Sjögren's Syndrome Foundation

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IS Sture Seek

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# Treatment Options for Peripheral Neuropathy

by Barbara A. Campbell, DPM, FACFAOM, CWS

here are many causes of peripheral neuropathy. The most common cause is diabetes. Other causes include but are not limited to vascular disease, alcoholism, metabolic problems, infections, medications, toxins, chemotherapy, trauma, genetic disorders, autoimmune disease, vitamin deficiencies, and idiopathic. Peripheral neuropathy in Sjögren's is a result of multiple autoimmune mechanisms. The white blood cells, lymphocytes, invade nerves, muscles and blood vessels resulting in an inflammatory response that destroys the tissues. The symptoms of peripheral neuropathy include but are not limited to burning pain, numbress of the hands and feet in a "stocking and glove pattern," weakness of the extremities, poor balance and altered gait.

In Sjögren's the lower extremity is more involved than the upper extremity. The most common peripheral neuropathies in Sjögren's are distal sensorimotor polyneuropathy (multiple sensory and motor nerves) and distal sensory polyneuropathy (multiple sensory nerves). Many patients with Sjögren's also have Rheumatoid arthritis (RA), Systemic Lupus Erythematosis (SLE), Scleroderma, Dermatomyositis/Polymyositis, and other auto immune diseases which are also associated with the presence of peripheral neuropathy. Treatment of the underlying disease will help to improve the response to the selected treatment of the neuropathy. For instance a patient who also has diabetes will find that strict adherence to maintenance of blood sugars will improve the symptoms of neuropathy.

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Foundation Founded by Elaine K. Harris in 1983

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# The treatment of peripheral neuropathy can be divided into several categories.

#### Medical

There are multiple classifications of medications used in the treatment of peripheral neuropathy.

#### Tricyclic antidepressants

These are the most commonly used drugs in the treatment of peripheral neuropathy. The tricyclic antidepressants affect the neurotransmitters to produce pain relief. Examples of these include amitriptyline, nortriptyline, imipramine, despramine and trazadone.

#### Anticonvulsants (anti-seizure)

These are used to relieve nerve pain but the exact mechanism of action is not known. It is thought that they may block the flow of pain signals from the central nervous system. The following drugs in this group include gabapentin (Neurontin<sup>®</sup>), pregabalin (Lyrica<sup>®</sup>), topriamate (Topamax<sup>®</sup>), carbamazepine (Tegretol<sup>®</sup>), phenytoin (Dilantin<sup>®</sup>), clonazepam (Klonopin<sup>®</sup>) and oxcarbazepine (Trileptal<sup>®</sup>).

#### Immunosuppressive

These agents are used to suppress the immune system's reaction and associated inflammation. These can be used either by an IV or taken orally. Included medications are corticosteroids (prednisone<sup>®</sup>), cyclosporine (Sandimmune<sup>®</sup>), azathioprine (Imuran<sup>®</sup>), hydroxychloroquine (Plaquenil<sup>®</sup>) and methotrexate (Rheumatrex<sup>®</sup>).

#### **Biologics**

These agents are genetically engineered proteins derived from human genes. They are designed to inhibit specific components of the immune system that are associated with inflammation. Biologics are extremely helpful when the neuropathy is associated with vasculitis (inflammation of blood vessels) Included are Enbrel<sup>®</sup>, Humira<sup>®</sup>, Remicade<sup>®</sup>, Rituxan<sup>®</sup> and Orencia<sup>®</sup>.

#### Hemorrhheologic agents

These agents are helpful when there is vascular impairment. The agent alters the viscosity of the blood to improve flow. Pentoxifylline (Trental<sup>®</sup>) is such an agent.

#### Local Anesthestics

This may include the use of local nerve blocks or Lidoderm patch (topical 5% lidocaine) to control pain in a specific area. IV lidocaine can also be used due to its sodium channel-blocking effect. When the sodium ions are blocked the small sensory nerves are unable to depolarize, thus decreasing pain detection.

