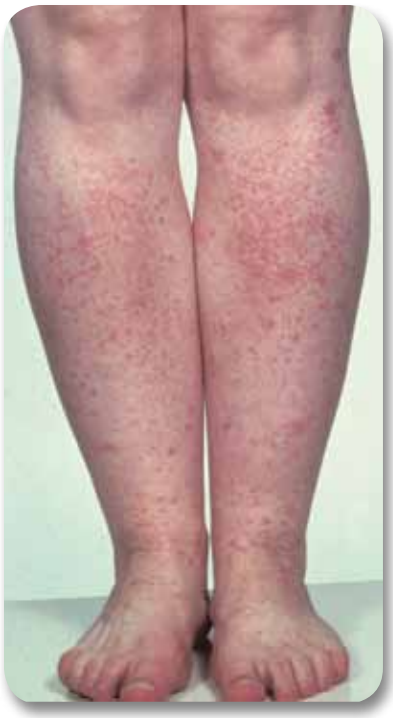
The Moisture Seekers

Sjögren's Syndrome Foundation

www.sjogrens.org

Volume 29, Issue 5 May 2011



Sjögren's Syndrome and the Skin

by Dr. Colin Pease, Consultant Rheumatologist Leeds, BSSA Medical Council Member

This article is reprinted with permission from Sjögren's Today *(Spring 2011, Volume 26, Issue I), the British Sjögren's Syndrome Association's newsletter.*

The skin is the largest organ in the body and as such is commonly the source of symptoms in patients with Sjögren's syndrome. The symptoms may not be as severe as those affecting the eyes or mouth but they are troublesome in approximately 50% of patients.

Dry Skin

Dry skin (or xerosis) is the most common symptom but perhaps the most difficult to specifically help. It presents as rough, dry, slightly scaly skin which can feel itchy (pruritis). But be careful not to scratch as sometimes this can stimulate pigmentation. This problem presents at a younger age in those with Ro or La antibodies than in those without these antibodies. Like many of the

continued page 2 ▼

Journey To Wellness for Sjögren's Sufferers

by Ruth Fremes, MA, and Nancy Carteron, MD, FACR
co-authors of the book A Body Out of Balance: Understanding and Treating Sjögren's Syndrome

We were sitting at the beach, letting our thoughts flow with the ocean; thinking how the ocean's waves remind us of the battle with autoimmunity; up, forward and receding, sliding back to the sea in search of equilibrium. The quest for water's resting place is like the pursuit of wellness, especially for those who suffer as Sjögren's patients do, with autoimmunity.

We constantly seek a time when we will be Better, Healed, Normal. It happens occasionally, and those times must be celebrated, but as with a wave that rises above the sand, there is the inevitable falling back. It's difficult to remember, but the wave will rise again.

There are as many suggestions for dealing with the disappointment of a flare as there are patients who suffer.

We want to talk about a search for serenity in spite of having a chronic disease.

One route to healing is joining the warmth and the welcome of a support group.* Does it work for everyone? Probably not, but here is how it worked for Sjögrens Syndrome Foundation Board member Estrella Bibbey:

"Being diagnosed so young with an illness I had never heard of and couldn't even spell didn't seem that important at the time. I thought I just needed to "fix" it and get

continued page 4 ▼

In This Issue 5 Social Security Testimony 7 Support Group Listings 14 Memoriam and Honors

"Sjögren's and the Skin" continued from page 1 ▼

problems in Sjögren's, symptomatic therapy is the mainstay of treatment. Fortunately, there are many moisturizers available which vary in their degree of greasiness. It is really a matter of trial and error to find the right one for the individual. Sometimes the addition of emollient bath additives (such as Oilatum) to bath water can help, but be careful as they make the bath very slippery! Avoidance of direct contact with washing up liquids by using rubber gloves may help. Overuse of soap and water can dry out the skin. Perfumed soaps can sometimes irritate dry skin; therefore, generally one should use simple soaps or gels. Sometimes dry skin can occur in other conditions such as diabetes; therefore, if it is a new symptom do consult your doctor.

Angular Cheilitis

This is when you develop sore fissured skin at the corner of the mouth. It can occur due to dryness of the skin/lip alone, but it is also seen in cases of malnutrition, iron deficiency and celiac disease. However, it can indicate infection; in particular, candidal infections are common at this location. Herpes virus infections can also be localized to this spot. Appropriate local antibiotic treatment will help.

Photosensitive rashes

This is a type of rash precipitated by exposure to sunlight. If you are prone to this sort of rash, then even winter sun can be enough to precipitate an attack. The skin of the face, upper chest and arms are the most commonly affected. It may appear as a blotchy red rash of irregular shape. Sometimes the rash covers a small area but it can be extensive depending on the severity of the sun exposure. It particularly occurs in people with Ro antibodies. Prevention is the most sensible advice; thus, if on holiday, avoidance of the midday sun, hats, long-sleeved shirts, etc. can be of help. You need protection against UVA and UVB. Many sun blockers are on the market; inevitably, only the stronger ones with an SPF 30 or 60 will be of the most benefit. But they must be used in accordance with the maker's instructions. Taking a photograph of the rash on your phone can be very helpful to show your doctor for accurate identification.

Annular Erythema

This is a more serious photosensitive type rash which, as the name suggests, presents as recurrent annular (circular) lesions which can be raised. The size can vary from 0.5cm to several cms. They typically occur on sun-exposed areas. They occur almost invariably in those people with Ro antibodies. Rashes of this sort are not exclusive to one connective tissue disease but can occur in other conditions such as lupus. Therefore, do not be surprised if these dis orders are discussed or investigated.

continued page 4 ▼

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

Sjogren's Patient Testifies in Front of the Social Security Administration

by Adam Gerard, SSF Vice President of Operations

Baltimore Support Group Leader Eva Plude recently testified on behalf of the Sjögren's Syndrome Foundation in front of the Social Security Administration's Compassionate Allowances Outreach Hearing on Autoimmune Diseases.

Eva did a wonderful job detailing her struggle to be diagnosed, the difficulties of living with Sjögren's as well as how disabling the disease can be.

Her written testimony also was submitted to the Social Security Administration (SSA) as part of their extensive consideration of autoimmune diseases needing "Compassionate Allowances" for Social Security Disability, and the SSA copied and distributed her testimony to attendees at the hearing.

Eva began her testimony by explaining that, although she was first diagnosed with Sjögren's in 1997, her story actually began 16 years earlier when she first noticed dryness symptoms throughout her whole body:

> *I first noticed multiple occasions of dry, gritty-feeling, very red eyes; dry, bleeding nose; dry, cotton-like mouth and painful bleeding mouth sores; dry skin and extreme dry vaginal area, causing bleeding during intercourse with my husband and just walking. I suffered countless urinary tract infections. I was thirsty all the time and had to drink water, even throughout the night. Also, my energy would come and go. I had always been energetic, but it seems that suddenly, I could go "like a house a-fire" one day and "crash" the next, to use my husband's terms. There were times that I could not raise my arms to wash my hair or walk upstairs due to weakness and fatigue. In 1989, I fell from a foot stool and broke both wrists, tailbone and neckbone. There was no evidence of osteoporosis. A few years later, I was walking and stepped on a manhole cover and broke my ankle. Again, there was no evidence of osteoporosis. I was on no medication. I was not a diabetic. Later I realized this was due to neuropathies caused by Sjögren's where I couldn't feel the ground beneath my feet.*

In her testimony, Eva explained how she went to numerous doctors for each symptom, but none of them – from her dentist to her eye doctor to her gynecologist to her primary care physician – put her systemic issues together as Sjögren's. All blamed something else for each symptom they saw.

