

2014 SSF National Patient Conference Highlights

On Friday, April 25, over 425 patients, family members and physicians traveled from 34 states and 2 countries to Rosemont, Illinois to help better understand “The Sjögren’s Puzzle” at the 2014 SSF National Patient Conference.

With over 80% attending their first SSF Conference, it was a great way to learn the latest Sjögren’s information from industry leading experts around the country and connecting with others who are going through the a similar health journey.

As part of the SSF’s mission to educate patients and their families, the SSF takes planning this Conference very seriously. We believe in offering a quality conference with the best speakers from around the country, talking on the most pressing and important topics. This annual Conference caters to both newly diagnosed patients looking to understand their disease and longtime SSF members furthering their education on the complexity of Sjögren’s. With only two days, we can’t hit every aspect of Sjögren’s, but try to mix up our topics each year. This year’s Conference topics included:



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Elaine K. Harris in 1983

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- Overview of Sjögren's Syndrome
- Pulmonary Issues and Sjögren's
- Dry Eye / Dry Mouth and Sjögren's
- What is in the Clinical Trial Pipeline?
- Gastrointestinal Issues and Sjögren's
- Clinical Practice Guidelines Overview
- Nutrition, Wellness and Autoimmune Disease
- Overlapping Major Connective Tissue Diseases

Being the SSF's largest event of the year, Foundation staff and the SSF voluntary Board of Directors always look forward to meeting attendees and watching as patients learn about new products from exhibitors, learn from our experts and share with one another. In addition, it was once again exciting to feel the energy of hundreds of people uniting to fight Sjögren's by participating at the Conference's awareness Walkabout on Saturday morning.

The SSF wants to thank everyone who attended and made this educational Conference possible. From our sponsors to patients and their family members, everyone committed themselves to helping each other learn and network to find new friends and supporters.

To help make the information available to everyone, the SSF will be offering some of our most popular talks from the weekend on audio CDs along with PowerPoint presentation printouts. You will be able to order these in the next issue of *The Moisture Seekers*.

For those members who were not able to join us this year, here are a few highlights about the SSF Volunteer Award Winners who were announced at the Conference Banquet Dinner. Following in the footsteps of Elaine Harris, a Sjögren's patient who founded the SSF over 30 years ago, this year's award winners show how an individual can make a difference just by getting involved!

SSF National Patient Conference Awards Winners

Healthcare Professional Leadership Award – Ann Parke, MD



Pictured from left to right: Steven Taylor, SSF CEO, Dr. Ann Parke and Kathy Hammitt, SSF VP of Research.

Dr. Ann Parke has been practicing rheumatology for over 20 years at the University of Connecticut and is Clinical Professor of Medicine at St. Francis Hospital Medical Center. Dr. Parke has held an interest in Sjögren's since the beginning of her career and is still one of the most sought after rheumatologists in the Northeast.

Dr. Parke's career has been highlighted by involvement with the SSF in many aspects including speaking at numerous

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patient conferences, serving as medical advisor to the SSF's Connecticut Chapter as well as writing articles for both *The Moisture Seeker's* and the *Sjögren's Quarterly* newsletters. Dr. Parke currently serves on the SSF's Medical & Scientific Advisory Board and also co-chairs our Rheumatological/Systemic Manifestations Working Group for the first-ever Clinical Practice Guidelines for Sjögren's.

One of Dr. Parke's most notable leadership roles in Sjögren's was her chairmanship of the Sixth International Symposium on Sjögren's Syndrome (ISSS), a gathering of Sjögren's researchers and clinicians that review the latest Sjögren's research and clinical experiences. Dr. Parke is a pioneer for both Sjögren's as well as female rheumatologists. Her commitment to patients is beyond the call of duty and it is an honor to have Dr. Parke as part of the SSF family!



Steven Taylor and Maurine Daniels

Volunteer Leadership Award – Maurine Daniels

Maurine Daniels began volunteering for the SSF almost 15 years, after being diagnosed with Sjögren's. As a local volunteer support group leader for Denver, CO, Maurine was approached in 2003 to help pilot the first-ever Sjögren's Walkabout in the country.

