the Foundation expand their knowledge about nutrition and Sjögren's. With nutrition degrees from University of New Hampshire, Yale and Tufts Universities, Tara began learning as much as she could about Sjögren's and has since spoken at numerous conferences as well as written articles for the SSF newsletter, *The Moisture Seekers*. Then, at the same time *Team Sjögren's* was being formed, Tara accepted the position of Team Nutritionist for the Boston Red Sox. That is when Steven Taylor realized Tara's commitment to Sjögren's combined with her experience alongside professional athletes would make a great addition to *Team Sjögren's*. Today, Tara serves as our volunteer *Team Sjögren's* nutritionist, helping to educate our runners on proper training nutrition as well as "day

of" marathon nutrition. She answers questions and is especially helpful to those running the marathon that also battle Sjögren's. Additionally, Tara is an avid runner herself and knows firsthand about completing a full or half marathon!

Together, Kalla and Tara have made a dynamic duo for *Team Sjögren's*! They both inspire our runners and have made such an impact on our program that we could not imagine *Team Sjögren's* without them. Thank you for standing up Kalla and Tara!

How will you Stand Up? Think about a way that you can use your passion, interest or experience to help the SSF. Contact us and let us know how you could help!



Kalla Ford running
in the Las Vegas
Marathon



Tara Mardigan with
Boston Red Sox
player David Ortiz

I will Stand Up in 2013!

"Laughter" continued from page 6 ▼

Developing your sense of humor:

Take yourself less seriously

One essential characteristic that helps us laugh is not taking ourselves too seriously. We've all known the classic tight-jawed sourpuss who takes everything with deathly seriousness and never laughs at anything. No fun there!

Some events are clearly sad and not occasions for laughter. But most events in life don't carry an overwhelming sense of either sadness or delight. They fall into the gray zone of ordinary life—giving you the choice to laugh or not.

Ways to help yourself see the lighter side of life:

- **Laugh at yourself.** Share your embarrassing moments. The best way to take yourself less seriously is to talk about times when you took yourself too seriously.
- **Attempt to laugh at situations rather than be-moan them.** Look for the humor in a bad situation, and uncover the irony and absurdity of life. This will help improve your mood and the mood of those around you.
- **Surround yourself with reminders to lighten up.** Keep a toy on your desk or in your car. Put up a funny poster in your office. Choose a computer screensaver that makes you laugh. Frame photos of you and your family or friends having fun.
- **Keep things in perspective.** Many things in life are beyond your control—particularly the behavior of other people. While you might think taking the weight of the world on your shoulders is admirable, in the long run it's unrealistic, unproductive, unhealthy, and even egotistical.
- **Deal with your stress.** Stress is a major impediment to humor and laughter.
- **Pay attention to children and emulate them.** They are the experts on playing, taking life lightly, and laughing.

Checklist for lightening up

When you find yourself taken over by what seems to be a horrible problem, ask these questions:

- Is it really worth getting upset over?
- Is it worth upsetting others?
- Is it that important?
- Is it that bad?
- Is the situation irreparable?
- Is it really your problem?

Using humor and play to overcome challenges and enhance your life

The ability to laugh, play, and have fun with others not

only makes life more enjoyable but also helps you solve problems, connect with others, and be more creative. People who incorporate humor and play into their daily lives find that it renews them and all of their relationships.

Life brings challenges that can either get the best of you or become playthings for your imagination. When you "become the problem" and take yourself too seriously, it can be hard to think outside the box and find new solutions. But when you play with the problem, you can often transform it into an opportunity for creative learning.

Playing with problems seems to come naturally to children. When they are confused or afraid, they make their problems into a game, giving them a sense of control and an opportunity to experiment with new solutions. Interacting with others in playful ways helps you retain this creative ability.

Here are two examples of people who took everyday problems and turned them around through laughter and play:

Roy, a semi-retired businessman, was excited to finally have time to devote to golf, his favorite sport. But the more he played, the less he enjoyed himself. Although his game had improved dramatically, he got angry with himself over every mistake. Roy wisely realized that his golfing buddies affected his attitude, so he stopped playing with people who took the game too seriously. When he played with friends who focused more on having fun than on their scores, he was less critical of himself. Now golfing was as enjoyable as Roy hoped it would be. He scored better without working harder. And the brighter outlook he was getting from his companions and the game spread to other parts of his life, including his work.

Jane worked at home designing greeting cards, a job she used to love but now felt had become routine. Two little girls who loved to draw and paint lived next door. Eventually, Jane invited the girls in to play with all the art supplies she had. At first, she just watched, but in time she joined in. Laughing, coloring, and playing pretend with the little girls transformed Jane's life. Not only did playing with them end her loneliness and mild boredom, it sparked her imagination and helped her artwork flourish. Best of all, it rekindled the playfulness and spark in Jane's relationship with her husband.

