

Can Food Be Making You Sick?

by Keri Lynn

It seems that no matter what the event these days, there is food criteria to attend to. From your child's school, to the local restaurant, to friends and family, food sensitivities are knocking on your door. Food sensitivities effect so many people that they can't be ignored.

The Center for Disease Control and Prevention (CDC) reports, "allergies are the 6th leading cause of chronic illness in the U.S. with an annual cost in excess of \$18 billion... 50 million Americans suffer from allergies each year." According to Food Allergy Research & Education (FARE), food allergy facts and statistics in the U.S., there are "more than 170 foods that have been reported to cause reactions."

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Sjögren's Clinical Trials: A Patient Experience

by Kathy McCarren

I was diagnosed with Sjögren's in 1990. At that time, there was no internet and information about the disease was hard to find. This inspired me to talk about my Sjögren's because no one understood what it was. People thought Sjögren's was rare, which is not true. I made it my mission to participate in any clinical study that I was eligible for. I did this because I thought it might help me, but also because the research might help other patients.

Recently, I was offered the opportunity to do a nine-month clinical trial that my doctor thought I may benefit from. The physicians conducting the trial provided me with detailed information in writing. There was a 15-page document given to me in order to give informed consent. This discussed what the requirements were, what the routine would be, what kind of visits I would have, what kind of lab work, doctor's evaluations, and more.

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Put a check in each box below that applies to you:

- Depression and/or mood changes
- Anxiety
- Muscle aches or joint pain
- Nasal congestion
- Constipation and/or diarrhea
- Acid reflux/indigestion
- Bloating or gas
- Dark circles or bags under your eyes
- Headaches
- Rashes or skin dryness/itchiness
- Fatigue
- Unintentional weight gain

Did you check one or more of the symptom boxes above? If you did, you could be suffering from *food sensitivities*.

Are you suffering from food induced inflammation?

Do you feel like your weight fluctuates or you just cannot get rid of those unwanted pounds? Do you feel like you have done it all and you just can't lose the weight? This can be truly frustrating indeed!

Food sensitives cause inflammation in the body. This inflammation increases our risk of developing disease, ultimately obesity.

Although we hear food allergies and food sensitivities interchangeably, they do differ. How do we know which one we are suffering from?

There two types of food mediated reactions, immune mediated and non-immune mediated.

Immune Mediated:

- Food Allergies

Non-immune mediated:

- Food Sensitivities
- Food Intolerances

Food allergies are known as IgE, immunoglobulin E, mediated

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type 1 hypersensitivity reactions and are generally immediate in response. These bodily reactions can range in severity such as hives to more critical in response such as anaphylaxis and can be fatal. Some of the most common allergy foods include tree nuts, peanuts, eggs, fish and shellfish, milk, gluten, and soy. Foods that we are allergic to must be avoided and cannot even be consumed in even small quantities.

Food intolerances are non-immune related and are a result of a metabolic reactions such as a lack of an enzyme to digest the foods such as lactase. When this happens, they are considered intolerant and will no longer be able to digest dairy foods.

Food sensitivities are delayed in onset, up to 72 hours or more, and are non-immune mediated reactions and are a result of an ingested food. Food sensitivities maybe present as any of the following conditions:

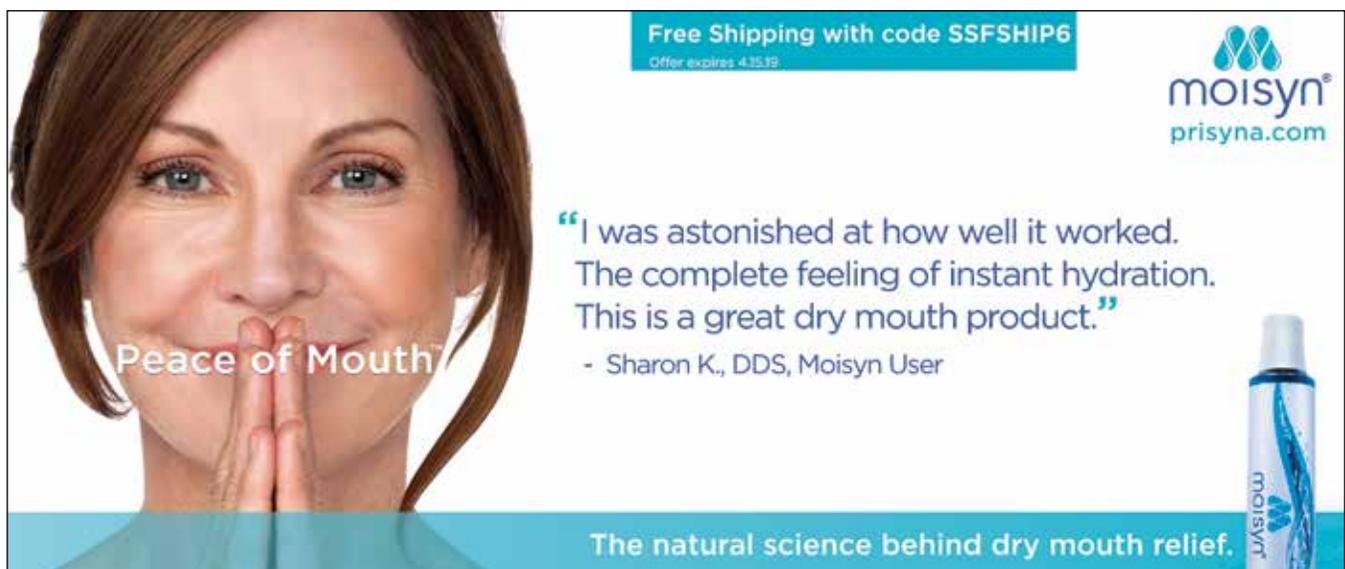
- Crohn's disease
- GERD
- Irritable bowel disease/diarrhea/constipation
- Migraines
- Ulcerative colitis
- Fibromyalgia
- Eosinophilic esophagitis
- Arthritis
- Attention deficit disorder
- Eczema

Food sensitivities can be the body's response to a chemical naturally occurring in a food such as solanine, histamine, and salicylates. These reactions many times are dose related and sometimes can be consumed in small amounts but when a threshold is reached, a reaction occurs. Each person's threshold will be different, and some people may need to remove these foods from their diet to become asymptomatic.

Four Common causes for food sensitivities

- *Leaky gut!* When our intestinal barriers break down from bad bacteria, parasites or infections passing through, this is considered leaky gut. When this happens, our immune system becomes compromised and food particles can enter the circularity system and create systemic inflammation. Sometimes these foods that cause our body havoc and can be difficult to assess because these reactions are often delayed. Food sensitivity testing can be done to help us get a baseline for what these foods may be. Elimination diets are implemented to remove those foods for generally 6-8 weeks to essentially calm or better yet reduce the inflammatory response.
- *Chronic antibiotic use.* The use of antibiotics sometimes can't be avoided, but this can compromise the immune system. Antibiotics kill off the bad bacteria it was intended to but also do

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“Food” continued from page 3 ▼

a number on the good bacteria that keep the ecosystem in balance.

- *Chronic stress and toxic exposure.* Every day we breath in air, drink water, and eat food that have chemicals and pesticides that our liver has to work overtime to filter out. This insult can result in toxic overload causing us to feel fatigue and run down. This can impact our immune systems negatively making our bodies even more susceptible to food sensitivities.
- *Too much of one food.* Ever think about how many times you eat the same food in one day? Let’s look at a scenario that can be commonly seen in many diets.

Eggs!

Breakfast time, you eat 2 eggs over easy over paleo bread (made with egg whites) and butter with a piece of fruit. Lunch time, chicken cranberry walnut salad made with mayonnaise (this contains egg), over bib lettuce. Snack: RX bar (contains egg). Dinner meal consists of veal parmesan (breaded and dipped in egg) with green beans. Sometimes we can eat a particular food in a small quantity but when we are exposed to it multiple times in one day, we can hit our threshold. In this case, it would have been 5 times in one day!

Can diet really make an impact on our health and significantly impact our day to day symptoms?

Yes, changing your diet can be life altering!

Five common food sensitivities for you to consider

- *Histamines.* The most common symptoms of histamine sensitivity include itching and headaches. Foods to consider reducing or eliminating from your diet plan include aged cheese and meats, citrus, spinach, bananas, and fermented foods and many spices too!
- *Solanine.* A common symptom of solanine sensitivity is muscle and joint pain. I find that this is one of the hardest groups to decrease because it contains tomatoes and potatoes, in other words, tomato sauce and french fries! Other solanine rich foods include eggplant, goji berries, and peppers.
- *Sulfites.* Common symptoms of sulfite sensitivity include difficulty breathing or wheezing, loose stool or trouble swallowing. Sulfites can be found naturally in food or added as a preservative. Foods that contain sulfites include dried fruits, shellfish and crustaceans, cruciferous vegetables such as broccoli, cabbage, brussels sprouts, premade packaged foods such as instant potatoes and doughs, and malt beverages and wines.
- *Soy.* Soy sensitivity can manifest itself in different ways in each person. Some symptom may include flushing, lip swelling, loose stool or abdominal cramping. Soy is found in soybeans, bean curd, edamame, miso, natto, soy sauce, soy milk, many vegan products and additives such as TVP (textured vegetable protein).
- *Gluten.* Common symptoms of gluten sensitivity may include brain fog, rash, loose stool, and bloating. Gluten can be found in breads, cereals, premade packaged foods, veggie burgers, breaded meats and malted products.

