

10 Lessons From A Great Teacher

by Alida Brill

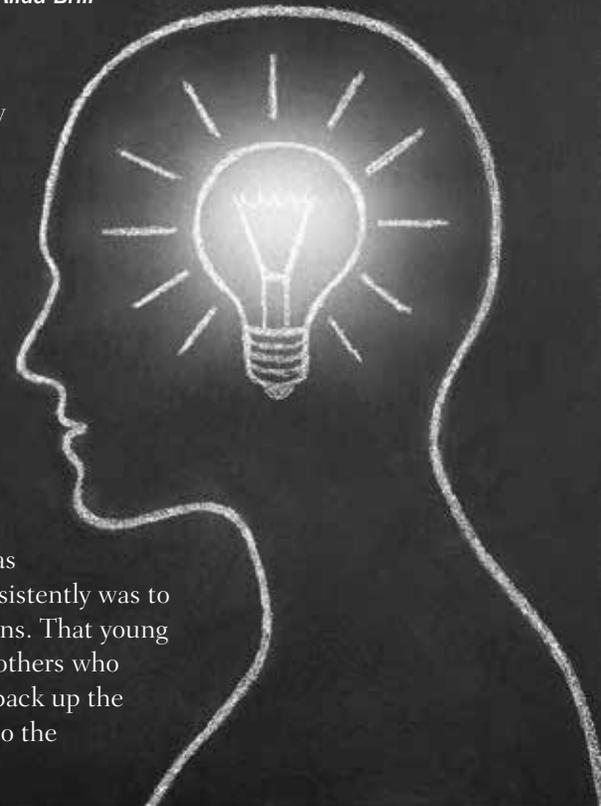
Most of us have memories of a teacher who influenced our lives. I certainly do. But my greatest teacher has been chronic inflammatory autoimmune disease. Obviously, I use the word great here not as in “wonderful” but as in “of extraordinary importance and weight.”

A few years ago a young woman approached me after a talk I gave about living with chronic disease for my entire life (well, from twelve forward, so close enough). She wanted to know precisely what I meant when I said: At the end of it all, it really hasn't been all bad.

Understandably, she wanted to know what wasn't all bad about always being unwell. She had been recently diagnosed with Lupus and saw the life she had known and valued disappearing. She was overwhelmed by the unknown and confused by conflicting medical opinions about treatment options. I said a few things, likely not useful, but her question stuck with me. Precisely what do I mean when I say that?

During virtually all of last year I was sidelined from doing almost anything as I went from one autoimmune crisis to the next. The only thing I could do consistently was to let my mind spin out of control, which often took me to destructive destinations. That young woman kept appearing in my daydreams. If I were to offer anything useful to others who live on this planet of chronic illness, I had better come up with something to back up the platitude. At first I thought the deeper meaning was that I pay more attention to the

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Fibromyalgia in Sjögren's Syndrome

by Frederick B. Vivino, MD, FACR

Fibromyalgia refers to a syndrome of diffuse and whole body musculoskeletal pain associated with poor sleep, chronic fatigue, morning stiffness, and waxing and waning symptoms that vary with changing conditions (e.g. weather, sleep patterns). Try to think of fibromyalgia (commonly referred to as “fibro”) as muscle spasms related to not sleeping.

Fibromyalgia Symptoms

Most people describe the pain as “aching pain” that involves the muscles or joints. It often starts in one area and over time will spread, eventually involving the whole body. It is significant, disabling pain. And though it may be felt

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things that count in life, and less to those that don't. But many of us do that, whether we're ill or not. I spent some time thinking about how to fashion a life of illness into a life of lessons. Here is how illness itself became a great teacher to me, and the ten lessons I took from it.

