

# The Sjögren's Syndrome Foundation Moisture Seekers



www.sjogrens.org

Volume 33, Issue 5 May 2015

f SjogrensSyndromeFoundation

@MoistureSeekers

## Health & Dental Insurance Reimbursement 101



The Sjögren's Syndrome Foundation (SSF) knows that obtaining healthcare and dental reimbursement can be a major challenge. Having Sjögren's places a high enough burden on patients, and adding the barriers patients face in obtaining health insurance reimbursement increases that burden greatly. These tips below should help you increase your chances of success when requesting reimbursement and appealing denials for a claim.

### Tips for Health Insurance

*Know your insurance policy and what it covers.*

- Note whether prior authorization is needed for a specific therapy or procedure.
- Understand co-pays and how much you will be expected to contribute to the cost.
- Know whether your insurance company requires "step therapy," which means you must try and fail one therapy before the next level of therapy can be covered.

*continued page 2 ▼*

## Sjögren's and Irritable Bowel Syndrome: Time to Consider a Low-FODMAP Diet?

by Cristina Montoya  
Registered Dietitian and Certified Diabetes Educator

Irritable Bowel Syndrome (IBS) is a functional bowel disorder characterized by a change in bowel habits in the absence of any other mechanical or inflammatory process.<sup>1</sup> IBS has been found in 39-65% of patients with primary Sjögren's in comparison to 10-20% of the general population. IBS is frequently seen in conjunction with fibromyalgia, chronic fatigue syndrome, depression, and anxiety.<sup>2-5</sup>

Symptoms may include:

- Change in bowel habit often alternating diarrhea and constipation
- Abdominal bloating and distension
- Gas (rumbling, flatulence, and wind)
- Sometimes abdominal pain, usually relieved after a bowel movement
- Feeling of incomplete defecation

*continued page 6 ▼*

In This Issue

7 You Stood Up

11 Advocacy Update

12 In Memory & Honor



### Board of Directors

#### Chairman of the Board

Ken Economou

#### Chairman-Elect

Stephen Cohen, OD

#### Treasurer

Vidya Sankar, DMD, MHS

#### Secretary

Janet E. Church

#### Immediate Past Chairman

S. Lance Forstot, MD

Esen K. Akpek, MD  
 Herbert Baraf, MD, FACP, MACR  
 Pamela S. Brown  
 Nancy L. Carteron, MD, FACP  
 Jack Faricelli  
 Denise Faustman, MD, PhD  
 Tricia Gooding  
 Cathy Ingels  
 Theresa Lawrence Ford, MD  
 Cynthia Lopynski  
 Mary McNeil  
 Kathy L. Sivils, PhD

### Medical & Scientific Advisory Board

#### Chairman

Denise Faustman, MD, PhD

Esen Akpek, MD  
 Richard Brasington, MD, FACP  
 Michael Brennan, DDS, MHS  
 Steven E. Carsons, MD\*  
 Nancy L. Carteron, MD, FACP  
 Troy Daniels, DDS, MS\*  
 H. Kenneth Fisher, MD, FACP, FCCP  
 Gary Foulks, MD, FACS  
 Theresa Lawrence Ford, MD  
 S. Lance Forstot, MD  
 Phillip C. Fox, DDS\*  
 Robert I. Fox, MD, PhD, FACP\*  
 Tara Mardigan, MS, MPH, RD  
 Austin Mircheff, PhD  
 John Daniel Nelson, MD, FACS  
 Kelly Nichols, OD  
 Athena Papas, DMD, PhD  
 Ann Parke, MD  
 Andres Pinto, DMD  
 Nelson Rhodus, DMD, MPH  
 Vidya Sankar, DMD, MHS  
 Daniel Small, MD, FACP  
 Neil Stahl, MD  
 Frederick B. Vivino, MD, FACP  
 Jeffrey Wilson, MD, FACP

#### Chief Executive Officer

Steven Taylor

#### Director of Marketing/Editor

Elizabeth Trocchio

e-mail: [tms@sjogrens.org](mailto:tms@sjogrens.org)  
[www.sjogrens.org](http://www.sjogrens.org)

*"Insurance" continued from page 1 ▼*

*Make sure your medical records are accurate.*

- Maintain copies of your medical records. You have the right to receive copies of all of your medical records. Note that you can be charged a copy fee.

*Include a Letter of Medical Necessity.*

- A Letter of Medical Necessity is usually written by the physician explaining why a therapy or other treatment is medically necessary. This can be included with an initial claim or included in the appeals process.
- A Sample Letter of Medical Necessity for dental treatment can be found on the SSF website under "Brochures and Resource Sheets."

*Know how your insurance company handles biologics if you are considering one.*

- Insurance companies can exclude a drug from coverage or it might be a "tiered" drug, meaning one that is designated at a certain level for how much the patient must cover.
- If not covered, or if the patient coverage is too high, request an exemption along with an explanation about why you need the drug from your physician.