Rather than guessing what these offending foods are, we can get this information from food sensitivity testing.

As a Nutritionist, I knew a lot about food but removing my food sensitivities was a true eye opener for me and one of the largest positive impacts I made on my health and well-being. ■

This article was originally published by the Blum Center for Health. Keri Lynn is a Functional Medicine Nutritionist at Blum Center for Health with over 20 years of professional experience as a Registered Dietitian. Learn more by visiting www.blumcenterforhealth.com.

SSF in Action!

The Surgeon General's Report on Oral Health



This past July, federal agencies, including the U.S. Department of Health and Human Services, the Office of the Surgeon General, the National Institutes of Health, the National Institute of Dental and Craniofacial Research and the U.S. Public Health Service's Oral Health Coordinating Committee announced the commission of a Surgeon General's Report on prominent issues affecting oral health. This new report, the first since 2000, will document the progress made over the past two decades, identify current gaps in knowledge and articulate a vision for the future.

The coordinating group recognizes that over the past two decades much has been learned about how changes across the lifespan can have an impact on oral health and how health promotion activities and interventions can benefit oral health and overall quality of life. This new report comes at an important time, as many in the U.S. still experience complications related to oral health, which can impact their overall well-being and have significant social and financial implications.

At the time of the announcement, potential priority areas of focus for the report included: a description of the epidemiology of disease and conditions that affect the craniofacial complex; a review of health promotion and disease prevention activities; factors that affect the etiology of poor oral health at the individual and population level; social determinants of health and their influence on oral health disparities; biological

factors including the microbiome; social, economic and health consequences of poor oral health; mental health, substance misuse and addiction impact on the oral health of individuals, providers and communities; the state of oral health care access and coverage as it relates to prevention and treatment for dental diseases and related conditions; integration of oral health into primary health care settings; organization and financing of the provision of dental care within the health care system; ethical, legal and policy issues; and the application of scientific research in the field, including methods, challenges and current and future directions.

To ensure the public has an opportunity to provide input throughout the process there have been both listening sessions as well as an open comment period. Katherine Hammitt, Vice President of Medical & Scientific Affairs at the SSF, participated in the U.S. Surgeon General's Oral Health Listening Session, held in November, to provide feedback and help inform the new report. A key theme from this event was that oral health is an integral factor to overall health and that primary care physicians and dentists need to collaborate to ensure better patient outcomes.

Hammitt attended the session as a representative of the special care needs for the Friends of the National Institute of Dental and Craniofacial Research (FNIDCR) Patient Advisory Council and the Sjögren's community. ■

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, headaches

Dry nose, recurrent sinusitis, nose bleeds

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

Fatigue, vasculitis, lymphoma, dry skin

Dry eyes, corneal ulcerations and infections

Swollen, painful parotid/salivary glands

Difficulty swallowing, heartburn, reflux, esophagitis

Arthritis, muscle pain

Recurrent bronchitis, interstitial lung disease, pneumonia

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

Peripheral neuropathy, Raynaud's

Stomach upset, gastroparesis, autoimmune pancreatitis

Irritable bowel, autoimmune gastrointestinal dysmotility

Interstitial cystitis

Vaginal dryness, vulvodynia

www.sjogrens.org





You Stood Up!

Carrie Ann Inaba Stands Up for Sjögren's

After publicly announcing her Sjögren's diagnosis in 2016, the Sjögren's Syndrome Foundation (SSF) was honored to have Carrie Ann Inaba, *Dancing with the Stars* judge, and new co-host of *The Talk*, step up as an SSF National Awareness Ambassador. Once again, she is standing up for all patients by opening up to *PEOPLE* about how she learned to navigate her life with a chronic illness.

In the magazine interview, all patients can relate to Carrie Ann who discusses the emotional and physical process of discovering one's new normal when living with pain and fatigue from Sjögren's. The SSF applauds Carrie Ann for being open about her journey with this complex disease and how she became her own best advocate.