1. How to Hold Your Tongue

People often say ridiculous things, especially to the sick. I've heard my share, and I'll bet most of you have as well. Sometimes it's hurtful – sometimes strangely amusing. I've learned not to take up every verbal challenge, not to inform others how wrong they are. There are those who are filled with bewildering misinformation but persistently engage in arrogant advice giving. I have dropped acquaintances or friends who could not find their way to compassion or understanding. Most of the time, I decide a solid friendship is worth preserving. I can usually separate thoughtlessness from cruelty. I also learned that the childhood rhyme: sticks and stones can break my bones, but words will never hurt me is a lie. Words can wound. Chronic disease has taught me to hold my tongue, still I use this phrase frequently (without hostility): Ouch! What you just said really hurt.

2. How to Be With Yourself

...And not by yourself. When we women walk into most restaurants on our own (other than diners or fast food chains) we're usually asked: "Will you be dining alone tonight?" Or, the even more grating: "Only one tonight?" I often dine solo for many reasons, but I'm not alone: I'm with myself. It is crucial for those of us with chronic disease to cultivate strong friendships – with ourselves. To be with yourself in your own company is essential to a feeling of independence and empowerment. There are times when a flare doesn't make me that great a companion – except to myself! Loneliness is not healthy, but solitude can refuel your soul.

3. How to Need Without Becoming Needy

I've been unwell for so long I could write an entire book about how people have left me. Chronic illness wears friends down, repels spouses and lovers, exhausts friendships and fragments intimacy. But this doesn't mean we're not entitled to ask for help. Be brave enough to say you need some assistance and strong enough to accept it if the person can't or won't come up with it. You are not a failure. You are not pathetic. There are people who can and will assist us. Keep your needs in perspective and in balance.

4. How to Forgive

First, forgive yourself. With chronic disease, we are not always reliable. We make plans and then cancel. We try to do a good job at work, as a parent, as a spouse, but it doesn't always stack up to an A+. Don't berate yourself. We've

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done the best we could and we can keep trying to improve. Keep in mind that days ahead may not be as awful as the ones where we couldn't go through with a project or a commitment.

Second, forgive others who let us down. Promises are words of good intentions. Sometimes they are not fulfilled, but everyone deserves a second, third, and perhaps even a fourth chance. Remember that even the well and able-bodied can become overwhelmed.

5. How to Listen

Illness has taught me to listen carefully to physicians as they are speaking rather than anticipating what they are going to say next. A wise doctor told me: All facts are friendly. He didn't mean that all medical facts were pleasant or joyful, but that information is power. You can't make a decision about what to do, or not do, or what to ask of another doctor if you've not bothered to take in what has been already given to you. There are times when we want to interrupt doctors; we have so many questions and they have such limited time. But letting doctors have their say too is the best first step to establishing patient-doctor dialogue. Don't make assumptions until you've had time to digest and consider.

6. How to Challenge Authority

Doctors have high status in our culture. Even if you're a person with a distinguished title or career, the power of doctors trumps most of us. Sometimes a doctor is wrong about what's best for you, or what you can manage at a particular time. There's a way to challenge a medical authority without blowing up the relationship. This is best done after you've had some time to formulate questions and your concerns. Doctor-patient relationships are similar to all other important ones and anger and accusation virtually never take us to a healthy place.

7. How to Try Again

...And again. I'm not sure there's a better teacher of resilience than chronic disease. I have often wanted to give up, to spend my time whining, to shift my gear into the "stall and wallow mode". But I haven't because life is out there asking us to challenge it – and our diseases – urging us to get up and get going to progress in our own fashion. Face the reality of your disease but just as strongly acknowledge you are still equipped to keep attempting the all but impossible. In the words of Samuel Beckett: Try Again. Fail Again. Fail Better.

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"10 Lessons" continued from page 3 ▼

8. How to Hope

Well or unwell, if we don't have hope we're doomed. Discouragement and chronic disease are best friends to each other. I've become almost euphoric at the prospect of a new drug or a respite from flares, and then fallen quickly into a ditch of despair when the drug doesn't work or when it makes me sicker, or when the containment of disease is short. For those who have spiritual faith, the job might be easier, because faith is said to fuel hope. But you don't have to profess a particular religious belief in order to hope. Hope means the belief in a better moment, a better cycle, a better result.

