Sjögren's Syndrome Foundation

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Can Sjögren's cause kidney disease?

About 5% of people with Sjögren's develop kidney problems. In most of these patients, the cause is inflammation around the kidney tubules, where urine is collected, concentrated, and becomes acidic. The

infiltrating blood cells (mostly lymphocytes) injure the tubular cells, so that the urine does not become as acidic as it should. This condition, called distal renal tubular acidosis, is frequently asymptomatic, but can cause excessive potassium to be excreted in the urine, and may lead to kidney stones or (very rarely) low enough blood potassium to cause muscle weakness or heart problems. Very occasionally, injury to the renal tubules can cause impairment in the ability to concentrate urine, leading to excessive urine volume and increased drinking of fluids (nephrogenic diabetes insipidus).

A smaller number of patients with Sjögren's may develop inflammation of the glomeruli, which are the tiny capillaries through which blood is filtered to produce urine. This may cause protein to leak into the urine, along with red blood cells. Sometimes a kidney biopsy is needed to establish the exact diagnosis and treatment. Treatment options may include corticosteroids and immunosuppressive drugs to prevent loss of kidney function.

> Philip L. Cohen, MD Professor of Medicine Temple University School of Medicine

What is Plaquenil and what are its benefits for Sjögren's patients?

Plaquenil (hydroxychloroquine) is a medication that has been used for many years to help musculoskeletal symptoms and fatigue in patients with autoimmune conditions such as rheumatoid arthritis, lupus and Sjögren's. While there is good clinical evidence demonstrating the drug's efficacy in rheumatoid arthritis and lupus, there are very few studies looking at hydroxychloroquine as a treatment for Sjögren's. The studies that do exist show mixed results (some show

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"Q&A" continued from page 1 🔻

benefit and some show no benefit) in whether or not the drug is effective in helping with pain, fatigue, dry eyes or dry mouth.

Nonetheless, despite the lack of clinical studies, rheumatologists feel that hydroxychloroquine may have a potential beneficial effect in helping patients with symptoms of fatigue and achiness, which are common complaints in patients with Sjögren's.

How the drug works is unclear, but recent research has pointed to an inhibitory effect on toll-like receptors that are proteins involved with inflammation. The good news is that hydroxychloroquine targets the immune system without causing an increase in the risk of infection or cancer that can be seen with other immunosuppressant medications. The typical dose for hydroxychloroquine is 200-400mg per day and is based on a person's body weight (or if you are overweight, your ideal body weight). While hydroxychloroquine is considered a relatively safe medication, like all medications there are potential risks. These include body rashes that often will itch. The rash typically occurs in the first 6 weeks and is usually mild. In general, the rash will resolve within 2 weeks after stopping the drug. A more severe rash affecting larger areas of the body may occur but is not common. If this type of rash occurs, other medications such as anti-histamines and steroids may be required to help with symptoms.

Over time, hydroxychloroquine may uncommonly have an adverse effect on the retina that can lead to permanent visual damage if not picked up early. In order to protect the eyes, a baseline exam is recommended before starting the drug if you are color blind, have prior retinal problems or have never had a dilated exam (checking color vision is one way the doctor monitors for early damage) or within the first 6-12 months if you have a history of healthy eyes and a recent retinal examination. After the baseline exam, it is recommended that patients get a dilated exam at the minimum of once per year. Retinal problems are more likely to occur after 5 years of use. Newer technologies are available (OCT-optical coherence tomography) that can pick up early changes. If early changes are found on exam, it would be uncommon to have progression of eye toxicity or visual changes.

Other potential side effects include but are not limited to nausea, changes in mood, muscle weakness, skin pigmentation and anemia. While the drug may be used during pregnancy, the potential benefits and risks should be discussed with your doctor.

In summary, if you have Sjögren's, hydroxychloroquine may be an option to help your symptoms. Because there are other more effective therapies available to treat dry eyes and dry mouth, it is typically prescribed to help musculoskeletal pain and fatigue. Be patient, as the drug may take up to 6 months to see a beneficial effect.