*Always appeal denials!*

- Appeal a denial at every level. Most patients receive at least partial reimbursement upon appealing a negative decision from their insurance company.
- Involve your doctor in helping you respond to a denial.
- Familiarize yourself with your insurance company's guidelines and deadlines for appeal. This information is usually included in the denial letter.
- Make sure you have the necessary documentation showing that your case meets the insurance provider's guidelines and demonstrates medical need.
- Maintain records of your communication with the insurance company and document every time you speak or hear from a company representative. Record the person's name, date, time and key messages from the conversation.
- Understand why you were denied, so you can address the reason(s) directly.
- If you are communicating with the Customer Service office of the insurance company and are dissatisfied with the response, ask for a Nurse Case Manager or a Supervisor who might be more understanding of your situation.
- When possible, demonstrate that treatment is more cost-effective than alternatives or non-treatment.

*If you are still denied following the final round of appeals, contact the advocacy or patient assistance program for the company that produces the therapy.*

- Most companies have divisions that take applications for financial assistance for their therapies.

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

Copyright ©2015 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.

## If Denied, Appeal!

### How to Draft an Insurance Appeal Letter

Always appeal a denial. Be persistent and do not give up if first denied. The following provides the information and documentation that will help you appeal a denial:

- Your policy and claim numbers, employer name if your policy is through an employer, and the full name of the insured.
- The therapy or procedure for which you were denied and why the denial letter stated you were denied.
- Medical records that back up your diagnosis and medical problem that relates to the therapy in question.
- A cost benefit analysis when relevant. For example, you can compare the cost savings of obtaining punctal plugs or cauterization compared to the higher cost of using more moisture drops and ointment over a long period of time.
- Letter of Medical Necessity –
  - This letter is usually written by the physician explaining why a therapy or other treatment is medically necessary.
  - If the Letter of Medical Necessity is not signed by your physician, have your physician provide a letter of support for your appeal and reason for recommending or prescribing your therapy.
  - A Sample Letter of Medical Necessity for dental treatment can be found in this issue or on the SSF website under “Brochures and Resource Sheets.”
- Two or more articles from respected medical journals backing your claim of medical necessity.
- Quotes from your health insurance policy that are helpful to your case –
  - For example, if your policy states that coverage is provided for a closely related disease and/or similar symptom quote that back to the insurance company. If the company cites a reason for covering the related disease or symptoms, such as an inflammatory response, use that. Quoting such statements and providing documentation about similar occurrences in Sjögren’s increases your chance for the success of an appeal.
- Refer to the SSF website ([www.sjogrens.org](http://www.sjogrens.org)) as an authoritative source of medical information on Sjögren’s.

### Tips for Dental Insurance

Ever since dentistry split from medicine, insurers have looked at dentistry as being solely confined to the mouth.

Because Sjögren’s is a systemic disease that affects the mouth, patients and their professional caregivers often have faced extreme frustration in obtaining reimbursement for care. This becomes even more difficult when trying to obtain reimbursement for care under regular medical insurance as compared to dental insurance.

The best tool is education. Have your doctor explain to your insurance company that Sjögren’s is a chronic and systemic illness that involves serious oral health complications and treatment. Preventive care and care when problems first arise are critical so that more major problems don’t develop in the mouth and affect the rest of the body. For example, infection in the mouth can spread in the body, and loss of teeth due to dry mouth can impact nutrition. Sjögren’s patients are susceptible to developing non-Hodgkin’s lymphoma, and this complication most frequently is manifested first in the salivary gland.

### Basic Dental Care Reimbursement Tips for Any Kind of Insurance:

- Keep the above health insurance tips in mind with dental insurance appeals too. Many of these are relevant for obtaining reimbursement for any kind of healthcare.
- Read your insurance policies carefully. Know what they will cover, will not cover, and what is not explicitly stated. The latter can provide a window for pushing for coverage. Be prepared to prove that your treatment qualifies for coverage under your plan.

*continued page 4 ▼*



**OraCoat** **XyliMelts<sup>®</sup>**  
for dry mouth

**Adhering discs for use while sleeping and daytime!**

**XyliMelts** long lasting adhering discs temporarily relieve dry mouth\* day and night, even while sleeping when dry mouth is worst.

- 500 mg of Xylitol coats, moisturizes and lubricates\*
- Discreetly sticks to gums or teeth
- Lasts all night
- May reduce risk of tooth decay
- **12 disc sample; just pay \$3.20 shipping (online or telephone orders only)**

**RITE AID** **CVS pharmacy** Available at Rite Aid and CVS. Call **877-672-6541** for telephone orders or visit **www.oracoat.com**

\* These statements have not been evaluated by the Food and Drug Administration. This product is not intended to diagnose, treat, cure or prevent any disease.