Hope is the glue of survival.

9. How to Endure Loss

I have endured loss by embracing it. It's not for everyone, but I think it's worth a try. Face the reality of what's gone and can't be retrieved – a relationship, a job or career, financial security, an independent lifestyle – for many of us it's a long list. Remember all that was given to you when you had these things or persons in your life. Find a place within your awareness where they can still reside, undisturbed. But at the same time do not long for a return of what can't be reclaimed. Find new things to claim and new ways to enrich your life. When my mother was very old (over 90) she could no longer walk in her

garden, but she could see it from her window and would recall the days when she worked in it. Undoubtedly she missed those days, but kept her garden by finding a new way of being with it.

10. How to Embrace the Unknowable Future

Here we're not different from anyone else. Nobody can predict the future. As an unwell woman, I've been particularly anxious about my future. Where will my disease choose to go next? What will be my further limitations? What if the drugs don't work at all? What if I run out of resources? And on and on and on. But we're all in this lifeboat together. Particularly as we get older the worries increase about how to navigate illness. If we've been sick from childhood, we feel prematurely old. It's good to step back and take in the moment of living as it is, and to understand that we can only find our way to the next moment in our life and then the next, and the next. We can't figure it all out at once.

Would I choose this life again? No. I think about the many who suffer, and I hope there will soon be cures and real remedies for us all. Autoimmune disease, in all its manifestations, is an area of medicine for which I want more attention, more research dollars, more independent drug trials, and more splendid young doctors (especially women). ■

©2014 Alida Brill — *Alida Brill is a writer in New York City. She has atypical Granulomatosis with Polyangiitis (formerly known as Wegener's). Her last book, Dancing At the River's Edge: A Patient and her Doctor Negotiate Life With Chronic Illness, (Schaffner Press) is a dual-memoir written with her long-time doctor, Michael Lockshin, M.D. She is an activist and advocate for girls and women with autoimmune disease. She is currently at work on a new book, The Invention of a Romantic Feminist: Growing Up with Princess Grace, Barbie and Betty Friedan, scheduled for publication by Schaffner Press in 2015.*

"Fibromyalgia" continued from page 1 ▼

throughout the whole body, the most commonly affected areas are the neck, back, hips, elbows and knees. Even though it feels like a problem in your muscles, it can also affect the joints, and often fibromyalgia symptoms will be confused with arthritis. Many patients suffer from chronic fatigue and simply do not sleep.

Changing conditions seem to affect the levels of pain and fatigue.

Weather: The weather may play a big role in your fibro symptoms. For example, a lot of people tell us their pain is worse when the weather is cold and rainy. Or conversely, people may feel better when the weather is warm and sunny.

Lack of Sleep: People usually notice their fibro symptoms are more severe when they do not sleep.

Stress and overexertion: Stress is a very big factor in fibro. Patients complain of worsening symptoms during periods of physical or emotional stress as well as overexertion. The mind-body connection plays a role in many rheumatic diseases, and this tells us that fibromyalgia is no exception.

Fibro can cause many symptoms in addition to the classic muscle and joint pain and fatigue. Patients frequently come to us with what we call a "sensation" of swelling. People will tell us that their joints are swollen, but upon examination we find that this is actually not the case. Many fibro patients also relate a variety of neurological symptoms. For example, some patients have odd sensations in the arms or legs and other extremities. This could lead to a patient undergoing an evaluation for

neuropathies, nerve damage or even multiple sclerosis (MS), but the tests come back normal. Fibro may cause patients to feel weak. And much like Sjögren's, fibromyalgia can cause cognitive dysfunction, or "brain fog," as a lot of Sjögren's patients call it. Fibro can also cause sicca (dryness) symptoms.