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The Moisture Seekers\* Newsletter is published by the Sjögren's Syndrome Foundation Inc., 6707 Democracy Blvd., Ste 325; Bethesda, MD 20817. Copyright ©2014 Sjögren's Syndrome Foundation Inc. ISSN 0899-637.

DISCLAIMER: The Sjögren's Syndrome Foundation Inc. in no way endorses any of the medications, treatments, or products mentioned in advertisements or articles. This newsletter is for informational purposes only. Readers are advised to discuss any research news, drugs, treatments or products mentioned herein with their health care providers. I used artificial tears often, like when at lunch with friends.

# So I saw my doctor-after all, these are my eyes.

My eye doctor said I have reduced tear production caused by inflammation due to a disease called Chronic Dry Eye. That's a big deal.

She told me I can use artificial tears for temporary relief. But to make more of my own tears, she prescribed RESTASIS<sup>®</sup> (Cyclosporine Ophthalmic Emulsion) 0.05% for continued use, twice a day in each eye, 12 hours apart, every day.

#### **Approved Use**

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

#### **Important Safety Information**

Do not use RESTASIS<sup>®</sup> 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<sup>®</sup> 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. Individual results may vary.

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

#### INDICATIONS AND USAGE

**RESTASIS**<sup>®</sup> 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

 $\mbox{RESTASIS}^{\odot}$  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**<sup>®</sup> 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**<sup>®</sup> 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**<sup>®</sup>. 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 feotoxic 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**<sup>®</sup> 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 0.300 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**<sup>®</sup> ophthalmic emulsion, caution should be exercised when **RESTASIS**<sup>®</sup> 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**<sup>®</sup> 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 was recently diagnosed with peripheral neuropathy that's primarily in my feet, but is now starting in my hands. Someone mentioned acupuncture as a treatment option. Would you recommend acupuncture as a treatment option to help with my symptoms?"

Acupuncture is certainly an option that can be used in the treatment of peripheral neuropathy. There have been studies indicating that acupuncture may reduce symptoms of peripheral neuropathy. Acupuncture is a part of traditional Chinese medicine that involves the insertion of fine needles into specific points on the body surface to alleviate pain, restore overall health and prevent disease. Chinese medicine is based on the concept of Chi energy. When disease is present Chi is blocked. When the points on the body meridians are

stimulated with needles, Chi is unblocked and healing energy can flow. Western medicine indicates that acupuncture triggers the production of endorphins our body's natural pain relief mechanism.

Acupuncture is a holistic treatment and there are no side effects. It is typically not a painful procedure as the needles are fine, placed quickly and shallowly. The number of treatments depends on the duration, severity and nature of the problem.

As a side to the treatment of peripheral neuropathy, acupuncture is being used to treat the dry mouth and dry eye associated with Sjögren's.

In summary if you and your doctor feel that acupuncture is a treatment option for you, I would recommend that you choose an acupuncturist who is well trained and has experience treating peripheral neuropathy. You may also find more information regarding the treatment of peripheral neuropathy in this issue's cover story, where more treatment options are discussed.

Barbara A. Campbell, DPM, FACFAOM, CWS

# 2014 SSF National Patient Conference Keynote Speaker Announced: Mary McDonough

f the name Mary McDonough sounds familiar, it may be because she portrayed Erin, the sensitive middle daughter, on the hit series *The Waltons* for a decade. Continuing her acting career into adulthood, Mary has appeared on numerous series including *ER*, *Picket Fences*, *Will and Grace*, *Boston Legal*, and *The New Adventures of Old Christine*.

Mary chronicles her Walton family and life beyond the mountain in her strikingly honest book, *Lessons From the Mountain, What I Learned From Erin Walton*. Mary shares the story of her overnight transformation from a normal kid in a working class, Irish Catholic family, to a Hollywood child star. Touching, funny, sometimes heartbreaking, *Lessons from the Mountain* is the story of everything Mary learned on her journey over—and beyond—that famous mountain.

An outspoken activist, Mary spent fifteen years lobbying congress on behalf of women's health. After experiencing and overcoming her own health crisis, she began performing hands-on work to help heal others heal their health, spirits and lives. With "can-do" determination, she adheres to an indomitable "*if life gives you lemons, make lemonade*" philosophy. Utilizing solutions she created to solve issues affecting her own life, she was founding director of the Lupus LA, and currently heads *In The Know*, an organization dedicated to educating women about their own health.