As laughter, humor, and play become an integrated part of your life, your creativity will flourish and new discoveries for playing with friends, coworkers, acquaintances, and loved ones will occur to you daily. Humor takes you to a higher place where you can view the world from a more relaxed, positive, creative, joyful, and balanced perspective. ■

This reprint is for information only and NOT a substitute for professional diagnosis and treatment



February

Breakthrough Bullet

"It's easy to come up with big ideas. Just think of something that everyone agrees would be 'wonderful' if it were only 'possible' – and then set out to make it possible."

—Armand Hammer

Help us make it **possible** for our future to be one where it takes patients half the time to be diagnosed, where Sjögren's is a household name and is taken more seriously by the medical community as a whole. As we pass the one year mark on the Foundation's 5-Year Breakthrough Goal, there's never been a better time or more ways to get involved.

We want to make a BIG awareness impact in as many communities as we can this year. As you read this issue, think of how you can take control and add your voice to making our goal not only **possible** but a reality. If you have questions about getting involved, contact us at 800-475-6473. ■

The Carroll Petrie Foundation Sjögren's Awareness Ambassador Program

Help Others Find an Answer!

Become a Sjögren's Awareness Ambassador!

The Carroll Petrie Foundation recently announced a two-year commitment to support the SSF's *Awareness Ambassador Program*. This donation will support the SSF's awareness projects including recruiting more volunteers to help increase Sjögren's awareness across the United States.

Over four million Americans are estimated to have Sjögren's, yet fewer than one million have been diagnosed! If only there were more people out there to tell the undiagnosed about this disease!

Do you remember when you first heard the symptoms of Sjögren's and realized that there is an explanation to what your body is going through?

Maybe you first heard about Sjögren's from your doctor or a friend or you read about it online. But the more people we have out there spreading the word, the greater chance the undiagnosed will find an answer sooner.

Last year, the SSF launched an aggressive 5-Year Breakthrough Goal: "To shorten the time to diagnose Sjögren's by 50% in five years!" You can help by becoming an Ambassador and increasing awareness in your community by talking with community members, local doctors, and local media outlets about Sjögren's.

If you would like to get involved but are unsure how you would accomplish any of this, do not worry: each *Awareness Ambassador* will be provided tools and training opportunities as well as specific themes and materials to increase Sjögren's awareness in your local community.

If you are interested in becoming an *Awareness Ambassador*, contact Kathy Ivory at the Foundation office at 800-475-6473 Ext. 213 or by e-mail at kivory@sjogrens.org.

Become an *Awareness Ambassador* and help educate thousands of people about Sjögren's and finally make Sjögren's a household name.



National Doctor's Day

March 30th is National Doctor's Day.

This year, show your doctors your appreciation by helping them stay updated on the latest Sjögren's information!

Purchase "The Sjögren's Book, Fourth Edition" for a physician (or physicians) in your life and the SSF will mail the book directly to them with a special card letting them know that it was purchased by you in honor of National Doctor's Day!

With this purchase, the SSF will give your physician a complimentary subscription to our professional newsletter, *Sjögren's Quarterly*, as well as brochures for their office.

With Sjögren's Awareness Month right around the corner in April, what better way to show your doctor appreciation than informing their entire staff about Sjögren's and raising awareness in your community! Please contact the Sjögren's Syndrome Foundation office at 800-475-6473. ■

Join the Fun!

2013 SSF Special Event Calendar

Join in the fun and help increase Sjögren's awareness. The SSF is very excited for all of our events coming this year. Look at our special event calendar below to see if there is an event coming to your area. More events to come!

Visit www.sjogrens.org

or contact the SSF office to

learn more about our events!

March

- 16** *Phoenix Walkabout & Health Fair*
Paradise Valley Mall, Phoenix, Arizona

April

- 12-13** *National Patient Conference*
Bethesda Hyatt Regency, Bethesda, Maryland
- 13** *Bethesda NPC Walkabout*
Bethesda Hyatt Regency, Bethesda, Maryland
- 27** *Team Sjögren's Country Music Marathon*
Nashville, Tennessee

May

- 4** *Philadelphia Tri-State Walkabout & Health Fair*
Philadelphia Zoo, Philadelphia, Pennsylvania
- 5** *Long Island Walkabout & Health Fair*
Roosevelt Field Mall, Garden City, New York