Symptoms of Fibromyalgia:

- Migratory "aching pain" pain often localized around the neck, back, hips, elbows & knees
- Chronic fatigue; no sleep
- Worse with bad weather, overexertion or during periods of emotional stress
- Sensation of swelling
- Funny sensations in the extremities (e.g. tingling)
- Weakness
- Cognitive dysfunction ("Brain Fog")
- Sicca symptoms

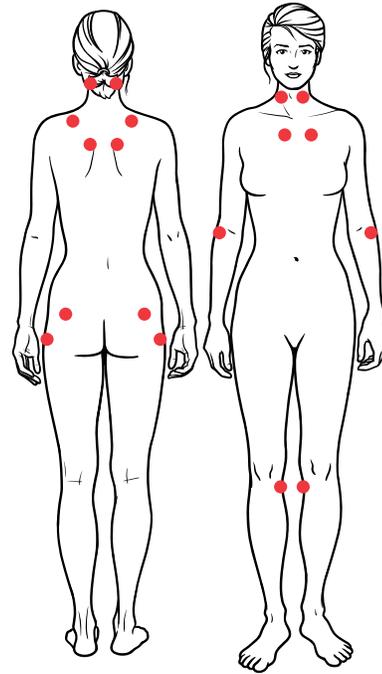
Looking at these symptoms for fibro, you can see that many symptoms overlap significantly with those of Sjögren's. As a result, it can be a challenge for doctors to tell the two disorders apart. Most rheumatologists have seen cases of patients who ended up having Sjögren's and were initially misdiagnosed with having fibromyalgia as well as the reverse. And to make things more confusing, the two disorders can coexist in one patient.

Fibromyalgia often travels with other diseases. We don't understand exactly why this is, but frequently fibro patients also suffer from: (See Figure 1)

- Depression (between 30-40% of patients have concurrent depression or anxiety).
- Jaw pain from TMJ (temporomandibular joint disorder).
- Non-cardiac chest pain (costochondritis).
- Irritable bowel syndrome (IBS) due to muscle spasms in the intestines.
- Migraine headaches.
- Irritable bladder syndrome or pelvic urethral syndrome.

Sjögren's can cause a rheumatoid-like arthritis. So when the doctor examines you, he or she may find a tenderness or swelling localized in the joints. With fibromyalgia, the pain is coming from the muscles, so all of the tender points will be coming from the muscles rather than the joints.

Tender Points in Fibromyalgia



Your doctor will examine you for tender points. There are 18 various tender points throughout the body (see illustration above):

- Along the chest
- Along bony prominences like the elbows and the knees
- In the lower neck region
- The upper back and the lower back region
- Around the hips

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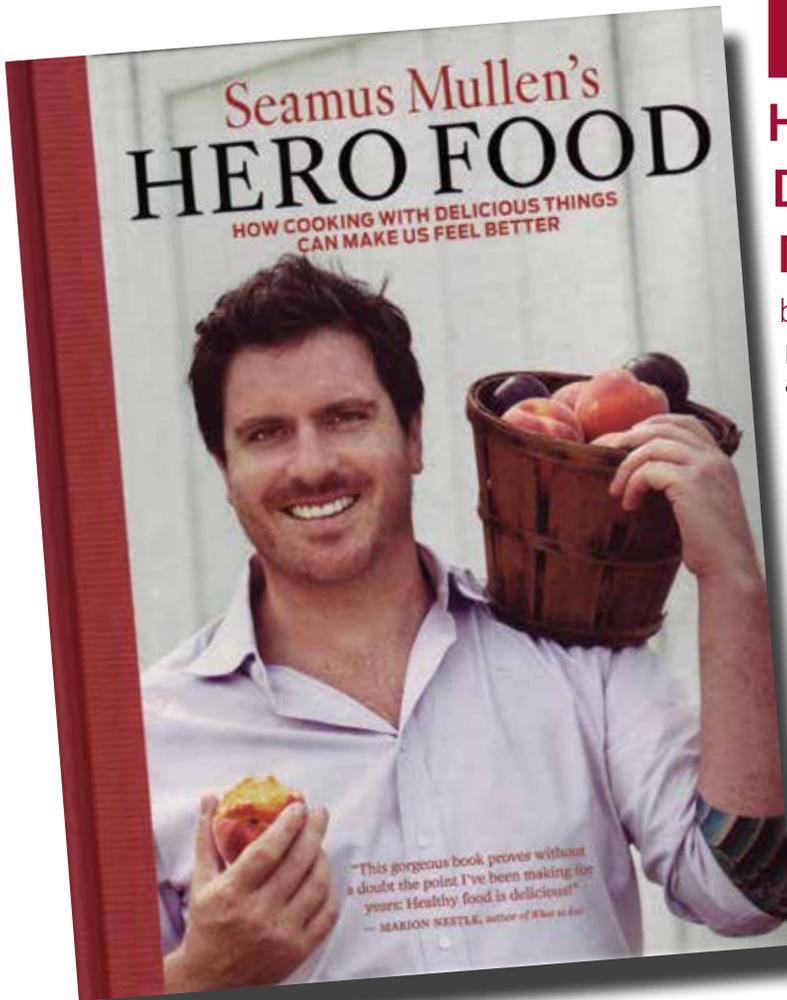
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Hero Food: How Cooking with Delicious Things Can Make Us Feel Better