We are delighted to have Mary McDonough as our 2014 Keynote Speaker – you won't want to miss this informative and moving presentation!



#### "Treatment" continued from page 2

#### Pain relievers

The use of Nonsteroidal anti inflammatory (NSAID) drugs may be helpful in relieving symptoms. These include over the counter (OTC) and prescription formulations. Ibuprofen<sup>®</sup>, Relafen<sup>®</sup>, Clinoril<sup>®</sup>, Advil<sup>®</sup>, Motrin<sup>®</sup> are a few. Opiates are not usually effective in treating neuropathy and are typically only used when other treatments fail. They include tramadol (Ultram®), oxycodone (Roxicodone<sup>®</sup>) and Morphine. Hydrocodone products and meperidine hydrochloride (Demerol<sup>®</sup>) are narcotic pain relievers that are also used in some instances.

#### Miscellanous

Muscle relaxers such as Baclofen® and Metaxalone® have been used in the treatment of peripheral neuropathy. Combinations of phenothiazines with tricyclic antidepressants and phenothiazines with anticonvulsants are other possibilities. Herbal agents such as evening primrose oil and borage oil have shown some positive effects.

#### **Topical Agents**

Capsaicin<sup>®</sup> is an agent that acts as a counter irritant to deplete substance P from the C type nerve fibers. It must be applied multiple times a day. Some patients also find relief from balms that contain camphor, menthol or methylsalicylate.

#### Vitamins

Metanx, a medical food, works to improve endothelial function and maintain blood flow in the vessels that carry nutrients and oxygen to the nerves. It contains L-methyl-



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folate, pyridoxal and methylcobalamin. Metanx has been shown to increase nerve fiber density. It has been shown to reduce burning pain, increase sensation, improve balance, reduce numbness and improve quality of life.

#### Other treatments to suppress the immune system

IV immunoglobulin therapy involves giving high levels of proteins that work as antibodies (immunoglobulins) in turn reducing the immune system's activity. Plasmaphoresis, a plasma exchange where immune cells are removed from the blood by a machine and the blood is returned to the body, thus suppressing immune system activity.

#### Surgical

Surgical options for neuropathic pain relief include nerve decompression and implantation of spinal electrodes. Surgical intervention should only be used when all medical and physical therapies have been exhausted.

#### Physical Therapy

The use of physical therapy including stretching, massage, balance and gait training can be very beneficial in the treatment of peripheral neuropathy symptoms. TENS units (transcutaneous electrical nerve stimulation), Anodyne therapy (near infrared light therapy), Peripheral Neuro Stimulator/P-stim device (percutaneous nerve stimulation) can be beneficial in decreasing neuropathic pain. Acupuncture has also been found to reduce symptoms of peripheral neuropathy. Orthotics and bracing can also be an integral part of physical treatment. Orthotics or other bracing systems act to support the lower extremity, relieve pressure on nerves, skin, joints and muscles, thus improving function and relieving pain. Patients with drop foot, charcot foot, tarsal tunnel syndrome and pedal deformities associated with severe pronation are examples of conditions which would benefit from orthotics and bracing.

#### Summary

In summary there are many options available for the treatment of peripheral neuropathy. It is best to have a coordinated multiple disciplinary approach in the treatment of peripheral neuropathy to optimize outcomes. It is imperative that discussions occur between the patient and health care providers so that informed decisions can be made. This will result in selecting the treatment that best fits the needs of the patient.



# Winter

# **Breakthrough Bullet:**

SSF at the American College of Rheumatology's Conference (ACR)





Pictured from left to right: Kathy Hammitt, SSF Vice President of Research, Dr. Nocturne, SSF 2013 Outstanding Abstract Award Winner, Steven Taylor, SSF CEO

ducating medical professionals about the complexity and severity of Sjögren's is strategic priority for the SSF achieving our 5-Year Breakthrough Goal: To shorten the time to diagnose Sjögren's by 50% in 5 years. The SSF presence at the American College of Rheumatology's (ACR) Conference is one of the most direct ways that we accomplish this.