> Scott Zashin, MD Internist & Rheumatologist in Dallas, TX

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"Q&A" continued from page 2

Is it safe or recommended for a Sjögren's patient to have LASIK eye surgery?

LASIK is a very safe and effective surgical treatment to improve vision and to decrease or eliminate the need for glasses and/or contact lenses. Among the most common post-operative issues are dry eyes and halos (e.g., around lights at night). When the "flap" is created on the eve, nerve endings are cut. This decreases the surface sensitivity to dryness, so the brain is not sent the message to tell the eyes to create more tears. In most cases, this is temporary, lasting 3-6 months. However, there are times in which the post-LASIK dryness can be permanent. Obviously for Sjögren's patients, most of who suffer from dry eyes, this poses a huge challenge. With Sjögren's and many other autoimmune disorders, LASIK is "contraindicated;" meaning that it is not considered to be an appropriate treatment for people who wear glasses or contact lenses. One concern for Sjögren's patients is the prior-stated decreased stimulus for tear production. Another concern with Sjögren's and other autoimmune disorders is that the body already tends to respond negatively to its own tissue. LASIK surgery, with the changes made to the surface of the eyes, may evoke a more pronounced autoimmune reaction, causing greater inflammation.

The Food and Drug Administration (FDA) considers diseases like Sjögren's to be a contraindication for LASIK surgery. That doesn't categorically mean that a person with an autoimmune disorder cannot have LASIK surgery. It just means that it is an "off-label" use of the technology and requires the medical discretion of the surgeon to proceed. Although members of my family, as well as many of my patients, successfully have had LASIK surgery, I advise against it for patients with Sjögren's. However, we can often provide alternatives to glasses with contact lenses, such as certain "daily replacement lenses" that are more resistant to dryness, and "scleral" gas permeable lenses (which is a larger, specially designed lens) that has worked well for many dry eye patients. In summary, LASIK is not a recommended option for Sjögren's patients.

> Stephen Cohen, OD Optometrist at Doctor My Eyes in Scottsdale, Arizona

I have heard about sclera contact lenses. Can you tell me about their pros and cons?

Scleral contact lenses (sclerals) are large-diameter rigid contact lenses that, unlike small-diameter rigid contact lenses and soft contact lenses, do not rest on the cornea, which is one of the most sensitive places on the body. Instead, they vault over the cornea and rest on the sclera, the white outer wall of the eye.

Sclerals are made of healthy materials and can be used by optometrists to help improve the health of the ocular surface when dry eye syndrome, due to Sjögrens and many other conditions, is unable to be managed with Restasis or artificial tears.

Benefits of scleral lenses

For the surface of the eye:

People who suffer from dry eye due to Sjögren's are likely to have at least some damage to the cornea, the front surface of the eye. Scleral lenses create a "pool" of fluid between the back surface of the contact lens and the cornea. This fluid can provide immediate relief from the irritation dry eye causes and in many cases, allows the corneal surface to heal while the lens is being worn.

Sclerals allow 2-4 times more oxygen to pass through to your eyes than regular soft contact lenses.

For your vision:

Many people who have an irregular cornea (due to dry eye disease, keratoconus, corneal transplant, LASIK, RK, PRK, or trauma) also have decreased and/or unstable vision. Scleral lenses mask this irregularity and provide a smooth, round front surface for light to enter the eye.

Some people are unable to wear other forms of contact lenses and may find that sclerals are more comfortable than the other contact lenses they've attempted due to their larger diameters.

Scleral contacts are available for people who need to wear multifocal or bifocal lenses to enhance their near and intermediate-distance vision.

Comfort:

The large diameter lens fits under the upper eyelid. This allows the lens to be very comfortable because the edge of the eyelid does not bump over the upper edge of the scleral.

Since the lens is custom-made for each eye, the edges can be optimized for best comfort on your eye. The scleral acts as a "bandage" to cover any irritating areas on the cornea, in a similar way dry eye irritation is relieved.

