

The Questions You Asked and the Answers You Need

Q *I've heard others talk about "having a flare" when discussing their Sjögren's. What do they mean and how can I prevent one?*

A A flare-up, often referred to as a "flare," is a sudden, severe onset of symptoms. As example, you've been managing well, your symptoms have lessened and, having momentarily forgotten the pain and dryness, you've been living 'full out' as you used to. Then, suddenly, those angry symptoms are back!

Several points are worth keeping in mind. First, the symptoms of flares are usually very similar to the symptoms you had when your disease began. If a headache signaled the beginning of your disorder before, the recurrence of a headache may indicate the beginning of a disease flare. If a vague feeling of having flu presaged your going to the doctor when you were diagnosed, and this feeling returns, it is likely to be a flare.

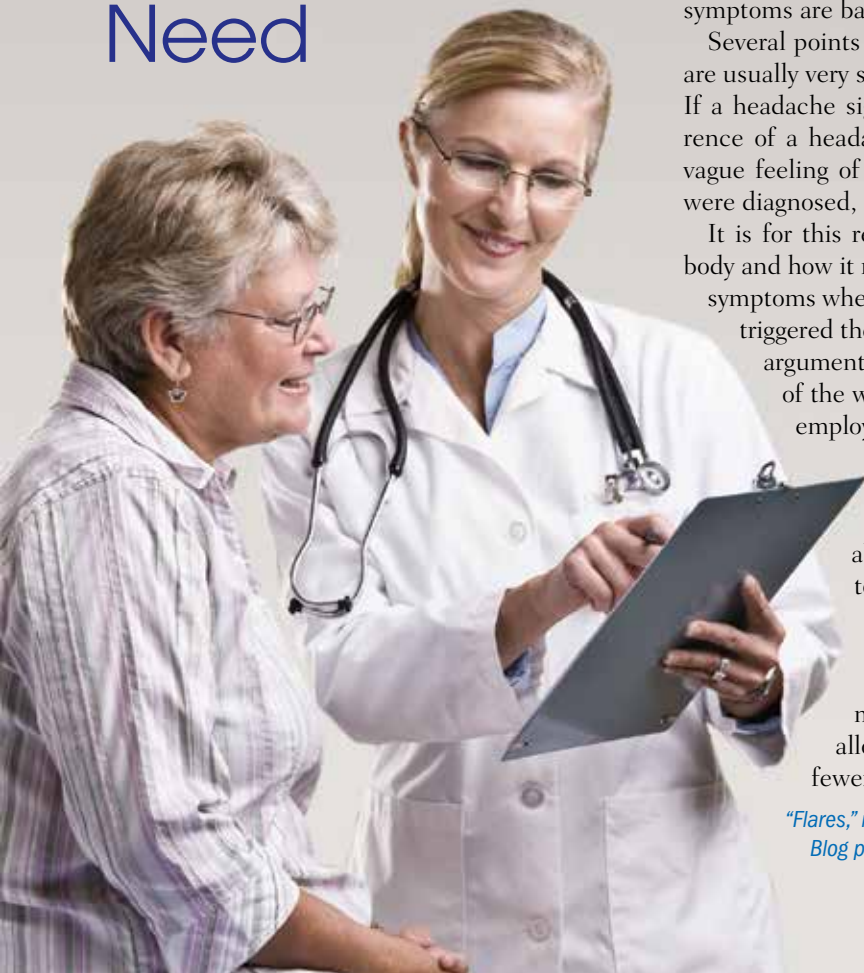
It is for this reason that you must constantly check in and know your body and how it reacts. A certain way of avoiding flares is to write a diary of symptoms whenever you feel them. Linking them to whatever might have triggered them. If, for example, you worked over-long hours, or had an argument with your son's soccer coach, write it down. In the case of the workload it will be clear that you need to discuss with your employer your need to arrange your work hours to allow for a rest, and in the case of that soccer blowout, it will be clear that such activities are bad for your health.

Also, this is the time to report to your doctor and talk about new feelings or pains that are unusual. New symptoms may not only indicate a flare, they may also herald complications of treatment.

Treating a flare with attention and care will help you have fewer of them. Step back, take care of yourself, rest more often or make inroads to arranging your work day to allow such things, and you will go a long way towards having fewer occasions of "flare-ups."

"Flares," retrieved September 20, 2013 from <http://www.sjogrensforum.com> ©. Blog posts by Ruth Fremes MA and Nancy Carteron MD, FACR with Questions and Answers about living with and treatment of Sjögren's, authors of "A Body Out of Balance," available for purchase on page 15.