Each year the SSF has an exhibitor booth to educate physicians about the seriousness of Sjögren's and let them know that the Foundation is available as a resource to both them and their patients. The Foundation is also proud of our partnership with ACR to award a Sjögren's student fellowship grant each year as a way to encourage young investigators into pursuing a career in Sjögren's.

Steven Taylor, SSF CEO, Kathy Hammitt, SSF Vice President of Research, Michele Champigny, SSF Director of Professional Awareness, and Dr. Denise Faustman, Chair of the SSF Medical & Scientific Advisory Board, travel to the annual conference. By attending and representing the SSF at the conference each year, our staff volunteers are able to build relationships with key opinion leaders in rheumatology as well as help to increase awareness and education of Sjögren's.

#### "Breakthrough" continued from page 7 🔻

At this past year's conference, the SSF helped secure 8 Sjögren's sessions, which was more than any previous year. These sessions included:

- Pre-Meeting Course: Epigenetics of Autoimmune Disease – MicroRNA Expression Profiles in Sjögren's Syndrome – Illias Alevizos, DMD, MMSc
- Meet the Professor: Controversies in Sjögren's Syndrome – Alan N. Baer, MD
- Winning at Clue: The Clinical Rheumatologist's Guide to Figuring Out Who Killed Who, With What and Where in the Rheumatic Diseases – Antony Rosen, MD
- ACR Study Group: Sjögren's Syndrome Jacques-Eric Gottenberg, MD, Moderator
- Oral Health in Rheumatologic Disease: What Every Rheumatology Practitioner Should Know About Oral Health and Diseases – Parish P. Sedghizadeh, DDS, MS
- Oral Health in Systemic Lupus Erythematosus and Sjögren's Daniel Wallace, MD
- Oral Health and Osteoporosis Therapy Stuart L. Silverman, MD
- Current Management of Sjögren's Syndrome
  - Management of Dry Eye Disease in Sjögren's Syndrome George Papaliodis, MD
  - Oral and Dental Care of the Patient with Sjögren's Syndrome Ava Wu, DDS

• Emerging Role of Biologic Agents in Sjögren's Syndrome – E. William St. Clair, MD

This conference is one of the largest awareness expenses of the SSF yearly budget. As we continuously work to focus our resources on initiatives that will make the largest difference to patients, our growth at the ACR reinforces that we are allocating funds in a way that will make the most direct impact.

The Foundation would like to give a special thanks to all physicians who spoke at these sessions and continue to be "Sjögren's Champions" by working to ensure all patients are given the care needed.



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7 Stood Up ....

### Team AJ!

ike many Sjögren's patients, AJ had never heard of Sjögren's until his diagnosis. At 9 years old, he's learning at a young age the need to explain his complex disease to the people in his life, like those in his elementary school, in order for them to understand the daily symptoms he's fighting against.

Even at the Children's Hospital where AJ is being treated, his case seems to be unique from the other patients. Frustrated by the lack of awareness and support in his community, AJ's family is determined to not let the diagnosis stop him from living a normal, healthy and happy life. This is why AJ and his mother Laura decided to get involved with the SSF to learn more about Sjögren's and educate others, especially the pediatric population.

To raise awareness of pediatric Sjögren's, AJ is not only sharing his story but for the second year in a row, he and his family are forming a team to participate at the upcoming 10th Annual Sjögren's Walkabout at the Philadelphia Zoo's on May 3, 2014.

Last year, Team AJ raised \$1,200 from over 30 supporters! Not only did he raise funds for the SSF research and education programs, Team AJ's supporters are now more knowledgeable about Sjögren's and specifically what symptoms he's dealing with. This year AJ is hoping to double his fundraising goal, and with the help of his family, he wants to be able to do more in order to help others who are fighting Sjögren's like he is.

Thank you AJ for standing up for Sjögren's!

If you would like to help AJ meet his new fundraising goal by donating to Team AJ or learn more about the other upcoming Sjögren's *Walkabouts*, please visit www. firstgiving.com/ssf or contact Stephanie Hilton at the SSF office at 301-530-4420x227 or shilton@sjogrens.org.