"It [being diagnosed with Sjögren's] was debilitating,' says Inaba... 'I was in so much pain, I just had to survive. I had to stay in bed three days a week, and I'm so fortunate because I had the kind of job where I could do that. There were days I could barely make my coffee because I was so exhausted.' In the process of coming to terms with Sjögren's, Inaba says she looked inward... 'I did a lot of soul searching. I learned about who I am besides being a sexy dancer chick. And ironically, as I let all that go, I found my way back to feeling vibrant and radiant again.'" ■

Nahas, Aili. "Carrie Ann Inaba: Happy & Healthy at Last." *PEOPLE* 21. Jan. 2019.

To read the full *PEOPLE* article about Carrie Ann, please visit: people.com/health/carrie-ann-inaba-discusses-living-chronic-illness/



Photo Credit: PEOPLE Magazine



“Clinical Trial” *continued from page 1* ▼

I learned that in order to be eligible for this specific study, you had to be between the ages of 18 and 65. At the time I was 61 and thought, “Oh my, my time to do this might be limited.” That was motivating for me and I knew I wanted to participate. I read all the information and found out what the requirements were. I learned that I’d have to stop taking one drug that I was currently on so that it wouldn’t interfere with the protocol, but after I read everything, I decided that it was still something I wanted to do.

The information outlined that for the first seven months of the nine-month study, all of the participants would be given the active drug. Then, the last two months would be double blinded. This meant that half of the people would get a placebo and the other half would receive the live drug. I thought this was cool because I knew that I would be getting the real medication and I would get the benefits of the active drugs for at least the first seven months.

I next had to be evaluated (blood work and a physical exam) to determine whether I was eligible. Luckily, I was accepted. Again, they fully informed me of everything and said that if I wanted to stop at any time during the study, for whatever reason, there were no repercussions. I was welcome to opt out at any time. This was reassuring but I hoped that I would stay in and would benefit from the medication. Another benefit was that throughout the study I would not only receive the medication for free, which was a costly drug, but I was given a monthly office visit. The visits would vary from lab work to a full evaluation by a rheumatologist. I got abundant attention from the study director, as well as the different doctors who saw me. It was great to get all this extra care at no cost to me. Additionally, they coordinated with my other regular doctors for the length of the trial. At one point during the study, I developed a rash that

was suspected to be autoimmune and they ran the test for it.

The doctors with the study coordinated with my regular dermatologist and rheumatologist, so I got all these extra opinions at no extra cost! It provided me with an additional level of care that was fabulous. Saving money on labs was another big benefit. I was also provided a \$50 check monthly for participating. My study was over a couple weeks ago and I got my last check in the mail today. The money more than covers my gas, time and expenses – it was a nice little bonus.

During the study, they gave me abundant information, attention, and

really cared about everything that was affecting me. It was interesting to share information, and I think I even informed them a little more about how Sjögren’s can affect patients differently.

Participating in a Sjögren’s clinical study was a very interesting exercise and educational for me. I fully recommend it to anyone who is eligible because you can learn a lot about yourself and help others. For me, it was a great experience. ■

“It was empowering to get the chance to really provide input about Sjögren’s and how it affects you.”



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A Caregiver's Reflection

by Jonathan Morse, husband of a Sjögren's patient and member of the SSF Board of Directors.

Today is not terribly different from any other day. The day begins... slowly. Introducing a reference to time... not recommended.

Because there is no way to know how the patient will feel. Will it be a sick day? Will it be a pain day? Will it be both? Too uncomfortable for breakfast?

Questions.

Questions are not helpful.

Rather, just know what to do, know what to say.

And find the sunshine. Project happy thoughts. (no questions). Everything hurts.

The role of a caregiver is demanding, unselfish and ever-present. The role requires an ability to not just listen but hear and then measure the appropriate response. Because the patient does not want help with everything. They still want to preserve whatever bit of independence they can, why, because they have lost so much. The tendency is to react, to offer to do everything...don't do that, the patient needs to retain any degree of independence they can.

It was not always like this.

The patient used to be able to do so much more. The patient was able to do everything. Clean the house, go for a run, take an exercise

class, take a spin class, work in the garden, get-up-n-go, have a job, have a schedule.

Over the many years of battling Sjögren's, so many therapies and medications have been tried. And while the disease chose its own paths of advancement, the therapies and medication side effects imposed their own blend of affect, interaction, ineffectiveness and ultimately uselessness.

The search for better and more effective treatment is endless. An infinite amount of time is spent reading blogs, web sources and drug explanations. Visits to specialists have become routine. The challenge in each encounter is to both cram as much background in as possible to set-the-table (mindful of the allowable 11-minute interval) then mine for gems that can be actionable, that can deliver hope.