Under Maurine's leadership, the Sjögren's Walkabout was a huge success and has now led to the event being held in over 15 cities. Maurine's ability to recruit volunteers, motivate area patients and help secure sponsors makes her a leader for the SSF. Today, the Denver Walkabout held at the Denver Zoo attracts over 300 walkers, and is celebrating their 11th event this June!

Maurine, who also serves as an Awareness Ambassador, coordinates one of the most aggressive awareness campaigns in the country by having her local support group participate in health fairs held throughout the Denver area. For the past five years, Maurine has successfully recruited and coordinated coverage for these health fairs, making her a true awareness champion.

Congratulations Maurine on showing us that a diagnosis of Sjögren's is not a reason to lay low, but a reason to stand up, shout from the Rockies and ensure that all patients get the care, support and love they all deserve!



Steven Taylor, Heidi Shierry and Sheriese DeFruscio, SSF VP of Development

Development Award – Heidi Shierry

Heidi Shierry has continued to make a difference for the SSF by leading the Chicago Area Support Group and Sjögren's Walkabout.

However, this past year Heidi wanted to change things up in the Chicago area and took the initiative to try something new. She decided to embark on organizing an event that would engage the community at large with a fundraising dinner event. Heidi began by reaching out to friends and members of her church community to start organizing the first-ever dinner and trivia night called "Streams in the Desert".

The evening was filled with music, food and fun! The guests enjoyed a silent auction, dinner and an interactive game of Trivia! The event brought many community members as well as area Sjögren's patients together and raised an incredible \$13,000!

Thanks to Heidi and her committee, a wonderful time was had by all and it surely set the stage for another event next fall. In addition to being a great fundraiser, the event also engaged community members that had never heard of Sjögren's!

Mission Award – Clinical Practice Guidelines Chairpersons (The Fearless Seven)

This year's Mission Award goes to seven exceptional individuals who have led the charge to develop the first-ever Clinical Practice Guidelines for Sjögren's.

Under the leadership of Dr. Frederick Vivino, the idea to create clinical practice guidelines for how to treat, manage and monitor Sjögren's patients was sparked and led to one of the largest initiatives ever undertaken by the SSF.

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Joining Dr. Vivino in this incredibly brave endeavor are Rheumatology Co-Chairs Steven Carsons, MD and Ann Parke, MD; Ocular Co-Chairs Gary Foulks, MD and Lance Forstot, MD; and Oral Co-Chairs Troy Daniels, DDS and Michael Brennan, DDS. These seven individuals all have shown that their dedication transcends far beyond their medical practice and teaching careers into fully committing to helping Sjögren's patients receive the care and treatment this disease deserves.

Each of our awardees has spent countless hours of volunteer time engaging in the highly rigorous process of defining how medical professionals should treat and manage Sjögren's patients. On behalf of the millions of patients with Sjögren's, the SSF applauds these "Fearless Seven," who are well on their way to pioneering the way that doctors' and patients' experience the management of the disease.

Awareness Award – Giving Library

The Giving Library has helped the Sjögren's Syndrome Foundation go viral in 2014 by funding two online Sjögren's awareness videos that help spread the mission of the SSF.

Founders of the Giving Library, John and Laura Arnold, wanted to help philanthropists learn more about which non-profit organizations to support by producing and funding educational videos of worthwhile nonprofits. After being chosen by the Giving Library in the fall of 2013, the SSF worked to script two videos, a brief overview of the Foundation and a ten question interview explaining the work being done by the SSF to fulfill its mission.

Steven Taylor, SSF CEO, then filmed the two videos, with resources provided by the Giving Library, that were revealed on February 2014. These videos can now be viewed on the SSF website!

Vision Award – Galewood Foundation



Thanks to the generosity of William & Jeanne Dale's family foundation, the Galewood Foundation, the SSF has been able to support innovative research grants and increase its professional education programs as well as awareness efforts.