We also encourage everyone to look at the SSF event calendar on the back of this issue or think about hosting an awareness event in your community. With many of our spring events just around the corner, there has never been a better time to get involved! It will take all of us working together as a community to raise awareness of Sjögren's, but imagine what a difference we can make for AJ and all Sjögren's patients – now and in the future!



Read more about AJ's journey with Sjögren's, along with other patients, on "Faces of Sjögren's" at www.sjogrens.org.

In Memory of Albert T. Herndon

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In Memory of Barbara McBride Larry & Robin Lorton

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# memoriam

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In Memory of William G. D'Arcy Mr. & Mrs. Frank L Maltino

In Memory of Joan Walton Miller David & Patty Alexander Russ & Sheila Murphy Rogene & Stewart Gillmor

#### In Honor of Sharon Adley

Lyle & Sue Adley-Warrick In Honor of Kathy Donnelly

Elvira Albert In Honor of Kathy Bozzetto

Katie Bozzetto

In Honor of Diana Burt Randolph Byrd

In Honor of Elizabeth DiFilippo Roseann Cordelli

In Honor of Linda & Dennis Howard Martha Costa

In Honor of Janelle K. Burnette L. Kelly Dixon

In Honor of Harry Spiera, M.D Laura Figueiredo

In Honor of Yvette & Andy Gontkovsky Colette, Anita & Raymond Gontkovsky



In Honor of Waltraud Schlanzky Ingrid Halling

In Honor of Erica Hanson JoAnn Hanson

In Honor of My Daughter Margaret Henderson

In Honor of Kate Snider Toni McKean

In Honor of Al, Debbie & Jill Herman Ken & Edie McPherson

In Honor of Barbara Birmingham Elisabeth Oliu

In Honor of Dr. Thomas Oven Dr. Valerie Perdue Stanley Pillemer

In Honor of John & Jeanne Scott Harold Scott

In Honor of Nelson Hubbell & Margaret Scott Harold Scott In Honor of Richard & Susan Scott Harold Scott

In Honor of Rick & Teresa Steinberg Jerry & Diane Steinberg

> In Honor of Emily Schetky Carolyn England Thomas

In Honor of Allen & Mary Tice Katie Tice

In Honor of Deborah Keppel Tracy & Ray

In Honor of Jennifer Bromberg Sharon Skip

In Honor of Margaret Rothman Gale & Bruce

In Honor of Stefanie Campbell Campbell Tax & Financial Services

> In Honor of Tom Simpson The Jessop Family

In Honor of Mrs. Virginia Kelly Susan Mactye You Can Cope with

Mims Cushing Norman Latov, MD

# You Can Cope With Peripheral Neuropathy: 365 Tips for Living a Full Life

#### by Mims Cushing and Norman Latov, MD

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

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

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

This book 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	
You Can Cope with Peripheral Neuropathy by Mims Cushing and Norman Latov, MD		\$19.00	\$16.00			
Maryland Residents add	6% sales tax					
Shipping and Handling:	US Mail:	\$5 for first item + \$3 for each additional item				
	Canada:	\$14 for first item + \$3 for each additional item				
	Overseas:	\$22 for first item + \$3 for each additional item				
Total Amount						

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Enclosed is a check or money order (in U.S. funds	s only, drawn on a U.S	. bank, net of all ba	ank charges) payable to SSF.
AmEx MasterCard VISA Discover AmEx	Card Number		Exp. Date
Signature			CC Security Code

# NEW

# *NeutraSal® Sjögren's Syndrome Support Kit*

### Containing:

- Eye Vitamin and Mineral Supplement for Dry Eye and Dry Mouth Comfort\*
- Sugar Free Dry Mouth Gum with Xylitol

\* Compare to the ingredients in Ocuvite™ (Bausch and Lomb).

Available at No Cost with Every NeutraSal<sup>®</sup> Prescription

NeutraSal® is a prescription item. For additional information on NeutraSal® or the Direct Access Program, please visit www.neutrasal.com or call 866-963-8881 ext #1.