It was almost through luck that she was eventually able to be diagnosed. A change in insurance caused her to find a new gynecologist who started to put the symptoms together. By coincidence, she found out one of her clients was also recently diagnosed with Sjögren's and recommended a rheumatologist with knowledge about the disease.

From there Eva received an official diagnosis and started assembling a team of doctors who were familiar with Sjögren's. Eva finally started to receive the care that she needed. It only took 16 years.

Eva went on to discuss her involvement with the Sjögren's Syndrome Foundation as a Support Group Leader and detailed several stories of members she has known over the years who have struggled in so many ways to live with this disease.

You can read Eva's complete testimony online and watch a video of the full hearing (including Eva) by visiting: www.sjogrens.org/ssahearings

"Sjögren's and the Skin" continued from page 2 ▼

Raynaud's Syndrome

This problem occurs in many patients with connective tissue disease. It is a reversible reduction of blood flow to the fingers and toes precipitated by a fall in ambient temperature. This results in cold blue fingers and toes, which may become white and then red as they warm up. Keeping your core temperature stable can help by wearing thermal underwear, enough layers, heavy socks and gloves. If this is not enough then vasodilators such as slow-release nifedipine can be of benefit.

Purpuric Vasculitis

This is a common problem for patients with Sjögren's who have Ro or La antibody and hypergammaglobulinemia (this is a raised protein level in the blood due to the overactivity of your B lymphocytes producing excessive amounts of immunoglobulin). It results in small pinpoint or slightly larger palpable red spots on your legs that do not fade with pressure. They tend to come up as a crop, last for a few days and then fade only to reoccur every few months. They may come up after periods of prolonged standing. Sometimes they can be controlled by wearing support stockings (pop socks are not sufficient). If medical therapy is needed then hydroxychloroquine might help. Only rarely is more immunosuppression needed for this form of vasculitis. If you have hypergammaglobulinemia, then you are quite likely to be Rheumatoid Factor positive. This does not mean that you have rheumatoid arthritis. It is what is called a false positive result and occurs as a consequence of the high immunoglobulin level in your blood. For the same reason your measures of inflammation such as the ESR or plasma viscosity can be artificially elevated, but, reassuringly, another measure of inflammation (not affected by a high immunoglobulin level), the CRP should be normal.

Vasculitis

Rarely, more severe involvement of the blood vessels can occur in which case the extremities are again most commonly involved. This can result in black areas appearing particularly on the fingers or around the ankles or toes. They tend to be painful. Vasculitis, though, can involve other parts of the body such as the nerves or kidney. Therefore, this type of skin condition might indicate a more serious problem which would certainly need immunosuppressive therapy and should be reviewed by your rheumatologist. ■

"Journey to Wellness" continued from page 1 ▼

back to my life as a photojournalist.

And so it was with this attitude I went to my first Sjögren's support group meeting. I just wanted a list of doctors names, medications to take and, in general, the short notes on how to fix this disease.

That first meeting was odd. A small group of women all older than I were sitting around in a pretty living room. Some had to sit here or there to help with this or that body part. Some couldn't sit facing the window and others needed to be beside a table to place their ever-emptying glass of water. But each was accommodated happily, and I was even offered an extra cushion or a footstool. It seemed a bit fussy, but what I didn't realize at the time was that this odd mix of women who had come together, were on their way to healing. All I knew at that time was how to suffer.

I didn't get the full "fix" at that first meeting, but like all those other women in that pretty living room, I found a place to start the healing process — a process for me similar to the five stages of grief: denial, anger, bargaining, depression and acceptance. In the presence of these women and my husband who came to all the meetings with me, I could freely be angry, sad, and overwhelmed. Finally I was even devastated when my denial about my illness turned into the realization that it was destroying my career, which was the purpose in my life.

These women listened to me, hugged me, and offered me more glasses of water. Sometimes, a few other husbands would come. My husband would talk about how he had to help his young wife wash her hair, how he often carried my camera bag at photo shoots, and how we were learning to be a young couple with a chronic illness.

The bond I formed with these women was strong and I worked toward the inevitable stage of acceptance. I made notes of their suggestions, bought new products to try and make appointments with new doctors. And soon, but very slowly at first, some new members would ask me for advice such as: What doctor did I see? What medication worked for me?

Having come full circle and beginning my healing, I was one of the ladies in the pretty living room with some, but not all, of the answers. My Sjögren's support group taught me how to stop suffering and how to start healing from a disease with no current cure."

But, perhaps the very idea of exposing your unhappiness

continued page 10 ▼

RESTASIS®
(cyclosporine ophthalmic emulsion) 0.05%
Sterile, Preservative-Free

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

ALLERGAN

Based on package insert 71876US14B Revised February 2010

Irvine, CA 92612, U.S.A.
 APC21MH10
U.S. Patent 5,474,979
Made in the U.S.A.

Fill a RESTASIS® Ophthalmic Emulsion prescription and we'll send you a check for $20!

It's easy to get your $20 rebate for RESTASIS® Ophthalmic Emulsion. Just fill out this information and mail.

Follow these 3 steps:

1. Have your prescription for RESTASIS® filled at your pharmacy.
2. Circle your out-of-pocket purchase price on the receipt.
3. Mail this certificate, along with your original pharmacy receipt (proof of purchase), to **Allergan RESTASIS® Ophthalmic Emulsion $20 Rebate Program, P.O. Box 6513, West Caldwell, NJ 07007.**

❑ Enroll me in the *My Tears, My Rewards*® Program to save more!
❑ I am not a patient enrolled in Medicare, Medicaid, any similar federal or state healthcare program, or a resident of Massachusetts.

Last Name **First** **MI**

Street Address

City **State** **ZIP**

For more information, please visit our Web site, www.restasis29.com.

RESTASIS® Rebate Terms and Conditions: To receive a rebate for the amount of your prescription co-pay (up to $20), enclose this certificate and the ORIGINAL pharmacy receipt in an envelope and mail to Allergan RESTASIS® Ophthalmic Emulsion $20 Rebate Program, P.O. Box 6513, West Caldwell, NJ 07007. Please allow 8 weeks for receipt of rebate check. Receipts prior to March 31, 2011 will not be accepted. One rebate per consumer. Duplicates will not be accepted. See rebate certificate for expiration date. **Eligibility:** Offer not valid for prescriptions reimbursed or paid under Medicare, Medicaid, or any similar federal or state healthcare program including any state medical or pharmaceutical assistance programs. Void in the following state(s) if any third-party payer reimburses you or pays for any part of the prescription price: Massachusetts. Offer void where prohibited by law, taxed, or restricted. Amount of rebate not to exceed $20 or co-pay, whichever is less. This certificate may not be reproduced and must accompany your request for a rebate. Offer good only for one prescription of RESTASIS® Ophthalmic Emulsion and only in the USA and Puerto Rico. Allergan, Inc. reserves the right to rescind, revoke, and amend this offer without notice. You are responsible for reporting receipt of a rebate to any private insurer that pays for, or reimburses you for, any part of the prescription filled, using this certificate.