"Insurance" continued from page 3 ▼

- **Always appeal a denial!**

- If denied, find out what led to the insurer's decision, and keep a careful paper trail. Mail your appeal certified with return receipt to document that your appeal was mailed within the specified time frame.
- The appeals claim address might be different from the submission address, so check carefully.
- In all corresponding documents, include: date, claim number, date of service, subscriber number, group or policy number, amount of charge, and dental provider name. In addition, describe the denial, why you are writing, and what you are requesting. Ideally this initial letter should be clear and concise. Templates are available on line to help with wording if you need to do the appeal yourself.
- Do not send original radiographs, as they might get lost.
- Provide a cost-benefit analysis when possible. For example: the cost of having more frequent dental check-ups and cleanings when someone has a dry mouth can save the insurance company the much higher cost of obtaining fillings, crowns and/or implants.
- Remember that you are the client and pay for your insurance. Don't be afraid to place the insurance company on the defensive and make it clear that the company must justify its refusal to cover what should be deemed medically-necessary care. Stress the medical repercussions if you do not get the care you need and the potential negligence on the part of the insurance company if you do not get that care.
- A common insurance phrase when considering reimbursement charges is "usual, customary, and reasonable" or "UCR." This can be extended to include the care required for a Sjögren's patient. The SSF Clinical Practice Guidelines for Oral Care and Management can be cited to prove usual and customary care.
- Provide a Letter of Medical Necessity. A Sample Letter of Medical Necessity for dental treatment can be found in this issue or on the SSF website under "Brochures and Resource Sheets."
- Include two or more articles from respected dental or medical journals backing your claim of medical necessity.
- Refer to the SSF website and the SSF brochure on "What is Sjögren's?" and "Dry Mouth" as an authoritative source of medical information on Sjögren's.
- If you do not already have dental insurance, consider obtaining it.
- Be persistent but friendly, and document all of your interactions. ■

## Sample Dental Appeals Letter

To Whom It May Concern:

This letter is intended to give you a brief summary of Sjögren's, associated oral manifestations and justification of the need for dental care.

Sjögren's is a systemic immune mediated disease of exocrine tissues, such as salivary and lacrimal glands resulting in oral and ocular dryness. The oral manifestations of Sjögren's include reduced quantity and quality of saliva, increased incidence of caries, dental decay and loss of teeth, mucosal atrophy, salivary gland enlargement, recurrent parotitis, and greater frequency of candidiasis and other infections.

Even though some medications stimulate saliva secretion, such as cevimeline (Evxac™) and pilocarpine (Salagen™) the mainstay in the treatment of patients with Sjögren's is dental care.

Patients suffering from Sjögren's require meticulous dentist-guided care, such as frequent visits to a dentist and prescription strength fluoride, to prevent and treat any complications associated with the disease.

The complexity of the Sjögren's requires multidisciplinary care by dentist, ophthalmologist, rheumatologist and primary care provider.

We would be happy to discuss any questions you might have regarding Sjögren's.

Sincerely,

[Your dentist or physician]

# Support your enamel health with BasicBites® ... everyday

Ortek  
Therapeutics, Inc.

## BasicBites® are essential for individuals with dry mouth.

These delicious soft chews contain a unique, patented blend of vital nutrients that naturally help support enamel health... **just like saliva.**

## The revolutionary technology in BasicBites Soft Chews was developed at Stony Brook University School of Dental Medicine.

- Landmark research identified beneficial bacteria on tooth surfaces.
- These helpful bacteria naturally convert a nutrient discovered in saliva (and contained in BasicBites) into tooth protective buffers which help keep teeth in their existing and healthy pH (acid/base) balance.
- Like healthy saliva, BasicBites also contain calcium to coat and support healthy enamel.

Two delicious BasicBites, everyday, work behind the scenes to help maintain enamel health.

Leading dental professionals are recommending BasicBites. See why at [www.basicbites.com/testimonials](http://www.basicbites.com/testimonials)

**Order Today** with  
Free Shipping at

[basicbites.com](http://basicbites.com)

or call

800 - 863 - 9943

Only

**\$39.95**

2 month

supply



sugar free  
soft chews  
essential for  
individuals  
with **dry mouth**

**BASIC** pH↑  
**bites**®



[basicbites.com](http://basicbites.com)

120 ct- 2 month supply carton, chocolate-flavored

\* Also an excellent source of calcium.