Value:

When properly cared for, sclerals are durable and have a long life of use, providing great value. (*This answer is continued on page* 8.)

Sjögren's Awareness Month

pril is Sjögren's Awareness Month and this year the Foundation wants help the general public understand this complex disease and how it affects those who live with its numerous daily manifestations with our *This is Sjögren's!* poster and social media campaign.

We know how isolating being diagnosed with an invisible illness can be, but you are not alone. There are an estimated 4 million Americans suffering from Sjögren's, both men and women of different ages and ethnicities. Since Sjögren's is often referred to as an invisible disease, for this year's April Awareness campaign we want to help close the gap between the reality of living with Sjögren's and the perception that many non-patients may have.

During the month of April, SSF volunteer Awareness Ambassadors and members will be going out into their communities to promote the *This is Sjögren's*! poster that you can view on page 6. This poster was designed to help others visualize what it is like to suffer from Sjögren's.

On the SSF blog, *Conquering Sjögren's*, we asked you to share with us one phrase that represents what it's like to live with Sjögren's because you are the voice of the SSF! Everyday in April we will post a different one of your phrases on social media that reflects living with this invisible disease. Each phrase will give a small glimpse into the life of Sjögren's patients and by the end of April, we hope these 30 phrases will help others better understand the disease.

We encourage you to look for opportunities to share how Sjögren's has impacted your life and share your poster from this issue. Remember that by talking with one person at a time, one community at a time, one physician at a time and one company at a time – together we will reach our goal and conquer Sjögren's!

Stay on the lookout for next month's issue of *The Moisture Seekers* to view all 30 phrases or visit www.sjogrens.org to learn more about our *This is Sjögren's!* April Awareness campaign.

This is Sjögren's...

"I look healthy on the outside, however my disease is attacking my internal organs and destroying me from the inside out"

"Sjögren's has started to attack my lungs and I have difficulty breathing and performing everyday tasks"

"I rarely smile or talk in public since my inability to produce saliva has caused embarrassing tooth decay"

"I lost my passion for dining out because Sjögren's has affected my ability to chew and digest most foods"

"Joint pain, aching muscles and inability to sleep is an everyday occurrence for me"

"My inability to produce tears causes extreme eye discomfort and makes me prone to chronic eye infections"

"This terrible disease sets a 'new normal' way of life, which is 'not normal' at all"

"I wake up each day hoping a treatment is developed that will allow me to live an active and normal life again"

Sjögren's ("SHOW-grins") is a systemic autoimmune disease that affects the entire body. Along with symptoms of extensive dryness, other serious complications include profound fatigue, chronic pain, major organ involvement, neuropathies and lymphomas. Neurological problems, concentration/memory-loss, dysautonomia

Dry nose, recurrent sinusitis, nose bleeds

Dry mouth, mouth sores, dental decay, difficulty with chewing, speech, taste and dentures

Fatigue, vasculitis, lymphoma, dry skin

Arthritis, muscle pain

Peripheral neuropathy, Raynaud's

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Dry eyes, corneal ulcerations and infections

Swollen, painful parotid/salivary glands

Difficulty swallowing, heartburn, reflux, esophagitis

Recurrent bronchitis, interstitial lung disease, pneumonia

Abnormal liver function tests, chronic active autoimmune hepatitis, primary biliary cirrhosis

> Stomach upset, gastroparesis, autoimmune pancreatitis

Irritable bowel

Interstitial cystitis

Vaginal dryness, vulvodynia



You Stood Up!

Bradley University – Game Design Program

Sjögren's awareness with the help of a sleepy Mama Koala!

As part of a year-long class project, undergraduate students in the game design program at Bradley University created a puzzle game App that is not only fun to play but also promotes Sjögren's awareness.

In honor of their Professor Monica McGill, the students chose the Sjögren's because Professor McGill's daughter was diagnosed with the disease. The students decided that their project should support the Sjögren's Syndrome Foundation (SSF) and that is when Dr. Monica McGill contacted the Steven Taylor, CEO of the SSF. From that call, a unique awareness partnership and collaboration began on designing Wake Up, Koala!