 Please allow 8 weeks for delivery of your rebate check. APC77DY10 Certificate expires 12/31/2011

SSF Personal Support System

Listed below are SSF Contact Persons, members who volunteer to be sources of information for Sjögren's syndrome. Asterisks (*) indicate the location of where a SSF Support Group meeting is held.

International support groups are available throughout the world. Please contact our office for specific information.

ALABAMA

Birmingham	Anne Rose*	(205) 972-4261 sjobham@gmail.com

ALASKA

Palmer	Judy Masteller	(907) 376-6275
Seward	Sandra Mikat	(907) 224-5191

ARIZONA

Phoenix Area	Lois Peach*	(480) 391-2522

ARKANSAS

Conway	Betty Webster	(501) 329-6627
Little Rock	Karen Fulton*	(501) 227-0813
Sparkman	Laurine Langley	(870) 366-4388

CALIFORNIA

Davis	Susan Ruth	(530) 753-3110
Fresno	Evelyn Bennett	(559) 436-8584
Glendale	Ricardina Astoquillca	(818) 241-8152
Hollister	Sharon West	(831) 634-0701
Inland Empire	Judy (Moffet) Whale*	(909) 624-1809
San Gabriel Valley	Susan Buller*	(909) 944-1773
Lakehead	Carol Sartain	(530) 238-8031
Lemoore	Deborah Romerosa	(559) 925-1585
Long Beach	Kathy Bostrom*	(562) 595-8208
Los Angeles – West Hills	Rhoda Dennison*	(818) 346-6694
Oroville	Lynne Gould	(530) 589-1158
Riverside	Lynn Davis	(951) 681-8517
San Diego	Suzanne Davies*	ssfsuzannedavies@gmail.com
	Dona Frosio*	(619) 303-9004
San Francisco Bay Area	Nancy Crabbe*	(650) 593-9022
	Claire Goodman*	(925) 258-6666

COLORADO

Arvada	Susan Joyce	(303) 422-3864
Boulder Area	Dawna (Bunny) Swenson	(303) 652-2927
Colorado Springs	Andrea Shafer	(719) 487-1300
Denver Area	Carol A. Denewiler	(303) 755-9985
	Catherine F. Tomczak	(303) 751-5531
Denver/Englewood	Maurine Daniels*	(303) 721-0241
Evergreen	Lisa Torales	(303) 670-9296 toralesl@msn.com
Ft. Collins/Loveland	Eunice Krivonak	(970) 203-0147
Littleton/Lakewood	Connie Walters	(303) 973-1878
Westminster	LaDonna Landry	(303) 426-5800

CONNECTICUT

Brookfield	Isabel Lopez	(203) 775-5552
Farmington	Mary Beth Walter*	(860) 569-6933
Wallingford	Kathy Heimann	(203) 269-0354
Wilton	Patricia Moran	(203) 762-8129

DELAWARE

Newark	Marsha Bates	(302) 593-3179

FLORIDA

Boca Raton	Mariella Carbone	(561) 488-2342
Bradenton/Sarasota	Melody Carpenter	(941) 761-1352
Coral Gables	Georgene Slepin	(305) 446-4834
Del Ray Beach	Jean Kaye	(561) 498-9364
Ft. Lauderdale	Georgie Littlefield*	(954) 977-0775
	Yvonne Sherrer, MD	(954) 229-7030
Jacksonville	Penny Oliver	(904) 535-9366
	Sally Vodney	(904) 363-9086
	Tana Still	(904) 269-6871
Lady Lake	Karen M. Marshall*	(352) 259-1309
Miami Lakes	Beth Geyer	(305) 821-2453
N. Hutchinson Is.	Elizabeth Brinamen	(772) 595-5873
Orlando/Lakeland	Joyce Tompkins*	(863) 701-0512
Tallahassee	Kay Tolworthy	(850) 877-5066
West Palm Beach	Janet Young	(561) 283-1670

GEORGIA

Atlanta Area	Suzi Wixson*	(770) 642-0323
Dunwoody/Atlanta	Penny Hamond-Wolk	(770) 730-8550
McDonnough	Linda S. Davis	(770) 898-5837
Warner Robins	Irene Shue	(912) 929-3941

IDAHO

Potlatch	Patty Gilbert	(208) 875-1590

ILLINOIS

Arlington Heights	Diana Bonadonna	(847) 398-0407
Bloomington	Joyce Kaye	(309) 663-0564
Chicago Area	Heidi Shierry*	(630) 279-9437 or (630) 853-6836
Fox Lake	Mary Ann Guisinger	(847) 629-5559
Liberty	Mary Ann Graham	(217) 645-3497
Mansfield	Linda Lanier	(217) 489-4281
Plainfield	Audrey M. Grey-Lowry*	(815) 436-5168
	April Flentge*	(815) 886-4715
Urbana	Waneta Mehaffey	(217) 367-8161

INDIANA
Indianapolis	Diana Altom*	(317) 356-2558

IOWA
Des Moines	Suzanne Sullivan	(515) 537-1345
Dubuque	Shirley White*	(563) 583-6795
Wilton	Connie I. Brown	(563) 732-2420

KANSAS
Lenexa	Janet Nichols*	(913) 492-9581

KENTUCKY
Louisville	Debra L. Henning	(502) 231-9130
	Karen M. Solomon	(502) 245-3120
Rineyville	Jisun Mudd	(270) 877-7729

LOUISIANA
Baton Rouge	Carolyn S. Lee*	(225) 262-1060
Baton Rouge	Debbie Fuselier	(225) 928-4341
Kaplan – Lafayette	Tanya Broussard*	(337) 643-3565
New Orleans	Connie Benton	(504) 488-6977
New Orleans	Lynn Weinberg	(504) 895-2595
Pineville	Mary Maddox	(318) 445-7448

MAINE
Alfred	Elizabeth Hayes	(207) 324-9654

MARYLAND
Bel Air	Eva L. Plude*	(410) 836-1040
		bigeva@qis.net
Frederick	Elizabeth E. Ward*	(301) 663-3947
Montgomery County Area	Bonnie Schneider*	(301) 774-4662
Prince George's & South Maryland	Ruth White*	(301) 246-4476

MASSACHUSETTS
Boston Area	Lynn C. Epstein, MD*	(617) 636-3932
East Long Meadow	Janet Young	(413) 525-8211
Plymouth Area	Joanne Levy	(508) 224-2262
Springfield	Kitty Berger	(413) 786-6552
Worcester	Helen Yaffe	(508) 757-5580
South Grafton	Gerry Lauria	(508) 839-4095

MICHIGAN
Dearborn	Helen Schauman	(313) 562-9591
East Lansing	Bill Mahler	(517) 332-5636
Grosse Pte Farms	Mary Lapish	(313) 885-7523
Jackson	Charlene Pung	(517) 788-9824
Kalamazoo	Shaney Robinson	(269) 226-9254
Lansing	Laura Hall	(517) 887-6663
Livonia	Charlotte Pumo	(734) 427-8335
Presque Isle	Rosemary Kause	(517) 595-3288
St. Clair	Bonnie Wright	(810) 329-9241
Stanwood	Karen M. Marshall	(231) 972-3110
Sturgis	Marcia L. Arend	(269) 651-6798