May continued

- 11** *Dallas/Ft. Worth Walkabout & Health Fair*
Grapevine Mills Mall, Grapevine, Texas
- 18** *New Mexico Walkabout*
Hoffmantown Church's "Mission Field"
Albuquerque, New Mexico

June

- 1** *Northeast Ohio Walkabout*
Brecksville's Oak Grove Picnic Area, Brecksville, Ohio
- 2** *Sip for Sjögren's Atlanta*
Nelson Mullins - Atlantic Station, Atlanta, Georgia
- 15** *Denver Walkabout*
Denver Zoo, Denver, Colorado





in memoriam

In Memory of Amanda Valentine

Judy & Bill Lois & Larry

In Memory of Barbara McBride

Robin Lorton

In Memory of Charlotte Adams

Laura Adams

In Memory of Cynthia Williamson

Terri & Tom Cloonan

In Memory of Douglas West

Susan West

In Memory of Evelyn J. Page

Richard Page

In Memory of Frances Stong

Ron & Karen Penaluna

In Memory of Gladys M. Sekera

Gary & Elaine Raymond Bob & Martha Rink

In Memory of Joilene "Joy" Beryl Hink

Richard & Mary Brunkhorst	Gary & Janet Carroll
Jack & Edith Coslet	Jean Dollar
Betty Emde	Delsine Fuehring
Debbie Fuehring	Lambert Gieselman
Sherman & Cindy Goocher	Laverne Gruber
Ken & Colleen Gruber	Larry & Karen Haase
Norma Jean & Norbert Hill	Melvin Hink
Blanche Knipmeyer	Jim & Doris Lieser
Albert Limback	Sheri & Randy Lovercamp
David & Debbie Lueck	Wanda Niemeier
Edward Ohrenberg	Larry & Jean Opfer
John & Sharon Pragman	Scott & Susan Ready
Fred & Carmen Schwenk	Collen Starner
Mark & Margaret Stockton	Kevin & Susan Thurman
Pam Whan	Larry & Mary Ellen Winter
Marilyn Yocum	

In Memory of Marie Cooley

Kathleen Treacy

In Memory of Martha Jane Harrison

Susan Harrison

In Memory of Mary A. Hines

Marie Hines

In Memory of Mr. Stinson

Sylvia, Susan & Elise

In Memory of Neil A. Hite

Janet Haley

In Memory of Patricia Barber

Virginia Hadley

In Memory of Rhoda Dennison

Dorothy England	Pat & Carmen Messina
Beverly Seidman	Judy Whale

In Memory of Sandra Blust

Kathy Boyd	Thomas Duszak
Lynn Petruzzi	

In Memory of Terri Elyane Downs Self

Wayne Self



in honor

In Honor of Bob & Katha Griswold

Susan & Richard Kogan

In Honor of Christine Pyle

Nathan Pyle

In Honor of Dr. Thomas Oven

Valerie Perdue

In Honor of Hugh Homer McPhail Family

Barbara McKay

In Honor of Liz DiFilippo

Roseann Cordelli

In Honor of Jamie Gaines

Hans & Mary Wasner

In Honor of Janelle K. Burnette

L. Kelly Dixon

In Honor of Jennifer Unger

Dad & Mom

In Honor of Joanne McPhail

Tania Young

In Honor of Kathryn Donnelly

Vera Albert

In Honor of Kathy Hammitt, for her tireless dedication to research

Stanley Pillemer

In Honor of Linda & Dennis Howard

Martha Costa

In Honor of Liv Von Lolhoffel

Butch

In Honor of Lois Pippin

Jean Finney

In Honor of Mr. & Mrs. Larry Levin's Anniversary

Alan & Barbara Levin

In Honor of Patricia E. Kelly

Janice Kelly

In Honor of Rick & Teresa Steinberg

Jerry Steinberg

In Honor of Shani Corbiere, for establishing the

Baylor Sjögren's Physicians Group

Sally S. Andrews

In Honor of Veneda Potts

Shorty & Ella Taraba

Remember your loved ones
and special occasions with
a donation to the SSF in
their name.

Sjögren's
SSF syndrome
foundation



TEAM SJÖGREN'S... ON THE ROAD AGAIN!

***Join Team Sjögren's in Nashville,
the home of country music...
...and the Country Music Marathon and Half-Marathon***

Join *Team Sjögren's* and train to run or walk in the 2013 Country Music Marathon and Half-Marathon in Nashville on April 27, 2013.

We are looking for 30 inspired individuals to join us as we begin to train for this challenge. We understand that not all Sjögren's patients are able to run or walk in a marathon, so we hope you will help us recruit someone else – your husband, wife, sister, cousin, daughter, son or friend – and have them run in your honor!