Wake Up, Koala! is a puzzle game/App for iOS and Android devices that features a very sleepy Mama Koala who really needs to wake up! In each level of the game, players will need to figure out how to position falling water drops to land on the sleeping Mama Koala in order to wake her up! The game showcases a sleepy koala because fatigue is often described as one of the most debilitating symptoms of Sjögren's and is one of the disease's four primary symptoms, along with dry eye, dry mouth and joint pain. The students also chose water as the mechanism to wake up Mama Koala, as a way to connect Sjögren's once again to the game.

The App will be available to download for free by May 2016 and will feature over 120 levels across seven worlds. As players maneuver through the levels, Wake Up, Koala! will share information about Sjögren's. In addition, players who want to earn extra points and awards can also take a "Koala Quest," a quiz about Sjögren's.

The Foundation would like to thank all of the students from Bradley University's Game Design Program as well as Professor Monica McGill for their commitment to creating this App and a new medium to raise Sjögren's awareness!

Stay on the lookout for more information about Wake Up, Koala! in next month's issue of *The Moisture Seekers* or visit koala.sjogrens.org.



"Q&A" continued from page 4 ▼ Drawbacks of scleral lenses

Measurements and customization:

Special measurements and customization are needed to fit the lens to your eye and visual needs. This fitting process will likely take place over several visits to your optometrist.

Lens handling:

There is a small learning curve with how to handle the lenses because of their unique attributes. Your optometrist and their staff will coach you on the best technique to get the lenses in and out.

However, the customization process and learning how to handle this special type of contact lens is a small hindrance considering the amazing things they can do for your vision!

> Martin O'Donnel, OD President/CEO of Vision Source in Holdenville, OK

Is it okay for a new mother with Sjögren's to breast-feed?

Yes, women with Sjögren's can breast-feed. There is passage of antibodies in breast milk that can protect the baby from infections until their own immune systems mature. Autoantibodies can be passed as well like SSA(Ro)/SSB(La), but they will be degraded and not persist past their normal life span. These autoantibodies also pass through the placenta to the baby during pregnancy occasionally causing neonatal lupus (rash) or congenital heart block.

I am not aware of any evidence that breast-feeding increases the known risks further, and there are many benefits to baby and mother of doing so. In general, I recommend women with any autoimmune disorder work with their specialist, usually a rheumatologist, and a High-Risk OB team during pregnancy to prevent any possible problems.

> Nancy L. Carteron, MD, FACR Consultant, Rheumatology Immunology | Autoimmune Disease Associate Clinical Professor UCSF

What would you recommend for coping with mouth sores and blister? And what causes them to flare?

Mouth sores occur commonly in patients with Sjögren's, and can range from a red/raw area to multiple painful ulcers in the mouth. The pain associated with these sores can

continued page 10 V

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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 Bess Atkinson at (800) 475-6473 ext. 218, or batkinson@sjogrens.org to receive your Bold Blue Day kit!



Win a Lifetime Membership



"Q&A" continued from page 8 🔻

make routine oral functions (e.g. talking, eating, drinking and swallowing) a challenge. The location of these mouth sores can appear in any area of the mouth, but commonly appear on the tongue, cheeks, and inside the lips.

The key to appropriately manage mouth sores is to establish the correct diagnosis and underlying cause of this common oral problem. Most mouth sores will only last for less than 2 weeks. The causes for these shortterm sores include: oral trauma (sharp food or biting), recurrent canker sores, allergy or microbial infections (i.e. bacterial, fungal or viral). Mouth sores that last longer than 2 weeks may be from chronic oral trauma (e.g. habit of biting cheek/tongue or presence of a sharp tooth), allergy, microbial infection, and autoimmune-related oral lesions (e.g. lichen planus).

Either a dentist or a physician should evaluate any mouth sore that is present for more than 2 weeks. This will help establish the correct diagnosis and management plan for chronic sores, which may require prescription medications or a biopsy to rule out rare conditions such as oral cancer.