MINNESOTA
Bloomington	Barbara Parrish	(952) 881-1048
Eden Prairie	Julie Ermer	(952) 943-9546
Maplewood	Phyllis Peterson	(651) 778-8035
Minneapolis	Patricia (Pat) Huber*	(952) 432-4870
St. Louis Park	Bette Tobin	(952) 920-2941
Stillwater	Elaine Zimmerman	(651) 436-1662

MISSISSIPPI
Biloxi	Della Mc Caughan	(228) 432-7748
Oxford	Linda K. Cox	(662) 234-1001
Tupelo	Holly W. Bullock	(662) 844-2877

MISSOURI
St. Joseph	Leona Stevens	(816) 364-3453
St. Louis	Janie Norberg	(314) 521-4663
	Jane Rombach FSM	(314) 776-5764

MONTANA
Bigfork – Kalispell	Virginia Hanson*	(406) 837-4673
Billings	Helen Armstrong	(406) 245-0549
Bozeman	Betty Dilbeck	(406) 582-1933
Polson	Tedi Schilling+	(406) 849-5537

NEBRASKA
Fairfield	Michele Boyce	(402) 726-2335
Gretna	Jean Swanson*	(402) 332-2554

NEVADA
Las Vegas	Grace Vallone	(702) 365-5267
	Mary Boettcher	(702) 240-0997

NEW HAMPSHIRE
Lyme	Len Wasser	(603) 795-2510
Nottingham	Carol Markee	(603) 895-4812

NEW JERSEY
Edgewater	Joanna Fabian	(201) 886-0805
Lakehurst	Marie Vella	(732) 657-0107
Monroe Twp	Sandra Rear	(609) 860-1648
Teaneck	Nan Lehmann	(201) 836-4239
Verona	Shirley Musikant	(973) 857-8434

NEW MEXICO
Alto	Mavis Reecer	(505) 336-8117

NEW YORK-
Albany Area	Kimberly Gross*	(518) 608-6727
Brooklyn	Gilda Kaback	(718) 769-7997
Buffalo – Depew	Judi Hayes*	(716) 684-4254
Huntington	Sandy Leon*	(516) 367-4104
Jackson Heights	Claudia Schellenberg	(718) 803-3279
North Hills	Iris Cohn	(516) 627-9054
NYC Area	Susan Needles*	(212) 724-7110
Ossining	Elaine Underhill	(914) 762-3302
Rochester – Syracuse	Sharon Hoffman*	(585) 582-6114
Rockland County – Nyack	Judith Mack	(845) 358-2747
Syracuse – Cicero	Diane Stadtmiller*	(315) 877-1117
		eruditepa@aol.com
St. James	Elizabeth Greening	(631) 862-9248
Woodstock	Evelyn Lyke	(845) 679-4970

NORTH CAROLINA
Asheville	Marge Kozacky*	(828) 687-2821
Boone	Marie Gaudin	(828) 733-3563
Charlotte	SS and Salivary Disorders Ctr at Carolinas Medical Center*	(704) 355-4197
Knightdale	Delores M. Fiedor, LPN	(919) 266-5961
New Bern	Shirley Dailey*	(252) 444-3216
Snow Camp	Joann Dollar	(336) 376-6346
Winston-Salem	Sue Palas*	(336) 760-6303

OHIO
Akron Area	Mary McNeil*	(330) 342-7870
Bay Village	Evelyn V. Sobczak	(440) 892-9765
Chesterland	Keith Koch	(440) 537-9969
Cincinnati	Cynthia Williams, RN	(513) 351-3023
Columbus	Janet Muench*	(614) 771-9295
Mentor	Cindy Larick	(440) 974-9641
Toledo Area	Judi Furlong, MD*	(419) 824-1927

OKLAHOMA
Ardmore	Nancy E. Brewster	(580) 224-2654
Edmond	Sharon Abrams*	(405) 330-2356

OREGON
Baker City	Susan Castles	(541) 523-3323
Bend	Angie Siefer	(541) 318-4751
Portland	Linda Shields*	(503) 266-3680
La Pine	Norma Werner	(541) 536-1175
Medford	Jane Finley	(541) 770-6558

PENNSYLVANIA
Bethlehem	Rebecca Ridgick	(610) 865-4795
Clarks Summit	Judy Rienzi	(570) 586-6635
Easton	Janet Kirk	(610) 253-9324
Chambersburg	Ruby Deitrich	(717) 369-3366
Harrisburg	Kathy Boyd*	(717) 737-3890
Mount Carmel	Orinda Ford	(570) 339-2223
Philadelphia	Maggie Goddard*	(215) 348-7615
	Sandra Pacini	(215) 672-2983
	Barb Barbon *(phone contact)*	(610) 775-7949
Pittsburgh Area	Jane Potteiger	(412) 922-9826
Montgomery County	Carol Heringslake*	(610) 948-1413
Scranton	Linda Rosengrant-Lohrey	(570) 885-0141
Scranton	Lupus Fndt./Resource Ctr for Autoimmune Diseases*	(888) 995-8787
Wallingford	Ruth Goldman	(610) 441-1441
		or (610) 565-6136
Wash. Crossing	Marge Hartman	(215) 345-8249

RHODE ISLAND
North Smithfield	Lynne Messina	(401) 766-8645
Warwick	Joyce Bert	(401) 738-0857

SOUTH DAKOTA
Beresford	Sue Christensen	(605) 563-2483

TENNESSEE
Johnson City	Deborah Harvey*	(423) 946-1750
Memphis	Betty Wetter	(901) 682-2073
Nashville Area	Nancy Hoesel	(615) 332-7443

TEXAS
Austin/Georgetown	Linda Frost*	(512) 255-6049
	Helen Smith*	(512) 869-8840
Bedford	Audra Johnson	(817) 498-6552
Conroe – Woodlands Area	Marilyn Adams*	(281) 298-9196
Dallas	Ibtisam Al-Hashimi, DDS	(214) 828-8145
El Paso	Michael Najera, DDS	(915) 833-3330
Harlingen	Barbara Ann Purdy	(956) 423-3192
Houston	Shani Corbiere*	(281) 221-0068
Lubbock	Jo Murdock	(806) 792-9862
Montgomery	Wanda Coleman	(936) 448-4325
Nacogdoches	Sidney Fowler, DDS	(936) 564-9401
Richardson	Kay Turner	(972) 235-8521
Roanoke Area	Shirley Stone*	(682) 502-4910
Tyler	Laura Moran, RN	(903) 534-9131

UTAH
Salt Lake City	Dr. Kathie Coopersmith*	(801) 476-9701
		kathie@xmission.com
	Linda Phillips*	(801) 544-9603

VIRGINIA
Dinwiddie	Denise Rainey	(804) 469-7505
Harrisonburg – Shenandoah Valley	Teresa C. May*	(540) 433-5638
Lynchburg	Ida B. Powell*	(434) 384-1092
Mount Jackson – Northern Shenandoah Valley	Robert & Jane Perry*	(540) 477-2088
		nsvsssg@yahoo.com
New Bern	Robert E. Wallace	(540) 674-2922
Northern Virginia	Gwyn Cannon*	(703) 709-7579
	Kathryn McCarren*	(703) 590-1367
Richmond	Sarah B. Cosby	(804) 467-4387
Salem	Carol Watson, RN*	(540) 389-7503