continued page 2 ▼





Founded by
Elaine K. Harris in 1983

Board of Directors

Chairman of the Board

S. Lance Forstot, MD

Chairman-Elect

Kenneth Economou

Treasurer

Kathryn P. McCarren

Secretary

Pamela S. Brown

Immediate Past Chairman

Lynn M. Petrucci, RN, MSN

Estrella Bibbey

Michael T. Brennan, DDS, MHS

Steven E. Carsons, MD

Nancy L. Carteron, MD, FACR

Janet E. Church

Stephen Cohen, OD

Jack Faricelli

Denise Faustman, MD, PhD

Theresa Lawrence Ford, MD

Mary W. McNeil

Shari Rood

Vidya Sankar, DMD, MHS

Medical & Scientific Advisory Board

Chairman

Denise Faustman, MD, PhD

Richard Brasington, MD

Steven E. Carsons, MD

Troy E. Daniels, DDS, MS

H. Kenneth Fisher, MD, FACP, FCCP

Gary Foulks, MD, FACS

Philip C. Fox, DDS

Tara Mardigan, MS, MPH, RD

Austin K. Mircheff, PhD

John Daniel Nelson, MD, FACS

Kelly Nichols, OD

Athena Papas, DMD, PhD

Ann Parke, MD

Andres Pinto, DMD

Nelson L. Rhodus, DMD, MPH

Daniel Small, MD, FACP

Neil I. Stahl, MD

Pamela Stratton, MD

Frederick B. Vivino, MD, FACR

Chief Executive Officer

Steven Taylor

Director of Marketing/Editor

Elizabeth Trocchio

e-mail: tms@sjogrens.org

www.sjogrens.org

"Q&A" continued from page 1 ▼



Is a Vegan Diet beneficial for people with Sjögren's?

A A vegan diet excludes any animal products. A raw diet limits cooking foods over 116 degrees. You may be wondering if this is the diet prescription to help you. Should you eliminate animal products? Do you have to avoid cooking your food to reap the optimal nutrition value?

Not necessarily. Each person suffering from Sjögren's (or any medical condition) should learn to individualize their treatment plan, including diet modifications. Learning to incorporate foods that are well tolerated and minimize foods that exacerbate symptoms of Sjögren's is the overall nutrition goal.

What works for others may be very different from what works for you. For example, raw foods are often more difficult to chew and digest. A person with dry mouth and digestive issues may have difficulty tolerating a plan that is vegan and raw. In that case, the raw/vegan diet is not the best approach to nourishment.

Another example of how nutrition should be individualized? Not every person with Sjögren's needs to avoid gluten. Only those with celiac disease (or a clear-cut worsening of symptoms) should eliminate gluten in the diet.

Nutrition strategies for the management of Sjögren's are consistent with an anti-inflammatory food pattern. This includes foods rich in phytonutrients such as fruits, vegetables, whole grains, beans, nuts, seeds, spices and tea. Phytonutrients are powerful nutrients found in plant-based foods that are thought to offer our cells protection from many diseases and conditions such as heart disease, cancer and autoimmune conditions. The balanced vegan diet (raw or not) has a heavy emphasis on phytonutrient rich foods and is therefore a good example of an anti-inflammatory pattern. That said, it is not the only type of diet that fits on the spectrum of an anti-inflammatory eating pattern.

We are in the preliminary stages of learning if animal proteins are harmful to those with autoimmune conditions. It appears that large portions of animal protein such as red meat and dairy and little intake of plant-based foods is the real problem and can influence your condition in a negative way. The typical American diet is rich in animal protein and lacks fruits, vegetables and other plant-based powerhouses.

A simple shift towards a more plant-based diet with less reliance on meat and dairy is likely sound advice for those with Sjögren's. The diet does not need to be exclusively vegan or raw to be healthful.

The Harvard School of Public Health's Healthy Eating Plate is an excellent visual of how to shift the plate to include more plant-based foods with a balance of lean proteins, healthful fats and adequate fluid.

Another new diet may be popular tomorrow. Your goal should be to discuss your symptoms and eating pattern with your physician. A registered dietitian (RD) can help you individualize and balance your eating pattern based on your specific needs.

Tara A. Mardigan, MS, MPH, RD

continued page 4 ▼

The Moisture Seekers® Newsletter is published by the Sjögren's Syndrome Foundation Inc., 6707 Democracy Blvd., Ste 325; Bethesda, MD 20817. Copyright ©2013 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.

Remembering Elaine Alexander, MD, PhD

On August 22, 2013, the Sjögren's community lost one of its greatest advocates when Elaine Alexander, MD, PhD, passed away. Dr. Alexander cared passionately about Sjögren's patients and was instrumental in helping the SSF to convince pharmaceutical companies to enter into clinical trials for new therapies for Sjögren's. Dr. Alexander was also one of the SSF's most sought after physicians and was often found speaking or writing about Sjögren's and its effect on the brain as well as the central nervous system.

Brain Fog – Q&A

*by Elaine Alexander, MD, PhD,
Former Chairman of the SSF Medical and Scientific Advisory Board.*



**What is
Brain Fog?**

A Brain Fog is a lay term to describe fluctuating mild memory loss that is inappropriate for a person's age. It may include forgetfulness, spaciness, confusion, decreased ability to pay attention, an inability to focus, and difficulty in processing information. Remember that gradual cognitive decline from early adulthood is a fact of life. Brain Fog can occur in Sjögren's, but other factors also might cause these symptoms and should be considered by you and your doctor.



**What can I do
about Brain Fog?**

A Manage your lifestyle to optimize your health and sense of well-being.