The Seriously Delicious Oral Care Breakthrough

"IBS" continued from page 1 ▼

There is usually no sign of structural damage to the wall of the intestine. It does not wake one at night where the bowel is usually on a relaxed mode. It's important to note your health care provider must rule out other organic conditions before diagnosing IBS.<sup>1</sup>

You must seek further medical assessment if you are experiencing symptoms such as:<sup>6</sup>

- Passing blood, pus or mucus on defecation
- Fever or night sweats
- Unplanned weight loss greater than 10 pounds a month
- Family history of Crohn's Disease, Ulcerative Colitis, Celiac Disease, Ovarian or Colon Cancer
- Foul smelling and/or fatty stools
- Osteoporosis or osteopenia
- Urge to move bowels waking you up at night
- Thyroid dysfunction
- Hereditary Fructose Intolerance

### Possible causes of IBS:<sup>1,4,6</sup>

- Abnormal contractions of the colon and intestinal muscles. Food can move throughout the gastrointestinal tract too slowly or too quickly and may cause intestinal muscle spasms.
- Disconnection between brain and gut possible related to a nervous system dysfunction. Stress may exacerbate the symptoms.
- Low-grade inflammation activated by certain foods, for example non-celiac gluten sensitivity.
- Bacterial imbalance perhaps after experiencing gastroenteritis (i.e. traveler's diarrhea), food poisoning, or use of antibiotics.

### Common therapies used to manage IBS:<sup>5,6</sup>

- Fiber supplements
- Laxatives
- Anti-depressants
- Anti-anxiety medications
- Antibiotics (in the presence of bacterial overgrowth)
- Probiotics
- Stress management
- Exercise
- Avoidance of milk, caffeine, fried foods, spicy foods, and red meat.

### The FODMAP Elimination Diet

The FODMAP Elimination Diet is meant for people who have tried standard therapies for IBS but failed to find relief of their gastrointestinal symptoms. It's not uncommon to have IBS in addition to another digestive condition, such as Crohn's Disease, Ulcerative Colitis, Gastro-esophageal Reflux Disease (GERD). You must consult with your Family Doctor or Gastroenterologist before initiating the FODMAP elimination diet (6-10).

FODMAP stands for Fermentable Oligosaccharides (Wheat, legumes), Disaccharides (Lactose), Monosaccharides (Fructose), and Polyols (Sugar alcohols). In simple words, it's a group of sugars or starches that are not well digested in the gut. This diet has been around since 2001 and a growing body of evidence is showing a sustained improvement of digestive symptoms in up to 80% of people with IBS after implementation of a Low FODMAP diet.

It is important that you seek guidance from a Registered Dietitian with expertise in this area. The low FODMAP diet should be tried for at least 2 to 6 weeks followed by a dietitian.

**You should not attempt this diet without professional advice!**

continued page 8 ▼



## 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](mailto: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.



# You Stood Up!

## *The Dodds Family!*

After suffering for more than eight years with symptoms that included headaches, dry eyes, fatigue and joint pain, Paula Dodds was finally diagnosed with Sjögren's in January of 2014. A few months later, her 14-year old twin sons, Justin and Brandon Dodds, were required to do a leadership project for their student government class. Having watched their mother struggle with the impacts of Sjögren's for more than half their lives, Justin and Brandon decided to host a charity bike ride in honor of their mother and to support Sjögren's research and awareness.

Because they couldn't be graded on the final outcome of a fall race, the event didn't actually end up working out as a project but they decided to put the event on anyway. After months of planning, securing event sponsors, planning a course, getting permits, recruiting participants, building a website and making numerous connections throughout the community, *Cycle for Sjögren's* took place on September 14, 2014.

Both avid cyclists, Justin and Brandon thought a charity ride was a perfect idea and Chico, California, was the ideal place to hold the event. The ride took place at Marsh Junior High School and included a 5-mile family ride and a 30-mile advanced ride. All proceeds from the event benefited the Sjögren's Syndrome Foundation.

While most 14-year old boys are more concerned about playing video games or hanging out with their friends, Justin and Brandon were focused on doing what they could to increase awareness for Sjögren's. Specifically, they wanted to help impact the Foundation's *Breakthrough Goal* of reducing the time to get diagnosed so others don't have to go through what their mom did in dealing with symptoms for eight years before receiving her official diagnosis.

The event was a huge success with nearly 100 riders showing up to participate, both serious and amateur riders alike. Participants were also provided with food, t-shirts and refreshments. In addition to those individuals that participated, there were numerous volunteers as well as family, friends and community members that came simply to support the brothers and the event, and cheer on the riders as well.