By signing up to join *Team Sjögren's*, you not only will receive world-class training but also leadership and mentorship from past runners and staff. You will receive coaching from our Team Trainer as well as our Team Nutritionist. The staff of the SSF will help guide you through the entire process and ensure you are ready to complete either the 13.1- or 26.2-mile course!

In addition to raising awareness for Sjögren's, you also will be helping to raise crucial funds for Sjögren's research and education.

Just imagine the difference you will be making as you run or walk in honor of all Sjögren's patients!

To learn more about *Team Sjögren's*, contact Steven Taylor at 800-475-6473, ext. 211, or staylor@sjogrens.org



 **Team
Sjögren's**

Register Now!

2013 SSF National Patient Conference “Discover the Possibilities” April 12-13, 2013

Hyatt Regency Bethesda, Bethesda, Maryland

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

Neurological Complications and Sjögren's

Dry Eye and Sjögren's

Dry Mouth and Sjögren's

Podiatry Issues and Sjögren's

Hope for the Future: Research Update

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.

2013 SSF National Patient Conference Topics and Speakers

Overview of Sjögren's Syndrome

Frederick B. Vivino, MD, MS, FACR, is Chief, Division of Rheumatology, Penn Presbyterian Medical Center, and Director of the Penn Sjögren's Center. He is also Associate Professor of Clinical Medicine, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania. Dr. Vivino will present a comprehensive explanation of the range of symptoms that Sjögren's patients experience, explain their causes, and offer practical tips for managing them.

Dry Mouth and Sjögren's

Carol M. Stewart, MS, DDS, MS, is a Professor in the Division of Oral and Maxillofacial Diagnostic Sciences at the University of Florida College of Dentistry. She maintains an oral medicine practice at the College. The primary focus of her practice and research is medically-complex patients with immune and autoimmune-related disorders. Since 1995, she has served as the Director of the Center for Orphaned Autoimmune Disorders, a multi-specialty clinic at the University of Florida with a primary focus on Sjögren's, lupus, and rheumatoid arthritis. She has published extensively in the area of Sjögren's and salivary gland disorders. Dr. Stewart's presentation will provide insights into how Sjögren's impacts your oral health as well as information to help manage and minimize the effects of dry mouth issues.

Dry Eye and Sjögren's

Mina Massaro-Giordano, MD, is Associate Professor of Clinical Ophthalmology, University of Pennsylvania, Scheie Eye Institute. She is also the Co-Director of the Penn Dry Eye and Ocular Surface Center. Dr. Massaro-Giordano is an experienced cataract micro-surgeon and is actively involved in lecturing and teaching surgery to the residents at Penn. She sees a myriad of patients and has a specific interest in treating patients with "Tear Dysfunction Syndrome" (dry eye) including the use of autologous serum eye drops. Dr. Massaro-Giordano will discuss your dry eye symptoms and complications and will describe the latest methods and treatment options available for managing dry eye.

Biologic Therapies and Sjögren's

Steven E. Carsons, MD, FACR, is Chief of the Division of Rheumatology, Immunology, and Allergy at Winthrop-University Hospital in Mineola, New York. He is also Associate Chairman of the Department of Medicine at Winthrop-University Hospital, Director of Clinical and Translational Research at Winthrop Research Institute, and Professor of Medicine at Stony Brook University School of Medicine. Dr. Carsons will discuss current and emerging biological agents that may provide promise in the treatment of Sjögren's.



Caregivers and Patients:

A Perspective on Sjögren's

Join us for a lively caregiver and patient panel discussion, answering questions and offering suggestions and techniques for managing day-to-day living with Sjögren's. This informative discussion will be a conference highlight!

Podiatry Issues and Sjögren's

Barbara A. Campbell, DPM, FACFAOM, CWS, is a private practice podiatrist in Phoenix, Arizona. She is a physician member of the Arizona State Board of Podiatry Examiners and an advisory board member of the Arizona Podiatric Medicine Program at Midwestern University in Glendale, Arizona. Dr. Campbell has been in practice for 25 years and her podiatric medical practice treats patients of all ages. She has a special interest in diabetes and wound management. Her interest in Sjögren's was stimulated by her patients with Sjögren's. Dr. Campbell will enhance our understanding of podiatry issues and Sjögren's.

Sex and Living with Sjögren's

Anne E. Burke, MD, MPH, is Assistant Professor of Gynecology and Obstetrics, Johns Hopkins University School of Medicine, Bayview Medical Center, Baltimore, Maryland, and is dedicated to providing excellent care for women. Areas of special interest to Dr. Burke include general gynecology, vaginal infections and sexual dysfunction. Dr. Burke will share her knowledge of gynecological issues and sexual dysfunction for women with Sjögren's.