Develop a close working relationship with your doctor(s):

- Always report changes in cognition/memory and mood (depression, anxiety).
- Make sure your physician knows about all the prescription and OTC medications you are taking. Especially in patients over 65-70 years of age, a major cause of cognitive dysfunction can be side effects of drugs and drug interactions.
- Inquire about your hormonal status, thyroid function, and blood pressure.

Additional actions:

- Rejuvenate with sufficient sleep. If after 8-9 hours of sleep you are still tired, tell your doctor.
- Minimize stress and anxiety
- Set realistic expectations
- Plan ahead
- Take breaks throughout the day



Elaine Alexander, MD, PhD

- Learn relaxation exercises and practice them at regular intervals
- Balance work and leisure
- Let yourself laugh
- Talk about feelings
- Limit multi-tasking and focus on one task at a time
- Reduce caffeine and alcohol
- Manage effectively musculoskeletal and joint pain
- Exercise regularly. Adequate physical exercise enhances cognition/memory.
- Train the brain! "If you don't use it, you will lose it."
- Boost your brain power: Continue to work into retirement (part time), learn new skills, volunteer, engage in social and mentally stimulating activities and establish new friendships and relationships.
- Take your body to the gym and don't forget to visit the "BRAIN SPA" – both will improve brain function.
- Recent scientific data show that longevity is associated with the successful management of chronic diseases such as Sjögren's, not the absence of any disease!

Suggested reading: *The Memory Bible*, by Gary Small, MD, Director of the UCLA Center on Aging, available from the Sjögren's Syndrome Foundation see order form on page 15. ■

"Q&A" continued from page 3 ▼

Q My fatigue from Sjögren's is extreme. Does this mean that I have a worse case of this disease than most others?

A No. But it depends on how "worse case" is defined. The perception of worse case may differ from the patient's perspective or the physician's/health care provider's perspective.

I am not aware of conclusive studies showing a direct correlation between fatigue and immunological activity. In fact, there are studies showing that fatigue did not correlate with SS-A (Marker antibodies for Sjögren's. 70% of Sjögren's patients are positive for SS-A).

From the doctor's side, there are instruments that have been validated to measure fatigue (VAS, FSS, PROF)¹ and instruments to measure disease activity, ESSDAI². See FSS Chart below.

Things like vasculitis (blood vessel inflammation), interstitial lung disease, lymphoma would be accepted as "worse disease" activity by most physician's and, thus, all patients should be remitted for those severe manifestations.

However, the fatigue in Sjögren's can be profound, often being the primary reason a patient's quality of life (QOL) is significantly impaired. It is often the top complaint of Sjögren's patients seen in our practice, even above severe dryness (eyes, mouth, upper respiratory).

¹ VAS (Visual Analog Scale), FSS (Fatigue Severity Scale), ProF (Profile of Fatigue).

² ESSDAI [European League Against Rheumatism (EULAR), Sjögren's Syndrome Disease Activity Index].

Nancy Carteron MD FACR

FATIGUE SEVERITY SCALE (FSS)

Date _____ Name _____

Please circle the number between 1 and 7 which you feel best fits the following statements. This refers to your usual way of life within the last week. 1 indicates "strongly disagree" and 7 indicates "strongly agree."

Read and circle a number.	Strongly Disagree	→	Strongly Agree
1. My motivation is lower when I am fatigued.	1	2	3 4 5 6 7
2. Exercise brings on my fatigue.	1	2	3 4 5 6 7
3. I am easily fatigued.	1	2	3 4 5 6 7
4. Fatigue interferes with my physical functioning.	1	2	3 4 5 6 7
5. Fatigue causes frequent problems for me.	1	2	3 4 5 6 7
6. My fatigue prevents sustained physical functioning.	1	2	3 4 5 6 7
7. Fatigue interferes with carrying out certain duties and responsibilities.	1	2	3 4 5 6 7
8. Fatigue is among my most disabling symptoms.	1	2	3 4 5 6 7
9. Fatigue interferes with my work, family, or social life.	1	2	3 4 5 6 7

continued page 6 ▼

*The tear film is more than just a few drops of water.
It's a complex microenvironment.*



TheraTears® with Osmo-Correction™ Restores Eyes' Natural Balance™

Increased tear film osmolarity is one of the primary causes of dry eye symptoms.¹ TheraTears® with Osmo-Correction™ is a unique hypotonic and electrolyte balanced formula that replicates the natural human tear film and corrects osmolarity imbalance.


ADVANCED
VISION RESEARCH
AN AKORN COMPANY

©2013 Advanced Vision Research, Inc. TTM13042
1. DEWS Report, The Ocular Surface, April 2007; 5(2): 69-204



www.theratears.com

"Q&A" continued from page 4 ▼

Q *I've been considering cataract surgery but am wondering if it's safe for a Sjögren's patient. What would you recommend?*

A Sjögren's (SS) patients suffer from dry eyes and may also have other ophthalmic problems such as cataract. In fact, if they have a history of oral steroid use, they may develop a cataract at an earlier age.