By partnering with the Galewood Foundation, the SSF has expanded efforts to educate physicians by continuing to develop and offer educational materials and courses through multiple professional conferences. The Galewood Foundation's financial support has led to greater SSF outreach to healthcare professionals and facilitated the distribution of SSF materials and brochures free-of-charge to any healthcare office that requests them. Finally, the SSF has been able to utilize the Galewood Foundation's support to remain a leader in Sjögren's research support while also launching the SSF's initiative to convince pharmaceutical companies to develop new therapeutics for Sjögren's through its Clinical Trials Consortium.

The Galewood Foundation's unwavering support for the mission and vision of the SSF will be seen for years to come through the impact their support is having and will continue to have on Sjögren's patients. ■

 A promotional graphic for the 2014 SSF National Patient Conference. The background features a puzzle piece being placed into a larger puzzle. The SSF logo is in the top left corner. The text reads:

Sjögren's Syndrome Foundation

2014 SSF National Patient Conference

"Solving the Sjögren's Puzzle"

NPC Audio CD's Coming Soon!

Please check online at www.sjogrens.org

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 continued use with RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05% twice a day, approximately 12 hours apart, every day.

Approved Use

RESTASIS® Ophthalmic Emulsion helps increase your eyes' natural ability to produce tears, which may be reduced by inflammation due to Chronic Dry Eye. RESTASIS® did not increase tear production in patients using anti-inflammatory eye drops or tear duct plugs.

Important Safety Information

Do not use RESTASIS® Ophthalmic Emulsion if you are allergic to any of the ingredients. To help avoid eye injury and contamination, do not touch the vial tip to your eye or other surfaces. RESTASIS® should not be used while wearing contact lenses. If contact lenses are worn, they should be removed prior to the 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

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

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RESTASIS® (Cyclosporine Ophthalmic Emulsion) 0.05%

BRIEF SUMMARY—PLEASE SEE THE RESTASIS® PACKAGE INSERT FOR FULL PRESCRIBING INFORMATION.

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 known or suspected hypersensitivity to any of the ingredients in the formulation.

WARNINGS AND PRECAUTIONS

Potential for Eye Injury and Contamination

To avoid the potential for eye injury and contamination, be careful not to touch the vial tip to your eye or other surfaces.

Use with Contact Lenses

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.

ADVERSE REACTIONS

Clinical Trials Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in practice.

In clinical trials, the most common adverse reaction following the use of RESTASIS® was ocular burning (17%).

Other reactions 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).

Post-marketing Experience

The following adverse reactions have been identified during post approval use of RESTASIS®. Because these reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

Reported reactions have included: hypersensitivity (including eye swelling, urticaria, rare cases of severe angioedema, face swelling, tongue swelling, pharyngeal edema, and dyspnea); and superficial injury of the eye (from the vial tip touching the eye during administration).

USE IN SPECIFIC POPULATIONS

Pregnancy

Teratogenic Effects: Pregnancy Category C

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 5,000 and 32,000 times greater (normalized to body surface area), respectively, than the daily human dose of one drop (approximately 28 mcL) of 0.05% RESTASIS® twice daily 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 3,000 and 10,000 times greater (normalized to body surface area), 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 postpartum, a maternally toxic level, exhibited an increase in postnatal mortality; this dose is 7,000 times greater than the daily human topical dose (0.001 mg/kg/day) normalized to body surface area assuming that the entire dose is absorbed. No adverse events were observed at oral doses up to 15 mg/kg/day (2,000 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.

NONCLINICAL TOXICOLOGY

Carcinogenesis, Mutagenesis, Impairment of Fertility

Carcinogenesis: 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 80 times greater (normalized to body surface area) than the daily human dose of one drop (approximately 28 mcL) of 0.05% RESTASIS® twice daily into each eye of a 60 kg person (0.001 mg/kg/day), assuming that the entire dose is absorbed.

Mutagenesis: Cyclosporine has not been found to be 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).

Impairment of Fertility: 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 2,000 times the human daily dose of 0.001 mg/kg/day normalized to body surface area) for 9 weeks (male) and 2 weeks (female) prior to mating.