by Seamus Mullen

Mullen was diagnosed with rheumatoid arthritis five years ago, and in that time, he has discovered how incorporating 18 key ingredients into his cooking improved his quality of life. In *Hero Food*, he shows how to make these key ingredients, or “hero foods,” your cooking friends; they can be added to many dishes to enhance health and flavor.

Hero Food is divided into four sections, each devoted to a season. Each season is introduced with a richly imaged “movie,” providing the context of Seamus’s life and the source of many of the imaginative and beautiful recipes contained in each seasonal section.

Seamus’s “heroes” are real food, elemental things like good meat, good birds, eggs, greens, grains, and berries. He cares about how his vegetables are grown, how his fruit is treated, and about the freshness and sustainability of the fish he uses. His hope is that you will eventually forget about why these recipes are good for you, and that you’ll make them just because they taste good.

Member Price: \$28

This book can be purchased using the order form below, online at www.sjogrens.org/ssfstore or by contacting the Sjögren’s Syndrome Foundation office at 800-475-6473.

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I Stood Up...

Seamus Mullen Stands Up for Sjögren's

On March 17, 2014, the Sjögren's Syndrome Foundation was excited to bring one of its signature events – “Sip for Sjögren's” – to New York City. While the event itself was a huge success, one of the highlights of the evening was having Seamus Mullen, award-winning chef, restaurateur, cookbook author & autoimmune patient, as the event's guest speaker.

Seamus is most famous for being one of 3 finalists on the popular Food Network series “*The Next Iron Chef*” and appearing as a judge on the Food Network series “*Chopped*.” These are just a few of the reasons that Seamus continues to rise in the ranks of chefdom and is considered a prominent chef in NYC and around the country.

But it was his diagnosis with rheumatoid arthritis in 2007 and how he has overcome that diagnosis that guests were most drawn to. Seamus spoke to the “Sip for Sjögren's” audience about how he discovered there were certain foods that reduced the inflammation in his body which he calls “*Hero Food*”. In 2012, Seamus released his first cookbook “*Hero Food: How Cooking with Delicious Things Can Make Us Feel Better*.” *Hero Food* is Chef Mullen's personal philosophy of well-being, illustrating how he believes delicious food and wellness can go hand in hand.

Much of Seamus' story resonated with our Sjögren's patients as he discussed looking healthy but struggling each day to simply get out of bed. His message was one of perseverance, hope and inspiration. The Sjögren's Syndrome Foundation was incredibly grateful for his time and willingness to stand up for Sjögren's!

Seamus Mullen's Top Anti-Inflammatory Foods*

Chef Seamus Mullen believes food that's grown locally, is pesticide- and antibiotic-free, is fresh and in season can fight inflammation. Here are a few of his favorites:

- Shell beans, both fresh and dried. “They're an incredible source of protein and omega-3s,” he says. “They are also delicious and versatile.”
- Sweet potatoes. “They're packed with protein and potassium – all sorts of good stuff.”