WASHINGTON
Bellingham	Linda Hughes*	(360) 676-1926
	Betty Willert	(360) 312-1597
Federal Way – Seattle	Karen Schlaht	(253) 815-8937
Mt. Vernon	Ursula Vecchi	(360) 299-8978
Pasco	Joretta Heath	(509) 547-3832
Spokane	Jaqueline Riley	(509) 466-2432
Tacoma – Spanaway	Judy Kay Reynolds*	(253) 531-7369

WEST VIRGINIA
Moundsville	Pat Kleinedler	(304) 845-8473

WISCONSIN
Brookfield	Carole Oldenburg*	(262) 786-3858
Madison	Nancy Johnson*	(608) 332-5928
Milwaukee	Wendy Liedtke	(414) 541-5857
River Falls	Mimi Trudeau	(715) 425-8183

Canada

ALBERTA
Edmonton	Sandra Anderson	(780) 434-8808

BRITISH COLUMBIA
Lower Mainland	Phyllis Hubeli	(604) 538-9855
Okanagan	Desiree Roell*	(250) 838-9378

NEW BRUNSWICK
Fredericton	Betty Ponder	(506) 450-9929

NEWFOUNDLAND
St. Johns	Joan Williams	(709) 579-9272

ONTARIO
Brantford	Sjögren's Society of Canada	
	Lee Durdon*	(888) 558-0950
	www.sjogrenscanada.org	info@sjogrenscanada.org
Brantford/Paris	Helen Shipp	(519) 442-4510
London	Alison Shaefer	(519) 657-2829
New Hamburg	Lynda Duckworth	(519) 662-3699
Ottawa	L. Gail MacDonald	(613) 526-5433
Sarnia	Carolyn Minielly	(519) 542-4874

QUEBEC
Montreal	Sjögren's Syndrome Association Inc.	
	Ginette Texier*	(514) 934-3666
		or (877) 934-3666
		www.sjogrens.ca
	Theresa Reade	(514) 934-3666

Welcome to our newest support group!

Alabama, Birmingham Support Group

Anne Rose, Group Leader

"Journey to Wellness" continued from page 4 ▼

to a group is unsettling. It could be that a group such as Estrella describes is alarming for you, while sitting quietly with a single trained therapist feels manageable. Or perhaps your minister or rabbi is open to listening and this could be your choice. But whichever you choose, taking time with another to unburden yourself is relaxing and helpful and, we might add, essential.

But we're getting ahead of ourselves. We feel strongly that the first step is to gain knowledge about the symptoms, prognosis, and possible treatments of your disorder. You wouldn't go to a math exam without studying. Similarly, one doesn't attempt healing without knowledge. Knowledge is the key, whether in a group or alone.

The Buddha said, "Every human being is the author of his own health." And in order to seek health, one must have information. We need information to help understand the basics of our ill-health. We are fortunate to have the internet with its oceans of answers and ease of operation.

Not long ago a dear friend suffering from a difficult neurological disease said, "I just don't know myself these days. All I do is think about myself. I've become totally self-absorbed."

She certainly has. My response to her, and to you, is that it comes with the territory. When anything hurts, or, worse still, is mysterious and hurts, all we can think about is ourselves. Here again it is helpful to have knowledge and someone with whom you can talk.

If you spend a lot of time ruminating on 'what's wrong' instead of focusing on 'what's right,' you can fall into a pattern of self-criticism. Then guilt and shame materialize. Unmanaged guilt or shame can be the outcome of remaining silent, totally wrapped in our own thoughts until we enter the downward spiral of depression. As with our friend, who, once she realized what was happening, began to turn herself around with positive thoughts, listening to calming music, practicing meditation along with weekly talks with her therapist and friends in a support group she joined. She is still self-absorbed but in a good way – seeking good health.

It takes a long time of constant work to turn your attitudes around. Positive thinking and community sharing are the building blocks of acceptance – acceptance of yourself and acceptance of the persistence and manageability of the disorder and, as the waves on the beach, the inevitability of a return to equilibrium.

The Doctor's Perspective

As a rheumatologist assisting those with Sjögren's, I have observed many journeys to wellness or at least wholeness. It rarely comes easily. It does take a lot of work, self-examination, and sometimes changing life and career goals, but traveling this journey often leads to an even more satisfying life. Grieving the loss has to happen and those who do it sooner seem to move along faster as do those willing to be proactive. Time seems to be important. Acceptance seems to rarely come before six months and for some it may take a year. For those taking longer than a year, often there is a deeper life issue that needs attention. One path does not fit ALL! Make your own. This is a very difficult journey, and a coach can be extremely valuable in speeding up the trip. I have seen people choose a friend, therapist, chronic illness coach, or spouse to provide encouragement. As Estrella tells us, learning about options and TRYING them allows you to find your unique path to wholeness. She is blessed to have a spouse who has been with her every step along the way. ■

*To join a group: Check the list on the SSF website (www.sjogrens.org) or the Foundation's newsletter, *The Moisture Seekers*, to find a support group in your area.

Ruth Fremes and Dr. Nancy Carteron are the co-authors of A Body Out of Balance: Understanding and Treating Sjogren's Syndrome, *and the blog www.sjogrensforum.com of Q&A submitted by those with Sjogren's and other autoimmune diseases.*

Brief Summary – See package insert for full Prescribing Information.

EVOXAC® Capsules

(cevimeline hydrochloride)

INDICATIONS AND USAGE
Cevimeline is indicated for the treatment of symptoms of dry mouth in patients with Sjögren's Syndrome.

CONTRAINDICATIONS
Cevimeline is contraindicated in patients with uncontrolled asthma, known hypersensitivity to cevimeline, and when miosis is undesirable, e.g., in acute iritis and in narrow-angle (angle-closure) glaucoma.

WARNINGS
Cardiovascular Disease:
Cevimeline can potentially alter cardiac conduction and/or heart rate. Patients with significant cardiovascular disease may potentially be unable to compensate for transient changes in hemodynamics or rhythm induced by EVOXAC®. EVOXAC® should be used with caution and under close medical supervision in patients with a history of cardiovascular disease evidenced by angina pectoris or myocardial infarction.

Pulmonary Disease:
Cevimeline can potentially increase airway resistance, bronchial smooth muscle tone, and bronchial secretions. Cevimeline should be administered with caution and with close medical supervision to patients with controlled asthma, chronic bronchitis, or chronic obstructive pulmonary disease.

Ocular:
Ophthalmic formulations of muscarinic agonists have been reported to cause visual blurring which may result in decreased visual acuity, especially at night and in patients with central lens changes, and to cause impairment of depth perception. Caution should be advised while driving at night or performing hazardous activities in reduced lighting.

PRECAUTIONS
General:
Cevimeline toxicity is characterized by an exaggeration of its parasympathomimetic effects. These may include: headache, visual disturbance, lacrimation, sweating, respiratory distress, gastrointestinal spasm, nausea, vomiting, diarrhea, atrioventricular block, tachycardia, bradycardia, hypotension, hypertension, shock, mental confusion, cardiac arrhythmia, and tremors.

Cevimeline should be administered with caution to patients with a history of nephrolithiasis or cholelithiasis. Contractions of the gallbladder or biliary smooth muscle could precipitate complications such as cholecystitis, cholangitis and biliary obstruction. An increase in the ureteral smooth muscle tone could theoretically precipitate renal colic or ureteral reflux in patients with nephrolithiasis.

Information for Patients: Patients should be informed that cevimeline may cause visual disturbances, especially at night, that could impair their ability to drive safely.