PATIENT COUNSELING INFORMATION

Handling the Container

Advise patients to not allow the tip of the vial to touch the eye or any surface, as this may contaminate the emulsion. To avoid the potential for injury to the eye, advise patients to not touch the vial tip to their eye.

Use with Contact Lenses

RESTASIS® should not be administered while wearing contact lenses. Patients with decreased tear production typically should not wear contact lenses. Advise patients that 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.

Administration

Advise patients that 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.

Rx Only



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I Stood Up...

Syracuse National Grid Lights Up BOLD Blue for Sjögren's

The National Grid in Syracuse, NY, boldly lit up their iconic building in blue this April to shine light on Sjögren's awareness in their community!

Diane Stadtmiller, the SSF's Syracuse volunteer support group leader and Awareness Ambassador, wanted to raise awareness of Sjögren's by asking her husband's company, the National Grid, to host a Bold Blue Day. However, one day wasn't enough for this bold group. Employees spent an entire week wearing blue and learning about Sjögren's.

As a leading northeastern energy company, the National Grid building is known for lighting up the sky in their community but at the end of their week of being Bold Blue, the building changed colors and glowed blue in honor of Sjögren's Awareness Month, which was captured by local media.

After contacting the Foundation about hosting a Bold Blue Day, Diane was sent free awareness materials and all the supplies needed for the building's employees to participate. Employees then dressed in blue or in blue jeans for a week and made a donation to the SSF. Sjögren's materials were distributed from a booth in the building's main cafeteria that was staffed with local support group members. The support group also hosted a lecture with a patient panel who answered questions from the employees in the audience.

Thanks to their awareness efforts, they were able to raise \$1,250 for the SSF research, education and awareness programs! Seeing how fun raising awareness can be, plans have already been started for the company's 2015 Bold Blue Day event and Diane hopes her story inspires other companies to step up for Sjögren's.

Thank you Diane, the local Syracuse SSF Support Group and National Grid employees for being BOLD and supporting Sjögren's awareness!

If you're feeling bold and would like to learn about how to host a Bold Blue Day, please contact Steph Hilton at shilton@sjogrens.org or (301) 530-4420 x227. Bold Blue Days can be held at any time throughout the year to help increase awareness of this debilitating disease. ■





7 Ways to Protect Dry Eyes When Traveling

The Sjögren's Syndrome Foundation knows that one of the joys of summer is getting to take a break and go on vacation! To make the most of your getaway, here are some tips for protecting eyes when traveling.

Exposure to sun, chlorine, ocean water and sweat can have bothersome effects on your already sensitive eyes. What's more, traveling in planes and staying in hotels, where heating and air circulation systems drain much moisture from the air can be detrimental to dry eye sufferers. And what good is a vacation if it isn't comfortable and relaxing?

It's important to take care of your eyes all year long, but it's a particularly good idea to give them a little extra care when traveling. Protecting your eyes from the harsh elements before symptoms arise can be the difference between that perfect vacation and one you'd rather forget. That said try the following tips to protect your peepers; whether you're heading South, on a business trip or flying to Florida to visit the in-laws.

7 Dry Eye Travel Tips:

Artificial Tears

Plane cabins have low relative humidity conditions and cause an increase in aqueous tear evaporation that can intensify dry eye symptoms. To be fully prepared for the dry cabin, apply preservative free artificial tears like TheraTears prior to boarding the plane whether you are experiencing symptoms or not.

Swim Smart

Swimmer's dry eye can be especially painful and it is a surefire way to ruin your much needed vacation. While swimming or partaking in water sports, remember that it's important to wear protective goggles. Moreover, avoid rubbing your eyes upon emerging from the water. Keep your chlorine-ridden paws away from your eyes until you've washed them with clean water.

Hotel Humidifier

Staying in a hotel abroad? Ask the concierge for a humidifier. Try requesting one at the time you book your room so that the hotel has time to accommodate.

Lower the AC

Turn off the air conditioning/heating system in your hotel whenever possible, especially when sleeping.