As for surgery, I want to make sure the cataract is truly the reason for decreased vision. Many times treating the dry eyes will improve vision. If the patient is to undergo cataract surgery I want to make their eyes as comfortable as possible. Treating the signs and symptoms of dry eye will not only help patients, it will also make it easier to perform intra ocular lens calculations. Just as dry eye treatment prior to cataract surgery is becoming more common in the general population, the same idea should hold true with SS patients. First off I make sure their systemic "autoimmune" condition is under control. They may need an adjustment of their immunosuppressant medications. I always do a full eye exam looking closely at the tear film break-up time and ocular surface staining pattern using lissamine green and fluorescein. I will consider starting Restasis at a higher dose or increasing the dose to help with inflammation pre and post-operatively. I may also consider adding a weak steroid eye drop before surgery then switch to a stronger one tapered over a longer period of time after surgery. With severe surface dryness I try to use preservative-free antibiotic and steroid drops to avoid corneal toxicity. I will also increase the use of preservative free tear drops and add a gel drop for night and may use temporary punctal plugs in the peri-op period. I will also avoid use of NSAIDS for inflammation control as that can cause problems with corneal epithelial regeneration.

If they have concomitant blepharitis and meibomian gland dysfunction, I advise patients to use warm compresses and lid scrubbing techniques and oral omega-3 supplements. This not only helps the tear film and symptoms but also reduces the chance for infection.

As far as intra- and post-op concerns the surgical technique is essentially the same as in non-SS patients with one difference, I may use a scleral tunnel or "near clear cornea" wound, rather than a true corneal wound, for more rapid and complete wound healing. The surgery itself may be more difficult if the patient is constantly coughing from dry mouth or lung problems, such as bronchitis or recurring pneumonia. In these patients the anesthesiologist can add medications and moisturizers to help. Additionally, patients with severe dry eye and SS may have corneal epithelial and subepithelial haze because of their poor tear film and ocular surface inflammation. The corneal haze might impair visualization during surgery, making it more challenging at times.

I usually avoid "specialty" lenses such as accommodative or toric IOLs as the pre-operative calculations may not be accurate and the patient may not be happy with the final vi-

sual outcome. Also the best corrected acuity may take a little longer to achieve because of the dryness.

Mina Massaro-Giordano, MD

Q *Do you recommend the shingles vaccine for your Sjögren's patients?*

A If the patient is not on a biologic or not on a disease modifying antiemetic drug, the answer is absolutely yes, we recommend that. Depending on where I see them in the evaluation, if I evaluated them and I have not found any evidence of any potential immunomodulation, I recommend it. But, if they are on a biological, there should be no live viruses given and it has to be really a specific decision for that patient. If there is no contraindication, then yes, absolutely I do. While I suggest that every patient talk to their physician, I generally allow most of my patients to get the vaccine.

Theresa Lawrence Ford, MD

Q *I have Sjögren's and have recently been diagnosed with GERD. What are the long-term complications of GERD?*

A Acid reflux, or GERD (gastroesophageal reflux disease), can cause symptoms of heartburn, chest pain, trouble swallowing, sore throat or unexplained cough. Many factors, such as obesity, smoking, or presence of a hiatal hernia, can contribute to GERD. As saliva helps to neutralize refluxed acid, individuals with Sjögren's may develop GERD symptoms due to lack of saliva.

The vast majority of individuals with GERD will not develop significant complications, especially when it is appropriately treated with lifestyle modification or medications. In patients with severe GERD, long-term complications that may arise include ulcerations of the esophagus (esophagitis), stricture formation (scarring of the esophagus that can cause difficulty swallowing), hoarse voice, chronic cough, or asthma exacerbation.

With chronic acid reflux, the lining of the esophagus can undergo a transformation from normal esophageal cells (squamous cells) to a different cell type (intestinal cells). This change, known as Barrett's esophagus, is completely without symptoms but does increase the risk of developing precancerous changes of the esophagus. The risk of Barrett's esophagus progressing to esophageal cancer is 0.5% per year, and probably less in individuals maintained on acid reducing medications. Barrett's esophagus is diagnosed through endoscopic examination and is typically managed with close surveillance and monitoring. Individuals with chronic acid reflux or on long-term acid suppression medications should discuss their risk of Barrett's esophagus with their physician.

Matthew Nichols, MD

Q What are the dietary modifications and medications (both prescription and over-the-counter) used to treat GERD?

A Lifestyle modifications can help with the GERD related symptoms. These include losing weight (if you are overweight), raising the head of your bed by 6-8 inches, stopping smoking, avoiding eating just before bed and avoiding especially large meals. Small, frequent meals are better than two or three large meals in a day. Some foods, such as coffee, alcohol, fatty foods, chocolate, and peppermint, exacerbate acid reflux by causing relaxation of the sphincter at the bottom of the esophagus and should be reduced for optimal management of acid reflux.

There are three main types of medications that are used to control acid reflux: antacids, histamine blockers and proton pump inhibitors. Antacids, such as TUMS® or Rolaids®, are available over the counter without a prescription. They work for mild, intermittent symptoms. Because they work by neutralizing acid that is present within the stomach, they often give the most rapid response, but only work for a short time and do not work at preventing future reflux events.

Histamine blockers (such as Zantac® (ranitidine), Pepcid® (famotidine), and Tagamet® (cimetidine) are available over the counter as well and are stronger and more effective than antacids; however, with regular, daily use they may become less effective over time.