As you can imagine, Paula was incredibly proud of her sons for taking this idea and going so far with it. And Justin and Brandon were thrilled with the outcome of the charity ride and hope to make this an annual event. They've already begun working with sponsors and volunteers for the 2<sup>nd</sup> annual event this Fall! ■



"IBS" continued from page 6 ▼

### Examples of High and Low FODMAPs:<sup>6-10</sup>

FOOD GROUP	HIGH FODMAP	LOW FODMAPS
Vegetables	Asparagus Broccoli Onions Garlic Leeks Peas Mushrooms Cauliflower	Carrot Celery Cabbage, common Eggplant Green beans Lettuce Tomato, cucumber Olives
Fruits	Apples, Pears (except prickly variety) Plums, Blackberries Cherries Mango Peaches Watermelon	Avocado (< 1/8) Banana, Cherries Pineapple Pomegranate (< 1/4 cup seeds) Lime Cantaloupe, Grapes
Grains	Wheat-based products: bread, cereals, crackers, cookies, couscous, pasta Rye-based products: bread, cereal, crackers Barley-based products Inulin	Gluten free cereals/breads Oat bran Oats < 1/2 cup Bread, spelt Cornflakes Pasta – gluten free Quinoa, Rice bran, Corn flour
Milk and Alternatives	Cow, sheep, and goat milk Ricotta and Cottage cheese if > 2Tbp Yogurt Ice Cream	Lactose free, soy milk, rice milk Brie cheese, cheddar cheese Havarti cheese, Swiss cheese Lactose free yogurt Sorbet and gelato
Meat and Alternatives	Chickpeas Baked beans Four bean mix Red kidney beans Soya beans Split peas Cashews, Pistachios	Chicken, beef, pork, fish Egg Tofu Almonds (< 10 nuts)
Other ingredients	Honey High fructose corn syrup Xylitol, Sorbitol	Maple syrup Sugar, Glucose sucralose, saccharin, aspartame

# Run Disney

*Run or Walk with Us at Disneyland, California!!*



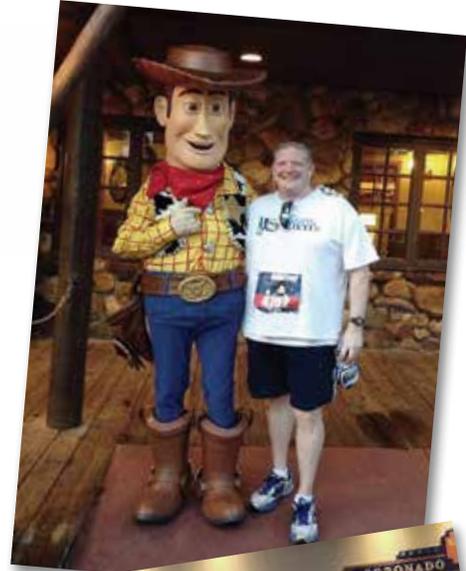
**T**eam Sjögren's is headed to the West Coast to participate in the 2015 Disneyland® Half-Marathon and 10K in Anaheim, California this September!

The SSF is looking for runners/walkers that want to train to participate in either the Disneyland half marathon (13.1 Miles) or the Disneyland 10K (6.2 miles). Both events happen the same weekend (September 5th/6th, 2015) and each runner/walker will be a part of the Team Sjögren's training program – where our experienced team will help you train and get ready for the race!

These magical courses will take you through the legendary Disneyland Park, Disney California Adventure Park and the beautiful City of Anaheim before a fun filled finish near Disneyland Hotel where you will receive your Disneyland half marathon or 10K Finisher Medal!

As a Team member, you will receive world-class training along with mentorship from past runners and Foundation staff. Our team trainer and nutritionist will be there to help guide you and ensure you're ready to complete the 6.2 or 13.1 miles. If you're unable to run or walk in a race, consider recruiting someone you know to run or walk in your honor. These events are sold out to the public, however the SSF has limited spaces available for both the half marathon and the 10K. Please contact Steven Taylor, CEO of the SSF at [staylor@sjogrens.org](mailto:staylor@sjogrens.org) as quickly as possible to learn more about our great program!

We hope you will join us at the most magical place on earth- Disneyland! ■



**Call or Email Today! Only 35 Spots are Available!**

# Host Your Own SSF Event and Help Increase Awareness!

## EVENT IDEAS

Special event fundraisers can be a great way to raise money and many require spending little or no money. It is also a great way to get involved and give back while getting your friends, family, neighbors, work colleagues, etc., to help raise funds while increasing awareness for Sjögren's at the same time. The possibilities are endless. Have fun and use your imagination. Some examples:

- Bake Sale
- Restaurant "Night Out"
- Movie Night
- Dress Down Day
- Car Wash
- Pancake Breakfast
- Yard Sale
- Sports Tournament
- Dinner Party
- Bingo Night
- Fashion Show
- High Tea

Please contact Michele Lee, Development Associate, at the Foundation office with any additional questions at 301-530-4420 ext. 218 or [mlee@sjogrens.org](mailto:mlee@sjogrens.org). ■





# Advocacy Update

## Breakthrough Bullet: SSF in Action!

International Dry Eye Workshop II set to begin with SSF Vice President of Medical & Scientific Affairs, Kathy Hammitt, elected to serve on the Steering Committee!

The Tear Film and Ocular Society (TFOS), led by David Sullivan, PhD, Senior Scientist, Schepens Eye Research Institute, and Associate Professor, Department of Ophthalmology, Harvard Medical School, is set to be their next international dry eye workshop, "DEWS II."