Eat Right

Ensure your nutritional intake is up to par long before traveling. Start a regimen of omega-3's, or begin adding flax seed to your smoothies to ease any inflammation and ensure dry eyes stay hydrated.

Sport Shades

Purchase 100% UVA/UVB blocking sunglasses. For especially sensitive eyes, try a wraparound style that blocks sun from the sides, too. (Yes, you need to wear your shades even on cloudy days—the sun's rays can deceptively pass through cloud cover, especially between 10 a.m. and 2 p.m.)

Wear a Hat

Never look directly at the sun and wear a wide brimmed hat to shield your eyes. Be sure to bring more than one hat, too! For example, if you'll be playing beach volleyball or badminton, pack a baseball cap and wear it accordingly.

Be Prepared

If you already know you're allergic to dust or rag weed that's sure to be found in desert or windy climates, stash an oral antihistamine in your suitcase to relieve ocular redness and itching. Better safe than sorry!

Even folks who don't typically suffer from the pain of dry eye disease can be affected when traveling. Low humidity, airplane cabins, hotel rooms and different climates are enough to make anyone experience some ocular discomfort. Whether you've been diagnosed with dry eye disease- or don't usually experience symptoms, it is smart to abide by the above-mentioned tips. Trust us; you'll be glad that you did everything possible to lessen your chances of dry eyes putting a damper on your trip South! Bon Voyage!

This article is a reprint from AllAboutDryEye.com, which is sponsored by TearLab Corporation



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NeutraSal[®] Sjögren's Syndrome Support Kit

Containing:

- **NeutraSal[®]**
- **Omega-3 with Vitamin E Supplement* for Dry Eyes and Dry Mouth comfort**
- **Dry Mouth Gum with Xylitol**

*Compare to the ingredients in Thera Tears Nutrition (Advanced Vision Research, Inc.)

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The symptoms of Sjögren's Syndrome can have devastating effects. Oral dryness can result in severe and chronic dental decay, fissures, infections, and difficulty in speaking and swallowing.

Introducing
NeutraSal[®]
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What is NeutraSal[®]

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- Sodium bicarbonate ions reduce the acidity of the saliva in the mouth and break up accumulating mucus
- The pH of NeutraSal[®] is similar to normal saliva which may protect the mouth against potential opportunistic fungal (oral thrush) and bacterial infections
- Clinically proven to relieve the symptoms of dry mouth in Sjögren's Syndrome patients with no reported side effects or drug to drug interactions

NO PATIENT LEFT BEHIND PROGRAM

The No Patient Left Behind Program is designed to provide access to NeutraSal[®] treatment for all patients regardless of their insurance coverage and includes no out-of-pocket costs for patients. NeutraSal[®] is a prescription only product. Ask your physician.

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in memoriam

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Abe & Shirley Judd
Thomas & Christine Ryan


in honor

In Honor of David Rabb
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In Honor of Elaine Rippner
Love from the AZ and CA Desberg Family
Karen Desberg

In Honor of Lari Lopp
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In Honor of Maura Barnes
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In Honor of Phyllis Hayes
Valerie Hayes

In Honor of Rona Karton Elias
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To track progress of the SSF *5-Year Breakthrough Goal*, to shorten the time it takes to diagnose Sjögren's by 50% in 5 years, the Foundation surveys newly diagnosed patients to see how long it took them from the time they sought a diagnosis to the time it took to receive a formal diagnosis. The data is then analyzed by an independent marketing research company that helped us to establish that it currently takes an average of 4.7 years to receive a Sjögren's diagnosis.

In addition to tracking the time of diagnosis, the surveys also ask questions about what symptoms our patients were suffering from while trying to gain a diagnosis. This data has shown that four symptoms are emerging as the leading symptoms that patients are seeking help for when they start to look for a diagnosis. These symptoms are: Fatigue, Joint Pain, Dry Eye and Dry Mouth.

From the recommendation of the marketing research company, which was approved by the SSF Board of Directors, the Foundation is adding fatigue and joint pain to the two previously recognized hallmark symptoms, dry eye and dry mouth.