If a patient sweats excessively while taking cevimeline, dehydration may develop. The patient should drink extra water and consult a health care provider.

Drug Interactions:
Cevimeline should be administered with caution to patients taking beta adrenergic antagonists, because of the possibility of conduction disturbances. Drugs with parasympathomimetic effects administered concurrently with cevimeline can be expected to have additive effects. Cevimeline might interfere with desirable antimuscarinic effects of drugs used concomitantly.

Drugs which inhibit CYP2D6 and CYP3A3/4 also inhibit the metabolism of cevimeline. Cevimeline should be used with caution in individuals known or suspected to be deficient in CYP2D6 activity, based on previous experience, as they may be at a higher risk of adverse events. In an *in vitro* study, cytochrome P450 isozymes 1A2, 2A6, 2C9, 2C19, 2D6, 2E1, and 3A4 were not inhibited by exposure to cevimeline.

Carcinogenesis, Mutagenesis and Impairment of Fertility:
Lifetime carcinogenicity studies were conducted in CD-1 mice and F-344 rats. A statistically significant increase in the incidence of adenocarcinomas of the uterus was observed in female rats that received cevimeline at a dosage of 100 mg/kg/day (approximately 8 times the maximum human exposure based on comparison of AUC data). No other significant differences in tumor incidence were observed in either mice or rats.

Cevimeline exhibited no evidence of mutagenicity or clastogenicity in a battery of assays that included an Ames test, an *in vitro* chromosomal aberration study in mammalian cells, a mouse lymphoma study in L5178Y cells, or a micronucleus assay conducted *in vivo* in ICR mice.

Cevimeline did not adversely affect the reproductive performance or fertility of male Sprague-Dawley rats when administered for 63 days prior to mating and throughout the period of mating at dosages up to 45 mg/kg/day (approximately 5 times the maximum recommended dose for a 60 kg human following normalization of the data on the basis of body surface area estimates). Females that were treated with cevimeline at dosages up to 45 mg/kg/day from 14 days prior to mating through day seven of gestation exhibited a statistically significantly smaller number of implantations than did control animals.

Pregnancy:
Pregnancy Category C.
Cevimeline was associated with a reduction in the mean number of implantations when given to pregnant Sprague-Dawley rats from 14 days prior to mating through day seven of gestation at a dosage of 45 mg/kg/day (approximately 5 times the maximum recommended dose for a 60 kg human when compared on the basis of body surface area estimates). This effect may have been secondary to maternal toxicity. There are no adequate and well-controlled studies in pregnant women. Cevimeline should be used during pregnancy only if the potential benefit justifies the potential risk to the fetus.

Nursing Mothers:
It is not known whether this drug is secreted in human milk. Because many drugs are excreted in human milk, and because of the potential for serious adverse reactions in nursing infants from EVOXAC®, a decision should be made whether to discontinue nursing or discontinue the drug, taking into account the importance of the drug to the mother.

Pediatric Use:
Safety and effectiveness in pediatric patients have not been established.

Geriatric Use:
Although clinical studies of cevimeline included subjects over the age of 65, the numbers were not sufficient to determine whether they respond differently from younger subjects. Special care should be exercised when cevimeline treatment is initiated in an elderly patient, considering the greater frequency of decreased hepatic, renal, or cardiac function, and of concomitant disease or other drug therapy in the elderly.

ADVERSE REACTIONS
Cevimeline was administered to 1777 patients during clinical trials worldwide, including Sjögren's patients and patients with other conditions. In placebo-controlled Sjögren's studies in the U.S., 320 patients received cevimeline doses ranging from 15 mg tid to 60 mg tid, of whom 93% were women and 7% were men. Demographic distribution was 90% Caucasian, 5% Hispanic, 3% Black and 2% of other origin. In these studies, 14.6% of patients discontinued treatment with cevimeline due to adverse events.

The following adverse events associated with muscarinic agonism were observed in the clinical trials of cevimeline in Sjögren's syndrome patients:

Adverse Event	Cevimeline 30 mg (tid) n*=533	Placebo (tid) n=164
Excessive Sweating	18.7%	2.4%
Nausea	13.8%	7.9%
Rhinitis	11.2%	5.4%
Diarrhea	10.3%	10.3%
Excessive Salivation	2.2%	0.6%
Urinary Frequency	0.9%	1.8%
Asthenia	0.5%	0.0%
Flushing	0.3%	0.6%
Polyuria	0.1%	0.6%

*n is the total number of patients exposed to the dose at any time during the study.

In addition, the following adverse events (≥3% incidence) were reported in the Sjögren's clinical trials:

Adverse Event	Cevimeline 30 mg (tid) n*=533	Placebo (tid) n=164	Adverse Event	Cevimeline 30 mg (tid) n*=533	Placebo (tid) n=164
Headache	14.4%	20.1%	Conjunctivitis	4.3%	3.6%
Sinusitis	12.3%	10.9%	Dizziness	4.1%	7.3%
Upper Respiratory Tract Infection	11.4%	9.1%	Bronchitis	4.1%	1.2%
Dyspepsia	7.8%	8.5%	Arthralgia	3.7%	1.8%
Abdominal Pain	7.6%	6.7%	Surgical Intervention	3.3%	3.0%
Urinary Tract Infection	6.1%	3.0%	Fatigue	3.3%	1.2%
Coughing	6.1%	3.0%	Pain	3.3%	3.0%
Pharyngitis	5.2%	5.4%	Skeletal Pain	2.8%	1.8%
Vomiting	4.6%	2.4%	Insomnia	2.4%	1.2%
Injury	4.5%	2.4%	Hot Flushes	2.4%	0.0%
Back Pain	4.5%	4.2%	Rigors	1.3%	1.2%
Rash	4.3%	6.0%	Anxiety	1.3%	1.2%

*n is the total number of patients exposed to the dose at any time during the study.

The following events were reported in Sjögren's patients at incidences of <3% and ≥1%: constipation, tremor, abnormal vision, hypertonia, peripheral edema, chest pain, myalgia, fever, anorexia, eye pain, earache, dry mouth, vertigo, salivary gland pain, pruritus, influenza-like symptoms, eye infection, post-operative pain, vaginitis, skin disorder, depression, hiccup, hyporeflexia, infection, fungal infection, sialoadenitis, otitis media, erythematous rash, pneumonia, edema, salivary gland enlargement, allergy, gastroesophageal reflux, eye abnormality, migraine, tooth disorder, epistaxis, flatulence, toothache, ulcerative stomatitis, anemia, hypoesthesia, cystitis, leg cramps, abscess, eructation, moniliasis, palpitation, increased amylase, xerophthalmia, allergic reaction,

The following events were reported rarely in treated Sjögren's patients (<1%): Causal relation is unknown:

Body as a Whole Disorders: aggravated allergy, precordial chest pain, abnormal crying, hematoma, leg pain, edema, periorbital edema, activated pain trauma, pallor, changed sensation temperature, weight decrease, weight increase, choking, mouth edema, syncope, malaise, face edema, substernal chest pain

Cardiovascular Disorders: abnormal ECG, heart disorder, heart murmur, aggravated hypertension, hypotension, arrhythmia, extrasystoles, t wave inversion, tachycardia, supraventricular tachycardia, angina pectoris, myocardial infarction, pericarditis, pulmonary embolism, peripheral ischemia, superficial phlebitis, purpura, deep thrombophlebitis, vascular disorder, vasculitis, hypertension