Proton pump inhibitors (PPIs) are the most effective medications at preventing GERD. They work by blocking the stomach's ability to secrete acid. Prilosec® (omeprazole) and Prevacid® (lansoprazole) are available both over the counter and with prescription. Prescription PPIs include Nexium®, Dexilant®, Protonix®, and Aciphex®. These medications are most effective at blocking acid production when taken on an empty stomach, about 15 to 45 minutes prior to eating. While generally quite safe, chronic high-dose PPI use may affect calcium absorption, potentially affecting bone density. While the data is still inconclusive as to this risk, often calcium and vitamin D supplementation is recommended in individuals at risk for bone fractures on chronic acid suppression therapy.

Matthew Nichols, MD

continued page 10 ▼

IS YOUR NOSE DRY? IRRITATED? PAINFUL?

Your Relief is Here!

INTRODUCING

GeloNasal®
DRY NOSE RELIEF

When the mucosa of your nose is dry and irritated, it can be very uncomfortable and even painful. GeloNasal Dry Nose Relief is here!

GeloNasal is a superior alternative to saline nasal sprays, lasting nine times longer for **at least three hours of dry nose relief.**

GeloNasal delivers gentle and effective dry nose relief for even the driest noses.

GeloNasal is available for purchase online at **www.gelonasal.com** and at select retail pharmacies.



Use this code at gelonasal.com to receive
\$4.00 OFF your first purchase: SSFMS



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



Sjögren's Syndrome Foundation is partnering with Tupperware to kick start your holiday shopping!

From **October 21 to November 22**, you can purchase Tupperware through the SSF website and 40% of your order will be donated back to the Foundation! Stock up on great items knowing that your purchase is helping the Foundation's life-changing initiatives.

Make sure to share the link with friends and family, because together we will conquer Sjögren's!

Look for the link on www.sjogrens.org to start shopping for Sjögren's today! If you have any questions, please contact Steph with the SSF at (301) 530-4420 x227 or shilton@sjogrens.org.

40%

of your purchase will be donated
to Sjögren's Syndrome Foundation!

Dry Eye Therapy

FROM THE EYE CARE EXPERTS AT **BAUSCH+LOMB**



MANUFACTURER'S COUPON | EXPIRES 12/31/2013

SAVE \$3

on your next purchase of Bausch + Lomb
Soothe® eye drops



BAUSCH+LOMB
Soothe®
Lubricant Eye Drops

CONSUMER: Coupons can only be redeemed at retail locations. Coupons may not be used for cash or used to purchase products directly from Bausch & Lomb. **RETAILER:** We will reimburse you at face value plus 8 cents handling per coupon if used in accordance with the terms of the Bausch & Lomb Coupon Redemption Policy (CRP#1). Coupon void if taxed or prohibited by law. Limit one coupon per purchase of specified products. Good only in USA. Void if copied, transferred or expired. Not valid with any other coupon. Not redeemable for more than purchase price. Void where prohibited by law and where reimbursed under Medicare, Medicaid, or other government programs, and in states, including Massachusetts, that prohibit patient rebates if a third party pays any of the prescription price. Mail to: Bausch & Lomb, CMS Dept. 10119, 1 Fawcett Dr., Del Rio, TX 78840.

© 2013 Bausch & Lomb Incorporated.
®/™ are trademarks of Bausch & Lomb Incorporated or its affiliates.
PNS06973 US/50A/13/0027



Discover Soothe® Dry Eye Drops.
Gentle Enough for Sensitive Eyes - Can Be Used as Often as Needed.
Visit SootheEyeDrops.com

© 2013 Bausch & Lomb Incorporated. ®/™ are trademarks of Bausch & Lomb Incorporated or its affiliates. PNS06973 US/50A/13/0027

BAUSCH+LOMB


in memoriam

In Memory of Carol Ann Simpson
Ghanshyam & Margaret Patel

In Memory of Barry Weyant
Tony & Judy Ptak

In Memory of Cheryl Westbury
Judy Vasconi

**In Memory of
Constance "Connie" Larson**
Larry & Kelly Jurgens
Larry & Becky Trefz
Sheri & Michael Fox
Penny & Art Glassman

In Memory of Connie Rodriguez
UPS

In Memory of Dave Baker
Cheryl & Doug Schaubhut
Bob & Cindy Baker
The Amoroso Family

In Memory of Dr. Elaine Alexander
Lynn Petrucci
The John M. and Sally B.
Thornton Foundation
San Diego and Imperial
Counties Chapter

In Memory of Frank Bertens
Paula & Ian Mercer

In Memory of Helen Harmelin
Joyce Lahn

In Memory of Ione Hoper
Nancy Jenull

In Memory of Isabel Gonzalez
Jeffrey Tacy

In Memory of James Kern
Bobette Morgan

**In Memory of
Jane Stockman Franklin**
Lloyd & Frances Rud, Karen & Gilbert,
Audrey, Kayla, Krysten & Stephen,
Felicia, Terry & Gage

In Memory of Kathy Barton
Elizabeth & Tyler Kearly

In Memory of Lea Ann Schnell
Larry & Blanche Swackhammer
Cynthia Rodden
Mr. & Mrs. Joseph Scragg