In my practice, the most common cause of mouth sores is related to poor mucosal lubrication (from low levels of saliva) of the different areas of the mouth leading to sores from chronic irritation. With low saliva, normal oral functions such as rubbing the tongue against the teeth or roof of mouth can lead to mucosal friction and subsequent mouth sores. Therefore, the best first-line therapy is to increase salivary stimulation and mucosal lubrication with various dry mouth products (see SSF product directory on the member section of www.sjogrens.org). If this does not address the mouth sores, further assessment by a health care provider is important.

> Mike Brennan, DDS, MHS Department of Oral Medicine, Carolinas Medical Center

IBS (Irritable Bowel Syndrome) and gluten sensitivity appear to have a lot of overlapping symptoms, is there a way of distinguishing between the two?

No there is not because IBS is a diagnosis of exclusion. We have tests that diagnose celiac disease but we don't have tests that diagnose gluten sensitivity. There's a gluten allergy we can test for, but gluten sensitivity is tricky. So because the same symptoms can cause gas, bloating and discomfort, we tend to lump them together.

Now, many people with IBS can benefit from going on a gluten light diet. Going on a gluten free diet can be tricky and should only be done with the help of a dietician. However, a gluten light diet is still very healthy and very safe, as long as it's not too restrictive and for many people can lead to a big improvement in IBS type symptoms.

Matthew Nichols, MD Gastroenterologist in Colorado with South Denver Gastroenterology, PC.

I use a number of products that contain xylitol (chewing gum, candies, baked goods and toothpaste) and recently heard that this sweetener can be harmful to pets. Can you explain why?

Xylitol toxicity in pets is becoming more common as this sweetener is used more often in human foods. It is particularly toxic to dogs due to the way xylitol is absorbed and broken down. At this point, it does not seem to be as toxic to other pets including cats and exotics.

In people, xylitol is absorbed slowly after ingestion. Unfortunately, in dogs it is absorbed rapidly and once in the bloodstream it acts as a strong promoter of insulin release. Insulin lowers blood glucose levels. When too much insulin is released, the blood glucose drops significantly, causing a dangerous hypoglycemia. Signs such as extreme lethargy or seizures can occur. Vomiting is often the first sign seen.

Xylitol toxicity in dogs can also cause liver failure. This may take up to 48 hours to develop. Bleeding, bruising, and even death can occur in these cases.

Ingesting even a small amount of xylitol can cause signs of toxicity. In a 20-pound dog as few as one or two pieces of gum may cause hypoglycemia and 5 to 10 pieces may cause liver failure. For the granulated form of xylitol used for baking, as little as 1/4 teaspoon may cause hypoglycemia or just over one teaspoon may cause liver failure in that 20-pound pooch.

If there is any chance your dog ingested a product containing xylitol, you should call a veterinarian immediately. Typical treatment may include inducing vomiting, running blood work, and giving intravenous fluids containing dextrose (sugar). Various blood work parameters should be monitored for up to three days.

Since xylitol is so toxic to dogs, handling of xylitol-containing foods is very important. Those dogs that experience uncomplicated hypoglycemia have a good prognosis if intervention is initiated promptly. Unfortunately, those dogs that develop liver failure have a poor prognosis.

Patricia Mackey, DVM

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Sjögren's Patient Education Sheets

Sigren's patient education sheets are one way the Foundation continues to provide the most up-to-date information to patients and healthcare professionals. Patient education sheets are one-page flyers written by healthcare providers on various symptoms of Sjögren's to help provide a better understanding and coping techniques.