Now, as difficult as managing the total body sickness, overcoming crushing fatigue, containerizing and filing pain, the sense of loss trumps all. The feeling of what was this body, what activities used to be possible, a job, housework, time with friends, time with family, possessing the energy to live...it's all different, it's not the same.

But. The patient looks fine.

What?

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“Caregiver” *continued from page 9* ▼

The patient looks good.

I know the depth of the battle, the dimension of sickness, the crush of pain, but no one else can see it. I know the effort to be ready-to-go is an extraordinary effort. Everything hurts. The shower water hurts. Standing on bare feet hurts. Food hurts.

And so we go places. We see people. And people ask the patient: “how are you?” “you look good!” “you look better.” “you sound better.” Hmm. Patient replies, “I’m fine.”

Next comes the judgment part. The patient looks good so the patient must be fine.

So much loss.

So many things have been taken away by Sjögren’s. Friends don’t know what to say, many stay away. Friends remain out-of-touch because they have been unable to listen, to comprehend, to empathize. And this may even apply to family. They arrive at the same point, unable to listen, to comprehend, to empathize. Then, when choices are made for travel, travel to locations that exclude the patient, the feedback is “we did not think you could handle it,” or “we did not want to be a burden.”

So much loss.

Sadly, family is precisely what the patient needs. The presence of family serves as fuel to flush the fatigue, to silence the body sickness, to file the pain away. Here is where you come to a fork in the road: to be honest with friends and

family as to the level of sickness, the level of life’s change, or, rather, choose to withhold, to internalize, to privatize as insulation to prevent any further pain, the pain of loss.

Loneliness sets in. For the patient, loneliness that few, maybe no one, understands what living with Sjögren’s is like. No doctor, no specialist, no pharmacist...no one knows. The same holds true for the caregiver. Dare we say, “what about me?” Does anyone know what it’s like to watch a person you love slowly disintegrate? Does anyone understand the feelings we have, the helplessness, the fear, the hurt, the sadness, the guilt, the loneliness? We are bystanders with a close-up view of the tick-tock disease progression, the effect of treatment side effects, the expression of discomfort, of sick, of pain, yet powerless without tools to help.

I have used the term *right-size* to describe the types of activities we can do. The plans I make (suggest) are *right-sized* to the level of ability of the patient. Forget the things we used to do, or more accurately stated, can no longer do, rather, “let’s go shopping,” “let’s go for a walk,” “let’s go to a movie.” As a caregiver, I have *right-sized* my activity to the mutually acceptable level of the patient.

And yet, we stay positive, we stay strong, we stay resolute because there is no other choice.

To all the caregivers out there, you possess the power to instill the seed of possibility, of promise and of hope. Smile. ■

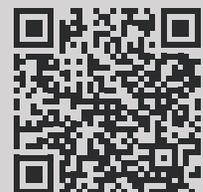


Learn more about Clinical Trials in Sjögren’s!

The SSF now has a section on its website devoted to clinical trials in Sjögren’s. Visit www.sjogrens.org/home/about-sjogrens/clinical-trials-whatsinvolved.

Links on this page take you to:

- An article by Theresa Lawrence Ford, MD, the SSF Medical and Scientific Advisory Board Chair and Chair of the SSF Clinical Trials Consortium
- A list of clinical trials in Sjögren’s that are currently recruiting Sjögren’s patients





in memoriam

In Memory of Carol Virginia (Woofter) McClain

NIOSH Field Studies Branch
Aunt Phyllis and Uncle Bernard

In Memory of Karen Caron

Donna and Mert Hornbuckle
John and Marylyn Clark
Brian and Michelle Bresnahan
Lisa Haynes
Andrew and Theresa Noble
Philip and Lisa Pleat
The Memorial Staff at TD Bank
Anna-Marie and Joshua Cook
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In Memory of Marlene Rideout

Henry and Betty Mazzeo
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Naomi Roberts

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Mary Ellen and Howard Benedikt
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KC Walsh

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Robert Wright
Lynn and Alan Maisel
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Sheila Vickers and Family

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In Memory of Rosaria "Sadie" Forte

Institute for Advanced Clinical Trials
(I-ACT) for Children



in honor

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Hannah and David Levin

In Honor of Elaine Levin

Bernice and Sam Greenberg

Donna and Bud Solk

Sy and Barb Oko

In Honor of Jackie Traw

Tiffany Morris

In Honor of Rachel Nazareth

Amy and Jeff Tecosky-Feldman

In Honor of Susan Gannon

Brad Beemer

In Honor of Dr. Cheryl Levin

Elayne and Barbara

SSF EVENT CALENDAR

To learn more about SSF events, please visit www.sjogrens.org or contact Jessica Levy at (301) 530-4420 ext. 218 or email jlevy@sjogrens.org.