### What is NeutraSal®

NeutraSal<sup>®</sup> is an advanced electrolyte solution indicated in the treatment of dry mouth (xerostomia) in patients with Sjögren's Syndrome. NeutraSal<sup>®</sup> consists of single use packets of dissolving powders that when mixed with water creates an oral rinse supersaturated with calcium, phosphate and bicarbonate ions.

- Clinically proven to relieve the symptoms of dry mouth in Sjögren's Syndrome patients with no reported side effects or drug to drug interactions
- Calcium and phosphate ions have been shown to aid in the the prevention of dental caries (cavities) and promote the remineralization of the teeth in normal saliva
- Sodium bicarbonate ions reduce the acidity of the saliva in the mouth and break up accumulating mucus
- The pH of NeutraSal<sup>®</sup> is similar to normal saliva which may protect the mouth against potential opportunistic fungal (oral thrush) and bacterial infections

New Product for Xerostomia in the U.S.\*\*

### **DIRECT ACCESS PROGRAM**

The Direct Access Program is designed to provide access to NeutraSal® treatment for all patients regardless of their insurance coverage or financial condition. The program includes no out-of-pocket costs (co-pay) for most patients and free trial medication for patients without coverage. The NeutraSal® Direct Access Program and Support Kits are only available through the NeutraSal® Specialty Pharmacy Network. (Not valid for local retail pharmacies).

# NEW

*NeutraSal® Burning Mouth Syndrome Support Kit* 

Containing:

- Alpha Lopic Acid for Burning Mouth Comfort\*
- Sugar Free Dry Mouth Gum with Xylitol

<sup>†</sup> This statement has not been evaluated by the FDA. This product (alpha lipoic acid) is not intended to diagnose, treat, cure or prevent any disease.

Available at No Cost with Every NeutraSal® Prescription

### **Proud Sponsor**



INVA Ď O

PHARMACEUTICALS NeutraSal is a registered trademark of Invado Pharmaceuticals LLC. © 2013 Invado Pharmaceuticals, Pomona, New York

\*\*Based on Q1-Q4, 2013 IMS Data and Published SEC-10k Data.

# SAVE THE DATE!

# 2014 SSF National Patient Conference "Solving the Sjögren's Puzzle" April 25-26, 2014

Hyatt Regency O'Hare Chicago (Rosemont, Illinois)

s 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 work on "Solving the Sjögren's Puzzle," taking 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 2014 SSF National Patient Conference in Chicago (Rosemont, Illinois).

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 twoday 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 25-26, we invite you to join with us and experience a weekend where you will heighten your understanding and work toward "Solving the Sjögren's Puzzle" at the 2014 National Patient Conference in Chicago (Rosemont, Illinois).

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

#### Presentation topics will include:

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 Update Nutrition, Wellness and Autoimmune Disease Overlapping Major Connective Tissue Diseases

## 2014 SSF National Patient Conference Topics and Speakers

#### Overview of Sjögren's Syndrome

Daniel Small, MD, is a practicing rheumatologist with a career-long interest in Sjögren's. He practiced rheumatology in California and Texas before settling in Florida and joining the Sarasota Arthritis Center 21 years ago. During his career, Dr. Small has reported clinical research findings related to Sjögren's at regional, national, and international rheumatology meetings. He authored a chapter in The Sjögren's Book about treatment of major organ involvement, and he is a member of the SSF Medical and Scientific Advisory Board. Dr. Small 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.

#### Pulmonary Issues and Sjögren's

Augustine S. Lee, MD, is Assistant Professor of Medicine at Mayo Clinic College of Medicine; Director, Chronic Cough Clinic, Division of Pulmonary Medicine, Mayo Clinic; and Program Director, Pulmonary and Critical Care Medicine Fellowship, Mayo Graduate School of Medicine, Mayo Clinic College of Medicine, Jacksonville, Florida. Dr. Lee also is Consultant at both the Division of Pulmonary Medicine, Department of Internal Medicine and at the Department of Critical Care at the Mayo Clinic in Jacksonville. Lung complications are sometimes the most misunderstood and life-threatening manifestations of Sjögren's. Dr. Lee will add to your understanding of the various pulmonary complications and leave you with knowledge to share with your own physician.