Participants of DEWS II are currently being finalized, and committees will get started this summer on topics ranging from basic scientific aspects to clinical diagnosis and management. The Sjögren's Syndrome Foundation (SSF) is thrilled that members of the SSF Medical and Scientific Advisory Board will be involved along with other Sjögren's and dry eye experts from around the world. SSF Board member Esen K. Akpek, MD, and Kathy Hammitt, SSF Vice President of Medical and Scientific Affairs, were elected to serve on the Steering Committee, and Stephen Cohen, OD, SSF Chairman-Elect also will serve as a member of DEWS.

Hammitt says, "I am thrilled to represent the SSF and be in a leadership role with DEWS II. The first DEWS workshop marked a major turning point for accelerating interest in dry eye. DEWS II will be critical for increasing the momentum and dramatically changing the future for dry eye research and the management and treatment of patients."

Topics will include sex and hormonal influence, definition and classification, epidemiology, pathophysiology, pain and sensation, iatrogenic dry eye, tear film, diagnosis, management and therapy, clinical trial design, and public awareness. The Tear Film and Ocular Society is managing the initiative. Watch upcoming newsletters for more information about this workshop as it becomes available. ■

"I am thrilled to represent the SSF and be in a leadership role with DEWS II. The first DEWS workshop marked a major turning point for accelerating interest in dry eye. DEWS II will be critical for increasing the momentum and dramatically changing the future for dry eye research and the management and treatment of patients."

*Kathy Hammitt,  
SSF Vice President of Medical and Scientific Affairs.*



*Steering Committee meets to launch DEWS II*



## in memoriam

**In Memory of Judy Gronner**

The Sunday Morning Bible Study Group

**In Memory of Anthony Dilanni**

Claims and Appeals Employees Angelo and Theresa D'Orazio  
Anthony and Maria Arcodia Sharp Family  
Susan Clark Thomas and Deborah Wolk

**In Memory of Bonnie Litton**

Tammy Meister, D.D.S., M.S., P.A.

**In Memory of Evelyn Reisner**

Karen and Neil Laufer

**In Memory of Freda Haas**

Adrienne Ginsberg

**In Memory of Jean L. Query**

Kenneth and Carlyle

**In Memory of Laura Margene Oswald**

Bradley and Jeanne Burch

**In Memory of Margene Oswald**

Marilyn Cox

**In Memory of Marjorie Ramsdell**

Gerald Breslauer

Joyce Klein

Susan and Jon Safier

**In Memory of Mary McCarthy**

Al and Dawn Toimil

**In Memory of Mimmie Klein**

Lila Kissin

**In Memory of Nancy Andreeko**

Andrew Andreeko

**In Memory of Patricia and Elfrieda Frank**

Diane and Tom Stadtmiller

**In Memory of Randolph R Moses**

Dana Resnick Mueller

**In Memory of Shirley Parker**

John and Dolores Jones

**In Memory of Thelma Catherine Skinner**

Bonnie Schneider



## in honor

**In Honor of Beth Axelrod**

Peter Brown

**In Honor of Charlotte Eglick**

Peter Eglick

**In Honor of Deirdre Perl**

Elyse & Marc

**In Honor of Dr. Cheryl Levin**

Orr Family Foundation

**In Honor of Jane Petrie**

The Raubs

**In Honor of Kerry Pigeon**

Tressa, Joey & Joseph Pigeon

**In Honor of LaRue Horst**

Carol Watson

**In Honor of Lina Galvao**

Sara and Yaniv

**In Honor of TEAM COOPER**

Karen Truman

**In Honor of Yvette Gontkovsky**

Von Lee



# Donate Your Old Vehicle

Sjögren's  
Syndrome  
SF Foundation

Call us today for  
more information.

## 800-475-6473

"IBS" continued from page 8 ▼

## Here are some simple recommendations for digestive health:

- 1) Choose cooked vegetables more often – it actually eases swallowing!
- 2) Avoid gut stimulants: caffeine, nicotine and alcohol. Such stimulants can increase dry mouth – double benefit!
- 3) Avoid gas-producing foods: lactose, carbonated beverages, pulses (lentils, beans), and sugar alcohols – be cautious with excess Xylitol!
- 4) Eat every 3 to 4 hours and no less than 2 hours between meals or snacks
- 5) Increase fluid intake – not a problem with SS patients!
- 6) Increase or decrease fiber intake
- 7) Eat real and fresh food more often. Eat processed food maximum once a day, less wheat (max. once a day)
- 8) Keep a food and symptom journal
- 9) Find a suitable exercise: walking, swimming, or yoga.
- 10) Practice mindfulness in your life. Enjoy yoga, tai-chi, meditation, and other anti-stress therapies.