- Strawberries. Seamus favors berries that are fresh, organic, in season and vine-ripened. Freeze for year-round eating.
- Green leafy veggies. Kale, collard greens, mustard greens and Brussels sprouts are packed with folic acid.
- Anchovies. These “unsung heroes” are high in omega-3s.
- Parsley. “It has incredible flavor and eases inflammation,” says Seamus, who drinks parsley juice if his hands hurt. He tosses parsley in a juicer and adds lemon juice and apple slices for sweetness.

*Reference: <http://www.arthritistoday.org/what-you-can-do/arthritis-stories/career/seamus-mullen.php>



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What is Bold Blue Day?

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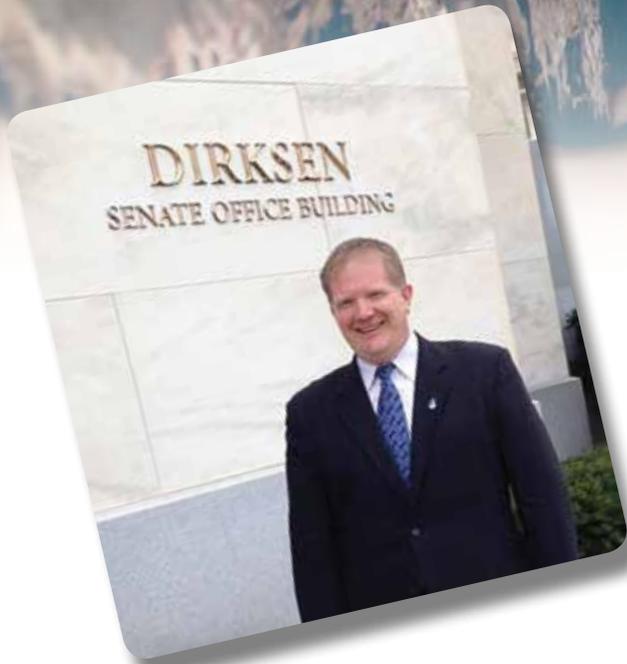
What if your company doesn't ever allow jeans?

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To receive more information or have a "Bold Blue Day" kit sent to you, contact Steph Hilton at (800) 475-6473 ext. 227 or shilton@sjogrens.org to receive your "Bold Blue Day" kit.

Sjögren's
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Steven Taylor, SSF CEO, was back on Capitol Hill this April to ensure Sjögren's patients are not forgotten in the discussion of having medically necessary over-the-counter (OTC) products covered under flexible spending arrangements (FSAs) and health saving accounts (HSAs) without having to obtain a prescription.

The SSF has been proud to be a leader in this fight, and we were honored when Steven Taylor testified two years ago before the Subcommittee on Oversight of the House Committee on Ways and Means on this very issue and how these limitations impact Sjögren's patients. We were thrilled to have won that fight in changing this law but then due to an unforeseen wording in the enactment of the Affordable Care Act, these limitations have once again been re-established and thus we must fight again to have them overturned.

Originally, FSA and HSA account holders could use their tax-free savings to purchase OTC medications WITHOUT a prescription, but then a legislative change required a prescription in order for coverage of OTC medications. This change meant patients would need to spend more time at doctor appointments obtaining these prescriptions for items that do not require a prescrip-

tion to purchase. This change significantly has impacted Sjögren's patients who largely depend on the use of OTC drugs and products to both treat their disease and prevent devastating complications.

In addition, these new limitations have a rippling effect not only impacting a patient's care, but also imposing an unreasonable administrative strain on physician's offices, resulting in longer wait-times for appointments and higher costs.

"The cost is untenable for patients and their families, as OTC treatments are not covered by insurance, are not tax deductible and are no longer even covered under Health Saving plans without obtaining a prescription. With so many OTC products needed for treatment, having to go to a physician or dentist for a prescription for each and every one presents an undue burden," said Taylor.