#### What is in the Clinical Trial Pipeline?

Theresa Lawrence Ford, MD, is the Medical Director of North Georgia Rheumatology Group and an Active Staff member at Gwinnett Medical Center Hospitals. She practices in a single specialty group in Gwinnett County, Georgia, with her sister who is also a rheumatologist. She has done research in the fields of lupus and rheumatoid arthritis and participates as an investigator in clinical trials. She has been recognized in Atlanta Magazine annually as a Top Doctor in her field since 2005. Dr. Lawrence Ford closes out the weekend by looking ahead to what the future holds for Sjögren's clinical trials.

#### Clinical Practice Guidelines Update: A Panel Discussion

**Michael T. Brennan, DDS, MHS**, is Professor and Oral Medicine Residency Director at the Department of Oral Medicine at the Carolinas Medical Center in Charlotte, North Carolina. He is also Director of the Sjögren's Syndrome and Salivary Disorders Center at the Carolinas Medical Center. Additionally, Dr. Brennan is Co-Chair of the Oral Medicine Sub-Committee of the SSF Clinical Practice Guidelines Committee.

**Gary N. Foulks, MD**, is Emeritus Professor of Ophthalmology in the Department of Ophthalmology and Visual Sciences of the University of Louisville School of Medicine. Former Director of the Cornea and External Disease Service, he was also Assistant Dean for Clinical Trial Research at the University of Louisville School of Medicine. Dr. Foulks presently is Editor-in-Chief of The Ocular Surface and is on the editorial boards of Cornea and the Eye and Contact Lenses. Dr. Foulks is also Co-Chair of the Ocular Medicine Sub-Committee of the SSF Clinical Practice Guidelines Committee.

Ann Parke, MD, is Professor of Medicine, University of Connecticut Health Center at St. Francis Hospital and Medical Center in Hartford, Connecticut. She is an expert in Sjögren's, rheumatoid arthritis, and systemic lupus erythematosus as well as pregnancy in patients with connective tissue diseases. Dr. Parke is also Co-Chair of the Rheumatology/ Systemic Disease Sub-Committee of the SSF Clinical Practice Guidelines Committee.

This panel of esteemed Sjögren's experts will discuss the Clinical Practice Guidelines for the management of Sjögren's, a major initiative launched by the SSF several years ago. These guidelines will be the first of their kind for Sjögren's and will establish a baseline for healthcare professionals to follow when treating Sjögren's patients. The panel will review the guidelines process and status, covering the management and treatment of ocular, oral, and systemic manifestations of Sjögren's.

#### Overlapping Major Connective Tissue Diseases

Lee S. Shapiro, MD, is a rheumatologist and a partner at The Center for Rheumatology in Albany, New York. Dr. Shapiro also is Director of the Steffens Scleroderma Center in Saratoga Springs, New York, and Clinical Professor at Albany Medical College, and is a 20-year member of the medical advisory board of the Tri-State Chapter of the Scleroderma Foundation. Dr. Shapiro will discuss the importance for individuals with Sjögren's to be aware of the symptoms that might indicate the development of "overlap" features with other connective tissue diseases.

#### Nutrition, Wellness and Autoimmune Disease

Lauri Lang, RD, LDN, CWPC, is a registered dietitian. licensed dietitian nutritionist. and certified wellness program coordinator based in Pittsburgh, Pennsylvania. She specializes in holistic nutrition, chronic disease prevention and improvement, and health promotion. She currently works for Cigna, Inc, as a Case Manager Specialist on the Integrated Personal Health Team. In her private practice, Ms. Lang has counseled individuals of all ages and medical conditions who seek wellness through nutrition and lifestyle modifications. Ms. Lang will explain how different aspects of nutrition can impact an autoimmune disease like Sjögren's and share insights into making the best nutritional choices to maximize functioning and well-being.