New education sheets are added to the Foundation's website every quarter. Topics include:

- Airline Travel Tips
- Anti-Inflammatory Diet
- Brain Fog
- Brittle Nails Tips
- Burning Mouth
- Chronic Pain Tips
- Dental Insurance Appeal Letter
- Dental Insurance Reimbursement Tips
- Dental Tips
- Disability Benefits Tips on Obtaining Them from the Social Security Administration
- Dry Nose and Sinuses
- Dry Skin
- Dry Eye Treatments

- Dry Mouth Treatments
- Eating Tips for Dry Mouth Patients
- Fatigue Fighters
- Health Insurance Tips Part 1
- Health Insurance Tips Part 2
- Interstitial Cystitis or Bladder Pain Syndrome
- Muscle and Joint Pain
- Neuro Tips
- Oral Candidiasis (Thrush) in Sjögren's
- Raynaud's Syndrome
- Reflux and Your Throat
- Rheumatoid Arthritis
- Salivary Glands Massage
- Sex and Sjögren's
- Sleep Tips
- Surgery, Hospitals and Medications
- Sun and Sjögren's
- Tracking Your Symptoms: Work Sheet

Visit www.sjogrens.org to learn more or view the education sheets directly at: http://www.sjogrens.org/ home/about-sjogrens/brochures-and-fact-sheets.



Patient Education Sheet

Neuro Tips

The SSF thanks Nancy L. Carteron, MD, FACR, Consultant, Rheumatology Immunology Autoimmune Disease, and Associate Clinical Professor, University of California San Francisco, for authoring this Patient Education Sheet.

Neurological disease is not uncommon in Sjögren's (SjS) and is often under-recognized. Nerve pain (neuropathic) occurs in ~20% of patients. More than 10% may have Small Fiber Neuropathy (SFN) that is not detected by EMG/NC studies but can be detected by a skin biopsy. SjS patients can have neurological involvement without dry mouth but have the SSA autoantibody or positive lip biopsy at presentation. Furthermore, patients may test negative for SSA/SSB Ab.

- Cognitive Impairment (particularly Executive Function) and Fatigue are very common and debilitating. Treating co-morbidities (depression and/or pain disorders) may help.
- Consider a consultation with a neurologist to define the type of neuropathy: Peripheral (weakness, numbness, and/or pain in peripheral nerves, such as the hands, feet, arms and legs), Autonomic (affecting involuntary bodily functions such as digestion, bladder function, and sweat glands), and Central (brain/spinal cord). A neurologist can exclude conditions such as thyroid and vitamin B deficiencies.
- Take a "Lifestyle Inventory" that includes stress, sleep and nutrition. Any areas for improvement?
- For severe peripheral neuropathies, SNRIs (serotonin-norepinephrine reuptake inhibitors (Duloxetine Cymbalta[®], Venlafaxine Effexor[®]) or neuroleptics/anticonvulsants (Gabapentin Neurontin[®]) can be tried. TCAs (tricyclic anti-depressants) are often too drying.
- For debilitating peripheral neuropathy, IVIG (intravenous immune globulin) has shown benefit.
- For the rare vasculitic type of neuropathy seen with cryoglobulins or transverse myelitis, steroid, immunosuppressive, Rituximab (Rituxan[®]) drugs are indicated.
- For gastroenterology (GI) symptoms (constipation, bloating, even intestinal "burning"), consider that small nerve fibers (without myelin) could play a role. Many GI specialists are aware of this, and centers that specialize in GI Motility disorders (NeuroGastroenterology) are available.

For more information on Sjögren's, contact the Sjögren's Syndrome Foundation at: 6707 Democracy Blvd, Suite 325, Bethesda, MD 20817 • 800-475-6473 • www.sjogrens.org • ssf@sjogrens.org.