APRIL



2019 SSF National Patient Conference

April 5-6, 2019
Hilton Boston/Woburn

Boston Walk for Sjögren's at the 2019 SSF National Patient Conference

Saturday, April 6, 2019
Hilton Boston/Woburn

Tastefully Georgia

Sunday, April 28, 2019
Nelson Mullins - Atlantic Station

**NPC
2019**



MAY

Philadelphia Walk for Sjögren's

Saturday, May 4, 2019
Philadelphia Zoo

Greater Washington Region Walk for Sjögren's

Saturday, May 18, 2019
Reston, Virginia

JUNE

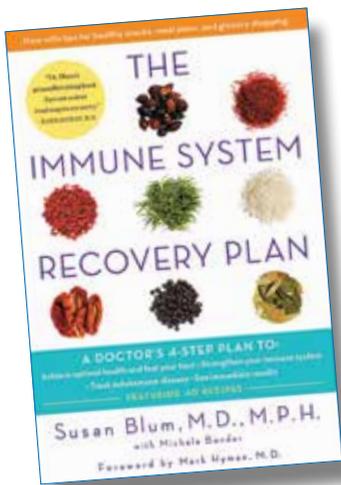
Denver Walk for Sjögren's

Saturday, June 8, 2019
Hudson Gardens

Dallas Walk for Sjögren's

Saturday, June 22, 2019
Parks at Arlington





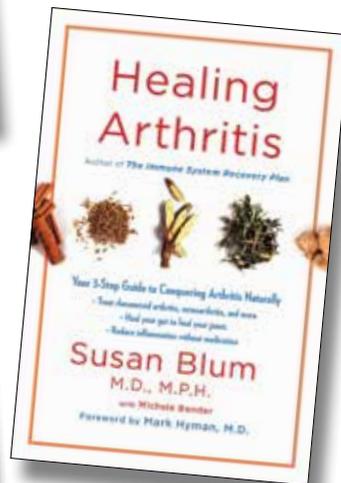
The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease

by Susan Blum, MD, MPH (Author), Mark Hyman, MD (Foreword), Michele Bender (Contributor)

Dr. Susan Blum, one of the most sought-after experts in the field of functional medicine, shares the four-step program she used to treat her own serious autoimmune condition and help countless reverse their symptoms, heal their immune systems, and prevent

Member Price: \$22

Non-Member Price: \$25



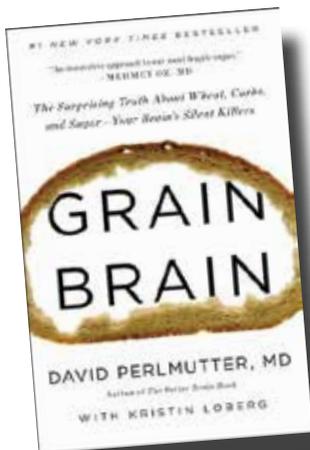
Healing Arthritis: Your 3-Step Guide to Conquering Arthritis Naturally

by Susan S. Blum, MD, MPH (Author), Mark Hyman (Foreword)

Author of the bestselling The Immune System Recovery Plan shares her science-based, drug-free treatment plan for the almost fifty million people who suffer from arthritis: an amazing 3-step guide to eliminate the disease naturally.

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Non-Member Price: \$24



Grain Brain: The Surprising Truth about Wheat, Carbs, and Sugar - Your Brain's Silent Killers

by David Perlmutter, MD (author) and Kristin Loberg (contributor)

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.

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	Non-Member Price	Member Price	Qty	Amount
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Conquering the Complexities of Sjögren's

April 5 – 6, 2019

Hilton
Boston / Woburn

2019 National Patient Conference

Sjögren's
SF
syndrome
foundation



2019 NPC – Speakers and Topics

The Complexities of Sjögren's: An Overview

Theresa Lawrence Ford, MD, is a private practice rheumatologist at North Georgia Rheumatology Group in Lawrenceville, Georgia. Dr. Lawrence Ford has done research in the fields of lupus and rheumatoid arthritis and participates as an investigator in clinical trials for Sjögren's. She has been recognized in *Atlanta Magazine* annually as a Top Doctor in her field since 2005, and is a current SSF national board member where she serves as Chair of the Medical and Scientific Advisory Board, and Chair of the Clinical Trials Consortium. Dr. Lawrence Ford will present a comprehensive explanation of the range of symptoms and complications that Sjögren's patients experience, including internal organ involvement, dryness symptoms and treatment options.