## References

- 1 Joneja J (2011). Irritable Bowel Syndrome: Mechanisms and Management. Dietitians of Canada Annual Conference. 2011.
- 2 Liden M, *et al.* (2008). Cow's milk protein sensitivity assessed by the mucosal patch technique is related to irritable bowel syndrome in patients with primary Sjogren's Syndrome. *Clinical and Experimental Allergy*, 38: 929-935
- 3 Ohlsson B, Scheja A, Janciauskiene S, *et al.* Functional bowel symptoms and GnRH antibodies: common findings in patients with primary Sjogren's syndrome but not in systemic sclerosis. *Scand J Rheumatol* 2009;38:391-3.
- 4 Nichols M (2012). Gastrointestinal manifestations of Sjogren's Syndrome. SSF National Patient Conference. April 21, 2012.
- 5 Anaya JM, Ramos M, Garcia M (2001). Síndrome de Sjögren. Capítulo 17: Compromiso pulmonar, gástrico y renal en el Síndrome de Sjögren. Primera Edición. Corporación para Investigaciones Biológicas. Medellín, Colombia. Pg. 175-177.
- 6 Catsos P (2012). IBS Free at last! With the FODMAP Elimination Diet. 2nd Edition. E-book.
- 7 Clairmont S (2014). The IBS Master Plan: A real food approach to relieve digestive distress. 1st Edition. 2014
- 8 Thomas JR., Nanda R., Shu LH. (2012). A FODMAP diet update: Craze or Credible? Nutrition issues in gastroenterology, series #112. December 2012.
- 9 Monash University (2014). Low FODMAP diet: reducing poorly absorbed sugars to control gastrointestinal symptoms. 4th Edition. Monash University, Melbourne, Victoria. Australia.
- 10 Holmes R (2011). The Low FODMAP diet. Reviewing the evidence: A systematic review. Dietitians of Canada National Conference. June 17, 2011.

# NEW

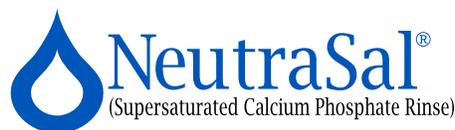
## NeutraSal® Sjögren's Syndrome Support Kit

### Containing:

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

\* This statement has not been evaluated by the FDA. This product is not intended to diagnose, treat, cure or prevent any disease.

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



### What is NeutraSal®

NeutraSal® is an advanced electrolyte solution indicated in the treatment of dry mouth (xerostomia) in patients with Sjögren's Syndrome. NeutraSal® 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 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® is similar to normal saliva which may protect the mouth against potential opportunistic fungal (oral thrush) and bacterial infections

**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 Lipoic Acid for Burning Mouth Comfort†
- Sugar Free Dry Mouth Gum with Xylitol

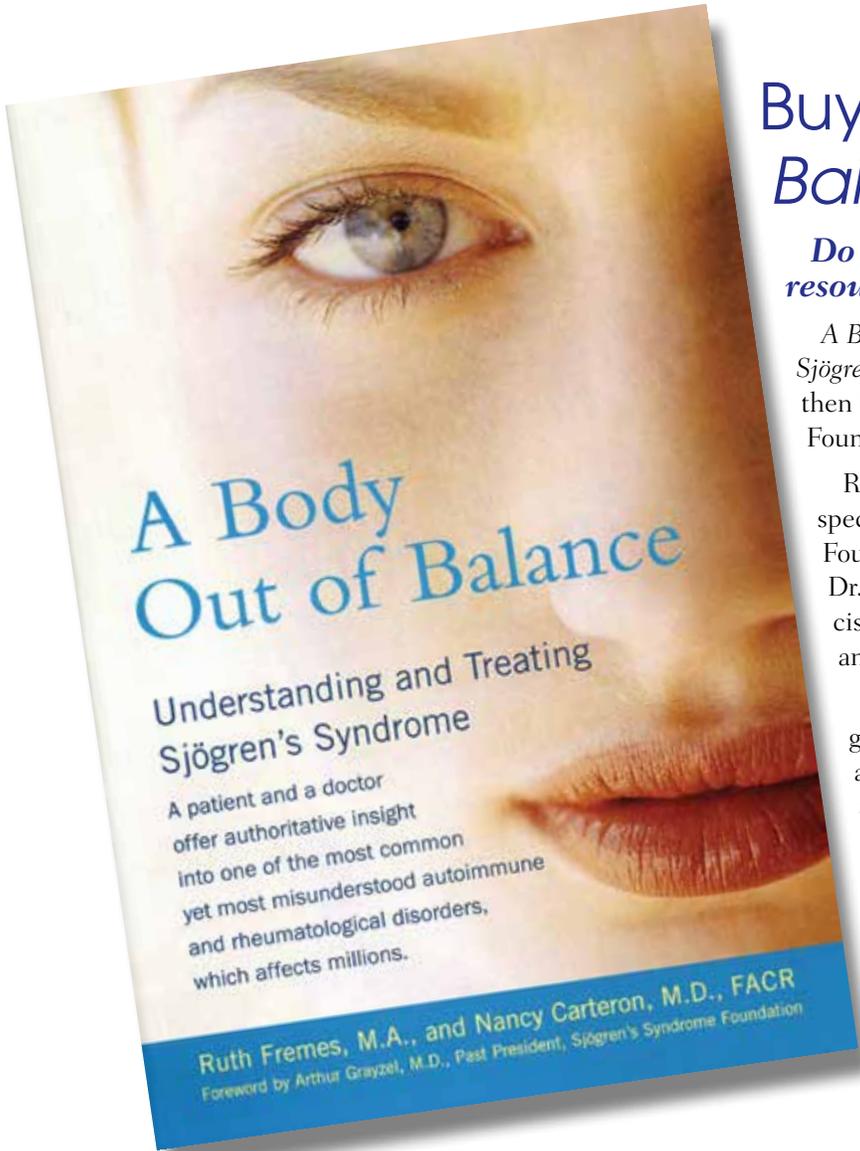
† This statement has not been evaluated by the FDA. This product (alpha lipoic acid) is not intended to diagnose, treat, cure or prevent any disease.