The SSF 5-Year Breakthrough Goal, was created to benefit all patients by getting Sjögren's to be taken more seriously and ultimately help those get diagnosed and then receive the proper treatment. This is why we will continue to fight for the coverage of OTC products so this unnecessary strain is eliminated for Sjögren's patients as they manage symptoms of this debilitating disease. ■

May

Breakthrough Bullet:

Advocacy Update: The high burden of over-the-counter medication costs


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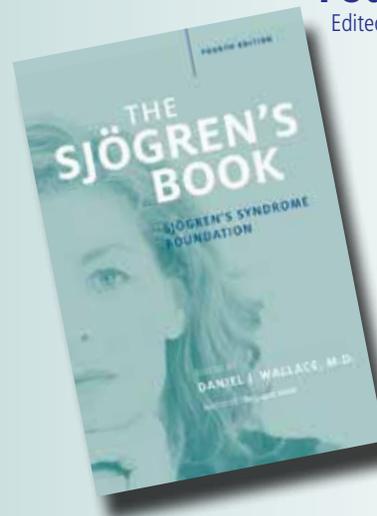
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Mom & Dad

"Fibromyalgia" continued from page 5 ▼

How Do You Treat Fibromyalgia in Sjögren's Syndrome?

One course of action is to treat the dryness, especially if you think the dryness is interfering with your sleep. With sleep in mind, it does help to take an extra dose of secretagogues before bed to take care of nighttime dryness. You can use a humidifier in your room. If you have dry mouth you can coat your tongue in a substance like Vitamin E oil or a moisturizing gel (e.g. Orajel™ or Oral balance™). For dry eyes, use a thicker ocular lubricant at bedtime which should last longer through the night than artificial tears.

If you have pain due to inflammation, then you need to treat it. But consult your doctor and see if you can take your Plaquenil or steroids in the morning rather than at night to avoid any problems with sleep.

Finally, if you are still not getting the proper sleep, consider participating in a sleep study. This could help

rule out restless leg syndrome or sleep apnea or help you find ways to improve your sleep.

Points to Remember

- Fibromyalgia may occur in anyone but is a common complication in up to half of those with Sjögren's.
- The symptoms of fibro overlap with those of Sjögren's, so make sure you communicate your symptoms to your doctors. Also make sure your doctor takes a step back from time-to-time to ensure that he or she has a complete understanding of all the possible complications of pain you might have. If you suspect that you have fibromyalgia, ask you doctor to examine you for tender points.
- Tender/trigger points are important, and if you have whole-body pain and are not sleeping it might be time to explore a clinical diagnosis of fibromyalgia.
- Multifaceted treatments work best. ■

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2014 SSF Special Event Calendar

Join in the fun and help increase Sjögren's awareness. The SSF is very excited for all of our events coming this year. Look at our special event calendar below to see if there is a *Walkabout* or *Sip for Sjögren's* coming to your area.

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

May

- 3 Philadelphia 10th Walkabout & Health Fair**
Philadelphia Zoo
- 10 Dallas Fort Worth Walkabout & Health Fair**
Grapevine Mills, Grapevine, Texas
- 31 Northeast Ohio Walkabout**
Oak Grove Picnic Area, Brecksville Reservation

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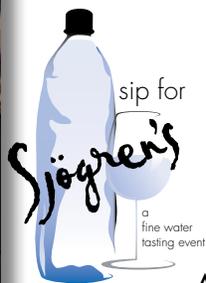
- 1 Columbus Ohio Walkabout**
Friendship Park, Gahanna, Ohio
- 1 Atlanta Sip for Sjögren's**
Nelson Mullins - Atlantic Station, Atlanta, Georgia
- 14 Denver Walkabout**
Denver Zoo
- 21 Greater Washington Walkabout**
SSF National Office, Bethesda, Maryland
- 22 Kansas City Walkabout**
English Landing Park, Parkville, Missouri