Digestive Disorders: appendicitis, increased appetite, ulcerative colitis, diverticulitis, duodenitis, dysphagia, enterocolitis, gastric ulcer, gastritis, gastroenteritis, gastrointestinal hemorrhage, gingivitis, glossitis, rectum hemorrhage, hemorrhoids, ileus, irritable bowel syndrome, melena, mucositis, esophageal stricture, esophagitis, oral hemorrhage, peptic ulcer, periodontal destruction, rectal disorder, stomatitis, tenesmus, tongue discoloration, tongue disorder, geographic tongue, tongue ulceration, dental caries

Endocrine Disorders: increased glucocorticoids, goiter, hypothyroidism

Hematologic Disorders: thrombocytopenic purpura, thrombocythemia, thrombocytopenia, hypochromic anemia, eosinophilia, granulocytopenia, leucopenia, leukocytosis, cervical lymphadenopathy, lymphadenopathy

Liver and Biliary System Disorders: cholelithiasis, increased gamma-glutamyl transferase, increased hepatic enzymes, abnormal hepatic function, viral hepatitis, increased serum glutamate oxaloacetic transaminase (SGOT) (also called AST-aspartate aminotransferase), increased serum glutamate pyruvate transaminase (SGPT) (also called ALT-alanine aminotransferase)

Metabolic and Nutritional Disorders: dehydration, diabetes mellitus, hypercalcemia, hypercholesterolemia, hyperglycemia, hyperlipemia, hypertriglyceridemia, hyperuricemia, hypoglycemia, hypokalemia, hyponatremia, thirst

Musculoskeletal Disorders: arthritis, aggravated arthritis, arthropathy, femoral head avascular necrosis, bone disorder, bursitis, costochondritis, plantar fasciitis, muscle weakness, osteomyelitis, osteoporosis, synovitis, tendinitis, tenosynovitis

Neoplasms: basal cell carcinoma, squamous carcinoma

Nervous Disorders: carpal tunnel syndrome, coma, abnormal coordination, dysesthesia, dyskinesia, dysphonia, aggravated multiple sclerosis, involuntary muscle contractions, neuralgia, neuropathy, paresthesia, speech disorder, agitation, confusion, depersonalization, aggravated depression, abnormal dreaming, emotional lability, manic reaction, paroniria, somnolence, abnormal thinking, hyperkinesia, hallucination

Miscellaneous Disorders: fall, food poisoning, heat stroke, joint dislocation, post-operative hemorrhage

Resistance Mechanism Disorders: cellulitis, herpes simplex, herpes zoster, bacterial infection, viral infection, genital moniliasis, sepsis

Respiratory Disorders: asthma, bronchospasm, chronic obstructive airway disease, dyspnea, hemoptysis, laryngitis, nasal ulcer, pleural effusion, pleurisy, pulmonary congestion, pulmonary fibrosis, respiratory disorder

Rheumatologic Disorders: aggravated rheumatoid arthritis, lupus erythematosus rash, lupus erythematosus syndrome

Skin and Appendages Disorders: acne, alopecia, burn, dermatitis, contact dermatitis, lichenoid dermatitis, eczema, furunculosis, hyperkeratosis, lichen planus, nail discoloration, nail disorder, onychia, onychomycosis, paronychia, photosensitivity reaction, rosacea, scleroderma, seborrhea, skin discoloration, dry skin, skin exfoliation, skin hypertrophy, skin ulceration, urticaria, verruca, bullous eruption, cold clammy skin

Special Senses Disorders: deafness, decreased hearing, motion sickness, parosmia, taste perversion, blepharitis, cataract, corneal opacity, corneal ulceration, diplopia, glaucoma, anterior chamber eye hemorrhage, keratitis, keratoconjunctivitis, mydriasis, myopia, photopsia, retinal deposits, retinal disorder, scleritis, vitreous detachment, tinnitus

Urogenital Disorders: epididymitis, prostatic disorder, abnormal sexual function, amenorrhea, female breast neoplasm, malignant female breast neoplasm, female breast pain, positive cervical smear test, dysmenorrhea, endometrial disorder, intermenstrual bleeding, leukorrhea, menorrhagia, menstrual disorder, ovarian cyst, ovarian disorder, genital pruritus, uterine hemorrhage, vaginal hemorrhage, atrophic vaginitis, albuminuria, bladder discomfort, increased blood urea nitrogen, dysuria, hematuria, micturition disorder, nephrosis, nocturia, increased nonprotein nitrogen, pyelonephritis, renal calculus, abnormal renal function, renal pain, strangury, urethral disorder, abnormal urine, urinary incontinence, decreased urine flow, pyuria

In one subject with lupus erythematosus receiving concomitant multiple drug therapy, a highly elevated ALT level was noted after the fourth week of cevimeline therapy. In two other subjects receiving cevimeline in the clinical trials, very high AST levels were noted. The significance of these findings is unknown.

Additional adverse events (relationship unknown) which occurred in other clinical studies (patient population different from Sjögren's patients) are as follows:

cholinergic syndrome, blood pressure fluctuation, cardiomegaly, postural hypotension, aphasia, convulsions, abnormal gait, hyperesthesia, paralysis, abnormal sexual function, enlarged abdomen, change in bowel habits, gum hyperplasia, intestinal obstruction, bundle branch block, increased creatine phosphokinase, electrolyte abnormality, glycosuria, gout, hyperkalemia, hyperproteinemia, increased lactic dehydrogenase (LDH), increased alkaline phosphatase, failure to thrive, abnormal platelets, aggressive reaction, amnesia, apathy, delirium, delusion, dementia, illusion, impotence, neurosis, paranoid reaction, personality disorder, hyperhemoglobinemia, apnea, atelectasis, yawning, oliguria, urinary retention, distended vein, lymphocytosis

The following adverse reaction has been identified during post-approval use of EVOXAC®. Because post-marketing adverse 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.

Post-Marketing Adverse Events: *Liver and Biliary System Disorders:* cholecystitis

MANAGEMENT OF OVERDOSE
Management of the signs and symptoms of acute overdosage should be handled in a manner consistent with that indicated for other muscarinic agonists: general supportive measures should be instituted. If medically indicated, atropine, an anti-cholinergic agent, may be of value as an antidote for emergency use in patients who have had an overdose of cevimeline. If medically indicated, epinephrine may also be of value in the presence of severe cardiovascular depression or bronchoconstriction. It is not known if cevimeline is dialyzable.

℞ Only

Distributed and Marketed by:
Daiichi Sankyo Pharma Development, a Division of Daiichi Sankyo, Inc.
Edison, NJ 08837

PRT40 Revised 11/2006 Printed in U.S.A.

Daiichi-Sankyo

For additional information
please call toll free:
1-877-437-7763

EVOXAC is a registered trademark of Daiichi Sankyo, Inc.
 DSEV10000226 Printed in USA 2010

Friends Helping Friends

In early April, you received a 2011 *Friends Helping Friends* campaign packet which focused on the Foundation's Clinical Practice Guidelines initiative. We asked you to consider using the materials provided to enlighten your friends and family about the seriousness of Sjögren's. Thank you to those who participated in the campaign and raised awareness of Sjögren's syndrome!