In Memory of Michael F. Zwicker
John Gill

In Memory of Louila Kaneaster
Dennis Boatright

Troy Kaneaster
Ross Boatright & Family

In Memory of Mary Aurelio Aceto
Lucy Aceto & Family
Marie & Paul Maloney
Patricia Osgood
Evelyn Parrella Sache

In Memory of Michael Goldman
Carole & Norm Weingarten
Stacy Snyder & Abbe Lyons
Karen & Gary McGuffin
Thomas & Rebecca Swartz
Arnold & Judy Yochelson
Rosalyn Chirnoff
Linda & Lenny Axelrod
Nannette & Ted Suss
Mary & John Bayne
Sylvia & Norman Kaplan
Rochelle & Richard Forman
Rick & Sharon Keller
William & Dorothy Dodge

In Memory of Mildred Duncan
Douglas Palmer

In Memory of Nancy Butler Kipp
Tony & Gussianne Adamo
Ellen Bevier
Sandra Bolmer
Steve & Susan Foster
Joe & Jan Kalla
Gale Belobrajdic, Phyllis Kipp,
Kipp Esteep
Tom & Pam Fife
Gina Lubrano
Joan & Bill Breher
Jon & Peggy Standefer
Naoye Kasubuchi
Lorraine & Ken Kasubuchi
Jim & Mimi Lee
Jen, Kenney & Anne Staggs
Ligsa Orenich

In Memory of Sue Henriksen
Lynn Henriksen


in honor

In Honor of Beth Chase
Barbara Cataldo

In Honor of Carey Mercier
Dr. Amin & Dr. Strouth

In Honor of Chelsea Mark – Graduation and Successful Career
Sheldon Feingold

In Honor of Dona Frosio
The John M. and Sally B. Thornton Foundation

In Honor of Dr. S. Lance Forstot's 70th Birthday
Bob & Susan Friedman

In Honor of Eric Rosenlund – Happy Birthday
Bob Pelletier

In Honor of Linda Wood's 61st Birthday
Jamar Rose

In Honor of Lynn & Peter Brickman – Wedding Anniversary
The Gansky Family

In Honor of Nana & Papa – Happy Anniversary
Your Biggest Fans

In Honor of Nancy Ritchey
Susan Wright

In Honor of Renee Garrick's Birthday
Deborah Morris

In Honor of Syddia Crespo – From your loving Daughter
Lizette Crespo-Ruiz



XyliMelts®
for dry mouth

Relief, even while sleeping!

XyliMelts time-release oral adhering discs provide dry mouth relief 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
- Reduces tooth decay
- **12 disc sample; just pay \$3.20 shipping (online or mail order).**



Available at Rite Aid starting March 2013.
Call 877.672.6541 for mail order or
visit www.XyliMelts.com

I Stood Up...

*Diana Campbell
Creatively Raising Awareness*



Diana Campbell thought of a unique and clever way to Stand Up for Sjögren's! Diana, who works for the University of Alaska Anchorage Athletics Department, informed the SSF of her idea to incorporate Sjögren's awareness at an upcoming race in her community.

The annual 24-mile distance race was held on July 27th in the Chugach Mountains near Anchorage, Alaska on the Crows Pass Crossing Trail. During the race, runners were given a wristband at a river crossing to prove that they crossed it at the correct place. Then at the finish line, every runner was checked to see if they were wearing their wristband, along with some other required survival gear, and were disqualified if they didn't have all their items.

Thanks to Diana, this year's race participants were given an SSF Sjögren's wristband at the river crossing! Diana had the idea to ask her dentist, Dr. Patrick Dorman of Century Dental, to sponsor the wristbands for the event.

As the sponsor, Dr. Dorman purchased wristbands from the SSF and donated them to be used as the race's official wristbands. SSF brochures were also displayed at the event's check-in table to educate everyone involved with the race about Sjögren's.

Congratulations to Diana for her creativity and success in engaging her dentist to increase Sjögren's awareness in her community!

How will you Stand Up?



"Q&A" continued from page 7 ▼

Q I have severe burning dry mouth that makes it very difficult for me to sleep through the night. When I wake up my lips seem "stuck together" due to the lack of saliva and moisture. Is there anything you recommend that would help my symptoms while I sleep or at nighttime?

A Severe burning sensation and dry mouth condition arise when flow of saliva is decreased in the mouth. Some of the most common causes for this problem are drug-induced and autoimmune conditions like Sjögren's. These conditions make it extremely difficult and challenging to deal with on a regular basis. In order to best answer the above question, taking simple measures will help you cope up with the condition.

Always brush twice daily and floss at least once a day especially before bedtime and remember to use a tongue scraper. Use ChapStick® or apply Vaseline® on the lips before bedtime. Please make it a habit to have a bottle of water accessible when you go to bed. Please talk to your dentist regarding the use of xylitol containing products oral adhering discs may also help the condition. Oral rinses are helpful in people with dry mouth condition's.

As the natural medium (saliva) is decreased one has to do their best to keep the mouth as moist as possible. This can be achieved by a few do's (sip plenty of water, use lozenges, sprays and gels) and many don'ts (stay away from all forms of nicotine products, please avoid drinking all kinds of soda, caffeinated drinks, Gatorade® and other energy drinks).