Denver



Sjögren's Walkabout



Atlanta



Kansas City



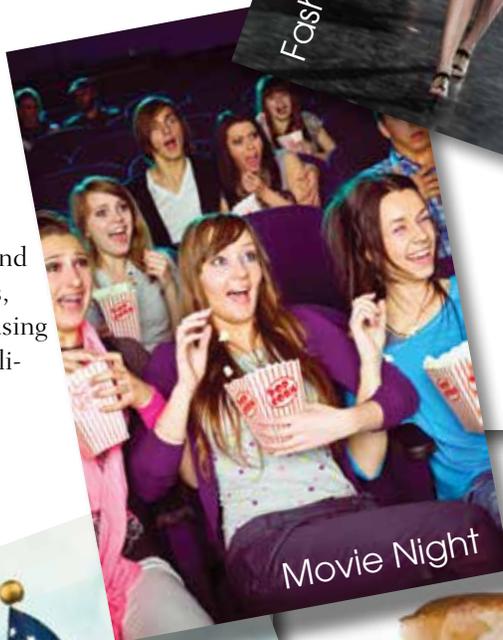
Host Your Own SSF Event And Help Us Reach Our Breakthrough Goal!

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 Stephanie Hilton, Special Projects Manager at the Foundation office with any additional questions at 301-530-4420 ext. 227 or shilton@sjogrens.org. ■



Donate Your Old Vehicle



Call us today for more information.

800-475-6473



Raise awareness about Sjögren's and spend

A Day at the Beach

Join other Sjögren's patients, family and friends as we walk and run

Six Miles for Sjögren's

July 27, 2014
Santa Cruz, California



To join our 5th annual fundraising team and to learn more about our full weekend of events for patients and their families, contact Team Director: Estrella Bibbey at (510) 396-6783.



Faces of Sjögren's

Lucy's Journey

When I was diagnosed with Sjögren's, my first thought was...



"Relief!" I had been experiencing so much pain and fatigue, that I just knew something wasn't right. The doctor explained that the first signs of Sjögren's were dry mouth and dry eyes. "No big deal," I thought. What I didn't realize was that dry mouth is caused from the absence of saliva. Saliva is important to the body for a number of reasons, including proper digestion.

That explains why I've had digestive problems all these years! I knew my vision was not as sharp as it used to be... That's what happens when you get older, right? After all... I'm almost 50!

But after a thorough examination, the doctor said that my lacrimal glands were so inflamed that I was not producing any tears at all causing severe dry patches on my eyes that were threatening my vision. I was shocked! I had been living with this illness for so long that these "first signs" never even fazed me. They were my "normal."

Luckily, through the Sjögren's Syndrome Foundation and contacting their local support group, I was able to find an excellent doctor who is a leading authority on this disease. It took nearly one year of treatment before I could really notice any improvements, but now, a year and a half after my diagnosis, I feel better than I have in a long time.

I pay closer attention to my diet and I run an average of 30 miles per week. I still have days when I struggle with pain and fatigue, but knowing what causes my symptoms helps me to keep them under control. Discovering you have a chronic illness can be devastating, but maintaining a healthy lifestyle and a positive attitude can make all the difference in the world!

Don't let Sjögren's keep you from doing the things that you love. It may take a little more effort on our part, but it's worth it!

- Lucy

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



Sjögren's Fast Facts

Sjögren's is pronounced "SHOW-grins".

The hallmark symptoms of Sjögren's syndrome are dry eyes, dry mouth, fatigue and joint pain, but the disease is systemic, affecting the entire body.

Sjögren's is one of the most prevalent autoimmune disorders, striking as many as 4,000,000 Americans.

Early diagnosis and proper treatment may prevent serious complications and greatly improve the quality of life for individuals living with Sjögren's.

It takes an average of 4.7 years to receive a proper diagnosis.

The SSF is the only national organization focused on increasing research, education and awareness for Sjögren's.