Proud Sponsor



INVADO  
PHARMACEUTICALS

2014 Invado Pharmaceuticals,  
Pomona, New York



## 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](http://www.sjogrens.org) or by contacting the Sjögren's Syndrome Foundation office at 800-475-6473.

	Non-Member Price	Member Price	Qty	Amount
<b>A Body Out of Balance</b> by Ruth Fremes, MA, and Nancy Carteron, MD, FACR	\$16.00	\$13.00		
<i>Maryland Residents add 6% sales tax</i>				
<b>Shipping and Handling:</b>	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			
<b>Total Amount</b>				

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 \_\_\_\_\_

# Coordinate a **Bold Blue Day** for Sjögren's!

**Help raise awareness by coordinating a Bold Blue Day and be entered to win a LIFETIME MEMBERSHIP to the SSF!**

By helping to recruit a company, school or small business to host a Bold Blue Day in your honor – you will be entered to win a SSF Lifetime Membership.

It is very simple. Contact the SSF to receive a Bold Blue Day Recruitment Kit. In this kit you will find information about how to recruit a coordinator to host a Bold Blue Day in your honor. Or you can host one yourself at your place of business!

Once you recruit a coordinator or commit to coordinating one yourself, you will send in a commitment form and then the SSF will send off a kit with all the materials they will need to host their Bold Blue Day. And if they host it by June 30th, you will be entered in a drawing to win a lifetime membership.

## **So, what is Bold Blue Day?**

Imagine your colleagues or classmates trading in their tailored slacks or dresses for a day in blue jeans or blue to raise vital funds for Sjögren's research and awareness. Ask your company or a local company or school to consider hosting a dress down day for the SSF.

## **How does it work?**

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

## **What if the company doesn't ever allow jeans?**

Then just have a Bold Blue Day – where on a certain day everyone chooses to wear his or her favorite Bold Blue outfit! Then collect donations for the SSF that day as well.

To receive more information or have a Bold Blue Day kit sent to you, contact Michele Lee at (800) 475-6473 ext. 218, or [mlee@sjogrens.org](mailto:mlee@sjogrens.org) to receive your Bold Blue Day kit!

**Win a  
Lifetime  
Membership**



## *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*

# Join in the fun! 2015 SSF Special Event Calendar

The SSF is very excited for all of our events coming this Spring. Look at our special event calendar below to see if there is a *Walkabout* or *Sip for Sjögren's* coming to your area.

## May

- 30** ***Northeast Ohio Walkabout***  
Brecksville Oak Grove Picnic Area –  
Brecksville, Ohio
- 31** ***Atlanta Sip for Sjögren's***  
Nelson Mullins at Atlantic Station –  
Atlanta, Georgia

## June

- 6** ***Denver Walkabout & Health Fair***  
Denver Zoo – Denver, Colorado
- 13** ***Greater Washington Region  
Walkabout & Health Fair***  
Bethesda, Maryland

## Start an event in your area!

With the Spring events underway we've also started planning for the fall and winter!

We want to make a BIG awareness impact in as many communities as we can this year and need your help!

Maybe there is already a Sip for Sjögren's or Walkabout in your area and you would like to get involved. Or maybe you are motivated and want to start an event in your area.

Contact Sheriese DeFruscio at 301-530-4420 x212 or by email at [sdefuscio@sjogrens.org](mailto:sdefuscio@sjogrens.org) to learn how you can get involved.



**Sjögren's Walkabout**

sip for  
**Sjögren's**  
a fine water  
tasting event