Oral Manifestations of Sjögren's

Vidya Sankar, DMD, MHS, is Clinic Director of the Oral Medicine and Dentistry Clinic at Brigham and Women's Hospital and Co-Director of the Oral Medicine and Oncology Clinic at Dana Farber Cancer Institute in Boston, Massachusetts. She is also a current member of the SSF Medical and Scientific Advisory Board and past SSF national board member. Dr. Sankar will provide insights into how Sjögren's impacts your oral health including tooth decay as well as share with us information to help manage and minimize the effects of dry mouth issues.

The State of Sjögren's: Transforming the Future

Steven Taylor, SSF Chief Executive Officer

The Sjögren's Syndrome Foundation (SSF) has been continuously launching new patient and healthcare professional focused initiatives that are changing the direction of Sjögren's! Join with Steve as he shares updated information about Clinical Trials and Clinical Practice Guidelines as well as other projects on the horizon.

Fatigue and Sjögren's

Donald E. Thomas, Jr., MD, has a special interest in systemic autoimmune diseases, especially Sjögren's. He is in private practice in Maryland, but he also enjoys teaching health care providers about Sjögren's. He is a current national SSF board member and is passionate about empowering patients. Fatigue is one of the most prevalent and disabling symptoms of Sjögren's. Dr. Thomas will add to your understanding of the variety of causes and will offer tips to help you cope, manage and treat the problem.

Product Showcase

Sjögren's patients use a number of over-the-counter products to treat their various complications. This session will highlight the vast array of products that are available for Sjögren's patients.

Banquet Awards Dinner and Keynote Speaker

"Finding Your Voice"

Brad Lemack is a Los Angeles-based talent manager, public relations consultant, educator and author. He established his agency, Lemack & Company Talent Management/Public Relations, in 1982 after serving as a publicity executive for pioneering producer Norman Lear's television and film production company, where he worked on such now-classic television series as "The Jeffersons" and the original "One Day at a Time," among many others.

Brad is a strong advocate of lending one's talents and voice to move a greater agenda forward. His efforts and support over the decades have helped raise funds and awareness for many important movements. He is currently helping the Sjögren's Syndrome Foundation with the creation and production of a series of patient information and awareness videos for the Foundation.

In addition, join us for this inspirational evening as we present our National Awards to volunteers, groups and organizations that have helped to further the mission of the Sjögren's Syndrome Foundation.

Understanding Blood Changes and Lab Results

Alan N. Baer, MD, is Professor of Medicine and Director of the Jerome L. Greene Sjögren's Syndrome Center at Johns Hopkins University School of Medicine in Baltimore, Maryland. He is also an Associate Investigator in the Sjögren's Syndrome Clinic at the National Institutes of Health (NIH). Dr. Baer is engaged in clinical research studies in Sjögren's and takes part in the SSF's Clinical Trial Consortium. Dr. Baer will describe the blood changes typically associated with Sjögren's as well as help us understand the rationale and meaning of the tests ordered and procedures performed by physicians.

Living with Sjögren's: A Patient Panel

Join us as Janet E. Church, SSF Chair of the Board and a fellow Sjögren's patient, moderates an informative and lively patient panel about living with Sjögren's and its many manifestations and complications. Each of these individuals will share tips for living with Sjögren's and how to find your voice to help increase awareness. We know you will learn from the experiences and stories of each of our panelists.

Esen K. Akpek, MD, is a professor of ophthalmology and rheumatology at Johns Hopkins University School of Medicine, Baltimore, Maryland. She currently serves as the director of the Ocular Surface Diseases and Dry Eye Clinic at the Wilmer Eye Institute and the associate director of the Jerome L. Greene Sjögren's Syndrome Center of Johns Hopkins Hospital. Dr. Akpek specializes in the field of medical and surgical treatment of ocular surface diseases and dry eye. Her main research interest centers around the effects of dry eye on visual function. In addition, Dr. Akpek is a current national SSF board member and a member of the SSF Medical and Scientific Advisory Board. Dr. Akpek will describe the latest dry eye therapeutic treatments, covering the extensive range of options.

Nutrition, Wellness and Autoimmune Disease

Lauri Lang, RD, LDN, is a registered dietitian and licensed dietitian nutritionist based in Pittsburgh, Pennsylvania. She specializes in holistic nutrition and lifestyle strategies for health promotion and to help suppress inflammation in autoimmune conditions. In her private practice, Ms. Lang has counseled individuals of all ages and medical conditions who seek wellness through nutrition and lifestyle modifications. Ms. Lang will explain how different aspects of nutrition can impact your Sjögren's and share insights into making the best nutritional choices to maximize functioning and well-being.