Your dentist may recommend more frequent dental visits

(every 3-4 months) and may also recommend fluoride tooth paste as there is increased risk for tooth decay in patients with dry mouth conditions. Please also discuss with your primary care provider to rule out drug induced dry mouth condition, which could make your Sjögren's dry mouth more severe. Maintaining good oral hygiene is critical when a person is experiencing dry mouth conditions.

Srinivas Challa DMD, MPH

IT'S TIME United Way Combined Federal Campaign State Payroll Deduction

Each fall your local United Way, Combined Federal Campaign, state employee, and private employer payroll deduction campaigns begin. We hope you will remember the Sjögren's Syndrome Foundation when choosing where to allocate your donation. (CFC #10603)

If we are not listed on the contribution form, you may write in the Sjögren's Syndrome Foundation.

Tell your co-workers, friends, and family members how important it is to choose and write in the Sjögren's Syndrome Foundation on their campaign form, too.

If you or your employer need more information, please contact the Foundation at 800-475-6473 and ask for Elizabeth Trocchio.

**Just think –
every dollar
counts.**

Remember, the Foundation
has received the:



"Around-the-Clock Relief From Dry Mouth"

MedActive®

Lozenges, Sprays & Gel

Designed to meet the needs of Sjögren's patients

Now available at your local
Independent Pharmacy



Proudly Made in the U.S.A.

www.medactive.com 1-866-887-4867





October

Breakthrough Bullet:

Professional Awareness

The SSF works to educate the medical community by increasing the SSF's visibility at healthcare professional conferences, especially among specialties that see patients before Sjögren's symptoms start to occur. Recently, the SSF traveled to both the American Academy of Oral Medicine (AAOM) and the American Optometric Association (AOA) annual conferences.

The AAOM conference had two presentations on Sjögren's: "Sjögren's Syndrome Update," by Troy Daniels,* DDS, MS, and "Management of Patients with Dry Mouth," by Vidya Sankar,* DMD, MHS. These two presentations, secured by Michael Brennan,* DDS, MHS, were attended by nearly 300 professionals who were able to take home SSF professional resources.

50%
in 5 years
Sjögren's
syndrome
FOUNDATION

The presentation at the AOA meeting's, "More than Meets the Eye - A Multidisciplinary Approach," used a new technique to highlight Sjögren's awareness. This session, arranged by Robert Prouty, OD (Optometry), was presented by a panel composed of professionals in various areas of medicine including: Nancy Carteron,* MD (Rheumatology), Linda Nguyen, MD (Gastroenterology) and Vidya Sankar,* DMD, MHS (Dentistry).

This uniquely organized panel showcased to the optometry community that Sjögren's is more complex than dry eye alone and is a systemic disease for which optometrists can be the first line of defense to identify and make referrals to other professionals.

While Sjögren's is much more than dry eye and dry mouth, these two symptoms are the most common reasons why people begin to seek a diagnosis and is why the SSF's presence is needed at these conferences. We need physicians to understand that correctly diagnosing Sjögren's is critical so that patients can be monitored for the disease's more serious manifestations.

Educating healthcare professionals about Sjögren's is one of the key strategies the SSF is using to reach our *5-Year Breakthrough Goal*, "To shorten the time to diagnose Sjögren's by 50% in 5 years." And by focusing SSF resources on teaching these specific providers to recognize the various manifestations of Sjögren's, we will speed up the diagnosis time, which is currently 4.7 years from the onset of symptoms.

Thank you to all the presenters for sharing their knowledge and helping us reach our *5-Year Breakthrough Goal*!

If you want to join in our effort of increasing Sjögren's awareness by volunteering with the SSF or asking your physician and dentist if they receive our *Sjögren's Quarterly* (healthcare professional newsletter), contact the SSF at 800-475-6473 or tms@sjogrens.org. ■

*SSF Board Member



Join Team Sjögren's as they heads to the most magical race on earth!

Team Sjögren's is hitting the road again and heading to The Walt Disney World® Marathon & Half-Marathon on January 11-12, 2014!

Instead of starting your New Year with a resolution, start it by walking or running in the upcoming Team Sjögren's Marathon & Half-Marathon at Disney. Sign up for this experience of a lifetime, while also raising awareness and vital funds for education and research of Sjögren's. If you're unable to run or walk in a marathon, consider recruiting someone you know to run or walk in your honor.

The Walt Disney World Marathon and Half Marathon course takes you through all four Walt Disney World Theme Parks. Starting at Epcot, you will continue on to the Magic Kingdom Park, Disney's Animal Kingdom Park and Disney's Hollywood Studios before a picture worthy finish back at Epcot, where you'll receive your all new Mickey Mouse finisher medal!

As a member of Team Sjögren's, 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 13.1 or 26.2 miles.

Due to the popularity of The Walt Disney World® Marathon & Half-Marathon, we have limited spaces available. For more information about training and fundraising requirements, please contact Steve Taylor at 800-475-6473 or staylor@sjogrens.org.

Just imagine how you will feel when you cross that finish line at the most magical place on earth!