#### Gastrointestinal Issues and Sjögren's

Matthew Nichols, MD, is a gastroenterologist and currently practices in Colorado with South Denver Gastroenterology, P.C. His areas of special interest include the management of chronic liver and inflammatory bowel diseases. Dr. Nichols is an active participant in the Rocky Mountain Chapter of the Crohn's and Colitis Foundation (CCFA). The manifestations of Sjögren's are multiple, and gastrointestinal involvement is common. Dr. Nichols will enhance your understanding of how the esophagus, stomach, liver, and intestines are affected by Sjögren's. Space is limited. Please register early!

# **Registration Form**

Registration fees include: Friday evening dinner, Saturday's lunch, hand-out material from speakers and entrance to exhibit area on Friday and Saturday.



# 2014 NATIONAL PATIENT CONFERENCE CHICAGO(ROSEMONT, ILLINOIS) — APRIL 25-26, 2014

Attendee Name(s)		
Attendee Name(s)		
		Zip
FEES – please circle appropriate SSF Members & Guests	fee(s) (Note: Early Bird Deadline is Ma March 31st and before \$170 per person	arch 31, 2014) April 1st and after \$190 per person
SSF Members & Guests Non-Members	March 31st and before	April 1st and after
SSF Members & Guests	March 31st and before \$170 per person	April 1st and after \$190 per person
SSF Members & Guests Non-Members	March 31st and before \$170 per person	April 1st and after \$190 per person
SSF Members & Guests Non-Members TOTAL:	March 31st and before \$170 per person \$190 per person	April 1st and after \$190 per person
SSF Members & Guests Non-Members TOTAL: PAYMENT – Mail to SSF, c/o B	March 31st and before \$170 per person \$190 per person	April 1st and after \$190 per person \$210 per person \$210 per person
SSF Members & Guests Non-Members TOTAL: PAYMENT – Mail to SSF, c/o B	March 31st and before \$170 per person \$190 per person B&T Bank · PO Box 890612 · Charlotte r (in U.S. funds only, drawn on a U.S. bank,	April 1st and after \$190 per person \$210 per person \$210 per person

- Refund requests must be made in writing. Registrants whose written requests are received by April 3rd 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 glutenfree dietary requests. If you require a vegetarian or gluten-free meal option, please contact Caroline Mullin at the SSF office (301-530-4420, ext. 214) by April 3rd.
- A limited number of rooms are available at the Hyatt Regency O'Hare (9300 Bryn Mawr Avenue, Rosemont, IL 60018) at the SSF rate of \$125 per night plus tax if reservations are made by April 1, 2014. Call the toll-free hotel Central Reservations number at 888-421-1442 or call the Hyatt Regency O'Hare directly at 847-696-1234 and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate.
- The Hyatt Regency O'Hare is approximately one (1) mile from the O'Hare International Airport. The hotel offers a 24-hour complimentary shuttle service to and from the airport that runs every 15 minutes. Alternate transportation suggestion: Taxi Fare/\$10 (one way).

### Q U E S T I O N S ? 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

# Be Part of the SSF Breakthrough Goal Team 2014 SSF Special Event Calendar Visit www.sjogrens.org or con-

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 a *Walkabout* or *Sip for Sjögren's* coming to your area.

Visit www.sjogrens.org or contact the SSF office to learn more about our events!

Sjögren's Walkabout

#### March

17	New York City Sip NYU Rosenthal Pavilion, New York, New York
30	Long Island Walkabout & Health Fair Roosevelt Field Mall, Garden City, New York
April	
25-26	National Patient Conference Chicago – Rosemont, Illinois
26	National Patient Conference Walkabout Chicago – Rosemont, Illinois
May	
3	Philadelphia 10th Walkabout & Health Fair Philadelphia, Pennsylvania
10	Dallas Fort Worth Walkabout & Health Fair Dallas, Texas
31	<b>NE Ohio Walkabout</b> Ohio
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#### June

- 1 Columbus Walkabout Columbus, Ohio
- 1 Atlanta Sips Atlanta, Georgia

sip for

- 14 Denver Walkabout Denver, Colorado
- 22 Kansas City Run / Walkabout English Landing Park Parkville, Missouri
- TBA GWR Walkabout / Family Day Washington D.C. Area

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