As a special thanks, the SSF will be awarding lifetime memberships to three of this year's *Friends Helping Friends* participants. If you participated in the *Friends Helping Friends* campaign by sending your letters and/or have collected donations from your friends and family, please forward them to the Foundation along with your Collection Summary Form provided in the packet.

Sjögren's Syndrome Foundation-FHF
6707 Democracy Blvd. Suite 325
Bethesda, MD 20817

If you have any questions, please contact the Foundation Office at 800-475-6473 ext 217.

Thank you for joining us in an effort to increase awareness one friend at a time!

Do we have your e-mail address?

If you want to receive all the latest updates from the Sjögren's Syndrome Foundation, then you should make sure we have your most up-to-date e-mail address! The SSF is starting to share more information via e-mail, from news about the SSF and Sjögren's, to information about the latest treatments and medicines, to local Support Group updates and more. So contact us at ssf@sjogrens.org to be certain we have your latest e-mail address in our database, and then keep an eye out in your Inbox for Sjögren's news.

Just like all information you give the Foundation, your e-mail address will remain private and will never be given or sold to an outside organization.

in memoriam

In Memory of Anne O'Steen Rowe
Lyndie Burris
Ed & Amy Burrows
Susan Irons
Beth & Ed Kasmeier
Sara Rowe Morton
Melinda Grace Rowe
Sarah Edna Rowe
James & Danna Thompson
Don & Karen Woodlee
Jerry & Mary Lee Wright
Margaret Young

In Memory of Barb Lambert
Robert & Jane Perry

In Memory of Frances Patricia Grunbok
Brian & Leslie Battistoni
Nancy Bedore
Joseph Crichton
William & Carol Eberle
MaryAnn & Fred Lohrey
Jon & Eve Scheetz
Gregg & Analissa Verrill
In Memory of Jackie Sciulli
Donna Beckley
Dona Frosio
Kara Harmon
Richard & Cynthia Kuehn
San Diego & Imperial Counties Chapter
San Diego Hattitudes
The Tempos Section, La Mesa Woman's Club
Kathy & Ken Trego

In Memory of Lucy Parks
Phyllis Carle
Patrick & Donna Dorsey
Arleigh & Aurleen Nelson
Mr. & Mrs. Harold Neuweg
Gail Parks
Joan & Jacob Steib
James & Nona Stufft

In Memory of Pat Mathis
Brick Church
Florence Young

In Memory of William E. Pittman
Deborah & Greg Margolis
Peggy Vassallo
Anthony & Linda Weshefsky

in honor

In Honor of Kristi Crosland Gazzo
Carol Harvey Ross

In Honor of LaDonna Landry
Loretta Thompson

In Honor of Susan Joyce
Scott & Louise Sternberg

Sjögren's Syndrome Foundation
Legacy of Hope

If you would like to receive information on how you can *Leave a Legacy* to support the Sjögren's Syndrome Foundation's critical research initiatives or to support one of our many other programs, please contact Steven Taylor at 800-475-6473.

Leave A Legacy – Remember Us in Your Will

I Stood Up...

Nominate Someone Who Stood Up for Sjögren's!

Every month we honor a supporter in this *I Stood Up* section who has worked to help raise awareness of Sjögren's syndrome. Honorees have ranged greatly in their activities.

For example, Taylor Mount and Miranda Sego are two 13-year-olds with Sjögren's who worked separately at local events in their communities to raise awareness of this disease. Another honoree, Estrella Bibbey, started a Team Sjögren's training group among her local mother friends. Diane Bilotti Lawlor promoted Sjögren's at her wedding and was honored in this section for Standing Up.

We hear about a lot of great supporters but we do miss some stories. Do you know someone in your community who has Stood Up for Sjögren's? Nominate them!

You can submit your nomination by calling our office at 800-475-6473, emailing their story to ssf@sjogrens.org, or even just leaving a post about the nominee on our Facebook page (facebook.com/SjogrensSyndromeFoundation)

Visit www.ShopForSjogrens.com before you shop online to benefit the SSF

Save money through our partnership with Drugstore.com

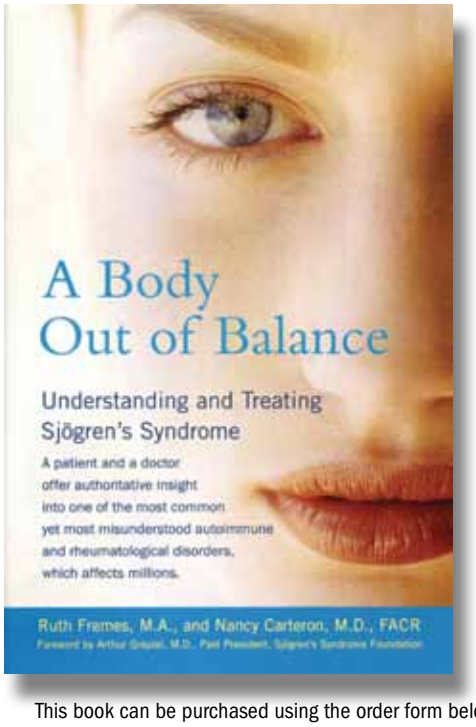
Many Sjögren's patients spend hundreds of dollars a month on over the counter products to cope with the myriad of symptoms associated with the disease. Shopping online for these products is often a convenient alternative to visiting an actual store and can frequently save you money.

Now you can shop online at Drugstore.com while having a portion of your purchases come back to benefit the SSF.

Drugstore.com is a leading online provider of health, beauty, vision, and pharmacy products. The website allows you to shop as if you were at your local drug store, offering a wide assortment of more than 45,000 products at competitive prices, all without leaving your house!

Just start your shopping at www.shopforsjogrens.com. There you will see a link to Drugstore.com. If you click on that link then 10% of anything you purchase during that visit will be donated to the Sjögren's Syndrome Foundation. It's that easy and over a period of time could really add up as a sizable donation to the SSF!

The Moisture Seekers
Sjögren's Syndrome Foundation Inc.
6707 Democracy Blvd., Ste 325
Bethesda, MD 20817
Phone: 800-475-6473
Fax: 301-530-4415



Buy A Body Out of Balance Today

Do you own one of our most popular resources?

A Body Out of Balance: Understanding and Treating Sjögren's Syndrome was published in 2003 and since then has been one of the best-selling books that the Foundation sells.

Ruth Fremes, a Sjögren's patient who is an author specializing in health and nutrition and a long-time Foundation volunteer, co-writes this book with Dr. Nancy Carteron, a rheumatologist in San Francisco who is a world-renowned expert on Sjögren's and autoimmunity.

A Body Out of Balance is a comprehensive guide to the wide array of symptoms, traditional and complimentary treatments, and invaluable coping methods, so patients may devise a personal treatment plan. It also offers the dual perspective of a woman living with Sjögren's and the thoughts of a physician who has treated countless Sjögren's patients.

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
A Body Out of Balance by Ruth Fremes, MA, and Nancy Carteron, MD, FACR	$13.00	$10.00		
Maryland Residents add 6% sales tax				
Shipping and Handling: US Mail: $5 for first item + $2 for each additional item Canada: $8 for first item + $2 for each additional item Overseas: $18 for first item + $2.50 for each additional item				
Total Amount				

Mail to SSF, BB&T Bank · PO Box 890612 · Charlotte, NC 28289-0612 or Fax to: 301-530-4415

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____ E-Mail _____

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

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

Signature _____ CC Security Code _____