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 Teri P. Rumpf, PhD, and Kathy Hammitt. A complete resource, providing medical information, research results, and treatment methods as well as the most effective and practical self-help strategies.	\$20	\$17		
Tales From the Dry Side <i>by Christine Molloy</i> . Thirteen personal stories behind the autoimmune illness. Sjögren's tales from courageous men and women who share their journey with Sjögren's.	\$16	\$13		
SHOWgrins – Women Who Walk on Water by Betty Collier. 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.	\$16	\$13		
Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop by Norman Latov, MD, PhD. Peripheral neuropathy is a widespread disease, yet many people do not even realize they have it.	\$19	\$16		
You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life by Mims Cushing and Norman Latov, MD. A compendium of tips, techniques, and life-task shortcuts that will help everyone who lives with this painful condition.	\$19	\$16		
A Body Out of Balance by Ruth Fremes, MA, and Nancy Carteron, MD, FACR. A Sjögren's patient and a doctor offer their authoritative insight into one of the most common yet most misunderstood autoimmune disorders.	\$16	\$13		
Vulvodynia Survival Guide: How to Overcome Painful Vaginal Symptoms & Enjoy an Active Lifestyle by Howard I. Glazer, PhD and Gae Rodke, MD, FACOG. 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 Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease by Susan Blum, MD, MPH. This book shares Dr. Blum's four-step program to help autoimmune patients reverse their symptoms, heal their immune systems and prevent future illness.	\$25	\$22		
The Memory Bible: An Innovative Strategy for Keeping Your Brain Young <i>by 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		
As My Body Attacks Itself: My Journey with Autoimmune Disease, Chronic Pain & Fatigue by Kelly Morgan Dempewolf, PhD This book is an honest, raw look at the thoughts, concerns, fears and struggles, as Kelly deal with Sjögren's.	\$15	\$11		
Grain Brain: The Surprising Truth about Wheat, Carbs, and Sugar – Your Brain's Silent Killers <i>by David Perlmutter, MD</i> (<i>author</i>) <i>and Kristin Loberg</i> (<i>contributor</i>) A #1 New York Times bestseller – the devastating truth about the effects of wheat, sugar, and carbs on the brain, with a 4-week plan to achieve optimum health.	\$25	\$20		
How to Live Well with Chronic Pain and Illness – A Mindful Guide by Toni Bernhard The book addresses challenges created from chronic illness to help readers make peace with a life turned upside down.	\$17	\$14		
Awareness Wristbands by purchasing these awareness wristbands, you are helping the SSF to achieve our 5-Year Breakthrough Goal. With the wording, "Conquering Sjögren's - www.sjogrens.org." <i>Pack of 10</i>	\$18	\$15		
The Moisture Seekers newsletter Volume 32, 2014 (10 issues) as originally published.	\$50	\$20		
The Moisture Seekers newsletter Volume 33, 2015 (10 issues) as originally published.	\$50	\$20		
Sjögren's Quarterly newsletter subscription (4 issues) a leading edge medical and scientific newsletter aimed at educating professionals about the latest information on Sjögren's research, treatments and products.	\$50	\$20		
Maryland Residents add 6% sales tax	1	1		
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AmEx Card Number				
Exp. Date Security Code Signature				

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Host Your Own SSF Event

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 include:

> 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 Bess Atkinson at the Foundation with any additional questions at (800) 475-6473 ext. 218 or batkinson@sjogrens.org.

Movie Night

Pancake Breakfast

oshion Show





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

2016 SSF Special Event Calendar

SSF events are organized in an effort to increase Sjögren's awareness in local communities, while raising funds to support research & education. They are also an excellent opportunity to connect Sjögren's patients and their families to others living with the disease.

May

- 1 Atlanta Sip for Sjögren's Nelson Mullins, Atlanta, Georgia
- 7 Philadelphia Walkabout and Health Fair Philadelphia Zoo, Philadelphia, Pennsylvania
- 17 Triangle Sip for Sjögren's UCB Biosciences, Raleigh, North Carolina
- 21 Northeast Ohio Walkabout Oak Grove Picnic Area, Brecksville, Ohio
- 23 New York City Sip for Sjögren's Rosenthal Pavilion at NYU, New York, New York

June

- 4 Denver Walkabout and Health Fair Hudson Gardens, Littleton, Colorado
- 4 Dallas Walkabout and Health Fair Parks at Arlington, Arlington, Texas
- **11** Greater Washington Region Walkabout and Health Fair Two Democracy Plaza, Bethesda, Maryland

If there is already an event in your area and you would like to get involved, or learn about starting one, please visit www.sjogrens.org or contact us at (301) 530-4420 x207