Resource Order Form

	Non-Member	Member	Qty	Amount
The Sjögren's Book, Fourth Edition: <i>edited by Daniel J. Wallace, MD.</i> The 2011 edition of the Sjögren's handbook has been completely revised and expanded with all new chapters and the latest information on Sjögren's.	\$32	\$28		
The Sjögren's Syndrome Survival Guide by <i>Teri P. Rumpf, PhD, and Kathy Hammitt.</i> A complete resource for Sjögren's sufferers, providing medical information, research results, and treatment methods as well as the most effective and practical self-help strategies.	\$15	\$13		
A Body Out of Balance by <i>Ruth Fremes, MA, and Nancy Carteron, MD, FACR.</i> A Sjögren's patient and a doctor offer their authoritative insight into one of the most common yet most misunderstood autoimmune disorders.	\$16	\$13		
SHOWgrins – Women Who Walk on Water by <i>Betty Collier.</i> The author has written an inspirational book that brings into the limelight the cases of five women who open their hearts and share their Sjögren's stories to help increase awareness and expedite new diagnoses and treatment options.	\$13	\$10		
Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop by <i>Norman Latov, MD, PhD.</i> Peripheral neuropathy is a widespread disease, yet many people do not even realize they have it. If you experience pain, numbness, or tingling in your feet or other extremities, this book is for you.	\$19	\$16		
You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life by <i>Mims Cushing and Norman Latov, MD.</i> A compendium of tips, techniques, and life-task shortcuts that will help everyone who lives with this painful condition.	\$19	\$16		
Vulvodynia Survival Guide: How to Overcome Painful Vaginal Symptoms & Enjoy an Active Lifestyle by <i>Howard I. Glazer, PhD and Gae Rodke, MD, FACOG.</i> A great resource for anyone experiencing vulvodynia symptoms. This book will help readers identify triggers, reduce symptoms, find medical help, reduce pain, and renew their enjoyment of life.	\$18	\$15		
The Woman's Book of Sleep: A Complete Resource Guide by <i>Amy Wolfson, PhD.</i> An overview of the latest findings pertinent to women's sleep, and it distills their practical implications in a direct and straightforward style.	\$16	\$13		
The Memory Bible: An Innovative Strategy for Keeping Your Brain Young by <i>Gary Small, MD.</i> This program has helped thousands of people improve their ability to remember everyday issues like where their car is parked as well as more important abilities to think fast and maintain a healthy brain.	\$16	\$13		
Awareness Wristbands wording: <i>Conquering Sjögren's – www.sjogrens.org.</i> By purchasing these awareness wristbands, you are helping the SSF to achieve our 5-Year Breakthrough Goal. <i>Pack of 10</i>	\$18	\$15		
Purchase a full set of last year's Moisture Seekers newsletter Volume 30, 2012 (11 issues) as originally published.	\$50	\$20		
Maryland Residents add 6% sales tax				
Shipping and Handling: U.S. 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				
Please consider an additional contribution: <input type="checkbox"/> \$25 <input type="checkbox"/> \$50 <input type="checkbox"/> \$75 <input type="checkbox"/> \$100 <input type="checkbox"/> \$250 <input type="checkbox"/> \$500 <input type="checkbox"/> Other: _____				
Join now and SAVE on your purchase! (Apply member pricing to all items.) Membership – Includes a subscription to <i>The Moisture Seekers</i> newsletter. Member dues (US dollars): <input type="checkbox"/> \$32 U.S. <input type="checkbox"/> \$59 2-year membership <input type="checkbox"/> \$38 Canada <input type="checkbox"/> \$45 Overseas <input type="checkbox"/> \$50 Healthcare professional				
Purchase a subscription of Sjögren's Quarterly newsletter (4 issues) a leading edge medical and scientific newsletter aimed at educating professionals about the latest information on Sjögren's research, treatments and products. non-member \$50 member \$18				
Total Amount Due:				

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 U.S. bank, net of all bank charges) payable to SSF.

☐ MasterCard ☐ VISA ☐ Discover ☐ AmEx Card Number _____

Exp. Date _____ Security Code _____ Signature _____

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

Run In Your Local Turkey Trot!

We hope this Thanksgiving you will consider participating in your community Turkey Trot as member of Team Sjögren's!

What a great way to start your day of giving thanks - by purchasing a Team Sjögren's Turkey Trot Kit and walking or running with others in your area, increasing awareness for Sjögren's and helping raise crucial funds for Sjögren's research.

Your Kit Includes:

- Awareness Bracelet
- Team Sjögren's T-shirt
- Certificate of Participation
- "What is Sjögren's Syndrome?" Brochures



Find Your Local Turkey Trot:

You can find a local Turkey Trot by visiting www.active.com. Then enter your state and type in "Turkey" under keyword search. You can also check with your local newspaper or search online.

If there's not a race near you, consider asking family and friends to join you for a morning walk on Thanksgiving in your neighborhood while wearing your Team Sjögren's T-shirts!

Price: \$30 plus shipping and handling

Order your Team Sjögren's Goes Turkey Kit today by calling 800-475-6473 or online by visiting www.sjogrens.org.



Team Sjögren's