Sjögren's Clinical Trials Update

Athena Papas, DMD, PhD, is the Erling Johansen Professor of Dental Research, and the Head of the Division of Oral Medicine at Tufts University School of Dental Medicine. Additionally, Dr. Papas is a member of the SSF Medical and Scientific Advisory Board and has led numerous clinical trials in Sjögren's. Dr. Papas has also worked tirelessly to encourage pharmaceutical companies to develop a systemic therapy for Sjögren's. Join us for Dr. Papas' informative presentation about how clinical trials add to our medical knowledge and, most importantly, how the result of these trials can make a difference in the care and treatment of Sjögren's patients.

How Sjögren's Can Impact the Central Nervous System

Edward A. Maitz, PhD, is a Diplomate in Clinical Neuropsychology and is also Board Certified in cognitive rehabilitation and biofeedback training. Dr. Maitz is in full time private practice in Pennsylvania and New Jersey. He has a special interest in Sjögren's and has published articles in the field, and is a member of the SSF Clinical Practice Guidelines Committee. Dr. Maitz understands the challenges that may impact patients with central nervous system complications and will share his vast knowledge, insights and strategies with you about the physical, cognitive ("brain fog"), and psychological manifestations of Sjögren's.

Conference Hours

Friday
12:30pm – 8:30pm

Saturday
8:30 am – 4:30pm

Space is limited. Please register early!

Registration Form

Registration fees include: Friday evening dinner, Saturday's lunch, hand-out material from speakers and entrance to exhibit area on Friday and Saturday.



2019 NATIONAL PATIENT CONFERENCE

Hilton Boston/Woburn, Woburn, Massachusetts

April 5 – 6, 2019

1 ATTENDEE – complete for each registrant

Attendee Name(s) _____

Attendee Name(s) _____

Street Address _____

City _____ State _____ Zip _____

Telephone _____ E-mail _____

2 FEES – please circle appropriate fee(s) (Note: Early Bird Deadline is March 11, 2019)

	March 11 th and before	March 12 th and after
SSF Members & Guests	\$170 per person	\$190 per person
Non-Members	\$190 per person	\$210 per person
TOTAL:		

3 PAYMENT – Mail to SSF, c/o BB&T Bank • PO Box 890612 • Charlotte, NC 28289-0612 or Fax to: 301-530-4415

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Signature _____

- Refund requests must be made in writing. Registrants whose written requests are received by March 11th will receive a 75% refund. After that time, we are sorry that no refunds can be made.
- Dietary Requests: Unfortunately, we cannot accommodate all special dietary requirements. We can accommodate vegetarian or gluten-free dietary requests.

I would like a vegetarian meal
 I would like a gluten-free meal
- A limited number of rooms are available, on a first-come basis, at the Hilton Boston/Woburn hotel (2 Forbes Road, Woburn, Massachusetts 01801) at the SSF rate of \$129 per night plus tax if reservations are made by March 11, 2019. Call the Hilton Boston/Woburn hotel directly at (781) 932-0999 to make room reservations and refer to the group name "Sjögren's Syndrome Foundation" for the discounted rate. (NOTE: The Hotel will require a deposit when you make your reservation. Please ask the Hotel about their cancellation policy.)
- The Hilton Boston/Woburn is approximately 12 miles from the Boston Logan International Airport.

QUESTIONS? Call 800-475-6473 or visit www.sjogrens.org



The Moisture Seekers
Sjögren's Syndrome Foundation Inc.
10701 Parkridge Blvd., Suite 170
Reston, VA 20191
Phone: 301-530-4420
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



April is Sjögren's Awareness Month: Conquering the Complexities of Sjögren's

April is Sjögren's Awareness Month and we hope you will join us in educating the public about this complex disease and how it affects those who are living with it!

Sjögren's Awareness Month was first established in 1998 when New York Congresswoman, Louise Slaughter, read it into the Congressional Record. Today, the Foundation works to keep the spirit of national awareness alive this April.

Even though Sjögren's awareness continues to rise, it is still one of the most prevalent but lesser known autoimmune diseases. This can lead to a misunderstanding about the seriousness of the disease and be extremely isolating for those living with it.

Using our *This is Sjögren's!* April Awareness Campaign, the SSF aims to help educate others about this complex disease and how we are working to conquer it.

Stay on the lookout for more information in next month's issue of *The Moisture Seekers* and follow us

on social media to learn more about the #ThisIsSjögrens campaign and how you can get involved! ■