While these are the new four hallmark symptoms of Sjögren's, it does not undermine the fact that Sjögren's is still a chronic autoimmune inflammatory disease that can affect every body organ and system. As you know, some of the more debilitating manifestations include dysfunction of the kidneys, gastrointestinal system, blood vessels, lungs, liver, pancreas, and the central nervous system. These four hallmark symptoms only recognize that they are the most popular symptoms that patients present with when visiting a doctor for a diagnosis.

By publicizing the new four hallmark symptoms, the SSF is hopeful that physicians will be better able to understand the seemingly unconnected symptoms that when coupled together may suggest a Sjögren's diagnosis.

We encourage you to watch upcoming issues of *The Moisture Seekers* for additional results and findings from our yearly survey! ■

June

Breakthrough Bullet:

Recent Data Shows the
Four Hallmark Symptoms of
Sjögren's: Fatigue, Joint Pain,
Dry Eye and Dry Mouth

50%
in 5 years
Sjögren's
syndrome
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SSF Book Table

SSF Walkabout Registration

Tales from the Dry Side Book Signing

Venta Airwasher

Special thanks to The Carroll Petrie Foundation for their generous educational grant.

NIH Hosts Dietary Supplement Database

Did you know that the National Institutes of Health has a database which will allow individuals to search the labels of dietary supplements?

The Dietary Supplement Label Database (DSLDB) is a joint project of the Office of Dietary Supplements (ODS) and the National Library of Medicine (NLM) of the National Institutes of Health (NIH).

The goals of the DSLDB are to:

- Include the full label information from all of the dietary supplement products marketed in the U.S. with a Web-based user interface that provides ready access to the data
- Serve the broader research community that has expressed the need for a DSLDB
- Serve as an educational and research tool for students, academics, other professionals, and potentially, health care providers and the public

Considering the number of Sjögren's patients who currently take dietary supplements to aid in the management of the disease, the DSLDB could prove to be a very useful tool. An individual can search products, brands and ingredients. This can allow them to review the suggested use of a particular supplement, calories and daily values as well as search other brands and combinations that might be available. For instance, if a patient is taking fish oil and vitamin D, they could find a combination supplement rather than two separate supplements. This can result in easier maintenance of supplements and cost effectiveness for the patient.

You will find more information and search the DSLDB at <http://www.dsldb.nlm.nih.gov>.

Information in this article was found on the NIH DSLDB webpage.

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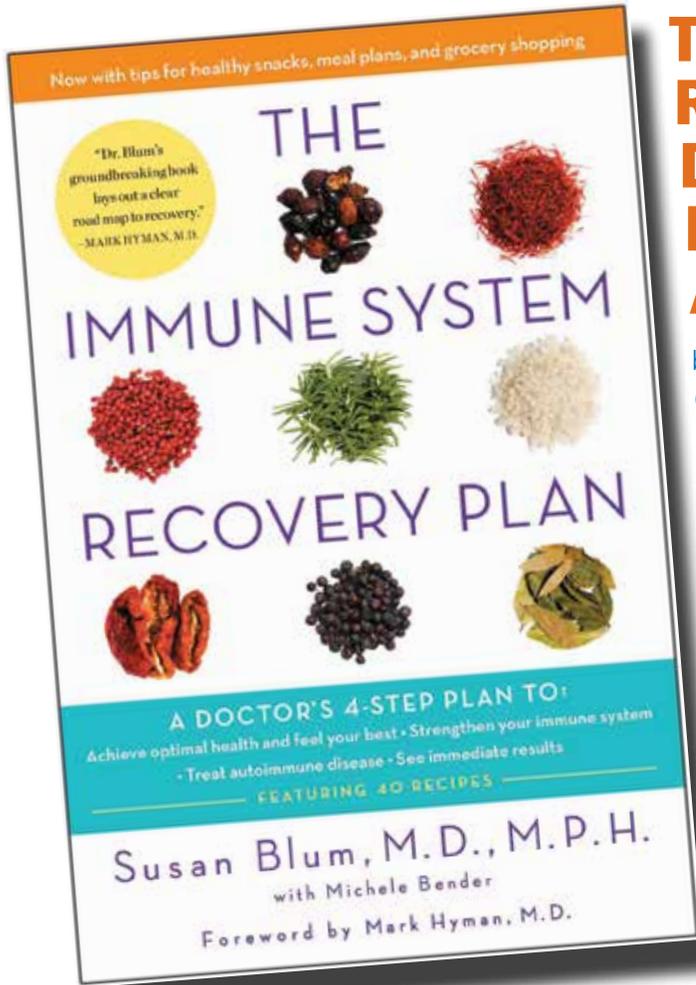
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The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease

by Susan Blum, MD, MPH (Author), Mark Hyman, MD (Foreword), Michele Bender (Contributor)

Dr. Susan Blum, one of the most sought-after experts in the field of functional medicine, shares the four-step program she used to treat her own serious autoimmune condition and help countless patients reverse their symptoms, heal their immune systems, and prevent future illness.

Dr. Blum's Method Focuses on:

- Using food as medicine
- Understanding the stress connection
- Healing your gut and digestive system
- Optimizing liver function
- Each of these sections includes an interactive workbook to help you determine and create your own personal treatment program. Also included are recipes for simple, easy-to-prepare dishes to jump-start the healing process.

This book can be purchased using the order form below, online at www.sjogrens.org/ssfstore or by contacting the Sjögren's Syndrome Foundation office at 800-475-6473.

	Non-Member Price	Member Price	Qty	Amount
The Immune System Recovery Plan: by Susan Blum, MD, MPH	\$25.00	\$22.00		
<i>Maryland Residents add 6% sales tax</i>				
Shipping and Handling:	US Mail: \$5 for first item			
Canada:	\$14 for first item			
Overseas:	\$22 for first item			
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Chickpea Salad

(from the Immune System Recovery Plan)

Beans are rich in fiber, which helps eliminate toxins through the digestive tract. When cooked with the sea vegetable kombu, the chickpeas are richer in essential minerals for good thyroid function. Here chickpeas get an abundance of flavor from fresh herbs and a vitamin C punch from lemon and red peppers. We've added rosemary for its flavor, and also because it helps support the detoxification of estrogens in the liver.

Makes 6 servings

2 cups cooked chickpeas	4 tbsp extra-virgin olive oil
¼ cup chopped red onion	2 small sprigs rosemary, minced
¼ cup carrot, diced small	2 tbsp minced parsley
¼ cup bell pepper, diced small	Salt
(if you are avoiding nightshade vegetables, substitute cucumbers or radishes)	Freshly ground pepper
1 tbsp fresh lemon juice	
2 tbsp apple cider vinegar	

Combine all ingredients in a serving dish.

Serve right away or chill for a few hours to allow the flavors to come together.

Raise awareness about Sjögren's and spend
A Day at the Beach
 Join other Sjögren's patients,
 family and friends as we walk and run
Six Miles for Sjögren's
 July 27, 2014
 Santa Cruz, California

Team Sjögren's California
www.TeamSjogrensCA.org

To join our 5th annual fundraising team and to learn more about our full weekend of events for patients and their families, contact Team Director: Estrella Bibbey at (510) 396-6783.

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

SSF Summer Sun Safety Tip

To protect yourself this summer
*Look for the words "broad spectrum," for protection from both
UVA and UVB light, as SPF ratings usually refer only to UVB rays.*

Tips from Mona Z. Mofid, MD, FAAD

Sjögren's patients, and those suffering from autoimmune disease in general, need to be cautious about their time in the sun.

Ultraviolet (UV) radiation emitted from the sun and other light sources (such as some fluorescent lights) can alter immune function and lead to an autoimmune response in the body and in the skin.

In Sjögren's patients skin rashes and disease flares can result, as well as ocular sensitivity and pain in response to the sun. In Sjögren's, sun sensitivity is associated with the autoantibody SSA/or Ro.