What Do the Numbers Mean? Understanding Blood Changes and Test Results

Guada Respicio, MD, MS, FACR, is a rheumatologist with Arthritis and Rheumatism Associates, one of the largest private rheumatology groups in the United States, in Wheaton and Rockville, Maryland. She also is Principal Investigator and Sub-Investigator for various clinical trials at The Center for Rheumatology and Bone Research, in Wheaton. Dr. Respicio will describe the blood changes typically associated with Sjögren's as well as help us understand the rationale and meaning of the tests ordered and procedures performed.

Neurological Complications and Sjögren's

Julius Birnbaum, MD, MHS, is Assistant Professor, Division of Rheumatology, and Assistant Professor, Department of Neurology, Johns Hopkins University School of Medicine, Baltimore, Maryland. He also is Associate Director at the Johns Hopkins Jerome L. Greene Sjögren's Syndrome Center. Dr. Birnbaum understands the challenges that may afflict patients with neurological complications of Sjögren's and is committed to improving the diagnosis and treatment of neuropathic pain. Dr. Birnbaum will share his insights and strategies with you.

Hope for the Future: Research Update

Steven Taylor, CEO of the Sjögren's Syndrome Foundation, will share an update on the Foundation's Research Program and the goals for 2013. You will learn about how research holds future promise, greater understanding and hope for better therapies for all Sjögren's patients.

Space is limited. Please register early!

Registration Form

Registration fees include: Lunch each day, snacks and beverages, Friday evening dinner, hand-out material from speakers and entrance to exhibit area on Friday and Saturday.



2013 NATIONAL PATIENT CONFERENCE BETHESDA, MARYLAND — APRIL 12-13, 2013

1 ATTENDEE – complete for each registrant

Attendee Name(s) _____

Attendee Name(s) _____

Street Address _____

City _____ State _____ Zip _____

Telephone _____ E-mail _____

2 FEES – please circle appropriate fee(s) (Note: Early Bird Deadline is March 18, 2013)

SSF Members & Guests

Non-Members

March 18th and before

\$170 per person

\$190 per person

March 19th and after

\$190 per person

\$210 per person

TOTAL:

3 PAYMENT – Mail to SSF, c/o BB&T Bank • PO Box 890612 • Charlotte, NC 28289-0612 or Fax to: 301-530-4415

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

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

Signature _____ CC Security Code _____

- Refund requests must be made in writing. Registrants whose written requests are received by March 22nd will receive a 75% refund. After that time, we are sorry that no refunds can 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 (301-530-4420, ext. 214) by April 2nd.
- A limited number of rooms are available at the Hyatt Regency Bethesda (One Bethesda Metro Center, Bethesda, MD 20814) at the SSF rate of \$129 per night plus tax if reservations are made by March 16, 2013. Call the toll-free hotel Central Reservations number at 888-421-1442 or call the Hyatt Regency Bethesda directly at 301-657-1234 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
- The Hyatt Regency Bethesda is approximately 18 miles from the Ronald Reagan Washington National Airport. The hotel **does not** provide a shuttle service. However, there is direct Metro subway access below the hotel to/from Reagan National Airport (Red Line/Bethesda Station). Alternate transportation suggestion: Taxi Fare / \$38 (one way).

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

The Moisture Seekers

Sjögren's Syndrome Foundation Inc.

6707 Democracy Blvd., Ste 325

Bethesda, MD 20817

Phone: 800-475-6473

Fax: 301-530-4415

If you would like to receive this newsletter but are not currently an SSF Member, please contact us! 800-475-6473

Coordinate a Bold Blue Day for Sjögren's!

What is Bold Blue Day?

Imagine your colleagues or classmates trading in their tailored slacks or dresses for a day in **blue jeans** or **bold blue** to raise vital funds for Sjögren's research and awareness.

Ask your company or your school (even your kid's school) to consider doing a dress down day for the SSF.

How does it work?

Each person choosing to dress down would donate a suggested amount to the SSF as their fee for participating. Some companies suggest \$5 while others companies/schools let each person decide how much they want to donate.

What if your company doesn't ever allow jeans?

Then just have a **BOLD BLUE DAY** – where on a certain day everyone chooses to wear their favorite **BOLD BLUE** outfit! Then collect donations for the SSF that day as well.

To receive more information or have a "Bold Blue Day" kit sent to you, contact Ben Basloe at (800) 475-6473 ext. 207 to receive your "Bold Blue Day" kit.

